

REPORT: CURRENT STATUS OF STUDY: PERCEPTIONS OF CHILDREN LIVING WITH A PARENT WITH A MENTAL ILLNESS

RESEARCH STUDY: Nursing Doctoral Dissertation, University of British Columbia

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Preamble

This study is a qualitative research study that uses the method of grounded theory as developed by Dr. Barney Glaser. Data collection began in August, 2002. Final analysis of the data is ongoing. In the method of grounded theory, there is a possibility, that some limited further data collection will take place as needed to develop the theory further. The anticipated completion date of the study and defense of the dissertation is November, 2004.

Research Questions

The research questions for this study are: How do children experience living with a parent with a mental illness? How do they manage this experience? What is helpful, what is unhelpful?

Description of the Sample

22 children between the ages of 6 years and 16 years have been interviewed, with 10 of these children being interviewed a second time. All children interviewed live either full or part time with the parent who has the mental illness. The parents suffered with depression, bipolar illness or schizophrenia. The majority of the parents who responded suffered with depression. The diagnosis of schizophrenia was the least common mental illness.

Characteristics of the Families

Single and dual parent families were represented. Generally, the parent with the mental illness initiated contact with the researcher. These parents were concerned about the effect of their illness on their children. Often, they saw the research interview as an opportunity for their child to express their feelings and were hopeful that this would be helpful to the child. It is of interest to note that the parents were concerned about their children and were open to their children discussing their perceptions. Parents did not have access to the child's comments and entered the study in the hopes that this research would benefit children and families living in these circumstances. Family configurations varied, some children being only children, some having siblings and some with half siblings. Children lived in a variety of situations, i.e. in a nuclear family with both parents, sharing homes with divorced parents, living one week at one home and one week at another.

Access Issues

Accessing the sample for this study has been a labourious process. The research could be classified as sensitive research considering the societal stigma often associated with mental illness. Numerous contacts were made with various agencies in the community via word of mouth, formal meetings with key people, posters and newspaper and email advertisements in order to gain access to the sample.

Publications

Children Living with a Parent Who has a Mental Illness: A Critical Analysis of the Literature and Research Implications by E. Mordoch and W. Hall was published in the Archives of Psychiatric Nursing, Vol. XVI, No. 5, October, 2002,pp 208-216. The paper provided an analysis and assessment of the literature that deals with children of a parent who has a mental illness. It argued that children's perspectives have not been taken into consideration. The article proposed a program of research that addresses the issues raised in the analysis. Funding sources were acknowledged in the postscript of the article.

Preliminary Findings

The purpose of doing a grounded theory study is to develop a substantive theory that will explain the phenomena of how children perceive the experience of living with a parent with a mental illness. The findings presented are preliminary and will be refined with the ongoing analysis. A brief summary of the key preliminary findings are provided.

Key Preliminary Findings

- 1. Children identify that they have to deal with their circumstances. Often they do so with only part of the information as to what is happening to their parent.
- 2. Children develop an antenna for watching changes in the behaviour of their parent. They begin to recognize patterns and interpret these patterns of behaviour. They adjust their own behaviour to manage the situation.
- 3. Children are capable of recognizing the losses associated with having a parent with a mental illness. They also may view the mental illness as a unique phenomena of interest. They develop the ability to view the parent as a whole person, not only a mentally ill person. Mental illness creates a situation whereby the child comes to know the parent at a different level.
- 4. Children sense a need to live their own lives despite the mental illness of the parent. They accomplish this with a variety of strategies some of which are: getting away, forgetting, distancing; seeking solace, finding an interest.
- 5. Children come to terms with the fact that their parent has a mental illness by accepting and/ or struggling with this fact. Children develop empathy embedded in mixed emotions towards the parent with mental illness. At times, the experience may be viewed as excruciatingly exhausting.
- 6. Children recognize a bigger picture than the immediate situation. They recognize the good things that their parent did for them.
- 7. All children experienced intense emotional responses to their parent's illness; even children who appeared to be doing well.
- 8. Children note a lack of opportunity for discussion of the mental illness of a parent.

These findings are presented in brief draft form indicative of the analysis at this time. The key points are indicators of the emergent categories the data suggests.

Significance of Preliminary Findings

There are several important implications related to the findings emerging from this study.

Implications for the Community

- 1. Ongoing efforts to decrease stigma about mental illness are needed.
- 2. Strategies to help families and children living in these circumstances require development.
- 3. Strategies to support families and children rather than remove the child from the home require consideration.
- 4. The community needs to develop ways to reach out to children in these circumstances.
- 5. Children need to be involved in healthy activities to offset some of their adverse circumstances.

Implications for Nursing

- `1. Ongoing education for nurses on family issues related to mental illness.
- 2. Increased awareness of the perceptions of children living with a parent with mental illness.
- 3. Proactive involvement with children and families in community and hospital settings.
- 4. Program development, acute and community, to help families and children in these circumstances.

Conclusion

There is increased recognition of the importance of including children in research studies. The inclusion of children in research will help develop knowledge around their experiences. This knowledge will potentially ground interventions for children to develop their optimal potential and to mitigate their adverse circumstances. Research endeavours such as this will help nurses best assist families and children who are living with mental illness. Innovative work has begun in Australia (Children of Parents Affected by a Mental Illness Scoping Project; March 2001, National Mental Health Strategy). The Center for Mental Health Services United States Department of Health and Human Services, Substance Abuse and Mental Health Services Administration (2001) in their paper Critical Issues for Parents with Mental Illness and their Families recommends inclusion of subjective experience in research as an important component of effective program development. Some sporadic programming exists in diverse areas of Canada to assist children and families. It is hoped that with continuing research in the area of children living with a parent with mental illness, that further interventions and policies will be developed in a consistent manner to assist families and children in these circumstances.

E. Mordoch, RN Ph D (c) January 15, 2004.