**Siblings’ caring roles in families with a child with epilepsy**

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**Abstract**

Despite large amounts of care for chronic conditions being provided within the family, information regarding the extent to which siblings contribute to informal care practices in families where a child has a chronic condition is limited. This paper draws on multiple perspective data from 24 families that had a child with epilepsy. In doing so, the paper illustrates siblings’ significant contribution to caring for their brother or sister and further develops the alert assistant concept. Two additional distinct caring roles that the siblings took on are also outlined – the substitute parent and parenting assistant roles. The relationship between siblings’ socio-demographic characteristics and their caring responsibilities is also explored. Indeed, it was found that siblings who were older, female and those in families with a higher child to parent ratio took on more caring responsibilities. Consequently, this paper contributes to the currently limited literature on siblings who care for a chronically ill brother or sister by increasing understandings of different caring roles and experiences of chronic illness in families.

**Children and Informal Care within the Family**

Family members undertake the majority of informal care tasks associated with chronic illness and disability, including monitoring or administering medications, providing personal care and carrying out daily chores (Arber and Ginn 1999; Chambers 2012). The majority of research in this area has been on the care work provided by adults, often within the home for elderly relatives, spouses or children; however, it is important to acknowledge that children also contribute to the informal care provided within families.

Children’s care work can be defined in a number of ways and Frank (2002) argues that there is a‘continuum of care’ on which all children can be placed, with some children providing small amounts of care and others taking on high levels of caring responsibility. Using a broad definition, such as that put forward by Weisner and Gallimore (1977), helps to incorporate such variation. Indeed, Weisner and Gallimore describe children’s care work as:

Activities ranging from complete and independent full-time care of a child by an older child to the performance of specific tasks for another child under the supervision of adults or other children. (1977: 169)

However, although this definition is broad, it seems to be somewhat incomplete as it is located within an adult-centred or hierarchical rhetoric that does not account for the fact that children provide care for adults and older children, as well as younger children.

Despite Weisner and Gallimore (1977) defining children’s informal care work, this topic has been overlooked from an academic standpoint for a long time (Kosonen 1996; Morrow 2008). Indeed, Morrow argues that:

The fact that childhood is constructed as a period of dependency prevents us from ‘knowing’ about those cases of children undertaking domestic work because such work, particularly caring, is socially defined as an adult role and is a marker of adult status. (2008: 111-2)

Consequently, there is a limited amount of research into children’s experiences of providing informal care.

Of the research that has been conducted, some have focused on ‘babysitting’ and found that the care work that siblings took on formed a significant part of the informal care provided within families (Kosonen 1996; Morrow 2008). Indeed, Morrow highlights the level of responsibility that children took on when caring for a brother or sister by arguing that ‘children who babysit are symbolically and socially (but not legally) taking over the role of parent for a period of time’ (2008: 114).

The only other literature exploring children’s informal care work is that focusing on children who are officially recognised as ‘young carers’1 and take on high levels of caring responsibility (Aldridge and Becker 1993; Frank 2002; Underdown 2002; Dearden and Becker 2004; Warren 2007; Aldridge 2008; Smyth et al.2011; Wihstutz 2011). Most young carers provide care for a parent with a chronic illness or disability, but a smaller number care for siblings (Dearden and Becker 2004). Within this literature, it has consistently been found that the nature of the condition of the person being cared for influenced the type of care provided (Aldridge and Becker 1993; Frank 2002; Dearden and Becker 2004; Smyth et al.2011). Additionally, similarly to the gendered nature of informal care work among adults (Arber and Ginn 1999; Sullivan 2000), girls have been found to provide more care than boys (Aldridge and Becker 1993; Dearden and Becker 2004). Some have also argued that older children take on more caring responsibilities (Dearden and Becker 2004; Smyth et al.2011), but others have found that age is not necessarily a factor that influences the level of care provided (Aldridge and Becker 1993). Furthermore, social circumstances have been found to impact on children’s care work, as having a larger familial social support network appears to reduce children’s workload (Dearden and Becker 2004; Aldridge 2008; Smyth et al. 2011).

Most research on young carers is policy focused and within this literature caring for siblings has not been explored in detail. Moreover, to date, there is very little research on children who are not officially recognised as young carers by social services but still provide care for family members with chronic conditions. Furthermore, Knecht et al. (2015) have argued that the different care-taking roles undertaken by siblings should be looked into in more depth. As a result, one aim for this paper is to begin to address this gap in the literature by detailing the informal caring roles that siblings in families with a child with epilepsy described. Furthermore, building on the literature on young carers, associations between siblings’ socio-demographic characteristics and their care work will be explored. This paper will also contribute to the literature on siblings’ experiences of having a chronically ill brother or sister, and it is to this literature that I now turn.

**Siblings and Chronic Illness**

Discussions on experiences of chronic childhood conditions within the family rarely detail siblings’ experiences (Wilkins and Woodgate 2005; Knecht et al. 2015). Some psychological studies have focused on siblings’ well-being (Moyson and Roeyers 2012) and two exceptions within the sociological literature are Dixon-Woods et al.(2005), who looked at families with a child with cancer, and the work of Bluebond-Langner (1991) who focused on families with a child with cystic fibrosis. Both detailed the negative implications of having a brother or sister with a chronic condition on siblings. For example, Bluebond-Langner (1991) described how siblings often felt jealous of the attention the ill child received, which has also been noted elsewhere in relation to children and young people with brothers or sisters with different chronic conditions (Van Riper 2003; Wilkins and Woodgate 2005).

There is, however, another side to the sibling relationship; the caring element is also a defining feature of siblings’ interactions and relationships with one another (Edwards et al.2005; Mauthner 2005; Sarre 2010). Wilkins and Woodgate (2005) note that siblings can gain a sense of pride when they are able to assist their brother or sister; however, the impact of chronic illness on the caring aspect of the sibling relationship has not been explored in detail. The purpose of this paper is therefore to explore the extent to which caring tasks featured in siblings’ descriptions of their experiences of having a brother or sister with epilepsy.

Turning to the condition of epilepsy more specifically, the literature on managing childhood epilepsy within the family has generally explored parenting a child with epilepsy and the focus has largely been on how parents concealed their child’s condition from others in order to protect the child and wider family from being stigmatised by the condition (Schneider and Conrad 1983; Scambler 1989). This paper, however, explores the caring roles and responsibilities that featured in siblings’ descriptions of their experiences.

**Methodology**

The data presented within this paper are drawn from a broader qualitative study on the experience and management of childhood epilepsy within the family. The focus of the data presented here is the perspective of children who had a brother or sister with epilepsy and their parents (the children with epilepsy’s views are detailed in Webster, 2016). During 2013 the research was advertised through seven UK based charities. The charities placed adverts on their websites, online forums, social media pages, and in their newsletters. All those who volunteered to take part in the study were included in the sample and the research was re-advertised and data were collected until saturation point was reached. In total, 24 families took part in the research. In 14 of these families the child with epilepsy was being treated with medications and in the other 10 the child was being treated with a combination of medications and the ketogenic diet.

In total, 28 parents (24 mothers and 4 fathers) and 14 siblings participated in the research. These families were living in households that ranged in size from three to six people. The majority were two parent families, two of which were stepfamilies, and two were single parent families. The majority of parents self-defined as White British and only two families that provided data had an income below the national average. Five of the siblings were male, nine were female and they ranged in age from six to 16 years. Furthermore, eight of these siblings were older than the child with epilepsy, five were younger and one was a twin.

In the families using only medications for treatment, firstly, a group interview with the parent(s) and their children was conducted (14 in total, including 14 mothers and two fathers. In one family the child with epilepsy did not participate and in another the sibling did not take part). Group interviews were included so that the children could to get to know the researcher before their individual interviews. Individual interviews were also conducted in order to give family members the opportunity to talk about their experiences in a more private setting. Semi-structured in-depth interviews were carried out with one or both parents in 13 of these families and lasted between half an hour and 2 hours. Lastly, autodriven photo-elicitation interviews were conducted with the children; 10 siblings participated in this stage of the research and their interviews lasted 20 minutes on average. (Due to attrition it was not possible to conduct the photo-elicitation interviews with all the children; the level of commitment needed to complete the research resulted in both lone parent families dropping out).

It was hoped that the same procedure could be followed in families using the ketogenic diet, but because it was only possible to recruit parents and one sibling in these families, one in-depth semi-structured interview was conducted in each family (10 in total; 10 mothers and two fathers participated).

The children’s interviews included a task in order to engage them and provide a stimulus for discussion. The children were given a single-use camera each and were asked to take photos on four topics: (i) Who I live with, (ii) What I like to do with my family, (iii) Food and meal times in my family and (iv) What epilepsy means to me. The age of the children and young people participating in the study varied considerably and, consequently, this methodological technique was chosen as it had been successfully employed with those aged 3-17 years (Cook and Hess 2007; Croghan et al*.* 2008). Furthermore, it has been argued that children find it easier to talk about topics when they have a visual prompt (Zartler and Richter 2014). Children have also been found to give more elaborate responses when they have photographs to refer to (Cappello 2005). The photos were not analysed, rather they were used to guide the interview; the children were asked to talk about their photos and as they sorted through the photographs the researcher asked questions about the people and activities that the children introduced. The researcher also used an interview schedule to ensure that similar topics were covered in each interview, but the children’s photos highlighted the significant aspects of their experiences (for detailed reflections regarding the use of photo-elicitation interviews with children see Webster 2017).

All interviews were conducted by the author, audio-recorded and transcribed *verbatim* by the author*.* The data were then coded using Nvivo and analysed using a constructivist grounded theory approach (Charmaz 2006). Codes were developed from the meanings in the participants’ speech and the researcher used the constant comparative method and wrote memos describing her thoughts on the developed categories and how they related to each other. Through the process of coding and memo writing, gaps in the developing theories emerged and the researcher was able to purposefully collect data to fill these gaps. Data collection continued until categories became ‘saturated’ (Charmaz, 2006).

Ethical approval was granted by the Centre for Criminology and Sociology’s ethics committee at Royal Holloway, University of London prior to beginning data collection. Each child participating in the study was sent an age appropriate information leaflet and consented to their involvement in the research. The children were also given copies of their photos as a thank you for their participation. In line with the ethical approval, participants and their family members are referred to using pseudonyms to maintain their anonymity.

Drawing on the siblings’ and parents’ interview data, the findings from the study are reported below. Where extracts from the children’s interviews are used or children are referred to, their age is given in brackets. Firstly, the three caring roles that the siblings took on are described. Next, the ways in which siblings’ socio-demographic characteristics appeared to be associated with their caring responsibilities are explained.

**Findings**

It has previously been argued that caring is one of the key aspects of the sibling relationship (Edwards et al.2005; Mauthner 2005; Sarre 2010). In almost all the families siblings and their parents described this caring aspect of the sibling relationship coming to the fore as a result of childhood epilepsy. Despite only one sibling in the 24 families being officially recognised by social services as a young carer, it was found that siblings in 20 of the 24 families, at times, provided care for their brother or sister who had epilepsy. Indeed, many took on specific caring roles, the first of which is discussed in the following section.

*Alert Assistants*

Charmaz (1991) originally used the term ‘alert assistant’ to describe those who help adults with a chronic illness to conceal their condition. Williams (2000) then developed the concept further when she explored the gendered aspect of care giving by mothers of teenage sons with asthma or diabetes. Williams (2000) described mothers as alert assistants when they identified or anticipated their sons’ needs and then met those needs. She also argued that this type of care work was often invisible and stated that the alert assistant concept could be developed further in other contexts. Here the concept is expanded by exploring the way in which age and children’s status was associated with the duties related to this role in the context of childhood epilepsy.

The alert assistant role in this context refers to the way in which siblings and their parents described them as monitoring their brother or sister with epilepsy for symptoms, recognising their seizures, alerting an appropriate adult and often caring for their brother or sister until an adult could be present. Consequently, here the ‘alert’ aspect of this role applies in two ways – firstly siblings were alert to their brother or sister’s symptoms and, secondly, they would alert an adult when their brother or sister was having a seizure. Although making others aware of their brother or sister’s condition seems to contradict the way in which Charmaz (1991) described alert assistants as helping someone to conceal their condition, Williams (2000) argued that informing others about providing appropriate care was a key feature of the alert assistant role.

Below Sarah is explaining how her daughter, Ellie (7), fulfilled the alert assistant role.

She was brilliant like because she’d be trotting along behind him [brother with epilepsy (11)] and just come running up to me and go ‘Mummy, Chris’s gone again’, when he had an absence [seizure]. And then she’d run back to him and stay with him until I got to him.

Similarly to the mothers described by Williams (2000), siblings’ care work went some way to meeting the needs of their brother or sister. However, when fulfilling this role, rather than caring for their brother or sister for the duration of the seizure, siblings would alert an adult who would then take over from them. Consequently, in this context, siblings were not only assisting their bother or sister, but also their parents. Indeed, parents described the trust they had in their children; for instance, Donna said ‘Layla [sibling (8)] will always watch out for him [child with epilepsy (5)]’.

Siblings did not necessarily take on this role automatically. In 13 of the 15 families where onset of the condition was spoken about in detail, parents explained that siblings did not immediately recognise their brother or sister’s behaviours as seizures. For example, Steve and Nicola spoke about one incident when their daughter, Chloe (6), had thought her brother, Zak (13), was ignoring her when he was actually having a seizure. However, in this instance Nicola and Steve taught Chloe to recognise Zak’s seizures to enable her to fulfil the alert assistant role. Below Chloe is describing her involvement in a particular incident when her brother, Zak, had a seizure in the garden.

What happened is he just started to just stare. And I knew, I went in [the house] and I said ‘Zak’s staring’. Because it didn’t look like, because about three seconds ago he was playing with us. So I just said ‘he’s staring’. Because I didn’t know if he was actually like having one or not. And Mum and Dad went out and they sorted it out while my friend got all her stuff together because she was going.

Here Chloe has explained that she recognised her brother’s symptoms and alerted her parents; for her, these two points are the central aspects of her story before her parents took over the responsibility of caring for her brother. Additionally, as Chloe’s description of this incident ended at this point, it suggests that she did not see herself as having any further role in the event.

Children described themselves, or were described by their parents, as fulfilling this role when they were not in the presence of their parents. Indeed, four of the children explained that they took on the alert assistant role at school when teachers did not notice their brother or sister’s seizures. This was particularly the case for the twin siblings that took part in this study, who were in the same class at school; in his individual interview, Elliot (8) explained that he would inform an adult when he saw his sister have a seizure at school:

Elliot: We get the nurse. And we get one of our really nice teachers, called Mrs. Murfitt, and if it’s really bad we get Mrs. Murfitt and Mrs. Murfitt calls my Mum.

I: So do you sometimes tell the teachers if you see her having one?

Elliot: Yeah.

Therefore, Elliot felt that he took on the alert assistant role when his parents were not present, even though other adults were.

Six parents spoke about how siblings filling this role meant that they could allow the child with epilepsy more freedom from parental supervision than they may have otherwise been afforded. For instance, Kate said that when her family were on holiday, although the park was very close by, she would not have let her son play there by himself in case he had a seizure. Kate explained, ‘I said that they could go and play in there. I said ‘you [sibling (13)] really do have to watch him [child with epilepsy (7)]’’. In this instance, the child with epilepsy was able to play in the park without his mum because his sister was there to monitor him. Therefore, in line with Charmaz’s (1991) definition of the alert assistant, siblings taking on this role may have helped the children with epilepsy to pass, as always being accompanied by an adult may have drawn attention to their condition.

The examples given thus far also illustrate what Williams referred to as ‘muting the effects of the illness’ (2000: 261), as the children with epilepsy were able to continue with their daily activities without being supervised by an adult because their brother or sister was acting as an alert assistant. Furthermore, in much the same way that Williams (2000) argued that the work of alert assistants was often invisible to the outside world, siblings fulfilling the monitoring aspect of this role often went unnoticed by those outside the immediate family. However, in contrast to Williams (2000) who found that alert assistants’ work was also invisible to the child with the chronic illness, this was not always the case in this study, as seven parents, at times, informed their child that they needed to stay with their brother or sister in case they had a seizure. The alert assistant role in this context also differs to the way in which the role has been described previously, as siblings were not only assisting their brother or sister, but also their parents, as was described above. As well as the alert assistant role, six siblings also took on the role of a substitute parent, which is discussed in the following section.

*Substitute Parents*

The substitute parent role entailed a sibling taking on the primary caring responsibility for the child with epilepsy when a parent was not present, rather than transferring that responsibility to an adult when necessary, as was the case with the alert assistant role. In two families where siblings took on a number of responsibilities related to the role, parents referred to the sibling as a ‘mini mum’ or taking on a ‘mum role’. For instance, Anita explained:

She [Natalie (14)] is like a mini mum. Obviously I’ve just finished my nurse training and I’ve had to rely on her a lot really … I don’t like her [sister with epilepsy (12)] cooking on her own. She does if I’m here, but Natalie will cook for her and stuff like that. Because pans of hot water if you’re making pasta and stuff, if you have an absence [seizure] isn’t great so yeah, you know, Natalie is like a mini mum.

Similarly to the way in which Mauthner (2002) described the care sisters provide as ‘minimothering’, Anita’s use of language suggests that this type of care can only be provided by females. Although mothers were the primary caregiver in all of the families, it was found that fathers provided the same or similar types of care, just less frequently; consequently, siblings taking on these responsibilities are referred to as substitute parents rather than substitute mothers.

Natalie supported Anita’s assertion that she provided a substantial amount of care for her sister, Lydia. The photographs Natalie had taken relating to epilepsy were mainly of comments she had written about the responsibilities she took on when caring for her sister. For example, when explaining one of these comments she said:

That’s what I have to do every morning, I walk her to and from school. And I cook Lydia’s tea if my mum’s at work or whatever. And then I look after Lydia all the time because of her epilepsy.

Natalie was Lydia’s only sibling and, as the extracts suggest, Natalie and her mum felt that she took on a number of practical responsibilities when caring for her sister.

Zoe (16) explained that she took on a similar role in her house. However, when describing her responsibilities, she also included measuring her sister’s medication and ensuring that her sister took her medication when her mum was not home. Below Zoe is explaining that she also took on this responsibility when adults other than her mum were present.

My Nan, like when she first started giving it [medication] to her [sister with epilepsy (9)] and that, like when we stay there she always was like worrying. She’s like ‘is it right? Is it right?’ And telling me, and I’m like ‘yeah’.

Much like the siblings who fulfilled the alert assistant role when other adults were present, Zoe was able act as a substitute parent because she had the necessary experiential knowledge that she had gained from taking on these responsibilities in the home on a daily basis.

Siblings also took on other responsibilities as part of the substitute parent role. Most commonly, all substitute parents would care for their brother or sister whilst they were having a seizure, as the following extract from Nathan’s (11) interview demonstrates.

Nathan: Usually I would stay with him [brother with epilepsy (9)] because I wouldn’t like Isaac to have one on his own, so I would stay with him. But after it me and Isaac would go tell that it’s happened … There’s nothing much we can do apart from sit with him and just talk to him.

I: What sort of things might you say to him?

Nathan: Just telling him it’s OK, it will be over in a bit. Things like that.

Here Nathan illustrates that the substitute parent role could incorporate the provision of emotional care work. Additionally, as Nathan explained, substitute parents would care for their brother or sister during a seizure and inform a parent afterwards. In contrast to this, alert assistants would alert an adult during the seizure. Although many of the features of the substitute parent role align with Williams’ (2000) definition of an alert assistant as someone who meets the needs of the person with the chronic illness, it has been deemed necessary to distinguish between these two roles as a result of the level of care provided and the amount of responsibility siblings took on when fulfilling the substitute parent role.

Siblings in five of the 10 families using the ketogenic diet also acted as substitute parents by ensuring that their brother or sister on the diet did not consume restricted foods. Furthermore, in one family the sibling took on responsibility for preparing her sister’s meals when her mother was not present, as Grace (11) explained:

Grace: Well, I would always know things that Faye [sister with epilepsy (9)] would like to eat in the diet so I could always prepare it or make it if Mum [Ellen] was away or going out somewhere or busy in the office. Or just wanted a break. [Laughs]

I: So you knew how to make some of the meals?

Grace: I knew how to make most of them and I could, using …

Ellen: That chart. That exchange …

Grace: Using, yeah, we had an exchange thing and I loved making up new menus and dishes for Faye. So I could easily just put something together if we didn’t have the right amount of courgette or banana or blueberries.

Here Grace is describing that not only did she follow ketogenic recipes, but she could also create new meals by substituting one food for another whilst still ensuring that the meal was of the correct nutritional value. Importantly, Grace also emphasises that she did this when her mum was not available to make her sister’s meals. Like many siblings, Grace continued to fulfil this role when other adults, in theory, had responsibility for their brother or sister. For instance, Ellen said ‘when Peter [husband] and I went away for a week my mother did the diet for a week but Grace actually really did it’. We can see Ellen’s pride in her daughter for the skill and care that she was able to demonstrate and the family went on to explain that the grandmother would have given Faye the same meal every night and that Grace had cooked for her sister so that she could eat something different. This story again illustrates that siblings who took on the substitute parent role often possessed practical skills relating to their brother or sister’s condition and/or treatment, and were consequently in a position to provide care when other adults were unsure. Furthermore, the detailed knowledge siblings had about their brother or sister’s likes and dislikes, which other adults sometimes did not possess, meant that they were able to provide personalised care.

It was found that siblings would sometimes care for their brother or sister differently depending on the type of seizure they were having or the situation in which their brother or sister’s seizure occurred. For example, when at home, Elliott (8) would alert his mum if his sister, Molly (8), had a tonic clonic seizure2, but if she had a ‘crinkle’ (a type of focal seizure3) he said he would ‘just hug her until it ends’. However, when at school Elliott said he would tell a teacher if Molly had any type of seizure. Therefore, although the alert assistant and substitute parent roles were different, six of siblings alternated between the two depending on the situation or the type of seizure their brother or sister was having.

The final way in which siblings supported their parents in caring for their brother or sister was by fulfilling the parenting assistant role, which is discussed below.

*Parenting Assistants*

Both parents and siblings explained that parenting assistants helped parents to implement care regimes or tried to ensure that their brother or sister was included in family practices despite their condition and/or treatment. Importantly, when taking on this role siblings aided their parents while their parents took the lead. The role of parenting assistant differed to the alert assistant and substitute parent roles because siblings would fulfil this role when their parents were present.

In one family using the ketogenic diet siblings acted as parenting assistants by encouraging their sister to comply with her treatment regimen by having their blood tested and also taking a mineral supplement so that their sister did not feel singled out. Additionally, siblings in 3 of the 10 families using the ketogenic diet assisted their parents by coming up with ketogenic meals when their parents were struggling. For example, Rachel said:

Emily [sibling (10)], you know, sometimes when I’ve been wracking my brains thinking ‘oh God, what can I give her [child with epilepsy (5)] next?’ And I’ve said to my husband ‘what can I give her?’ And he’ll come up with some really ridiculous answer and then Emily will say ‘well, what about if you put some butter in’, because she’s seen me preparing things. And she’s actually come up with some really good ideas.

Rachel’s extract helps to explain why siblings were able to provide personalised care for their brothers and sisters; through observing parents they were able to hone their caring skills. Consequently, it is reasonable to suggest that acting as a parenting assistant enabled siblings to go on to successfully fulfil the alert assistant and substitute parent roles.

Siblings also fulfilled the parenting assistant role by waiting outside for ambulances or fetching items for their parents whilst their brother or sister was having a seizure. For instance, Catherine said ‘they [siblings] just sort of stand back or if I need help if Leon [partner] isn’t here they’ll run and get a cushion. You know, they’re just there’. Therefore, once siblings had fulfilled the alert assistant role they would sometimes then take on the parenting assistant role. Alternatively, siblings could be called upon to fill this role when they had not been the person to notice their brother or sister’s seizure.

Parents in 18 of the families spoke about how grateful they were for the support that their children provided; for instance, Kate explained ‘afterwards I spoke about it [seizure] and I said ‘thank goodness you were there Amelia (13), because you really helped keep me calm’’. Therefore, it was not only the practical support, but also the emotional support that parents appreciated.

Above, it was shown that the nature of the child’s condition and also the context within which a seizure occurred influenced the caring roles that siblings took on. An additional influence on siblings’ caring responsibilities was their socio-demographic characteristics, which is the focus of the next section.

*Socio-Demographic Characteristics and Siblings’ Caring Roles*

Although siblings in 20 of the 24 families provided some care for their brother or sister, it was found that certain socio-demographic characteristics were associated with higher levels of care. Age seemed to influence the level of responsibility taken on; of the siblings as a group it tended to be those who were at the younger end of the age spectrum who only took on the alert assistant or parenting assistant role, whereas those who were older were more likely to take on the broader substitute parent role. This appeared to be linked to parents’ perceptions of the competencies and abilities that children are deemed to develop as they age. For example, Kate said ‘now Amelia’s (13) a bit older, obviously she’ll help’, highlighting the importance parents placed on age. Furthermore, although parents were proud of their children for caring for their brother or sister with epilepsy, as was evident in Ellen’s extract above, there was also an internal tension, as some parents also discussed not wanting to burden their children with too many caring responsibilities. For instance, Steve commented ‘she’s fully aware of it. But with that comes the responsibility, and again you wouldn’t really in an ideal world want to put that kind of responsibility on a six year old’.

Although the alert assistant and parenting assistant roles did not appear to be gendered, as male and female siblings seemed equally as likely to fulfill these roles, with regard to the substitute parent role it seemed that gender was related to the extent of the care work taken on by siblings. There were four female siblings and two males siblings who, at times, took on the substitute parent role; however, the girls took on more caring tasks than the boys. The two male siblings who took on this role would care for their sibling during a seizure but did not take on any further caring responsibilities. The female siblings, however, also cooked for their brother or sister, measured and/or administered their medications and provided emotional support beyond the time when seizures occurred. Consequently, it appears that, in line with the existing literature (Aldridge and Becker 1993; Dearden and Becker 2004; Morrow 2008), some care work is gendered among children. This is likely to be because parents, and the siblings themselves, had gendered expectations regarding the appropriateness of different tasks; for instance food work is still largely seen as women’s work and females are often considered to be naturally more caring (Morgan 1996).

Additionally, the makeup of the household had some bearing on the care roles that siblings took on. The siblings who lived in single parent families or families where there was often only one parent present due to work commitments were more likely to take on higher levels of caring responsibility. For instance, Natalie and Zoe, who took on the most responsibilities out of all the siblings, both lived in these types of household.

Due to the sample size, the relationships between socio-demographic characteristics and siblings’ caring roles discussed in this section are tentative; however, these trends could be a starting point for further research. Overall, it appears that when taking all of these socio-demographic characteristics into consideration and when comparing the siblings as a group it was those who were older, female and/or those from families where the child to parent ratio was higher (single parent families or those where one parent worked away a lot) that took on the most caring responsibilities. Indeed, it was typically the siblings who had all of these socio-demographic characteristics that took on the most caring responsibilities and those who had none or only one of these characteristics that took on the least caring responsibilities.

**Discussion**

This paper has outlined the caring roles and responsibilities taken on by siblings in families with a child with epilepsy. Williams (2000) developed Charmaz’s (1991) concept of the ‘alert assistant’ and concluded her paper by arguing that the alert assistant concept could be developed further in other contexts. The analysis presented in this paper shows that it is not only adults that are capable of taking on this role in order to help manage chronic conditions within the family. Furthermore, in contrast to Williams’ (2000) work, in this context the role was not gendered as male and female siblings regularly took on this responsibility. However, similarly to Williams’ (2000) arguments, the association between the alert assistant role and the management of stigma was still evident; although parents encouraged siblings to fulfil this role as a result of their perceptions of the physical risks presented by the condition, siblings fulfilling this role did enable the child with epilepsy to pass more easily. Being monitored by a sibling was often less conspicuous in comparison to being supervised by a parent when in public or with peers; consequently, the invisible nature of this role and the fact that it was fulfilled by a sibling aided the children with epilepsy in their attempts to pass.

As well as the alert assistant role, siblings also took on two further caring roles – the substitute parent and parenting assistant roles. The development of these three distinct caring roles as concepts has demonstrated the extent of the care provided by siblings and the important role siblings played in managing childhood epilepsy on a daily basis. Children are often overlooked and the skills they currently possess are ignored in contemporary discourse, because instead there is a focus on the skills they need to acquire in order to progress successfully into the adult domain (Hockey and James 1993; Prout 2000). However, this paper illustrates that siblings are active in the management of chronic conditions in the family and often display competencies that adults do not possess. For instance, when acting as alert assistants and substitute parents, siblings could provide levels of care that adults outside the immediate family could not and, on occasion, these adults turned to siblings for help and advice.

This research has also built on previous research on siblings’ experiences of chronic illness within the family (Bluebond-Langner 1991; Dixon-Woods et al.2005). Whilst past research has focused on conflict and rivalry between siblings, this paper has detailed the impact of a chronic condition on the caring side of the sibling relationship. This is not to say that family members did not feel that childhood epilepsy caused conflict in family relationships (which has been reported in Webster 2016), but that the sibling experience of having a brother or sister with a chronic condition may be broader than these studies suggest. Indeed, the caring tasks that siblings took on formed a substantial part of their experience.

The study has also provided a new insight into the management of childhood epilepsy within the family. Previous studies have tended to explore the way in which the condition is managed by parents (Schneider and Conrad 1983; Scambler 1989). However, the multiple perspective methodological approach that was taken in this study has highlighted that the management of this condition is not always solely the responsibility of parents and in most cases was shared among all family members.

Despite the use of the gender neutral term ‘substitute parent’, it was found that gender seemed to be associated with some of the care provided by siblings. Indeed, similarly to the work on the provision of informal care by adults (Arber and Ginn 1999; Chambers 2012) and the literature on young carers (Aldridge and Becker 1993; Dearden and Becker 2004; Morrow 2008), it was girls who took on the most caring responsibilities when fulfilling the substitute parent role. However, both female and male siblings were equally likely to fulfil the alert assistant and parenting assistant roles, suggesting that gender may not be an important factor in relation to all caring roles that siblings can take on.

However, again similarly to previous research on young carers, it was found that age (Dearden and Becker 2004; Smyth et al.2011) and family circumstances (Dearden and Becker 2004; Aldridge 2008) were related to the extent of the care work undertaken. It is widely acknowledged that childhood is a social construct (James et al. 1998) and that in contemporary society children are seen to develop skills as they age (Prout 2000); as a result, when siblings were younger they were often not seen to be able to take on certain tasks. Equally, we live in an individualised society where parents feel individually responsible for protecting their children (Lee et al. 2014); they, therefore, were likely to feel that they did not want to burden siblings by asking them to take on caring tasks that they could fulfil themselves. This may help to explain why siblings in families with a higher child to parent ratio took on more responsibilities for caring for their brother or sister with epilepsy, as parents did not have the resources to be able to provide all the caring tasks that they may have liked to.

Although this paper has highlighted the associations between socio-demographic characteristics and siblings’ caring responsibilities that were found among the participants, it would only be possible to generalise on theoretical grounds (Seale 2004) as a result of the sample size. Further research is needed in this area and a quantitative study exploring the relationship between siblings’ socio-demographic background and their caring responsibilities for brothers or sisters with chronic conditions would be a useful way of finding out which characteristics are most influential and whether there is a causal relationship between certain characteristics and the type of care provided.

Overall, it has been demonstrated that siblings in families with a child with epilepsy significantly contributed to the informal care provided within the family. Siblings did this by taking on three caring roles – the alert assistant, substitute parent and parenting assistant roles. The paper, therefore, increases understandings of the management and experience of chronic childhood conditions. Furthermore, it is argued that the informal caring roles and responsibilities taken on by siblings should be given more attention in order to truly understand the management of chronic childhood conditions within the family and siblings’ experiences of having a brother or sister with a chronic condition.

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**Notes**

1 In the UK, anyone under the age of 18 who provides care for a relative with a disability, illness, mental health condition or drug or alcohol problem is defined as a young carer. However, local councils have to carry out an assessment in order for children and young people to be officially recognised as young carers.

2 A tonic clonic seizure begins with a tonic phase where the muscles contract. The clonic phase then involves symmetrical jerking movements in the limbs.

3 Focal seizures are located in one hemisphere of the brain and can take a number of forms.

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