Review: mothers of children with physical or mental disabilities experience emotional compromise between acceptance and denial


QUESTION: What are the experiences of mothers of children with physical or mental disabilities?

Data sources
Studies were identified by searching CINAHL, Medline, PsycINFO, ERIC, Sociological Abstracts, and Dissertation Abstracts.

Study selection
Qualitative studies about mothering children with physical or mental disabilities were selected. Children could be of any age and have any condition.

Data extraction
Key phrases, themes, concepts, or metaphors from each study were listed and juxtaposed in tables. Studies were translated into one another and synthesised.

Main findings
12 studies were included. The process of mothering entailed 4 steps. (1) Becoming the mother of a disabled child. Timing: mothers of newborns with obvious anomalies held diminished roles as staff cared for their infants. Mothers felt frustrated when staff made decisions about their ability to cope and when staff provided a false protection. When a child’s disability was discovered, mothers had to deal with the loss of the “normal” child and acceptance of a different child. Emotions: emotions commonly expressed by mothers were injustice, fear, anxiety, grief, shock, disappointment, despair, and guilt. (2) Negotiating a new kind of mothering. The learning curve: mothers learnt the “extras” of caregiving through self education, trial and error, or education provided by healthcare staff. Relationship with the healthcare system: initially, mothers held a naïve trust in physicians and medicine. Over time they became proactive in their child’s care. Mothers sometimes felt that the medical staff was insensitive and disrespectful of their child’s humanity. Mother-child relationship: mothers devised unique ways to communicate with their child and reported an intensity in the mother-child relationship because of the child’s dependency. Intrafamily relationships: there were positive and negative familial responses to the presence of a disabled child. Lack of family support or critical relatives led to strain and emotional pain. Awareness of societal judgment: mothers felt guilt or blame for their child’s disability and were aware of the lack of societal acceptance of their child’s condition. (3) Dealing with daily life: it will never be the same. Caregiver burden: mothers’ lives were the most changed because they were the primary caretakers and had little daily help. Alteration in employment status: many mothers chose to stop or reduce their work outside the home to meet their caring demands. Social isolation: mothers expressed psychological and physical isolation as a result of adhering to strict medical regimen, a perceived lack of acceptance of their child by others, and feelings of great responsibility for their child’s wellbeing, all making it difficult to get out alone. Uncertainty: uncertainty was related to the susceptibility, instability, and unpredictability of their child’s condition. They often second guessed their efforts, fearing doing something wrong. (4) The process of acceptance/denial. The significance of “normalcy”: mothers wished their child could be “normal” and looked for signs of normalcy. They perceived that children were treated differently if they looked “normal”. The embrace of paradox: mothers came to an emotional compromise between acceptance and denial. They accepted their children as they were but never gave up hope for improvement.

Conclusions
Mothers of children with physical or mental disabilities learnt new mothering roles. Mothers had an intense relationship with their child. They accepted their child but never gave up hope for improvement.

COMMENTARY
Nelson has conducted a meta-synthesis of the findings of 12 separate studies about mothering children with physical or mental disabilities. Meta-synthesis is a research method in which the findings of qualitative research are analysed and synthesised to identify similarities and differences and to generate new or expanded theory about the phenomenon under study. Sandelowski notes that a good meta-synthesis provides sufficient information for readers to track the sources and decisions made by the researcher and focuses on synthesising, not merely analysing, the findings. Nelson’s work achieves the first criterion; she also provides considerable detail about the meta-analytic procedures recommended by Noblit and Hare. However, she has produced an analysis of the findings rather than a synthesis. It was startling to discover that Nelson could find so few qualitative studies on this topic. Further research is needed in this area. The author did not elaborate on the implications to her data analysis of referring to disability as “other than normal”, nor did she discuss the implications of including research on mothering in both life threatening and non-life threatening childhood illness. The author provides a detailed list of the implications of this research. Her findings are important because they remind us of the continual fluctuations in the experience of living with a chronic illness or disability. This message is important for practitioners who may view chronic illness and disability as essentially static. Many of the examples in the article are provocative and touching. They remind us that mothering a sick child is highly complex, characterised by the possibility of both negative and positive outcomes. We cannot assume that parenting such children is entirely characterised by loss and burden. Mothers of all children may also experience profound rewards. Although the research has important insights for clinicians, the work by Dewar and Morse about what people with chronic illness experience as unbearable incidents might have been helpful in understanding the findings. In addition, referral to more recent literature on meta-synthesis would have enhanced the discussion about methods and research design.

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1 Sandelowski M. “To be of use”: enhancing the utility of qualitative research. Nurs Outlook 1997;45:125–22.