

The Age of Supported Independence

Beatrice Hale · Patrick Barrett · Robin Gauld

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Voices of In-home Care

 Springer

Dr. Beatrice Hale
c/o University of Otago
Dept. Preventive & Social
Medicine
Dunedin
New Zealand
bahale@xtra.co.nz

Dr. Patrick Barrett
University of Waikato
Dept. Political Science &
Public Policy
Hamilton
New Zealand
pbarrett@waikato.ac.nz

Dr. Robin Gauld
University of Otago
Dept. Preventive & Social
Medicine
Dunedin
New Zealand
robin.gauld@otago.ac.nz

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Preface

This book is dedicated to people like Mr Perry whose anguish over his disabilities was such that he contemplated suicide; and Mrs Martin who laughed and cried as she recounted the experiences of receiving and recovering from a double amputation; of Mrs Jackson whose intelligence and vigour had led her to prominence in the community and who was desolate in her later years to find her experiences and knowledge dismissed by agencies and their care workers.

Family carers too have their own tales: of the tensions between caring for a parent while wanting to be with grandchildren; of Mrs Lee's problem of caring for a sick and demanding husband while others helped care for her own terminal cancer; of Mrs Barton's anguish of watching others care for her husband and getting it wrong. She sobbed in the Carers Circle that 'they won't listen to me, and he can't see to eat, and they don't feed him, and I have to go in to the ward and feed him.' Her husband's carers were unable to understand too that Mr Barton couldn't unwrap the sandwiches on his plate let alone see to eat them—and they reported him as 'not being hungry.'¹

In this book we contest how society thinks about older people, especially those with frailties and vulnerabilities. Instead of the homogeneity, expressed as 'the elderly', which normally describes those of 65 and over, we offer a perspective of transition, of changes and differences in status and identity, as we focus on older people as they become more frail and vulnerable and move into increasing dependence.

The Age of Supported Independence offers a detailed view of significant changes experienced by older people and their families, as they face the frailties and disabilities which require formal care to remain at home. 'Challenging' is the best description of these later years, for older people, for the services they require to remain at home safely, and for their families to continue caring.

Remaining at home with care confronts the ideals of stability and continuity of both home and care, by challenging the identities of older people who face disruptions to their agency and autonomy in these later years. These senior citizens also

¹ These instances are from Hale's work and writing (2000, 2006).

experience challenges to their feelings about their homes, their bodies, their relationships with family and friends, and their relationships with formal providers of health and care. To examine the changes which, to repeat, ‘challenge’ older people and their families, we use a secularised version of the classical rites of passage model. Ours is the first book to apply this concept fully, despite its being considered of use by many social gerontologists. The concept’s value lies, in the first place, in its holistic focus on transition and its grouping of spatial, temporal and relational changes which accompany the passage from independence to increasing dependence. Subsequently, the value lies in emphasizing a third stage, of ‘reconnection’, leading us to consider the situation of frail older people in terms of the wider society.

This concept of rites of passage has a further value in that it helps us identify a specific population who share a culture of ageing with disabilities at home and with care. We suggest these experiences lead to a distinct late-life stage, different from independence and from greater dependence. We describe this stage as one of ‘supported independence’ where remaining at home is intended to provide continuity and stability, but where living and coping with disabilities and receiving care presents a major disruption of this apparent stability.

Our conclusions recognise the critical necessity for considering how best to support, enable, or empower older people to maintain agency and autonomy. This, then, is the third stage suggested by the rites of passage model, of reconnection to the wider society, or perhaps, in our terms, maintaining interests and valued roles, and assuming a status of a valued identity in our society. We emphasise the role of in-home care work here, and offer other ideas to assist in fulfilling the wish of New Zealand and other governments to age-in-place successfully.

This perspective has emerged through the work and research of the authors in the field of ageing and health, and care at home. Beatrice Hale worked in the field of community development, with older people as a social worker, and as a volunteer coordinator, before completing her doctorate on ageing and home care. Patrick Barrett writes in his capacity as lecturer and researcher in health and policy issues, and has recently spent time at Aristotle University of Thessaloniki in Greece where he lectured on New Zealand social policy. Health policy specialist, Robin Gauld, who currently holds a Harkness Fellowship in America, studying American health and care systems, writes from his wide knowledge of New Zealand and American health issues.

The authors would like to acknowledge the help and support they received from their families, friends and colleagues. We owe special thanks to Andrew Parsloe for his meticulous work on the index.

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Introduction: Stake in the Ground

We invite you to explore with us the conception of a new social category within the once considered homogeneous group, ‘older people’. We invite you to reflect on the situation of those older people who experience disability and who receive care and support at home. Such individuals sit between the full independence of the Third Age, those also described as the young old, and the dependence which necessitates institutional care.

With an increasingly ageing population there are growing numbers of older people with later onset disabilities who choose, or are encouraged, to remain at home, with care. These are revealed in new demographic categories in a number of countries, prompting the reflection that here we have a new social group, identified as a specific category by social statisticians.

There is, however, a danger in reducing vulnerable people to mere statistics in the demographic classification process, and in ignoring their lived experiences. There is also a serious risk in assuming that the reality of these lived experiences is derived from and maintained by the twin ideals of home and care.

The ideals of home and care evoke notions of warmth, familiarity, continuity and stability. Such an ideal permeates the ageing in place philosophy but as Twigg (2000) and Dalley (2002), among others, observe, the privacy of the home obscures many different situations. What takes place behind closed doors can be lonely, isolating, abusive, violent, and far from the ideal notions permeating ageing in place. The unspoken belief in remaining at home is that it is *the* place where the provision of support and care will best ensure wellbeing, comfort and safety. Thus, the assumption is that the cared-for individuals will continue to remain safely and comfortably in the familiar home environment to continue with their lives as they wish.

Our exploration of this time of life shows a somewhat different picture, one which reveals considerable challenges associated with the experience of advancing into receiving in-home care. Such a progression produces a series of not only physical, but also social and emotional disruptions, and not only for the older individual. Family members who become carers also experience their own significant disruptions as they move deeper into a caring role.

Given the number of people moving into in-home care, and the unique but shared experience of doing so, we suggest that this period of time be known as The Age

of Supported Independence, a title which groups together those individuals with experiences in common, but also highlights the apparent contradiction in requiring help to be independent. Older people who experience the slow or sudden onset of disabilities find themselves moving from independence, caring for themselves and others, to a situation where they are dependent on help at home, but supposedly sufficiently independent to maintain other activities and interests.

For family members, this passage of a spouse or parent into increasing dependence is often accompanied by a now well-recognized transition to a new role of carer (Hirst, 2004). For the older person, many late-life transitions, such as retirement, bereavement, or a move into residential care, have long been recognized, often through formalised social events. However, this transition at home is only now beginning to be understood as another significant late-life stage (Bury, 1995; Efrainsson, Hoglund, & Sandman, 2001; Hallman, 1999; Kingston, 2000; Barrett, Kletchko, Twitchin, Ryan, & Fowler, 2005; Hale, 2006). Nevertheless, it lacks wide recognition as an important development.

Analysing the move to increasing dependence reveals the real nature of the disruptions involved: the need to adjust to living with an age-related disability, change in the daily patterns of living, the disruption of family and social relationships, and challenges to self-identity. Becoming a recipient of services in the home often encourages passivity, even when the goal is independence. With our practitioner gaze, we see such disruptions as amenable to informed interventions. For example, passivity and acceptance, or struggle and resistance, may mean an intervention to assist in regaining or maintaining autonomy is appropriate. This, of course, leads to questions about the relationship between autonomy and independence, something which will be discussed in more detail in the chapters. Such questions include: what is the independence in the phrase 'supporting independence'? What does independence mean in this context? Is it synonymous with autonomy, and if not, what is the distinction between independence and autonomy, and how important is this in older age?

As Laslett (1996) observed, our world has never before experienced this increasingly ageing population with increasing numbers of older people. Members of the current generation of older people receiving formal in-home care have no models on which to base their actions. Their experiences are themselves the models for future generations. In the past, where there were needs, these were usually met by informal family care (although Laslett's (1996) research shows that this was less so than we have always believed), with minimal formal home care and institutional responses including residential care and hospital care. Now family care is supplemented with in-home care, and often day care and respite care, and for the family carers, time out in the form of carer support breaks.

Families themselves are changing. Families today are more mobile and geographically dispersed, more likely to experience spousal separation and family reconstitution, and women are more likely to be in paid employment, usually outside of the home. For many, this means that they are unable to care for older members. Such changes contribute to the need for more formal home support for older people.

In our minds, these changes suggest that this cohort of older people is a ‘threshold’ generation, who, given broader changes in the economy, society and family, are experiencing for the first time the provision of formal home care provided on such a large scale. Members of this generation stand between the arrangements that involved predominantly informal care and those involving institutional care, due in part to their level of need, often greater than the families can manage, and their wishes to remain at home, now able to be fulfilled due to the current arrangements of formal paid care.

Our Approach

To clarify this process, and to emphasize that there is such a group, we have drawn a line round this particular set of experiences, and concentrate on the changes and experiences specific to this situation. Our goal is to examine these changes and experiences in greater depth. Our initial observations of the experiences of older people undergoing these changes suggested patterns of events similar to those of a secular rite of passage. We therefore draw on the rites of passage notion and use it in this secular situation, as Turner (1974) suggested, as a means of providing ‘flashes of insight’ to illuminate the personal and social dimensions of these experiences.

Van Gennep’s (1909) tripartite rites of passage concept depicts key life stage transitions as constituting three distinct processes. The first of these is a separation from the current stage through some type of disjunctive experience. The second is a stage of liminality, an ‘in-between’ stage characterised by an unsettled social status and identity. The third involves reincorporation and reconnection with the wider society, with ‘a new set of rules, roles and obligations’ (Hockey & James, 2003, p. 25). Focusing on these broad processes has potential, we suggest, to highlight this little-explored period of ageing and provide a fresh understanding of the experience of transition. By following this period of ageing from the onset of frailty, through assessment to acceptance of care and thence to a question of ‘reconnections’, we have a closer view of some of the key dynamics of the transitions within the home from independence to increasing dependence.

We position this work alongside examinations of ageing, structured dependency, and agency. Our concern is with not only locating the experience of the individual within structural contexts that disempower and isolate, but also with challenging those contexts with the specific aim of empowerment and promoting greater inclusion of older people in decisions that affect them (Achenbaum, 1978; Moody, 1988; Minkler, 1996; Phillipson & Walker, 1986). Like Polivka and Longino (2004), we aim to achieve a synthesis that gives

equal weight to ensuring the economic security of the elderly and creating more flexible self-empowerment-oriented policies that reflect the freedom and individual autonomy (p. 5).