THE PSYCHOSOCIAL CONSEQUENCES OF SEVERE HEAD INJURY FROM THE PERSPECTIVE OF RELATIVES WHO CARE FOR HEAD-INJURED PERSONS IN THE COMMUNITY:

A CROSS-SECTIONAL CASE STUDY APPROACH

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ABSTRACT

The primary aim of this research was to gain insight into the "world" of carers of head-injured persons in the community, identify their major areas of stress, and explore support needs. A cross-sectional multiple case study design was chosen. The patient sample had all experienced severe to extremely severe head injuries. They were not interviewed. Semi-structured interviews were conducted with eleven carers of the head-injured persons, all but one being a relative of the patient. A verbally-administered questionnaire was used during the interviews to ensure that standardised questions were asked of all respondents. Many of the questionnaire items were closed, but others were partially or fully open-ended. The questions addressed: historical information, changes in the patient, changes in overall life-style, changes in relationships, carers' personal and practical support needs, and their perceptions of the future. A single quantitative analogue rating scale was used to measure levels of respondents' reported distress. Respondents were encouraged to provide comments freely during the interviews. The obtained data was systematically presented in the form of group frequencies and occasional measures of central tendency. This data was supplemented by eleven individual case studies. The main patterns and themes were apparent in the grouped data, but the individual case studies permitted examination of both common and unique responses within a "real life" context. There was thus across-study and within-study investigation. The approach to the research was exploratory and descriptive. No hypotheses were held but some expectations were indicated in the existing literature. The present study found similarities with previous research in that psychosocial changes in the patient were reported more frequently by carers than broadly physical changes, reported stress levels were generally high, and there were complaints by respondents about lack of head injury information, and lack of family counselling. The most notable differences were that respondents in this study considered that (in terms of reported frequencies) communication, conversation and interactional changes in the patients, together with patients' social restrictions/isolation, were the most distressing changes for the carers. A major area of reported distress by respondents in this study related to insensitivity by others towards the patient. However, a number of positive, optimistic comments were made by respondents. Practical support needs were generally met, as were personal support needs in the form of confidantes and friends. The methodological limitations of the present study were discussed, and theoretical and practical implications examined. Suggestions were made for further research.

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CHAPTER 1

INTRODUCTION

Carers of head-injured persons in the community deserve special recognition. Their role is one which has usually been thrust upon them, and for which they receive little or no training. Living with, and caring for, a severely head-injured family member can result in major disruptions to a previous life style and a high level of experienced stress.

The primary aim of the present study is to gain insight into the "world" of those caring for head-injured persons in the community, and to identify and explore both the carers' major areas of stress and their support needs. There are two secondary aims: the first of these is to examine the findings in the context of previous relevant research, and the second is to provide information which may be of assistance to agencies and professionals involved in rehabilitation fields.

There have been a great number of studies into the effects of head injury in terms of resultant patient deficits, especially those of neurological origin. In contrast, research into the psychosocial effects of head injury within the context of the family has received relatively much less attention. Although interest has been growing during the past decade, there is still a need for a great deal more research. This is indicated by the present relative absence of comprehensive models and unified theories.

The research carried out to date indicates that relatives of head-injured persons experience high levels of stress (Brooks et al, 1986; Livingston et al, 1985; Oddy et al, 1978a; Panting & Merry, 1972; Rosenbaum & Najenson, 1976). There is substantial evidence from these studies that the emotional and behavioural changes in the head-injured family member contribute in a major way to the carer's stress. However, the multi-dimensional nature and effects of other variables on a carer's stress have been less well researched (e.g. changes in roles and relationships, changes in life style, non-provision of personal and practical support, and so on). Identification and description of these variables is seen as a necessary pre-requisite to the formulation of hypotheses; in turn, these hypotheses form a basis for systematic applied research. Only minimal research has been carried out in New Zealand and this has focused on patients, although family difficulties have been noted (Blyth, 1981; Crawford, 1983).

It is not the intention of the present research, then, to test hypotheses but, rather, to collect data which will allow hypotheses to be generated. In presenting eleven individual case studies, supplemented by standardised data from a questionnaire administered to all respondents, it is seen that the descriptive data subsequently presented will have a depth and breadth often lacking in conventional quantitative designs. The present essentially qualitative approach permits the examination of both common group patterns, and individual or unique experiences. It does not subsume individual differences in group data. Identified group patterns, however, provide information which can be valuable in formulating rehabilitation policy with a holistic, family-oriented focus.

The present study's design is not a new or novel approach in the area of relevant research. Instead, it seeks to make a contribution which will enlarge existing findings. Similarities and differences in the present study's findings, relative to previous research, will serve to provide additional data in consideration of issues of overall validity and reliability in the general area of the research. The questionnaire used in the present research is derived from that used in earlier studies in Glasgow (Brooks & Aughton, 1979).

The present thesis contains eight chapters. Following on from this first chapter, chapter 2 will examine the literature as it relates to head injury per se. Chapter 3 continues the literature review by examining the family in relation to head injury; these two chapters are inter-related but each contains a change of focus, and together they provide an overall context within which the present study can be viewed. Chapter 4 discusses the aims and design of the present research. Chapter 5 describes the sample, and the material and procedures used in this study, while chapter 6 presents the results in two sections. Chapter 7 discusses the results of the present study. Chapter 8 summarises the findings, discusses the methodological limitations of the present study, examines its theoretical and practical implications, and makes suggestions for further research.