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Title: Sources of stress among adult siblings of Irish people with intellectual disability

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ABSTRACT

Siblings play an important role in the lives of their brothers and sisters with intellectual disability when they reside in the parental home. Many assume a primary caregiving role following the death of their parents or when parents are no longer able to give care. Sources of stress reported by 39 adult siblings of Irish men and women with intellectual disability were explored. Siblings who were primary caregivers were older and earned less income than their counterparts in a second group who lived in the parental home and who had an especially close bond with their brother or sister with intellectual disability. Perceived social support as well as their brother or sister's independence were significantly related to the stress reported by siblings on the short form of the QRS-F. Neither levels of reported stress nor the presence of a plan for their relative's future distinguished the two groups of siblings.

Introduction

Family care is the dominant form of residential support for individuals with intellectual disabilities throughout the world (Health Research Board, 1996; Seltzer & Krauss, 1994). Trends in life expectancy suggest that adults in this population will increasingly outlive their parents and rely on siblings or other relatives for care (Seltzer, Greenberg, Krauss, Gordon & Judge, 1997). Arguably, those charged with planning residential services can best meet current or future requirements if they are aware of the strengths and limits of this intra-generational form of family care. A greater understanding of the complex care required by adult family members with intellectual disabilities is emerging. Within current paradigms focused on promoting self-determination and social inclusion, these men and women are increasingly seen as citizens whose rights to independence must be fostered (Walmsley, 1996). Neither children nor helpless dependants, they look to their families for an array of emotional and practical supports enabling them to direct the course of their own lives.

It remains to be seen whether their Siblings will temper their caregiving to meet these freshly defined, second-generation needs. Relatives who take over care for a family member with intellectual disability may assume this new role as a bequest which they may have inherited, but also as one which is naturally theirs (Whittick, 1989). Siblings' wishes for the family member with an intellectual disability have been found to mirror closely the desires of their parents (Zeitlin, 1986). When an adult sibling formally adopts the caregiving role, the relationship between adult siblings may become a hierarchical one resembling that of parent to child, or of a more powerful adult caring for a less powerful brother or sister (Walmsley, 1996). Many adult siblings anticipate the role they will adopt in the future by growing into the role they ultimately adopt over time. This outcome may be rooted in childhood patterns in the family: the eldest sister, especially, may have been expected to be extensively involved in baby-sitting and otherwise caring for her brother or sister (McHale & Harris, 1992). Krauss, Seltzer, Gordon, and Friedman (1996) reported that two-thirds of a sample of siblings (N=140) expected to become the legal guardians of their brothers or sisters with an intellectual disability on the death or incapacitation of their parents. These authors also found that women and their sisters with an intellectual disability formed the most common care dyad, and that higher levels of interaction prior to death of parents or a parent were associated with a higher likelihood that the sibling would take over the caring role.

Other siblings may have the caregiving role thrust upon them as the result of parental death or some other family crisis. They also provide informal support in the absence of spouses or children, relatives acquired by few individuals with intellectual disability. Siblings have been found to dominate the informal networks of adults with intellectual disability, providing frequent contact, strong commitment and performance of a range of instrumental tasks on behalf of a brother or sister (Bigby, 1997). Of all relatives, siblings of individuals with intellectual disability tend to take over the primary support role after their parents are not able to function in this role (Seltzer, 1985).

This intergenerational transfer of caregiving is of obvious importance to those charged with planning and funding services for individuals with intellectual abilities (Krauss et al., 1996). Planning for the eventual out-of-home placement of a family member with intellectual disability is itself a complex process which may last over years or decades of family life, and involve siblings (McCallion & Tobin, 1995). When places in formal residential service systems are scarce, waiting lists lengthen and families perceive that they cannot count on a residential place in the foreseeable future. An essential aspect of the decision of a sibling to take on the caring role is that families of individuals with intellectual disabilities do not always make plans for the future care of their son or daughter.

Cross-cultural differences in the prevalence of future planning are apparent. Only twelve per cent (12%) of a sample of older caregiving mothers in the United States reported that they had failed to make plans. By contrast, in the Republic of Ireland forty percent (40%) had no plans and sixty-two percent (62%) of a comparable group in Northern Ireland had failed to make plans (Seltzer Krauss et al., 1995; Walsh, Conliffe & Birbeck, 1993). Prosser (1997) found that just half of the siblings (N=10) in her sample had made plans for the future residential placement of their brother or sister. Among American caregiving families, predictors of residential placement included poorer maternal health, older age of the adult child with intellectual disability and the fact that the individual's name had already been placed on a waiting list for residential services. Although family adjustment to the presence of a family member with disabilities is often positive, threats to the well-being of family carers have been thoroughly documented (Helff & Glidden, 1998). Factors related to carer stress include reduced leisure time, lowered earning potential, increased reported frustration and fewer perceived social supports (Fisman & Wolf, 1991; Shearn & Todd, 1997). Other factors related to increased stress in carers have been found to include a more severe degree of intellectual disability in their brother or sister, poor self care skills (Blacher, Nihira & Meyers, 1987; McHale & Harris, 1992) and the presence of behavioural problems (Seltzer & Krauss, 1989). The relationship between levels of stress reported and socio-economic class have been inconclusive; at most, this relationship has been shown as weak (Donovan, 1988; Beckman, 1983).

This study explores the impact of caregiving on the stress reported by siblings who are either the primary caregivers of a brother or sister with an intellectual disability or who live in the family home and are the most involved in caring for their family member. Three research questions were addressed. First, do siblings who have become primary caregivers experience and report different levels of stress than those who have a secondary caring relationship in the parental home? Second, what factors are related to stress reported by siblings? Finally, to what degree do sibling caregivers make residential or financial plans for the future of their brothers or sisters?

METHOD

Participants

Participants in this study were 39 adult siblings of Irish men and women with intellectual disability. Of these, 22 were primary caregivers while 17 lived in the family home and had, according to their mothers, an exceptionally close relationship with their brother or sister. Information on the characteristics of adults with intellectual disability and their siblings-most of whom were sisters-appears in table 1.

Table 1. Characteristics of siblings by group.

Demographic information	Group I (N=22) Sibling Carers	Group II (N=17) Involved Carers
Sex of sibling carer (%)		
Male	36.4	23.5
Female	63.6	76.5
Age of sibling carer	45.77	30.64***
Marital status of carer (%)		
Single	27.3	64.7
Married	68.2	35.3
Divorced	4.5	0
Occupation of carer (%)		
Home	27.3	17.6
Unemployed	22.7	11.8
Full-time	36.4	58.8
Part-time	13.6	11.8
Income of family (%)		
Less than £10,000	18.2	0
£10 - £15,000	31.8	0
£15 - £20,000	13.6	11.8
£20,000+	36.4	70.6
NO. of people Living at home	4	4.6
Sex of sibling with a learning disability (%)		
Male	59.1	41.2
Female	40.9	58.8
Age of sibling with a Learning disability	45.14	30.59
Level of sibling's learning disability (%)		
Mild	50	52.9
Moderate	31.8	35.3
Severe	13.6	5.8
Profound	4.5	4.6
% with additional physical disability/illness	31.8	30.59***

*= significance at $p < .05$, ** at $p < .01$, *** at $p < .001$

Primary caregivers were significantly older than siblings who lived in the primary home but were involved in care for their brother or sister (45.77 and 30.64 years). It was striking that dyad members in both groups were very close in age to each other. Primary caregivers and their brothers or sisters with intellectual disability were significantly older than their counterparts. Family income reported by caregiving siblings was significantly lower than that of involved siblings living in the family home. About half of the adults in both groups (50% and 52.9%) were described as having a mild level of intellectual disability, reflecting the pattern of residence among all Irish adults with intellectual disability living at home (Health Research Board, 1996; Table 2.4). One third (31.8%) of adults whose siblings were primary caregivers and 41.2% of those living with involved siblings in the parental home reported an additional physical disability or illness.

Measures

1. Short form of the Questionnaire on Resources and Stress (QRS-F) (Friedrich, Greenberg and Crnic, 1983).

The QRS-F consists of 52 items which are divided into four subscales. It was developed to assess the impact a person with intellectual disability has on other family members. The four factors the questionnaire measures are; (a) parent and family problems, (b) pessimism, (c) child characteristics, and (d) physical incapacitation. The QRS-F also yields a total combined score of the four scales and this is a global index of carer's reported stress. The measure has been used extensively internationally and it has good validity and reliability (Scott, Sexton, Thompson & Wood, 1989; Seltzer Krauss et al., 1995).

2. General Health Questionnaire-12 (GHQ-12) (Goldberg and Williams, 1988).

The GHQ-12 is a measure of psychological distress in an individual, with higher levels of mental health difficulties. Graetz (1999) in an extensive review of the GHQ, reported that it was a valid and reliable instrument.

3. Multidimensional Scale of Perceived Social Support (MSPSS) (Zimet, Dahlem, Zimet & Farley, 1988).

This scale is a 12-item self report inventory measuring levels of perceived social support from family, friends and significant others on a seven point Likert scale. The MSPSS has been found to be valid and have strong internal reliability (Zimet, Powell, Farley, Werkman & Berkoff, 1990).

4. Barthel Index-Revised (Mahoney & Barthel, 1965).

This index is a 31 item scale of personal and instrumental functional skills and because of its good face validity and strong psychometric properties, is one of the most widely used measures of performance in the activities of daily living (Wade & Langton-Hewer, 1987).

5. Marlow-Crowne Social Desirability Scale (M-C SDS) (Strahan & Gerbasi, 1972).

This is a shortened version of Crowne and Marlowe's social desirability scale (1960), with items split into two ten-item scales.

6. Level of behavioural problems

Harris's Management Difficulty self report scale (1993) was adapted by McClean (1996) to measure a carer's perception of how difficult they believe their family members behaviour is. It consists of a 17- item, 7 - point Likert scale.

Procedure

Participants were identified through a database held by an Irish service agency. A total of 55 primary caregiving siblings were identified and contacted directly; of these, 22 (40%) agreed to take part in the study. A second group of 75 family homes with an adult sibling or siblings still in co-residence with their brother or sister with intellectual disabilities were identified. For this group, their mothers were contacted by letter and asked to give the enclosed pack of questionnaires to the brother or sister who had an exceptionally close relationship with the individual with an intellectual disability. Only 17 (23%) completed questionnaires, Formal consent was secured by inviting all respondents to sign an enclosed statement and to return completed forms through the post to the first author.

RESULTS

To address the first research question, mean scores on two measures of stress, the total score of the QRS-F and the GHQ were compared. There were no significant differences between the primary and secondary sibling carers (Table 2).

Next, multiple regression analysis was used to explore the factors predicting sources of stress among siblings measured by the QRS-F.

Table 2. Group differences (one-tailed test) on measures of stress

Group	Siblings Carer		Involved Carer		t	p
	Mean	sd	Mean	sd		
QRS-F Total Factors	19.22	8.99	20.71	8.58	0.302	>0.05
I Parent & Family Problems	6.14	5.12	7.24	4.62	0.244	>0.05
II Pessimism	6.82	2.60	7.59	1.97	0.151	>0.05
III Child Characteristics	5.32	2.92	5.12	2.98	0.418	>0.05
IV Physical Incapacitation	0.95	1.21	0.76	1.44	0.333	>0.05
GHQ	12.63	4.27	12.41	4.26	0.435	>0.05

Independent variables for this analysis were selected after scores on the Harris Management Difficulty Scale (revised), Barthel Index, Multidimensional Scale of Perceived Social Support and adults' level of learning disability were identified as being correlated with QRS-F scores. Results indicated that a model in which a measure of siblings' perception of social support (MSPSS) was combined with a measure of the dependence of adults with intellectual disability (Barthel Index) accounted for 29% of the variance (Table 3).

Table 3: Factors predicting stress: Results of multiple regression analysis.

Dependent variable	Predictive Factors	Adjusted R ²	F	p
QRS-F	(a) MSPSS	.194	10.158	.003
Total Score	(b) MSPSS And Barthel Total scores	.289	8.723	.001

Finally, a minority of siblings reported that they had made any plans for the future of their brother or sister with intellectual disability. Results of Chi square analysis indicated that there were no differences in the percentages of siblings in the two groups as to the levels of future planning reported (Table 4.).

Discussion

The findings of this study indicated that perceived social support as well as

their brother's or sister's independence in carrying out daily activities were significantly related to the stress reported by a group of Irish siblings. Those who had assumed the role of primary caregiver were older than their counterparts and earned less income. Income was higher among siblings who were involved in care within the family home, possibly expressing the greater discretionary income at the disposal of younger wage-earning adults not yet responsible for their own households, as well as the lack of such income among older, married sisters. Whether sibling carers will, as they age, swell the ranks of elderly parents seeking residential placements for adults with intellectual disability remains to be seen (Essex, Seltzer & Krauss 1997; Walsh et al, 1993).

Table 4: Number of siblings reporting levels of future planning.

Caregiver Group	Plans for sibling In will	Residential plans	Financial plans
Primary (N=22)	8	10	6
Secondary (N=17)	3	3	3
Total (N=39)	11	13	9

The siblings who lived in the family home had already identified themselves as being involved in caring for their brother or sister according to their mothers' appraisal. Were they building relationships with their brothers or sisters for the future? The relatively low rate of response among siblings providing secondary care in this study suggests that maternal perceptions of the nature of their adult children's involvement with each other are possibly ill-founded. Alternatively, it may be that although siblings may declare themselves to be personally attached to brothers and sisters, they prefer not to become explicitly engaged in service planning processes within the family. Krauss et al. (1996) found that the level of current involvement of siblings with their brothers or sisters, for example, expressed in the activities they shared during the previous year, was a significant predictor of future plans to co-reside. However, this measure of involvement between siblings was not gathered in the present study. It is striking that just one-third of all siblings declared that they had made some plan for their brother or sister's future, reflecting the level of future planning reported earlier by 39.5 % of a sample of older Irish mothers giving primary care to their adult children (Seltzer et al., 1995).

Neither levels of stress nor of future planning differed between primary caregiving siblings and siblings involved in care for their brother or sister

with intellectual disability in the family home. The stress reported by caregivers is one thread woven into a complex, often long-lasting fabric. Yet the continued dominance of research on stress experienced by family caregivers may reflect current service paradigms founded on the continued scarcity of suitable residential places for an increasing population of older people with intellectual disability. Antonovsky (1993, cited in Helff and Glidden, 1998) notes the desirability of researchers taking a "salutogenic" approach- that is, studying variables such as well-being, meaningfulness and sense of coherence - rather than a pathogenic one. Identifying the adult, sibling and interactive factors related to the successful intergenerational transfer of family caregiving for adults with intellectual disability is but one task for future researchers.

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