

The experience of socially isolated older people in accessing and navigating the health care system

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ABSTRACT

Objective

This article reports findings from a study exploring the challenges experienced by socially isolated and unwell older people as they attempted to access the health care system. Understanding the specific issues confronting these individuals would inform the development of more appropriate models of community-based aged care.

Design

A longitudinal qualitative, interpretive study using a case study approach with indepth interviewing.

Setting

This study was conducted in metropolitan Brisbane, with frail older people who were accessed via their GP service.

Participants

Six participants who met pre-determined selection criteria were recruited to this longitudinal study, and interviewed twice over a six month period.

Findings

Fear emerged as a common experience embracing aspects of daily life such as depletion of social networks, being dependent on others, loss of mobility and diminishing ability to drive. Inadequate or unreliable public transport resulted in extended waiting times to attend medical appointments.

Conclusions

Despite efforts to address the specific issues of frail older people living independently, this study highlights the suffering experienced by those who are socially isolated and lack the knowledge, skills, physical wellbeing and support to locate and access relevant health services.

INTRODUCTION

Social isolation is, sadly, a significant component of the lives of many older people (age cohort 75 years and over) living independently in Australia. Although descriptions vary, social isolation is generally understood to occur when a person has minimal levels of social participation and perceived inadequate social experiences (Fratiglioni et al 2000; Copeland 2002; Findlay and Cartwright 2002; Victor et al 2000; Greaves and Farbus 2006). There is evidence that social isolation is linked to negative health outcomes and decreased quality of life (Findlay and Cartwright 2002; Victor et al 2000). This can become a spiral for older people who lose what limited capacity they do have for meaningful social interaction in the face of the challenges associated with their illness.

Accessing the health system can be challenging for many older people, but potentially even more so for the socially isolated and unwell older person who has to do so alone without the support and sharing of knowledge which is part of being in a good social network. In response to increasing awareness of this issue, the *Cross Government Project to Reduce Social Isolation of Older People* was instituted in 2004 to reduce social isolation of older people in the Brisbane North area. This multidisciplinary initiative was developed by the Ministerial Advisory Council for Older Persons (MACOP) 2002 and incorporated the Seniors Interest Unit (SIU) of the Department of Communities. The aims of this initiative were to identify key issues leading to or influencing the development of social isolation in older people. Following this *Community Links*, a Brisbane North Division of GP's initiative was undertaken in 2006 to inform GP's and practice nurses of community services to people with findings published in 2007.

The current study, with data collected in 2006/7, is a longitudinal study using grounded theory to explore the experiences of socially isolated, frail older people in accessing and navigating the health care system, via a series of three in depth interviews. The study aims to ascertain needs, modes of access and process of navigation of socially isolated older

people within the health care system. This paper reports findings from the first set of interviews with participants,

METHOD

Design of study

This study adopted a qualitative, interpretive approach, which has allowed the researcher to listen closely and report narratives of the socially isolated older person.

Using a general inductive approach allows for both flexibility and rigour, and to achieve both the study has followed the guidelines of Thomas (2006), Morse (1997) and Thorne (2000). Thomas (2006) stated the main principle of the general inductive approach is to allow research findings to materialize from the recurrent, dominant or significant themes inherent in raw data, without the restraints imposed by structured methodologies.

Explicit themes (those that provide direct answers to specific research questions) and implicit themes (themes that fit into the overall context of the dialogue and connects with other aspects of the text) were identified and manually colour coded throughout transcriptions of the interviews. Categories and sub-categories were generated using numbered line by line coding. In addition, similar meaning words and phrases were grouped together and re-coded to reduce the number of sub-categories and categories that were placed into major themes.

Approval to conduct this study was granted by the Human Research Ethics Committee (University of Southern Queensland).

Participants

Through a collaborative initiative, the General Practitioners (GP's) at a medical centre located in the Northern suburbs of Brisbane were approached to compile a list of potential participants based on pre-determined selection criteria developed by the researchers. These included: age 75 years and over, married or single, limited meaningful social contact per week (defined as active social networks comprising two or less individuals), and able to give informed written consent. From this list, six individuals agreed to participate in the study.

Data Collection

This article is based on information analysed from the first round of interviews. These audio taped interviews were conducted in the participant’s home or at the Medical Centre according to participant preference. Interviews were between one and two hours in length.

Interview transcripts were checked for accuracy by carefully checking each line against the audiotape. Attempts to verify the interviews via member-checking were relatively unsuccessful, with only one participant agreeing to read and comment on their transcript. Instead, trustworthiness of findings was determined by intra interview respondent validation.

Data Analysis

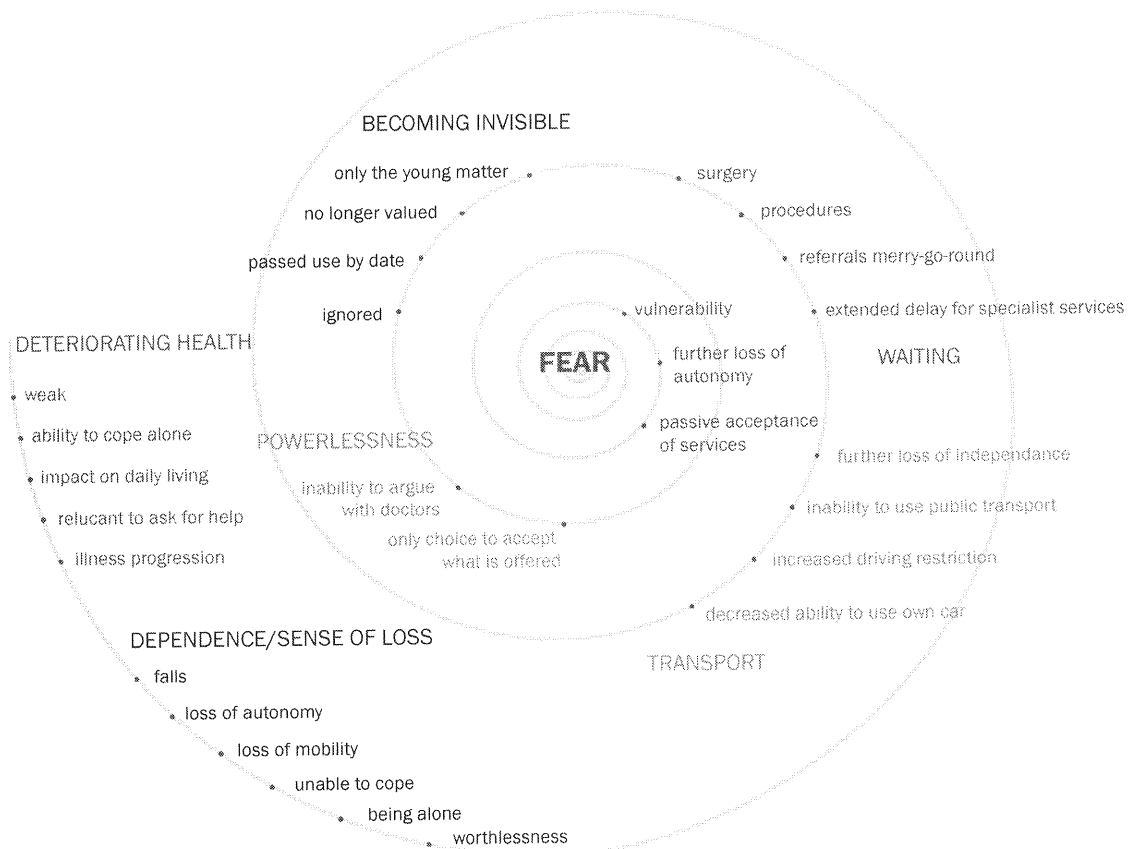
Initial interviews were transcribed and subsequently coded by numbering each line of dialogue. Rigorous reading and re-reading of each transcript revealed stories that were categorised into broad themes via thematic analysis.

STUDY FINDINGS

A spiral of deterioration

The thematic analysis of data from the in-depth interviews revealed fear as a central feature of the experience of socially isolated older people as they confronted their deteriorating health. This fear was experienced by all participants, and was the culmination of a spiral which appeared to be initiated by deteriorating health, and escalated by difficulties experienced in accessing appropriate health care. Figure 1 demonstrates this spiral, and indicates how the suffering associated with deteriorating health (such as increasing dependence and loss of autonomy, mobility and increased social isolation) was exacerbated by increasing difficulties in attempting to access health care. These difficulties were practical (problems with transport and having to wait for care) as well as emotional (a sense of becoming invisible and feeling powerless).

Figure 1: A Spiral of Deterioration: Socially Isolated, Old and Getting Sicker



Deteriorating health

The cycle commences with deteriorating health. This influenced participants' perception of ageing and appeared to be interwoven with their sense of fear. Several accepted this as a normal sequence of events, such as Ken: *'I've never sort of worried about my breathing, you know, I don't know what this is, but I suppose it's common with old age'*. Others verbalised their anger and frustration with the negative impact of advancing age and illness progression. *'I'm old and weak and I don't like it. I hate being old and wrinkled'* (Bette); and. *'I can't make a bed and I can't sweep the floor. I vacuum with one hand and then I take painkillers'* (Win). Monica tells a similar story, *'Because of my breathlessness I can't walk any great distances...I'm slower these days and it's difficult getting groceries into the house'*.

Decreasing social networks and a reluctance to ask for assistance from close friends, family or neighbours resulted in self imposed isolation as participants did not want to be seen as a nuisance or burden to others. Shirley verbalised, *'We don't intrude...while you love to talk, you don't really ask them for physical help[neighbours]*. Win spoke of her neighbour, *'Mary would do everything for me if I'd let her, but I won't let her'*. Ken talked about his experiences in the caravan park. *'...for two to three weeks you mightn't talk to anyone...I don't like talking to a lot of people because sometimes, you go back and think, "what have I said that I shouldn't have said?.. I just didn't ask [for help], I don't know why, I guess I didn't want to bother them like, you know'*.

Dependence / Sense of Loss

Loss of independence and subsequent dependence on others was closely linked to concerns of perceived decrease in autonomy, decreased ability to care for self (and spouse), a general inability to cope with life changes and increasing health problems. Win's fears were falling and pain: *'I fell over one day and you know they walked around me. I was here at the hospital and nobody helped me...I mean you're invisible. I'm terrified of the pain that I'm going to have when I get up...the morphine doesn't work'*. Bette comments, *'my balance is very bad...there*

is a lot of fear attached to it but you are always frightened you're going to fall... I'm very anxious when I go outside... I can lose my balance very easily. I'm very frightened of falling...' While fear of falling was common, these extracts also highlight the loss of autonomy in being able to recover from falls and the sense of loss felt when one feels no longer valued and thus invisible.

Reduced social contact in the neighbourhood meant fear of being alone for some. This is increased by the desire to be independent and a reluctance to ask for help from neighbours and family. *I haven't got anyone and these days you don't know your neighbours in the streets'*. Fay states *'...there was absolutely no rest, I was totally exhausted. I am really so worn out that I cannot cope any longer...you're obviously there and you just keep going'*.

Limited mobility and decreased ability to carry out activities of daily living were of major concern to several participants. Participation in activities once enjoyed was also affected by decreased mobility as Bette's story confirms, *'I love watching plays and old movies. I couldn't go out now; I wouldn't be able to sit through anything now. I used to go out a lot but not any more and I never go out at night'*.

Transport

Participants used their own transport almost exclusively to access all their health care needs with one participant riding a pushbike from the northern suburbs into the city for treatment at a major hospital. In some cases, public transport was unreliable or non-existent in some streets. Personal transport was essential to Monica, *'If I didn't have my car I would find it very, very difficult. I couldn't come to see doctor here at the clinic. I would use public transport if it were regular...the buses don't stop at all the stops now - they've changed the transport system.'* Participants in this situation were physically unable to walk to the nearest bus stop and were therefore precluded from this service. Jack (on behalf of Shirley) comments, *'If I wasn't available and we didn't have the old vehicle I don't know how we'd survive'*. Three participants had restricted driving times and distances. Others preferred not to drive in heavy traffic or late in the day. This limited their

availability to accept appointment times offered outside their preferred times. Several participants were initially unaware of City Council Cab Services as a possible alternative to buses, but even when this was known still preferred to utilise their own transport. Taxis were not a viable ongoing option due to the expense of this mode of travel.

Waiting

Waiting times for hospital specialist appointment times were protracted in all cases. Three participants accessed specialist services through the public health system. Waiting times varied from eight weeks to two years for specialist appointments. Experiences of re-categorisation were common and there is evidence that it was not unusual for these people to receive no notification of altered appointment schedules. Participants' also recounted feelings of being on a 'merry-go-round' where inter hospital referrals to different departments and specialists left them bewildered and frustrated.

Win's greatest fear is ongoing pain in her shoulder as she waits for an operation. She has been on the waiting list for two years. *'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. ...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.'*

Long waiting times for GP's and specialist review discouraged several participants from actively seeking medical assistance preferring to manage on their own in most instances. This was exacerbated by the "merry-go-round" of different specialists, all which served to increase waiting times and resolution of health concerns. *'We have private health cover but we still have to wait a long time sometimes for things to get done. You don't want to wait around when you are feeling unwell'* (Bette, 87 years).

Becoming Invisible

Five participants revealed they felt 'invisible' when attempting to access health care. Win reiterates, *'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. Once you're needy you're supposed to be invisible. Don't bother me you're of no consequence'. Others related stories of their GP's not listening to them at consultations. Fay's story concurs, *'I suggested to the doctor that he check him [husband] out for memory problems and so forth and after about 12 months he sent us over to a doctor who diagnosed Alzheimer's'*. All participants felt that society in general focused on the health needs of the younger generation. Bette's summation is mirrored in other participant accounts. *'I haven't got much faith in doctors. I feel we're past our use by date – no one really cares. We've had our time here, only the young matter today. Yes, lots of money is spent on the young'* (Bette).

Powerlessness

An inability to challenge perceived experts was evident as interviews progressed. Several participants expressed their dissatisfaction and frustration with their attempts to access and co-ordinate care with their GP's and specialists. *'I asked doctor if he could get me an appointment with the specialist and he just kind of stared at me. Nobody did anything about it and he didn't write to the hospital to ask them for an appointment like I asked him to – I pleaded with him. I didn't ask him, I pleaded with him!'* (Win).

'I have on occasion spoken to a doctor about taxi vouchers, but the response has always been negative. I don't know why. I think they think the application for it is a bit hard for them to handle' (Jack on behalf of Shirley). Ken relates, *'I seen the same bloke [doctor] and he seemed to be a bit different. I think I must have blotted his copy book or something you know, like when I first seen him...I just walked away, what else could I do?'*

Participant stories reflected the significant difficulties encountered by those who were unable or unwilling to demand a better service and as a consequence became bewildered and disillusioned. Win constantly described this as "hitting a brick wall." *'I was supposed to be done [operation] within four to six weeks and I'm still waiting...you walk up into a brick wall and you just...there's just not anything*

you can do. You talk, you ask, you plead, you get nowhere'. Shirley's case is particularly distressing. She describes her experiences during radium treatment for maxillary cancer. '*...sometimes it was quite openly mal-administered...but I was the one who was the sufferer of that, never to be able to be mended and I was burned seriously. I put my hand up but nobody came...I ended up with skin and hair like molten toffee...because I was by myself, I should have insisted on taking this [gown] off and walked out but I was locked under and there were all these people around me.... Shirley felt impotent to stop the radium treatment, 'I felt like nothing ...a non-entity that's the word'.*

DISCUSSION

The descriptive narratives of the participants highlight how fear pervades many aspects of their lives. Though not directly stated by some, this phenomenon underpins how they react to and interact with health care interventions.

The findings of this study are disconcerting and highlight the vulnerability of frail older people living in socially isolating circumstances. Sensitive and ethical strategies are required to encourage this cohort to accept health care initiatives whilst maintaining their autonomy, self esteem and value as members of society. It is of concern that these findings follow the implementation of a local project, *Community Links*, which was designed to enhance GP and Practice Nurse awareness of available community services for older people. While the current study is not an evaluation of that project, it is sad to note that for this cohort of older people at least, the *Community Links* project appears to have made little difference to their journeys.

Findings of this study support previous research. Research undertaken by Baltes (1996), Oldman and Quilgars (1999), Peel, Westmoreland and Steinberg (2002) and Godfrey and Randall (2003) identified loss of independence as a major concern for older people irrespective of cultural diversity and personal circumstance.

In this study, fear was a key aspect of the study participant's emotional response to their diminishing health. This finding resonates with results from a number of other studies. For example, Minichiello, Browne and Kendig (2000) examined the experiences and perceptions of ageism by older Australians and reported that fears of vulnerability and loss of relevance were central to their experiences. Quine and Morrell (2007) discovered issues of fears for self incorporating loss of independence and possible nursing home admission to be of greatest significance. Fear of falls was the focus of research by Lord, Menz, Sherrington and Close (2007) while loss of independence relating to personal transport was a key feature of research by Peel, Westmoreland and Steinberg (2002).

In the current study, it is anticipated that a further two rounds of interviews will ascertain the levels of knowledge of health care services and generate possible strategies in navigating the health care system which, if implemented, may go some way at least to address the problems described in this paper. The findings of the study to date indicate that an underlying principle for intervention is that of a partnership approach, where the focus is on ensuring that socially isolated older people are reassured they will be able to maintain their dignity and autonomy whilst accessing health services.

This is especially relevant for aged care, community and practice nurses who work regularly with older people. Despite the challenges of a time-pressured work environment, taking the time to build respectful and trusting partnerships with older people is an investment which is likely to enhance the likelihood that older people will feel comfortable in seeking the health care they need and deserve.

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