Experiences of coping for caregivers of adolescents with intellectual disability in Edinburgh, UK

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Introduction

The provision of health care in the UK has changed with a shift in policy from institutional to community-based care for many illnesses, including people with intellectual disabilities (ID) (Simpson, 2007). With regard to this policy, many of these people are being cared for at home, often by a family member, for as long as possible. Additionally, the medical system has improved in healthcare, which leads to more people with health problems surviving for longer. The field of caregiver is important because they are valuable and a fundamental and essential part of community care. Regarding the Working Group Report of the Scottish Executive (2001), caregivers are defined as being a key partners in the provision of providing care. The right and role of caregivers and cared for persons are in equally important status.

The number of people with a variety of disabilities in the UK has increased over the last 35 years. Researchers estimate an increase of 1.2% a year between 1960 and 1995 of people with severe problems, with a significant increase in those who are older (Scottish Executive, 2001). In the area of family caregiving for children with special needs or disabilities, parents have a key role. Research has shown that parents of children with developmental delays experience greater stress than parents...
of children without disability (Lopez, Clifford, Minnes, & Ouellette-Kuntz, 2008). Some studies have identified specific aspects of burden, including maternal depression (Hoare, Harris, Jackson, & Kerley, 1998; Veisson, 1999), and marital conflict (Kazak & Marvin, 1984). Moreover, adolescent tradition is a time of change and challenge. Beresford (2004) recognizes it as problematic, Townsley (2004) report that it brings increasing levels of stress to family and child alike. The challenge presented by this aspect of the transition has interested many researchers in recent studies (White & Hastings, 2004; Todd & Jones, 2005).

Schneider, Wedgewood, Llewellyn and McConnell (2006) conducted a study, based around interviews with twenty families of adolescents with disability, investigating the issue of family restructuring. The study reported that restructuring is most problematic at the stage when other normally able siblings begin to leave home, and also at the point when the disabled adolescent transfers from child-based to adult-based sources of formal external support. Presumably, the stage at which siblings begin to leave home and achieve greater independence is a pertinent transitional issue for families in general, liable to affect the younger siblings who are left behind whether they are disabled or not, although the ramifications of such changes are liable to be more keenly felt in any family which contains a child less likely to be able to make a similar transition. Importantly, coping is most often conceptualized as a response to the demands of specific stressful situations (Lazarus & Folkman, 1984). Coping, then, refers to the things that people do to deal with stressful situations or events. Significantly, the issue of coping for caregivers is essential topic.

Literature Review

Coping Strategies

Lazarus and Folkman (1984) identified two functions of coping: problem-focused and emotion-focused. Problem-focused coping strategies are similar to problem-solving tactics, which include defining the problem, finding the solutions, and carrying out the change (i.e. to alter or manage the situation in an active and constructive way). Problem-solving implies an objective, analytic process that is focused primarily on the environment; problem-focused coping also includes strategies that are directed inward. Moreover, emotion-focused coping strategies are directed toward decreasing emotional distress (i.e. to relieve the emotional impact of the stressful situation by using expressions, thoughts and indirect actions). These tactics involve such efforts as distancing, avoiding, selective attention, and wishful thinking. A range of coping strategies helps people cope more effectively (Kenny & McGilloway, 2007).

Problem-focused coping strategies and caregiver burden

Problem-focused coping strategies are more likely to be employed in situations under control (Lazarus & Folkman, 1984). Problem-focused coping strategies theoretically aim at reducing the effects of the stressor causing the emotional reaction. It also associates with long-term positive effects on psychological health. A number of cross-sectional quantitative studies focus on the effectiveness of coping strategies of caregivers of children with a disability and found that the use of problem-focused coping is related to less psychological distress (Frey, Greenberg, & Fewell, 1989; Wright, Lund, Caserta, & Pratt, 1991; Kramer, 1997). Although
these studies found a consistent result, there are too many different quantitative measures of coping used. It should be noted that these questionnaires or scales might obscure some similarities as well as revealing differences. Almberg Grafström and Winblad (1997) found that problem-focused coping strategies, such as seeking information and seeking social support combined together, seemed to be effective coping strategies. Female caregivers use emotion-focused coping strategies whereas male caregivers use problem-focused coping strategies (Lee, 2005). Webb and colleagues (1998) found that caregivers’ had a tendency to use problem-focused oriented coping strategies for dealing with negative symptom behaviors, but seldom used problem-solving oriented coping strategies for dealing with positive symptom behaviors.

Emotion-focused coping strategies and caregiver burden

In contrast, emotion-focused coping strategies are more like to be employed in situations over which one exerts little control (Lazarus & Folkman, 1984; Beresford, 1994b). Some quantitative cross-sectional studies found that using emotion-focused coping was related to greater depression (Stephens, Norris, Kinney, Ritchie, & Grotz, 1988; Pruchno & Resch, 1989) and high levels of stress (Rose et al., 1997; Knight, Silverstein, McCallum, & Fox, 2000). Knight and his colleagues (2000) compared African and non-African caregivers and found a tendency on the part of former to use more emotion-focused coping and thereby increase their emotional stress than did the later. Importantly, the ethnicity of caregivers could be taken into account in exploring and understanding the process of coping. Similarly, emotion-focused coping was found to relate to higher levels of stress in parents of children with disability (Frey et al., 1989; Sloper, Knussen, Turner, & Cunningham, 1991; Miller, Gordon, Daniele, & Diller, 1992; Seltzer, Greenberg, & Krauss, 1995; Patrick & Hayden, 1999). On the other hand, Koch (1985) suggested being able to express emotions is important in order to release the tension of the stressful event.

‘Acceptance’ coping strategies and caregiver burden

‘Acceptance’ is recognized as a coping strategy, but it sometimes is categorized into emotion-focused coping (Almberg, Grafström, & Winblad, 1997) or cognitive-focused coping strategies (Pratt, Schmall, Wright, & Cleland, 1985) or attitude (Hartley, Ojwang, Baguwemu, Ddamulira, & Chavuta, 2005). Accepting the situation, as understanding it cannot be altered, might indicate that the caregiver has come to terms with the situation. It helps caregivers to live and to accommodate in their caregiving situation (Pruchno & Resch, 1989). Almberg and colleague’s (1997) study, Kneebone and Martin’s review (2003) recommended that the most beneficial coping strategy amongst caregivers is problem-solving and an acceptance style of coping. However, this confusion of categorization might lead to misunderstanding of the functions of acceptance coping strategies.

In summary, there is no evidence of which coping strategies are the best. Clearly, whatever the coping strategies being used, if they can ameliorate the stressful situation, they would be more effective. Importantly, coping is a multidimensional and developable process. The motivation for adopting any individual coping strategy might relate to the availability of resources. However, the literature on specific coping techniques used by either caregiver of adolescents with ID is still a relatively new area.
of study, and consequently, our understanding of the coping strategies that are most effective in dealing with specific stresses in the caregiving context is still in development. A longitudinal design was recommended in the coping literature (Kneebone & Martin, 2003).

**Aim**

The overall aim of this study was to explore, identify and describe how caregivers who caring for adolescents with intellectual disability cope with their caregiving demands over time.

**Methods**

**Research Design**

The grounded theory approach was applied in this study. This approach was developed by the sociologists Glaser and Strauss (1967). The term grounded means that the theory or concept is derived from the research data which are gained from those who experience the particular phenomenon. Additionally, it also serves to initiate new theory and to reformulate, refocus, and clarify existing theory (Hutchinson, 1993). Longitudinal design was also employed to understand the process of coping on caregivers of adolescents with intellectual disability.

**Sampling**

Initially, purposive sampling was chosen in order to get suitable participants based on the overall aim of the study. However, on further reflection, and in response to the caregiver’s organization in Edinburgh city approached to obtain the sample it has become clear that the researcher would have not control over the people who may volunteer to take part. In response to the Data Protection Act 1998 (Data Protection Act, 1998), the organizations have made it clear that they would only approach their members, and would leave it up to the potential participants to contact the researcher independently. This means that it is possible that participants who do not fit the set criteria would respond. Afterward, theoretical sampling was to apply to refine ideas, identify conceptual boundaries and build clear delineation in each category (Morse, 1995; Denzin & Lincoln, 2000). Further it aims to maximize opportunities to compare events, incidents or phenomena (Strauss & Corbin, 1998). Inclusion criteria of caregivers of adolescents with ID were the caregiver is the significant other looking after a teenager person who suffers from ID who is between 13-18 years of age. The caregiver was one who helps with the client’s activities of living everyday. If the main caregivers were both parent, it would be both invited for the same interview. Certainly, the consent form should be signed by two of them before the interview take place. The participants will live in the Edinburgh area. In addition, the process of theoretical sampling is that data are collected and analyzed simultaneously after each interview and the findings of previous interview will influence the next interview. Finally, there were seven mothers recruited from the caregivers’ organisation. However, one of the mothers dropped out of the Phase 2 interview because of lost contact. The mothers’ ages ranged between 36 to 50 years old (mean age 42.71) including one adoptive mother who adopted her son when he was a few months old. The age of the adolescents ranged from 11 to 17 years (mean age 13.86). Most mothers stayed with their husbands and only one mother stayed with her partner. In addition, there was one mother who had two children with ID (aged nearly 10 and 14 years old). All families were Scottish. In terms of mothers’
self-reported total annual household income, one family earned 20,000 pounds to 25,000 pounds, three families earned 25,001 pounds to 30,000 pounds, and two families earned 30,001 pounds to 45,000 pounds. In terms of educational status, 50 % (n=3) had a high school diploma, and 50 % (n=3) had some post-high-school education. In all, 100 % (n=6) were multipara.

Data collection

To collect data open-ended, in-depth, face-to-face interviews was used. Semi-structured interview guide was applied. Interviews were conducted with participants in their own homes where they were most comfortable and convenience. The length of an interview varied from 1 to 4 hours and a 2-hour interview was typical at the Phase 1. Phase 2 and Phase 3 interview normally lasted shorted around 1 and 1.5-hour. The early interview guide was developed from a review of relevant literature. Participants were asked to talk broadly about their caregiving experiences which included both positive and negative aspects of their experiences. The first question in the Phase 1 interview was, ‘As you know, I’m interested in your experience of being a caregiver. First, can you tell me who are you looking after? Could you tell me more about that?’ ‘How do you cope with or switch off ?’ The Phase 2 and 3 interviews opened with the question, ‘How are you coping?’ Subsequent questions and interviews were developed and/or modified on the basis of previous interviews, and in response to ongoing analysis of data. All interviews were conducted with participants in their own homes, ensuring that they felt, as far as possible, comfortable and at ease. Interview length varied from one to two hours. All interviews were digital recording and transcribed verbatim in order to maintain or increase the accuracy of data collection.

A series of pilot interviews was carried out before the main study. The purpose of the pilot single interviews was to enhance the interviewer’s self-confidence and increase the ability to maintain or create safe and stimulating interactions. These however was transcribed which would also increase this skill.

Data analysis

Constant comparative analysis was carried out by the researcher, which was essential to analyze data during the development of a ground theory. While data are being collected, the researcher is also analyzing it developing and assigning particular categories simultaneously. In other words, data are analyzed continuously during the process of the study. The result of analyzing each interview certainly influences the next interview and facilitates the development of a fuller picture or account to emerge from future participants.

There are three levels of coding namely, open, axial, and selective coding (Strauss & Corbin, 1998). The first level, open coding, resulted in reading the raw data from the transcripts and field notes, and identifying, naming and categorizing in terms of their properties and dimensions into concepts. Doing line-by-line analysis was used during this stage. These properties and dimensions were then subjected to axial coding which fixed data together into categories or subcategories. Finally, these categories were selectively coded by integrating the concepts around a core category. A constant comparative method was used aided by QRS NVivo, a computer assisted qualitative data analysis software. The benefits of using this software were setting and restoring the database for efficiently search engine which easily kept track of the analysis process. For example:
<table>
<thead>
<tr>
<th>Raw data</th>
<th>Open Code</th>
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<tr>
<td>’I went to the GP and I said “look it’s getting, you know, too difficult now, both for her and I” so they said “we’ll take her into hospital for observation and er… try, try different drugs” that sort of thing for six weeks…’ (Mrs. Young, Phase 2, p.4)</td>
<td>Coping</td>
</tr>
<tr>
<td>’Well it’s part of the whole package isn’t it. It’s sad but it’s inevitable. There’s nothing you can do about it. So you have to accept it. There’s no, there’s no other thing you can do.’ (Mrs. Young, Phase 3, p.13)</td>
<td>Call for help</td>
</tr>
<tr>
<td>’I don’t look at the future. I’m just living day to day because the inevitable is going to happen and I don’t want to face it.’ (Mrs. Young, Phase 3, p.15)</td>
<td>Accept</td>
</tr>
<tr>
<td>Four criteria were used to evaluate the development of grounded theory. These were: fit, work, relevance, and modifiability of concepts (Glaser and Strauss, 1967). These criteria were concerned with the idea that collected data must fit the categories generated; theory must be practicable and readily acceptable to others to explain the phenomenon and related to the research setting; and theory should be open to modification in the light of new information. Writing memos helped me keep track of insights, thoughts, perceptions, and analytical ideas during data collection and analysis. Memos also helped in the development of categories into core categories, and ultimately theory. This practice is in accordance with recommendations made by Strauss (1987) and Denzin and Lincoln (2000), who point out that memo writing should be started at the beginning of data collection and analysis to link analytic interpretation with empirical reality. Memos were additionally used to reflect on ideas, and to define and refine ideas and processes further. These stages in the process of coding analysis were useful in guiding me, as a novice researcher, in step-by-step analysis of data. At the same time I remained aware that the coding process does not yield a strict procedural flow, but is merely a guideline enabling assimilation and depiction of the general research field.</td>
<td>Don’t want to face it</td>
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The issue of trustworthiness

Rigour is a concept about the evaluation of the quality of any research, which generally includes reliability and validity. This also relates to openness, scrupulousness and coherence from a philosophical perspective, and thoroughness in collecting data (Burns & Grove, 2001). However, it is difficult to examine qualitative data by objective measurement since these criteria may not be suitable for this paradigm. Horsburgh (2003) points out that since the foundation of qualitative research is to explore, understand or describe a phenomenon or experience measurement is inappropriate. On the other hand, Kvale (1996) suggests that qualitative research need not reject the positive trinity. This means that the concepts of reliability, validity, and generalizability, rather than being rejected should be reconceptualized within social interaction to understand and verify what starts in the lived world. This means that issues of reliable observations, interviews, and transcriptions,
or indeed generalizations from one case to another must be pursued and examined.

First, truth value or credibility, namely internal validity of qualitative research refers to confidence in presenting the true data, which involves believability and demonstration. For this research, there were many ways to enhance the credibility of the study. These included asking the caregivers to read a portion of their transcribed interview and make comments on the accuracy of their reported thoughts, improving the researcher’s ability on the collected data and analysis, depending on the time and place of the interview decided by the participants. In addition, a semi-structured interview guide gave participants more space to expand their thinking and talking, and queries can be addressed and clarified by researcher with the participants within the interview. Second, transferability, namely external validity correlates with the findings from the data and is transferable to another setting or group. It was achieved by the interview and transcribed without alteration or omission and this records the feelings and experiences of the participants. Third, the consistent value of this study was kept by the method of data collection, and the findings were discussed by peer debriefing. Finally, confirmability was associated to the objectivity of this research. That meant the collected and analytical data were unbiased by the researcher.

In this study, collected data from interviews and informal observations was triangulated for ensuring the validation of data analysis. In terms of reacting the qualitative data is the situation within particular interviews or observations. It was no doubt that the researcher is part of the research interaction. In other words, the researcher and research could not be significantly separated. Kvale (1996) agrees with that and it is not easy for the researcher to be a detached communicator within the interview. As a result, reflexivity is important to cultivate during the whole stages of the research. Reflexivity is an ability to acknowledge and examine one’s own thoughts, actions, perceptions, beliefs, value, feelings and decisions (Horsburgh, 2003), and to understand the impact of the researcher’s values.

Ethical consideration

The ethical issues have been considered and accepted by the Napier University Health Schools Ethics Committee. Access to this permission was available to anyone connected with the project that wishes to see it.

Findings

Coping strategies are physical and mental mechanisms which enable the caregiver successfully to consider, manage, resolve and reflect upon the various difficulties and challenges of the caregiving situation. Numerous strategies were applied differently by every participant; it is clear in the evidence that there is no single optimum approach to the variety of problems and difficulties they must encounter.

Category 1: Learning experience

“You learn from experience” (Mrs. Gill, Phase 2, p.47), this phrase epitomizes one of the commonest coping strategies amongst most of caregivers. It refers to a fundamentally practical long-term attitude to the development and acquisition of necessary caring skills. At its root seems to be the belief that the only way to learn how to care successfully is by doing it – because only in that way can you understand the nature of the physical, psychological and emotional demands, and develop the necessary
skills and resilience to meet them. Many participants confirmed that they had developed broader outlooks, and acquired new skills as a direct result of finding themselves in situations which required them. This basically pragmatic attitude to coping is summed up by Mrs. Murray below:

*Life doesn't come with a guarantee and unfortunately I had to learn in a bit of a big bump but, no, I mean, it's sad because, even though, they are a lot of hard work...* (Mrs. Murray, Phase 1, p.42)

The sources of learning are many, such as friends, support groups and personal experiences. Learning from other people provides an example of dealing with certain things or situations but there is still an uncertainty and a potentially unhelpful risk in applying it to practice as the effective strategy may differ from person to person in different circumstances.

Mrs. Gill: *I was very stressed then, because I had Dan, who was 22 months old and was a little two year old rushing around like a two year old and having two year old tantrums and not sleeping and pulling the baby this way, that way and the other way and was ill and special needs. Yes. That was very stressful, yes. Hugely stressful.*

Researcher: *Yes? How about now?*

Mrs. Gill: *Less stress.*

Researcher: *Oh, so she doesn’t need any health... No. She doesn’t need any appointments?*

Mrs. Gill: *Oh yes, she has a lot of appointments, but you don’t get into the same level of stress, because you’ve done it all hundreds of times before so it’s not stressful.*

Researcher: *Yes?*

Mrs. Gill: *Do you see what I mean? If you’ve done something loads of times you know where you’re going and you know where you’re going to see and...*

Researcher: *Uh-huh.*

Mrs. Gill: *You learn from experience.*

*(Mrs. Gill, Phase 2, p.47)*

**Category 2: Emotional release**

Strategies of emotional release may also be specific to the individual caregiver. Mrs. Murray, for instance, admitted she often found relief through shouting, as she explains:

*Actually the shouting quite often helps me. It does, it’s just like the pressure cooker or the... you know, just a steaming pot and you just let the lid go where you just... and then you come down and you think ‘oh right, right’...* (Mrs. Murray, Phase 1, p.34)

Mrs. Murray’s account demonstrates a very necessary form of coping strategy - the need to regulate the tension which can mount up inside a caregiver, by finding some means of expressing it. The frequency of such outbursts also varies considerably from individual to individual, so too the specific triggers which provoke them, although these tend to be characterized by some species of ‘crisis’. It may also be that a caregiver would resort to differing release strategies, often depending upon the specific nature of the crisis which provokes them. Mrs. Murray explained that she sometimes found relief in simply withdrawing from the scene of a provocative crisis, or ‘putting her thoughts away for the day’ as a way of coping with emotional fatigue:

*I’ve got quite a good filing cabinet up there that we just, put it away for another day. Because you can’t... I mean sometimes it gets on top of you and you could have a*
big bubble and say, “Why me?” But then you just have to... (Mrs. Murray, Phase 2, p.9)

There are perhaps some similarities between the approach Mrs. Murray describes and escape-avoidance coping strategies, and it might be tempting to ascribe her behavior to a form of denial. But there may be a danger of over-simplification in making such a judgment. Rather, it should be perhaps asked whether the particular dilemma she is addressing – via the question ‘why me?’ is soluble in any other way. It is not, for the simple reason that this caregiver is responding, in this instance, to the reality of a situation which has been thrust upon her, whose progress she cannot significantly alter. Therefore, in this case, the act of putting her troubles to one side represents an expedient and effective coping strategy.

To put the matter in its simplest terms, ‘why me?’ for Mrs. Murray represents a question to which there is no rational or valuable answer. To desist from trying to answer it is more useful than allowing her inability to do so to exacerbate her frustration.

**Category 3: The sense of control**

In an interview conducted during Phase 3 of the current research (p.21), Mrs. Macleod used the above phrase, referring to the sense that she is ‘on top’ of the caring situation. A number of participants were like her in expressing the importance to them of a sense of control, and the ability to manage their lives. This sense of control may derive from a variety of sources, and apply not only to the caregiver’s confidence in their control of the cared-for individual, but also to those bodies or individuals connected to the case. Mrs. Murray, mother of Lisa (Down’s Syndrome) and Tom (Autistic Spectrum Disorder), for instance, refers to the importance of routine in providing her with this confidence:

...I’m the boss so I know when she [Lisa] is away to Respite, I know when she’s doing all those different things. That means that I know for a fact that she’s away from Monday to Friday next week, so that’s a big bonus. So I don’t know, Tom’s at Respite next Thursday, I’m away to Aberdeen with my mum for the day next Thursday, and I’m trying to think because I always have everything worked out well in advance. (Mrs. Murray, Phase 3, p.21-22)

Levels of mastery are generally reported to be constant - neither increasing nor decreasing. This tends to suggest that the sense of mastery is in some way significantly linked to the relative stability of the cared-for person’s condition. Potential improvement of condition among children of caregivers is reflected in the range of structured care situations – playgroups, respite, friendship networks, schools – into which they may be integrated, providing the opportunity for the mother to attain a greater sense of control over her life.

**Category 4: Approach to life**

People with an upbeat and positive perspective tend to be healthier and enjoy longer lives than those who are generally gloomy and cynical about the future (Hogg & Vaughen, 2005; Franzoi, 2006). This observation might be summed up as representing the importance of positive thinking, and epitomizes a simplistic, but nonetheless important and successful coping strategy, exemplified by those participants in the current study who seem to cope most successfully with the difficulties they face. It is an attitude which persuades the caregiver, as far as possible, to accept with equanimity, cheerfulness, and good grace the
inevitable vicissitudes of caring in the home.

Sub-category 1: Acceptance

A further cognitive coping strategy is represented by the ability to accept inevitable situations, rather than objecting to, avoiding, or attempting to deny them. The importance of acceptance was mentioned by many participants, as being synonymous with knowledge and understanding of their role in providing care. Mrs. Young, an adoptive mother, pointed out that it was her choice to have a child with ID, indicating her awareness of the fact that she, unlike her fellow participants, had knowingly accepted the demands of care:

*I think we both really accept the situation we’re in, we really accept... we’re lucky we have a nice home, we have five fabulous kids, and we accept our lifestyle, we’re not looking for anything more....* (Mrs. Young, Phase 1, p.19)

Her expression (smiling) and tone of voice (light and cheerful), as she explained her outlook clearly indicated an equable acceptance of her situation.

Sub-category 2: “Take it day-by-day...”

With these words (above), Mrs. Campbell (Phase 3, p.5) referred to an important element of her coping strategy - describing a deliberate and pragmatic decision not to dwell on future possibilities, or look any further ahead than the immediate concerns of the day in front of her. The attitude is based in a realization that attempting to anticipate the course of future events within the care situation is largely pointless, and liable to lead to additional unnecessary anxiety. This strategy was of benefit to a number of participants - Mrs. Young, for instance, who explains her outlook in the following excerpt:

*...I think we’ve had a much better life because we’ve had all the kids and because we’ve got Stuart. And so therefore, we’ve never, never kind of mourned a life that we haven’t got, because we think it’s greener on the other side. We’ve always had a really positive attitude and loved it....* (Mrs. Young, Phase 3, p.17)

Individuals with a positive attitude tend to entertain positive ideas, and manifest similarly positive behavior. They are likely to look for positive and meanings and optimistic interpretations in the situations they encounter. Such determined positively may frequently take the form of positive comparison - a strategy found amongst caregivers, which is illustrated in the following quotation from Mrs. Murray:

*...it’s sad because even though they...*
are a lot of hard work, but they’re not really when you compare other families as well, you know, they’re not in wheelchairs, they’re not tube fed, you know, and, you know, they’ve not got epilepsy, they’re not on medication... (Mrs. Murray, Phase 1, p.42)

**Discussion**

Several other studies (Almberg et al., 1997; Grant & Whittell, 2000; Kim, Greenberg, Seltzer, & Krauss, 2003) reiterate this point, and emphasize the particular importance of learning as a means of altering difficult situations. Such ‘learning’ strategies may be grouped with problem-focused coping strategies identified in Lazarus and Folkman’s Stress and Coping Model (1984). On the other hand, Pruchno and Kleban (1993) could identify no relationship between problem-focused coping and improved mental health, stating that the existence of such a relationship could only be advanced on the basis of further investigation. However, in reflecting on the disparity between these findings, it may be worthwhile to consider the nature of Pruchno and Kleban’s research sample: their study investigated the role of coping strategies in four hundred and twenty-four adult or child caregivers of institutionalized parents. It is conceivable that, within this group of participants, perception of the benefits of problem-focused coping strategies may be obscured by negative emotions connected with the inability to keep their parents at home.

Emotional release of coping strategies bears close resemblance to certain emotion-focused coping strategies identified by Lazarus and Folkman (1984). Several previous studies (Frey et al., 1989; Miller & Cafasso, 1992; Seltzer et al., 1995; Patrick & Hayden, 1999; Knight et al., 2000) have reported negative affects associated with emotion-focused strategies (for example, caregiver burden or caregiver depression). On the other hand, some qualitative studies (Brown & Hepple, 1989; Beresford, 1994b) have suggested that certain emotion-focused coping strategies, such as watching a comedy program, having a hot bath, or even, as in the current study, doing a crossword were helpful. On the basis of the evidence in the current study, it certainly seems to be the case that emotion-focused strategies may bring the benefit of diminishing psychological distress. The broad view might be that the effectiveness of such strategies is very much dependent upon the individuality of the caregiver.

Caregivers referred to various means by which they achieved this release, including crying, shouting, and walking away from the source or trigger of the outburst. Although such outbursts are clearly spontaneous, not in any way premeditated, their value as a coping strategy should not be underestimated. A number of mothers and elderly female caregivers admitted to crying. This is not uncommon, particularly in female caregivers. Some previous studies (Vingerhoets & van Heck, 1990; Baum & Grunberg, 1991; Ptacek, Smith, & Dodge, 1994) identify crying as a necessary and healthy outlet, and point out that it is more usual among female than male caregivers. This finding can be linked more generally with the understanding of the differences in emotional expression between genders - differences which may be due both to innate expressive tendencies as well as the effects of social and cultural conditioning.

This sense of control clearly has to a positive effect on her life. This accords with the findings of a previous quantitative study (Helmes, Green, & Almeida, 2005) which suggested that a measurable
sense of control is associated with reduced levels of psychological distress and caregiver burden, positively affecting caregivers’ ability to manage their situations. It is interesting and significant that this sense of control was more predominantly reported amongst mothers.

A three-year longitudinal quantitative study conducted by Glidden and Pursley (1989) investigated the situations of forty-one mothers in adoptive families, and reported that they attained a more stable adjustment than birth mothers. The evidence provided by Mrs. Young, in tandem with these findings, simultaneously confirms the value of acceptance, and the greater ease of acceptance amongst adoptive mothers, identifying the process of acceptance with the premeditated decision to adopt. The experience for birth mothers of children with ID is obviously different, and more likely to be problematic, since they are confronted at one and the same time with the practical burden of care, and the emotional burden of adjustment to an unforeseen, and often emotionally charged situation.

A study conducted by Grant and Whittell (2000) of families of children with ID, identified the strategy of positive comparison as a common and beneficial resort. Borden and Berlin (1990) have also focused on the issue of positive comparison. They suggest that this appraisal of circumstances amongst caregivers increases the ability to cope, and contributes to caregiver well-being by bolstering self-esteem and morale. Moreover, such approaches to life bear significant similarities to cognitive-focused and reframing coping strategies.

**Conclusion**

The process of coping is multidimensional. The concept of coping is a process that includes the use of goal-directed strategies that are initiated and maintained over time and across encounters by means of cognitive appraisal and regulation of emotion and physiologic responses. Modes of coping include motor and expressive behaviors aimed at changing the stressor and regulation of emotional and physiologic response aimed at preservation of integrity. The possibility of choice a coping strategy relates to the availability of coping resources. In this study, coping strategies refer to how caregivers approach and deal with their life changes, and four types of coping strategies were identified: Learning experience; Emotional release; The sense of control; and Approach to life. A major limitation of this study was only three interview points in the space of 18 months were possible in getting enormous growing data because of time constraints.; this meant that this longitudinal design was limited.

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Experiences of coping for caregivers of adolescents with intellectual disability in Edinburgh, UK

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Abstract

The dynamics of caregiving situation is stressful. Although much research has been carried out in this field, there was still a lack of agreement about the process of coping in the caregiving is poorly understood, and also a poverty of longitudinal investigation. Adolescence is recognized as a critical phase for individuals with intellectual disability and for their families. The overall aim of this study was to explore, identify and describe how caregivers cope with their caregiving demands over time. Qualitative longitudinal design using a grounded theory approach was applied. Six caregivers of adolescents with intellectual disability were recruited from the caregivers’ organization. There were three interviews carried out with each caregiver at the beginning, 6-month, and 18-month later. The interviews were semi-structured. Each interview was digital-recorded and transcribed. A constant comparative method was used aided by QRS NVivo. The finding of the study identified four types of coping strategies: Learning experience; Emotional release; The sense of control; and Approach to life. Importantly, whatever the coping strategies being used if it can ameliorate with the stressor would be more effective. The process of coping is multidimensional. The changes of adopting any of coping strategies relate to available coping resources.

Key words: caregiver, coping strategies, adolescents with intellectual disability, grounded theory approach

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