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CONDITIONAL EXPERTISE
IN
CHRONIC ILLNESS

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Abstract

The incidence of chronic illness is increasing in the developed world. This means that there is an increased utilisation of acute health care services by people with chronic illnesses, either for treatment of exacerbations or for unrelated health problems. Acute health care services are based on the notion of finite, curable episodes of ill-health, and as such they do not always meet the needs of people with chronic illnesses.

This study uses a grounded theory approach to examine the issues surrounding hospitalisation in acute care facilities for a group of eight people with chronic illness. Participants were interviewed within two months of an admission to hospital. Analysis of data, further interviews and other data collection, and generation of theoretical concepts were performed in accordance with the grounded theory method.

The key finding from the research was a state of conditional expertise for the chronically ill. While living at home, and in a state of relative well-being, participants were acting as experts in the management of their illnesses. During encounters with health providers in the primary care setting, particularly those whom participants knew, a process of negotiation occurred, engendered by mutual trust in each other's expertise. However, once the acute care setting was entered, participants discovered that their expertise was neither valued nor acknowledged. In response, they went through the processes of informing health carers, by repeatedly telling their stories to different health professionals they encountered, and finally withdrawing from participation in care. This withdrawal could be either physical, where the participants sought early discharge, or emotional in terms of becoming passive recipients of care.

The implications of this study, given its limitations, are numerous. In order to provide satisfactory care for people with chronic illnesses, health professionals working in acute care settings must move beyond the dominant model and seek to establish trust relationships which acknowledge and value patient expertise. This requires, first, that education programmes for health carers encourage the recognition of important data about patients that do not relate to biological and disease states. Second, a system of care needs to be developed within the acute care setting that allows ongoing relationships to be established between individual patients and carers. This in turn would generate trust between patient and carer, which would enhance the abilities of each to acknowledge expertise. The Partnership model of nursing care is proposed as a possible solution to this problem.

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Table of Contents

Abstract	ii
Acknowledgements.....	iv
Table of Contents	v
Chapter One – Introduction	6
Chapter Two – Review of the Literature	9
Chapter Three – The Research Approach	26
Chapter Four – The Research Outcome: Part I.....	39
Chapter Five – The Research Outcome: Part II	46
Chapter Six – Discussion and Conclusion	60
Appendix I	71
Appendix II.....	73
Appendix III	77
Appendix IV.....	80
References.....	82