

The Family Stress and Coping Interview for families of individuals with developmental disabilities: a lifespan perspective on family adjustment

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Abstract

Background The present study investigated the psychometric properties of the Family Stress and Coping Interview (FSCI), a questionnaire designed to quantitatively and qualitatively examine the experiences of parents of children with developmental disabilities (DDs).

Methods The participants consisted of 106 primary caregivers of 106 individuals with DDs from centres in Eastern, Central and North-western Ontario, Canada. The participants completed a demographic questionnaire, the FSCI, and the Vineland Adaptive Behaviour Scales.

Results The results of this study indicate that the FSCI has adequate reliability (i.e. internal consistency and long-term stability) and validity (i.e. independent item ratings and discriminant validity).

Conclusions The results of this study support the use of the FSCI as a measure of family stress in research and practice.

Keywords family adjustment, Family Stress and Coping Interview, lifespan perspective

Introduction

Stress in families of children with developmental disabilities (DDs) has been the focus of many studies (e.g. Minnes 1988; Frey *et al.* 1989; Dyson 1993; Cummins 2001). One relatively neglected area concerns stress over the lifespan in response to normative events, including typical developmental milestones and non-normative events which are unexpected (Wikler *et al.* 1981; Wikler 1986).

The Family Stress and Coping Interview (FSCI) was developed to address parents' experiences related to events in the lives of their child with a developmental disability (for a description, see Minnes & Nachshen 1997). The FSCI has a number of advantages for use in research and clinical practice: (1) in response to the recommendation that participatory research methods should be used more frequently (Turnbull *et al.* 1993), the FSCI was developed in collaboration with families; (2) the FSCI uses qualitative and quantitative research methods (Patterson *et al.* 1993); (3) in response to a broader, lifespan perspective in family research (Blacher 2001; Seltzer *et al.* 2001), the FSCI addresses issues across the lifespan; and (4) in response to the recommendation that efforts be made not to 'pathologize' research participants (Patterson *et al.* 1993) and a gradual shift in research emphasis to include coping and adapta-

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tion of families (Glidden 1993), the FSCI encourages discussion of family successes.

The purpose of the present paper is to provide data on the psychometric properties of the quantitative portion of the measure.

Subjects and methods

Participants

The participants consisted of 106 parents of 106 individuals with DDs from centres in Eastern, Central and North-western Ontario, Canada. The parents ranged in age from 23 to 88 years (mean = 59.38 years, SD = 14.89 years). There were 96 female and 10 male caregivers from 106 different families. The majority (63.2%) of parents were married. Level of education was distributed fairly evenly, with 26.7% having some post-secondary-school education, 26.4% having completed high school and 46.7% having less than a high-school education.

The offspring with DDs ranged in age from 2 to 59 years old (mean = 30.12 years, SD = 14.30 years). There were 41 females and 65 males. Level of disability ranged from mild (26.4%) to moderate (56.6%) and severe (15.1%). Aetiologies included Down syndrome and unknown cause (23.6%, each), autism (14.2%), cerebral palsy (9.4%), problems at birth (8.5%), and fragile X syndrome (4.7%). The majority (80.2%) of the offspring with DDs lived with their parents.

Measures

Demographic information

A family information checklist was used to obtain demographic information regarding the parent's age, sex, education and marital status, and the child's age, sex, type of disability and living accommodations.

Family stress

The FSCI (Nachshen & Minnes 1996; Woodford 1998) is a quantitative and qualitative measure of stress and coping in families of individuals with DDs. The FSCI was developed in 1996 (then called the

Family Stress and Support Questionnaire, FSSQ) to address the shortcomings of previous measures of family experiences (for a complete description, see Minnes & Nachshen 1997). In its initial version, the FSSQ consisted of 17 lifespan issues, and was later revised to include five issues which were more relevant to the families of older adults (Woodford & Minnes 1998). It was also decided that the measure was more effective as an interview rather than a questionnaire, and the emphasis was placed on the family's experiences. Therefore, the name was changed to the FSCI.

To begin, parents are asked to rate the level of stress of each issue on a five-point Likert scale ranging from (0) 'not stressful' to (4) 'extremely stressful'. Individual items can be summed to create a total score (for a full list of issues, see 'Appendix 1'). The present study analyses the quantitative information obtained in this rating scale. In addition to quantitative data from the rating scale, interview questions were asked to gather qualitative information that was not analysed in the current study. The interview provides rich qualitative information (for an example, see Nachshen & Jamieson 2000). 'Appendix 2' contains a list of these interview questions.

Maladaptive behaviour

The Vineland Adaptive Behaviour Scales – Maladaptive Behaviour Domain (VABS-MBD; Sparrow *et al.* 1984) consists of 37 statements related to maladaptive behaviour of the person with DDs (e.g. 'Is overly dependent'). Each item is rated: (0) 'no, Never'; (1) 'sometimes or partially'; or (2) 'yes, usually'. The total score ranges from 0 to 74.

Procedure

The sample was obtained from parents' support groups, social service agencies and community groups who work with people with DDs in Eastern, Central and North-western Ontario. The agencies contacted potential participants by mail, and a follow-up phone call was then made to confirm interest in participating. Individuals either contacted or were contacted by the researcher (depending on agency protocol), who arranged an interview time. Before the interview, an information sheet was given to the

participants and written consent to participate in the study was obtained. The interviews lasted between 1.5 and 3 h.

Results

Reliability

Internal consistency

The internal consistency of the FSCI, as assessed using alpha coefficients (Cronbach 1951), was found to be high ($\alpha = 0.89$).

Long-term stability

The long-term stability of the FSCI was examined for 21 participants (12 mothers and nine fathers) who were administered the interview twice with an interval of approximately one year. These participants were older (mean = 64 years, SD = 10.36 years) and the majority were married (85.7%). It was found that the pair-wise correlation between the full-scale scores was adequate ($r = 0.80$, $P < 0.001$), indicating that full scale scores on the FSCI are relatively stable over the long-term. Changes tended to involve an increase over time.

Validity

Independent item ratings

The face validity of the FSCI items was assessed using independent item ratings by 25 professionals and graduate students who were attending an annual research day organized by the Research Special Interest Group of the Ontario Association on Developmental Disabilities. The sample included graduate students (36%), psychologists (28%), social workers (12%) and others, with a mean of 8.4 years of experience (SD = 7.08) in the field of DDs. They were given forms asking them to rate the relevance of each issue to the experience of the parents of children with DDs on a scale from (0) 'not relevant' to (10) 'extremely relevant'. The mean rating for the relevance of the scale overall to the experiences of parents of children with DDs was 8.04 (SD = 1.46), indicating that these knowledgeable individuals found the overall scale to have face validity.

Discriminant validity

The FSCI was created to address issues across the entire lifespan of individuals with DDs. As such, it was expected that there would be differences between three age groups. The first group was composed of 0–21-year-olds ($n = 30$). The age of 21 years was chosen as a cut-off since it represents a transition between child and adult services in Canada. The second group was composed of younger adults between the ages of 22 and 39 years ($n = 45$). The third group consisted of older adults above the age of 40 years ($n = 31$). It was found that issues tended to be most stressful for parents of individuals at the relevant age. The results for the individual items are reported in Figure 1. Overall, parents of younger children (mean = 32.36, SD = 17.63) reported more stress on the FSCI than parents of younger adults (mean = 23.34, SD = 16.32) or older adults (mean = 23.58, SD = 18.75) ($F = 3.42$, $P < 0.05$).

Eighty older parents also completed the VABS-MBD (Sparrow *et al.* 1984). The FSCI was found to discriminate between individuals with different levels of maladaptive behaviour ($F = 3.70$, $P < 0.05$). The parents of individuals with high levels of maladaptive behaviour ($n = 16$; mean = 34.81, SD = 19.67) were found to experience significantly more stress than parents of individuals with medium ($n = 39$; mean = 24.62, SD = 14.81) ($P < 0.05$) and low levels ($n = 25$; mean = 19.92) ($P < 0.01$).

Discussion

The results of the present study indicate that the stress rating scale on the FSCI is a reliable and valid measure for use with parents of individuals with DDs. The scale has a high level of internal consistency and, at least for parents of older adults, relatively high long-term stability. Further research is needed to examine changes in the FSCI over longer time periods with multiple age groups.

The face validity of the FSCI was high. Another important finding is that the total score on the interview is useful in discriminating between parents of individuals at different age groups and parents of individuals with different levels of maladaptive behaviour. In this study, the parents of individuals under

Family Stress and Coping Inventory

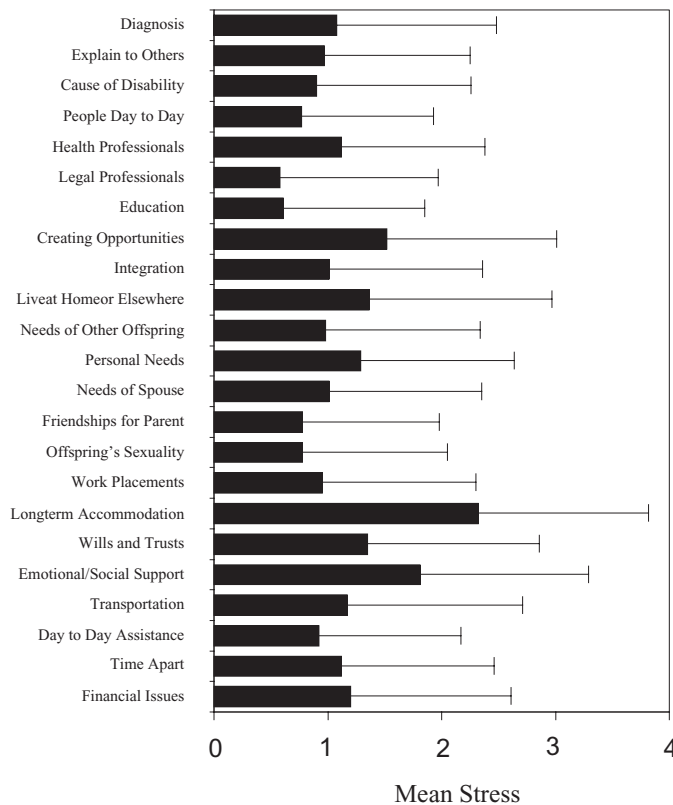


Figure 1 Parent's mean stress rating (\pm SD) for each issue on the Family Stress and Coping Inventory.

the age of 21 years experienced more stress than parents of either younger or older adults. Consistent with previous research, the parents of individuals with more severe maladaptive behaviour were found to experience more stress than parents of individuals with mild or moderate maladaptive behaviour (Friedrich *et al.* 1985). Research is currently underway to examine the ability of the FSCI to discriminate among parents of individuals with different types of DDs.

Overall, these results provide preliminary support for the reliability and validity of the stress rating scale portion of the FSCI. Although research with different populations and longer time periods would add to our knowledge of the psychometric properties of the FSCI, the present study demonstrates the instrument's promise for use in research and practice. Researchers and clinicians who are interested in using a measure developed in a participatory approach, incorporating qualitative and quantitative

methodology, and respecting the expertise of caregivers and avoiding an assumption of maladjustment are invited to consider using the FSCI as a measure of stress and coping in parents of individuals with DDs.

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Appendix I

Issues on the Family Stress and Coping Interview

- 1 The diagnosis of _____ as having a developmental disability.
- 2 Explaining to others about _____'s developmental disability.
- 3 Your feelings about the cause of _____'s developmental disability.
- 4 Dealing with friends/family/people in the neighbourhood on a day-to-day basis.
- 5 Dealing with doctors and other allied health professionals.
- 6 Dealing with legal professionals.
- 7 Dealing with _____'s teachers and the educational system.
- 8 Creating and/or finding opportunities for _____ to make friends and participate in activities.

- 9 Deciding on the best level of integration for _____.
- 10 Making the decision concerning accommodation in the home or in the community.
- 11 Meeting the needs of your (other) children.
- 12 Meeting your own personal needs.
- 13 Meeting the needs of your spouse.
- 14 Maintaining satisfying friendships for yourself.
- 15 Dealing with _____'s sexuality.
- 16 Work placements or employment for _____.
- 17 Long-term planning for accommodation for _____.
- 18 Planning for wills, trusts and guardianships.
- 19 Planning for emotional and social support for.
- 20 Transportation.
- 21 Day-to-day assistance with care of _____.
- 22 Time apart from _____.
- 23 Dealing with financial and insurance issues.

Appendix 2

Qualitative questions on the Family Stress and Coping Interview

- a What challenges have you faced in this particular issue?
- b What successes have you had and how did you achieve them?
- c How have you tried to cope with this challenge? Why did you choose this strategy? Has this been helpful?
- d Has the stress related to this issues changed:
 - i over the past 5 years? Increase No change Decrease
 - ii in the last year? Increase No change Decrease
 If changes in stress have occurred, why?
- e What would you like to see change that would help make this experience easier for you and for parents of other children with special needs?