A QUALITATIVE STUDY OF ADAPTATION AFTER DETERIORATION IN FUNCTION IN THE ELDERLY

By

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DECLARATION

I, Dr GH Cleveland, hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

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BACKGROUND

The number of older persons worldwide is expected to more than double from 831 million in 2013 to more than 2 billion in 2050 (1). By 2050, one fifth of the population in the developing world, and one third in the developed world, is expected to be over 60 years old (2). Care for this increasingly prominent group is, however, hampered by a number of factors.

Often doctors caring for the elderly are very much younger, and may lack training in Geriatric Medicine (3). Scientific medicine is largely focused on curing and managing disease, whereas the focus in care of the elderly is more about maintaining function (4). The medical model is so dominant that many consultations with the elderly are focused on the inevitable failing of the body. This negative perspective ignores the evidence that many older people report high levels of wellbeing and, in fact, are often more likely to report satisfaction with their lives than younger people (5).

There is a need for a different approach to caring for our elderly patients in family practice. We cannot "cure" many of their ills. We cannot arrest the inevitable decline in their bodies. What is important is quality of life.

Interestingly, it is not uncommon for older people to have serious illness or disability, and to report a good quality of life (5). Bowling et al (6) reported that 62% of participants with severe restrictions in daily living reported good quality of life. Research (5) suggests that ageing is highly specific to each individual and that the pathway of old age is not predetermined. Ageing involves a series of losses, yet some appear to cope better with these losses than others.

Insight into why some appear to age "more successfully" than others would undoubtedly help us to better care for our elderly patients. It would also better equip us to advise our younger patients on preparing for older age.

What has been looked at historically?

LITERATURE REVIEW

AIMS:

1. To look at published models of ageing
2. To look at what has been published with regard to coping in illness

METHODS:

Pubmed was searched using the following search terms:

1. Models of ageing
2. Successful ageing
3. Ageing successfully after illness
4. Ageing well
5. Coping after illness
6. Coping in chronic disease

Models of Ageing:

The term Gerontology was coined in 1903 by Metchnikoff. It is distinguished from the medical discipline of Geriatrics, which focuses on the diseases of the elderly.

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Gerontology studies ageing through the four components of *chronology* (how many years lived), *biology* (physical changes), *psychology* (changes in personality, cognition and adaptive capacity) and *social ageing* (changing roles and relations within family and society).

Within the field of Gerontology, theories of how people age have been developed. In the 1960s and '70s, the three dominant social theories were the following:

Disengagement Theory described by Cumming and Henry in 1961 (7) described a "necessary" gradual withdrawal of the individual from society and, in turn, society from the individual.

Activity Theory, described by Havighurst in 1961 (8), held that ageing results in the falling away of roles and activities that help define an individual and give their life meaning. It thus followed that what is important is for people to maintain, or substitute, these activities in order to remain as active in society as possible.

Continuity Theory put forward by Atchley in 1971 (9) proposed that individuals need to hold on to "continuity" in their life-course. This would entail maintaining the "*internal self*" (beliefs, personality style, etc.) and "*external self*" (social roles, relationships, etc.) from birth to death through continuous small adjustments. This would help maintain psychological wellbeing.

These theories have been criticized as being one-dimensional and simplistic.

In the 1980s and '90s, studies suggested that some cognitive skills actually improve with age (10), that the brain does not lose as many neurons as previously thought but, in fact, continues to sprout new connections all the time (10), and that, with age, people tend to become happier, with better mental health, and are better at handling interpersonal relationships (11).

More positive models of ageing began to emerge. Terms such as "Successful Ageing", "Active Ageing", "Productive Ageing" and "Ageing Well" were spoken about. These have in common a belief that, within the constraints of the realities of ageing bodies, ill health and sometimes limited finances, ageing individuals can choose a positive path of ageing. Research has been focused on trying to define the components of this "Successful Ageing".

Successful Ageing: What is it?

The term was introduced as the main theme of the Gerontological Society of America's annual meeting in 1986 and has been intensively studied ever since. Researchers worked on models that explored biological and cognitive as well as psychosocial components of the ageing individual.

The three dominant models to emerge were the Rowe and Kahn model (1987), the Ryff model (1989) and the Baltes and Baltes model (1990). The first views successful ageing as something that can be defined at a point in time, ie a measurable state of being. The other two view successful ageing as an adaptive process that is always changing.

Rowe and Kahn Model (12)
These researchers drew the distinction between "**usual ageing**" with age-related decline in physical, cognitive and social functioning, exacerbated by extrinsic factors and "**successful ageing**" where there was minimal loss in these three factors.

They proposed that successful ageing has three components:

1. Avoidance of disease and disability
2. Maintenance of cognitive functioning
3. Active engagement in life (including maintaining social support and remaining involved in activities that are meaningful and purposeful).

This model is still widely used. It has been criticized because its rigid criteria do not allow for the many possible patterns of successful ageing, and it does not deal with the reality that a disease-free old age seldom occurs.

Ryff Criteria (13)
In her article "Beyond Ponce De Leon, [a reference to the Spanish explorer apparently linked to the search for the Fountain of Youth in the Americas] and life satisfaction: new directions in the quest for successful ageing", Ryff was the first to describe ageing as a developmental process in which growth was still possible.

She described six criteria for successful ageing:

1. Self-acceptance;
2. Positive relations with others;

3. Autonomy;
4. Control over one's environment;
5. Purpose in life; and
6. Personal growth.

Baltes and Baltes Model (14)

Rather than formulating criteria, these researchers attempted to outline the processes involved in successful ageing.

Their model is based on the concept of "**selective optimization with compensation**" (SOC). It is an attempt to analyze how "successful agers" make adaptations when faced by changes brought about by the ageing process.

An example from the author's book illustrates this. The pianist Rubenstein explained how, in order to deal with age-related weaknesses in his playing ability, he chose a smaller repertoire to perform (**selection**). He then practiced these pieces more intensively (**optimization**). Lastly, he slowed down his playing speed before a fast section, thereby creating the impression of speed when playing the *allegro* sections of the piece (**compensation**).

Selection is a process during which the individual adjusts their expectations so as to allow the subjective experience of satisfaction and personal control. Optimization is a behaviour that allows them to reach a higher, or more desirable, level of functioning and compensation is a strategy that is employed when the adaptive potential of the individual is inadequate for optimal functioning. Examples are using a mnemonic to aid memory or a hearing aid to augment hearing.

The Baltes and Baltes Model views successful ageing as the successful adaptation of an individual to the changes inherent in the ageing process. It has the strength of being applicable to almost any circumstance, whether someone needs to adapt to physical disability through ageing or to non-biological loss such as retirement or loss of a spouse. It allows for non-prescribed, individual paths of successful ageing.

In a 2007 review of studies looking at whether the SOC model contributed to successful ageing, Ouwenhand et al (15) concluded that it is a widely used strategy in ageing people and it does contribute to successful ageing. In particular, compensation and optimization are most closely associated with ageing well.

Other empirical research

Hartman-Stein and Potkanowicz (16) reviewed the literature on predictors of successful ageing in 2003. They stated evidence that what we do at 50 is likely to affect what we feel at 80.

In particular, the following factors seemed to be important in preventing disease-related disability, cognitive impairment and late-life depression:

1. Regular physical exercise
2. Being engaged in mentally stimulating activities;
3. Finding meaning in life and
4. Having an optimistic mental outlook.

The last point is important because there is substantial evidence that a positive attitude (optimism, feeling hopeful and enjoying life) has protective benefits against poor health, leads to higher levels of social activity, better coping abilities in the face of stress and greater perceived control over life (17). What is not clear is whether optimism can be "learned" (17) or whether personality traits remain relatively stable throughout one's life (10).

Bowling (17) quotes evidence from the Tenman Longitudinal Study which followed up a group of Californian schoolchildren for more than 70 years. This suggested the following factors were important for achieving "very old age":

1. Remaining disease-free
2. Preserving cognitive abilities
3. Maintaining preventative (healthy) lifestyles
4. Having "stress-resistant" personalities
5. Being "immune to neuroticism" and
6. Genetic factors.

In summary, both theoretical models and empirical research propose that successful aging depends on physical, emotional, cognitive and social factors.

"Lay" models of successful Ageing

When older people themselves are asked about what constitutes successful ageing, the same multidimensional model emerges. Fernandes-Ballesteros (18) quotes seven studies that asked various groups of older people: "What is ageing well?"

Five factors consistently emerged as being of importance:

Health and independent functioning

Engagement with life ("enjoy life", "life satisfaction", "interests and goals", "physical, mental and social activity", "social roles", "social relationships")

Attitude and adaptability (variously defined as "sense of humour", "accepting change", "optimistic outlook", "compensating for losses and selecting activities")

Positive relationships ("family relationships", "receiving emotional care", "feeling helped and supported") and

Security and stability (financial, feeling safe at home and in community, access to facilities and transport).

Interestingly, these themes seem to be fairly consistent across diverse cultural contexts. Fernandes-Ballesteros goes further by saying: *"In sum, it can be concluded that a set of key components, such as health, psychological and social components of successful ageing, constitutes a quasi-universal conceptualization in older people themselves."* (18)

Bryant et al (19) conducted a qualitative study of 22 older people. A model of healthy ageing was drawn from the by the participants as **going and doing something meaningful.** He stated that this activity required four parts:

1. Having something worthwhile to do;
2. Having a balance between abilities and challenges;
3. Having appropriate resources to draw on and
4. Having a positive attitude.

Phelan et al (20) highlighted the following as contributing to a sense of wellbeing in older people: accomplishments; physical appearance; being productive; a sense of purpose and a sense of humour.

Central to many of the theoretical models of ageing, as well as the "lay" models, is the concept of maintaining health. If this central pillar is compromised, the possibility exists that other factors such as social support, positive attitude, finding purpose and meaning, may not be enough to sustain ageing well. Yet, despite compromised

health, many elderly people appear to adapt and to continue leading meaningful lives. How does this occur?

Salutogenesis

In 1979, Antonowsky (22) proposed the **salutogenic** model of health. This is an approach that looks for the resources that promote good health and it challenges the dominant model of **pathogenesis** where the focus is on obstacles to, and deficits in, health. He saw health as a *"movement in a continuum on an axis between ill health (dis-ease) and total health (ease)"* (23*).* The theory attempts to explain how people move along the axis towards total health despite stressful situations and hardships.

Salutogenic thinking focuses on the resources of older people. It directly asks the question: *"What are the forces that let people grow old healthily and that lead to 'good' adaptation to age-dependent changes?"* (21)

The core concepts of this theory are Generalized Resistance Resources (GRR) and Sense of Coherence (SOC).

Generalized Resistance Resources are factors that a person is exposed to throughout their life span that cumulatively affect the way that person interacts with the world. They may be internal such as self-esteem, sense of humour, intelligence or external such as social support, cultural stability, religion. Antonowsky defines a GRR as "any phenomenon that is effective at combating a wide variety of stressors" (22).

With repeated exposure to these generalized resistance resources over a lifetime, a person develops a **Sense of Coherence (SOC)**, or "dispositional orientation" (24), that allows them to understand their situation, to find meaning in it and to have the capacity to move in a health-promoting direction (23). Healthy ageing seems to be more possible if the older person can maintain a strong sense of coherence (21).

A strong sense of coherence, according to Antonowsky, involves high comprehensibility of one's world; high manageability of one's outcomes and high levels of meaningfulness in one's life (22).

More recently, a fourth criterion has been added - emotional closeness. This refers to the extent to which one has close bonds to others and feels part of a community (25).

The sense of coherence (SOC) concepts were developed into a scale (26) and used by many researchers. A recent review in 2013 by Tan et al (24) concluded that: "a strong sense of coherence among older people was correlated with better physical, social and mental health"

Eriksson et al (27) described the salutogenic model as a health promotion tool that can improve the resilience of individuals resulting in an improved quality of life.

A sense of coherence was found to help adjustment in both those who were disabled and their partners.(28) And a large study in Sweden (29) found that a sense of coherence actually increases with age, at least until the mid-70s on a population level.

Promotion of a strong sense of coherence should be the focus of gerontological interventions in public health and of our daily practice in family medicine.

Summary of literature review

It has been noted by many that, despite the ageing process continuously challenging the ageing individual, many older people continue to lead subjectively happy and productive lives, appearing to age "more successfully" than others.

In the 1960s and '70s, "Social" theories of ageing such as Disengagement, Activity and Continuity theories attempted to explain the process of ageing. They were generally regarded as one-dimensional.

In the 1980s and '90s, the concept of "successful aging" emerged. The three dominant models were Rowe and Kahn's "usual ageing vs successful ageing", the Ryff criteria, and the Baltes and Baltes "selective optimization with compensation".

Since then Hartmann-Stein et al, and then Bowling, looked at empirical evidence and proposed physical, emotional, cognitive and social factors that seem to be important in successfully ageing. So-called "lay models" of successful ageing seemed to confirm similar factors were important, and these seemed to be similar across different cultures.

The concept of salutogenesis was introduced by Antonowsky. A sense of coherence (SOC) develops in response to a lifetime of exposure to Generalized Resistance Resources (GRR). Studies suggest that a well-developed sense of coherence helps older people cope with the challenges of ageing, and that it may be possible to enhance a sense of coherence in older people.

METHODOLOGY!

Aim

To deepen the understanding of the process of adaptation to deterioration of functioning in the elderly, in a General Practice setting in Cape Town.

Objectives

To interview and record the experiences of elderly people who have had an unforeseen deterioration in their functioning.

To determine the resources used by the elderly in adapting to deterioration of functioning.

To identify factors that elderly people have found useful in adapting to deterioration of function, so that these can be shared with others.

Study design

This is a qualitative study, involving nine semi-structured one-on-one interviews carried out by one investigator. Interviews were conducted at the convenience of the participants in their own homes.

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Study Population

People 70 years or over, who live in Cape Town.

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Inclusion Criteria

People aged 70 years or older, who were previously well, and had experienced an unforeseen prolonged or permanent deterioration in their ability to function in daily life. "Unforeseen deterioration" was defined as deterioration beyond the expected slow deterioration in functioning that accompanies ageing.

Participants had to be able and willing, to communicate well in English. They needed to be cognitively able to fully comprehend the nature of the investigation and able to give informed consent to participate.

Exclusion Criteria

People with fluctuating comprehension (such as dementia) were excluded. Patients from the investigator's own clinical practice were not included so as to maintain a clear distinction between the roles of investigator and doctor.

Recruitment and Sampling

Participants were recruited from four general practices in Cape Town on recommendation from colleagues. Purposive sampling was used. Doctors were asked to recommend people who they felt were "successfully" handling their health challenges. These were people who appeared to be actively engaging in their lives despite their medical conditions. The group consisted of both men and women who could communicate well. Nine participants were approached to participate, and all agreed to be interviewed.

Instruments

An interview guideline (see Appendix A) served as a guide to facilitate more open discussion and to ensure that topics of interest were covered.

Data Collection and Management

Interviews were conducted between May 2013 and August 2013. All interviews were conducted by Dr GH Cleveland (the "Investigator") who received training in Qualitative Interview technique by Mr Craig Irving, who holds a Bachelor in Sociology and runs a qualitative-research company.

The advantage of the interviewer and the investigator (the person doing the analysis) being the same person is that nuances of phrase and body language and notes written at the time of interview become part of the data. All interviews were digitally audio-recorded and then transcribed. These audio recordings and transcriptions were coded and stored on the hard drive of the investigator's

computer. No names of participants were on the research records. The investigator

kept a list of names linked to codes, and the key to the codes was kept secret. Any identifiers linking data to a participant were kept separately from the research record and were destroyed on completion of the research. Only the investigator and the transcriber handled the original interview files. The transcriber was a professional who had been trained in confidentiality and information management.

Data Analysis

Data, which included transcriptions, notes and observations recorded at the time of the interviews, were analyzed using the method of Thematic Analysis. Taped interviews were transcribed immediately after the interviews by a professional transcriber. The process of analysis began after the first interview so as to allow the preliminary results to inform subsequent interviews.

The interpretation process consisted of two phases. First, the audio record of each interview was listened to a number of times, and the transcript, notes and observations from the interviews also read through at least three times, to get an understanding of the participant's experience.

The second phase was the structural analysis. This involved a detailed analysis of the text, aimed at identifying the parts and patterns of meaningful consistency. These "data sets" were systematically coded. These codes were grouped into "basic themes". These basic themes were organized to become the "core themes"

Ethics Considerations

These are discussed under the headings of non-maleficence/beneficence, autonomy and justice.

Non-maleficence/Beneficence

Due to the nature of in-depth interviews and the sensitivity of the topic and the vulnerability of elderly people who had experienced a loss of function, there was a risk of the participants becoming distressed. The investigator was aware of this possibility and actively looked out for signs of distress. If this had occurred the interview would have been immediately stopped and, if necessary, an appropriate referral organized to contain the participant's emotions.

Confidentiality has been discussed above under the heading "Data Collection and Management".

One needs to acknowledge the potential power imbalance between the elderly participants and both the investigator and the general practitioners who had recruited. The participants may have felt obliged to participate, or to continue even if distressed, because of a sense of being beholden to their doctor. The elderly are a potentially vulnerable population to study as they are dependent on others for many of their activities of daily living and resources.

Secondly, the participants might have revealed more than they felt comfortable with, thinking this was a therapeutic as opposed to a research encounter. To prevent confusion of the role of the researcher, no participants were drawn from the researcher's practice. It was also made clear at the beginning of the interview that the investigator was in the role of researcher and not clinician.

The inconvenience and "opportunity cost" to participants needed to be acknowledged. No payment was made, but inconvenience was minimized by doing the interviews in the participants' own homes. In addition, the principle of reciprocity was respected by keeping participants informed about research progress and providing feedback. Published research will be made available to participants at the end if requested.

Although not the primary aim of the research, there were some potential benefits to the participants. This includes the chance to contribute to understanding that will have practical implications in medical practice. The participants seemed to gain a sense of purpose and empowerment as a contributor to the research, and a heightened self-awareness as they reflected on the questions asked.

Autonomy

This involves respect for the person. Fully informed consent was undertaken. Consent was explicitly regarded as a "process" - if potentially sensitive information was disclosed it was ensured that the participant was still comfortable with it forming part of the data. It was made clear that participants had the right to freely decide whether or not to participate, as well as the right to withdraw at any time without penalty.

A comprehensive consent form (Appendix B) explained the study. Participants were assessed as being capable of giving informed consent both by the referring doctor and by the researcher on first meeting.

Justice

This involved avoiding exploitation and abuse of the participants by recognizing their potential vulnerability and acknowledging their contribution to the study as described above.

RESULTS:

All participants were white, middle-class, English-speaking people between the ages of 75 to 90 years old. All lived in an urban setting and attended a private general practitioner or community health centre as their primary health-care provider.

Table 1 shows the participants' demographic data.

The **core theme** was identified while analyzing the data as "In search of a new normal life". (H)

This "search for a new normal life" was made possible by four **themes** of "Groundwork", "Support", "Spirituality" and "Character".

Some of these were further clarified by **subthemes** (Table 2).

Table 1 Demographics

Age	
75–80 years	3
81–85 years	4
86+ years	2
Marital Status	
Married	3
Widowed	5
Never Married	1
Gender	
Women	5
Men	4

Support

Spirituality

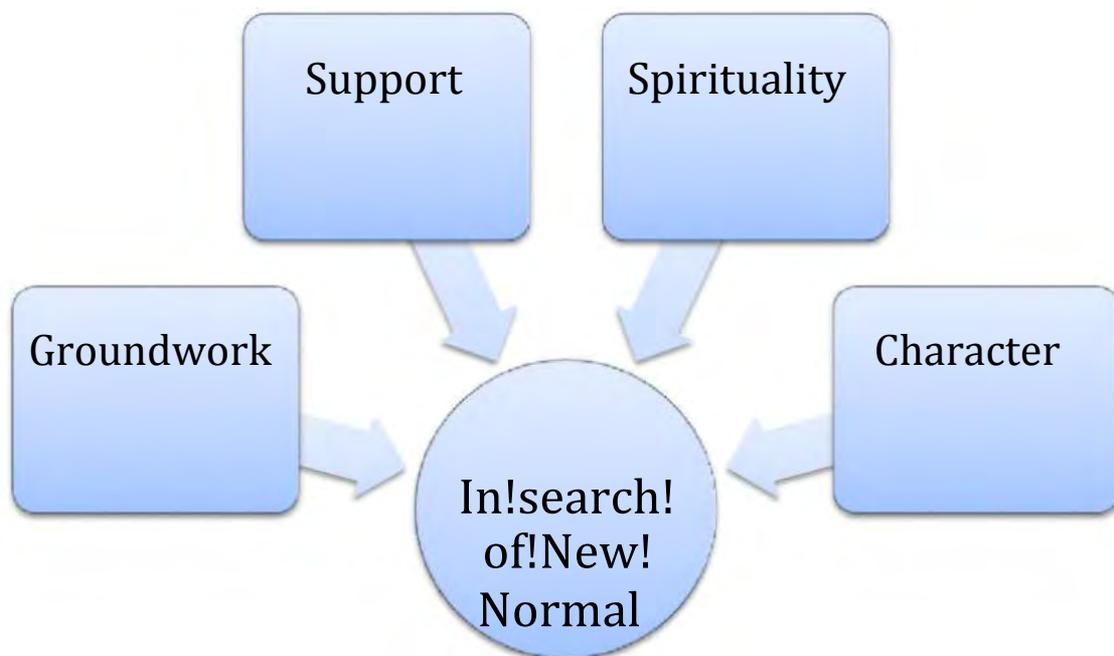Groundwork

Character

In!search!
of!New!
Normal

Table 2 Themes

Core Theme: In Search of a New Normal Life

What emerged strongly from the interviews was that a process of integration of a new health reality into participants' lives was necessary in order for them to move forward, and that this process was, in large or small ways, transformative of them:

"Funnily enough, the following day I woke up, still in hospital, and said to myself there were only two alternatives. One was to live and one was to die… then I knew already that I would never be the same person, I would be a different person." (H)

"I must do whatever I can do to reach my new potential. This is a new potential and forget about the rest." (H)

The name of this core theme came from one participant whose words summed up a process that seems to be a necessary one:

*"…the patient in the meantime tries to set goals in the constant battle to meet the new normal life levels … those objectives move upwards, **in search of a new normal life**." (H)*

The acceptance of a new reality and the integration of this reality into their life going forward seemed to be the key to successfully dealing with the effects of an unexpected deterioration in health:

"…you've got to accept; you either accept or what do you do? Jump?" (B)

"Yes, I think that one must accept." (E)

The acceptance and integration was not a once-off event, but rather a process. The embarkation on this process enabled the transformation. The latter manifested in dramatic fashion:

"After the stroke, perhaps I suddenly realized the urgency in doing certain things. I and a friend of mine (also a "stroker") went paragliding off Signal Hill… We experienced the feeling of weightlessness … after five years of lugging half my body as "dead weight", what a relief." (H)

And in more subtle, but very significant, ways:

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"…people say I'm quieter, I'm not quite as outgoing … I had a lot of time in hospital to meditate and think about things, and I suppose that is quite a positive." (I)

"I am more sensitive to other people, I know that. I'm less self… I'm less selfish…I've learned more compassion." (G)

"…I am becoming far more tolerant." (D)

"I think I like myself more now… I'm a happier person, I'm a more sociable person. I care more." (E)

"I appreciate little things now, which I never used to." (B)

"I'm learning to think more." (B)

This core theme is "In search of a new normal life" and involves a process of acceptance, integration and transformation/self-transcendence. This is facilitated by the following four themes that explain, partly, how it can happen.

Theme'1: Groundwork

Groundwork describes the preparatory steps that participants took, both before and during older age, that they felt was now helping them cope. The theme is described by subthemes of "Physical", "Intellectual", "Financial" and "Social".

Physical
Most participants stressed the importance of physical exercise throughout their lives and into the present:

"…I was always keen on physical development and training. I was strong, robust and full of the joys of spring." (A)

"…I feel I was a reasonably fit person." (F)

"…I am known as one of the hard workers in aquarobics … I reckon I'd have been dead … it kept my heart going." (G)

"…it was the degree of fitness that I had … if I had not done that I would have died." *(H)*

Intellectual

Participants stressed the importance of two aspects in particular. Firstly, they felt that cultivating enduring interests in life was essential:

"You must try and develop an interest that will hold you in those years where you can't walk around very much, where you are limited, perhaps you can't drive, you mightn't be able to afford to drive, where you need companionship, where you're lonely." (A)

"We have the resident's association … it is like the House of Commons, and I am an MP, and my portfolios are education funds, the library, news and views, the magazine, the garden club and the choir." (G)

Interests mentioned were reading, bridge, hiking, gardening, dancing ("I was an 'In the Mood Dance Club' fanatic" [F]) and helping out with others in need:

"…I've been a volunteer at Highland House, the Jewish old age home… that's my baby and I look forward to a Tuesday to go there'. (C)

The other interesting aspect of "intellectual groundwork" was training and information gathering. Participants stressed the importance of gathering information about their medical conditions and about what effects they would have:

"Understand everything there is to understand." (H)

In addition, practicing and training in their new reality was important. One striking example was someone with progressive macular degeneration who was coaching herself to prepare for blindness:

"I am preparing for it… learning to turn taps off hard … finding my way around in the dark. Sometimes I do that just for fun." (G)

Some suggested that perhaps training should be started a lot earlier than in old age:

"I think at one stage of one's life we must go through a training. I think here by 50, or even 40s, we could even have a course running: 'How to cope'." (E)

Financial

Almost all participants brought up the importance of money. Some said that they did not have much but could get by. Most said that they wished they had more. Most did not realize that their old age would be so expensive:

"…I should have financially tried to provide more for myself." (E)

"…to have plenty of money, you need it today, which I haven't got. That's important." (B)

Social

Consciously, or unconsciously, most had built up a supportive social network. Some had done so their whole lives, while others only started this in older age when other interests and activities fell away.

"When I came into this retirement village I was very involved…" (I)

Many realized the importance of "paying it forward". Helping others with the understanding that someone would do the same for them when the time came:

"…I have done shopping for others … I am sure somebody will shop for me." (G)

Theme 2: Support

These are the important external factors that helped participants in successfully engaging with the challenges that come with ageing. The theme is described by subthemes of "Family and Friends", "Accepting Help" and "Expectations of Doctors".

Family and Friends

This was the most universally quoted source of external support:

"I was very fortunate in that I had a very supportive family… I have a very supportive wife." (I)

"…my children are very caring, very concerned." (C)

"But my son is unbelievable … I actually could not cope without him." (B)

"My wife's been – oh, she's tremendous, you know." (F)

When all family members are out of the country, support and involvement from a distance are important:

"I'm involved in every way… they think of me … send me photographs … my involvement with family is quite incredible, actually." (D)

Even where no blood relatives existed "family" was still important:

"I have been a surrogate mother to a whole host of them… that's family… the people who know me, put up with me and love me…" (G)

Friends follow close on family as a source of practical and emotional support:

"I actually couldn't cope without X, to be honest with you." (B)

"…this good friend that I made – and she's really like a sister to me, she is caring…" (C)

"We have some wonderful friends, and you can't survive in this life without friends, but one has to learn to accept and appreciate them." (I)

"I didn't go to Friday night synagogue… I was missed as a person, not because they missed me because I wasn't there to pray. I was missed as a person, which makes me feel good." (C)

One participant found encouragement and understanding from members of a support group. They had become friends because of a shared experience: all were learning to live with the same medical condition:

"…there's a special group of people … who were hit at the same time by this thing, and they relate to each other. The important thing is that they all know what the other person has gone through … sometimes one of us will get in there and say, 'You know what I discovered…'. If you do something like this…. it has got tremendous value." (H)

Accepting Help

The concept of asking for help came up strongly in the interviews. Participants remember making a conscious decision at some point to actively ask for help, and the experience seemed often to be accompanied by a sense of relief in not having to carry on completely alone:

"So I was my worst enemy. I didn't go out there and say, 'Will somebody please help me?'… I've learned now that it's ok to ask… Okay, if you've got to cry, cry, but don't be too proud to ask." (E)

For some, to accept offered help was as active a decision as asking for help:

"Yet I'm old now, you know, this is the whole thing, and then you realize that you do have to have help and assistance in things." (D)

"…if somebody gives you advice it's a good idea to take it, and not say that 'I can cope on my own'. I do need help and if it's offered I should accept it. You've got to accept help and also guidance." (I)

Expectations of Doctors

Doctors could, in theory, be a source of support to their patients that are in similar circumstances to the study participants. Interestingly they were, in the main, not mentioned as such. However, because one of the objectives of this study is to inform health-care workers to better care for the elderly, the question was specifically asked of participants: "What can doctors do better in caring for the elderly?"

These were the factors that participants felt were important:

Time and Thoroughness

Participants appreciated being examined:

"He was fantastic. I mean he examined me and made me do things; I had to press against him and he – to feel if I had any strength in my legs, in my feet, in my toes, in my arms. You know I can only speak good of him now." (C)

And felt quite neglected when only "targeted examinations" were done:

"You know, he can jump up and he just feels your pulse in your foot and says, 'Right, there you are, off you go' … is my blood pressure or the rest of me all right, and he doesn't even bother with it." (F)

Lamented was the passing of the era where family doctors seemed to have time:

"You know what I do miss? … If I called a doctor he would come here, he would talk to me. That doesn't happen anymore. They're too busy. I mean even ***, he's a lovely doctor but he's busy…"(B)

"…the trouble is that often you are so busy… it's like a rabbit warren, it's churning out. You can't give them much time." (G)

Participants felt that this lack of time pressurized the consultation, and constrained their communication with their doctor.

Listening and Empathy

One participant expressed this beautifully:

"Doctors don't listen enough. I want to tell them but they are in a hurry, so I don't like to worry them… I think I know what the approach (should be): to say, 'Is there something worrying you, really worrying you? Tell me if there is,' rather than 'Yes, what can I do for you?'" (G)

"I think that's what doctors need sometimes… a different look at this person, not 'My Patient', but 'This Person'." (G)

This is straight out of the principles of Family Medicine.

A common complaint was of not being really heard by their doctor:

"I suppose doctors should listen… they are inclined to discount what old people say: 'Oh well, that's just old age.' But it's not necessarily old age. One should listen to what people have to say and maybe be more understanding of people who are older." (I)

"…I kept telling him, not once, not twice. I don't know how many times… he should have said, 'We'll go into it', but he never did…" (C)

"…I have noticed that they become very impatient because they have seen it all before and they think you should have seen it too." (D)

Expense

Many felt that the cost of consultations limited their access to help:

"It's difficult for people …what was a doctor's consultation when I was working? R30, R33 … that's probably a house doctor, and then they got their money's worth for half an hour." (E)

"…and they're bloody expensive." (B)

"…doctors should be careful about charging their fees to old people who are not finding it easy to make ends meet, and I think a lot don't." (A)

Theme 3: Spirituality

Spirituality was a very important theme that emerged. It is described by the subthemes of "Religious Wellbeing" and "Existential Wellbeing".

Religious Wellbeing

This is the traditional side of spirituality – the involvement of a god in one's life and the role of religious ritual. Participants talked about an ever-present God as a source of support, and of the importance of attending a place of worship for the companionship and sense of community. When pushed as to whether attending a place of worship was important mainly because of communion with their God, or communion with other people, most said that both were equally important:

"I believe in God and I believe that He's looked after me and that's why I am as I am today." (C)

"My faith is important to me. I'm not too concerned because I know someone else is looking after me. It takes away the worry from me." (F)

"It [the church] means everything to me. It's there for me, it's… I don't know – I can't imagine my life without it. It's the fellowship and my relationship with God…" (E)

"Oh yes, I couldn't survive without it. I have always believed in HaShem, in God." (B)

'I not only believe in Christ and God but I believe in love, and I try and live love in my life… It's been a pattern in my latter life … say from 60 onwards."(A)

Existential Wellbeing

Existential, or personal, wellbeing refers to finding meaning in a given situation. Most participants experienced this by playing a meaningful role helping others, and when they spoke about it, they did so with animation and passion. It was obvious that helping others around them held great meaning:

"To be needed as a friend or needed as an advisor is, I think, very, very important… and you need to care for other people. You need to care. You need to ask where you can help, even if you can't help and you know you can't, just say, 'Look, if you need something you come and ask me. If I can help, maybe I can't, but if I can…' And I mean, it's not idle… You can give somebody a good compliment and make them feel that they are great. Give compliments. Give compliments. Say yes when you can, and not no." (G)

For some it was obvious that doing something for others had helped pull them out of a dark place:

"…I sat being miserable and depressed, and feeling sorry for myself … and I just happened to hear somebody talking about wool and knitting … and I said, 'What are you girls talking about wool?'… 'Oh, we get wool from St Margaret's and we knit for the children.' I said, 'Dear God, just bring me some wool. I can do something for children.' And I've never looked back – and I've got more involved." (E)

Activities that involved helping out seemed to revitalize and energize the participants. This came through strongly in their body language and animation in the interviews. It was clear that giving was hugely beneficial to the giver:

"…I go every Tuesday morning [to a home for senior citizens] … and I help in the hair salon. I pass the rollers, I bring the old ladies in when they are in a wheelchair or, you know, that just need help, and I love it. That's my baby, and I look forward to Tuesday to go there." (C)

"You know, the thing that interests me most apart from my family in my life now is carting people round to the doctor… I just wish that I had more of that because – and I don't allow payment of any sort. This is my contribution to this village, and if they insist on paying they take all my pleasure away… it's the only thing I can do for this village because… I can't stand for any length of time because of this compact ankle… I'd like to do more in assisting older people because there are a lot of lonely older people in a place like this." (A)

Others found existential wellbeing in meaningful encounters with others. Outward focus from self and the vulnerability that circumstances had brought about led many to appreciate people differently:

"And people who I never thought would become a friend have become a friend of mine, because they visit and they come and talk, and suddenly you realize that this person has more to them than you ever thought they had, and that's perhaps what I'm learning – one of the processes of this whole thing is that there's more good in a lot of people than you ever give them credit for." (D)

"I'm more sensitive to other people, I know that. I'm less selfish… and I have learned to appreciate people for what they are." (G)

"So I've realized that you've got to appreciate people for what – you know, not necessarily for what they do for you, but just for being there. I think that's important, just to appreciate them and to reciprocate." (I)

"…and trying to listen and to shut up, you know what I mean, to really shut up. I've got to actually tell myself, 'Shut up, you're here to listen.' … There are so many people living here alone and that haven't even got children, so that all they want to talk about is just whatever happened 10, 20, 50 years ago." (E)

Some found meaning in choosing to adopt a different attitude in the face of adversity. This man found it empowering, after a severe stroke that left him immobile, to choose a path where it was up to him to get better:

"That was when I hit the bottom. Funnily enough, the following day I woke up, still in hospital, and said to myself there were only two alternatives. One was to live and one was to die. So I thought to myself that, 'Okay, this is going to take a long time.'"
(H)

Lastly, some found meaning in simple, everyday experiences that were, perhaps, previously not significant:

"Enjoy every day… well, if it's not every day, enjoy everything that is enjoyable… enjoy very simple things."(H)

"Or just pick up the wife and say, 'Well, look at this, look at that, isn't this mountain beautiful, and the sea and this and that' … but a person has got to find out what's important for him." (H)

"…just stop and sometimes just be conscious." (B)

Theme'4: Character

In the interviews with the participants, who had all been faced with an unexpected health event and were in the process of adapting to a new reality, it became clear that they shared certain character traits. The most prevalent were the following:

Adaptability and an ability to keep learning
Each participant in the study had had to adapt due to their change in circumstances. Some adaptations were large, and some relatively minor. Some seemed to embrace the challenge:

"I am preparing for it (blindness). I am learning… I am coaching myself." (G)

"We're state patients, we go to hospital… I had to be in for three nights. I went to a bed in that huge ward … and I was the only white. I had the most interesting time, marvellous time…" (G)

"You learn a lot by visiting over there (frail-care). I've learned a lot. I've learned to be gentler with people…" ["So you're still learning?"] *"I hope so. I hope so. Till the day I die." (G)*

And some had reluctantly been compelled to adapt:

"I had lots of time in hospital to meditate and think about things… so maybe it's time to improve my life and change things." (I)

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"That is how I have had to adapt." (B)

"I had to adapt, to not be impatient… you learn to adapt and to fit in…" (E)

An ability and willingness to learn facilitated this adaptation

"You know, you learn when you're old what you should have known when you were young." (B)

"I always try something else, you know, to improve, to walk… I decided I was going to get a driver's licence [after his disability] *and so I went through the whole performance: I talked to people who had to do something mechanically to the car, I then went to a school…who taught me how to drive again … and finally I got it." (H)*

"I have learned now … how it is to be patient … I was not a patient person before." (H)

Determination and an ability to be proactive

Most participants talked about the determination that it had taken, and was taking, to deal with the changes in their lives. What was interesting was how proud people were of this trait in themselves. Some felt that they had always been determined, but many expressed pleasant surprise at the degree of determination that they had been able to draw upon when tested. One got a sense of inner resources being activated:

"I think I'm quite proud that I can accept it, just as I can accept death." (G)

"Sometimes there are people who say, 'Oh, you are very brave', or something like that. I don't think so. I think it's a thing that I felt within me, from that low point coming up and growing inside." (H)

"I got control of that, but I got it right here first…" [points to her head] *(E)*
"Because it takes a lot of determination." (E)

"…I think my sheer determination to stay alive must have kept me going." (I)

" So they thought I was being very brave to face it like that, and that is quite frankly how I face it every day." (D)

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"But there is a determination from me to get back onto my feet again and to take up my life where it seemed to have stopped for a while." (I)

"I must have been very strong, but I was able to cope with that. I was able to cope because I think I wanted to survive this…I didn't want to go just yet." (I)

Hand in hand with determination went a proactive attitude. At some point in their process, most participants had had to actively take steps to start changing things:

"So from that day onwards I looked at therapy as something that had to be done, and it was through that that I would recover." (H)

"…when anybody says, 'No, you can't do that', well, I feel like then I must start immediately…" (H)

"Once you convince yourself that you have to achieve it, it might take some time to get there, but you'll get there." (H)

"… so then I took over. I phoned, I made an appointment, I went…" (C)

One participant summed up the attitude well:

"I mean to live until I die." (G)

Lack of Self-Pity

"…pity is the one thing that must not come in this, you know, and self-pity is the killer." (H)

"I don't sit and dwell, or you know – with, 'Things are so bad, and I'm lonely.' I don't think like that; I'll come home and I'll do what I have to do." (C)

Humour

"I was always the sort of clown around there…" (H)

"I think your sense of humour, very important…" (E)

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"I've got a good sense of humour… I've never lost it, yeah." (F)

!

DISCUSSION'

What this study shows is that the elderly who seem to be coping well with health challenges have undergone some form of transformation or self-transcendence. The study further shows that four of the most important factors that facilitate this process are:

Groundwork - physical, intellectual, financial and social. Support –
family and friends, and the willingness to accept help. Spirituality -
religious and existential wellbeing.
Character - adaptability and learning, determination and being proactive, lack of
self-pity, humour.

The central process has been variously described by other authors as
"transformation", "integration" and "self-transcendence".

Transformation

Kat Duff (30) writes about her own illness in her book "The Alchemy of Illness": "The alchemists insisted that two things must happen before the cure can be extracted from the disease. The problem must be kept in a closed container, and it must be reduced to its original state through a process of breakdown. The limitations and immobility of illness provide the closed container that enables this **transformation** precisely because there is no way out".

She goes on: "I realized that my illness had come to serve the function of initiation… these (initiation rites) are intended to prepare the individual for the powers, privileges and responsibilities of the phase of life they are entering, by actually cultivating the strengths and awareness that will be needed."

A meta-study (31) looking at the concept of transformation in people of all ages living with chronic diseases describe three distinct phases of transformation.

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The "Initial Reaction Period" lasts up to five years. The diagnosis of a chronic illness causes a personal response, and a response from significant others. This triggers a "catalytic experience" that acts as a turning point.

This is a stepping stone to the second phase: "Embracing the Challenge" where those affected make a decision to acknowledge the challenges with which the disease presents them. This includes "taking stock, exploring, experimenting and learning". In this phase, critical reflection leads to adjustments being made, such as changing one's perspective and differentiating the self from the body.

The last phase of the transformation process is described as "Integration of new ways of being" (32). In this phase a person identifies and experiences the outcomes of the transformative process, some of which are described as "heightened sensitivity to life, objectification of the body, desire to make a meaningful contribution and service to others" (32). This mirrors some of what is discussed in the section on existential wellbeing in the section on "spirituality" above.

The authors (32) describe this model of transformation as being "surrounded by a penetrable boundary that represents the social and personal contexts, which includes interaction with peers and health-care professionals, social support and the person's own willingness and ability to transform". Again this is mirrored in what is described above as the four themes that facilitate transformation.

In the meta-study (31), the authors make the point that most people appear to go through this process of transformation on their own. They have contact with health care practitioners, but for the most part these contacts are seen as a "minor part of their lives". Indeed, these contacts are often considered a frustration due to the medical model's focus on disease control having little meaning in their lives.

The authors end by stressing the iterative nature of this process of personal change, and suggest that health-care providers act as facilitators of the process by making themselves aware of the different stages of, and possible barriers to, change.

An integrative review of 18 studies (32) explored the experiences of people living with heart failure - a condition that mainly affects the elderly, is incurable and is, essentially, a terminal disease. One of the major conceptual categories that emerged was "Concept of Self". The effect and impact of the illness caused people to have to re-evaluate their lives, and ultimately their concept of themselves. The authors (32) describe it as "reconstructing their self" and "affirmation of a new self", and

their success at this is dependent on how the person manages to "create a relationship with the illness and (position) it within their essence or sense of self".

Again, as in my study, there are certain facilitating factors that aid this transformation. Collaboration from family, friends and neighbours was important. Being "of use" to themselves and others by fulfilling certain roles was mentioned as being important. Religious spirituality was also listed. Lastly, positive coping behaviours emerged as a common practice among study participants: "making the best of it", "getting on with it" and "refusing to take on the sick role".

Similar complaints about health-care professionals' "lack of time" and the perception of "not being heard" came up, and the importance of a trusting, ongoing relationship with a health-care professional as "pilots to support them in making decisions and to offer guidance through periods of instability" were mentioned.

These authors conclude by stressing that an essential care component for people living with heart failure should be an ongoing assessment of the patient's experience of the situation that they live with. One could make the assumption that the same would apply to elderly people living with any significant ongoing health issue. The authors go further and describe this type of care as both "ethical and a prerequisite".

A qualitative study (33) of personal transformation was conducted with retirement-aged adults who were living with chronic skin wounds. The research was grounded in Newman's theory of health as expanding consciousness (HEC).

Newman (34) proposes that individual human development is the process of continuous and innovative change, as the human interacts with its environment. Consciousness is defined as the information of the system (the human) and its "exchanging capacity" with the environment. Newman proposes that health is manifested in the process of "expanding consciousness". This would happen when a period of relative stability is disturbed for example by an illness, triggering transformative stages. The first stage is Binding, where persons do not distinguish between themselves and the group (as in childhood). Then comes Centering, where people become aware of a sense of individuality through a process of trial and error. This is followed by a stage of Choice, where illness or circumstance disrupts daily living. This is a turn of consciousness with a realization that life is now different. A person moves towards a deeper awareness of self and realizes the need for new behaviours to solve problems. This is followed by Decentering, or "boundarylessness", where new behaviours have been learned and transformation

is happening. The last is Unbinding, or timelessness, where there is a higher level of freedom.

With time, this process becomes increasingly diverse and complex, allowing the individual to respond to the environment in a myriad of ways. Inherent to it all is pattern recognition, the ability to allow individuals to "apprehend the meaning of the whole in which one's past, present and future in the world become clearer and impart increasing definition and direction" (33). In short, to "transform, grow and choose order out of turmoil" (33).

With this background, Rosa's study found strong links between an individual's past experiences, their psychological processing of these experiences and their present-day ability to react creatively to present health challenges. She further found that a close, ongoing therapeutic relationship between a skilled nurse who was able to support, reflect and validate an individual with chronic skin wounds, resulted in both better healing and enhanced self-care and ability to make lifestyle changes. Participants integrated their problems, created deeper connections with others, and accelerated personal growth and healing" (33).

Rosa's findings are echoed in the process of transformation described in my study. This adds weight to the call for health practitioners who work with the elderly to look beyond the biomedical model, and to knowledgeably facilitate this transformative process.

Rosa proposed a model called a "Process Model of Wholistic Healing and Personal Transformation", which describes this facilitation of transformation. It has implications for care of other groups grappling with chronic illness, including the elderly.

Integration

Integration in chronic illness has been described as "a human-environment interaction whereby new life experiences are reconciled with past and present identities and roles" (35).

Dungan (36) suggested a model of dynamic integration in which integration was defined as "optimum functioning and the integrity of one's body, mind and spirit within a constantly changing environment".

Another definition of integration is "complex person-environment interaction whereby

new life experiences such as transitions, illness, self-management are assimilated into the self and activities of daily living resulting in an overall life balance" (37).

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A study of how adults with chronic illness integrate the illness experience into their life context (38) found the process to be "non-linear and unpredictable". Study participants reporting a "fluctuating tension between living a life and living an illness". As described elsewhere, support in the form of family and friends, support groups, church groups and health-care providers, was an important facilitator. Again, as described in my study, connecting with others, finding purpose and engaging in meaningful work and activities were all-important facilitators of integration. Other facilitative aspects were spirituality, humour and focusing on the positive.

SelfRTranscendence

Flood (39) proposed transcendence as one of the most important predictors of successful ageing.

Maslow (40) identified transcendent behaviours as: "moving beyond weakness, fears and dependency; transcending the opinions or expectations of others; achieving a sense of unity with oneself, others and a higher power; and possessing an awareness of a greater meaning in life".

Reed (41) described transcendence. as a developmental resource that was a gradual, nonlinear expansion of one's personal limits or internal rules, and expectations of oneself, others and the world. This expansion transpired within four dimensions:

1: Expansion of *intrapersonal boundaries* involved a greater awareness of one's own values and dreams (introspection).
2: Expansion of *interpersonal boundaries* involved expanded and changing interaction with others and the environment (concern about others welfare).
3: Expansion of *temporal boundaries* allowed integration of past and future to make sense of the present.
4: Expansion of *transpersonal boundaries* relates to connection with dimensions beyond the here and now.

She found that "transcendent individuals were able to tolerate greater ambiguity and uncertainty" and that "the outcome of self-transcendence was wellbeing, marked by life-satisfaction, positive self-concept, hopefulness and a sense of meaning in life" (42).

She asserted that self-transcendence is an inherent part of maturation and development but is especially triggered when individuals are "faced with a loss, trauma or illness that created a sense of vulnerability and awareness of mortality" (42).

It builds on the idea mentioned above of conflicts arising from human-environment interaction generating energy for development, that "the multiple health-care problems and losses that accompany the ageing process may provide energy for the older adult to adapt and overcome the challenges and hazards of daily life" (43).

McCarthy and Bockweg (42) developed a model of "Transcendence in Maturation and Ageing", to provide a theoretical framework for cost-effective and effective interventions to facilitate this process in the elderly. They identified "antecedents of transcendence" that seem to promote it. These included:

- belonging in a family, group or community
- self-actualization
- spiritual activities
- sense of connectedness with self, others and God
- sense of purpose or meaning
- productive engagement
- sharing wisdom with others
- altruism
- increased self-acceptance and acceptance of others

Luchtman Harrison (43) lists "involvement in community, exploring new outlooks on life, sharing experiences with others and finding spiritual meaning".

All of these echo the experience of my own study participants.

Transformation, integration and self-transcendence describe parts of the same concept. It seems that what has been described by these various authors in populations dealing with chronic illness applies equally to my study population of the elderly dealing with a permanent change in their health.

What seems clear is that part of our role as health-care providers should be to familiarize ourselves with this transformative process and its facilitating factors, so that we can support and accompany our elderly patients on this journey.

Areas of future research should be to look at practical interventions that might aid the process.

How is the present study similar to the literature?

The findings of this study show a process of personal transformation that is triggered by, and helps to make sense of, chronic ill-health. It is a process that allows continuation of a meaningful life.

It describes facilitating factors that help drive the transformation. Specifically, "support" (family, friends and community), "spiritual and existential wellbeing" (finding meaning in activities), and "character" (humour and positivity) are mentioned in previous studies.

The study highlights the fact that, although this transformative process is essentially a "lone journey", it may be open to intervention by the health care system. The potential for this is in two areas:

1: Both this study and some previous studies, discussed above, describe the limitations of our present biomedical model when it comes to the elderly and chronic illness. They also describe the frustrations that some elderly experience with doctors. Therefore, educating ourselves as health care workers about this, and making appropriate changes to perspective and practice in treating the elderly, can be helpful.

2: Because the transformative process is iterative and is helped along by factors such as social interaction, involvement in meaningful activities, proactive and positive outlook , health care workers could be trained to intervene at various levels and steps along the way to facilitate the process.

How is the present study different to the literature?

Most studies looked at chronic disease irrespective of age whereas this study looked specifically at the elderly with deterioration in function. (More especially at a group who are "ageing well" despite chronic disease.)

This study is the only one so far to look at this topic in the South African context

Two factors facilitating transformation were not mentioned in previous studies. *These were a conscious acceptance of the the need to ask for help (*At some stage in their process almost all participants found that they consciously had to do this, and it turned out to be an important step for them) and the *character traits of adaptability and the ability to keep learning*

What does the present study add to our knowledge?

The Elderly are capable of growth and transformation.

This transformation and growth seems to be necessary in the face of failing health in order to carry on living a life with meaning.

This transformation is facilitated by quantifiable factors, some of which may be able to be learned.

Implications for Practice

Health-care practitioners need to look beyond the biomedical model when working with our elderly patients. Ill health is more than just the disease. It also involves spiritual, social and psychological dimensions that all contribute to the goal of continuing to lead a "meaningful life".

We need to be aware that, in dealing with ill-health in old age, our elderly patients may be going through a transformative process. We need to be ready to assist them if needed. Further research in this area would be helpful to develop practical interventions.

Based on what has been learned about the factors that facilitate transformation, we need to educate adults about what measures they can put in place to prepare for their old age.

Limitations of the study design

There has been much debate about how one ensures validity in qualitative research, or indeed, whether it is even possible to do so.

Many qualitative researchers now subscribe to the ideas of Guba (44) when it comes to assessing the "trustworthiness" of their research. He proposed four criteria by which qualitative research could be assessed:

a) credibility (in preference to internal validity)
b) transferability (in preference to external validity)
c) dependability (in preference to reliability)
d) confirmability (in preference to objectivity) (45)

I will look at this particular study's design according to these criteria.

Credibility:

The following provisions were made in this study to promote credibility.

a) Adoption of appropriate, well-recognized research methods
b) Development of an early familiarity with the culture of participants, through the researcher interacting on a daily basis in medical practice with elderly patients in similar circumstances
c) Ensuring honesty in informants, through establishing early rapport, making it clear that participants could refuse interview or withdraw at any time, and emphasizing the independent status of the researcher
d) Member checks. This was done with two participants only, and should ideally have been done with more. This was done in two ways. First, accuracy of the raw data was checked with two participants by asking them to look over transcriptions of their interviews. Second, emerging themes in the analysis phase were checked with the same two participants.
e) Examination of previous research findings to check congruency of results with those of past studies

The following provisions, which might have strengthened its credibility, were not made in this study.

a) triangulation, by using different methods (interviews and focus groups) and different sites

b) frequent debriefing sessions between the researcher and supervisors

c) peer scrutiny of the project

d) a reflective commentary by the researcher, to give insight into decisions taken in process of research

e) "thick description" of each participant's context

f) independent validation of themes by another researcher (cost constraints)

Transferability

All forms of data in their original form have been maintained in order to promote the criterion of transferability. Again, " thick description", more descriptive detail about the context of the participants, would have been helpful to do the same.

The socio-economic characteristics of the study participants were all similar, namely urban-dwelling, middle-class elderly. This obviously precludes making generalizations about the findings to elderly with different socio-economic characteristics.

Dependability

Guba (44) stresses the close relationship between credibility and dependability. What would have strengthened dependability in this study would have been to use triangulation of methods, for example focus groups as well as interviews.

More detail in the description of the study methods also would have strengthened this criterion

Confirmability

Three factors, if implemented in this study, would have strengthened its confirmability – triangulation, an ongoing reflective summary and an audit trail. Triangulation would mean confirming the data using a different source or technique. A "reflective commentary" (45) is a commentary by the investigator throughout the process of research of the investigator's thought processes in an attempt to reveal his beliefs and assumptions. A diagrammatic audit trail would " allow any observer to trace the course of the research step-by-step via the decisions made and procedures described". (45)

Strengths of the study design

The qualitative design with in-depth interviews lends itself to describing and analyzing a topic which is complex, multi-layered and involves descriptions of emotions and beliefs.

CONCLUSIONS:

The research has met the objectives of documenting the experiences of elderly people who have had an unforeseen deterioration in their functioning. The

resources used to adapt successfully have been described and understanding what elderly people have found useful in this adaptation has been developed.

The experience has been recorded, and the process and feelings accompanying it, have been richly described by the participants own words.

Both the revealing of a process of transformation in the face of deterioration in function, and the enumeration of facilitating factors to this transformation, describe the resources used by elderly and the factors that can be shared with other elderly, younger people interested in preparing for older age and health care workers involved in working with the elderly.

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Interview Guideline

Please give some thought to the following questions before our interview.

1: What has been the impact of this condition on your life?

   – think broadly, including how it may have affected your roles and relationships, your enjoyment, your attitudes, etc.

2: What aspects of your life may have made the process of dealing with this easier?

3: What do you think are the important features of "Ageing Well", and have your ideas about this changed with time?

4: What can you tell other people about what it is like to go through this process that would help them if it happens to them?

5: What can you tell doctors about what it is like to go through this that would help them better care for others going through a similar process?

Interview Guideline

Consent to participate in research

A Study Looking at the Experience of Adapting to a Change in Health Circumstances

You are being asked to participate in a research study conducted by Dr Gregory Cleveland ("the investigator") in completion of his Masters in Family Medicine at the University of Cape Town. The study investigates the experience of attempting to adapt to a deterioration in the ability to function. You have been selected because you fit into the particular group involved in this study.

Purpose of the Study

I believe that we can learn a lot by understanding how older people adapt when they face a loss related to their health. The study aims to gain a deeper understanding of how older people meet these challenges. It is thought that with a better understanding, health-care workers could provide better care to this group.

Procedures

If you agree to volunteer to participate in this study, you will be asked to do the following:
The interviewer will conduct one interview with you, lasting approximately one hour.
The interview will be audiotaped so that a detailed study of it can be made.

Potential risks and discomforts

There are no clear risks in this study, although it may be uncomfortable to talk about some subjects that are sensitive to you. You will only be asked to share that with which you are comfortable.
The investigator appreciates, and respects, your time.

Potential benefits to participant and/or society

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There are no direct benefits to you in volunteering for this study. However, in the longer run, there should be benefits to those older people who receive health care from better-informed health-care workers.

Dispersal of study findings.

The results of the study will be communicated with you if you wish. Others who see the results will be those supervising and examining the thesis, and those who provide health care for older people. Information may be published in a medical journal, and presented to health-care workers and others in the care of the elderly.

Payment for participation

There is no payment for participation in this study.

Confidentiality and anonymity

Anonymized interview transcripts will be available to the research supervisor, Dr B Schweitzer from the Division of Family Medicine at UCT, and a professional transcriber only.
The final research dissertation and any publication will not carry your name nor identifying details, but the thoughts and ideas of all participants will be presented.

Participation and withdrawal

You can choose to volunteer for this study or not. If you have volunteered, you may withdraw at any time of your choosing. You retain the right to not answer any question that you find disagreeable or unacceptable.

Identification of the investigator

Dr Gregory Cleveland
Longbeach Medical Centre
13 Carlton Close, Noordhoek
7979
(021)7853900
gregcleve@me.com

Rights of research subjects

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study.

If you have any questions regarding your rights as a research subject, contact the Research Office at the Faculty of Health Sciences at University of Cape Town on (021) 650 4015.

Signature of Research Subject

The information above was described to me by…………………………………….
in English and I am in command of this language. I was given the opportunity to ask questions and these questions were answered to my satisfaction.

I hereby consent voluntarily to participate in this study. I have been given a copy of this form.

…………………………………………..

Name of subject/participant

…………………………………………..   ………………………….

Signature of subject/participant   Date

Signature of Investigator

I declare that I have explained the information in this document to

……………………………………………   (name of participant)

He/She was encouraged and given ample time to ask me any questions. This conversation was conducted in English.

……………………………………….   …………………………..

Signature of Investigator   Date