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**IGNITING THE DIABETES SELF-CARE PILOT LIGHT:
UNDERSTANDING INFLUENCES
ON HEALTH ACTIVATION**

A thesis presented in fulfillment of the requirements for the degree of
Doctor of Philosophy

**MASSEY UNIVERSITY
PALMERSTON NORTH
NEW ZEALAND.**

HELEN JULIA SNELL

2011

Acknowledgements

I have been fortunate to have been supported by many people throughout the course of this study and thesis writing. I am greatly appreciative to all of them for putting up with me and for offering encouragement and inspiration. I am especially grateful to the participants in this study who so generously shared their experiences and perceptions in the hope that what they expressed may help others.

Thank you to my three supervisors, Professor Jenny Carryer, Associate Professor Tim Kenealy and Dr. Stephen Neville who so freely offered their expertise and wisdom throughout my course of study. All had complementary skills and qualities which were so readily shared throughout the different stages of the research. As primary supervisor, Professor Jenny Carryer provided exceptional scholarly guidance and unfailing encouragement. Associate Professor Tim Kenealy provided excellent guidance in planning and executing the study, in particular expert advice on statistical testing and reporting. Dr. Stephen Neville provided sound guidance, critique and critical challenge throughout the research and writing processes. I must also acknowledge the Eli Lilly Research scholarship and a grant from NZNO which provided me with the ability to fund aspects of this research.

Thank you to my colleagues and friends at MidCentral Health who contributed support, advice and time. In particular Victoria Perry who kept me focused in amongst the competing demands of my full time employment, local and national professional commitments and doctoral studies; and Sue Wood, Director of Nursing whose brilliance and leadership inspires me to be the best I can be. I am especially grateful to my husband Gary who has endured being second place while sustaining me with a ready supply of love, cups of tea and chocolate. My mother and sisters have all offered unfailing encouragement and nurturing which kept me on track.

Approval to conduct the study was obtained from the Central Region Ethics Committee and Massey University Human Ethics Committee prior to commencing the study (CEN/07/06/036).

Abstract

Diabetes presents a serious health challenge for New Zealand because it is a significant cause of ill health and premature death. It is well recognised that self-care in diabetes, can be demanding and is influenced by numerous factors. Health activation is a composite notion focusing on four major elements believed to influence active engagement in self-care: these are beliefs, knowledge, skills and confidence, and behaviours. In this study I set out to elicit an understanding of influences on diabetes-related health activation in general, and specifically to provide explanations for how diabetes-related distress and/or health professional communication and decision-making styles impact on health activation. An additional aim was to generate new ideas on how diabetes care can be structured to maximise personal resourcefulness and promote health activation.

Mixed methods methodology allowed for a pragmatically structured research approach. In particular the use of both quantitative and qualitative methods ensured that participants' perceptions were comprehensively explored. Two hundred and twenty participants completed a semi-structured questionnaire and eighteen participated in a subsequent interview.

Health activation was found to be dynamic and influenced by many factors. Diabetes-related distress and health professional communication and decision-making styles explored in this study were important contributors to health activation. This information has complemented and expanded knowledge of these constructs and has extended understanding on relationships between them. In particular it has generated knowledge about health activation, diabetes-related distress and health professional communication and decision-making styles specific to the New Zealand context.

Preface

My interest in influences on diabetes-related health activation grew from considering how I, as a nurse, help a person with diabetes to live and care for their diabetes in a way that is not overwhelming, is constructive, and contributes towards positive health outcomes. Some people with diabetes seem able to accommodate the changes to their lifestyle without any disruption to their lives or to those around them, while others live with a constant struggle.

Diabetes is a pathologically complex long term condition, where people with diabetes are burdened with the responsibility for providing the majority of care to manage their condition, and the demands of this can be overwhelming. Juxtaposed with this is the requirement for the contribution of the multidisciplinary team “as co-morbidities interact to produce a complex and challenging clinical dynamic” (Grumbach, 2003, p. 5). No one discipline alone can meet the health needs of people with diabetes. Nurses, doctors, dietitians, podiatrists, obstetricians, paediatricians, psychologists, and others all have a role to play. However, this can create difficulties for the person with diabetes who may be seeing multiple health professionals in a variety of settings.

Over the past 20 odd years I have met and been engaged in therapeutic partnerships with many people with diabetes. I have repeatedly observed people who have had diabetes for many years who have not previously been active participants in their care, suddenly become more active, more interested and focused on improving their situation. Each time I have been unable to determine what has contributed to this change in focus, or more importantly perhaps, what has stopped it from happening before. Those who have been aware of the change in focus have articulated that ‘something’ changed and they ‘woke up’ to the need to be more actively engaged in self-care. A variety of responses have been offered when I have asked, as part of a routine clinical consultation, what precipitated their change? For some it was the diagnosis of a non reversible diabetes related complication; for others it was a similar diagnosis in someone else; some described struggling emotionally with the requirement of the daily self-care demands; and others expressed that

they had seen a different doctor or nurse with whom they ‘clicked’ and it was the way they interacted with them that had made the difference.

Reflecting on these responses led me to consider the ways in which care is provided for people with long term conditions, in particular diabetes and, the vast number of health professionals and ‘helpful others’ encountered by people with diabetes on their health seeking journey. Over the years I have formed impressions about what the focus for the person with diabetes may be when interacting with various health professionals. For the person with diabetes it may not necessarily be on ‘fixing something’, but rather: ‘how can I keep doing what I need to do?’; or ‘what is an approach to this that will help me to sustain my efforts?’; or ‘talk to me in a way that I understand and that respects me?’; or ‘share information with me that my family and I can understand and use in my daily decision-making about how to best care for myself’; or ‘acknowledge that I am a person with life issues and that these issues may be greater than my concerns about my diabetes that doesn’t actually bother me day to day’.

On the other hand, I am acutely aware that health professionals are faced with the challenge of determining what might assist the person with diabetes to effectively self-care in the midst of conducting their assessment, making diagnoses, care planning and evaluating care/treatment effectiveness - all within the limits of consultation timeframes.

As health professionals have limited opportunities to spend any length of time with a person with diabetes, consideration for that person’s world view, their specific beliefs and circumstances influencing their life choices is imperative to make the time effective. Nursing espouses holism - but is it practised? And if it is, does it make a difference to how actively engaged a person is with their diabetes self-care?

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