Mediators of Well-being in Ageing Family Carers of Adults with Intellectual Disabilities

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Background Increasing numbers of adults with an intellectual disability are being cared for at home by ageing parents. The purpose of this study was to determine whether carer resources (i.e. social support and formal service use) and carer appraisals of ageing and stress/burden mediate the relationships between (1) maladaptive behaviour and carer depression; (2) carer health and carer depression; (3) maladaptive behaviour and carer quality of life; and (4) carer health and carer quality of life.

Methods Eighty parents over the age of 50 were interviewed using a number of measures concerning their overall health, perceptions of ageing and stress, depression, and their child’s maladaptive behaviour.

Results Carer perceptions of ageing and stress emerged as significant mediators of the relationship between carer health and depression. In addition, perceived carer stress emerged as a significant mediator of the relationship between maladaptive behaviour and carer depression. Resources and appraisals did not emerge as significant mediators in analyses using quality of life as a positive outcome.

Conclusions Results highlight the important contributions of appraisals to well-being and raise questions for future research regarding the role of resources such as informal and formal support in the coping process.

Keywords: ageing carers, depression, intellectual disability, mediators, quality of life, well-being

Introduction

The purpose of this study was to explore the contributions of variables in McCubbin & Patterson’s (1983) Double ABCX model to well-being in older family carers of adults with intellectual disabilities. Mediation analyses were conducted to explore whether family resources and appraisals served as mediators of the relationships between (1) maladaptive behaviour of adults with intellectual disabilities and carer depression; (2) carer health and carer depression; (3) maladaptive behaviour and carer quality of life; and (4) carer health and quality of life. Eighty parents who were primary carers of an adult with an intellectual disability were interviewed using a number of measures. Maladaptive behaviour and carer overall health represented the aA factor (stressors) in the Double ABCX model, social support and use of formal support from services (resources) represented the bB factor, perceived family stress and perceived adverse age-related changes (appraisals) represented the cC factor and depression and quality of life (negative and positive outcomes) represented the xX factor. The results of model testing yielded three significant mediators. Perceptions of ageing emerged as a significant mediator of the relationship between carer health and carer depression. In addition, perceived carer stress emerged as a significant mediator of the relationship between (1) maladaptive behaviour and carer depression and (2) carer health and depression. Contrary to expectation, significant mediators did not emerge in analyses with quality of life as positive outcome.

The numbers of older parents providing ongoing care at home for adults with intellectual disabilities are growing (Heller & Factor 1993: Minnes & Woodford 2004). In normative ageing, there is a shift of responsibility from parent to child; however, in the case of families of individuals with intellectual disabilities, parents function in an increasingly non-normative role as their child passes through adolescence and into adulthood (Minnes et al. 2003). Periods of transition such as adolescence and early...
adulthood have been noted as times of particular stress for families (Thorin & Irvin 1992; Baine et al. 1993; Heller & Factor 1994; Hayden & Heller 1997; Minnes 1998; Freedman et al. 1999). The concerns of older parents include: planning for long-term accommodation and for ongoing emotional and social support for their family member and organizing wills and trusts (Minnes & Woodford 2004). As carers age, declining health, strength and patience can add to the stress of providing care for their adult family member whose dependency needs will also increase with age (Roberto 1995). However, adults with intellectual disabilities can also provide support to their ageing parents. Research by Heller et al. (1997) has demonstrated a relationship between the support parents received from their family member with an intellectual disability, carer satisfaction and perceived burden. Such findings highlight the complex relationships involved in carer coping and adjustment and the need for studies using multidimensional designs.

Theoretical models of stress, coping and adjustment have facilitated family research contributing to studies of the relationships between these constructs. Three of the most frequently used models in research on stress and coping are the Transactional Model of Stress and Coping (Lazarus 1999), the Multidimensional Model of Stress, Anxiety and Coping (Endler 1997) and the Double ABCX model of Family Stress and Adaptation (McCubbin & Patterson 1983). The Double ABCX model was chosen for this study as it was developed for use with families in crisis, and has been widely used to guide research focusing on the needs of families of children and adults with intellectual disabilities (e.g. Bristol 1987; Cole 1986; Gats et al. 1990; Konstantareas & Homa-tidis 1991; Minnes 1988; Orr et al. 1991; Smith et al. 1995) The model includes pre-crisis variables: the A factor refers to stressors, the B factor refers to existing resources and the C factor refers to perceptions/appraisals of stressors contributing to potential development of a crisis. In addition, the model includes post-crisis variables: the aA factor refers to the pile-up of stressors, the bB factor refers to changing family resources and the cC factor refers to perceptions/appraisals and related coping strategies. Family adaptation represented by the xX factor is depicted in the model as being positive or negative (bonadaptation or maladaptation). Given that the participants in this study were older parents of adults with intellectual disabilities, the post-crisis components of this model were used to explore the pile-up of stress (aA factor), family resources (bB factor), carer appraisals of stress and coping strategies (cC factor) as potential mediators of well-being (xX factor).

A recent review of the literature on families of individuals with a developmental disability (Benn 2005) found 34 studies using the Double ABCX model. These studies can be divided into three types. In the first, the model was used as a theoretical framework to guide variable selection or to facilitate discussion of findings. These studies often measure individual stressors and resources (e.g. Saloviita et al. 2003) and correlational analyses are often used to explore relationships between variables (e.g. Grant & Ramcharan 2001; Gray 2002). A second approach focuses on elements of the model as predictors of outcome (e.g. Lustig & Akey 1999; Baxter et al. 2000; Saloviita et al. 2003). A third approach focuses on causal modelling and the ordering of variables (e.g. Lavee et al. 1985; Orr et al. 1991).

**Research Findings on Individual Components of the Double ABCX Model**

**Pile-up of stress (the aA factor)**

The pile-up of demands related to caring for a family member with an intellectual disability has been well documented in the literature (Krauss & Seltzer 1998). Previous research has found maladaptive behaviour to be associated with high levels of caregiving stress and burden (Minnes 1988; Heller & Factor 1993; Westling 1996; Heller et al. 1997). However, research with older carers has questioned whether the caregiving experience over time can have positive as well as negative elements. Research has yielded mixed results regarding this assumption. While the severity of disability including maladaptive behaviour has been found to be associated with greater caregiving burden (Heller & Factor 1993; Nachshen et al. 2002; Pruchno et al. 1996), Heller et al. (1997) found that a family member with an intellectual disability can be helpful to older parents thus potentially reducing stress.

Pile-up has been described as a complex set of changing conditions, normative and non-normative events that add strain to a family’s ability to cope with post-crisis events (Lavee et al. 1985). One stressor that is particularly pertinent to ageing family carers is health. Carer health has been included in a number of studies (Epel et al. 2004; Heller et al. 1997; Lawton et al. 1991; Pruchno et al. 1996; Seltzer et al. 2001). However, in some cases this variable has been used as a stressor (Heller & Factor 1993; Krauss 1993), in others as a resource (Greenberg et al. 1993; Heller et al. 1997) or as an outcome (e.g. Seltzer et al. 2001; Epel et al. 2004). The assumption that health is associated with less carer burden has not been
supported consistently (Smith 1996; Heller et al. 1997). Indeed, some studies have found the health status of mothers of adults with intellectual disability to be similar to national health norms (Chen et al. 2001) and similar to the physical health of parents without a child with a disability (Seltzer et al. 2001).

Given the older age range of the sample and findings that health is an important predictor of well-being (Pruchno & Resch 1989), parental health as well as maladaptive behaviour were included as pile-up stressors in this study.

Family resources

Social support is generally considered to be an important mediator of caregiving stress. However, research findings do not always support this relationship. Social support is a multidimensional construct. Consideration needs to be given to the nature of the support (i.e. formal or informal) and to the support provider (e.g. friends, family, agency personnel or professionals) (White & Hastings 2004). Some research has shown that informal supports are associated with lower caregiving burden (Heller & Factor 1993) or depression (Krauss & Seltzer 1998), but other studies (Heller et al. 1997) have not found a significant relationship. Similarly, studies of formal supports have yielded mixed results. While some have found no relationship between professional and service supports and parental depression (Krauss & Seltzer 1998) or well-being (White & Hastings 2004), others have suggested that disagreements with those providing formal supports contribute to greater parental stress (e.g. Baxter 1987; Sloper & Turner 1992). In contrast, King et al. (1999) have highlighted the benefits of family-centred services for parents. For purposes of the current study, both availability of social support and use of formal services and supports were measured.

Appraisals and coping

Research by Folkman et al. (1987), Folkman & Moskowitz (2000) and Lazarus & Folkman (1984) has highlighted the importance of appraisals in the process of coping with stress. Perceptions or the eC factor in the Double ABCX model have been described as shaping the meaning the family gives to their situation. A variety of measures of appraisal have been used in the literature including: reframing (Hayden & Heller 1997), perceived caregiving burden (Smith et al. 1995; Heller et al. 1997) and self-perceived adverse age change (Smith et al. 1995). Constructive coping strategies include: planning, active and problem-focused coping, suppression of competing activities to permit greater concentration on managing stress and positive reinterpretation and growth. Maladaptive strategies included denial, emotion-focused coping and disengagement (Krauss & Seltzer 1998). Emotion-focused coping has been found to be related to greater subjective burden and depression, whereas problem-focused coping has been found to effectively regulate well-being of mothers of adults with intellectual disabilities (Kim et al. 2003). In an earlier study, Essex et al. (1999) found a significant interaction between emotion-focused coping and perceived burden depending upon the level of functioning of the child. When the child had less severe functional limitations there was no association but when severe limitations were present mothers reported fewer feelings of burden if their use of emotion-focused coping was limited. In the current study, carer perceptions were measured in two ways: (1) carer appraisals of stress associated with caregiving (burden) and (2) carer perceptions of adverse age changes.

Adaptation

Family adaptation is described in the Double ABCX model as either the positive or negative result of family responses to crisis and the pile-up of demands (Lavee et al. 1985). Maladaptation is defined in terms of the imbalance between the pile-up of demands and the family’s resources for meeting those demands, whereas in bonadaptation, pile-up and resources are more evenly matched. Lavee et al. (1985) described the outcome in terms of well-being or psychological health. Depression in parents of children diagnosed with developmental disabilities has been well documented in research with younger and older parents (e.g. Beckman 1991; Blacher 1984; Blacher et al. 1997; Bristol et al. 1988; Krauss 1993; Olsson & Hwang 2001; Seltzer 1992). A recent meta-analysis (Singer 2006) of research between 1982 and 2003 comparing depression in mothers of children with and without developmental disabilities found that 29% of mothers of children with developmental disabilities in these studies were experiencing depression. In contrast, higher depression was not found in the one study of adults in the Singer (2006) review. This finding adds support to studies suggesting that depression may decline over time (Flaherty & Glidden 2000; Glidden & Schoolcraft 2003). Indeed, some of the 71% of mothers not reporting depression might have been included in this older group. In research with older parent carers, higher levels of depression have been found to be
associated with stressful life events unrelated to a child with a disability including declining health and loss of a spouse (Seltzer 1992). Given research demonstrating that people experiencing even minor depression function at lower levels than those with chronic illnesses (Hays et al. 1995) and the significant impacts that minor and major depression can have on individual familial and societal outcomes (Singer 2006), the current study chose to include a measure of depression as an outcome variable.

Positive outcomes in family research have been addressed in research only relatively recently. Studies by Hastings & Taunt (2002) for example have demonstrated that despite experiencing considerable stress, families also describe positive outcomes such as an increased sense of purpose in life and the development of new skills and career opportunities as a result of raising a child with a disability. While the quality of life of individuals with developmental disabilities has been the focus of numerous studies (see Schalock & Verdugo 2002; Brown & Brown 2003), the concept of family quality of life has only recently become the focus of research (Poston et al. 2003). In this study, parental rather than family quality of life was used as a positive outcome variable.

Predictors of outcome

Although the Double ABCX model was developed to represent change over time, most research has focused on the second post-crisis segment of the model measuring the components on a single occasion (Lavee et al. 1985; Orr et al. 1991; Clark 1999; Brannan & Hefflinger 2001; Shin & Crittenden 2003). For purposes of this study, the crisis was considered to be the birth of a child with an intellectual disability and post-crisis was viewed as including the pile-up of stress, resources and appraisals, positive and negative adaptation reported by a sample of older parent carers. The model proposes several directional and non-directional relationships between variables with each variable having a directed path to the outcome. Studies have used regression analyses to determine predictors of outcome and path analysis to test model fit. Path analyses conducted by Orr et al. (1991) led to the recommendation that the model factors be ordered ACBX rather than ABCX. Orr and colleagues found a linear progression from (aA) the stressor, to (cC) the family’s perceptions of the stressor, to (bB) the family’s use of resources, and to (xX) the experience of stress (ACBX model). Further research has failed to find a direct effect of the stressor (aA) on the family’s resources (bB) (Herman & Marcenko 1997; Shin & Crittenden 2003). More recently, however, structural equation modelling has provided support for the ACBX model (Nachshen & Minnes 2005). A linear relationship was found in which parent well-being and resources mediated the relationship between the stressor (child behaviour problems) and the outcome (empowerment).

While the study of constructs of stress and coping can be informative, Lazarus (1999) has suggested that research also is needed to analyse the process (i.e. mediating effects) of such variables. Mediation analyses (Baron & Kenny 1986; MacKinnon et al. 2002) provide a more conservative approach and have the added advantage of requiring smaller sample sizes than those required by structural equation modelling. In this study, mediation analyses were used to study more complex relationships between the variables. Specifically, whether resources, (bB factor) and appraisals (cC factor) mediate relationships between (1) stress (aA factor) and depression (xX factor) and (2) stress (aA factor) and quality of life (xX factor). For purposes of this study, maladaptive behaviour and carer health were considered to be stressors.

Hypotheses

A number of hypotheses listed below were generated based upon past research to address the relationships between factors in the ABCX model including stressful characteristics of the family member with an intellectual disability, family resources, appraisals and outcome:

1. Social support and formal support use (bB factor) would have mediating effects on the relationship between maladaptive behaviour (aA factor) and depression (xX factor) and between maladaptive behaviour (aA factor) and quality of life (xX factor).

2. Carer appraisals of stress associated with caring for a family member with an intellectual disability (cC factor) would have mediating effects on the relationship between maladaptive behaviour (aA factor) and depression (xX factor) and between maladaptive behaviour (aA factor) and quality of life (xX factor).

3. Carer appraisals of ageing (cC factor) would have mediating effects on the relationship between maladaptive behaviour (aA factor) and depression (xX factor) and between maladaptive behaviour (aA factor) and quality of life.

4. Social support and formal support use (bB factor) would have mediating effects on the relationship.
between carer health (aA factor) and depression (xX factor) and between carer health (aA factor) and quality of life (xX factor).

(5) Carer appraisals of ageing (cC factor) would have mediating effects on the relationship between carer health (aA factor) and depression (xX factor) and between carer health (aA factor) and quality of life (xX factor).

(6) Carer appraisals of stress associated with caring for a family member with an intellectual disability (cC factor) would have mediating effects on the relationship between carer health (aA factor) and depression (xX factor) and between carer health (aA factor) and quality of life (xX factor).

**Method**

**Research participants**

The sample consisted of 80 parents who were primary carers of adults with intellectual disabilities living in south-eastern and central Ontario, Canada. Inclusion criteria limited the sample to parents over the age of 50 who could speak and understand English well enough to participate in an interview and parents who were the primary carer of an adult with an intellectual disability over the age of 16 living at home. Participants were recruited from seven agencies providing a variety of services to individuals with intellectual disabilities and their families living in 10 towns and small cities (populations ranging from 20,000 to 100,000) and the surrounding counties. Carers ranged in age from 50 to 88 years with a mean age of 65.7 years. The sample included 71 mothers and 9 fathers. Only one parent from each family was interviewed. The majority (62.5%) of these parents were married while 22.5% were widowed and 15% were separated or divorced. The level of education was distributed fairly evenly with 25% having some post-secondary education, 30% having completed high school and 35% less than a complete high school education.

The adult children of the participating parents ranged in age from 17 to 59 years with a mean age of 35.7 years. There were 30 females and 50 males. The level of disability ranged from mild (27%) to moderate (58%) and severe (15%). Several aetiologies were identified with Down syndrome being the most common (26%) followed by unknown cause (22.5%), cerebral palsy (12.5%) and problems at birth (e.g. lack of oxygen and premature birth) (11%), fragile X syndrome (6%) and autism (6%).

**Measures**

**aA factor: stressors**

*Maladaptive behaviour.* The Vineland Adaptive Behaviour Scales - Maladaptive Behaviour Domain (Sparrow et al. 1984) was used to measure the level of maladaptive behaviour of the adult with intellectual disabilities. This domain of the Vineland consists of 37 statements related to maladaptive behaviour of the person with intellectual disabilities (e.g., I feel very close to'). Each item is rated as 0 (no, never); 1 (sometimes or partially) or 2 (yes, usually). The total score ranges from 0 to 74.

**Carer health.** Given concerns regarding the length of the interview, a standardized questionnaire such as the General Health Questionnaire was replaced by a simple rating of overall health. Participants were asked to rate their overall health on a four-point scale: (1) poor, (2) fair, (3) good and (4) excellent. Self-rated health using a single item found support in a meta-analysis of 27 studies (Idler & Benyamini 1997). In addition, the Center for the Study of Aging and Human Development (1978) reported that the criterion-related validity of a single item measure of physical health with a physical examination to be 0.70.

**bB factor: family resources**

**Social support.** The Interpersonal Support Evaluation List (ISEL; McColl & Skinner 1995) was used to measure the availability of social support. Four response options are provided: never true, sometimes true, usually true and always true. The instrumental support subscale consists of eight items regarding the availability of practical support (e.g., If I needed someone to drive me to an appointment I could find someone'). The informational support subscale consists of 10 items relating to obtaining advice or guidance (e.g., There is someone who can give me advice about money.). The emotional support subscale consists of 16 items regarding understanding, acceptance and friendship (e.g., I have friends I feel very close to'). Respondents are asked to indicate the source of each type of support (family, friends and professionals).

**Formal support.** A Checklist of Services and Supports for Individuals with Intellectual Disabilities (Woodford
generated in consultation with parents and service providers was used to measure the number of services and supports used by the adult with an intellectual disability.

**CC factor: appraisals**

**Perceived stress.** The Family Stress and Coping Interview (FSCI; Nachshen et al. 2002) was used to measure perceived stress related to caregiving issues. The FSCI measures the stress reported by parents of individuals with intellectual disabilities in relation to 24 issues including: (1) diagnosis of intellectual disability, (2) seeking a second opinion, (3) explaining the disability to others, (4) the cause of disability, (5) day-to-day interactions with others, (6) dealing with health professionals, (7) dealing with legal professionals, (8) education, (9) creating opportunities for family member to make friends and participate in activities in the community, (10) finding the best level of integration for the family member, (11) decisions about accommodation in the home or the community, (12) meeting the needs of other children in the family, (13) meeting the carer’s own personal needs, (14) meeting the needs of the carer's spouse, (15) maintaining friendships, (16) child’s sexuality, (17) work placements, (18) long-term planning for accommodation (19) wills, trusts and guardianship, (20) ensuring ongoing emotional and social support for the family member with intellectual disability, (21) transportation, (22) assistance with care of the family member, (23) time apart and (24) financial issues. For each issue, quantitative and qualitative data are collected. There are questions pertaining to the level of stress associated with each issue, availability and helpfulness of support, changes in stress level over time, successes and challenges when dealing with the issue, and changes that could make experiences associated with the issue easier. Each item is rated from 0 (not stressful) to 4 (extremely stressful). As in past studies (Nachshen et al. 2002, 2005; Nachshen & Minnes 2005), the sum of these stress ratings was used as an overall perceived caregiving stress score with a range from 0 to 96. In addition, for purposes of this study, only the quantitative data were included in the analyses. Some of the qualitative data from this project are reported in another publication (Minnes & Woodford 2004).

**Self-perceived adverse age-change: carer.** This six-item scale (Smith et al. 1995) measures how respondents perceive themselves to be affected adversely by their own ageing (e.g. As I get older, it is harder for me to get through the day). Each item is rated from 1 (strongly disagree) to 5 (strongly agree). Items are summed for a possible score ranging from 6 to 30.

**XX factor: outcome/well-being**

**Depression.** The Centre for Epidemiological Studies-Depression Scale (CES-D) (Radloff 1977) was used to measure depression. The CES-D is a 20-item scale containing items measuring how the respondent has felt over the last week (e.g. I was bothered by things that usually don’t bother me). The possible responses range from 0 – rarely (<1 day) to 3 – most of the time (5–7 days). The total score ranges from 0 to 60.

**Quality of life.** There are two main approaches to the measurement of quality of life: the multi-item index and the single-item global question (Wade 1992). The use of subjective, single-item global ratings has been recommended because such ratings reflect the values and preferences of the individual respondent without the constraints of specific item content (Gill & Feinstein 1994). Therefore, for purposes of this study, quality of life was measured using a single item: ‘Overall, how do you feel about the quality of your life?’ Participants were asked to use a rating scale from 1 (terrible) to 7 (delighted).

**Procedure**

Following approval of the study by the Queen’s University Research Ethics Board, meetings were held with a number of agencies to discuss the proposed project, to solicit participation and to discuss procedures for recruiting participants. There were no particular concerns raised by the ethics review committee except to ensure that procedures were in place if a participant became distressed during or following the interview. Seven agencies agreed to participate. The agencies contacted potential participants by mail and a follow-up phone call to confirm interest in participating and to obtain consent for their names to be passed on to the researcher. Those who agreed to participate in the study were contacted to arrange an interview time. On average, interviews lasted 2–3 hours. In a few instances, interviews were held over two or even three sessions to accommodate participant needs. Most interviews took place in the participant’s home. In a few exceptions another venue was arranged if it was more convenient for the participant. With consent, the more detailed portion of interviews regarding the three most stressful
issues rated on the FSCI was tape-recorded to ensure accuracy and completeness of information. Although exact response rates were not available, potential participants were contacted by members of their local agency. Reports from recruiters indicated that parents contacted were pleased that their concerns were of interest and very few declined to participate. Although there were no adverse reactions to the questions reported, interviewers had telephone numbers of resources that participants could contact if the interview raised issues or concerns.

Results

Mean scores and reliability coefficients for each of the measures are shown in Table 1. All scales were found to be internally consistent with satisfactory alpha coefficients.

Data preparation

Four of the scales used in this study were found to have univariate outliers. The Vineland Maladaptive Behaviour Scale had two outliers with values of 67 and 46. The FSCI had one outlier with a value of 80. CES-D had one outlier of 51. It was important to include these data, as they represented the actual responses of the parents, but there was a concern that these few points not have undue influence on the results. It was decided, therefore, to recode the outliers (Barnett & Lewis 1984) to 3 standard deviations from the mean. The mean and standard deviation for each of the scales, with the outliers excluded, were calculated. The values were recoded as follows: maladaptive behaviour – 39; FSCI – 65; and CES-D – 33. The recoded values were then used for the rest of the analyses.

Reliability for each of the measures with multiple items was acceptable (Table 2). Alpha could not be calculated for the overall health and quality of life measures as they contained only one item.

Stressors (A factor)

Maladaptive behaviour

Scores on the Vineland Scale for Adaptive Behaviour - Maladaptive Subscale scale ranged from 0 to 33 with a mean of 13.73 (SD = 9.0). The most common problem behaviour was poor attention and concentration (71%), followed by overly dependent behaviour (67%), stubborn or sullen behaviour (65%), extreme anxiety (56%), negativistic or defiant behaviour (50%) and withdrawal (46%). Compared to the norms for mentally retarded adults in non-residential facilities, aged 18 years and older (Sparrow et al. 1984, p. 257), 31% of the adults with developmental disabilities were in the nonsignificant range (0–50th percentile) with a score of 0–8. Forty-nine per cent were in the intermediate range (51st to 84th percentile) with a score of 9–20 and 20% were in the significant range (85th percentile and above) with scores of 21–39.

Carer health

The majority of parents participating in this study reported that they enjoyed good health with 52.9% rating

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their health as ‘good’ and 17.6% rated their health as ‘excellent’. A small proportion of parents (4.9%) rated their health as ‘poor’ and 24.5% rated their health as ‘fair’.

Family resources (bB factor)

Social support
The mean total score on the ISEL was 42.56 (SD = 9.65) indicating relatively good social support overall.

Service use
Parents, on average, reported using 2.84 services for their family member. The most frequently used service was Case Management (63%) followed by Social and Recreational Services (48%) and Respite Care (44%).

Perceptions/appraisals (cC factor)

Self-perceived adverse age change
The mean score on this scale was 19.79 (SD = 5.67) with a range of 6–29 out of a maximum of 36. The majority (62.5%) of parents reported that they had been adversely affected by age-related changes while 37.5% had either experienced no change or experienced a positive change.

Perceived family stress
The mean score on the FSCI was 24.79 (SD = 16.6) with a maximum score of 96. Not all issues were identified by parents as being of concern; however, between 50% and 83% of parents identified eight of the following issues as stressful to extremely stressful (i.e. mean stress score >2.5) : long-term planning for accommodation (83%), planning for emotional and social support (68%), creating opportunities for their child to participate in activities and make friends (56%), meeting their own personal needs (55%), making decisions about accommodation in the home or the community (54%), time apart from their family member with an intellectual disability (51%), planning for wills, trusts and guardianship (50%) and dealing with health professionals (50%).

Depression (xX factor)
The primary carers participating in this study ranged in age from 50 to 80 years with a mean age of 65.7 years. On average, parents’ scores on the depression measure were within the normal range for the age group (Murrell et al. 1983). However, 16% of parents obtained scores above the cut-off for clinical depression.

Quality of life (xX factor)
More than two-thirds of parents in this sample reported positive quality of life with 29.4% reporting that they
were ‘mostly satisfied’, 21.6% stating that they were ‘pleased’ and 17.6% stating that they were ‘delighted’ with their quality of life. Only 2% of parents reported that they were ‘unhappy’ with their quality of life, 3.9% said that they were mostly dissatisfied and 23.5% reported that they had mixed feelings.

**Mediation model testing**

A mediation model occurs when an independent variable indirectly affects a dependent variable through a third variable known as a mediator (Cole & Turner 1993). According to Baron & Kenny (1986), testing of mediation models first requires that mediation assumptions are met (i.e. the independent, dependent and mediator variables must all be significantly correlated). Therefore, correlations were computed between the variables in the ABCX model. As indicated in Table 2, these included: aA factor – characteristics of the adult with DD – maladaptive behaviour and carer characteristics – overall carer health, bB factor (Resources – Social Support and Use of Formal Support Services, cC factor (Appraisals/Perceptions – Carer Stress/Burden and Perceived Adverse Age Changes) and xX factor (Adaptation – Depressed Mood and Quality of Life).

Six sets of three variables were significantly correlated. The first three included depression as the outcome: (1) maladaptive behaviour (aA), perceived stress/burden (cC) and depression (xX); (2) overall carer health (aA), perceptions of ageing (cC) and depression (xX); (3) overall carer health (aA), perceived stress/burden (cC) and depression (xX). The next three included quality of life as the outcome variable: (1) overall carer health (aA), perceptions of ageing (cC) and quality of life (xX); (2) overall health (aA) perceived stress/burden (cC) and quality of life (xX); (3) overall health (aA), social support (bB) and quality of life (xX).

In order to test the mediation models stated earlier, three hierarchical multiple regression analyses were conducted with depression as the dependent variable. In the first regression, maladaptive behaviour (aA) was entered as the independent variable and perceived stress/burden (cC) was entered as the mediator. In the second regression, overall carer health (aA) was entered as the independent variable and perceived stress/burden (cC) was entered as the mediator. The mediation model is supported when there is little or no relationship remaining between the aA factor and the xX factor when the appraisal variable is added to the model (Baron & Kenny 1986).

**Regression I: maladaptive behaviour, perceived carer stress and depression**

In the first step, maladaptive behaviour emerged as a marginally significant predictor of depression. In the second step, perceived carer stress emerged as a significant predictor of depression. Analyses using Goodman’s test (Preacher & Leonardelli 2003) indicated that perceived stress was significant as a mediator ($z = 2.18; P < 0.030$) (Table 3).

**Regression II: overall health, perceptions of ageing and depression**

In the second regression, overall carer health emerged in the first step as a significant predictor of depression. In the second step, perception of ageing and overall health both significantly predicted depression; however, the beta weight for overall health was reduced. Analyses using Goodman’s test (Preacher & Leonardelli 2003) indicated that perceptions of ageing was significant as a mediator ($z = 2.18; P < 0.030$) (Table 3).

**Regression III: overall health, perceived carer stress/burden and depression**

In the third regression, overall carer health emerged in the first step as a significant predictor of depression. In the second step, perceived stress and overall health both significantly predicted depression; however, the beta weight for overall health was reduced. Analyses using Goodman’s test (Preacher & Leonardelli 2003) indicated that perceived stress was significant as a mediator.

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE</th>
<th>β</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 1</td>
<td></td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Maladaptive behaviour</td>
<td>0.217</td>
<td>0.095</td>
<td>0.248</td>
<td>2.29</td>
<td>0.025</td>
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<tr>
<td>Perceived stress</td>
<td>0.195</td>
<td>0.056</td>
<td>0.369</td>
<td>3.45</td>
<td>0.001</td>
</tr>
<tr>
<td>Step 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maladaptive behaviour</td>
<td>0.118</td>
<td>0.093</td>
<td>0.134</td>
<td>1.26</td>
<td>0.212</td>
</tr>
<tr>
<td>Perceived stress</td>
<td>0.195</td>
<td>0.056</td>
<td>0.369</td>
<td>3.45</td>
<td>0.001</td>
</tr>
</tbody>
</table>

$R^2 = 0.06$ for step 1 and 0.18 for step 2.
Despite overall health continuing to have some predictive value ($z = -2.08; P < 0.037$) (Table 5).

In order to test hypotheses with quality of life as the outcome variable, three additional regression analyses were conducted. In the first regression, perceptions of ageing did not emerge as a significant mediator between overall health and quality of life. In the second regression, carer perceived stress/burden was not found to be a significant mediator between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life. In the third regression, partial mediation was found with social support partially mediating between overall health and quality of life.

Maladaptive behaviour of adults with an intellectual disability has been found to be a strong determinant of increased caregiving burden over time (Heller et al. 1997; Minnes & Woodford 2004). Indeed in this study, 69% of the individuals with intellectual disabilities were reported by parents to have moderate to severe maladaptive behaviours. It was hypothesized that resources (i.e. social support and formal service use) and carer appraisals would have mediating effects on the relationship between maladaptive behaviour and carer depression. Contrary to expectation, resources did not meet the criteria for mediation. However, carer appraisals of stress were found to be a significant mediator of the relationship between maladaptive behaviour and depression.

The Double ABCX model has been used in a number of studies of family stress and coping. In the original model put forward by McCubbin and Patterson, the relationships between the A, B, C and X factors were not clearly delineated. However, it was suggested that stressors, appraisals and resources influence outcome over time. The results of this study highlight the complex relationships between these factors. Although previous research has found that support resources (bB factor) can play a significant role in reducing caregiving burden of older parents of an individual with an intellectual disability (Heller & Factor 1993; Minnes & Woodford 2004), and can act as a mediator of parenting stress (Dunst et al. 1986; Quittner et al. 1990; Nachshen & Minnes 2005), neither of the measures representing the bB factor in this study (i.e. social support

### Table 4

<table>
<thead>
<tr>
<th>Variable</th>
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<tr>
<td>Overall health</td>
<td>-5.50</td>
<td>1.21</td>
<td>-0.454</td>
<td>-4.56</td>
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<td>Perceptions of ageing</td>
<td>0.606</td>
<td>0.204</td>
<td>0.340</td>
<td>2.97</td>
<td>0.004</td>
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$R^2 = 0.21$ for step 1 and 0.29 for step 2.

### Table 5

<table>
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<th>β</th>
<th>t</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall health</td>
<td>-3.21</td>
<td>1.39</td>
<td>-0.265</td>
<td>-2.31</td>
<td>0.023</td>
</tr>
<tr>
<td>Perceived stress</td>
<td>0.157</td>
<td>0.053</td>
<td>0.298</td>
<td>2.31</td>
<td>0.023</td>
</tr>
</tbody>
</table>

$R^2 = 0.184$ for step 1 and 0.29 for step 2.

Discussion

The Double ABCX model has been used in several studies to explore the relationships between stressors, resources, appraisals and outcome in families of individuals with intellectual disabilities. Past research has highlighted carer health as an important predictor of well-being (Pruchno & Resch 1989; Greenberg et al. 1993; Smith 1996; Krauss & Selter 1998). In this study parental appraisals of ageing and stress associated with caring for an adult with an intellectual disability were found to mediate the relationship between carer health and depression.

Cognitive reappraisal is an important coping strategy that can help individuals to reframe their situation and view it more positively (Folkman & Moskowitz 2000). The majority of parents (62.5%) in this study reported that they had been adversely affected by age-related changes. The mean score on this scale of 19.79 (SD = 5.67) was within the mid range and higher reported adverse age changes were significantly correlated with depression. These findings highlight the need to increase both carers’ and service providers’ awareness of the effects of ageing. Moreover, parents’ perceptions of ageing need to be considered in addition to chronological age and overall health. Similarly, while the mean score on the stress measure of 24.79 (SD = 16.6) was low, higher carer appraisals of stress/burden were significantly correlated with depression.

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and formal support use) emerged as significant mediators in these analyses. This negative finding is similar to previous research (Krauss & Seltzer 1998) in which the number of formal supports provided to an adult with an intellectual disability and the use of respite care services were not related to carer depression. The results of this study, however, did highlight the importance of assessing carer characteristics such as health as potential stressors in addition to maladaptive behaviour of the individuals with an intellectual disability receiving care. The results also provide support regarding the importance of carer appraisals of ageing as well as appraisals of stress related to caring for an adult with an intellectual disability.

The Double ABCX model recognizes that outcomes can be positive (bonadaption) as well as negative (maladaptation). In this study, quality of life was included as positive outcome. Contrary to expectation, neither resources (bB factor) nor appraisals (cC factor) emerged as mediators between carer health and quality of life, and between maladaptive behaviour and quality of life.

**Limitations and Directions for Future Research**

This study included a relatively small sample of parents of adults with intellectual disabilities living in Ontario. While participants were obtained from agencies in both urban and rural regions, the findings may not be representative of wider samples of older parent carers in other jurisdictions. The data are also cross-sectional and therefore do not represent variations in experience over time. Nevertheless, a number of significant findings did emerge despite the small sample. These findings highlight the importance of carer health as well as stress in relation to carer adaptation and well-being. With increasing attention being given to the healthcare needs of individuals with intellectual disabilities (Ouellette-Kuntz et al. 2005), the results of this study also highlight the importance of addressing the healthcare needs of their carers. Furthermore, the results point to the importance of carer appraisals in the adaptation process. Whereas reduction in maladaptive behaviour may well facilitate well-being in carers, the results of this study indicate that the ability to reframe stressful experiences can also have an important impact on parental well-being. Although social support and service use did not emerge as significant mediators in this study, further research to evaluate the relative and combined effectiveness of different types of formal and informal support is needed. Given the association found in past research (Heller & Factor 1993) between unmet needs and higher carer burden, inclusion of a measure of unmet needs as well as a measure of satisfaction with supports might yield more informative results. Finally, given research highlighting the resiliency of carers into their senior years and the positive as well as negative outcomes that can result from caregiving (Heller et al. 1997; Hastings & Taunt 2002), more research focusing on positive as well as negative outcomes is needed. More detailed assessments of quality of life might prove to be more useful than a global rating of quality of life on a single item, but other assessments of positive outcomes specifically related to having a child with an intellectual disability in the family should also be included.

The Double ABCX model provides a useful framework to guide research on family stress and coping. One challenge however is the lack of consensus on the definition of various components in the model and the resulting use of different instruments as measures of each component. In this study, carer health was included as a pile-up stressor (aA factor) in the model when it might have been included as an outcome (sX factor). As maladaptive behaviour was not significantly correlated with overall health and another stressor variable (aA) was not available, it was not possible to test mediation models with overall health as outcome (sX). Further research is needed to explore the contributions of carer health to stress and to outcome over time. The use of objective measures of health as well as carer ratings also would be useful.

**Acknowledgments**

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References


