

Exploring coping strategies of carers looking after people with intellectual disabilities and dementia

Introduction

10% (5.8 million) of the population of England and Wales provide unpaid care for family members, friends, neighbours or others (Office for National Statistics 2011). They contribute immensely to the UK economy by undertaking this unpaid role. It is estimated to be nearly £87 billion per year (Buckner and Yeandle, 2007). There are no such figures for paid carers. The role of carers is vital in the intellectual disability (ID) population. People with ID are cared for either by their families, paid carers or both. 60% of adults with ID live with their family in England and Wales (Department of Health, 2001). However, this percentage declines as age increases and most end up in residential/nursing home settings (Parrott and McGrother, 2009). With increasing life expectancy for people with ID (Office for National Statistics, 2004) their needs have increased significantly (Emerson and Hatton, 2008). This highlights the importance of the role of carers at present as well as for the future. These needs further rise when they develop mental illnesses such as dementia which have an increased incidence rate among people with ID (Cooper et al., 1997; Holland et al., 1998; Strydom et al., 2007).

Even though caring is challenging and stressful, research into the caring role has shown satisfying aspects (Nolan and Lundh, 1999). Care giver and recipient factors, quality of relationship and wider family and social aspects can influence how manageable and satisfying the carer's role is (Oyebode, 2003). Nevertheless, these are often outweighed by the stressors. Carers experience more health disorders and depressive disorders. Depression is almost four times more common among female carers (McGrother et al., 1996). Depressive disorders further increase with the development of dementia in the person cared for (Schulz et al., 1995). Types of coping strategies used have been shown to have an important relationship with the occurrence of depression among carers (Saad et al., 1995).

There are theoretical frameworks to understand the coping process (Carver et al., 1989; Folkman and Lazarus., 1985; Lazarus 1966, 1993). To date, the majority of studies have focused on how carers cope when looking after people with schizophrenia, Alzheimer's dementia, chronic medical conditions and mental illnesses (Chambers et al., 2001; Huang et al., 2007; Kartalova-O'Doherty and Doherty, 1998; Lane et al., 2003; Nolan and Lundh, 1999). Studies on carers looking after people with ID focus on various factors that cause stress and burnout (Rose et al 2003) with some studies looking at coping strategies as a sub analysis (Donald et al.. 2006; Hatton et al., 1999; Hill and

Dagnan, 2002; Kenny and McGilloway, 2007; Snow et al., 2007; Whittington and Burns, 2005).

Various studies have looked at burden of looking after someone with ID and dementia. Only a few differences were observed on measures of burden among foster family carers and paid carers in ID service settings (McCallion et al 2005). Onset of dementia in people with ID is associated with increased emotional exhaustion even when there is little difference in care giving task following dementia (Lloyd et al 2008). Worsening severity of dementia was associated with higher comorbidities suggesting needs for increasing caregiving needs (McCarron et al 2005). Studies have looked at various interventions to reduce the burden of care giver stress. Education, training and support groups have shown to be effective in reducing carers burden of looking after someone with ID and dementia (Acton & King 2001).

Aim

The aim of this study was to explore coping strategies of both paid and family carers looking after people with Intellectual disability and dementia.

Method

A qualitative research methodology was used to investigate coping strategies of carers. The local NHS research ethics committee granted ethical permission. Purposive sampling technique, which is 'purposefully picking a wide range of variation to identify important common patterns that cut across variations' (Patton, 1990) was used to interview carers from different backgrounds and experience to cover a wider range of coping strategies. This included choosing carers working in residential and nursing home settings, carers with wide range of experience and carers from different cultural and religious backgrounds. Two focus group interviews with community learning disability nurses were followed by nine face to face in-depth semi structured interviews with family and paid carers looking after people with ID and dementia. All carers who participated in the study gave their written consent. Interviews were conducted by the principal investigator. Carers were asked to talk about three main areas, 1. Normal day of the person they look after, 2. Physical, psychological and social needs and 3. Difficult times with the person they look after.

Each interview lasted approximately 45-60 minutes. They were digitally recorded. Paid carers were interviewed at their work places and family carers at their homes. Interviews were stopped when data saturation was achieved (when new themes stopped emerging). All interviews including focus group interviews were transcribed verbatim by the principal investigator. Analysis ran

concurrently with data collection. Transcribed interviews were analysed using the six step guide for thematic analysis from Braun and Clarke (2006). Initial coding was done by the principal investigator. The principal and co investigator worked together to create broader themes. A clinician (J.J) joined the final stage of finding main themes from codes and creating a thematic map.

Results

Three main themes emerged: Narrative, Strategy tool box and Compartmentalisation. Some of the main themes had subthemes.

Main theme	Sub theme	
1. Narrative	Me the carer	- Caring Style - Optimism - No choice
	He/She the client	- Know the past - Relationship -Redeeming characteristics

2. Strategy tool box	Tools to reduce stress	<ul style="list-style-type: none"> - Distancing - Release frustration in a safe environment - Recognised strategies for client's problems -Other sources of gratification
	Tools to support them	<ul style="list-style-type: none"> - Extra pair of hands - Support in making decisions - Provision of resources - 'Kick upstairs'
3. Compartmentalisation		

1. "Narrative"

Some carers told a story about their experience of looking after the person with ID and dementia. This story communicated their construction of their identity and role or that of the person they cared for. These two types of narratives were named “Me, the carer” and “He/she, the client/family member”.

“Me, the carer”

There were three main subthemes for this narrative: “Caring style”, “Not having any choice” and “Optimism”.

-Caring Style:

“Caring style” highlighted carers’ narratives of their styles of coping. They were often targets of physical and verbal abuse and carers provide narratives which illustrated the different styles they adopted in response to challenging situations. One way was to not ‘personalise’ actions of their clients and try to view those challenges from a different perspective. A paid carer tried to make the distinction between why they cope in situations with clients, but not when outside work.

“I do not really like being spat on, but I do not think it will make me feel ‘why am I doing this job’, because I would not take it personally. If somebody took a dislike to me in a pub, it would be worse than if it was here”

Carers talked about being flexible in their style of work. A support worker with 10 years experience stated that as a reason for her survival as a carer.

"I just take it as it comes. You go totally mad if you get so wrapped up. I think that's why I have been here so long"

This linked with some carers' description of the patience they required when working with clients with ID. A support worker described how it was important to be patient and let clients do various activities which they appear to enjoy.

"We just leave him. There is no rush. We have some deadlines, but he likes to help out as well. He likes to dry pots and take them into kitchen, do his sandwich and things like that. It takes a long time, but he likes to do that"

Some carers described this as having high tolerance as their coping style. A carer assistant who has worked in different settings made comparisons with her past experience of looking after people with ID.

"Some of the people brought in are not half as bad as some others. So it's almost if you build up a tolerance [that is] personally acceptable and effective"

Sometimes they made comparisons with another client living in the same place which helped them to set up a tolerance level. Sometimes they compared different days of the same client.

“They are not bad as such and such”

“They are not bad as yesterday”

“They are not as loud as that or not as repetitive as that person”

However, it was important to recognise that tolerance had a limit.

“I just got to the point where I knew I couldn’t deal with it anymore so that’s when you have to walk away, go and find your colleague and say I have had enough. I think it is just recognising that point”

Intellectual disabilities are different in nature to a physical disorder and carers described how expectations and outcomes needed to be realistic and not too ambitious.

“We celebrate little steps because that is how we keep our self sane. You have to set very achievable targets, if not we are going to get very frustrated”

Humour and being cheerful helped some carers. A paid carer from a nursing home for people with ID include this in her narrative about herself.

“I always had that kind of sense of humour, a dry humour. I like to make them laugh. I like to chirp them up. I can’t walk into a place and sit there really quiet. You need to talk to them and make them laugh”

-Optimism:

The second subtheme “Optimism” helped carers to cope with the unpredictable nature of the role of caring. This was an essential element of coping with ever changing stressors. Identifying times when the situation might be better helped them to deal with current difficulties.

According to a paid carer:.

“Everything depends on her mood. You can go to her one day, like today; she is relaxed, happy, talkative and cooperative. But on another day she would argue with everything. She will not want to take her medication, she will not want to have a shower, she does not want to get out of bed, she won’t eat, everything you try to get her to do, she won’t do”

This gave them a narrative that there will be better times which might even be of very short duration which helped them to cope even when they are overwhelmed by stressors of looking after their clients. The optimism that appeared in the narrative of a family carer had its roots in his religious beliefs. He described how his belief in god gave him hope and positivity.

-Not having any choice:

The third subtheme was “not having any choice”, but having to deal with the challenges they face in day to day life. Paid carers considered that they have to get on with the task they have undertaken as carers. They further added that there was an expectation at work that they had ‘got to be able to cope’. As a result, they had no choice, but to make various changes to their life style in order to cope better. A paid carer from a residential home commented that,

“You do cope better at work than home. I do not know why. Maybe because I think you know you got to”

Family carers had a similar narrative. However the reasons that they narrated were different to paid carers.

A 72 year old family carer looking after his brother with ID and dementia explained:

“It is one of those things; you have to put up with it. There is no other option. Apart from putting him in a home which we are not very keen on, we would like to look after him as long as we can”

Some family carers produced narratives around obligation which were embedded in traditional, religious and cultural expectations. These narratives helped them to cope with the stressors of looking after their family member.

“He/she, the client/family member”

Carers also constructed a story about the person they look after as this helped them to look at the person as a whole and to understand any difficult behaviours in that context. There were three main sub themes under this narrative: “Knowing the past” “Relationship” and “Redeeming characteristics”.

-Knowing the past:

Carers described how the absence of information during the first few weeks of someone moving into a placement made that period very difficult as they did not have a narrative on that person. A paid carer highlighted this as below.

“I like to know their background. I get to know all their family which does help and it’s just having the knowledge as well at the back of you to deal with clients”

This narrative comprised a summary of their clients’ past. A paid carer from a residential home narrated stories on how her client with Down’s syndrome used to be before he moved into their care.

“He could read a magazine at one time when he was younger. Watch all programs, choose what he wants to watch, go shopping, knew what money exchange was, everything. He used to do everything, he used to ride his bike, he used to go and play normally with everyone else. It is only when he got older and he got really ill, and got took into hospital. He also lost his mum and it has started from there”

-Relationship:

Carers’ construction of their narrative of their “Relationship” with clients/family member helped them to deal with challenges. A 72 year old family carer explained why he continues to care for his brother who has got Down’s syndrome and dementia despite increasingly challenging behaviours since his brother developed dementia.

“Once it becomes too difficult, then of course we have to think about putting him in a home. He is very much attached to me, my wife and son”

Paid carers also produced narratives about their relationships with clients. Carers who talked about having a good relationship with a client reported feeling more confident in meeting the needs of their clients compared to a carer who did not have a good narrative.

"I have got a very good relationship with A [client]. I get a smile from him. If some certain staff can't do some things for him I will go and do it for him because it's the trust. He has known me for a long time. Sometimes he can't see me very well but he knows my voice"

Sometimes this relationship was defined in more specific terms.

"You treat them as babies in a sense. Yeah, you try not to. I think if somebody heard us talking to our clients, it is like you talking to a child. They still value things from early learning centre. Even they are too hard. Somebody looking after adults would not understand"

This helped them to construct a story about their clients that was meaningful to them.

-Redeeming characteristics:

Carers produced narratives that focussed on positive aspects of their clients' personality/character as part of developing a liking towards the people they care for.

“He is a happy chap, he will talk to you, things that he comes out are comical. He is quite funny” “He is very friendly. If you take him out, he tries to talk to everyone. He will sit in a middle of a family and shakes hands, sometimes trying to get him to move really takes time, but eventually he will. He is out-going”

Even though a client is very challenging, the ability to have a positive narrative about that clients ‘redeeming characteristics’ helped them to deal with challenges.

“When he first came in, he was quite challenging to say the least. But because of his personality, you cope with it better, because you can’t help laughing”

2. “Strategy tool box”

Carers also needed practical strategies for problems that arose on a regular basis. This was called a “strategy tool box” from which they pick a tool and check if it works and if it does not, they try a different tool. There were two main types of tools within the toolbox: one to “reduce stress” and one to “support them”.

“Tools to reduce stress”

-Distancing:

Carers often distanced themselves either physically or emotionally from stressful situations. Extra support for family carers from support workers, family members, friends and respite placements gave them the time to physically distance themselves and engage in other activities. A family carer described how he and his wife use their time when support workers look after their foster son.

“It gives us a short break if you want to go shopping or somewhere, to keep doctor’s appointments or whatever, we do that during that time”

Paid carers distanced themselves by doing other activities such as having a cigarette, a coffee or going out for a walk.

“I just go and have a little wander around, 5 minutes out if I get stressed. Luckily here, we are allowed to have breaks whenever we want to. So if we want to nip out for 5 minutes, we can wander around. For me that 5 minutes is enough to chill and calm down and go back to work again. That’s how I deal with it, especially when it is noisy constantly”

Some carers tried to emotionally distance themselves and this emerged as 'Going on autopilot' and 'being like a robot' when they had stressful days at work.

"You go on an automatic pilot. There is some reason your body just automatically goes, and sometimes you feel like I can be walking up the corridor and I'm just tunnel visioned"

-Release frustration in a safe environment:

Carers talked about the importance of discussing their feelings towards their clients with other carers. They found it helpful to talk to other carers who were able to empathise as they have been in similar situations. They highlighted the ability to do this in a 'safe' environment without getting in to trouble and some carers used clinical supervision for this. One carer stated that she 'screamed it off' in her car after work which she found helpful whilst others engaged in activities such as martial arts and exercise after work.

Recognised strategies for client's problems:

Most carers had recognised strategies for their client's challenges as a result of exploring reasons for their client's problems coupled with years of experience. These strategies were very much individualised with carers new to their job being offered possible strategies by more experienced carers. A carer talked about one of her clients with dementia and ID with long standing behavioural problems. Playing Irish music gave them an opportunity to spend time with her and attend to her needs without much aggression.

"You play certain Irish music, and then she will sit there with a big smile on her face, tapping her foot, and is quite happy. Because she is listening to something she remembers. So usually that's the time we spend with A [client]. We will sit next to the cassette and let her listen to the music. That brings a little bit of joy and happiness in her life"

-Other sources of gratification

During the process of working with challenges carers sought various 'sources of gratification' at work as well as at home and at work used the time of physical distancing for their pleasurable activities. Most carers listed smoking and having a coffee as their main source of gratification at work. When they are not at work, they used various other methods such as having a bath, taking a glass of wine,

talking to children, taking dog for a walk, listening to music and watching football.

“Tools to support them”

When carers ran out of tools from ‘tools to reduce stress’ they moved to ‘tools to support them’. These were:

-Extra pair of hands:

The ability to get help from another person when needed was important for all carers. Paid carers often looked for an extra hand from their colleagues.

“Here you know if something bad is happening, somebody will always come and help me. You are not dealing with bad things on your own”

Family carers did not have that support all the time and help from support workers and other family members were a key ‘extra pairs of hands’ for them.

-Support in making decisions:

Various decisions needed to be taken on a daily basis when looking after people with ID. Some of these decisions were complex and hence made the

caring role challenging and stressful. Carers, therefore often stressed that the support they received with the decisions they took was very helpful for them to be able to cope with daily tasks.

Provision of resources:

Family carers stressed the importance of 'resources' as they dealt with their family member. The main resources they referred to were having respite care, access to incontinence pads and a disabled car badge. Family carers considered these resources to be crucial in making their lives easy to look after their family member.

"It's actually what surrounds you when you are caring for somebody. The caring is fine. We have always cared and we hope to do the same for A [foster son] like the other two we cared for till they died. It is other structures that are not in place as they should be"

'Kick upstairs':

When circumstances were difficult they then turned to their next strategy which was 'kicking upstairs'. One support worker stated that when she got stressed, she would refer to 'upstairs' (the residential home management office was based upstairs in that unit). Carers talked with relief of being able to do this

when they ran out of options and considered that as an advantage in their job as a carer/support worker. “Kicking upstairs’ included seeking help from local psychiatric services. They also emphasised the easy accessibility of medical and psychiatric services.

3. “Compartmentalisation”

Carers often separated their work life from ordinary day to day activities. This distinction emerged often as a theme especially during interviews with paid carers. Paid carers managed to ‘switch off’ from their work life as soon as they left the work premises. They used various ways to separate their work life from home life. Some carers stated that being able to ‘switch off’ was part of their nature and some were able to describe how they actually did it.

“I try to keep my home life separate, so when I go from here, I perhaps go and say I had a really bad day, but then I talk to my family, find out what my husband has done, what my children have done and it [stressors at work] just goes, it does not stay with me until I come back next day”

One carer stated that before she left work she wrote a list of things that needed to be done when she was back at work the next time. This helped her to forget

what had happened at work when she went home. Compartmentalisation did not appear as a theme in family carers' interviews.

Discussion

The striking theme to emerge from the analysis of the interviews was the telling of a 'narrative' as all interviewees told a story of their lives and of the people they cared for. These stories helped them to construct meanings for the to day to day difficulties they experienced, hence cope better. One of the narratives carers used was optimism which has been shown to be a predictor of carers' positive response to people with ID and challenging behaviour (Dagnan et al 1998). 'Narrative' is a recognised concept in research and therapeutic process (Fisher, 1985; Greenhalgh, 1998). Fisher (1985) considered that people used narratives to approach the world and make decisions within a narrative paradigm. Greenhalgh (1998) in her book on 'Narrative based Medicine' described narrative as 'the forward movement of description of actions and events making possible the backward action of self reflection and self understanding'. She also discussed that it offers an understanding of difficult situations, which cannot be derived by any other means. The emergence of a carer's narratives as a main theme signifies the importance of this process to

help them cope with difficulties that they encounter. This provided them with a rationale for their decisions and actions which was a feature of narrative phenomena (Fisher, 1985).

The second overarching theme was the use of a 'strategy toolbox'. Most carers repeatedly talked about the various strategies when dealing with difficulties. Carers developed this coping strategy with more experience working as a carer. It appeared that more experienced had more strategies. This coping theme could be viewed from a theoretical point of view as 'problems and emotion focused coping' explained by Folkman and Lazarus (1980). 'Finding a reason for stress/difficulties', using a 'Recognised strategy for problems', 'Extra pair of hands', 'Resources' and 'Kicking upstairs' could be viewed as problem focused coping. 'Distancing' could be viewed as emotion focused coping. Problem solving strategies were often used when something can be done constructively. Emotional coping is used when people felt that it had to be endured (Folkman and Lazarus, 1980). Some coping strategies could be helpful and healthier in the long term whilst some that were described in the present study such as sources of gratifications (alcohol) were considered as avoidance strategies by Scazufca and Kuipers (1999).

Compartmentalisation was the third theme that emerged from the interviews. This involved carers separating their caring role from the rest of their life. Paid carers were easily able to do this but this did not appear as a major theme from family carers' interviews. This is understandable as they look after their family member at their family home. Even though there were no sub-themes under compartmentalisation, it was included as a main theme as carers often emphasised the importance of it in the coping process.

Conclusion:

The above organisation of themes is helpful to understand and assess current coping strategies and suggest ways of promoting new coping methods. Narrative as a coping strategy highlights the importance of having a social story about the person looked after. This can be viewed as the principle behind various methods such as life stories, person centred care plans and use of photo albums of the person looked after. This research highlights the importance of having a social narrative of the person looked after as a coping strategy. Services could develop various methods of helping carers to use this coping strategy. Helping carers to create narratives about the clients they look after, for an example creating a narrative about redeeming characteristics of a client they look after, may help them to cope better with day to day challenges. Professionals who see carers, for an example in an out patient clinic or during a

home visit, can use the opportunity to listen to carers' 'narrative' and help them to create their own narrative about them (me, the carer) and their service users (He/she, the client). This could be a useful way of helping the carers to build up their coping skills in addition to other help given.

Some helpful strategies such as 'support making decisions' through supervision highlight the importance of such mechanisms which can be easily overlooked and missed due to increasing work load and financial pressures. Some strategies, especially 'sources of gratification' such as alcohol could enable the carer to cope with stressors in the short term, but could potentially lead to additional problems such as health hazards.

Interventions to change the carers' coping styles can alleviate the impact of challenging behaviour of clients (Cooper, 2010). Health and social care professionals can use the above framework of coping strategies to help carers. Professionals can educate carers on different coping strategies and make arrangements to provide some services, which are recognised in this study. These methods will not only help carers to cope, but will help them to thrive in their role as carers.

As the population of people with intellectual disabilities grows, more and more people are being looked after at home by family carers due to the limited availability of resources. Therefore it is important that future service planning and decision making processes are geared towards supporting this group of people who continue to provide an important and invaluable role as carers. Understanding of carers' coping methods is an important part of this and it should be integrated into the future planning of service provisions.

Limitations:

In drawing conclusions from the study it has to be considered that carers may be able to discuss ideal, fictional and assumed coping strategies that they have not used in real life. Interviews may also be affected by various factors such as the ability of carers to reflect on themselves and articulate. Prompts were used to help carers recall difficult times they had with their clients to facilitate them discussing what they actually did at that time to be able to cope rather than what they believed was the most socially desirable way to cope. However this potential source of bias could not be eliminated completely. The small number of interviews led to a limited external validity and the ability to generalise findings. On the other hand, in-depth interviews brought up rich material for analysis which would not have been possible with questionnaires or short interviews targeted at a larger sample.

Even though this study did not try to differentiate coping strategies of family and paid carers, it appeared that both groups shared most coping methods. In this research, the study sample was a group of carers who seemed to cope well in their role. It would be useful to study coping strategies of carers who are struggling to cope in their carers' role as this might identify maladaptive as well as adaptive coping strategies.

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