

The impact on mothers of bringing up a child with intellectual disabilities: A cross-cultural study

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Abstract

Background: Most research into the impact on mothers of having a child with an intellectual disability has been done in Western cultures. These mothers are at increased risk of stress, along with poorer health and weakened family relationships. Nurses are well placed to support these mothers.

Objectives: (1) To describe across three different cultures—Irish, Taiwanese and Jordanian—the inter-relationships among three indicators of maternal well-being. (2) To identify the coping strategies of mothers and the professional and informal supports available to them. (3) To identify the variables that have a negative impact on maternal well-being and possible moderating influences on them.

Design: A survey approach with three groups of self-selected mothers.

Participants: The characteristics of the child determined the inclusion criteria; namely aged 5–18 years with a diagnosis of intellectual disability of such severity that the children attended special schools or centres. In each country, the special services within particular geographical areas were approached and all families known to them were given the opportunity to participate. In all 206 mothers agreed to participate.

Methods: Mothers were interviewed individually at home or in the day centre attended by their child. They completed various rating scales of known reliability and validity. In addition they described in their own words, the impact the child had on their lives and how they coped.

Results: In all three countries, mothers experienced poor mental health, increased levels of child-related stress and poorer family functioning which the qualitative data further illuminated. Their child's behaviour problems were a major factor in this. The impacts on mothers' well-being were not alleviated by access to professional supports or use of coping strategies.

Conclusions: Health professionals need to adopt family-centred approaches that embrace the support needs of mothers. Similar strategies would apply across all cultures although they must be responsive to individual need.

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What is already known about the topic?

- Mothers have increased stress and poorer health.
- The child's behaviour problems makes mothers more stressed.
- Certain coping strategies and social supports assist parents.

What this paper adds

- Mothers in Taiwan, Jordan and Northern Ireland also report an impact on family functioning.
- A similar set of predictor variables was found for mothers in the three samples.
- Informal rather than professional supports were related to mothers' perceptions of family functioning but neither form of support was linked with measures of maternal stress and mental health.

1. Introduction

Intellectual disability occurs in every culture and in every generation. Internationally, it is mothers who provide most of the care for their son or daughter, often in addition to many other responsibilities. The extra attention and support needed by the affected child often extends into adulthood. Moreover, the stigma of having a child with marked disabilities has often not abated in cultures around the world (Gartner et al., 1991).

There is growing evidence that these responsibilities impact on maternal well-being. It is well recognised that families of children with disabilities are under greater stress than other families (Baxter et al., 2000) due to the additional demand on the parents' time, energy, finances, emotions and possible feelings of inadequacy about their competence to deal with their child's needs (Olsen et al., 1999). Mothers tend to have poorer health, for example reporting more depressive symptoms or higher levels of malaise, depression and anxiety than do mothers of normally developing children (Andersson, 1993, Blacher and Mink, 2004).

There can also be detrimental effects on the way family members relate to one another and often parents of children with disabilities receive decreased levels of social support (Dunst et al., 1986). Key people in their support network, such as family members, often do not know how they can help, so they withdraw. Parents may also experience loneliness or isolation after the birth of a child with disabilities because they have less time and energy to make visits outside the family home. This can result in the deterioration of relationships (Valentine, 1993). Kazak and Wilcox (1984) found that in comparison to families with children without disabilities, the

social networks of families with children with disabilities were smaller.

Nonetheless most families do manage to cope although it is unclear the extent to which their intuitive coping strategies alleviate the strains of care giving. Lazarus and Folkman (1984) proposed that a person's coping strategies can moderate the effects of stress and subsequent research with parents has tended to support this view (Seltzer et al., 2004). Likewise, social supports have been identified as a significant factor in mediating stress and enhancing coping in families with children with disabilities (Dyson, 1997). However, the contribution of professional supports in helping mothers is not well understood.

To date, most research has focussed on white European or North American mothers with sparse attention paid to other cultures such as Arab or Chinese (Blacher and Mink, 2004). Child-rearing practices are to an extent culturally determined and yet this dimension has been rarely explored in the field of disability; with the exception of immigrant populations in Western countries. It may well be that certain cultures adapt differently to the presence in the family of a child with disabilities. For example, Latina mothers in the USA report higher levels of depression than do other mothers (Blacher and Mink, 2004).

The coping strategies used by mothers are likely to be influenced by culture as could be the informal supports available to mothers from family and friends. However, it is likely that the greatest differences exist in the realm of professional supports which are more likely to be found in more affluent Western countries. Yet the extent to which these formal supports directly assist mothers is an unresolved question. One possible reason for this, is the limited understanding that we have of the major influences on maternal well-being. Descriptive studies across cultures are lacking that would identify the major impacts on mothers' well-being. Armed with this information, health services would be better placed to support mothers. The main aims of this study can be summarised as follows:

1. To describe the well-being of mothers living in Northern Ireland, Taiwan and Jordan, on three indicators: namely family functioning, mental health and child-related stresses.
2. To describe the coping strategies of mothers in the three countries and how these relate to the professional and informal supports available to families.
3. To identify the variables that have a negative impact on maternal well-being and possible moderating influences on them.

This information is particularly relevant to nurses who tend to have contact with parents in all countries around the world through their public health role, such as health visitors in the UK or as school nurses.

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