



The Experience of Parents of Young People with Mental Health Problems

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A better understanding of parents' experiences with service providers is essential if the goal of promoting more family-centered children's mental health services is to be realized. This article presents the results of a qualitative study investigating "the experiences of parents of young people with mental health problems and their relations with health care professionals".

Method

The data were collected as part of a larger research project in Great Britain investigating the experience of parents of young people, aged 13-16 years, living with mental health problems or chronic illness due to asthma or head injury. Only data from parents of children with mental health problems are considered in this article. A previous phase of the research, approximately 18 months earlier, investigated the experiences of the young people themselves. Parents were approached for this second phase following agreement by the youth participants from phase one. The sample comprised of 25 White parents (18 mothers and 7 fathers) representing 18 families from a range of socioeconomic backgrounds. Three of the mothers were lone parents. Semi-structured interviews were conducted with parents in their homes. Topics addressed included participants' view of the child's health problems; relations with health care professionals; impact on the family and lifestyle; and forms of coping. The interviews were audio taped and transcribed. Qualitative data analysis methods including thematic and textual analysis were used to interpret the data.

Results: Understanding parents' experiences

The author argues that parents' experiences of caring for children with mental health problems can only be understood when "contextualized in terms of wider understandings of parenting and in particular, ideas of parental responsibility, childhood and the transition to adulthood, and the nature of mental health problems" (p. 220). Based on analyses of the interview data, the researcher identifies two major themes to describe parents' experiences. The first theme of "parental deskilling" refers to "ways in which parents felt that their parenting skills were challenged by the illness [of their child] and by the medical profession" (p. 211). The second theme of "parental reskilling" refers to "direct and indirect ways in which parents addressed these challenges [of deskilling]" (p. 211).

Parental deskilling. The researcher identified four subthemes to explain parents' experiences of deskilling in their role as their child's primary caregiver. These were not being listened to by the medical profession, feeling helpless, being excluded from care, and experiencing blame. Parents' distress about their child's problems was exacerbated by the need to rely on professionals with expertise in mental health, but who did not seem to take parents' concerns seriously, instead perceiving them as 'overreacting'. Protracted times to reach a diagnosis, slow responses, negative judgments from professionals, and inadequate practical information about their child's day-to-day

care contributed to parents' feelings of helplessness in fulfilling their parental role. Parents reported that they were hampered in their ability to help their child because of exclusion from decision-making about their child's care. This was particularly difficult when young people reached the legal age of adulthood, but parents' concerns and feelings of responsibility persisted due to the ongoing vulnerability of the young person with mental illness.

Parental reskilling. Three subthemes were identified to describe parental reskilling. These were "critiquing psychiatric knowledge and practice, acquiring knowledge, and renegotiating the parental caregiving role" (p. 216). Parents' experiences of the inadequacies of psychiatric care, including the time required to reach a diagnosis and limited treatment success, led them to develop their own expertise in mental health. Parents' increased knowledge about their child's mental health condition, combined with their knowledge as parent of their child, enabled them to reposition themselves as caregiver, for example by questioning medical expertise particularly in relation to general aspects of their child's care. However, the data indicated that parents were more likely to accept medical expertise with regard to specific aspects of care such as prescribed medication. The transition from youth to adult status was also an important part of parents' renegotiation of their caregiving role. Parents described ways in which they redefined their role as a parent and managed the increased risk of exclusion from care during this period.

Discussion & Implications

This article provides empirical evidence about the experiences of parents of children diagnosed with a mental health disorder, with a particular focus on the meaning of these experiences in the context of parenting roles as perceived by the different stakeholders involved in the child's care. The author recommends a number of changes relevant to improving the care of children with mental health disorders, including greater sensitivity to causal explanations and parents' experiences of being judged by professionals, not dismissing parents' concerns, providing greater emotional and practical support, and enabling parental involvement. Further research is required to examine the experiences of a more representative group of parents and how the experience of parents may change over time. Exposing differences in perceptions of childhood, parenting, mental health, and stakeholder roles is an important agenda for research if it is to contribute to informing the development of family-centered services. While not addressed directly in this study, the principle of designing research that takes account of the context in which families seek and use mental health services for their children is particularly relevant to developing ways to improve services and support for families from diverse cultures. Of note is that although this study was recently conducted in Great Britain, the findings are strikingly consonant with findings from U.S. studies conducted in the 1980s and 1990s (e.g., see Friesen & Huff, 1996).¹

¹ Friesen, B.J., & Huff, B. (1996). Family perspectives on systems of care. In B.A. Stroul (Ed.), *Children's mental health: Creating systems of care in a changing society*, pp. 41-67. Baltimore: Paul H. Brookes.

