**Caregiving and quality of life**

**Abstract**

The increase in life expectancy for adults with learning disabilities has extendedthe caring role for their parents. This study examined the experiences of older parents who provide long-term care for their adult children with learning disabilities and how they conceptualise their quality of life. Data were collected using semi-structured interviews with 27 older parent carers from four London boroughs and were analysed using framework technique. Findings indicate that most parents appraised their quality of life positively and reported benefits, despite the challenges they had to negotiate daily. The benefits from caregiving, more so in later life, were: a connected family from shared caregiving; a sense of belonging; purposeful living; a reciprocal relationship with their adult children; and personal transformations from providing care that improved their quality of life. The challenges that participants regularly encountered were: multiple losses (sleep, career, identity and friends); the added stress of the government’s Personalisation Agenda of caring services; struggles for access to services; searching for a diagnosis; worry about future care and fear of abuse when carers are unable to continue in their role; unhelpful attitudes of health and social care professionals; and a lack of empathy from friends as well as the public towards people with learning disabilities. Caregiving and quality of life are inextricably linked and the difficulties that parents experienced were mainly associated with socio-structural barriers, rather than their children’s disabilities. Importantly, the findings inform the practice of social workers and others who support this unique group of carers by providing new insights into how caring impacts on quality of life over time and how best these parents’ needs can be met. This study makes a specific contribution to understanding the lived realities of older carers and extends current conceptualisations of caregiving and quality of life among older people.

**1. Introduction**

The phenomenon of an ageing population has brought about an increase in the number of older people needing long-term care (Ross, Lloyd, Weinhardt, & Cheshire, 2008) as a consequence of which older people are perceived more as recipients of care rather than caregivers (Arber & Ginn, 1990). Hence there is greater interest in their quality of life as care recipients (Smith, 2000), rather than as caregivers, particularly their subjective understandings and experiences of quality of life **(**Hendry & McVittie, 2004). This is the case in the UK for older parents of adults with learning disabilities.

Caregiving for adults with learning disabilities can be perceived as a continuation of parents’ earlier child care role (Twigg & Atkin, 1994) and differs from spousal caregiving which is generally enacted in later life as dependency increases (Perkins, 2009). Drawing on a life course perspective, which focuses on events and roles that people assume over time (Giele & Elder, 1998) and the impact these transitions have on families (Hunt, 2017), parents of adults with learning disabilities tend to accept their caregiving role unprepared (Nolan & Grant, 1989) and unaware of its impact (Werner, Edwards, & Baum, 2009).

Most research to date has focused on understanding quality of life from the perspective of younger parents of children with learning disabilities (Buzatto & Beresin, 2008). The increased lifespan of adults with learning disabilities (Emerson et al., 2012) and the de-institutionalisation of care in the United Kingdom (UK) with the advent of the National Health Service and Community Care Act 1990 (NHSCCA 1990), resulted in many adult children living at home (Yoong & Koritsas, 2012) with parents who are 70 years or over (Care Quality Commission, 2012). As a result, many parents are providing substantial care in their later years, which previously was not the case. Consequently, the caring role for these parents has extended (Cuskelly, 2006). However, research has indicated that due to the symbiotic relationship between parents and their adult children with learning disabilities there is reluctance for parents to ‘let go’ (Bowey & McGlaughlin, 2007) and the adults with learning disabilities to leave home (Bowey & McGlaughlin, 2005).

**2. Review of the literature and legislative frameworks**

This section presents an overview of the literature on caregiving and the quality of life, and legislation that frames informal caregiving and service delivery. In the concluding section we discuss previous research further in relation to our key findings and from a life course perspective.

Traditionally stress and burden have been central in defining caregiving (Grant, Ramcharan, McGarth, Nolan, & Keady, 1998). This deficit model perpetuates the notion that caregiving is problematic, and families struggle to cope in their caring role (Grant & Whittell, 2000). However, studies have emerged that report positive experiences of caregiving (Green, 2007; Jokinen & Brown, 2005; Scorgie & Sobsey, 2000). Intertwined with this deeper understanding of the caring experience is the issue of the caregivers’ quality of life.

Quality of life is difficult to define (Moons, Budts, & De Geest, 2006) and previous studies with older people have focused mainly on health-related aspects (Idler, McLaughlin, & Kasl, 2009) as a basis for health interventions (Hendry & McVittie, 2004). Alongside this focus, researchers have become interested in global quality of life due to the prolonged life of older people (Bowling & Gabriel, 2007; Bowling, Hankins, Windle, Bilotta, & Grant, 2012). However, most of these studies have used standardised quantitative measures to assess older people’s quality of life (Caples & Sweeny, 2010; Farquhar, 1995). These measures cannot capture all the complexities that constitute quality of life for older people (Hendry & McVittie, 2004). Similarly, studies on quality of life of older parents of adults with learning disabilities have utilised quantitative approaches (Caples & Sweeny, 2010; Lin et al., 2009; Walden, Pistrang, & Joyce, 2000). Consequently, there is an urgent need for more qualitative research, to understand how older people conceptualise their quality of life as their subjective perspective remains under-explored, more specifically the voices of those with caring responsibilities for adults with learning disabilities are lacking in the research.

In relation to support for informal carers in the UK, the Care Act 2014 is a watershed moment, having repealed the previous legislation such as the National Health Service Community Care Act 1990 and the Carers Recognition and Services Act 1995. The Care Act 2014 was implemented in April 2015 towards the end of the current study and places a duty rather than a power, which was the case previously, on local authorities to provide a service to informal carers, to meet the needs identified in their assessments. The Act also broadens eligibility criteria for informal carers’ assessments by removing the condition of ‘regular’ and ‘substantial’ and gives informal carers new rights for the first time which are at the same level as the people they care for (Carers Trust, 2016).

In relation to service delivery, the 2014 Act endorses personalisation which is the government’s agenda for the transformation of adult social care giving service users choice and control in the way their services are delivered (Gardner, 2011). The main levers of personalisation are direct payment which is cash given to services users to purchase their services (Gardner, 2011) and a personal budget which involves practitioners being clear with service users about how much money is available to meet their needs and allowing them maximum control over how this money is spent on their behalf (Glasby & Littlechild, 2009). However, due to the ‘cuts’ to adult social care, service users might have difficulty in exercising the choice and control promised by personalisation (Lymbery, 2012).

**3. Aim of study**

There is a paucity of qualitative studies on quality of life and caregiving perspectives of older parents of adults with learning disabilities and their experiences of the social care system. This study addresses the limitation by examining the experiences of older parents who provide long-term care for adult children with learning disabilities and how they conceptualise their quality of life in relation to their caring role.

**4. Methods and presentation of data**

A qualitative constructivist approach, using interviews, was employed for the study. This approach was considered appropriate because the researchers’ aim was to understand the complexity and richness of older parent carers’ experiences and their subjective understandings of quality of life (Denzin & Lincoln, 1994).

***4.1 Ethical considerations***

Ethical approval was obtained from Brunel University after which parent carers were recruited from four south-east boroughs in England. Parents with cognitive impairment were not included in the study. Cognitive ability was determined by observing the parents’ level of engagement during the interviews and whether they understood the questions. Parents were encouraged to seek emotional support through counselling, if they felt the need to do so after interviews.

***4.2 Participants***

Participants were recruited by one of the researchers attending monthly parent carers’ meetings, to present the study. Those who expressed an interest in the study were given information packs and a form to complete to confirm their participation. In keeping with the constructivist approach, purposive sampling was employed whereby participants were selected to meet specific criteria (Ritchie & Lewis, 2003), and to generate appropriate data when interviewed (Green & Thorogood, 2004). Those who met the inclusion criteria as shown in Table 1, were contacted by telephone to arrange convenient times for the interviews. Data were collected during the period 2009 to 2012.

**[Insert Table 1 here]**

A total of 27 older parents (17 mothers and 10 fathers) participated in the study as shown in Table 2. All mothers except for two, left work to care for their children. In contrast, but in line with traditional gender roles, all fathers except for one who was retired on medical grounds, continued to work full time after the birth of their children. At the time of the interviews, all participants were retired except for two parents. Sixteen parents were co-resident carers and the other 11 parent carers had adult children who lived out-of-home (residential or supported housing). All the adults with learning disabilities were receiving social services support when their parents were interviewed.

**[Insert Table 2 here]**

***4.3 Procedure***

All parents were interviewed at home with the exception of one, who was interviewed at a Carers’ Centre. Participants were given the opportunity to ask any questions, and the purpose of the study was explained to them. Prior to beginning the interview, the consent form was signed and permission was sought to tape record the interviews. Participants were also reminded that their participation was voluntary and that they were free to withdraw from the study at any time. An interview guide capturing parents’ experiences about the past, present and future (see appendix A) was used to conduct the interviews which lasted between one to two hours. The data were stored on a password protected computer.

***4.4 Data Analysis***

The interviews were transcribed verbatim and parents’ names were anonymised. Framework technique (Ritchie & Spencer, 1994) was used to analyse the data. This is a matrix-based analytic method for managing and organising data according to key themes, concepts and emergent categories (Ritchie, Spencer, & O’Connor, 2003), and has a strong focus on ‘preserving the integrity of the participants’ accounts’ (Green & Thorogood, 2004, p. 184) unlike other analytical approaches such as grounded theory where the data are analysed to the last word to find meaning (Green & Thorogood, 2004). The choice of framework analysis was a very important consideration here, because the parent carers should be able to recognise themselves in the findings, thereby placing value on their contribution. The analysis was aided by using field notes to make sense of the emerging themes. The data were managed in five steps, as shown in Table 3.

**[Insert Table 3 here]**

***4.5 Rigour and quality of the study***

For the current study, quality was assured by the researchers throughout the research process. In line with the constructivist approach, member checking was carried out (Rodwell, 1998) by sending participants their transcripts and a summary of the findings to check the accuracy. One of the researchers also had regular supervision; presented to colleagues and annual review panels for discussing key issues such as the study design throughout the study; additionally, a reflexive journal was kept to record the researcher’s thoughts and feelings. These activities enhanced the credibility and authenticity of the study by providing an audit trail and demonstrating transparency.

**5. Findings**

This study examined the experiences of older parents who provide long-term care for adult children with learning disabilities and how they conceptualise their quality of life in relation to their caring role. Significantly, the participants who reported their caregiving experiences as negative, appraised their quality of life as poor, thus highlighting the influence one construct has on the other. Parents’ accounts illustrated the enmeshed experiences of caregiving and quality of life and two overarching themes were created from the analysis. This was due to the ‘fluidity’ with which participants spoke about their caregiving experiences and their quality of life. These were created from the five themes and their corresponding subthemes on experiences of caregiving and conceptualisations of quality of life, as shown in the model of Figure 1.

**[Insert Model –Figure 1]**

The first overarching theme ‘Enhancing experiences of caregiving and quality of life’ concerns the ‘high points’ of participants’ caregiving and quality of life experiences. These were captured as shared family caring and shared experiences with other parent carers; sense of purpose, gratification and personal transformation; and a reciprocal relationship with adult children. These findings offer a counter narrative to the dominant discourse on caregiving which tend to focus on stress and burden (Grant et al., 1998), providing a balanced and a more nuanced understanding of the complexities of caregiving (Miller & Lawton, 1997).

The second overarching theme ‘Psychological and practical challenges influencing caregiving and quality of life’ relates to the negative experiences participants recounted, and describe the ‘low points’ or challenges of caregiving and quality of life they encountered. These were: multiple losses and constraints; socio-structural barriers to formal services; searching for a diagnosis; uncertainties and fears about future care and negative professional and societal attitudes.

***5.1 ‘Enhancing experiences of caregiving and quality of life’***

*Shared family caring and shared experiences with other parents*

These sub-themes relate to sharing the caring responsibilities for the adult child between parents and other adult children, and parents sharing their experiences with other parents whose children have learning disabilities. Most parents reported that, due to the complexity of the task, caring was best done by more than one person. Therefore, they shared the caring role with their spouses and their other adult children. This division of labour meant support for each other, in addition to caring for the adult with learning disabilities.

Some parents were of the view that the stresses associated with caregiving have the potential to divide couples and family members, but for these families, this was not the case. On the contrary, shared caring fostered family connectedness.

Father 4: I personally retired from full-time work almost three years ago now to provide a bit more support. I wanted to do a manual lifting course because [son] is awkward to handle, and [my wife’s] knees are now playing up. I am very conscious that I am the [one] to do the lifting around here.

Some parents reported sharing the caring responsibilities with their other adult children. Father 6 said: ‘He [their son] had three other siblings and they have been very supportive in the purest way, which held the family together.’

Evident in all parents’ accounts was sharing their experiences with other parents. They employed a range of positive coping strategies to parent and care for their children successfully. These included joining organisations that supported adults with learning disabilities, attending carers’ meetings and conferences. In addition to a coping strategy, these groups provided a sense of belonging and opportunities for making valuable friendships, and support networks. Father 1 recounted: ‘We used to visit with other friends and it was a big social event … over the years that kept us sane because we had that support, you are not on your own.’

*Sense of purpose, personal transformation and rewards/gratification*

All 27 parents acknowledged that caring for their adult child gave them a sense of purpose. Having a sense of purpose concerns the feeling of being ‘needed’ which many older parents derived from active caregiving, well beyond the period when their ordinary child-caring role would have ended. This is how Mother 10 put it: ‘Well you feel needed. One of my sisters always said, although they’ve all got children, they grow up and the leave home, and they said for instance I am needed.’

Most of the 27 participants felt that their own well-being was enhanced by caring for their adult children. All spoke about personal transformations such as being aware of the needs of others and having a sense of humility. These different positive experiences brought about a change in parent carers’ focus and they felt they became ‘a better person.’ Father 6 explained: ‘Quality of life is not expressed in sea cruises and river cruises and the like, because quality of life is one’s contribution towards their fellow man.’

Mother 17 said: It [quality of life] is good, we have to be patient, we have to be calm to look after a person like this. You have to learn, you have to be strong. You need to love, to show the person because that person is damaged, body and brain and everything, you have to look after a person like this. Be caring, very caring from the heart.

Twenty-three of the 27 parent carers reported that caregiving had enhanced their quality of life. They felt having a child with a learning disability allowed them to view life through a different lens. Father 3 commented: ‘My conclusion about quality of life might shock you and everybody else but I think having a disabled daughter has improved my quality of life. It made me a better person.’

More fathers than mothers reported a sense of reward/gratification in providing care for their children. Of the 27 parent carers, two fathers were identified as main carers because most of the fathers were in full time jobs. Mothers therefore provided most of the care particularly during the day and they reported more stress and less gratification than fathers. However, the two fathers who were main carers reported more stress and less gratification similarly to the mothers. This indicates that there may be a link between the level of care provided and rewards/gratification, rather than the influence of gender as reported by Scorgie & Sobsey (2000). Despite this, all 27 parents derived a sense of gratification from their children’s achievement. The following quotes convey parents’ feelings of pride from their children’s achievement. Mother 15 related: ‘He did a photography course and was awarded a camera. He was very happy to be given an award.’

Father 9: When she was passing all her subjects, that was really wonderful and it was nice to see all of her certificates. [She] likes to see that I was there, even more so after my wife had died. I would be going to the prize giving in July. She was really chuffed that I was there and she knew that people were watching her. She was really pleased. That’s great for me that she is doing well.

*Reciprocity*

All parents experienced some form of reciprocity with their adult children which was expressed in differing ways, such as providing companionship for each other (intangible), and doing household chores and making simple snacks for their parents (tangible). For this group of parents, their caring role has been extended as they are actively caring in their later years due to the increase in life expectancy for their children and themselves. Reciprocity was prevalent across the participants’ accounts and many older parents valued their adult children’s company and the mutual support they derived from being together. To this end, reciprocity was one of the main factors that parent carers reported as enhancingtheir caring experiences and quality of life. This was particularly so for the older parent carers whose adult children were co-resident. Although some adults, due to the severity of their disability, were unable to reciprocate in a tangible way – for example, making a cup of tea – their presence meant a lot to their parent carers as they provided companionship, especially for parents who were widows or widowers. For these parents, their adult children played a vital role by ‘filling’ the void left by the death of spouses. Evident in the following quote is the mutual sharing and caring highlighting the symbiotic relationship between mother and son.

Mother 5: It’s good to have someone else in the house now I’m on my own … he always makes sure all the doors are locked up at night, that’s his job and I let him do it. So, I’d miss him terribly if he wasn’t here, because he is good company. He’s good fun.

***5.2 ‘Psychological and practical challenges influencing caregiving and quality of life’***

*Multiple losses*

Parents reported multiple losses: sleep, career and career identity, and friends as a result of their caring role. However, a few of them experienced a combination of the losses identified. These parents were generally ‘immersed’ in their caregiving role, and they were very dependent on formal services due to having few or no informal support networks.

All parents in this study experienced the loss of sleep. However, the sleep deprivation that is generally associated with caring for children in their infant years continued into their children’s adulthood and was reported as one of the main challenges that older parent carers faced in their caregiving trajectory. This experience had the potential to impact negatively on their health and general well-being.

Mother 4 explained: I was not getting any sleep with the baby being awake half the night and [daughter with disability] being awake the other half. I wasn’t getting any sleep at all and I was cracking up gently … I was really cracking up and I asked for help and they said there isn’t any respite.

Similarly, Mother 1 (sole carer) reported: I could not sleep for two nights because he was restless. I get up every time he wets so I have to change him. Sometimes he soils, so I have to shower him at four o’clock in the morning. Nobody wants to know.

Lack of sleep was problematic for most parents as it impacted on parents’ health and well-being. On the contrary, for Mother 16, waking at nights became routine because of working night shifts. She explained: ‘No, well I put it this way, it [my sleep] is not interrupted … that is no problem, because in the days when I worked at nights in the hospital.’

#### Loss of career was reported by mothers who left paid employment, when they realised that their children would need extra care except for two who continued to work full time. With mothers giving up paid employment, this meant that there was less family income and they were also at risk of isolation, as being out of work reduced their social contacts. A few mothers compensated for the loss of income by doing part-time work, which in most cases was menial work when their children went to school or college. However, most of the mothers stayed at home; although they were reluctant to give up paid work, they had no other choice. They joined parents’ groups which helped to extend their social contacts and gave them the opportunity to share their experiences of caring for their children. While these social contacts were welcomed by most mothers, a few mothers stated they did not join parents’ groups because they did not have anyone to help with their adult children. A few mothers felt unfulfilled by not being able to work. Mother 12 explained: ‘I haven’t been able to go out to work … there is a whole part of me that feels as if it hasn’t been lived, which I very much regret.’ Mother 1 expressed similar sentiments: ‘I had to give up my career because I found absolutely no help … I couldn’t return to work because he was falling ill and I could not do a 9.00 [a.m.] to 5.00 [p.m.] job.’

Apart from the financial reward and the opportunity to socialise, some parent carers linked their identity to their career, so having lost their career, they also experienced loss of their identity. Mother 4 reported: ‘I am a frustrated teacher … I had to give up work, something that I am really passionate about. I love teaching and I love kids.’

All carers spoke of the loss of friends after their children were born. When the differentials between their children and their friends’ children became apparent, their friendships waned, and as a result they drifted apart. Although some parents wanted to maintain this friendship others did not. For example, Mother 13 explained: ‘We make the best of caring, but the fall off in friends and family … I think one day there is just going to be me and him [husband].’ Mother 10 reported: ‘It’s completely unlike me, I completely changed, my whole personality changed … I did not want to be in touch with those people [previous friends] anymore.’

The experience of multiple losses related by parents, indicates that while some parents adjusted to their situation, for others the challenges remained unresolved and impacted negatively on their quality of life.

*Socio-structural barriers to formal services*

Parents reported that they all had experienced inadequate services which seemingly was the rule rather than the exception. They described their difficulties as ‘fighting a battle’. Mother 1 explained: ‘A battle, accessing services, it has been a battle.’ Father 2 expressed similar sentiments: ‘To be honest we were frustrated with the authorities … people jumped to conclusions without understanding what was going on. So we lived a battle.’ Respite services for their adult children were in great demand, but in many instances were not available. Mother 12 said: ‘It’s like getting blood out of a stone with the borough. It’s as if you are a criminal in terms of asking for facilities for your child, like respite.’

Father 8 also explained: Respite, that is another problem. There were occasions when respite was withdrawn at short notice. We prepared him. We got him to agree. We would tell him respite is on Friday. On Friday we would have them [respite providers] saying, we’ve got an emergency and it is off … this is a problem as they push aside pre-planned respite, and in the case of someone with autism, it is very difficult.

In addition, parents reported that the government’s Personalisation Agenda, especially direct payments, was burdensome as it added another ‘layer’ of stress to their caring role. Some parents reported that direct payments were forced on them without proper consultation. Parents perceived this as a barrier to services and parents regarded accessing services as a struggle. Mother 6 commented: ‘I’m fearful that what wouldn’t be helpful is the special direct payment that is being awarded to our sons and daughters … and we are getting on in life we don’t want the hassle.’

Mother 1: They [the borough] have taken on this thing which government is now starting. That everybody be in charge of their money, direct payment. They are giving all the responsibility and doing nothing to help. I refuse, but they said you have no escape, you have got to take it. I said I can’t take on any more.

*Searching for a diagnosis*

Most participants spoke of being aware that something was wrong with their child at birth, but they needed a formal diagnosis. This was to confirm their suspicion and the validation that would enable them to obtain the appropriate support and benefit entitlements. All reported that they felt devastated by the news, but it was better to know rather than ‘groping’ in the dark.

Mother 8: But because she never had a diagnosis, she never had any financial help and don’t know of any that was available, but she was about … well eight or nine years ago now, she got referred by the General Practitioner for incapacity benefit, which she got and we could have done with that thirty years sooner.

*Fears about future care and abuse*

The main worry parents reported centred on who will take over the caring ‘baton’ when they are no longer able to care. All were worried about future care, even those whose children were already living in a residential setting. These parents felt they needed someone to be as watchful and alert as they had been for all these years. The general consensus among the parents whose adult children were living at home was that a sibling would take over caring.

Some parents reported that their children had been abused and they would need family to protect them. While future care ‘lingered’ at the back of many parents’ minds, for a minority, this thought consumed their lives because they felt they were left with few or no options and they described future care and fear of abuse as the ‘elephant in the room.’ Father 8 said: ‘We had reason to believe that he was assaulted. Now, I don’t know if that was behind why we found it difficult for him to go to respite.’

Mother 1: Even though we were full of anguish, and I said that I don’t know what the future has for him and I was wondering what would happen if I die … if both of us [mother and other son] go what will happen to my son [with learning disability]? That is the ultimate thing that worries me … it [the future] gives me sleepless nights. I know that if he does not go before me. That is my prayer to God. Let him go first. I would go at peace then. If he goes I am quite ready to go. If he is here and I die, I will die a very tortured soul.

*Negative professional and societal attitudes*

Some parent carers felt quite hurt by the negative attitudes of professionals, some of their friends, other parents with non-disabled children, and the general public. They reported feelings of humiliation, exclusion and rejection. Mother 12 said: ‘We were told that she had a learning disability and might never walk or anything like that, in front of a group of twenty-five other people, by Dr [name], which I think is the most appalling way.’ Mother 8 explained: [‘Daughter’s name] and this girl were friends, she was the only friend [daughter’s name] had but the mother was very cunning in the way she tried to separate them. And it was hurtful, I remember.’

Mother 3: Sometimes there’s this really hurtful exclusion. One of the most hurtful things for us was that one of my really good friends was getting married down in [name of place] and we got an invitation to the wedding. She had written in it I hope you don’t mind this is just an invitation for you and [husband’s name], not [son’s name] because children are not being invited to the wedding. At the wedding we went to the reception, there were at least 20 children there.

**6. Conclusion**

Generally our findings resonate with previous research, and in what ways this section will highlight. However, in relation to practical and psychological challenges, we identified some unreported experiences among older parents caring for their adult children with learning disabilities. We discuss the key results below and how they and our work manifest a life course perspective of caregiving as all parents recounted their experiences from the birth of their children to the present, relating how their past shaped their present circumstances and concerns for the future.

Most of our findings on practical and psychological challenges mirror previous research. All parents experienced multiple losses (Caples & Sweeney, 2010) sleep (Grant et al., 1998) career and identity (Yoong & Koritsas, 2012) and friends (Scorgie & Sobsey, 2000). These challenges were exacerbated by negative professional and societal attitudes (Caples & Sweeney, 2010; Green, 2007) and the added stress of the Government’s Personalisation of care services (Rosenthal, Martin-Matthews, & Keefe, 2007).

In relation to challenges, fear of abuse as a barrier to planning future care and the impact of a late diagnosis were identified as new knowledge. In planning for future care, parents expressed a preference for family care because they feared that their children would be abused in a residential setting. Also, parents of adults who had a late diagnosis, felt that their children were doubly disadvantaged because they were not able to access the specialised support, and benefit entitlements in their earlier years. These findings provide a deeper understanding of the challenges/barriers which parents encountered, but seemingly have not been reported previously in the literature on caregiving.

There are also similarities between the current study and previous work on enhancing experiences of caregiving and quality of life these include: family connectedness from shared caregiving for adults with learning disabilities (Jokinen & Brown, 2005) and from shared experiences with other parents, a sense of purpose and belonging (Yoong & Koritsas, 2012). The experience of becoming ‘a better person’ (Scorgie & Sobsey, 2000), rewards from caregiving (Green, 2007) and reciprocity between parents and their adult children (Grant, 2010) were also reported in other studies. However, our work further suggests that the reciprocal relationship which is characteristic of the life course experiences (Hunt, 2017) enhances parent carers’ quality of life, more so in their later years and challenges the binary of carer and cared for by highlighting that caregiving is not unidirectional.

The current study confirms that parents’ caregiving and quality of life experiences were positive, despite the stressful challenges they had to negotiate on a daily basis. The many challenges experienced by all parents originated mainly from socio-structural barriers such as inadequate and unreliable services, the lack of a formal diagnosis of their children at birth and the imposition of direct payments on parents, rather than from having a child with a learning disability.

Our findings capture parents’ experiences of caring for a child with a learning disability from birth to adulthood and reflect a life course perspective (Giele & Elder, 1998) by considering the developmental changes which occurred over their caregiving trajectory. This theoretical lens highlights how parents’ past influenced their present appraisal of quality of life and their concerns about fear of abuse, in relation to future care when they can no longer continue in their role. They also offer a counter narrative to the dominant discourse on caring for a child with a learning disability which tends to portray an implicit ‘deficit’ model, focusing upon the negative and undermining positive reporting as a coping strategy (Green, 2007). The limitation of this study lies in its small sample size and therefore its findings cannot be generalised. However, this qualitative study explores in-depth the experiences of older parent carers of adults with learning disabilities and offers a nuanced understanding of their caregiving role and their quality of life.

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**References**

Arber, S., & Ginn, J. (1990). The meaning of informal care: gender and the contribution of elderly people. *Ageing and Society,* 10, 429–454.

Bowey, L. & McGlaughlin, A. (2005). Adults with learning disability with elderly carers talk about planning for the future: aspiration and concerns. *British Journal of Social Work,* 35, 1377–1392.

Bowey, L. & McGlaughlin, A. (2007). Older carers of adults with a learning disability confront the future: issues and preferences in planning. *British Journal of Social Work,* 37, 39–54.

Bowling, A., & Gabriel, Z. (2007). Lay theories of quality of life in older age. *Ageing and Society,* 27, 827–848.

Bowling, A., Hankins, M., Windle, G., Bilotta, C., & Grant, R. (2012). A short measure of quality of life in older age: the performance of the brief Older People’s Quality of Life questionnaire (OPQOL-brief). *Archives of Gerontology and Geriatrics,* 56, 181–187.

Buzatto, L. L., & Beresin, R. (2008). Quality of life of parents with Down syndrome children. *Einstein,* 6, 175–181.

Caples, M., & Sweeney, J. (2010). Quality of life: a survey of parents of children/adults with an intellectual disability who are availing of respite care. *British Journal of Learning Disabilities,* 39, 64–72.

Care Act (2014). (http://www.legislation.gov.uk/ukpga/2014/23/contents).

Care Quality Commission (2012). *Annual Report and Accounts 2011/12*. Newcastle upon Tyne: Care Quality Commission.

Carers (Recognition and Services) Act (1995). London: The Stationery Office.

Carers Trust (2016). (http//carers.org/care-act-one-year-commission).

Cuskelly, M. (2006). Parents of adults with an intellectual disability. *Family Matters,* 74, 20–25.

Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage.

Emerson, E., Hatton, C., Robertson, J., Roberts, H., Barnes, S., Evison, F., & Glover, G. (2012). *People with Learning Disabilities in England 2011: Improving Health and Lives*. Lancaster: Learning Disabilities Observatory.

Farquhar, M. (1995). Elderly people’s definitions of quality of life. *Social Science and Medicine,* 41, 1439–1446.

Gardner, A. (2011). *Personalisation in Social Work*. Learning Matters Ltd. Exeter.

Giele, J. & Elder, G. (1998). *Methods of Life Course Research: Qualitative and Quantitative Approaches*, Thousand Oaks, CA: Sage.

Glasby, J. & Littlechild, R. (2009). *Direct Payments & Personal Budgets-Putting personalisation into practice*. Bristol: Policy Press

Grant, G., & Whittell, B. (2000). Differentiated coping strategies in families with children or adults with intellectual disabilities: the relevance of gender, family composition and the life span. *Journal of Applied Research in Intellectual Disability*, 13, 256–275.

Grant, G., Ramcharan, P., McGarth, M., Nolan, M., & Keady, J. (1998). Rewards and gratifications among family caregivers: towards a refined model of caring and coping. *Journal of Intellectual Disability*, 42, 58–71.

Grant, V. (2010). Older carers and adults with learning disabilities: stress and reciprocal care. *Mental Health and Learning Disabilities Research Practice,* 7(2), 159–172.

Green, J., & Thorogood, N. (2004). *Qualitative Methods for Health Research*. London: Sage.

Green, S. E. (2007) ‘We’re tired, not sad’: benefits and burdens of mothering a child with a disability. *Social Science and Medicine,* 64, 150–163.

Hendry, F. & McVittie, C. (2004). Is quality of life a healthy concept? Measuring and understanding life experiences of older people. *Qualitative Health Research,* 14(7), 961–975.

Hunt, S. (2017). *The life course: A sociological introduction*. 2nd ed. London: Palgrave Macmillan.

Idler, E. L., McLaughlin, J., & Kasl, S. (2009). Religion and the quality of life in the last year of life. *Journals of Gerontology: Social Science,* 64B(4), 528–537.

Jokinen, N. S., & Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research,* 49(10), 789–793.

Lin, J., Hu, J., Yen, C., Hsu, S., Lin, L., Loh, C., Chen, M., Wu, S., Chu, C., Wu, J. (2009). Quality of life in caregivers of children and adolescents with intellectual disabilities: use of WHOQOL-BREF survey. *Research in Developmental Disabilities,* 30, 1448–1458.

Lymbery, M. (2012). Critical commentary: social work and personalisation. *British Journal of Social Work,* 42(4), 783–792.

Miller, B., & Lawton, P. M. (1997). Introduction: finding balance in caregiver research. *Gerontologist,* 37, 216–217.

Moons, P., Budts, W., & De Geest, S. (2006). Critique on the conceptualization of quality of life: a review and evaluation of different conceptual approaches. *International Journal of Nursing Studies* 43(7), 891–901.

Nolan, M., & Grant, G. (1989). Addressing the needs of informal carers: a neglected area of nursing practice. Journal of Advanced Nursing, 14, 950–961.

Perkins, E. A. (2009). *Caregivers of adults with intellectual disabilities: the relationship of compound caregiving and reciprocity to quality of life*. Unpublished doctoral thesis.

Ritchie, J. & Lewis, J. (2003). *Qualitative Research Practice. A Guide for Social Science Students and Researchers*. London: Sage.

Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman and R. G. Burgess (eds), *Analysing Qualitative Data*, 173–194 London: Routledge.

Ritchie, J., Spencer, L., & O’Connor, W. (2003). Carrying out qualitative analysis. In J. Ritchie and J. Lewis (eds), *Qualitative Research Practice: A Guide for Social Science Students and Researchers*. London: Sage.

Rodwell, M. (1998). *Social Work Constructivist Research*. New York: Garland.

Rosenthal, C. J., Martin-Matthews, A., & Keefe, J. M. (2007). Care management and care provision for older relatives amongst employed informal care-givers. *Ageing and Society,* 27, 755–778.

Ross, A., Lloyd, J., Weinhardt, M., & Cheshire, H. (2008). *Living and Caring? An Investigation of the Experiences of Older Carers*. London: National Centre for Social Research.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with parenting children who have disabilities. *Mental Retardation,* 38(3), 195–206.

Smith, A. (2000). *Researching Quality of Life of Older People: Concepts, Measures and Findings*. Keele: Centre for Social Gerontology, Keele University.

Twigg, J. & Atkin, K. (1994). *Carers Perceived: Policy and Practice in Informal Care*. Buckingham: Open University Press.

Walden, S., Pistrang, N., & Joyce, T. (2000). Parents of adults with intellectual disabilities: quality of life and experiences of caring. *Journal of Applied Research in Intellectual Disabilities,* 13(2), 62–76.

Werner, S., Edwards, M., and Baum, N. T. (2009). Family quality of life before and after out-of-home placement of a family member with an intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities,* 6(1), 32–39.

Williams, V., Simons, K., Gramlich, S., McBride, G., & Snelham, N. (2003). Paying the piper and calling the tune? The relationship between parents and direct payments for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities,* 16, 219–228.

Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research,* 56, 609–619.