The role of coping in maintaining the psychological well-being of mothers of adults with intellectual disability and mental illness

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Abstract

Background Mothers who have a child with intellectual disability (ID) or mental illness face a lifetime of caregiving responsibilities and challenges. The present study investigated changes over time in how mothers cope with the challenges of caring for an adult child with disabilities and the effects of changes in coping on maternal well-being.

Methods A sample of 246 ageing mothers of adults with ID and 74 mothers of adults with mental illness was drawn from two parallel longitudinal studies of later-life caregiving.

Results There was considerable variability at the individual level in the degree to which mothers changed over time in their use of problem-focused and emotion-focused coping strategies. For both groups, an increase in their use of emotion-focused coping led to declining levels of well-being. For the parents of adults with ID, an increase in their use of problem-focused coping resulted in a reduction in distress and an improvement in the quality of the relationship with their adult child. For the parents of adults with mental illness, an increase in the use of problem-focused coping had no effect on levels of distress, but led to an improved relationship with their adult child.

Conclusions The present study underscores the importance of coping in the lives of older mothers of adults with disabilities.

Keywords ageing, coping, family caregiving, life span

Introduction

Parents who have a child with a disability such as intellectual disability (ID) or mental illness face a lifetime of caregiving responsibility. Unlike family caregivers for ageing parents or spouses, the length of active caregiving by parents who have a daughter or son with a disability often extends for many decades. During this long time span, parents must cope with a variety of challenges, including those emanating from caregiving as well as from the pile-up of other life stressors (McCubbin et al. 1982; Seltzer et al. 1995). The present study focuses on whether processes of stability and change in maternal coping styles account for why caregiving and other life chal-
Challenges take a toll on the mental health of some mothers who are in the caregiving role, whereas others are able to maintain their psychological well-being over time or even show gains.

The present authors contrast mothers who have an adult child with ID and those who have an adult child with mental illness because they face similar yet distinct sets of challenges. A common history of deinstitutionalization in the USA in the 1960s and 1970s increased the importance of the family in the lives of both adults with ID and those with mental illness. In addition, their parents share similar experiences with respect to many of the caregiving tasks which they must perform for their adult child since both ID and mental illness are chronic conditions which limit the extent to which an individual can live independently in the community without support. The recognition of these limitations often gives rise to feelings of loss and grief in parents, and also leads to concerns about their child’s future when they will no longer be able to provide the needed care or supervision (Wasow & Wilder 1983; Pruchno et al. 1996).

There are also a number of differences in these two caregiving contexts. One difference pertains to the mother’s stage of life when the child is diagnosed. Intellectual disability tends to be diagnosed at birth or in the first few years of life when the mother is generally in her twenties or thirties, whereas severe mental illness, particularly schizophrenia, tends to be diagnosed in late adolescence or early adulthood when the mother is in mid-life. Thus, there are life course developmental differences in the timing of the onset of caregiving in these two groups.

Another major difference in the stresses which these two groups of mothers face is the degree to which their caregiving challenges are predictable and stable over time. The severity of ID is generally constant over the life course, with a pattern of stability in cognitive and functional skills (Eylman & Widaman 1987). In contrast, there is considerable heterogeneity in the course of mental illness. Longitudinal studies have found that approximately one-third of people with mental illness improve with age, one-third remain stable and one-third show progressive declines in functioning (Harding 1988), and even within any of these patterns, there are fluctuations in symptoms over time.

Furthermore, the parents of adults with ID may have a greater ability to influence their daughter or son’s life choices than the parents of adults with mental illness. In the case of ID, the parent–adult child relationship evolves in the context of the child’s disability and need for care. In contrast, because mental illness strikes in late adolescence or young adulthood, the onset of the disability comes during a period of life when young adults are generally moving toward increasing independence from their parents. Adults with mental illness may feel that their parent’s guidance challenges their autonomy.

A stress and coping paradigm (Pearlin & Schooler 1978; Pearlin et al. 1990) is used in the present analysis to investigate the longitudinal effects of maternal coping on the well-being of mothers who have provided long-term care to an adult with either ID or mental illness. In accordance with this perspective, stresses arising from the caregiving role as well as from the pile-up of other major life events have the potential to produce psychological distress (Noh & Avison 1988; Greenberg et al. 1997). The behaviour problems of the adult with disabilities have been shown to increase the stress of caregiving (Greenberg et al. 1993; Biegel et al. 1994; Reinhard & Horwitz 1995; Heller et al. 1997; Webb et al. 1998). In addition, these ageing mothers may experience stress from other sources in their lives, including their own health problems, becoming divorced or widowed, or assuming the caregiving role for another family member or friend. These caregiving and other life stressors may affect mothers in multiple ways, including increasing their experience of caregiving burden, elevating their risk of depression, and diminishing feelings of closeness to their daughter or son with the disability (Greenberg et al. 1993; Minnion 1996).

When people are faced with stressful situations, they are sometimes able to avoid psychological distress by using effective coping strategies. Lazarus & Folkman (1984) defined two major types of coping strategies: problem-focused coping and emotion-focused coping. Problem-focused coping involves cognitive and behavioural problem-solving strategies aimed at altering or managing the stressful situation. On the other hand, emotion-focused coping involves cognitive and behavioural efforts to reduce or manage emotional distress, but which are not focused directly on solving the problem.

A question of growing interest is the degree of stability and change in patterns of coping as individuals age and gain experience with chronic sources of...
stress or encounter new life challenges. Several researchers have found that coping strategies are relatively stable over time (Holahan & Moos 1987; Kahana et al. 1987; McCracken et al. 1995). As Carver et al. (1989, p. 270) noted, people ‘do not approach each coping context anew, but rather bring a preferred set of coping strategies’. In contrast, other researchers have found that people use different coping strategies depending on the changing nature of life circumstances (Patterson et al. 1990; Wright 1994; Stewart & Schwarzer 1996; Scazuca & Kuipers 1999). The context of caring for an adult child with a serious mental illness is more likely to vary over time than the context of caring for an adult with ID because of the cyclical nature of mental illness as contrasted with the relatively stable course of ID. If coping strategies vary with the nature of the life challenge presented, it would be expected that mothers of adults with mental illness would show less stability in their style of coping than mothers of adults with ID.

It is important to distinguish between using a coping strategy and benefiting from it, i.e. using a particular coping strategy does not necessarily mean that it will have a beneficial effect on psychological well-being. In order to determine the effectiveness of coping, it is necessary to examine whether the use of various coping strategies predicts reduced psychological distress and enhanced well-being. Indeed, some coping strategies may have deleterious effects even though the intent is to reduce distress. Cross-sectional studies have consistently found that caregivers who use emotion-focused coping strategies have higher levels of depression and distress (Haley et al. 1987; Seltzer et al. 1995; Patrick & Hayden 1999). Similarly, longitudinal studies have found that the use of emotion-focused coping at an earlier point in time is related to declining well-being at a later point in time (Aldwin & Revenson 1987; Moeller & Richards 1992; Kling et al. 1997; Essex et al. 1999). Based on these studies, the present authors hypothesized that, for both the mothers of adults with ID and those of adults with mental illness, an increase in the use of emotion-focused coping during the 3-year study period would lead to decreasing levels of well-being.

In contrast, the evidence from studies of the effectiveness of problem-focused coping is less conclusive. Although a number of researchers have found that the use of problem-focused strategies results in improved well-being (Haley et al. 1987; Aldwin 1991; McCracken et al. 1995; Seltzer et al. 1995; Kling et al. 1997; Essex et al. 1999), others have found that problem-focused coping has no effect (Pruchno & Kleban 1993) or results in increases in psychological symptoms (Folkman et al. 1986). These studies raise the question: Under what conditions is problem-focused coping effective? According to Folkman (1984), problem-focused coping strategies are likely to be most effective when an individual perceives the stressor to be within his or her control. The present authors have argued that the mothers of adults with ID experience a greater sense of mastery in being able to manage their child’s caregiving needs because of the greater stability of the disability and, historically, the greater responsiveness of the service system to the needs of families of people with ID than mental illness (Seltzer et al. 1995). Thus, the present authors hypothesized that, for mothers of adults with ID, but not for mothers of adults with mental illness, the increased use of problem-focused coping over time would be related to improved psychological well-being.

In summary, the present authors’ hypotheses are as follows:

1. Mothers of adults with ID will show greater stability in their use of problem-focused and emotion-focused coping strategies than mothers of adults with mental illness.
2. For both groups of maternal caregivers, increases in the use of emotion-focused coping over time will lead to declining levels of psychological well-being.
3. For mothers of adults with ID, increases in the use of problem-focused coping strategies over time will lead to improved psychological well-being. For mothers of adults with mental illness, increases in the use of problem-focused coping over time will have no effect on psychological well-being because of their reduced control over the caregiving context.

**Subjects and methods**

**Sample**

The present analysis is based on two longitudinal studies of mothers who have an adult daughter or son with a disability, either ID or mental illness. In both studies, mothers were recruited who met two criteria:
(1) the mother was aged 55 years or older; and (2) the adult child with disabilities lived at home with her. The majority of families for these two studies were recruited from public agencies responsible for providing services for people with either ID or mental illness. Others were recruited in response to newspaper articles about this study or were nominated by participating family members. All 107 of the mothers of adults with mental illness who initially participated in the study lived in Wisconsin, USA, whereas half of 461 mothers of adults with ID lived in Wisconsin and half lived in Massachusetts, USA. Since the Wisconsin and Massachusetts mothers of adults with ID did not differ significantly on multiple study variables, data collected from the mothers from the two states were pooled.

The study of mothers of adults with ID consisted of eight points of data collection, each 18 months apart, spanning the years 1988–2000. The study of mothers of adults with mental illness consisted of two points of data collection separated by 36 months, spanning the years 1990–1995. The present two-wave longitudinal analysis uses data collected from mothers of adults with ID at time 2 and time 4 to match the timing of and duration between the two points of data collection in the study of mothers of adults with mental illness. For this paper, the present authors refer to the first point of data analysed from both studies as wave 1 and the second as wave 2.

The present analysis includes 246 mothers of adults with ID. The other members of the sample were excluded from the present analysis because of refusal to continue participation in the study (n = 25), the death of the adult child (n = 11), the death of the mother (n = 14) or relocation of the adult to a non-family care setting prior to the first point of data used in the present analysis (n = 14). These latter mothers were excluded in order to match the residential arrangements of the sample of mothers of adults with mental illness, all of whom lived at home at the first point of data used in this analysis. For another 151 mothers of adults with ID, frailty interfered with participation in the full interview, and instead, they participated in an abbreviated interview that did not include measures of coping. Thus, these mothers could not be included in the present analysis. Mothers who were not included in this analysis were significantly older (t = 2.26, P = 0.02), had older adult children with ID (t = 3.94, P = 0.001) and reported higher levels of subjective burden (t = 2.03, P = 0.04) than those who were included.

Out of the 107 mothers of adults with mental illness, 74 were re-interviewed 36 months later. Out of those who were not re-interviewed, six mothers died or became incapacitated, three moved and could not be located, two adult children died, and 19 refused.

An additional three mothers had incomplete data. The mothers included in this analysis were more likely to be married (χ² = 10.91, P < 0.01), and had poorer relationships with their daughter or son (t = 2.58, P < 0.05) at wave 1 than mothers not included in this analysis.

Table 1 describes the characteristics of the mothers and adults with disabilities who were included in the present analysis. The two groups of mothers (i.e. those of adults with ID or mental illness) were quite similar in their characteristics. They were in their mid-60s. Over 80% had at least a high-school education and about one-quarter had a part- or full-time job. About 60% were married and just under one-third of the mothers reported their health as fair or poor.

The adults with disabilities in both groups were approximately 35 years old. A significantly higher percentage of adults with mental illness than adults with ID were male. Significantly more adults with ID lived with their mothers at wave 2 as compared to the adults with mental illness. The adults with ID had primarily mild (34.9%) or moderate (44.4%) retardation. Approximately 40% had Down’s syndrome. All adults with mental illness had a serious mental illness, including schizophrenia (73.0%), bipolar disorder (17.6%), major depression (5.4%) or other psychiatric diagnoses (4.0%), and on average, they had been ill for 13 years.

Data collection and measures

The mothers of adults with ID participated in an in-home interview and completed a self-administered questionnaire at both waves of data collection. For the mothers of the adults with mental illness, data were collected at wave 1 through an in-home interview and a self-administered questionnaire. At wave 2, which occurred 36 months later, the mothers of adults with mental illness were interviewed by telephone and returned a self-administered questionnaire by mail.
The present analysis focuses on three dependent variables measured at waves 1 and 2. Two were indicators of psychological distress (subjective caregiving burden and depression) and one was an indicator of positive well-being (the mother’s perception of the quality of her relationship with her adult child with disabilities). The independent variables included sources of stress, coping strategies and background variables. All variables were measured identically for the two groups.

Subjective caregiving burden was measured by the Zarit Burden Scale (Zarit et al. 1980), which consists of 29 items assessing the subjective discomfort and strain experienced as part of the caregiving challenge. Mothers were asked to rate on a three-point scale from (0) ‘not at all’ to (2) ‘extremely’ how they felt about the personal impacts of providing care. The scale had Cronbach’s alphas of \( \alpha = 0.82 \) (wave 1) and \( \alpha = 0.84 \) (wave 2) for the mothers of adults with ID and \( \alpha = 0.88 \) (wave 1) and \( \alpha = 0.89 \) (wave 2) for the mothers of adults with mental illness.

Depressive symptoms were measured using the Center for Epidemiological Studies – Depression (CES-D; Radloff 1977). The CES-D has been widely used in studies of caregivers as well as older people (Pruchno & Resch 1989; Gatz & Hurwicz 1990), and also has been shown to be a reliable and valid measure of depressive symptoms (Himmelfarb & Murrell 1983). For each of 20 depressive symptoms, mothers were asked to indicate how often in the past week they experienced the symptom on a four-point scale from (0) ‘never’ to (3) ‘5–7 days’. The Cronbach’s alpha reliabilities were \( \alpha = 0.84 \) (wave 1) and \( \alpha = 0.90 \) (wave 2) for the mothers of adults with ID and \( \alpha = 0.88 \) (wave 1) and \( \alpha = 0.91 \) (wave 2) for the mothers of adults with mental illness.

The 10-item Positive Affect Index (Bengtson & Schrader 1982) was used to measure the quality of the mother–adult child relationship. The mother was asked to indicate how she feels about her daughter or son, and how she thinks the daughter or son feels about her with respect to five dimensions (i.e. trust, intimacy, understanding, fairness and mutual respect) on a six-point scale ranging from (1) ‘not at all’ to (6) ‘extremely’. The alpha reliabilities of the scales were \( \alpha = 0.89 \) (both waves 1 and 2) for the mothers of adults with ID, and \( \alpha = 0.90 \) (wave 1) and \( \alpha = 0.91 \) (wave 2) for the mothers of adults with mental illness.

Measures of two sources of maternal stress were included: behaviour problems and the pile-up of life stressors. For the first source of stress, mothers indicated whether their daughter or son had each of the following eight behaviour problems: hurtful to self; destructive or hurtful to others; destructive to property; disruptive behaviour; unusual or repetitive habits; socially offensive behaviour; withdrawn or

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Table 1 Socio-economic characteristics of the sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mothers of adults with ID (n = 246)</th>
<th>Mothers of adults with mental illness (n = 74)</th>
<th>Test statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Characteristics of mothers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years):</td>
<td>66.6</td>
<td>66.0</td>
<td>NS</td>
</tr>
<tr>
<td>mean</td>
<td>66.6</td>
<td>66.0</td>
<td>NS</td>
</tr>
<tr>
<td>range</td>
<td>56–85</td>
<td>55–78</td>
<td>NS</td>
</tr>
<tr>
<td>Education (%):</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>less than high school</td>
<td>15.4</td>
<td>16.2</td>
<td>NS</td>
</tr>
<tr>
<td>high-school graduate</td>
<td>41.5</td>
<td>37.8</td>
<td>NS</td>
</tr>
<tr>
<td>some college</td>
<td>43.1</td>
<td>45.9</td>
<td>NS</td>
</tr>
<tr>
<td>Employment (part- or full-time)</td>
<td>26.0</td>
<td>27.0</td>
<td>NS</td>
</tr>
<tr>
<td>Marital status (married)</td>
<td>59.0</td>
<td>59.0</td>
<td>NS</td>
</tr>
<tr>
<td>Physical health (poor/fair)</td>
<td>30.1</td>
<td>28.4</td>
<td>NS</td>
</tr>
<tr>
<td><strong>2. Characteristics of adults</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td>34.1</td>
<td>35.0</td>
<td>NS</td>
</tr>
<tr>
<td>Gender (male) (%)</td>
<td>55.8</td>
<td>73.0</td>
<td>( \chi^2 = 7.06^{**} )</td>
</tr>
<tr>
<td>Lives with parents (%)</td>
<td>91.5</td>
<td>68.9</td>
<td>( \chi^2 = 24.38^{***} )</td>
</tr>
</tbody>
</table>

**P < 0.01; ***P < 0.001; NS = non-significant; ID = intellectual disability.**

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inattentive; and uncooperative behaviour (Bruininks et al. 1986). The wave 1 measure of behaviour problems, as well as the change in behaviour problems between wave 1 and wave 2 were included in the analysis to capture both the severity and the changing nature of such problems in individuals with disabilities. The pile-up of life stressors, the second source of stress, was a count of up to eight life events which occurred during the 3 years between interviews. The life events included declining maternal health, declining health of the adult child with disabilities, becoming widowed, getting divorced, having a child die, having a child divorce, becoming a caregiver for other family members or friends, and moving from one home to another.

In order to examine how mothers cope with stress, seven subscales of the Coping Orientations to Problems Experienced scale (COPE; Carver et al. 1989) were used. Each subscale included four items on which mothers indicated how often they used a specific strategy to cope with stress in general, measured on a four-point scale from (1) ‘not at all’ to (4) ‘a lot’.

For the present study, these seven subscales were collapsed into two categories of coping: problem-focused (three subscales) and emotion-focused (four subscales) coping. Problem-focused coping was defined as the sum of the three subscales measuring active coping, planning, and positive reinterpretation and growth. As described by Carver et al. (1989), active coping involves taking direct action to remove the stressor or reduce its effect. Planning involves thinking about actions to cope with a stressor. Positive reinterpretation and growth involves efforts to create positive meanings from a stressor. Although Lazarus & Folkman (1984) regarded positive interpretation and growth as a form of emotion-focused coping, Carver et al. (1989) suggested that it may more appropriately be classified as a problem-focused coping strategy because it moves an individual to change or alter the nature of the stressor. The alpha reliabilities of the problem-focused coping scale were 0.89 (both waves 1 and 2) for the mothers of adults with ID, and 0.90 (wave 1) and 0.91 (wave 2) for the mothers of adults with mental illness.

Emotion-focused coping was measured by summing four subscales of the COPE scale: denial, focusing on and venting emotions, behavioural disengagement, and mental disengagement. Denial involves denying that the stressor exists or acting as if the stressor is not real. Focusing on and venting emotions is the tendency to focus on the source of stress and to ventilate those feelings. Behavioural disengagement is reducing one’s effort on other activities in order to deal with the stressor. Mental disengagement involves a variety of activities which help distract one from thinking about the stressor. The alpha reliabilities of the emotion-focused coping scale were 0.78 (wave 1) and 0.80 (wave 2) for the mothers of adults with ID, and 0.79 (wave 1) and 0.83 (wave 2) for the mothers of adults with mental illness.

Based on the significant differences in background characteristics between the two groups of mothers and their adult child which were reported in Table 1, two control variables were included in the present analyses: the gender and residential status at wave 2 of the adult child. Gender was coded ‘0’ if female and ‘1’ if male. Residential status at wave 2 was coded ‘1’ if the adult child moved out of the parental home, and ‘0’ if she or he continued living at home. Furthermore, the mother’s age, measured in years, was included as a control variable in the regression analysis because of its established relationship to subjective burden and depression (Cook et al. 1994; Kessler et al. 1992).

Data analysis

The present authors’ first hypothesis concerns the extent of stability or change in sample members’ use of problem- and emotion-focused coping between waves 1 and 2. Two different approaches were used to assess the extent of change. The first approach, which tracked group-level change, involved computing group differences in the mean level of problem- and emotion-focused coping at waves 1 and 2 through repeated measures analysis of covariance. The covariates were the gender of the adult with disabilities and whether the adult co-resided with the mother at wave 2. In the second approach, change was defined as more than one half of a standard deviation increase or decrease in coping scores from waves 1 to 2, based on a strategy used by Schulz et al. (1992). The present authors defined a meaningful change as more than one half of a standard deviation unit because it corresponds to Cohen’s (1988) definition of a ‘medium effect’. For the present sample, a half standard deviation of change in problem-
focused coping was 2.63 for the mothers of adults with ID and 2.95 for the mothers of adults with mental illness, while a half standard deviation of change in emotion-focused coping was 2.62 and 2.59 for the mothers of adults with ID and mothers of adults with mental illness, respectively.

For the present authors’ second and third hypotheses, multiple regression analysis was used to investigate whether changes in coping between waves 1 and 2 predicted maternal well-being at wave 2, net of maternal well-being at wave 1. The wave 1 measure of the dependent variable was included to control for prior levels of well-being. The mother’s age, and the gender and residential status of the adult with disabilities were also included in the analysis as control variables. The sources of stress were behavioural problems at wave 1, a term representing change in behavioural problems from waves 1 to 2, and the pile-up of life stressors between waves 1 and 2. The wave 1 level of problem-focused coping and a term representing change in the use of problem-focused coping between waves 1 and 2 were included. In parallel fashion, the present authors included the wave 1 level of emotion-focused coping and a term representing change in the use of emotion-focused coping between waves 1 and 2. The wave 1 level of coping measured the absolute level of either problem- or emotion-focused coping at wave 1. The coping change score measured the degree of change from this initial level.

Because of the small sample of adults with mental illness, the authors conducted preliminary analyses to reduce the number of independent variables. The gender of the adult child was not significant in any regression analysis and did not significantly change the coefficients for the other variables in any of the models. Therefore, it was dropped from the analysis. Table 2 portrays the bi-variate correlations among study variables along with their means and standard deviations.

### Results

**Group and individual differences in the stability of coping**

The present authors hypothesized that the mothers of adults with ID would show greater stability in their use of problem-focused and emotion-focused coping...
Table 2 Continued

<table>
<thead>
<tr>
<th>Variable</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
<th>13</th>
<th>14</th>
<th>15</th>
<th>16</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>(7) Problem-focused coping</td>
<td>-0.02</td>
<td>-0.14</td>
<td>-0.13</td>
<td>-0.08</td>
<td>0.05</td>
<td>0.09</td>
<td>-</td>
<td>-</td>
<td>0.31***</td>
<td>-0.07</td>
<td>0.09</td>
<td>-0.13</td>
<td>-0.14**</td>
<td>0.17**</td>
<td>0.17**</td>
<td>36.85</td>
<td>6.93</td>
<td></td>
</tr>
<tr>
<td>(8) Change in problem-focused</td>
<td>-0.15</td>
<td>0.05</td>
<td>-0.05</td>
<td>0.13</td>
<td>0.02</td>
<td>0.22</td>
<td>-0.26</td>
<td>-</td>
<td>0.09</td>
<td>0.00</td>
<td>0.08</td>
<td>0.03</td>
<td>-0.02</td>
<td>-0.13*</td>
<td>-0.04</td>
<td>0.04</td>
<td>-1.14</td>
<td>5.26</td>
</tr>
<tr>
<td>(9) Emotion-focused coping (wave 1)</td>
<td>-0.11</td>
<td>-0.06</td>
<td>-0.20</td>
<td>0.34**</td>
<td>-0.28*</td>
<td>0.02</td>
<td>0.30*</td>
<td>-0.04**</td>
<td>-</td>
<td>0.47***</td>
<td>0.49***</td>
<td>0.42***</td>
<td>0.54***</td>
<td>0.44***</td>
<td>-0.11</td>
<td>-0.02</td>
<td>28.18</td>
<td>6.51</td>
</tr>
<tr>
<td>(10) Change in emotion-focused</td>
<td>0.00</td>
<td>-0.03</td>
<td>-0.13</td>
<td>0.02</td>
<td>0.17</td>
<td>0.01</td>
<td>0.03**</td>
<td>-0.29**</td>
<td>-</td>
<td>-0.18**</td>
<td>0.09</td>
<td>-0.20**</td>
<td>0.09</td>
<td>0.05</td>
<td>-0.11</td>
<td>1.16</td>
<td>5.23</td>
<td></td>
</tr>
<tr>
<td>(11) Subjective burden (wave 1)</td>
<td>-0.02</td>
<td>-0.09</td>
<td>-0.29**</td>
<td>0.49**</td>
<td>-0.14</td>
<td>0.01</td>
<td>0.13</td>
<td>0.17</td>
<td>0.55***</td>
<td>-0.01</td>
<td>-</td>
<td>0.67**</td>
<td>0.47**</td>
<td>0.43***</td>
<td>-0.38***</td>
<td>-0.36***</td>
<td>29.63</td>
<td>6.63</td>
</tr>
<tr>
<td>(12) Subjective burden (wave 2)</td>
<td>-0.09</td>
<td>-0.13</td>
<td>0.01</td>
<td>0.27**</td>
<td>0.13</td>
<td>0.20</td>
<td>0.11</td>
<td>0.18</td>
<td>0.40**</td>
<td>0.19</td>
<td>0.68**</td>
<td>-</td>
<td>0.40**</td>
<td>0.52***</td>
<td>-0.32***</td>
<td>-0.41***</td>
<td>28.43</td>
<td>6.92</td>
</tr>
<tr>
<td>(13) Depression (wave 1)</td>
<td>0.11</td>
<td>0.14</td>
<td>-0.16</td>
<td>0.24*</td>
<td>-0.08</td>
<td>-0.14</td>
<td>-0.07</td>
<td>0.04</td>
<td>0.54**</td>
<td>-0.18</td>
<td>0.56**</td>
<td>0.28**</td>
<td>-</td>
<td>0.57***</td>
<td>-0.17**</td>
<td>-0.11</td>
<td>9.55</td>
<td>7.78</td>
</tr>
<tr>
<td>(14) Depression (wave 2)</td>
<td>-0.01</td>
<td>0.00</td>
<td>0.02</td>
<td>0.06</td>
<td>0.17</td>
<td>-0.08</td>
<td>0.08</td>
<td>-0.05</td>
<td>0.41***</td>
<td>0.11</td>
<td>0.46**</td>
<td>0.52***</td>
<td>0.50***</td>
<td>-</td>
<td>-0.12</td>
<td>0.17**</td>
<td>9.38</td>
<td>8.07</td>
</tr>
<tr>
<td>(15) Quality of relationship (wave 1)</td>
<td>0.07</td>
<td>-0.03</td>
<td>0.14</td>
<td>0.05***</td>
<td>0.16</td>
<td>-0.18</td>
<td>0.15</td>
<td>-0.15</td>
<td>-0.34**</td>
<td>0.03</td>
<td>-0.61***</td>
<td>-0.51**</td>
<td>-0.42**</td>
<td>-0.26**</td>
<td>-</td>
<td>0.70**</td>
<td>51.09</td>
<td>5.93</td>
</tr>
<tr>
<td>(16) Quality of relationship</td>
<td>0.01</td>
<td>0.05</td>
<td>-0.03</td>
<td>-0.31</td>
<td>-0.10</td>
<td>-0.28*</td>
<td>0.15</td>
<td>-0.01</td>
<td>-0.18</td>
<td>-0.17</td>
<td>-0.29**</td>
<td>-0.55***</td>
<td>-0.22</td>
<td>-0.26**</td>
<td>0.64***</td>
<td>-</td>
<td>50.92</td>
<td>6.24</td>
</tr>
<tr>
<td>Mean</td>
<td>64.04</td>
<td>0.73</td>
<td>0.69</td>
<td>2.96</td>
<td>-0.73</td>
<td>1.04</td>
<td>36.11</td>
<td>-1.51</td>
<td>31.64</td>
<td>-1.55</td>
<td>37.09</td>
<td>34.92</td>
<td>11.22</td>
<td>11.61</td>
<td>43.51</td>
<td>43.00</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>SD</td>
<td>5.53</td>
<td>0.45</td>
<td>0.47</td>
<td>2.04</td>
<td>2.14</td>
<td>0.88</td>
<td>6.45</td>
<td>5.91</td>
<td>6.55</td>
<td>5.18</td>
<td>10.25</td>
<td>8.93</td>
<td>7.94</td>
<td>8.02</td>
<td>8.15</td>
<td>7.23</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

*P < 0.05; **P < 0.01; ***P < 0.001.

Coefficients in the upper diagonal are based on data from the mothers of adults with ID, while the lower diagonal presents coefficients based on data from the mothers of adults with mental illness. (SD) standard deviation.
than those of adults with mental illness. As shown in Table 3, the mothers of adults with ID did not differ in their use of problem-focused coping strategies from those of adults with mental illness. In addition, neither group evidenced mean level change during the study period. Neither of the two covariates was significant. The lack of significance of co-residence and gender indicates that the pattern of problem-focused coping was similar for those mothers living with and those living apart from their adult child with disabilities at wave 2, and for mothers of sons and mothers of daughters.

Regarding emotion-focused coping strategies, the mothers of adults with mental illness reported significantly more frequent use of emotion-focused coping than those of adults with ID at both waves 1 and 2. However, there was no significant time effect, nor was the interaction between disability group and time significant. The covariates, including co-residence, were not significant. Again, these data suggest stability at the group level in the use of emotion-focused coping over time.

However, this pattern of mean-level stability masks a great deal of individual-level change during the 3-year study period. Table 4 shows the magnitude of change in problem-focused and emotion-focused coping experienced by the sample members, measured in intervals defined by half of standard deviation units. Regarding problem-focused coping, whereas 41.0% of the mothers of adults with ID and 41.8% of the mothers of adults with mental illness remained stable in their problem-focused coping scores during the study period (i.e. their wave 2 score was within half a standard deviation above or below their wave 1 score), approximately 60% increased or decreased by more than half a standard deviation. Whereas one-third of the mothers reported a decrease in problem-focused coping by half a standard deviation or more, slightly more than 20% in both groups showed an increase in problem-focused coping of a similar magnitude.

An analysis of individual-level change for emotion-focused coping reveals that approximately 40% of both groups showed a decline by at least half a stan-

### Table 3 Mean level changes in problem-focused and emotion-focused coping

<table>
<thead>
<tr>
<th>Type of coping</th>
<th>Mothers of adults with ID (n = 246)</th>
<th>Mothers of adults with mental illness (n = 74)</th>
<th>F-value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Wave 1</td>
<td>Wave 2</td>
<td>Wave 1</td>
</tr>
<tr>
<td>Problem-focused coping</td>
<td>36.9</td>
<td>35.8</td>
<td>35.9</td>
</tr>
<tr>
<td>Emotion-focused coping</td>
<td>28.3</td>
<td>27.1</td>
<td>31.5</td>
</tr>
</tbody>
</table>

***P < 0.001.

The analysis controlled for the gender of the adult child with disabilities and the co-residence of the adult child with their parent. Neither of the covariates was significant.

### Table 4 Individual-level changes in problem-focused and emotion-focused coping

<table>
<thead>
<tr>
<th>Wave 2 to wave 1 coping difference</th>
<th>Problem-focused coping (%)</th>
<th>Emotion-focused coping (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ID (n = 246)</td>
<td>Mental illness (n = 74)</td>
</tr>
<tr>
<td>Decrease of more than 1 SD</td>
<td>17.8</td>
<td>21.6</td>
</tr>
<tr>
<td>Decrease of between 0.5 and 1 SD</td>
<td>18.5</td>
<td>13.5</td>
</tr>
<tr>
<td>No change (within –0.5 and +0.5 SD)</td>
<td>41.0</td>
<td>41.8</td>
</tr>
<tr>
<td>Increase of between 0.5 and 1 SD</td>
<td>14.1</td>
<td>13.6</td>
</tr>
<tr>
<td>Increase of more than 1 SD</td>
<td>8.6</td>
<td>9.5</td>
</tr>
</tbody>
</table>

standard deviation unit between waves 1 and 2 in their use of emotion-focused coping, and about 20% reported a similar increase in the use of emotion-focused coping. Thus, whereas the analysis of group means portrays relative stability in both problem-focused and emotion-focused coping over time, an examination at the individual-level indicates considerable change in coping during the 3-year study period.

Predictors of change in maternal well-being

The present authors’ second set of hypotheses concerned the effects of coping on changes in maternal well-being (i.e. subjective burden, depression and quality of relationship). For both groups of mothers, the authors hypothesized that increases in the use of emotion-focused coping would lead to declining levels of well-being. For the mothers of adults with ID, but not for the mothers of adults with mental illness, the increased use of problem-focused coping was expected to result in improved psychological well-being.

Predictors of subjective burden

As shown in Table 5, the wave 1 measure of subjective burden was a significant predictor of wave 2 burden for both the mothers of adults with ID and the mothers of adults with mental illness. Net of the prior level of subjective burden, the residential status of the adult with both types of disabilities at wave 2 was a significant predictor of burden for both groups, suggesting that, when an adult moved away from home between the two points of data collection, the mother had declining levels of subjective burden.

Regarding sources of stress, an elevated level of behaviour problems at wave 1 was related to significant increases in burden over time for the mothers of adults with ID. For both the mothers of adults with ID and those of adults with mental illness, an increase in behaviour problems over time predicted higher levels of subjective burden at wave 2. Furthermore, for the mothers of adults with mental illness, the pile-up of life stressors was a significant predictor of higher levels of burden.

For the mothers of adults with ID, both the prior level of problem-focused coping and the degree of change in problem-focused coping were significant predictors of burden at wave 2, as the present authors had hypothesized. Higher initial levels and the increased use of problem-focused coping during the study period predicted declining levels of burden among the mothers of adults with ID. For the mothers of adults with mental illness, neither the initial level nor the degree of change in problem-focused

Table 5 Predictors of psychological well-being at Wave 2

<table>
<thead>
<tr>
<th>Independent variables</th>
<th>Subjective burden</th>
<th>Depression</th>
<th>Quality of relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ID</td>
<td>Mental illness</td>
<td>ID</td>
</tr>
<tr>
<td>Wave 1 dependent variable</td>
<td>0.57***</td>
<td>0.59***</td>
<td>0.35***</td>
</tr>
<tr>
<td>Mother’s age</td>
<td>0.06</td>
<td>–0.10</td>
<td>0.09*</td>
</tr>
<tr>
<td>Co-residence</td>
<td>0.13***</td>
<td>0.27***</td>
<td>-0.04</td>
</tr>
<tr>
<td>Wave 1 behavioural problems</td>
<td>0.13*</td>
<td>0.20</td>
<td>0.05</td>
</tr>
<tr>
<td>Change in behavioural problems</td>
<td>-0.20***</td>
<td>0.33***</td>
<td>0.13*</td>
</tr>
<tr>
<td>Pile-up of life stressors</td>
<td>-0.01</td>
<td>0.17*</td>
<td>0.08</td>
</tr>
<tr>
<td>Wave 1 problem-focused coping</td>
<td>-0.11*</td>
<td>-0.01</td>
<td>-0.26***</td>
</tr>
<tr>
<td>Change in problem-focused coping</td>
<td>-0.15***</td>
<td>-0.05</td>
<td>-0.26***</td>
</tr>
<tr>
<td>Wave 1 emotion-focused coping</td>
<td>0.28***</td>
<td>0.23*</td>
<td>0.46***</td>
</tr>
<tr>
<td>Change in emotion-focused coping</td>
<td>0.31***</td>
<td>0.25***</td>
<td>0.39***</td>
</tr>
<tr>
<td>$R^2$</td>
<td>0.60***</td>
<td>0.68***</td>
<td>0.55***</td>
</tr>
</tbody>
</table>

$^*P < 0.05; ^**P < 0.01; ^***P < 0.001.$

Standardized beta coefficients are reported: (n = 246) intellectual disability (ID); and (n = 74) mental illness.

coping predicted change in subjective caregiving burden during the study period, again consistent with the present authors' hypothesis. The mothers of adults with ID and those of adults with mental illness who initially scored high on emotion-focused coping were more likely to feel an increased level of burden over time. In addition, change in emotion-focused coping over time predicted change in feelings of burden for both groups, with mothers who increased their use of emotion-focused coping strategies reporting increasing levels of burden during the 36-month study period, whereas mothers who decreased their use of this type of coping reporting the opposite pattern.

**Predictors of depressive symptoms**

Wave 1 levels of depressive symptoms were predictive of wave 2 levels for both groups of maternal caregivers, although the degree of stability in this dependent variable was less pronounced than with respect to burden (see Table 5). Among the control variables, maternal age predicted increasing depression for mothers of adults with ID. Among the sources of stress, an increasing number of behaviour problems over the 3-year study period was predictive of higher levels of maternal depressive symptoms for both groups.

For the mothers of adults with ID, a similar pattern was found with respect to the effect of problem- and emotion-focused coping on depression as was found in the analysis of subjective burden. Both the initial level of each type of coping strategy and change in coping were significant predictors of wave 2 depressive symptoms, net of the wave 1 depression score. High wave 1 use of problem-focused coping and low wave 1 use of emotion-focused coping predicted declining depressive symptoms, as did increases in problem-focused coping and decreases in emotion-focused coping over the study period.

For the mothers of adults with mental illness, neither indicator of problem-focused coping was related to changes in level of depressive symptoms. However, as in the prediction of burden, both initial level and change in emotion-focused coping were predictive of change in depressive symptoms, with high wave 1 levels and increasing use of emotion-focused coping likely to lead to increases in depressive symptoms during the study period.

**Predictors of quality of relationship**

Consistent with the analyses of change in subjective burden and in depressive symptoms over the 3-year study period, the wave 1 measure of the quality of the mother–child relationship was a significant predictor of the wave 2 measure for both groups (see Table 5). Among the sources of stress, a change in behaviour problems and the pile-up of life stressors were predictive of change in the quality of the mother–child relationship among the mothers of adults with mental illness. Mothers who experienced a greater number of stressful life events and whose child had an increasing number of behavioural problems reported a declining quality of the relationship over time.

For the mothers of adults with ID, both initial level and change in problem-focused coping during the study period were related to changes in the quality of the mother–child relationship, with mothers who initially used high levels of problem-focused coping and who increased in this type of coping over the 36-month study period reporting an improved quality of relationship with the adult child with ID. For emotion-focused coping, only the change score was predictive, with the increased use of this type of coping leading to declines in the quality of the mother–child relationship.

In contrast with the prior findings, for the mothers of adults with mental illness, both initial level and change in problem-focused coping were significant predictors of changes in the perceived quality of the relationship with the daughter or son with the disability. Mothers who used higher levels of problem-focused coping at wave 1 and who increased their use of problem-focused coping between waves 1 and 2 showed improvements in the quality of the mother–child relationship over time. For emotion-focused coping, only the change score was significant, with increasing use of emotion-focused coping leading to declines in the quality of the relationship during the study period.

**Discussion**

Most previous studies of coping by family caregivers, including the present authors' own past work, have been either cross-sectional (e.g. Pruchno & Resch 1989; Kramer 1993; Seltzer et al. 1995) or used data from one point in time to measure coping in the
context of a longitudinal investigation (e.g. Aldwin & Revenson 1987; Kling et al. 1997; Essex et al. 1999; Pakenham 2001). Few studies have investigated the dynamics of coping over time and how change in coping affects change in well-being (an exception is Moggi & Crosby 1999) and none of these are studies of family caregivers.

The present study tracked change in coping over a 3-year period in the lives of ageing mothers with ongoing caregiving responsibilities. It is particularly interesting to examine change in coping in these women since they experience both forces of stability and change in their caregiving context. Among the forces of stability are the ongoing and long-term and more acute stressors. The chronic nature of the caregiving context for both groups of maternal caregivers may have led to an increasing familiarity with the challenge, and thus, gradually lower levels of coping activation. Additional longitudinal research on how coping efforts change as the nature of the stressor unfolds over time would be helpful to further understand this finding.

With respect to the effect of coping on well-being, for both groups of mothers, an increase in the use of emotion-focused coping between waves 1 and 2 was related to higher levels of subjective burden and depression, and a poorer quality of relationship with their adult child. Thus, consistent with the general caregiving literature, an increase in the use of emotion-focused coping over time appears to amplify rather than diminish feelings of distress.

The findings regarding the effect of problem-focused coping on maternal well-being are quite complex, and depend on the type of disability as well as the nature of the outcome variable of interest. For the mothers of adults with ID, an increase in the use of problem-focused coping over time was related to lower levels of subjective burden and depression, and better relationships with the adult child at wave 2. The findings of this analysis confirm the present authors’ prior findings that problem-focused coping is an effective way to regulate the well-being of mothers of adults with ID. In the present analysis, the authors extended their past research by demonstrating that change in coping, as well as level of coping, is predictive of change in well-being. Thus, the association between coping and well-being is dynamic, not static, even in mothers who have been coping with the challenge of caring for their adult child with ID for many decades.

The present authors have also extended their past research by expanding the duration of the study period. Their prior longitudinal analyses of coping in mothers of adults with ID (Essex et al. 1999) spanned an 18-month period. In the present analysis, they demonstrate the durability of the association between coping and well-being over a period of time twice as
long. The authors attribute this durable effect of problem-focused coping on maternal well-being to the high level of control that the mothers of adults with ID have over their caregiving context, which increases the likelihood that efforts to resolve problems are successful, which reduces in turn maternal feelings of depressive symptoms and caregiving burden.

In contrast, for the mothers of adults with mental illness, an increase in the use of problem-focused coping between waves 1 and 2 was related to better parent–child relationships at wave 2, but not to changes in levels of subjective burden and depression. By way of explanation, it is possible that the mothers of adults with mental illness who use high levels of problem-focused coping may experience frustration in their attempts to resolve problems in their daughter or son’s life because of the inadequate supply of needed mental health services, and confidentiality laws which may limit the parent’s access to treatment information (Sveinbjarnardottir & Casterle 1997; Rose 1998). Thus, problem-solving efforts may be less effective, and may not diminish feelings of subjective burden and depression. However, the present authors also found that problem-focused coping leads to a better relationship with the adult daughter or son with mental illness. It is possible that problem-focused coping efforts may increase maternal involvement with her daughter or son, and enhance her understanding of the struggles which her adult child encounters in seeking mental health treatment. This dynamic might explain why mothers who used increasing levels of problem-focused coping reported an improving relationship with their daughter or son with mental illness, even though they did not experience reduced burden or depression. This finding also raises the question of whether the use of problem-focused coping strategies might contribute to enhanced feelings of well-being in specific areas of the lives of mothers of adults with mental illness, even though they may be ineffective in reducing general feelings of distress.

The findings of the present study have implications for practice with the families of people with disabilities. Elevations in behaviour problems of the adult with disabilities led to increasing levels of burden and depression for both groups of maternal caregivers, and a decreasing quality of the relationship among mothers of adults with mental illness. These findings point to the importance of clinicians focusing on treatments which stabilize or decrease the incidence of behavioural problems in adults with disabilities. During the past decade, many new medications have been developed to manage behavioural problems, as well as the application of existing psychosocial therapies, in particular, cognitive behavioural therapy, which have proven effective in reducing the behavioural symptoms associated with significant disabilities and mental health disorders.

In addition, the focus of professionally led psycho-educational programmes and support groups for the families of people with mental illness has been on enhancing problem-focused coping strategies by helping families learn new problem-solving strategies, and ways of managing their child’s behaviour and stressors related to caregiving. The findings of the present study suggest that an equally important focus should be on decreasing the family’s use of emotion-focused coping strategies. The authors found that a reliance on the use of emotion-focused coping resulted in increasing levels of burden and depression, and poorer quality of relationships among both groups of maternal caregivers. Professionals should assess caregivers’ use of emotion-focused coping strategies and help those who rely on such coping strategies to develop alternative ways of dealing with the stressors of caregiving.

There are several limitations of the present study. First, both samples of mothers consisted of volunteers and are predominantly White. Consequently, the representativeness of the samples and the generalizability of the findings are unknown. Second, the coping measures used in this study provide information about general coping styles of these mothers, but do not assess coping responses to specific stressors related to caring for an adult child with disabilities. It is possible that, if the present authors had included a measure of role-specific coping, they might have found a different pattern of results. Thirdly, the small sample size of adults with mental illness may have limited the statistical power to detect differences, and therefore, the findings need to be replicated with larger samples.

In conclusion, the present analysis underscores the importance of coping in the lives of older mothers of adults with chronic disabilities. For the mothers of adults with ID, using problem-focused coping and refraining from using emotion-focused coping pre-
predicts enhanced well-being. Furthermore, these effects are dynamic, even in these later years of the life course, such that changes in coping are linked with changes in well-being. In contrast, the mothers of adults with mental illness have fewer coping resources to draw upon to maintain or enhance well-being since, for the most part, problem-focused coping was not effective. Nevertheless, for this group, as for their counterparts whose adult child has ID, refraining from use of emotion-focused coping is an effective vehicle for maintaining psychological well-being.

Acknowledgements
Preparation for this paper was supported by the National Institute on Mental Health (R03 MH465644 and R01 MH55928) and the National Institute on Aging (R01 AG08768). This manuscript was based on the doctoral dissertation research of the first author (H.W. Kim).

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Accepted 19 February 2003