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Abstract

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Keywords

Older People, Elderly, Change, Lifestyle, Complex Support Needs, and General Inductive Theory

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Older People with Complex Health Needs Desire for Change: A Qualitative Study

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As a sub study of another study we examined older people with complex health and disability support needs' desire for change. The aim was to compare this across different ages, residence, and gender. Semi-structured interviews were held with 129 participants and the data were analyzed using a General Inductive Approach. Six themes emerged, Health, No Change, Personal Changes, Family, Housing, and Services. The two most popular themes were a desire for health changes and to have no change. Health professionals might note that older people in their 80s with significant health and disability impairments have a decrease in both the desire for health changes and any other changes. Key Words: Older People, Elderly, Change, Lifestyle, Complex Support Needs, and General Inductive Theory

Introduction

The focus of ageing and disability policies is to support older people to continue to live in their own homes and to support people with functional limitations to participate as fully as possible in society. These goals are inherent in the current policies of developed countries. Similar to other Organisation for Economic Co-operation and Development (OECD) countries the New Zealand Government's Positive Ageing Strategy (Office for Senior Citizens, 2001) described freedom of choice by developing and improving services within the community to enable ageing in place (the older people having a real option of staying in their own homes). In addition to ageing strategies, such as ageing in place, there are disability policies oriented towards realising an inclusive society that is non-disabling and enabling all people to participate. In New Zealand this overarching perspective is based on the goals set out in the New Zealand Disability Strategy (Ministry of Health, 2001), the Health of Older People's Strategies (Ministry of Health, 2002), and the New Zealand Positive Ageing Strategy (Office for Senior Citizens).

To establish the level of support needed by people aged 65 years or over, older people are referred to a multi-disciplinary team (MDT) to be assessed for their level of support, which includes referral to residential care (Ministry of Health, 2005). The older people are categorised according to their needs, that is, non-complex support needs (such as housework) or complex support needs (such as needing the level of support provided by residential care). People with complex support needs have been described by the New Zealand Ministry of Health in the following statement: "The disabled person's ability to remain in their environment is compromised due to significant safety issues and complex support needs" (Ministry of Health, 2005, p. 3). When the level of support is decided, the

person is referred to government funded service coordination agencies to organise and administer the required assistance.

Older people with complex support needs often experience a lifestyle change, such as increasing the level of support, or downsizing their homes, or moving in with family or into residential care. Anticipated satisfaction with the change must be a strong motivator for the change itself, but that depends on the information available, how it is communicated, the choices, the desired results and their implications. With the number of people 65 years and older increasing, it is becoming important to establish what older people want from their point of view rather than from their careers', or health professionals' perspectives.

When change is presented to older people it is usually perceived as positive or negative, rather than neutral, which could have a significant bearing on the outcome (Tversky & Kahneman, 1981). Older people's propensity for change could also have a bearing on personal goals (Lapierre, Bouffard, & Bastin, 1992), their satisfaction, and feeling of well-being. Since authors have defined well-being as a sense of control, purpose, and positive feelings, (Plaut, Markus, & Lachman, 2002) and a feeling of good health and social integration (Baltes & Mayer, 1999; Netten et al., 2002), it could be assumed that positive or negative feelings about change could influence older people's sense of well-being. To contemplate change there must be a choice, even if it is not to change. In the case of a move to residential care, choice is one of the critical elements in the process of older people's relocation to enable a sense of control (Davidson & O'Connor, 1990; Nolan et al., 1996). How a decision for change is made depends on the communication and information, and how the changes or choices are presented. Probing what changes older people want would allow a better understanding of their current needs, thus improving their life-satisfaction, or well-being (Rapkin & Fischer, 1992). Few articles were found relating to older people with complex support needs' desire for change, which leaves gaps in our knowledge and impedes the development of strategies. The aims of this study were to find out if older people with complex support needs wished for changes, and if so, did the changes differ across ages, upon entering residential care, or between genders?

Researcher context

This question was raised as part of my doctoral thesis completed in December 2006, under the guidance of my supervisors: Professor D. R. Thomas (Professor of the School of Population Health) and Associate Professor Matthew Parsons (Senior Lecturer Gerontology, Faculty of Medical and Health Sciences) both at The University of Auckland, New Zealand. After receiving my MBA, I worked in a gerontology policy area within the New Zealand Ministry of Health and then as CEO of a group of retirement villages which included residential care facilities. I began to wonder why some people with similar support needs could live at home, while others lived in residential care. This became the topic of my doctorate, which also included who made the decisions for older people to enter residential care, and if the older people were happy with that decision. During the pilot study it became obvious to me that many older people said in conversation "if only" in relation to some change they wanted, or could have had. Answering this question became a sub study of the main study.

Methods

Sampling

Older people from three New Zealand cities with populations over 100,000 were invited to participate. To be eligible for the main study people had to be 65 years or older and be categorised by a multi-disciplinary team as having complex health and support needs. People with significant cognitive dysfunction or people who were medically unfit to participate were excluded. For the main study, 569 potential participants were approached between December 2004 and August 2005, with 129 (23%) agreeing to participate. The low acceptance rate was attributed to other research studies involving the same group of older people at the same time. The sub study discussed here used the same group of participants.

The ranges of disabilities of the sample group varied from being totally bed-bound, to an inability to perform one or more of the activities of daily living. Ninety percent of the older people were New Zealanders of European descent, 4% Maori or Pacific Islanders, and 6% other races. The mean age was 82.75 with a median of 81 years. To enable comparisons among ages, participants were divided into three groups 66 to 79 (n=45), 80 to 89 (n=54) and 90 plus (n=30) to discern any differences among people of different ages. Half of the participants had a care-giver (spouse, child, or close relative), 46 were males, and the group was of varied socioeconomic status.

Service coordination managers approached the potential participants to gain their acceptance for the study, then all participants received detailed information about the study and signed consent forms. The study was approved by the Government Ministry of Health's Ethics Committee.

Data collection procedures

The main research question asked of the participants was, "if there was one thing you could change what would it be?" An interview pro forma with prompts was developed to help the participants answer the research question. Demographics, such as age, gender, and place of residence were also gathered. Because of distances participants living at home in two of the cities were interviewed by telephone while participants in the third city were interviewed face-to-face. All participants in residential care were interviewed face-to-face as well. The majority of the interviews (69%) were held within a month of the assessment, with the remainder taking place three to six months after the assessment due to an inability to contact them sooner.

After the consent form was signed I received the participant information sheets identifying the participants' ages, genders, addresses, telephone numbers, informal care-givers' information (non paid, usually family members), and if they were on a social welfare benefit (i.e., which is given to people with low incomes). The interviews lasted approximately 45 minutes. I conducted both the telephone and face-to-face interviews and recorded them using a tape recorder and hand-written notes. Older people were encouraged to express their feelings freely with few guidelines and prompts (Pope, Ziebland, & Mays, 1999). When there were hearing difficulties the care-givers assisted with relaying the answers from the older people.

Analysis of the qualitative data

The interviews were transcribed verbatim and entered into NVivo for analysis (Rich & Patashnick, 2002). The data gathered were analyzed using a general inductive approach derived from grounded theory, and described by Thomas (2006). A major point of inductive theory is to avoid narrowing what is observed and theorized to preconceptions (Ezzy, 2002). Many researchers using inductive studies agree that the intended outcome of the coding process is the creation of three to eight summary categories, which the coder views as the most important themes given the research objectives (Campbell et al., 2003; Jain & Ogden, 1999). The raw data was read and reread many times to gain a good insight of what it contained. Using NVivo, codes were developed line by line, or sentence by sentence. The codes were collated and broad categories were formed. The data was again reread to ensure that the categories were appropriate, and then the related categories were grouped to form six themes. Five transcripts were given to two senior researchers to recode. These transcripts were then compared with the original coding for similarities and differences (Patton, 2002). Where there were differences the transcripts were reviewed and a consensus gained among the researchers. In order to give a full picture of both the themes illustrated by the narrative, and significance of the themes, the data was also organised as percentages. The ages of the participants were grouped into three groups: 66 to 79, 80 to 89, and 90 years and over. These and the genders were also grouped under the six theme headings and given a percentage of the total number of participants.

Results

The changes were grouped into themes, (shown in Table 1) which were descriptively designated by the nature of the change. Six major themes were developed from the 29 groups of changes mentioned by the older people. The themes were: Health, No Change, Personal Changes, Family, House and Services. The themes, Health (33%) and No Change (28%) combined to make up the largest group. A change to Personal Changes and Family represented the next largest groups at 15% and 13% respectively, while changes to House and Services made up 6% and 5% respectively. The themes are described separately as follows:

Table 1

Changes and Themes

Major themes	***Percentages in each theme***	***Changes suggested by the older people***	***Number of people who nominated each change (N=129)***
Health	33%	• To be more healthy • To be more mobile • To never have started smoking • Not to be incontinent	23 17 2 1

No change	28%	• No change • Don't know • To have peace in the world	31 4 1
Personal Changes	15%	• To have done more things when younger • To have more money • To be younger • To live my life over again differently • Not to be a bother to anyone • To drive my car again • For my cat to come home • To go to Australia	1 6 6 1 2 1 1 1
Family	13%	• To have spouse back or healthy • To have more family contact • To get married again • To have a family • For my son to communicate with me	11 3 1 1 1
Housing	6%	• To change house • To have the shops closer • To stay in my own home	5 2 1
Services	5%	• Combine the services given to me • To improve the way they organise this hospital • To have more help • Better talking books • To get a scooter • To have more interesting visitors	1 1 1 1 1 1

Health

The change desired under the theme Health described the older people's physical or mental health. Results indicated that the largest group of older people (33%) expressed the desire for a change to their health status, such as: "to be able to get around a bit faster," "not to have had a stroke," and "to have good health, that is what I would want, and then you are rich." Table 2 shows the youngest group (66-79) wanted a health change most frequently (15%) with comments such as, "my health; I would like to change to be as I was a few years ago" and "do for myself and be more independent." The percentage

of people in the older two groups (80-89 and 90+) who wished for a Health Change were lower at 12% and 7% respectively One older person commented, "I would like to be rid of my incontinence." Health related changes (Table 2) were preferred for females (20%), with comments such as: "I would like a new head, I haven't got a brain at the present, don't know about the face, but with a new head I would get through." Males' (13%) comments were:

> I wish I had never started smoking. If I lived my life over again I wouldn't have taken it up. I started when I was 12 you know, well we all did in those days. Some of us [his friends] are still alive like me, but only just…
>
> and
>
> ... to walk well and to walk without a frame. The family wanted me to go into a rest home because they thought I might fall; they have always had that fear that I would fall and no one would hear and I would be left there. I am still here and I haven't fallen, yet.

Table 2

Male and Female Preferences for Change

	Males	**Females**
Themes	***n***	***n***
Health	17 (13%)	26 (20%)
No Change	11 (9%)	25 (19%)
Personal Changes	9 (7%)	10 (8%)
Family	3 (2%)	14 (11%)
Housing	4 (3%)	4 (3%)
Services	2 (2%)	4 (3%)

Another comment made about a change was referring to a man living in residential care:

> I wish that I had died when I had my last stroke, I don't have any friends here in this place. I sit at the table with five others and none of them speak. Two are deaf, one just answers in monosyllables and the other sleeps all the time. I just stay in my room and watch television because there is little else that I can do when I have no friends.

Another reference to being admitted to residential care was a woman's desire for a change in health to avoid having to leave her home.

> Primarily my problems were getting worse. I tried getting help in [at home] and it just wasn't working mainly from my husband's point of view, partly because of the nature of the house...so they decided that my

> husband could get relief from me by my going into a rest home. I dearly wish my health had improved prior to going into this place.

Again with reference to residential care, incontinence seemed to trigger some of the admissions.

> If I hadn't been incontinent, then the nurse from the rest home wouldn't have made me come in here [residential care] from my flat. That would be my change, to not be incontinent and not be in here.

People related stories of having to fight for what they wanted especially with the health professionals in the acute hospitals. One lady, when discussing her desired change said:

> I had a big fight to get back here to my flat. The doctors and the others at the hospital wanted to put me in a rest home. They even had me booked into one. I had no relatives or anyone to speak for me so I had to become really stroppy to get my way and come back here. I probably wasn't all that capable in hospital, but I knew that I would be better in my own environment. Once I got back here I began to improve and I can manage fine now see. So you see if I hadn't had the stroke I wouldn't have had to do that, so that is what I would change, that and the doctor's attitudes.

Table 3

Older People in Each Age Bracket

	Ages		
Themes	***66-79*** ***n***	***80-89*** ***n***	***90+*** ***n***
Health	19 (15%)	15 (12%)	9 (7%)
No Change	9 (7%)	16 (12%)	11 (9%)
Personal Changes	6 (5%)	9 (7%)	4 (3%)
Family	3 (2%)	10 (8%)	4 (3%)
Housing	5 (4%)	3 (2%)	0
Services	3 (2%)	1 (1%)	2 (2%)

Figures are rounded to the nearest whole number

No change

The theme of No Change was the second most often mentioned at 28% and by more people over 80 to 89 years (12%). However, it was the highest preference of the 90-plus age group at 9% (Table 3). Comments included:

> I wouldn't like to change my wife or my living conditions. I am really satisfied.

> Nothing really, you can't reach for the moon. We are comfortable and able to afford to pay a gardener.

Twice as many females at 19% wanted No Change compared to 9% of males. One older lady said: "I am not discontented. I am rather blessed with all my family." The wife of an older person in residential care commented:

> He went into respite and then just stayed there [residential care].The practice nurse referred him to residential care. He was very depressed at home and non-communicative, but now in the rest home he is very much happier and seems more alert too. Neither my husband nor I would change anything now, we are content. Well, I am, knowing he is.

Personal changes

Personal changes described something that the older people wished for to make their lives better. This was the most diverse theme and included personal changes such as: "to be young again as there is no joy in being old," "more visitors, that is interesting people who I could talk to and have a laugh with," and "to have more control over my temperament in the past. I was too likely just to let things happen." This theme ranked third (15%). There was no significant difference between Personal Changes in any of the age groups, with a range of 3% to 7%, and gender 7% to 8%. One older female commented: "I would have loved to have done other things earlier, but we didn't have the money so couldn't do them and we had to put our children through university." Wanting more money and wanting to be younger were the most popular changes in this theme with comments such as: "to be 20 years younger" and "to have freedom from money worries."

Family

This theme describes changes involving one’s family. Most often the change was to have a spouse back.

> To be with my husband. We have been married 60 years and this is the only time we have been apart. I am sad about it. I would like us to have a room together in the rest home. He is in a different part from me, and I would like my husband back. You see we were married for 52 years and then he had a sudden cancer and died four years ago, and I still miss him.

Another comment regarding a spouse was "to change my partner's health so he is not sick." People also mentioned their families, usually with reference to seeing them more, such as:

> I have a son with a PhD who is working nearby. My wish is he would talk to me. He refuses to talk to any of the family and it really hurts me.

When referring to family one older male said:

> I wish that I had a family. I have a … disorder and I didn't want to have children and pass it on, but now I wish that I had some children to talk to, be near, and watch grow up.

Females choosing the Family change far outstripped the males at 11% as compared to 2%. Family ranked third above Personal Changes for females, and well below Personal Changes for males. The age group which most often mentioned Family was the 80 to 89 year old people (8%), and the youngest group mentioned it least (2%).

Housing

The Housing theme described changes to the house, locations of the house, or the sale of a house. One lady in residential care lamented the fact that she was there and wished to be home again:

> I would have like to continue in my own home. It still makes me sad when I think about it. One of the saddest things was that I had to leave my cats. I had two lovely cats...they [the son and daughter-in-law] took my cats away from me. I don't know what has happened to them, and I don't like to ask. They were really my family. There are no cats in here; I do so much miss them. I am still sad about all this and in here I get no sun in my room and just sit here all day...I guess you could say I am home sick.

In a similar vein another lady wished to change, and in fact had changed; she moved from her daughter's house back to her own home, saying:

> I lived upstairs in their house and they were good to me. I had nothing to do except to wander around and look at the gardens, and you can't do that all the time. One day I said that I wanted to go back to [city] because I was away from my friends. I came here to [city] to live when I was married, and so my daughter brought me back.

Services

The Services theme was about personal help, or help in the home that people thought they would like altered, while at home or in residential care. Two statements referring to services are: "I would like more domestic help, and when they have holidays that they are replaced" and "I would like changes to the way they organise this hospital [residential care]." Another lady commented:

> When my daughter is at work I am worried that perhaps the [paid] support-worker won't come and I will have to call my daughter home. I do wish that the carers were more reliable and then my daughter, who is in one of the top jobs [in a government department] wouldn't have to leave that and come home to change my [urine] bag here.

There were small numbers across all age groups and genders in the Housing and Services themes. In the 66 to 79 age group Housing (4%) also ranked above Family at 2%. More males chose the housing option, while no one in the 90-plus age group made housing their choice for change.

Discussion

It is important to note some limitations to the study: some of the older people were interviewed by telephone while others were interviewed face-to-face. While this could have caused some bias this was not noted by the researchers. This concurs with what others have found that there is no conclusive evidence that telephone interviews in relation to health and illness provide lower-quality data than face-to-face interviews (Wilson & Roe, 1998; Worth & Tierney, 1993). Interview length was equal for both types of interviews. One other limitation should be noted. In those instances in which a care giver provided answers for people who were hard of hearing, it is possible that the meanings might have been change through the reporting.

The findings raise an interesting question of what influenced the older people's decision to mention a Health theme, or to want No Change more often than any other option. The core belief of a person's self-control is the foundation of many human functions such as motivation, well-being, and accomplishments (Pajares, 2002). People's abilities to do or change something are one of the basic principles of self-efficacy. I have discussed in this report what older people with complex health needs wish to change. Of the people interviewed, the most common wish was for an improvement in health, but as people aged health became less of a concern. A considerable number of older people wanted the status quo. Men were substantially different from women on the Family theme, possibly due to fewer men living alone (Barnes & Parry, 2004). Even though all the participants were receiving substantial support services, few mentioned these as possible wishes for change.

Policy makers and family place risk avoidance highest on the list of reasons for changing residence to residential care, however, older people in this study did not mention a lessening of risk as one of their desired changes. Likewise, older people in Netten, Bebbington, Darton, and Forder's (2001) study were most concerned about retaining control of their daily living tasks. When health professionals and families are interacting with very dependent older people it is worthy of note that as they increase in age the importance they attach to issues alters, with few older people remaining interested in substantial change.

Future studies could investigate the reasons why older people's wish for a change in their health status decreases as they age. The increasing desire for the status quo as one ages could be investigated, to see what differences time makes to people's desire for change over a longitudinal study.

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