'*What is going to happen to me now*?' Systemic uncertainty and complexity between hospital and home for older people, people with disability, carers and service providers

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September 2009

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ABSTRACT

The focus of this thesis is on the impact that a hospital admission can have on the continuing ability of Home and Community Care[1] (HACC) clients (older people and people with disability) to remain living in their home. Of concern to HACC service providers were their clients' readmissions to hospital and/or unnecessary institutionalisation after hospitalisation. Both events were considered poor outcomes by HACC service providers. The desire to improve these poor outcomes and to alleviate discontinuous care led the HACC program to fund a project in Adelaide, which I undertook as action research.

In this thesis I investigated how poor outcomes could be avoided and continuity of care improved in the South Australian hospital and HACC systems. A literature review revealed that population ageing, the demand and resource pressures on acute hospitals and community services and the paucity of discharge planning were factors leading to discontinuity of care of older people and people with disability, as well as impacting on their carers. Theoretical perspectives first look at the divisions between the biomedical and social models of health, as well as the critiques of medical care and the role of bureaucracy put forward by iatrogenesis and medicalisation. Next, the theoretical lens turns to the lives of people, where the centrality of 'care' and interdependence are considered, along with the need to improve our understanding of the nature of vulnerability and the importance of resilience to moving beyond the dominant 'problem-based' discourse of ageing and disability.

Processes in the action research included two cyclical phases of making plans, embarking on actions and observing the results of the actions. Methods for collecting data included surveys (n=16 older patients and 10 carers), an evaluation (n=28), face-to-face interviews (n=52), one focus group (n=8), three Reference Groups (n=46), a workshop (n=14) and a nominal group (n=14). The interviews and surveys provided the opportunity to analyse the admission, hospitalisation and discharge issues for HACC clients and their carers from the perspectives of hospital nurses (n=19) and 33 community care providers. The latter participants were clinicians and case managers from domiciliary care[2] (n=23) and community nurses[3] (n=10). These interviews were analysed thematically.

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[1] The HACC program, funded jointly by the Australian, State and Territory governments, targets community-dwelling frail aged people, people with disability, and their carers, who in the absence of basic maintenance and support services are at risk of premature or inappropriate long-term residential care.

[2] Domiciliary care services are provided to older people (aged 65 years and over) and younger people with disability whose ability to care for themselves is reduced. Domiciliary care assists them to stay living in their own homes, by providing physical assistance, rehabilitation and personal care, as well as respite and support for carers. By promoting independence and improving quality of life for clients, domiciliary care services aim to prevent unnecessary admission into hospital or residential care.

3 Community nursing services provide community based health and care services, including rehabilitation, therapy and nursing care.

Results from the action research project yielded valuable research insights and successful actions which were reflexively planned, implemented and evaluated. The actions increased local linkages between the hospital and community service providers, collaboration, communication and access to information about the HACC program. Despite this, the action research project appeared to have little or no direct effect on avoiding poor outcomes or improving discontinuity of care. Such effects were more complex and beyond the scope of a project of this size. Achieving the necessary systems and structural changes to address these problems would have required more time, resources, capacity and leadership to be committed by government departments and the agencies.

The descriptive statistics of surveys with patients and carers and the key issues identified by the Reference Group supported triangulation of the interviews with domiciliary, community nursing and hospital participants. Findings from the interviews with domiciliary, community nursing and hospital participants point to uncertainty and complexity before, during and after hospitalisation of older people, people with disability, their carer/family, and also for service providers. Before admission to hospital there are four ‘dimensions of uncertainty’, and during hospitalisation, there were four categories which contributed to ‘complexity in discharge planning’. When leaving hospital, ‘adjustment and adaptation’ highlights individual patients’ and carer/families’ adjustments. In addition, it points to the need/potential for service adaptation to support people’s ability to return home. Putting these dimensions together, the main themes to emerge in this context are ‘systemic uncertainty and complexity’. In building upon these themes, I have developed a model of systemic uncertainty and complexity before, during and after hospital. Given this new knowledge about the context of uncertainty and complexity on the one hand, and adjustment and adaptation on the other, I conclude by considering the implications of these understandings for theory, policy and practice.

DECLARATION

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution to Rosie King and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis, when deposited in the University Library, being made available for loan and photocopying, subject to the provisions of the Copyright Act 1968.

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Rosie King
September 2009

ACKNOWLEDGEMENTS

I have experienced many inspiring, humbling and transforming moments on the long and winding road of this thesis. These moments have reminded me of one of the ideas I discuss at a conceptual level in this thesis, and have been reminded about experientially many times since I began. I refer to our interdependence on others for all kinds of physical, emotional and intellectual nurture. I think about my thesis and interdependence with others as the village that helped raise this thesis, the many fellow travellers who have walked along beside me and helped me to cross the rocky and unpredictable terrain towards completion. This is my expression of gratitude to you.

I dedicate this thesis to my father and mother. Dad, without knowing you always managed to 'keep it real' and in the last months of your life when I had only just began this project, your experiences galvanised me into believing that this real-world topic was important enough to stick it out. Mum, for being 'the carer' that I know you are and for looking after dad in his time of greatest need. This is for you both, Billy and Val.

At the closest level of support, I give thanks to my partner Peter, and children, Lucy and Carlo. I express my gratitude to each of you for your belief in me and your encouragement, for reminding me that 'yes, you can!' Peter, your love and endurance over the long haul has been invaluable. Lucy and Carlo, you are my treasures. Thank you for giving me the luxury of having my own home-made cheer squad.

An individual thanks goes to my supervisors, John Moss and Dr Anne Hamilton-Bruce. John, my thanks to you for keeping me on the path, for running up ahead with the wisdom of your experience, for inspiring me, making me laugh with your dry sense of humour and for making me push my boundaries. Anne, your encouragement and commitment has been invaluable.

Thank you to all the participants who so generously contributed to and collaborated in this research. In particular, the patients, carers and nurses at the hospital, practitioners at the domiciliary and the community nursing service, and to all the other community service providers in the specified region of Adelaide. You gave flesh and bones to the story of this thesis. A special mention goes to the Hospital hOme Pathways Steering Committee members and Jennifer Fischer for your support.

Others who gave their time, knowledge, expertise and thoughts include: Associate Professor Annette Braunack-Mayer, for your helpful 'can do' problem-solving (a cherished attribute), the University of

Adelaide and Discipline of Public Health for providing this opportunity, Dr Afzal Mahmood for your early contribution, Dick Leeson and Kristyn Willson for your statistical support.

I also acknowledge Dr Bill Winser, who edited this thesis, according to ASEP Standards: 'Language and Illustrations' and 'Completeness and Consistency'.

Last but not least among the village that helped raise this thesis, I'd like to acknowledge all my fellow students from the School of Population Health and Clinical Practice. Thank you to those who finished the marathon ahead and passed on the 'inspiration' baton to me (especially Emma, Pip, Jo and Tessa), and to those who I throw it to now, I can see that finishing line just up ahead (Kelly, Emily, Alana and Susan).

ABBREVIATIONS

ABS:	Australian Bureau of Statistics
ACAT(s):	Aged Care Assessment Team(s)
ACCT:	Australian Coordinated Care Trials
AIHW:	Australian Institute of Health and Welfare
ADL:	activities of daily living
ACC:	Ageing and Community Care
ATSI:	Aboriginal and Torres Strait Islander
CASA:	Carers’ Association of South Australia
CALD:	culturally and linguistically diverse
CCC:	Commonwealth Carelink Centres
CEO:	Chief Executive Officer
CIK:	Carers’ Info Kit
CNM:	Clinical Nurse Manager

CSP(s):	Community Service Provider(s)
CSTDA:	Commonwealth State Disability Agreement
DHS:	Department of Human Services
DoHA:	Department of Health and Ageing
GP(s):	General Practitioner(s)
HACC:	Home and Community Care Program
HOP:	Hospital hOme Pathways
HREOC:	Human Rights and Equal Opportunities Commission
IADL:	instrumental activities of daily living
ICF:	International Classification of Functioning, Disability and Health
LGA:	Local Government Areas
LGCSAA:	Local Government Community Services Association of Australia
LOS:	length of stay
MDS:	Minimum Data Set

NESB:	non-English speaking background
NGO(s):	non-government organisation
NOA:	Notification of Admission
OECD	Organisation for Economic Co-operation and Development
RAC:	Residential Aged Care
RCT:	randomised control trial
RMO(s):	Resident Medical Officer(s)
RN:	Registered Nurse
RW:	Recommendations Workshop
SA:	South Australia
SCRGSP:	Steering Committee for the Report on Government Services
UK:	United Kingdom
UN:	United Nations
USA:	United States of America

UNESCAP:	United Nations Economic and Social Commission for Asia and the Pacific
YHR:	Your Health Record
WHO:	World Health Organisation