CORA Cork Open Research Archive
Cartlann Taighde Oscailte Chorcaí

Title	Siblings caring for siblings with Intellectual Disabilities: naming and negotiating emotional tensions
Authors	Leane, Máire
Publication date	2019-04-19
Original Citation	Leane, M. (2019) 'Siblings caring for siblings with Intellectual Disabilities: Naming and negotiating emotional tensions', Social Science & Medicine, 230, pp. 264-270. doi: 10.1016/j.socscimed.2019.04.022
Type of publication	Article (peer-reviewed)
Link to publisher's version	http://www.sciencedirect.com/science/article/pii/S0277953619302229 - 10.1016/j.socscimed.2019.04.022
Rights	© 2019 Elsevier Ltd. All rights reserved. This manuscript version is made available under the CC-BY-NC-ND 4.0 license - http://creativecommons.org/licenses/by-nc-nd/4.0/
Download date	2026-10-17 08:59:46
Item downloaded from	https://hdl.handle.net/10468/8400

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

Accepted Manuscript

Siblings caring for siblings with Intellectual Disabilities: Naming and negotiating emotional tensions

Máire Leanem

PII: S0277-9536(19)30222-9

DOI: https://doi.org/10.1016/j.socscimed.2019.04.022

Reference: SSM 12270

To appear in: *Social Science & Medicine*

Received Date: 22 November 2018

Revised Date: 15 April 2019

Accepted Date: 16 April 2019

Please cite this article as: Leanem, Má., Siblings caring for siblings with Intellectual Disabilities: Naming and negotiating emotional tensions, *Social Science & Medicine* (2019), doi: https://doi.org/10.1016/j.socscimed.2019.04.022.

This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

ACCEPTED MANUSCRIPT

Manuscript Number: SSM-D-18-03691R1

Title: Siblings Caring for Siblings with Intellectual Disabilities: Naming and Negotiating Emotional Tensions

Author: Máire Leane, School of Applied Social Studies, University College Cork, Ireland.

Corresponding Author: Máire Leane, School of Applied Social Studies, University College Cork, Ireland. m.leane@ucc.ie

ACCEPTED MANUSCRIPT

ABSTRACT

Extended longevity among adults with Intellectual Disabilities (ID) and increasing rates of diagnosis of Autism Spectrum Disorders (ASD) mean that parents are unlikely to remain primary carers throughout the lifecourse of adults with ID and ASD. In the context of decreased funding for disability services and policy moves toward de-congregated living, non-disabled (ND) siblings of people with ID/ASD are increasingly likely to be drawn into support and care roles for their siblings. Drawing on literature on moral emotions and the ethics of care, and on narratives collected from 25 ND siblings in Ireland in 2015/6, this paper explores the emotional dynamics entwined in the care and support roles ND siblings engage in. Findings indicate that relationships forged in childhood underpinned the moral ethic to care exhibited by many participants and that their caregiving was experienced as moral practice and emotional engagement, shaped by and constitutive of biography and moral identity. When making care choices, siblings undertook evaluative judgement of their own behaviours, which was informed by perceptions about obligations to care and about what constitutes good care. Decisions about care had emotional resonance, with guilt, other-oriented empathy and righteous-anger emerging as the key emotions in the narratives. Dilemmas between autonomy

and relatedness caused siblings to grapple with feelings of resentment and guilt, and many struggled to exercise self-compassion in the face of perceived moral failings. Others experienced conflict characterised by a struggle to reconcile competing care and nurturing expectations within their intimate relationships. Through ongoing self-evaluation of their care behaviours siblings' moral identities were continually reconstituted. It is imperative that service providers and professionals understand and acknowledge such moral and emotional dynamics when working with people with ID/ASD and their families.

KEYWORDS

Sibling care for siblings; Intellectual Disability; Autism Spectrum Disorder; Emotions; Ethics of Care

RESEARCH HIGHLIGHTS

Explores care practices and aspirations of siblings of people with ID/ASD

Reveals how moral emotions of guilt, anger and self-compassion shape the moral identities of carers

Argues that looking at care from the perspective of emotions can inform supports for carers

ACCEPTED MANUSCRIPT

1. Introduction

Extended longevity among adults with Intellectual Disabilities (ID) (Coppus, 2013) and increasing rates of diagnosis of Autism Spectrum Disorders (ASD) (Matson & Kozlowski, 2011) mean that parents are unlikely to remain primary carers throughout the lifecourse of adults with ID and ASD. Concerns about what will happen when parents are no longer in a position to care are a source of anxiety for ND siblings (Benderix & Sivberg, 2007; Orsmond & Seltzer, 2007). A sense of responsibility for the future of brothers and sisters with ID/ASD (Benderix & Sivberg, 2007; Orsmond & Seltzer, 2007) and an expectation of involvement in care or support work (Gomez de la Cuesta & Cos, 2012; Heller & Arnold, 2010) have also been identified. Explorations of adult sibling relationships in cases where one sibling has ID/ASD are limited, but are consistent in finding high levels of involvement and strong emotional ties between ND siblings and their brother or sister with ID/ASD, throughout the lifecourse (Doody et al., 2010; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007). Siblings' commitment to their brother or sister with ID/ASD is usually attributed to their shared history and the siblings' unique understandings of their brothers or sisters (Tozer & Atkin, 2015:349). In families with more than one ND sibling, one sibling frequently assumes the role of 'most involved sibling' (Heller & Arnold, 2010:22) or 'key person' (Bigby,

1997). Factors such as life stage and personal circumstances impact on the emergence of this role (Davys et al., 2016), with those assuming it usually having a lifelong, close relationship with their brother or sister with ID/ASD (Tozer et al., 2013). Sisters are more likely to be involved with, provide emotional support to, and have a closer relationship with the sibling with ID/ASD (Greenberg et al; 1999; Heller & Arnold, 2010). They are also more likely to be perceived by others as potential primary caregivers (Greenberg et al., 1999), reflecting gendered constructions of caregiving.

Notwithstanding the close ties identified between ND siblings and their brothers and sisters with ID/ASD, tensions associated with caregiving exist (Atkin et al., 2014; Atkin & Tozer, 2015; Davys et al., 2010, 2014, 2016; Gomez de la Cuesta & Cos, 2012). A UK survey (Gomez de la Cuesta & Cos, 2012) of 111 adult siblings of people with ASD aged 40 and older indicated that nearly half the participants felt they had no choice but to support their brothers or sisters. However, they reported being willing to do so out of love and a sense of duty and responsibility. Recent UK research with older adults with ID found, however, that despite some strong ties with siblings, which translated into 'small acts of care and sociability', the older adults lived in a 'care desert' (Power & Bartlett, 2018:6). 'Harmonizing dilemmas' (Dellve et al., 2000:172) experienced as tensions between wanting to care but feeling that one has no

choice about it, and as challenges with reconciling conflicting demands and roles at emergent life stages, have been identified by ND siblings. So too has resentment at the demands being made on them, and guilt about moving on with their own lives (Atkin et al., 2014; Atkin & Tozer, 2015; Davys et al. 2010, 2014 & 2016; Gomez de la Cuesta & Cos, 2012).

In the context of neo-liberal politics of austerity, decreased funding for disability services (Power & Bartlett, 2018; Taylor-Gooby et al., 2017) and policy moves toward de-congregated living and personalised budgets (Mansell & Beadle-Brown, 2010), ND siblings of people with ID/ASD are increasingly likely to be drawn into support or care roles. Of the 28,388 individuals registered with ID in Ireland in 2017, 49.1% were aged 35 and above, an increase from 37.9% in 1996 (Hourigan et al., 2017:11). This is significant as Irish research suggests that people with ID tend to live with parents until around the age of 35 (Chadwick et al., 2013:92) and that siblings become actively involved as carers at this stage (Barron et al., 2006:32). The majority (69.0%) of people with ID in Ireland live with family members including almost one-third (31.6%) of those aged 35 years and above (Hourigan et al., 2017:12). However, recent Irish research with 17 families with an ageing member with ID found that both parents and adult siblings identified an absence of future caregiving capacity within the family (Brennan et al., 2018). This is significant

given that an immediate unmet need for new full-time residential placements for 2,179 people with ID has been identified in Ireland with the majority of places (60.2%) being required by the 35 years and above age cohort (Hourigan et al., 2017:16). Residential facilities in Ireland have only been subject to statutory monitoring since 2013 and a high-profile exposure of abuse by staff and managers at one facility (Irish Times, 2016), has raised questions about the quality of residential care. Despite a policy agenda prioritising community living (Department of Health, 2012; Health Service Executive, 2011, 2012), sustained austerity measures continue to reduce homecare supports (Inclusion Ireland, 2017:2) and respite services (Hourigan et al., 2017:13). Shortages of residential places, concerns about the quality of residential care, and limited family engagement with future care planning (Brennan et al., 2018), suggest that decisions about who will provide care, in what setting and to what standard will be of increasing concern for siblings. Given the strong connections between siblings and their brothers and sisters with ID/ASD identified in the literature, it is to be expected that such decisions about care will have a strong emotional dimension. However, the literature on ND sibling carers remains largely silent in relation to the emotional dynamics of caregiving. Indeed, the limited exploration of emotions in caregiving in general has recently been flagged (Pulcini, 2017; Tangney et al., 2007). Based on the

narratives of 25 ND sibling carers in Ireland and informed by literature on the ethics of care and the role of emotions in caregiving, this article will explore the emotional dimensions of caregiving aspirations, decisions and practices. It will focus on the relations that motivate ND siblings to care and the emotional resonance of type and place of care as revealed in ND siblings' moral evaluations of what constitutes good or acceptable care. It will also consider the ways in which ND siblings grapple with their roles as moral care subjects in the context of shifting biographies, limited resources and competing relational ties.

2. Emotions and the ethics of care

Feminist ethics of care theorists (Gilligan, 1982 & 2011; Held, 2006; Kittay, 1999; Tronto, 1993 & 2013) highlight the relational basis of care relationships and conceptualise care as a moral practice. The altruistic and selfless behaviour involved in care relationships clashes with constructions of the neo-liberal subject making rational choices out of self-interest, and carers are frequently compromised in their caregiving by their own needs, competing responsibilities and inadequate access to resources (Tronto, 1993). Pulcini (2017) argues that while recognising the relational basis of care and the tensions that can arise between self-care and care for others, ethics of care

theorists pay little attention to emotions, and she calls for exploration of how they are implicated in motivating care and in the everyday negotiation of care relationships. She bases this call on Nussbaum's (2001) understandings of emotions as 'forms of evaluative judgement that ascribe to certain things and people a great importance and value for our well-being or flourishing' (Pulcini, 2017:64). For Nussbaum (2001:2), emotions are integral to the system of ethical reasoning, and she argues that understanding what motivates people to care involves understanding emotions '…including their cultural sources, their history in infancy and childhood, and their sometimes unpredictable and disorderly operation in the daily life of human beings who are attached to things outside themselves'. Tangney et al. (2007:346), following Haidt (2003:276), use the term 'moral emotions' to refer to emotions which are linked to the interests or welfare of others outside of the individual actor. They understand these emotions as providing the impetus for individuals to behave in ways which do good and avoid doing harm. In particular, they highlight 'self-conscious emotions' (Tangney et al., 2007:346) such as shame and guilt, which are evoked by self-evaluation or self-reflection and act as a 'moral barometer' providing individuals with feedback on their behaviour. Tangney et al. (2007:349) identify shame as an emotion premised on a negative self-evaluation of the full self, while guilt is premised on negative self-evaluation of

a specific behaviour and gives rise to 'tension, remorse, and regret over "the bad thing done"'. They also emphasise that shame and guilt are differentially related to empathy. As experiences of guilt focus on specific instances of bad behaviour, this in turn highlights 'the negative consequences experienced by others, thereby fostering an empathetic response and motivating people to 'right the wrong' (Tangney et al., 2007:350). In contrast, feelings of shame focus on the bad self and focus attention inwards. These self-conscious moral emotions also have anticipatory effect in that individuals can anticipate, based on past experiences, the moral emotions that certain behaviours would evoke (Tangney et al., 2007:346). In this regard they play a significant role in shaping moral choices and decision making. Tangney et al. (2007) also draw attention to the role which empathy plays in shaping moral behaviour. Following Feshbacch (1975), they describe empathy not as a discrete emotion but rather as an emotional process involving a 'shared emotional response between an observer and a stimulus person' (Feshbacch (1975) cited in Tangney et al., 2007:362), where the other person's perspective is recognised and shared. This recognition frequently elicits behaviour aimed at elevating or avoiding the distress of the other.

ACCEPTED MANUSCRIPT

The role of emotions in caregiving based on personal relationships or 'care out of love' contexts (Pulcini, 2017:66) has been considered in some geographies of care literature (Bondi, 2005; Chattoo & Ahmad, 2008; Evans & Thomas, 2009; Mackenzie & Stoljar, 2000; Wiles, 2003). Different senses of moral responsibility in relation to obligation to care among members of the same cultural-religious group are identified by Chattoo and Ahmad (2008), indicating that decisions about caregiving are influenced, but not totally determined, by available cultural scripts. This suggests that efforts to understand the dynamics of caregiving must also pay attention to moral subjectivity and indeed to the biographical and social contexts that constrain or enable moral behaviour. Hughes et al.'s (2013) exploration of assumptions of carer identity among relatives and friends of people with multiple sclerosis revealed tensions in the negotiation of moral responsibilities and around the adoption of the identity of carer. Some participants rejected a carer identity, constructing their care work as an aspect of their relationship with their relative or friend. Others resented the change to their relationship brought about by the adoption of care activities, and yet more expressed their dislike of the care role and identity, seeing it as an obligation or responsibility about which they did not have a genuine choice. Differences in care practices related to gendered assumptions about obligation and capacity to care, and different

individual orientations to care, were revealed in Seaman's (2018) work on spousal caregivers in the context of Alzheimer's disease. Care recipients have also questioned understandings of care, challenging the attribution of dependency to those receiving support and arguing for individualised budgets which allow people with support needs to employ people to assist them (Milligan & Power, 2010:571).

The work involved in managing emotions within care relationships has received some limited attention. Wiles' (2003:1322) work on family carers for older people shows that family caregiving situations are 'driven by intense emotions and generate strong emotional effects'. Herron and Skinner's (2013:188) research, which also explored older people and their caregivers, found that the 'emotional overlay' or the work of managing emotions was experienced as a key challenge within care relationships and that within the family context, care work or care experiences were rarely discussed. The hiding of emotion by caregivers and care receivers was identified by Evan and Thomas (2009) in their study of family care for relatives with HIV, which revealed that feelings of guilt, resentment and stigma identified by both caregivers and care receivers remained for the most part unexpressed.

The review of literature above highlights the centrality of emotions to decisions about caregiving and experiences of it. As Lynch (2009:413) points

out care is '…not just a practical dilemma about a set of tasks to be undertaken, it is also an emotional and moral dilemma about who one is relationally and what is best care.' The nature of these emotional and moral dilemmas needs to be teased out. Detailed exploration of the moral emotions (Tangney et al., 2007) that are implicated in care can shed light on the processes though which individuals make decisions about whether to care and what type of care to engage in. It can also provide insights into the tensions which threaten the provision of good care and point to potential ways of renegotiating or addressing unsatisfactory care situations. Through exploration of the decision making and caregiving experiences of non-disabled siblings of people with ID/ASD, this paper seeks to deepen understandings of the ways in which emotions are implicated and managed in this caregiving context.

3. Methods

This article draws on semi-structured interviews with 23 self-selecting adult siblings (aged between 18 and 45) of people with ID/ASD and two written accounts collected from participants who lived abroad and elected to write a response rather than conduct a phone interview. Participants were recruited through Inclusion Ireland, a co-ordinating body for disability services and through two ASD support groups. Ethical approval was granted by the Social

Research Ethics Committee (SREC) in University College Cork. Written consent was provided by participants and all data were anonymised. The interviews, which were conducted between September 2015 and April 2016, explored siblings' relationships with their brother or sister during childhood and adulthood, and their expectations and aspirations in relation to caregiving in the future. Specific questions around emotions were not included and the emergence of emotion as a dominant theme in the narratives was unexpected.

The majority of the participants were female (n=20) reflecting expected gendered patterns of care and there was a dispersal of participants across the prescribed age range: five participants were aged between 18 and 24, five were aged between 25 and 30, seven were aged between 31 and 35, two were aged between 36 and 40, and six were aged between 41 and 45. Participants came from families of various sizes. Four participants were the only sibling to the brother/sister with ID/ASD, seven had one ND sibling, 10 participants had two ND siblings and four had three ND siblings. Nine of the participants were the oldest in their families, four were second oldest, six were the middle child in the family, two were the second youngest in their families, and four were the youngest.

Verbatim transcriptions of the interviews and the two written contributions were subjected to a thematic analysis following Braun and

Clarke's (2006) guide to thematic analysis. Emotion was identified as a key theme due to its prevalence in the narratives and its importance in explaining why siblings care and how they experience and manage the care relationship. The data related to emotion were subsequently subjected to a narrative analysis (Riessman, 1993), which considered how participants spoke about emotions and the ways in which they drew on emotions to make sense of their care experiences.

4. Choosing to care – moral dispositions and emotions

In explaining why they were involved in caring for their brother or sister, or expected to be so in the future, most participants described their disposition to care primarily in relational terms, emphasising strong emotional attachments that had evolved from childhood. Nussbaum's (2001:2) suggestion that emotional engagement in infancy and childhood is one of the factors that needs to be considered when seeking to understand the emotions that motivate care, is validated by many participants' accounts. Consistent with previous research on siblings of people with ID/ASD (Tozer & Atkin, 2015), many participants described a childhood in which they were the sibling who engaged most with their brother or sister and were most keenly attuned to their needs, likes and dislikes. Mary (aged 34) explained that she knew from

her mid-teens that she would be the sibling most involved with her brother (aged 38) with Asperger's syndrome. 'I was the one closest to him and kind of understood him the most and spent a lot of time with him.' A strong bond is also evident in Carmel's (aged 42) depiction of her relationship with her brother Jack (aged 39) who has a severe ID. Her narrative reveals how an orientation to the needs of her brother shaped her biography and she constructs her relationship with him as being akin to a mother/child bond:

> I've always felt responsible for him. … I would never have emigrated. I would never have worked abroad because I didn't want to break that relationship, any more than I would leave my child.

Carmel also related how as a child she prioritised Jack's needs over her own by making as little demand on her parents as possible. 'I kind of looked after myself so that my parents could mind him more.' The altruistic and self-denying behaviour described by Carmel mirrors the traditional gendered construction of women as selfless carers which has long been flagged by feminists (Finch & Groves, 1983). Childhood awareness of how her brother Peter (aged 29) who has Downs Syndrome might feel in particular situations is evidenced in Anna's (aged 30) account of an incident that occurred when he came with her parents to collect her from basketball:

> And Peter took a basketball and tried to play basketball. And I remember the kids there mocking him and laughing at his attempts and I never went back. I refused to go back. So it was almost like if you didn't accept Peter you weren't accepting me … And I've always been kind of his protector and I didn't want to put him in a situation… Probably I didn't want myself in that situation.

What Anna describes reflects the emotional process of other-oriented empathy described by Tangney et al. (2007:362), in which recognition of the other's perspective elicits behaviour from the actor aimed at alleviating or avoiding the distress of the other. Avoiding distress for her younger sister Lisa (20) who has ASD was also a concern for Sarah (aged 22), who reported that she frequently worries about Lisa's future:

> I think I make more of an effort with her [Lisa] than my older sister does... I would be a really empathetic person...whereas my older sister... she'd be much more emotionally removed from it.

Sarah's narrative clearly constructs her 'effort' as based on an emotional connection to her sister and the empathy she feels toward Lisa, something which she believes is less evident in her more emotionally distant sister. Lynch's (2009:413) concept of love labour as 'the emotional and other work

oriented to the enrichment and enablement of others, and the bond between self and others' is clearly aligned with the roles described by the siblings above.

Accounts of caring disposition based on relational ties, such as those just considered, were provided by the majority of participants. However, a minority did not emphasise bonds of affection, constructing their caring involvement in terms of duty or obligation. For example, Harry (aged 27) who has two other ND siblings and whose brother Tom (aged 24) has an ID and currently lives with his parents, has thought about his brother's future since he was a teenager and always felt that he would 'probably have some duties in it'. He envisages being involved in his brother's life as an organiser or overseer reflecting the role of 'care commander' rather than 'care footsoldier' as understood by Lynch (2009:413). Currently he sees his brother every few weeks and is not actively involved in his life. He believes his future role will reflect a similar level and type of involvement:

> From my perspective I don't want Tom to be literally under my wing...I can tag in organisationally and see him as often as I see him now.

Harry believes that he is best placed to be the sibling with most responsibility for Tom, because he '...would carry that responsibility better than my other siblings, simply put.' This belief is based on assumptions around obligation and capacity to care, with Harry explaining that he is likely to be the most

financially stable of his siblings in the future 'maybe I see those with financial security as having greater responsibility, which I think is fair enough.' A sense of responsibility rather than an emotional attachment also underpins Chloe's (aged 31) understanding of her future role in the life of her brother Diarmuid (aged 35), who has mild ID and has lived since the age of 20 in a faith-based residential community. She described having very little involvement with her brother growing up and now sees him about six times a year. Chloe does not envisage a need for either her or her sister to be more involved in Diarmuid's life. She does, however, expect to 'sort of up the ante and see him more' when her parents are no longer alive but does not believe that he will place any constraints on her life. Chloe clearly feels a sense of responsibility to visit her brother occasionally but does not expect to undertake any formal care role.

In the next section, consideration is given to the emotions that motivate sibling caregiving, and in particular to the connections between emotions and understandings of what constitutes good care.

5. Shaping care practices – unravelling the emotional resonance of care

Concern about the place and type of care their brother or sister with ID/ASD might experience was expressed by many siblings. Sarah (aged 22), sister to

Lisa (aged 20) who has ASD, anticipates becoming her primary carer despite being very conscious of how demanding this will be. A key factor in this decision is Sarah's belief that if her older ND sister took on the role, Lisa might live in a residential care setting, which would be unacceptable to Sarah who has grave reservations about the quality of residential care in Ireland:

> She [older non-disabled sister] wouldn't really feel guilty about it [residential care] I don't think, whereas I probably would. I'd find it really hard… I just couldn't put her [Lisa] in a care home. Like I just couldn't do that.

Sarah anticipates that her emotional reaction to Lisa entering residential care would be guilt and this anticipatory guilt (Tangney et al., 2007:346) is a key factor influencing her moral decision to become Lisa's carer. Nussbaum's (2001) conceptualisation of emotions as forms of evaluative judgement, which ascribe meaning or value to people or things considered important for well-being, provides further insight into Sarah's decision. Following Nussbaum, Sarah's decision reflects the moral value she ascribes to care as a component of well-being. Care out of love for someone with whom one has a personal relationship was perceived by some siblings as morally superior to 'care work' involving remuneration (Pulcini, 2017:66). Annie (aged 45), a single woman without children, experienced an

emotional struggle when deciding whether or not to have her brother James (aged 41) move in with her when her mother was no longer able to care for him. She explained that after much reflection she consciously chose the live-in care arrangement:

> … him [James] living with me is the right thing, because it's safe in that he will be cared for and cared about and not just by someone who's paid … and knocks off at a certain time and goes home to their own family.

Disquiet around care provided outside a home setting or outside a care out of love relationship may, in part, be explained by what Lynch (2009:413) refers to as the 'inalienable dimension' of love labour. This inalienability is experienced as a knowledge that one 'cannot pay someone else to build or maintain one's own relationship with intimate others' (2009:413). Carmel (aged 42) grappled with reconciling acceptance of residential care with her own moral orientation to care for her brother Jack (aged 39), despite believing that the care setting was more appropriate to his needs:

> He needed to be with people that he could relate to and have his friendships and his independent social life rather than being – I don't know – in a flat somewhere with me living on disability allowance.

ACCEPTED MANUSCRIPT

In recounting her reaction to Jack's transition into residential care she describes a battle between reason and emotion where she subjected her own behaviour to moral evaluation:

> … he was there for a long time before I could visit because I felt that it should be my responsibility to look after him if my parents couldn't. And I knew rationally that that was ridiculous… but I suppose I felt guilt about it because I felt that maybe I'm just saying that because I don't want to be a full-time carer.

Geraldine (aged 39), along with her ND brother, sought a residential placement for their brother Robert (aged 40) who has ASD, having spent three years as Robert's primary carers following the death of their widowed mother. Despite being in daily phone contact with Robert and having him to stay every second weekend, Geraldine continues to feel guilt for what she perceives as a moral breach of expected standards of family care:

> It's easy to say, you know, what your parents would want you to do is for you to look after your brother… and in some way I really would like to do that because no-one will look after him as well as his own family … and you want to care for him but it's so draining… It can be so isolating … Nobody wants to mind a challenging needs adult. … And there's that level of guilt that you will have, you know…

The self-conscious emotion of guilt, elicited when participants evaluated some aspect of their caregiving behaviour, appears frequently in the narratives. What appeared much less frequently was the other-directed emotion of anger. Tangney et al. (2007:360) draw attention to 'righteous anger' where anger is felt at morally repulsive behaviour directed not at the self but at another whose rights are perceived as being violated. This emotion, they suggest, frequently incites the observer or bystander to take action to address the perceived injustice. Inadequate care in the day service her brother James (aged 41) attends aroused righteous anger in his sister Annie (aged 45). In explaining her response to the dangerous situation James was exposed to Annie noted that 'It's all done now and it's sorted. But in order to get this care for him I did have to get very cross with some people.'

As the examples above show, when making care choices siblings undertake evaluative judgement of their own behaviours, which is informed by perceptions about obligations to care and about what constitutes good care or appropriate care. As such, decisions about care have emotional resonance, with guilt, other-oriented empathy and righteous anger emerging as the key emotions in the narratives of the siblings. How these emotions are managed, how they shift and change as biographical and social contexts evolve and what

implications they have for the wellbeing of sibling carers, are examined in the next section.

6. Managing care biographies – negotiating the emotional complexities of care

Conflicts in negotiating autonomy and relatedness were reflected in the narratives of many participants who were consciously reflecting on how to balance their orientation to care for their sibling with other relationships, responsibilities or opportunities. Many of the younger participants expressed concerns about how their anticipated care roles might impact on their life choices and biographies. Aoife (aged 24), only sibling of Seamus (aged 22) who has a rare syndrome, expressed this concern in terms of a challenge in balancing her needs with those of her brother:

> I worry about how I can best look after Seamus and make sure he lives his best life, while also having one of my own.

The potential limitations that caring for her sister Niamh (aged 20) with ASD would impose on her life were also being reflected on by Líosa (aged 22). Her narrative depicts an ongoing process of moral deliberation around about future care plans:

> Originally before I went to college, I was like great, I'm going to go home, going to mind her [Niamh] for the rest of my life. A husband – that's fine - we'll put that in there. But now I don't know what's going to happen because, do you know, I've kind of realised, like, you know, she'd have to come down here. So she'd have to move or I'd have to move and I don't know how she'd feel about that, would she be stressing out and stuff. So I'm not really too sure about what's going to happen now.

Some participants who had already assumed care roles experienced what Dellve et al. (2000:172) referred to as harmonizing dilemmas, where they struggled to reconcile orientations to care with emergent aspirations and responsibilities. A number of younger participants who foresaw themselves being the most involved sibling in the future and who were single at the time of interview were conscious of needing to consider future care responsibilities when choosing partners. David (aged 32) explained that acceptance of his sister (Laura aged 35 with ID) would be a 'prerequisite' for any relationship, while Sarah (aged 22) expressed a similar sentiment but was cognisant of the significance of such a demand:

> It's a massive ask to put on someone else and sometimes I don't know if it's fair. So I don't know what way that'll go.

ACCEPTED MANUSCRIPT

Geraldine (aged 39), sister to Robert (aged 40 with ID), acknowledged that concerns about her capacity to manage any additional relationship demands was a factor in her remaining romantically unattached:

> I've sheltered myself away from opportunity [to have relationships]. I can't blame Robert. But it does obviously play a big part in it… It's so stressful, the last thing you want to do is put up with somebody else coming in who has their own needs and expectations.

A dilemma between a desire to be a parent and anticipatory guilt about the demands that would impose on her ability to support her sister and her ageing parents was expressed by Christine (aged 34), who is heavily involved in the care of Fiona (aged 17) who has profound ID and complex medical needs:

> …I do someday want to have a child. But how would I do both? How would I do okay by her [Fiona] and by a child… So yeah, that would be a worry for me. And the guilt. ... And it's the sense of duty, the sense of responsibility. The <u>wanting</u> to do it, it's not that you don't want to, but it's very hard then when that comes into conflict with the other relationship.

The guilt and sadness associated with decisions to step out of, reduce or refuse care roles was flagged by some participants. Marion (aged 32) who was

actively involved in supporting her brother Sean (aged 29) with ASD, told her parents that he cannot live with her in the future:

> I just had to sit them [parents] down and say 'If I take Sean I can't have a family of my own.' I think they were so shocked. They were like, 'Oh my God, we would never do that and we didn't expect it.' But I think that deep down they hoped... Like I really feel guilty about that. A lot of people do.

In a context where cultural scripts emphasise the primacy of the parent child bond, new parenthood was particularly challenging for siblings involved in caring and often resulted in renegotiation of care responsibilities. Carmel (aged 42), who has a 20-month-old son, felt guilty about being able to spend less time with her brother Jack (aged 39) who has severe ID, but was committed to re-establishing more contact in the future:

> I was always much more hands-on… I'm aware of that and I'm aware that I don't want that to be the long term.

The extracts above suggest that contemplating new relationships and responsibilities was clearly perceived as challenging by many participants. Some participants who were actively engaged in balancing the moral

orientation to care with competing relational demands acknowledged that they grappled with feelings of resentment. Anna (aged 30), brother to Peter (aged 29) who has Downs Syndrome, reflected on how she coped with occasional feelings of resentment in a way which was compassionate to herself and avoided negative self-evaluation:

> There are times I've felt a little bit of resentment that he has held me back … and of course you feel guilty. He's special needs… It's not his fault. Aren't I a bad person for thinking that? … I kind of had to come to my own acceptance of it, that it's a very human emotion. … It doesn't define your relationship. ... It's fleeting. It'll come, it'll go.

Other participants recounted how they sought professional support to deal with the emotional distress associated with negotiating or managing their carer identities. The significance of having a choice about whether or not to care was identified by Angela (aged 32), who at times felt 'bogged down' by responsibilities to her brother Patrick (aged 30) who has mild ID. She explained how counselling helped her recognise that she had a choice about caring and enabled her to reconcile her own needs with her sense of responsibility for, and connection to, her brother:

> …I do have a choice and I do at times, when I need to, take a step back and stuff like that for my own happiness and wellbeing… I could never just walk away.

Angela's adoption of self-care practices reflects an assertion of self-love which Pulcini (2017:67) argues challenges notions of sacrificial or selfless caring. Christine (aged 34), sister to Fiona (aged 17) who has severe ID and epilepsy and requires 24-hour monitoring, also contested the idea of carer selflessness, asserting the duty of all individuals to attend to their own needs. She drew on professional support to help her manage her own wellbeing and deal with her mother's sadness and distress:

> It's very difficult and, you know, I certainly have been down about it and depressed about it and everything. But I'm learning to … I've gone for counselling myself, you know, to try and come to terms with it and try to deal with my mum and try to not let that kind of constantly get in on me. … you've a duty to kind of make the most of your life.

That participants moved outside of the family to seek help with addressing emotional dynamics is consistent with previous findings that the emotional overlay of caregiving remains largely hidden and unspoken.

7. **Discussion**

This research suggests that a methodological approach which renders emotions as objects of study can be fruitful in illuminating various dimensions of caregiving. These include the ways in which individuals make decisions about caregiving, how they evaluate it, how they make sense of it, and indeed, how they seek to manage or negotiate it.

The data presented here suggest that a relational sense of self is a key motivator of care. Consistent with previous research (Doody et al., 2010; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007) into sibling relations where one has ID/ASD, our analysis of the narratives of ND siblings highlighted that the shared spaces and practices of childhood created close emotional bonds with brothers and sisters with ID/ASD and a heightened sensitivity to their needs and feelings. These connections, reflective of love relations (Lynch, 2009:413) characterised by 'high interdependency, strong attachment, intimacy and responsibility over time', underpin the moral ethic to care exhibited by many participants. Siblings who described less strong attachment to their brother or sister envisaged less involved care relationships in both an emotional and practical sense. While some siblings envisaged care as financial support and/or occasional meetings, most understood it to involve close engagement in the lives of their brothers or sisters informed by awareness of their needs and sensitivity to how they experience things. Attention to

emotions and relationships would thus appear to be useful in understanding why siblings raised in the same families display different dispositions in relation to caring for brothers or sisters with disabilities. The different orientations to care experienced by siblings suggests that in families with more than one ND sibling, it is likely that these siblings will envisage or assume different types of care roles *vis a vis* their brother or sister with ID/ASD. Awareness among service providers and professionals, and indeed among family members, of possible variations in siblings' senses of moral responsibility would provide a starting point for exploring what roles, if any, individual siblings may be comfortable in assuming in the lives of brothers or sisters with ID/ASD.

The detailed exploration of the moral emotions (Tangney et al., 2007) implicated in the caregiving engaged in by participants in this study sheds light on the types of care they engage in and draws attention to the emotional resonance which siblings attach to the care being received by their brother or sister with ID/ASD. Where care was provided, and who provided it, were key concerns for siblings. Care practiced by someone with whom the recipient had a close relationship, i.e. care out of love, was perceived as more morally acceptable than paid care or care work. The focus in this work on sibling dyads, as distinct from parent-child or spousal dyads, in which there is a strong

social expectation of continued caregiving, allows for consideration of how relational obligation is continually negotiated as people move through the life course from young to middle adulthood. The data presented indicates that siblings engaged in ongoing moral evaluation of their own care behaviours, and frequently experienced guilt about what they perceived as their less-than-ideal care practices. Dilemmas between autonomy and relatedness caused siblings to grapple with feelings of resentment and guilt and many struggled to exercise self-compassion in the face of perceived moral failings. Others experienced conflict characterised by a struggle to reconcile competing care roles related to their intimate relationships. Through ongoing self-evaluation of their care behaviours, siblings' moral identities were continually reconstituted. This understanding of caregiving as an ongoing, fluid negotiation of moral choice, in which emotion is intrinsically embedded, allows for acknowledgement of the emotional and relational tensions that can threaten the provision of good care which is cognisant of the needs of both care provider and care receiver. It also provides opportunities for thinking about how statutory care packages and support services can be designed to accommodate the changing care roles which siblings might assume at various life stages. Policy moves toward personalisation of care and individualised budgets may provide siblings with ways of allowing paid-others to assume

certain care tasks in ways that are compatible with their moral orientation to care for their brother or sister. It is, of course, imperative that those with ID/ASD are consulted in as far as practicable given their capacity for communicating their needs, when care choices are being made. Consultation with people with ID/ASD about where, how and from whom they want care and support may help their siblings re-evaluate the standards of care to which they hold themselves.

Finally, a methodological focus that considers emotions as objects of study, provides insights into how caregivers make sense of and strive to manage the moral and emotional dilemmas they experience in relation to their caregiving. The range of emotions identified by participants in this study included empathy, guilt, anticipatory guilt, resentment, righteous anger and self-love. Untangling and naming the emotions experienced by siblings opens up spaces for understanding how they experience, make sense of and try to manage their caregiving. Opportunities need to be afforded to siblings to explore and voice their emotions and talk through the moral dilemmas they experience around their care roles. Given the high proportion of women who are involved in caregiving, providing such opportunities must be a vital micro-element of wider attempts to change the gendered order of care relations. Research with sibling carers exploring what such opportunities

might look like and how they could best be provided would be useful.

8. Study limitations

A number of limitations have been identified in this study. The exclusive focus on the perspectives of ND siblings means that the voice of only one party in the sibling dyad is captured in this work. The diversity of the participant sample is limited in terms of gender and class given that only five participants were male and all participants had completed or were pursuing a third-level qualification. The recruitment of participants through a disability organisation network inhibits participation from siblings in families who have not engaged with such organisations. Nonetheless, the data set succeeds in providing detailed insight into the complexities of caregiving as experienced by ND siblings.

9. Conclusion

In conclusion, attention to the emotional dynamics of care as played out over time and place can inform the development of policy and practice that is sensitive to the needs of ND siblings striving to negotiate moral practices of care. Supports devised for this cohort must be cognisant of their competing

responsibilities and aspirations and of the gendered, cultural and policy expectations that shape localised care regimes for people with ID/ASD.

References

Atkin, K. and Tozer, A. (2015) Personalisation, family relationship and autism: Conceptualising the role of adult siblings. **Journal of Social Work,** 14 (3), 341–351.

Atkin, K. and Tozer, A., & Wenham, A.M. (2014) My brother likes meeting new people, but don't ask him any direct questions': involving adults with autism plus learning disability in a qualitative research project. **British Journal of Learning Disabilities**, 4 (42), 292-300.

Barron, S., McConkey, R. & Mulvany, F. (2006) **Journal of Policy and Practice in Intellectual Disabilities**, 3 (2), 87–94.

Benderix, Y., and Sivberg, S. (2007) Siblings' experiences of having a brother or sister with autism and mental retardation: a case study of 14 siblings from five families. **International Paediatric Nursing**, 22, 410 – 418.

ACCEPTED MANUSCRIPT

Bigby, C. (1997) When Parents Relinquish Care: Informal Support Networks of Older People with Intellectual Disability. **Journal of Applied Research on Intellectual Disabilities,** 10 (4), 333-344.

Bondi, L. (2005) The place of emotions in research: from partitioning emotion and reason to the emotional dynamics of research relationships. In Davidson, Joyce, Bondi, Liz, Smith, Mick (eds). **Emotional Geographies**. Ashgate, Aldershot, 231-246.

Braun, V. & Clarke, V. (2006) Using Thematic Analysis in Psychology. **Qualitative Research in Psychology,** 3 (2), 77-101. doi.org/10.1191/1478088706qp063oa.

Brennan, D., Murphy, R., McCallion, P. & McCarron, M. (2018) "What's going to happen when we're gone?" Family caregiving capacity for older people with an intellectual disability in Ireland. **Journal of Applied Research in Intellectual Disabilities**, 31, 226–235. https://doi.org/10.1111/jar.12379.

Chadwick, D., Mannan, H., Garcia Iriarte, E., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. & Harrington, G. (2013) Family Voices: Life for Family Carers of People with Intellectual Disabilities in Ireland. **Journal of Applied Research in Intellectual Disabilities**, 26 (2), 119-132.

Chatoo, S., Ahmad, W. I.U. (2008) The moral economy of selfhood and caring: negotiating boundaries of personal care as embodied moral practice. **Sociology of Health & Illness**, 30 (4), 550-564.

Coppus, A.M.W. (2013) People with intellectual disability: What do we know about adulthood and life expectancy? **Developmental Disabilities Research Reviews**, 18 (1), 6–16.

Davys, D., Mitchell, D. and Haigh, C. (2010) Future planning, parental expectations and sibling concern for people who have a learning disability. **Journal of Intellectual Disability**, 14 (3), 167-183.

Davys, D., Mitchell, D and Haigh, C. (2014) Futures planning: Adult sibling perspective. **British Journal of Learning Disabilities**, 43, 219-226.

Davys, D., Mitchell, D. and Haigh, C. (2016) Adult Siblings Consider the Future: Emergent Themes. **Journal of Applied Research in Intellectual Disabilities**, 29 (3), 220-230.

Dellve, L., Cernerud, L., Lillemor, R.-M. Hallberg. (2000) Harmonizing dilemmas: siblings of children with DAMP and Asperger Syndrome's experiences of coping with their life situations. **Scandinavian Journal of Caring Sciences,** 43, 172-178.

Department of Health, (2012) **Value for Money and Policy Review of Disability Services in Ireland.**

Doody, M.A., Hastings, R.P., O'Neill, S. and Grey, I.M. (2010) Sibling relationships in adults who have siblings with or without intellectual disabilities. **Research in Developmental Disabilities,** 31, 224-231.

Evans, R. Thomas, F. (2009) Emotional interactions and an ethics of care: Caring relations in families affected by HIV and AIDS. **Emotion, Space and Society,** 2 (2), 111-119.

Feshbacch, ND. (1975) Empathy in children: some theoretical and empirical considerations. **Counselling Psychology**, 5, 25-30.

Finch, J. & Groves, D. (1983) **A Labour of Love: Women, Work and Caring**. Routledge, London.

Gilligan, C. (1982) **In a Different Voice: Psychological Theory and Women's Development.** Harvard University Press, Cambridge, MA/ London.

Gilligan, C. (2011) **Joining the Resistance**. Polity Press, Cambridge, UK/Malden, USA.

Gomez de la Cuesta, G. and Cos, M. (2012) **We exist too: Valuing the contributions of siblings,** National Autistic Society, UK.

Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M.W. (1999) Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. **Psychiatric Services**,

5, 1214–1219.

Haidt, J. (2003) Elevation and the positive psychology of morality. In Keyes, CL., and Haidt, J. (eds) **Flourishing: Positive Psychology and the Life Well-Lived**. American Psychological Association, Washington, 275-289.

Health Service Executive, (2011) ***Time to Move on From Congregated Settings***.

Health Service Executive, (2012) **New Directions**.

Held, V. (2006) **The ethics of care: Personal, political and global**. Oxford University Press, UK.

Heller, T. and Arnold, C.K. (2010) Siblings of adults with developmental disabilities: psychosocial outcomes, relationships, and future planning. **Journal of Policy and Practice in Intellectual Disabilities,** 7 (1), 16-25.

Herron, R.V., Skinner, M.W., (2013) The emotional overlay: Older person and carer perspectives on negotiating aging and care in rural Ontario. **Social Science & Medicine,** 91, 186-193.

Hodapp, R.M. and Urbano, R.C. (2007) Adult siblings of individuals with Down Syndrome versus with Autism: Findings from a large-scale US study. **Journal of Intellectual Disability Research,** 51 (2), 1018-1029.

Hourigan, S., Fanagan, S. and Kell, C. (2017) **HRB Statistics Series 37 Annual Report of the National Intellectual Disability Database Committee 2017 Main Findings.**

Hughes, N., Locock, L., Ziebland, S. (2013) Personal identity and the role of 'carer' among relatives and friends of people with multiple sclerosis. **Social Science & Medicine**, 96, 78-85.

Nussbaum, M.C. (2001) **Upheavals of Thought: The Intelligence of Emotions.** University of Chicago Press.

Inclusion Ireland (2017) **Submission to the Department of Health On homecare services in Ireland.**

Irish Times (2016), Aras Attracta manager successfully appeals prison sentence. Published October 26, 2016.

Kittay, E.F. (1999) **Love's Labour: Essays on Women, Equality and Dependence**. New York/London: Routledge.

Lynch, K. (2009) Affective Equality: Who cares? **Development,** 52 (3), 410–415. doi:10.1057/dev.2009.38

Makenzie, C., Stoljar, N. (2000) Autonomy refigured. In Mackenzie, C. and Stoljar, N. (eds) **Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self**. New York/Oxford: Oxford University Press.

Mansell, J. and Beadle-Brown, J. (2010) Deinstitutionalisation and community living: Position statement of the Comparative Policy and Practice Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities**. Journal of Intellectual Disability Research**, 54 (2), 104-12.

Matson, J.L. and Kozlowski, A.M., (2011) The increasing prevalence of autism spectrum disorders. **Research in Autism Spectrum Disorders**, 5, 418–425.

Nussbaum's (2001).

Milligan, C. and Power, A. (2010) The Changing Geography of Care, in Brown, T. McLafferty, S. and Moon, G. (eds) **A Companion to Health and Medical Geography**. Wiley/Blackwell, UK.

Orsmond, G.I. and Seltzer, M.M. (2007) Siblings of individuals with autism or Down syndrome: Effects on adult lives. **Journal of Intellectual Disability Research,** 51 (9), 682-699.

Power, A. and Bartlett, R., (2018) Ageing with a learning disability: care and support in the context of austerity. **Social Science & Medicine**, https://doi.org/10.1016/j.socscimed.2018.03.028

Pulcini, E. (2017) What emotions motivate care? **Emotion Review,** 9 (1), 64-71.

Riessman, C.K. (1993) **Narrative Analysis**. Thousand Oaks, Sage.

Seaman, A.T. (2018) The consequence of “doing nothing”: Family caregiving for Alzheimer’s disease as non-action in the US. **Social Science & Medicine,** 19 (7), 63-70.

Tagney, J.P., Stuewig, J. and Mashek, D.J. (2007) Moral emotions and moral behaviour. **Annual Review of Psychology,** 58, 345-372.

Taylor-Gooby, P., Leruth, B. and Chung, H. (2017) **After Austerity: Welfare State transformation in Europe after the Great Recession**. Oxford University Press, Oxford.

Tozer, A., Atkin, K. and Wenham, A. (2013) Continuity, commitment and context: adult siblings of people with autism plus learning disability. **Health & Social Care in the Community**, 21 (5), 480-488.

Tozer, A. & Atkin, K., (2015) ‘Recognized, valued and supported’? The experiences of adult siblings of people with autism plus learning disability. **Journal of Applied Research in Intellectual Disabilities**, 25, 341-351.

Tronto, J.C. (1993) **Moral Boundaries: A Political Argument for an Ethic of Care**. Routledge, New York/London.

Tronto, J.C. (2013) **Caring Democracy: Markets, Equality and Justice.** New York University Press, New York/London.

Wiles, J. (2003) Daily geographies of caregivers: Mobility, routine, scale. **Social Science and Medicine**, 57, 1307-25.

ACCEPTED MANUSCRIPT

Acknowledgements

I wish to acknowledge and thank my colleagues, Dr Claire Edwards and Dr Anna Kingston, for their contribution to the research on which this paper is based. Sincere thanks also to the reviewers for very helpful comments, to Inclusion Ireland for help with sourcing the research sample and to the National Disability Authority who funded the project.

ACCEPTED MANUSCRIPT

ACCEPTED MANUSCRIPT

RESEARCH HIGHLIGHTS

- Explores care practices and aspirations of siblings of people with ID/ASD
- Reveals how moral emotions of guilt, anger and self-compassion shape the moral identities of carers
- Argues that looking at care from the perspective of emotions can inform supports for carers

ACCEPTED MANUSCRIPT