# 'Once I became a pensioner I became a nobody – a non-entity': The story of one woman's experience of the health care system

### MOIRA GREAVES AND CATH ROGERS-CLARK

University of Southern Queensland, Toowoomba, QLD, Australia

### ABSTRACT

This article highlights one socially isolated older person's experiences of ageing in a large metropolitan Australian location and the problems she encounters in attempting to access appropriate and timely health care. As society moves into a phase of rapid demographic ageing, this personal account provides health professionals with an in-depth insight in to what it can be like to live in social isolation as one ages and needs ever increasing health care. Win is part of a larger study investigating difficulties encountered by socially isolated older people in accessing health care needs, and preferred her real name to be used for this article. All other names used are fictitious to preserve anonymity.

KEYWORDS: invisible; pensioner; non-entity; ageing; social isolation; health care

### BACKGROUND

There definitions and are numerous conceptualisations of social isolation with most identifying socially isolated individuals as rarely or never spending time in the company of friends, associates or other people in social groups (Cattan, White, Bond, & Learmouth, 2005; Findlay, 2003). Social isolation has been consistently identified as a significant factor in the development of negative health outcomes (Dugan & Kivett, 1994; Findlay, 2003; Findlay & Cartwright, 2002; Hensher, 2006; Machielse, 2006; Wenger, Davies, Shahtahmasebi, & Scott, 1995) and while a number of issues play a role in the development of social isolation of older people, illness and disability appear to be the most common among risk factors (Grundy, 2006; Murray, 2001; Schröder-Butterfill & Marianti, 2006; Tanner, 2003, 2007).

#### FRAMING THE CASE STUDY

Social isolation is a significant component of the lives of many older people, particularly those aged 75 years and older who are living independently within the Australian community. While the impact of social isolation is dependent on a diversity of socioeconomic, personally adaptive, cultural and health influences, descriptions of 'isolation' often vary. Several researchers (Copeland, 2002; Greaves & Farbus, 2006; Mann, 2000; Victor, Bowling, Bond, & Scambler, 2003) have postulated that social isolation occurs in the absence of meaningful and sustained relationships with significant others or when a person experiences minimal levels of social participation and *perceived* inadequate social interactions. Yet others (Cattan et al., 2005; Findlay, 2003) argue that social isolation, particularly of

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older people, remains a complex phenomenon involving psychosocial, physiological, economic, demographic, cultural and religious or spiritual aspects of a person's life. A review of the related literature revealed substantial consideration of the phenomenon of social isolation and its causative and contributory factors (Cattan et al., 2005; Findlay, 2003; Machielse, 2006; Russell & Schofield, 1999; Victor et al., 2003). These factors included but were not limited to; long term illness, age related disabilities, chronic pain, recent bereavement, geographical isolation, relocation, living alone, decreased social and family networks and financial losses related to retirement and loss of income.

Theoretical perspectives on social isolation in older people have evolved over time (Ebersole, Hess, & Schmidt Luggen, 2003) and include disengagement, activity, continuity and gerotranscendence theories; which were developed in response to varying degrees of withdrawal by older people from mainstream society. Disengagement theory, proposed by Cumming and Henry (1961) argued that withdrawal or 'disengagement' was a natural and unavoidable occurrence of ageing. Latter researchers (Berkman, 1995; Dugan & Kivett, 1994; Payton Fay, 2004) largely debunked this theory asserting that disengagement is often precipitated by life changes that make it difficult for people to remain active within a social context which often led to social isolation. While Cumming and Henry (1961) proposed disengagement theory, Havighurst (1961) formalised activity theory suggesting that people who maintained participatory activity levels and social networks were less likely to withdraw from social contacts or become lonely. However, critical debate ensued as activity theory did not differentiate between types of activity assuming that any activity could substitute for significant losses of social involvement. Havighurst subsequently proposed continuity theory in 1968 in response to discussion surrounding activity and disengagement. This theory symbolized a more formal clarification by exemplifying a life course perspective to delineate typical ageing. Atchley (1989) further expanded continuity theory emphasising the significance of personality and highlighting the relationship between past, present and future; and why continuity of ideologies and lifestyles were central to processes for coping with the inevitable changes that ageing brings. While some withdrawal may be seen, essential aspects of personality and activities undertaken in younger years were observed to be maintained (Atchley & Barusch, 2004). Amidst the evolution of such theories, gerotranscendence theory (Tornstam, 1996, 1999) was offered as an explanation for selective withdrawal from societal obligations. Its premise was based on ageing from a positive perspective and does not imply withdrawal or disengagement but rather describes a developmental pattern beyond the dualism of activity and disengagement theories. Tornstam argued that although the older individual becomes less occupied, they are more selective in their choices of social activities. In addition there may be a decrease in interest in materialism, an increase in solitary meditation (positive solitude) and decreased interest in superficial social interaction.

Averting further development of, and alleviating social isolation and loneliness among older people has been the topic of much research (Cattan et al., 2005; Findlay & Cartwright, 2002), particularly over the last decade with policy makers attempting to ameliorate these ongoing and pervasive phenomena by developing community based interventional programs. However, concern continues regarding the efficacy of these programs (Bartlett, 2003; Cattan et al., 2005; Findlay, 2003; Sabir et al., 2009), as reported incidences of social isolation and its sequelae continue to be problematic for health care providers and policy makers.

# METHOD AND SETTING OF THE WIDER RESEARCH

Win's story was sought as part of a larger longitudinal study to explore the experiences of socially isolated, frail older people in accessing and navigating the health care system. This research was conceived as a result of the principal author's experiences as a Practice Nurse coordinating care for ageing people.

In this project, six participants, aged from 78 to 88 years, were recruited from a medical practice in a Brisbane suburb. Inclusion criteria were: age 75 years or over, married or single, male or female with social networks comprising two or less individuals and limited meaningful contact per week. Three interviews length ranging from 45 min to one and a half hours with each participant were conducted over a 2-year period. Ethics clearance was obtained from the University of Southern Queensland before this research began. Throughout we were conscious of and observed the Principles of Ethical Conduct as set out by the NHMRC National Statement reflecting 'basic values of integrity, respect for persons, beneficence and justice' http://www7.health.gov.au/ nhmrc/publications. Written informed consent was obtained from all participants. All participants were contacted by telephone after the initial interviews to discuss acceptance of pseudonyms from their narratives. All declined confidentiality expressing a unanimous preference for their real first names to be used throughout the research study to maintain ownership of their stories and therefore, their identity:

Once you're past 65 you're invisible. Don't rock the boat, keep out of the way, don't ask for anything, just be invisible, that's all they want, that's all they want. Well I don't want to be invisible. You can use my name, it's my life, it's happening to me and I'm still here. If you use someone else's name or no name at all then – who am I? (Win 86 years: 1st Interview)

A grounded theory approach (Glaser, 1992; Glaser & Holton, 2004) was adopted to analyse data in the wider study. Participant interviews were transcribed and each line of text numbered followed by sequential line coding. Multiple readings of each line detected significant and commonly used descriptive words which were circled, underlined or highlighted. This resulted in the identification of interrelated categories and sub-categories which were grouped into major themes surrounding the main core category. The participants' access and progress within the health care system were observed and documented over a 2-year period.

### A CASE STUDY OF ONE

Focusing on one person's story provides a rare opportunity to isolate one voice and lived experience. Win is chosen both because of the striking clarity in her description of the escalating frustration in negotiating the health care system and its emphasis on the dilemmas associated with accessing information and timely appropriate help.

# Win's adversarial relationship with ageing

Win is an 86-year-old fiercely independent woman who survived World War II and reported a lengthy marriage marred by domestic violence. She has not had contact with her seven children for many years. Despite significant health problems and gradual deterioration of health she continues her work as a volunteer making numerous craft items for the Cancer Fund. Win disclosed her happiest and saddest times of life but discussed, with obvious anger, her attempts at obtaining appropriate and timely health care in recent years. The culmination of three interviews spanning 2006-2008 resulted in closely similar descriptions of experiences in attempting to access timely and appropriate health care. While Win's responses were largely negative, comments by several other participants in the larger study group were comparable to Win's personal encounters with the health system.

Win believes that she has been a victim of ageism, and her anger seems to be overwhelming. She makes particular reference to young people being more important than older people 'the old don't matter – only the young matter'. Her belief

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in this stems from her perception of years of being treated unjustly:

People don't treat me like a female, like a human being. They treat me like a something that hasn't got a brain. They don't treat you like a human being and you are a human being and you feel more when you get older. You are invisible.

Win's dialogue clearly reveals her bitterness and anger as she frequently uses the words 'pensioner' in self derogatory terms. This term has taken on significant negative meaning for Win and now influences her daily activities and interactions with others. Once labelled and categorised as 'pensioner' in this way Win shares complicity with the ideological definition of herself and the creation of the binary young and visible/old and invisible:

You feel more when you get older because you know jolly well that when you say 'Oh, I'm a pensioner', oh that's it, you know, you're a pensioner, you're nothing, you're lower than the lowest. I mean you could crawl under a bloody snake with a top hat on ...You're angry because you know jolly well that you can't do anything. You can talk and you can talk but you might as well go and talk until your bloody head falls off. You don't get anywhere.

She is now reluctant to tell anyone her age and avoids revealing that she is a 'pensioner' wherever possible. Win also reported several cases of being ignored when she sought medical advice for health problems. Other such occurrences have been investigated by Minichiello, Browne, and Kendig (2000) who found disparity of goals and less joint decision making between physicians and their older patients a significant factor in contributing to stereotypical ageist attitudes:

I went to Dr Knightsbridge three times in one week gasping for breath, I couldn't talk. I was trying to fill my lungs and I couldn't and I knew I was ill but I didn't know what was wrong with me and in the finish I think he got sick of me and sent me for x-rays. He looked at the x-rays and he said, 'Oh, come and see me one day next week' and I said, 'Do I make an appointment? 'Oh no, any time' so I went home.

Later that same day Win rang the ambulance and was taken to the emergency department of the Royal Brisbane and Women's Hospital.

The left lung had completely collapsed and the right lung had an abscess in it.

Win has experienced protracted waiting times for elective surgery. She has waited nearly 2 years for a shoulder re-construction operation and reports constant, severe pain. Prior to being accepted as a candidate for this surgery she reports asking her general practitioner (GP) on numerous occasions for referrals to specialists without success and in frustration and despair she sought medical opinion from another GP:

I changed doctors and I've been waiting now for two years, I'm still waiting! I haven't had anything – I haven't had a call, I haven't had a letter, I've had nothing and I mean it's just not good enough.

Win expresses anger and frustration that her current GP, who unlike the previous one, contacted the hospital on Win's behalf, was given the same negative responses as Win. However, Win recognises and appreciates the efforts of her GP to obtain appropriate and timely health care:

I mean the doctor was as damn frustrated as I was. She got absolutely nowhere. But Dr Hinchcliffe tried and tried and tried and I give her first prize for trying. Waste of time, waste of breath, a waste of a phone call because she got nowhere!

On two occasions Win phoned the ambulance as the pain her shoulder became unbearable. She was taken to the emergency department of a major Brisbane hospital where she was told by a doctor that she was unable to help: I can't help you, we're only doing life threatening operations', and I said 'Oh, pain doesn't matter', and she said 'No'. The doctor at the emergency told me that. There's a waiting list – you get to the top and they bring you to the bottom again and so it goes, ring-a-rosy. You get nowhere, absolutely nowhere. I had to get two buses home; I was in agony, agony! I don't know how I did it, I had no one to help me and I couldn't afford a taxi.

The world of Win's immediate experience of pain contrasts with the objective world of medical science. The apparent lack of recognition of the authenticity of her pain reinforces her sense of being invisible, 'a nobody'. Even though Win complained to the doctors, spoke up about the waiting times to hospital staff and co-incidentally the lack of care provided by hospital personnel; she felt largely ignored.

The ability to continue living in her own home and maintain her independence is paramount to Win. According to Whelan, Langford, Oxley, Koppel, and Charlton (2006), transport concerns play a significant role in accessing health care for mobility impaired or frail aged people. Win has significant mobility issues due to painful arthritic knees, both requiring total knee replacements. Getting on and off a bus has become increasingly problematic and there have been several occasions when she has almost fallen. Maintaining a vehicle is a significant financial expense for Win however, she views having a car *as* a necessity for several reasons:

I drive because there is no public transport [close to her home]. I couldn't walk down here [to the medical centre]. I get to the bottom of the damn street which isn't far and I'd be sitting down on the ground. But, you are just so in fear of your life when you go out and that's why I can't do without a car. Well at one time I could go out, I could get on a bus and go into town and go to the pictures or we used to go to the dances at the English UK Club and you never worried about being mugged or knifed or anything of the like.

Moore and Shepherd (2007) argue that fear of crime is a primary cause of social isolation amongst older people with the most likely affected being female (Killias & Clerici, 2000), and those living alone. The physical, fiscal, environmental and societal factors associated with ageing can influence the impact of feelings of victimisation as does the necessity of relying on public transport or walking to facilities for essential food requirements or health care. Win's concerns regarding her physical safety reflect these findings and foreground the influence this has on avoidance of using public transport. Such *perceived* threats are often seen as too great a risk for some older people and as a consequence an ever increasing pattern of social isolation occurs.

Furthermore, many older people without their own transport feel uncomfortable about accepting offers of transportation, especially when they cannot reciprocate (Davey, 2007). This unwillingness to be a burden on, or beholden to friends and family often results in fewer acceptances of lifts and consequently fewer social interactions thus potentiating the development social isolation:

Because you don't want to bother anybody because you know that you are bothering them. They don't want – they say, 'Well, you know if you've got any problems let us know'. But they don't really want to know. They really don't.

Win's neighbour is a well meaning person who has taken a keen interest in Win's health. However, Win finds her seemingly parental, overbearing attitude upsetting:

Rosemary, she's trying to dominate me which I don't take lightly because I'm a very independent person. She said she will do this for me, she will do that but [sic] I'd like her to do a few things but I can't ask her. I won't ask her because I'm not going to let her think I'm dependent on her and she's over stepped the mark by so many things, getting me these

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books and leaflets and that on going into an aged home and first thing I looked at was this leaflet that said 'Who will look after me when I go into an aged care home'? I'm not going into an aged care home, not yet!

Win is aware of several community services, such as Chermside Community Health and Burnie Brae Respite Centre, and uses the telephone directory in an effort to find out about home services. At times she has utilised contact numbers on pamphlets she has picked up at the medical centre or hospital:

I got these leaflets, 'Ring HACC, ring CHATS'. That's Home Assist. Home Assist is good. And I've rung, I don't know how many HACC's that [sic] are - you get nowhere, absolutely nowhere. I can probably get a lot of help from different sources, but they need paying for it and I haven't got the money. Some of them will do two hours housework for you for so much but then what do you take it from, your food bill? I'd been to see Dr. Gaythorne [specialist] and he said to me, 'Are you in a health fund?' And I said 'No why?' He said, 'Oh, pity, I could have done that [shoulder reconstruction] for you tomorrow.' Money, money, it comes down to money. If you've got the money they will operate. If you've got the money they will do your mowing. If you've got the money they will do everything for you!

Win's conversation indicates her desire and willingness to accept assistance however she perceives that she cannot afford any extra expenses on her limited income. The comments expressed by the specialist reinforce Win's financial inequity when compared to those who maintain private health membership and are financially secure.

### DISCUSSION – FINDING A WAY FORWARD

This article provides an opportunity for one socially isolated older person to reveal the difficulties experienced in her attempts to gain appropriate and timely health care. It also highlights gaps in health care strategies that continue to impact negatively on socially isolated older people. Win's fierce independence and determination are clearly seen as she fights for respect and acceptance from seemingly less than empathetic health care professionals and service providers in the wider community.

Loss of family networks, transportation costs, fear and physical mobility problems are significant issues that Win attempts to deal with while living within the boundaries of being a 'pensioner'. While studies over a decade ago (Berkman, 1995; Hall & Havens, 1998; Reid, 1994) identified causative phenomena for the development of social isolation, in more recent years there has been an increase in research encompassing psychosocial aspects of ageing (Greaves & Farbus, 2006; Machielse, 2006; Victor, Scambler, & Bond, 2008). This is of major significance as historically, the majority of research has been of a quantitative nature.

While statistical information can be useful for predicting trends and ascertaining demographic data, qualitative research embraces an epistemological and ontological perspective which provides rich and vibrant information not obtainable by quantitative methods alone. Despite the diversity of information gathered by these methods, there are still areas of ageing that are under researched and where qualitative methodologies like this may provide much valuable information on which to base policy making in an ageing society.

Win's story highlights her frustration and anger with some health care professionals and a system who she perceives is unwilling to help her. This frustration and bewilderment is evident in her recounting of being turned away from the emergency department of a major hospital. Despite community based health care programs, socially isolated older people still remain a marginalised group whose needs remain mostly unmet by such initiatives. Findlay and Cartwright (2002), Findlay (2003), Cattan et al. (2005), Machielse (2006) and Greaves and Farbus (2006) have illustrated that social isolation has a significant negative impact on the health of older people. Evidently current health policies are proving largely inadequate to address this insidious and prevalent phenomenon in westernised society.

In discussing aged care services Bartlett (2003) focused attention on the fragmentation and lack of coordination across health policy which has remained problematic despite the development, implementation and extension of specific community services for older people. Win's testimony foregrounds a persistent paucity of easily accessible, relevant information regarding linked community services and eligibility criteria despite extensive community based programs designed to ameliorate these issues. Essentially, close family members continue to be the major providers of direct care while social support networks comprising extended family and friends provide vital links to accessing appropriate health care for older people. Where these networks are not in evidence, socially isolated older people continue to experience poor health outcomes influenced by lack of awareness of health services and how to access them.

### CONCLUSION

This article explored the experiences of a socially isolated older woman as she attempted to access health care requirements in metropolitan Brisbane. Though the views stated in this article are of one frustrated and angry individual, other participants in the larger study reported similar experiences and feelings.

Difficulties in accessing appropriate and timely health care continue to be an ongoing issue for a number of socially isolated older people despite research spanning several decades and the establishment of community based programs catering for the older persons health needs. While we can't generalise from a case of one, Win's story illustrates the problems that many socially isolated older people may experience in accessing and navigating the health care system. It also raises the issue of professional medical and associated care increasingly becoming imbued by discourses of scientific expertise and the world of business where patients become clients, dehumanised and rendered invisible by age, poverty and social isolation.

On a positive note, the trend towards community based preventative health care has seen the appointment of an increasing number of nurses in general practice in an effort to more easily identify those in need of specific health care interventions. Through the undertaking of health assessments and health management plans by nurses, risk factors can be identified, and strategies formulated and implemented for those people who may not otherwise access health care relevant to their specific needs. Unfortunately, there are still too few GPs willing to increase expenses by hiring these 'experts' or keeping abreast of services available. This preoccupation with treatable illness marks the medical model. By increasing awareness of the issues surrounding accessibility and navigation of health care services by this woman and the cohort of the wider study, nurses in general practice may be able to provide increased opportunities for the socially isolated older person.

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