

**Older persons and the New Zealand health
system:**

A user perspective of service provider attitude

Peter Ivan Simunovich

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Department of Public Health and Psychosocial Studies

Abstract

The purpose of this study was to phenomenologically examine the question, “How do older New Zealanders experience the attitudes of healthcare providers?” Much literature is framed around the viewpoint of the healthcare providers’ experience, yet little is available from the perspective of the older person residing in the community. Through an interpretive phenomenological process it was possible to listen into and draw meaning from the participant’s stories and attempt to give voice to older individuals’ lived experiences of health provider attitudes. The study utilised a hermeneutic phenomenological methodology as guided by the writings of van Manen and strongly influenced by Heideggerian philosophy. Participants were recruited from the greater Auckland area through communication and placements of advertisements with Age Concern calling for volunteers. The researcher, using unstructured interviews, explored the lived experiences of six community dwelling participants over the age of 74 years. Stories were transcribed then read and re-read to reflectively reveal emerging themes. Three overarching themes became apparent: those of feeling diminished; being forgotten and being resilient. The stories were carefully analysed by reflecting phenomenologically upon the participants’ stories. Examples were drawn from the texts which illustrated the underlying meaning from both the spoken and unspoken words residing within as reflected by the researcher’s interpretive depiction. The findings uncovered a deeper understanding of how the participants experienced their healthcare providers’ attitudes. This revealed that the way in which one chose to experience life may affect one’s encounters with healthcare providers though this should not be solely relied upon to ensure a satisfactory, compassionate experience. It is suggested that the approach of health providers to older people ought to be more considered. This combined with the application of better communication skills may provide simple yet effective tools with which to help reduce the likelihood of feeling diminished or forgotten. The study recommended education for health providers likely to encounter older people in the course of their work, should look to inform and provide an understanding of the potential negative and positive effects of their attitudes towards older persons.

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Attestation of Authorship

I hereby declare the this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.



Peter Ivan Simunovich 23/04/2015

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I dedicate this thesis to my mother, Louisa, who to my deepest regret passed during the production of this work and was never able to see the completion of the project she inspired.

I love you and miss you.

Chapter one

Introduction

So many people are shut up tight inside themselves like boxes, yet they would open up, unfolding quite wonderfully, if only you were interested in them.

— Sylvia Plath, *Johnny Panic and the Bible of Dreams*, 1968

The term ageism has been used for over four decades to describe a discriminatory attitude toward older people (Butler, 1969). Research has established the prevalence of such negative stereotypical views in this population which, when reinforced, may contribute to poorer self-maintenance behavior and a higher probability of earlier mortality (Stewart, Chipperfield, Perry & Weiner, 2011). Many national health policies acknowledge the existence of inequitable treatment of older persons and attempt to manage the existence of discrimination through a variety of strategies.

In New Zealand, the manner in which older people are considered in society has been the subject of much discussion and remains a concerning issue given the increasing age profile of the population (Ministry of Health, 2004). It is particularly pertinent as baby boomers become eligible for Government-funded universal superannuation as they reach 65 years of age.

Little research exists which examines independently living elders' encounters of their health provider attitudes. This study, therefore, aimed

to explore how older people in New Zealand experience health providers' attitudes when accessing health services. Using a hermeneutic phenomenological methodology enabled the exploration of older people's feelings, providing them with a voice to express their lived experiences in their own words.

Conveying my experiences

To recognise and understand what my own experiences bring to this hermeneutic phenomenological study, I have considered the philosophy of Gadamer (1900-2002), who asserts that one cannot approach a question without preconceptions, or without pre-understandings. I assume that my experiences influence what I may bring as a researcher to these investigations and rather than attempting to set these aside, and in the spirit of full objectivity, it becomes important to acknowledge these own lived encounters. Intuitively, this influences how I may interpret others' experiences. Even though impartiality is the keystone for many research approaches, the lived experience of the researcher remains as integral a part of the study as it does for whom one is attempting to understand. The next section will therefore outline the objective of this project and my motivation for selecting this particular subject matter. It will present my pre-understanding as a researcher and delve into what I have brought to the project in terms of my own experiences and how they have influenced me. Prior to data gathering for this study, my primary supervisor conducted a presupposition interview with me. The purpose for the

interview was to uncover my own history and experiences in relation to the phenomenon of interest. It helped to uncover the way in which I had come to know something about the experiences of older people and health providers' attitudes and why these inspired me to embark upon this topic. The interview was effective in helping outline the partiality I brought with me to the research.

Pre-understandings as a researcher

I was born an only child of post-World War II European immigrants. Both parents worked long hard hours. My mother worked from home as a millinery seamstress so that she could raise me whilst earning a living at the same time. My father worked six days a week as a stone mason and as a staunchly religious man spent half of his seventh day attending church services. In spite of living in New Zealand he never mastered the English language, relying instead on my mother for day to day dealings as well as taking care of my needs. As much as I knew how much my father cared for me, he struggled with the generational, cultural and language barriers that existed between us and as such my mother became the role model and my main focus as I grew.

Watching my mother age caused me to reflect on the process that barring catastrophic failure would affect us all. The noteworthy changes which affected her, constituted diminished mobility, concessions to her ability to perform the tasks of day to day living and the relegated interaction she had with the outside world. I observed an individual whose world became

smaller as the years passed; the gradual downward spiral of her quality of life culminating in the seemingly inevitable point where she required fulltime care merely to maintain the daily functions of life.

As the years dissolved; it is not clear in my memory exactly when, I would accompany her to doctors' visits when she began to complain of not really understanding what the doctor was telling her. In these encounters, one could be mistaken for thinking I was the patient rather than my mother. The dialogue was addressed to me and little or no eye contact was made with her. When she did speak, the attention of the doctor was distracted by his computer. My mother often commented after such visits that the doctor didn't listen to her and "fobbed her off" so he could get through as many patients as possible. She felt depersonalised and marginalised; a number, who like the days of a calendar, simply came and went alongside others.

Years later, after a protracted hospital stay, her diminished independence resulted in her requiring full time institutionalised care; she was never to live in her own home again. As time passed my mother and I came to accept the changes and commented light heartedly on occasion that at least in the home she would see a doctor who was better trained in dealing with older adults and might listen to her more carefully. The sad irony was manifested in the form of the same practitioner providing medical care for the facility in which she had become domiciled. She lacked the confidence to use another physician; not wishing to have her feelings of low importance reinforced by yet another doctor.

When we talked, she often described the home as a prison, questioning; “What did I do to be put here”? She held herself responsible for becoming old. Diminishing then ultimately losing her eyesight totally further closed in the walls of her metaphorical prison, inexorably sealing her in the confines of her perceived existence. If her encounters whilst still in the community and later in the aged care home had been different, what might have been the outcome? How many other older adults were living the same experience, travelling a parallel path? I commenced looking into what was known about this phenomenon which revealed that little research existed which examined the feelings that older people had of their healthcare providers. I began to wonder whether my mother’s experience was an isolated one or if a commonality existed with other older people; those seeking help from people with the perceived power to heal. Could such experiences, which involved marginalisation of older adults, contribute to feelings of isolation and could some of the stolen independent years have been averted? The gap unearthed in the research led me to the question of this study; to explore, from an older persons view, how they were made to feel when seeking healthcare in this country.

After commencement of work on this study; on a sunny morning while I was at work, I learnt my mother had suffered a major stroke. At the hospital, the emergency room doctor stated drugs could be administered which would “undo” the damage of the stroke though these had a finite functional window for application of which my mother was already near the cusp. I had the sense that there was no urgency in making this

decision. The doctor had already opted not to administer the drugs. She was old and it was almost as if the window of opportunity was allowed to expire. Her brain was later scanned to confirm the diagnosis. My wife and I, her only family, were not told of the scan results till some thirty hours later in spite of repeated attempts to procure this information by telephone and in person. She had not been administered fluids or provided with comfort care for at least 18 hours after her admission. She was discharged back to her home facility, unable to swallow and with no other means of receiving fluids. No care plan accompanied her discharge further delaying the time that comfort care could be initiated after arrival back at her own facility. She regained consciousness briefly some days later and though unable to speak I was again able to spend a few precious moments with my mother. One week exactly after the stroke, with my wife holding her hand, my mother passed away at 5.17 am on August 5, 2013 during these writings.

As my wife and I watched and waited, we noted two diametrically opposed situations unfold as her life drew to a close; firstly, the unceasingly compassionate manner in which the nurses and physiotherapists worked to monitor and make her comfortable within their prescribed limitations. Secondly, the seeming disregard of the doctors after stating she could no longer be helped, which to my eyes appeared as to be discounting her care to the point of failing to provide her the basics of comfort and dignity. If we are indeed the sum total of our experiences what impression has been left upon us and our outlook for a future

scenario not unlike that of my mother? It is through her inspiration that I am led to the question of this study.

Terminology used in this thesis

In this thesis older people are defined as those greater than 74 years of age. This was to differentiate between young-old; which ranges from the age of 65 years to the threshold of old-old of >74 as defined by Orimo, Ito, Suzuki, Araki, Hosoi & Sawabi, (2006). The rationale for this distinction was to recognise that those over the age of 65 are not a homogenous group and many young old may still retain a high standard of health and activity and be less likely to require access to health services (Adelman, Greene & Charont, 1991).

Unless explicitly stated, the terms healthcare providers, practitioners and clinicians are used as a generic description for those involved in the process of providing healthcare services. It includes first responders such as paramedics, hospital and clinic administrative staff, nurses, doctors, specialists or indeed anyone encountered as a result of the participant needing to access to health services. The decision to include stories regarding administrative staff was made as these individuals form a significant part of the health service process and are often among the first contact a participant will have, thus contributing considerably to the healthcare experience. The terms, medical centre, clinic and hospital refer to places of access to healthcare for the participant and exclude mobile services outside these establishments such as ambulances and house calls.

Overview of the thesis

Chapter one

This chapter outlines the reasons for conducting this research and provides a context in which the study is set. It includes the background and what has been brought personally to the writing in the spirit of full and open transparency.

Chapter two

This chapter reviews the literature surrounding age and healthcare. Firstly, it will discuss what is known on the subject of discrimination toward older people in healthcare both internationally and nationally. Secondly, it will discuss the policies designed to mitigate some of the effects arising from inequitable treatment. The reason to include policy discussion was the acknowledgement that attitudes by healthcare workers toward this population have been scrutinised worldwide and influence the manner in which policy makers believe the problem should be addressed. Thirdly, the review will examine the literature surrounding older people's lived experiences of healthcare and how they interpret living in the world as they become older.

Chapter three

This chapter describes the methodology and the use of hermeneutic phenomenology to explore the participants' stories. The writings of van Manen (1990), which are largely informed by Heidegger among other

philosophers, have been the predominant guide for this methodology. The chapter will then go on to explain the methods used to produce this study ensuring all steps are outlined and full transparency is maintained.

Chapters four, five and six

These chapters will present the findings and explore the themes as uncovered through the interpretation.

Chapter seven

This chapter will discuss the findings to determine how the various parts give meaning to the whole and how this in turn provides relevance to the constituent parts. Findings will be contextualised in light of research carried out by others in the field.

Summary

This chapter has introduced the nature and reason for this study. In the spirit of full disclosure it has outlined the researcher's pre-understandings which have influenced this project in addition to the nature of the study.

The next chapter will unravel the literature surrounding older person's experiences with healthcare and the complex issues surrounding attitudes to older people.

Chapter two

Literature review

It is lovely to meet an old person whose face is deeply lined, a face that has been deeply inhabited, to look in the eyes and find light there.

— John O'Donohue, *Anam Cara: A Book of Celtic Wisdom*

Introduction

This chapter will examine the literature as it relates to older people and how they encounter healthcare practitioners' attitudes towards them. It will first provide a definition of old age as described by the literature followed by examining ageism; the preconceptions associated with age and how this is acknowledged and managed both in New Zealand and overseas from a Governmental perspective. It will consider societal attitudes toward the elderly and the manner in which these may have arisen. Lastly it will discuss research regarding the experiences of older people and the attitudes of healthcare workers towards them.

Literature search method

An initial scoping review using Google scholar was undertaken to determine the status of knowledge using the keywords, ageism, healthcare, old age and elderly. Data bases which yielded relevant journal articles of interest; SCOPUS, EBSCO CINAHL and MEDLINE, were then searched using the terms or combinations of the terms; healthcare, old age, psychosocial and phenomenology. No limiters were used in the search and

not all available literature was utilised. Much research examined how health care professionals perceived the attitudes of older people and as such literature may have been rejected due to the perspective of an article not being sufficiently aligned with the research question. Literature may further have been rejected once saturation had been reached and no further information of significant difference had been identified.

Defining age

When looking into the effects of attitudes toward older persons, it is useful to first examine how old age is defined. Even though the term “old” is commonly utilised to describe a non-heterogeneous population it has been suggested that designations of age have become increasingly necessary as the human lifespan has lengthened (Nilsson, Sarvimaki & Ekman, 2000). Many international studies have utilised an age of 65 as the starting point to define old age while others have used retirement or eligibility for retirement to satisfy this criteria (World Health Organization, n.d.). Often these are one and the same, though a more detailed designation has been suggested in which the older population is divided into three cohorts; those 65-74 as young-old, 75-84 as middle-old and 85 and older as old-old (Adelman et al., 1991). These categorisations were based on the proposition that the populations within each category may require different levels of care and assistance and may have a progressively greater reliance on health services. A more basic delineation has been proposed in which phases of old age are demarcated by the terms early

and late elderly, categorised as those aged 65 to 74 and people 75 and older respectively (Orimo et al., 2006).

It seems that older populations are far from the homogeneous group often portrayed by society. Indeed, the application of such age graduation when viewed in a wider societal context has been suggested as a possible root cause for ageist behavior creating an attitude of us and them (Hagestad & Uhlberg, 2005). The manner in which humans age is affected by numerous determinants, including socioeconomic status, social support, personal relationships, resilience, autonomy, emotionality and education, not only across the lifespan but particularly in later years. For example, individuals with college or university education generally attain equivalence of age of death or disability a decade later than people with a lesser educational status (Larzelere, Campbell, & Adu-Sarkodie, 2011). Therefore, to impose an expectation on an individual's state of physical or mental condition on no other basis than chronological age is both inconsistent and unjust. Determinants which may affect the perception of ageing and being old are as varied as the individuals themselves. Therefore, it is vital that expectations for non-ageist treatment relate to condition rather than uniformity of age.

A global perspective of healthcare and older people

As international and domestic policies attempt to address inequality and prejudicial behavior, the question remains how such policies influence the conduct of healthcare providers toward some of the most vulnerable

members of our society. If health professionals harbour negative or discriminatory attitudes there may be significant psychosocial ramifications on the lives of their older patients. Globally, many health policies such as those which exist in the United Kingdom (UK) expressly forbid discrimination against age in the access to assessment and appropriate treatment (Department of Health. UK, 2001). The United Nations Department for Economic and Social Affairs (2011), state as an ultimate goal, “to provide a system which ensures the health and wellbeing of all elderly citizens” (p. 63). Synonymous terms for wellbeing are comfort, safety, health and happiness. Yet, in spite of international accords such as the Ottawa Charter (1986) and Bangkok Charter (2005), which espouse equality for all, discrimination against the aged continues to pervade societies within developed countries, devaluing older persons’ rights to equal treatment regardless of age (United Nations, 2011).

There remains much doubt as to the efficacy of attempts to address ageist attitudes. Research indicates that discrimination has been a persistent and seldom acknowledged characteristic of much of clinical practice (Kapp, 1998), with narrative studies of elders recounting feelings of segregation, powerlessness and depersonalisation during hospital stays in the UK (Minichiello, Browne & Kendig, 2000). A report on the British National Health Service stated there was a failure by the service to address older people with care, dignity and respect (Commission for Healthcare Audit and Inspection, 2007). The report further stated that age discrimination complaints to the British Ombudsman for Health had reached an all-time

high. Such evidence suggests that in the face of global policies and accords which clearly prohibit age discrimination, incidences of such events were continuing to rise. Acknowledging attitudinal concerns toward the older adults, the New Zealand Government adopted an approach to mitigate the effects of ageist behavior known as the Positive Ageing Strategy (Ministry of Social Development, 2007). The Positive Ageing Strategy recognised the need for society in general to attend to pervasive ageist attitudes within healthcare (Ministry of Social Development, 2007).

Indeed, three of the four planning recommendations within the strategy involved improving the levels of expertise of those charged with caring for older individuals; at the forefront of which was the recommendation for an up-skilling of any health practitioners such as medical, nurses, therapists, social workers and public health professionals whose work included association with older people (Ministry of Social Development, 2007).

The document however, appeared to focus on wellbeing of older people being coupled to economic benefit; for instance, to be productive is to be happy. The view that the positive discourse used in this and counterpart documents from Australia and the UK would lead to a happier healthier old age came under criticism (Davey & Glasgow, 2009). The Positive Ageing Strategy endorsed the rights of older people to contribute in useful and productive ways going so far as to actively discourage retirement at 65 years of age, whilst endorsing the fiscal benefits of promoting active

contribution. The Ministry of Social Development (2007), document, however, paid scant attention to the existence of barriers to these objectives such as societal attitude, illness or mobility. Davey and Glasgow, (2009) suggested that frailty, as a reality for some, meant that such idealistic goals of healthy ageing were not achievable. The intent of the Positive Ageing Strategy was clearly to promote healthy active ageing. However, in doing so it underplayed many of the barriers; indirectly suggesting that being healthy and active in old age were self-modifiable factors and within the control of older people.

This situation indicates that policy may not necessarily reflect the reality of lived experiences. Policy makers, with good intentions, may view the promotion of equity in healthcare as a means of ultimately improving productivity of an ageing population. In practice, however, there appears to be a lack of participatory consultation when drafting such policy.

Taking into account the patients' perspective, such as the manner in which health services provide for those with ever increasing needs, may require acknowledging in the first instance that those needs exist. Wellbeing is not merely the absence of disease or illness, it is also an expression of a state of mind (World Health Organisation, 1986) and therefore, should not to be viewed solely as physiological in nature but also as psychological to fulfill the full scope of the term. Thus, the manner in which older persons are treated when seeking healthcare may well reflect either an environment of care and dignity or placation and dismissal.

Understanding discrimination

Discrimination has been described as unfair or inequitable treatment and the derived beliefs of one socially defined group toward another (Kearney, Miller, Paul & Smith, 2000). Discrimination can reflect an attitude of domination and subordination toward more vulnerable groups differentiated, for example, by ethnicity, religion or age and based on ideologies used to justify such behaviour (Krieger, 2001).

It is evident that social justice within the arena of aged health care should not only encompass fair and equitable access to resources but also the basic right to be treated in the same manner as any person regardless of age. Finite resources may necessitate the need for rationalisation of healthcare toward those with the greatest need; however, this should be seen to be carried out not only equitably but also in a compassionate manner.

Rationalisation and distribution of healthcare have become unavoidable factors in the management and treatment of illness for all strata of society and in themselves may not be interpreted as evidence of inequitable behavior toward older people (Whitehead, 2000). However Whitehead (2000), described possible manifestations of inequitable behaviour as the failure of health practitioners to apply the same professional expertise to older persons, such as through a lower likelihood of referrals to specialist care or shorter consultation times when compared to other social groups.

Ageism in clinical practice

It would appear reasonable to expect that those involved in healthcare should be by nature of a sympathetic, tolerant disposition (Herdman, 2001). However, even in well-meaning individuals, a lack of training and preparation for dealing with the complex health needs associated with an older population may present difficulties such as the accurate diagnosis of illness. Turcotte (2003) discussed the tendency of clinicians to misdiagnose health complaints of older persons citing training as a major determinant. Only three of 145 medical schools in the United States provided dedicated geriatric departments and as few as ten percent of the remaining 142 required any course work at all in gerontology. An unintended consequence of insufficient training in the area of elder healthcare was therefore, the failure to generate the same interest as other areas in spite of reporting the highest rate of job satisfaction for any medical subspecialty (Adelman, Capello, LoFaso, Greene, Kpnopasek & Marzuk, 2007). Indeed, it was observed that medical graduates were exceedingly unlikely to specialise in careers involving older adults (Weir, 2004), leading to a resultant shortfall of clinicians who were adequately prepared to work with older people. Given that pervasive social attitudes toward older individuals may be the subjective frame of reference for many professionals, it seems possible that accessing suitably trained health providers becomes in the least problematic. Turrcotte (2003), further reported that clinicians poorly educated in geriatric needs not only tended to misdiagnose older people but were more inclined to offer fewer

treatment options, opting to focus on symptomatic aspects only. It has been suggested that when compared to younger patients, not only was the standard of care poorer for older individuals but consultation times were also routinely shorter (Fernando, Arora & Chrome, 2011). Moreover, combined with reduced consultation times a paternalistic approach to making decisions about healthcare options with older patients may have contributed to misdiagnoses, exacerbating the issues associated with polypharmacy (Stewart, et al., 2011). Certainly it has been acknowledged in literature for many years that managing the co-existence of a variety of medical conditions in addition to altered tolerance to polypharmacy in older individuals necessitates considerable proficiency (Stewart, et al., 2011). Many geriatricians have conceded that multiple visits are often required to satisfactorily assess a patient resulting in some clinicians assessing a given medical condition differently if at all (Adelman et al., 1991).

Options for treatment or ongoing investigation may also be limited for older patients. The Alliance for Ageing Research (2003), discussed five areas of concern for older individuals when seeking healthcare, these were: inadequately trained health professionals; less preventative care; failure to administer preventative treatment including referral for screening; exclusion from established medical interventions; and finally, exclusion from clinical trials. A systematic review of 109 clinical trials showed that almost half of the trials utilised inclusion criteria which disproportionately affected older people with a further 22 excluding

people above a certain age (Zulman, Sussman, Chen, Cigolle, Blaum & Hayward, 2011). It is possible, therefore, that short comings in treatment may be a result of the lack empirical research into different options, thus, leading to varying outcomes in clinicians treating an older patient.

It may be possible that a solution lies in the manner in which older people's health is introduced to upcoming health professionals. Wilkinson and Sainsbury (1998) examined the effect of gradual exposure of medical students to older patients in a Christchurch teaching hospital over three years. Year one commenced with predominantly well patients and culminated in year three with contact with patients in advanced degrees of illness. The authors demonstrated that exposure and instruction in geriatric care was able to alter positively the attitudes of medical students toward older patients. Results such as these are supported by similar studies which highlight the importance of exposure and preparation for managing older health (Barnett, Mercer, Norbury, Watt, Wyke & Guthrie, 2012; Bernard, McAuley, Belzer & Neil, 2003).

However, a search by this author of leading medical teaching institutions in New Zealand has indicated that study of the needs associated with older people remains predominantly the domain of elective course work or post graduate specialisation. A danger exists that in the absence of the appropriate skills with which to manage older health, some health professionals may resort to what has been described as the fair innings argument as a measure of value (Weir, 2004). This refers to the

prioritisation of care based on the crude equation of years lived versus years likely to live. For example, under the fair innings argument an older individual may be by-passed for treatment in favour of a younger one centred on a criterion of remaining functional years.

Health and old age

It is accepted that some level of physiological and psychological decline is inevitable with advancing age and that this will impact on the majority of people (Stewart et al., 2011). Ageist paradigms have persisted however, which portray older people as frail, ineffective, a burden on health resources and highly reliant on social services (Bowling, 1999). The World Health Organization in 2005 approximated that 80 percent of registered deaths were associated with modifiable factors of stroke and heart disease. Importantly, the findings suggested that these deaths were less likely to be as a result of old age. The beliefs, however, of these illnesses' association to old age still endures (Stewart et al., 2011).

Clearly, to entirely dismiss age as a factor in some conditions would be unreasonable. However, it then falls to the clinician to be aware of, and to resist any preconceptions solely based on age and avoid stereotypes when treating older people.

It has been shown that the harmful stereotypical characteristics attributed to the aged, when adopted by individuals in later life may prime an individual to behave in a manner which fulfills these same stereotypes (Levy, 2003). The activation by triggers of self-stereotypes, as suggested

by Levy, Ashman and Dror, (2000), may indeed produce adverse effects on the quality of life of older individuals such as lower self-esteem and feelings of being a burden. Therefore, the attitude of those held in high regard, such as doctors who have the ability to influence an individual's approach toward life, becomes critically important. Acceptance by older people of the effects of multiple chronic conditions has been shown to occur in conjunction with a resignation toward "just becoming old" and a concomitant acquiescence to reduced function and mobility (Clarke & Bennett, 2012). Should this acceptance become further reinforced by those with a perceived ability to heal, the effects of decline may well become magnified. Hence, it is important to explore the perceived attitude of health professionals and the unintended health effects they may have on older patients.

Ageism as a social phenomenon

If ageism does indeed influence decision making by health professionals the genesis for this behaviour may be found by examining a wider societal context. The initial perceptions made when first encountering others have been divided into three main categories of race, gender and age (Nelson, 2005). Nelson (2005) identified 3,111 research articles relating to racism, 1,385 to sexism compared with only 294 relating to ageism and suggested this empirical discrepancy could be the result of socially condoned prejudice and a reflection of society's prioritisation of these issues.

If this is the case, it may be possible for wider social prejudicial opinions to also permeate the fabric of an industry purported to support and care for older individuals. The proposition has been made that long term exposure to older patients may predispose clinicians to developing ageist attitudes (Kearney et al., 2000). Furthermore, Cuddy, Norton and Fiske (2005), suggested that medical practitioners subject to the same societal outlooks on age were likely to convey these attitudes through implying older individuals were helpless or dependent. Should ageism be entrenched in societal attitudes it becomes increasingly important to establish not only the effects of this behaviour on our older population but also to determine its origins.

Priming stereotypical behaviour

Theories abound as to the root cause of ageism. Humans have a cognitive tendency to establish stereotypes when interacting with each other; expecting certain behavioral traits of individuals within their environment (Cuddy et al., 2005). Aversion to old age by young and middle age people may be due to prognosticating on an inevitable future, mirrored in the aged individuals they encounter. This may stigmatise older people due to certain undesirable aspects such as loss of mobility, eyesight, hearing, cognitive ability or even appearance (Hagestad & Uhlenberg, 2005). For example, Hagestad and Uhlenberg (2005) suggested that unpleasing traits associated with older age may be perceived as so unacceptable or threatening that they should be kept out of sight, thus, leading to division

of age groups and a failure to coalesce, effectively becoming a form of age based segregation. The authors asserted such perceptions must be overcome if society is to move beyond an attitude of us and them.

The aversion to becoming old may lie deeply rooted within an individual's psyche, conditioning or priming them for ageist behaviour earlier in life than commonly thought (Levy, Slade, Kasl & Kunkel, 2002). Priming describes exposure to, or behavior which implants a notion, concept or attitude and which may result in a preconception or idea. This suggestion is based on the belief that ageism might be internalised and subject to negative or positive priming (Levy, 2003). Such internalisation was demonstrated to manifest as early as six years of age with non-verbal expression in the form of children observed physically distancing themselves when in the presence of older individuals (Isaacs & Bearison, 1986). It was further noted that the behaviour was more pronounced toward older women rather than men, though no explanation was posited to describe this observation. The observed internalisation and distancing by children was suggested to be subconscious behaviour, which may later develop into a conscious belief when achieving the verbalisation stage (Levy et al., 2000; Klein, Council & McGuire, 2005). To offset likely negative biases, which might be encountered and reinforced throughout life, it was proposed that children should receive positive reinforcement regarding successful ageing at the earliest possible opportunity. The effects of priming, however, are not

the sole domain of the young with the phenomenon also apparent amongst older people.

Establishing stereotypes

The suggestion has been made that harmful stereotypical characteristics attributed to the aged as adopted in later life prepares an individual to behave in a self-fulfilling manner (Levy, 2003). It has been proposed that an attitude of “to be old is to be ill” is a more compelling contributor to health than clinical factors such as misdiagnosis, genetics or unhealthy attitudes to chronic illness (Stewart et al., 2011). Levy et al. (2002) suggested that such attitudes may have had serious implications for the psychosocial aspects of ageing in that, the psycho-social link between longevity and self perception may be based upon intrinsic negative ageing stereotypes. This may have a detrimental effect on the lifespan of older people whilst positive self perception may produce quite an opposite effect.

The hypothesis that ageist behavior may influence the receiver’s physical performance was tested in older individuals, with an association established between positive or negative priming and the quality of the gait in test subjects. Hausdorff, Levy and Wei (1999), in a randomised intervention study, tested the effect of ageist subconscious reinforcement and stereotyping, with a primary focus on walking performance and functionality. Forty-seven community residing participants aged from 63-

82 years of age were recruited. Inclusion criteria required all participants to consider themselves to be healthy and to walk unaided.

Participants were exposed to negative or positive priming words hidden within random flashes disguised as a computerised game. Measurements of gait speed and leg swing time were taken before and after playing the game. The study showed that negative stereotyping could contribute to the reduced functionality of older people and through positive reinforcement reversal was possible at least in the short term. A possible limitation of the study may be solely recruiting participants who considered themselves as healthy. This implied a more positive preexisting state of mind and may have contributed to the magnitude of improvement in gait making it difficult to generalise the results. Including participants who considered themselves as somewhat less than healthy may have provided the researchers with a more accurate demonstration of any priming effect.

In a much larger study, Levy et al. (2002) later strengthened the hypothesis that negative outcomes could be produced from negative stereotypes, whilst positive priming produced beneficial results for general health and longevity. The author demonstrated in a twenty year longitudinal, community based study involving 660 participants that those who maintained a positive mental attitude lived on average 7.6 years longer than those subject to intrinsic negative stereotypes. Not only was the lifespan significantly longer, after controlling for variables such as

health, socioeconomic status, gender and loneliness; it proved to be the most significant contributor lending credence to the notion that attitude could influence health or longevity.

Stereotyping and segregation, which tend to render older people as invisible occurs at a time when increasing numbers of older, healthy, educated individuals still have much they may wish to contribute (Hagestad & Uhlenberg, 2005). If the activation of triggers for self-stereotyping, as suggested by Levy et al. (2000), does indeed produce adverse effects on the quality of life of older individuals, the attitudes toward older persons by those held in high regard such as healthcare workers, becomes of critical importance. It therefore befalls health professionals to become aware of the potential effects of negatively or positively primed terminology and the possible effects on health outcomes this may have on older people.

Manifestations of ageism

A manifestation of dissimilar attitudes toward older persons may sometimes be represented through the manner in which communication is made, (Caporael & Culbertson, 1986). Dubbed secondary baby talk by the authors, it includes patronizing language modified toward older people and characterised by paralinguistic elements such as simplified language, slow rates and higher registry of speech amongst others. Given the upper registry of hearing is commonly the first to deteriorate amongst older individuals, a condition known as presbycusis, the resultant failure to

comprehend speech may be interpreted as diminished comprehension and information processing (Adelman et al., 1991). Furthermore, deterioration of eyesight and the concomitant inability to discern visual cues could serve to exacerbate this situation. Such secondary baby talk was considered by health professionals to convey an attitude of nurturing support particularly when addressed to more frail or dependent individuals. An unintended effect would appear to be that although older persons in residential care demonstrated a preference for simpler, slower speech; those remaining active and in independent community living, when addressed in the same manner indicated feelings of being undermined, or diminished (Giles, Fox & Smith, 1993; Caporael & Culbertson, 1986). This indicates that older persons may be treated in a manner which though sometimes intended to be compassionate can be characterised by a condescending demeanor (Binstock & Post, 1991). Thus, the context under which health providers convey attitudes toward older people becomes of key interest when investigating the experiences of older persons.

Experiences of older people

A search for literature utilising phenomenological studies examining the experiences of independent living older people impacted by attitudes of healthcare workers revealed little research. The vast majority of literature concentrated on the experiences of people in controlled institutionalised care, retirement home scenarios or from the perspective of healthcare

workers experiences such as nurses managing the needs of older patients. One study examined what nurses believed was required to restore the dignity of elders in hospital situations (Hall & Hoy, 2012). Two major themes which emerged from this study were that of ensuring that the patient was seen as a unique person and that nurses recognised when they believed elders felt more vulnerable. Hall & Hoy, (2012), acknowledged that a discrepancy appeared to exist between what the nurses identified as important and what actually occurred in practice, supporting the premise that more could be done to preserve the dignity of older people. However, in spite of attempts such as this to understand the complex relationships between care providers and older people, the underlying concern was that it focused on subjective judgments to determine what was best for elders, often excluding the opinions of the older people themselves (Walsh, Olsen, Ploeg, Lohfeld & MacMillan., 2010).

One study which did investigate elders' impressions of the attitude of society toward them, described feelings of being disregarded when seeking health services, leaving them with feelings of being ignored and "weakening of their person hood" (Taylor, Campbell, O'Brien, Begley & Carter, 2014, p. 230). The overall impression was one of loss of self-confidence and a sense of isolation leading to a fear of the future. The participants went further to describe the loss of respect they believed society had toward them as a form of elder abuse.

One study from Mexico, which specifically examined the perceptions of older people toward their healthcare providers, described participants feeling a lack of sensitivity and patience (Ruelas-González, Pelcastre-Villafuerte & Reyes-Morales, 2014). The participants spoke of feeling rushed, rejected or being invisible and of being unable to adequately communicate their needs within a strict ten minute consultation time limit. The two settings for the Mexican study were described as a hospital and primary care clinic though it is not clear whether these locations were the normal source of medical care for the participants or an emergency room context, which may in part explain such rigid time constraints.

Experiencing fear of rejection and abandonment were highlighted in a Scandinavian study, which examined the way older couples wished to be treated by their visiting registered nurses (Pejner, Ziegert & Kihlgren, 2014). Twelve older couples were asked to describe their feelings currently and then to project how they might feel in future years.

Participants spoke of presently feeling anxiety, sorrow and melancholy, though also described a sense of confidence in knowing the visiting nurse was there to listen to their concerns. One of the greatest future obstacles was described as a fear of abandonment when vulnerable. Rather than being concerned about future physical care, the participants discussed the need for confidence in the ability to hand over their emotional care should they need to move to a nursing home environment (Pejner et al., 2014). A point of interest from this study was a lesser regard by the participants for the physical self rather than for the emotional self. This highlights again

the importance by health providers of considering the psychosocial aspects of health as well as the physical when working with older people.

Conclusion

Within a clinician patient relationship, any decisions which affect health and wellbeing should reflect the patient's best interests as an individual rather than being related to their age. For the promotion of health to older persons to be effective, beliefs surrounding the homogeneity of this population must be amended to recognise the diversity of physical and psychosocial needs (Stewart et al., 2011). For this to be effective, a deeper understanding of the feelings older people face must be established.

This study aims to explore how older people in New Zealand who still live independently, experience the attitude of their healthcare providers. It seeks to hear these experiences; in the participants' own words and through phenomenological interpretation, uncover the meanings thereby giving voice to that which might otherwise remain hidden.

In the next chapter the methodology used to interpret these experiences will be outlined in conjunction with the methods used in conducting this research project.

Chapter Three

Methodology and Methods

The pages are still blank, but there is a miraculous feeling of the words being there, written in invisible ink and clamoring to become visible.

— Vladimir Nabokov

Introduction

This chapter will describe the methodology utilised and why it is appropriate to this study, followed by the methods used in conducting the research processes. The hermeneutic phenomenological methodology used in this study was reliant upon participants being able to recall and recount stories about recent healthcare events, and to communicate an understanding of why they thought events happened as they did.

The methods used were guided by the methodology which supported an engaged approach with participants with the aim of developing an understanding of how they experienced health provider attitudes towards them. As such, the telling of the stories in their own words, allowed participants the freedom of expression when relaying their experiences.

Methodology

Hermeneutic phenomenology, also referred to as interpretive phenomenology, is the study of how a phenomenon appears (Wright-St Clair, 2015). It is a methodology which seeks to address an identified gap in knowledge through the understanding of the phenomenon of interest. This study used hermeneutic phenomenology to investigate older persons' experiences of the attitudes of health providers. The writings of van Manen (1990), who was influenced primarily by the German philosopher Martin Heidegger (1889-1976), are predominantly used to guide the implementation of this study. The Heideggerian stance was the most appropriate to bring to this project as it embraced the experience of the researcher. The contrasting philosophical notion of phenomenological reduction as described by Husserl (1913-1982), suggested that personal experience could be put to one side, or bracketed (Lavery, 2003). It was proposed that this brought clarity to a phenomenon. However, Heidegger discounted this, suggesting that it was not possible to separate out one's own experiences but rather to acknowledge that which influences the lens through which the world is seen (Lavery, 2003).

Hermeneutic phenomenology was also particularly well suited to this project as rather than merely providing a description of the phenomenon of interest, it sought to explore hidden meanings and to delve into deeper feelings which may have otherwise remained concealed. Central to this, it

was important to elicit and explore these stories from the perspective of older people themselves (Wright-St Clair, 2008).

Hermeneutic phenomenology

Van Manen (1990) describes the term hermeneutic as to interpret, whilst phenomenology is the expression or depiction of the interpretation.

Interpretive phenomenology is based on a Heideggerian philosophy, that an observable phenomenon has within itself something which is not self-evident (Wright-St Clair, 2015). Through a process of thoughtful effort on behalf of a researcher, using the phenomenological approach requires consideration of what lies beyond what is known or is observable. Thus, the portrayal of what is to be interpreted is distinctive in that it does not attempt to re-describe the original experience. Rather, the phenomenological description is made up of examples which expose subtle subtexts as suggested by the original. Van Manen (1990) speaks of how through unlayering by applying thoughtfulness, writing, reapplying thoughtfulness and rewriting, the phenomenological description is “strengthened and made more transparent” (p. 122). This transparency allows the researcher to at first see hidden themes as they emerge and the underlying meaning of the themes as they become more apparent.

Hermeneutic phenomenological study is not only about asking a research question but of asking the question in a way that is congruent with the methodology. It asks, “what”; as in what is an experience like, or “how”; as in how does an experience feel (Wright-St Clair, 2015). Hence, the

research question asked in this study is how older people in New Zealand experience the attitude of their health care providers. The intention of the methodology is not to establish a causal relationship or to quantify, but to explore reflectively what may be hidden within a lived experience (Wright- St Clair, 2008). Therefore hermeneutic phenomenology becomes an appropriate method of inquiry to gradually reveal what is unapparent. Through repeated reexamination, much as if removing opaque layers, an increased level of clarity and sensitivity is directed toward the way in which stories are presented. This is congruent with Heidegger's assertion that one cannot be separated from the world and one's own experience of being in the world (Inwood, 2000). This, Heidegger has described as Dasein or being there, not only in the corporal sense but also in the abstract. Understanding and being in the world may be realised through the investigation of the deeper, unseen elements of a contextual story to achieve a better comprehension of the experience as a whole. Such understanding of the whole reflectively helps bring clarity to the stories' essences. This interpretative loop is known as the hermeneutic circle.

The hermeneutic circle

Hermeneutic phenomenology concerns itself with interpreting meaning. As the implications of different experiences are brought to light they are seen both as exclusive and inclusive parts of the whole (Inwood, 2000). Heidegger's interpretation of the hermeneutic circle tells that the parts and the whole, though distinct are inseparable and understanding of one

provides a fuller, richer understanding of the other (Martin, 1972). For example, the significance of a single word may change through the context of a sentence and as words give meaning to sentences so do sentences give meaning back to words, such is the hermeneutic circle. It seeks to uncover the subtleties of individual encounters and how they provide meaning to living in the world as a whole. Through reading and re-reading the stories and listening in to the meanings of the words, the stories from the individual encounters become like a series of threads from which themes will emerge. By reflecting on the participant's encounters, as if pulling together these different threads, meaning is given to how older persons experience health provider attitudes and the context in which they experience living in the world. The following chapters, through the use of a hermeneutic phenomenological approach seek to expose the hidden meanings, which demonstrate the themes as they have emerged from the stories of lived experiences.

Methods

Peer review

Prior peer review of the research proposal was conducted via the University's Postgraduate Review process. The project was approved, without amendment, for enrolment in the Master of Public Health thesis paper on 12th of February, 2013, (appendix A).

Research ethics

Ethics approval was granted, without amendment, by the Auckland University of Technology Ethics Committee (AUTEK) on the 18th of June, 2013 (appendix B). At all times the principle of do no harm was maintained. Given the nature of recalling an event that might possibly be distressing, provision was made for counseling to be available through the University. The details for access to this service were included in the distributed participant information sheet (appendix D). Counseling services were offered but not sought by any of the volunteers.

Inclusion and exclusion criteria

The criteria for inclusion in the study were men and women aged 75 years or older who were community dwelling, in a private residence and within the greater Auckland metropolitan area. For inclusion, potential participants must have accessed either primary or secondary health services in New Zealand at least once in the twelve months preceding commencement of the study. Exclusion from the study would only apply if the potential participant was unable to recall encounters clearly or was unable to relate encounters in conversational English. No other exclusions were applied.

Defining age

The literature suggests that whilst most older adults maintain community based independent living, the requirements for health, hospital or

residential care services increase with age, particularly in the last decade of life (Leung, LoGiudice, Schwarz & Brand, 2011), Therefore, due to the increased likelihood for individuals over the age of 74 years to require access to healthcare services, this age was selected as the threshold for participation in this study.

Recruitment

Age Concern was selected as a source of recruitment primarily due to its wide geographical spread and diversity of membership. The initial recruitment involved an approach to the chairperson and President of Age Concern¹ for approval to advertise within the organisation. Subsequently, invitations were offered by Age Concern to address group meetings and functions. The first opportunity to achieve this presented through an invitation to address an Age Concern meeting and Christmas function. At this function a general address outlining the purpose of the study was made, after which informal discussions were held in four smaller groups of up to 10 people over lunch. The study was presented in greater detail to these smaller groups at this time. Each group was offered an opportunity to ask questions surrounding the project. From this, individuals acknowledging their interest in participation provided contact details and were distributed information sheets and consent forms for further consideration.

¹ Age concern is a principle non Governmental organisation dealing with affairs of older New Zealanders

As the forum under which this particular stage of recruitment had taken place was quite public in nature, consistent with ethics approval, it was felt prudent to offer the volunteers a second opportunity to meet on a one to one basis. There were two main reasons for the second meeting: to allow sufficient time for volunteers to examine and consider the information provided and to consult with friends or family regarding the research should they so desire. Any questions or concerns that may have arisen could then be answered to their satisfaction at the second meeting.

Following the secondary one on one meeting, each volunteer confirmed that they were still willing to participate further and that all questions had been answered to their satisfaction. The second meeting also provided an opportunity to get to know and understand some of the background of each participant and to put them at ease with the telling of their stories. It was important to develop a rapport and an environment of trust between the researcher and the participant during the recruitment and data collection processes. This was so that those involved should feel as though they were a part of the project; investing their experience as individuals in a participatory capacity rather than being merely a source of information.

Further purposive recruitment was conducted using:

- Advertisement in the Age Concern newsletter which is distributed to its members (appendix C).
- Advertisements posted on notice boards at Age Concern community gatherings (appendix C).

- The snowballing method; recruited participants were asked if they knew of anyone who they considered might meet the inclusion criteria. They were accordingly provided a copy of the advertisement (appendix C), and invited to pass it on to that person.
- The information sheet (appendix D), and consent forms (appendices E & F), were provided electronically to the AUT Person Centred Research Centre to be passed on to anyone who met the inclusion criteria. Such persons would have indicated a willingness to be approached regarding future studies, or who had made unsolicited contact with the centre indicating they were interested in participating in research based around older populations.

An information pack was produced which contained a copy of the recruitment advertisement (appendix C), calling for volunteers, a detailed information form (appendix D) outlining the purpose of the study, the requirements for participation and any potential risks and what remedies were available, along with an individual consent form (appendix E).

Participants were invited to have a support person present. In this event a support person confidentiality form was included with the information pack (appendix F). A self-addressed, postage paid envelope was provided should the participants wish to return the forms by mail. No participants self-identifying as being of Māori background volunteered for the study.

The volunteers signed a participatory consent form prior to commencement and were reminded that the interview could be stopped at any time should they wish.

Participants

Seven individuals meeting the inclusion criteria consented to being involved in the research. After considering her involvement, one participant chose not to proceed with the interview feeling that as she enjoyed particularly good health and consequently had very little contact with health professionals, was unable to recall an instance of merit she could discuss. No further volunteers were sought at this time due to the nature of rolling recruitment.

The six participants were three women and three men; ranging from 75 to 86 years of age and did not identify themselves with a particular culture or ethnic group. Three participants lived within the central Auckland area in an independent living village environment whilst three who resided in the greater Auckland periphery lived in and owned their own homes. The participants had all been married though only one had a surviving partner. They all had access to private healthcare and were able to choose their own general practitioners.

Participant profiles

<i>Participant (pseudonym)</i>	<i>Gender</i>	<i>Age</i>	<i>Local</i>
Jan	Female	75	Central/West Akl
John	Male	75	West Akl
Neville	Male	77	Central Akl
Trevor	Male	86	Central Akl
Margaret	Female	82	Central Akl
Moira	Female	77	South Akl

Data gathering

Data were gathered using unstructured, individual interviews. The interviews were conducted on a rolling basis to allow for preliminary data analysis prior to the next interview. The purpose for this was to allow the information gathering to develop as the interviews progressed and allow for new questions to be included, while exploring the evolving data. In the interim, those waiting to be interviewed were periodically contacted via email or telephone to ensure participants were kept up to date with progress and remained willing to contribute. Those who had completed their interviews were also contacted to thank them for their contribution and advised that a summary of the findings would be forwarded to them upon completion.

Participants were offered the option of having a support person present throughout any of these processes and during the interview itself. Data were gathered through individual, in-depth interviews conducted at a time and place convenient to each participant. Meetings and interviews were scheduled at locations of the participants choosing to ensure comfort, privacy and being conducive to open conversation. Three participants chose to be interviewed in their own homes whilst three from the residential village chose to hold their interviews in a communal lounge attached to their community setting. To protect confidentiality and ensure privacy in this location, a time was selected when the lounge was not used and in a space which afforded privacy away from traffic areas.

Participants were offered the opportunity to either select a pseudonym or to only be identified by their first name. All participants chose to use their own first names. Interviews were recorded on a digital voice recorder. Open ended questions based upon the topic of experiences when seeking healthcare were used, such as “tell me about an experience you’ve had which stands out for you” and “how did that make you feel”? These questions were utilised to encourage dialogue and to help uncover meaning hidden beneath the stories. Supplemental field notes were written immediately after each interview by the researcher. Voice recording was transcribed verbatim by an independent transcriptionist. Coherent stories were drawn from the transcripts which were carefully edited to remove the researcher’s text and any repetition or conversation that was not related to the interview topic. The remaining text was

fashioned to present the participants stories in a coherent manner whilst carefully preserving the essence of the meaning. To ensure full disclosure, the versions were returned to participants for validation and approval. Return of the stories was followed up after one week to allow sufficient time for participants to read and validate their stories for use in the study. All participants gave approval for the stories to be used.

Data analysis

It is important during the analysis to retain a strong and oriented relationship to the research question (van Manen, 1990). The participant-validated stories were interpreted by carefully reading and re-reading the text. Van Manen (1990) tells of the reflective process as being a thoughtful one, making the “important distinction between how an experience may appear and its essence” (p. 32). The content was contemplatively considered and an initial narrative version of the events portrayed was written by the researcher. This formed a framework for the writings and commenced the process of reflecting on the deeper understandings hidden within the accounts. The interpretive text was further written and re-written between immersive consideration of the participants’ own words and phrases to guide the gradual uncovering of concealed meaning. As particular themes began to emerge these were considered across other participants’ stories. Three core themes became apparent and as these started to emerge there came an ever increasing awareness of the tone and attitude of the teller which roused an

understanding of how the participants had experienced the world. Stories which demonstrated examples of the themes were then selected and grouped together under a theme heading. The researcher's interpretation was written around the storied text, ensuring it remained grounded in the participants' own words to present how the experiences exemplified the themes and the deeper meanings hidden within. Reflective consideration was given to how these deeper interpretive meanings which formed the parts gave meaning to the whole and in turn how the whole provided insight into the parts. In each of the following findings chapters, only stories which were highly illustrative of the emergent themes were presented and then followed by interpretations of the storied text.

Chapter four

Feeling Diminished

Being an outsider means not being heard; not having a voice. It means being treated as a second class citizen, being diminished in the eyes of others. We have all felt this way at one time or another, but some feel it more consistently.

-Chris Crutcher

Introduction

Embedded within the stories which participants recalled about encounters with health practitioners, were words suggesting they experienced practitioners' attitudes as somehow belittling; making them feel somewhat diminished in their standing as a person. Each person possesses an intrinsic sense of their own value, both to themselves and to others. As humans, we interpret our value or place in the world in different ways (van Manen, 1990). For example, interpreting one's place in the world as a parent may be seen as different when compared to interpreting one's place as a workmate.

To be diminished speaks of having one's value reduced. Should one feel diminished by those held in high regard the effect may prove to be detrimental. Doctors may be often held in high esteem, indeed, they may not be viewed just as ordinary by the patient, they are seen as a doctor; someone apart from ordinary people to held in a higher regard. A notion may exist of what a doctor is; he or she is seen as someone who heals but

deeper than this it may be difficult reflectively to interpret what actually it means to be a doctor (Inwood, 2000). For example, an interpretation of a doctor may not include terms related to clinical practice or healing but instead contain references to being knowledgeable, trustworthy or respected. Thus, to be diminished, by an individual who is seen as being outside the ordinary, may impose a previously unconsidered or different sense of self, changing our experience of being in the world.

The word diminished is derived from the Latin roots, *dīminuere* meaning to lessen; *minūtus*, meaning small and *minishen*, to reduce (American Heritage Dictionary of the English Language, 2011). Thus to be diminished is to be reduced or lessened in value; setting one apart as being different from others. It is to make small through cheapening, reducing or belittling. Some of the storied experiences pointed to a participant's awareness of dissimilarity; of being different or in some way apart from the world in which they exist, diminishing their own sense of significance.

Moira describes her encounters when seeking healthcare which caused her to question her own value:

“One experience I can recall was when I felt that I had been ignored after being called in to have a bone scan even though I told the receptionist that somebody had rung me to say to come in. The answer was “Sit over there”. And I felt like a child; go sit over in the corner and wait, which I did. And that's as far as I got. I had been waiting for about three hours. Yeah, they made you feel like a

child. How would you put it; well like you had no brain because you had to be told, you know?

The radiologist had noticed I had been waiting for three hours. She came and got me from where we normally go and said “No darling, we go down here”. Well, the radiologist was fine, she was good and once I had seen her, the receptionist sort of looked at me as we came out and she said, “You didn’t have an appointment today”. So I thought, no, I’m not going there because I’m going to get really mad. I had been asked to come in! It made you feel as if you had been wrong in being there and you weren’t supposed to be there in the first place and you go out feeling pissed off. Really, you want to cringe out in the car park and you don’t want to go back again. But you need to go back. You know? You go because you have to not because you want to and I feel that it doesn’t matter what the service is, you’ve got to put up with it in case you get thrown in the “too hard basket”; you go or else. What the hell’s going on? You know, where do they get these people from? Aren’t they trained to be tolerant of the elderly you know? Is it because you’re older? “Oh, here comes another one”. You know, “On its last legs” sort of thing? You know that’s it. It makes you feel as if your age is a barrier to getting good service or something. You’re not worth it once you’re past a certain age.

Moira recalls the receptionist's response to her arrival at the clinic as merely an instruction to "*sit over there*". She points to experiencing the receptionist's tone as making her feel less valued; she feels suddenly reduced from being wanted at a clinic appointment to feeling unimportant; indistinguishable from any other patient. Her words convey a sense of her worth at the clinic as having been diminished. Yet Moira is there because someone rang her to say to come in. They had wanted her to be there and in saying she was "*called in*" Moira conveys an expectation they were waiting for her to come for her bone scan. She then encounters the receptionist's indifference which suggests to her that her presence is almost arbitrary. She has fulfilled her role in coming to the clinic but her effort seems to be of little consequence. In this place which exists solely for the wellbeing and care of individuals, her overall impression is one of not mattering.

Moira points to the feeling of being put to one side with the words, "*I felt like a child; go sit over in the corner and wait, which I did*". This tells of not quite being discarded, but a sense that she can simply be put to one side. She then tells of feeling little priority, "*And that's as far as I got. I had been waiting for about three hours*". There is a sense that the time she had taken from her day meant little to anyone here and she could be simply made to wait.

She then tells of being treated "*like you had no brain because you had to be told*" and the feeling of having her intelligence diminished. She has

come to a place of healing with the expectation that she be treated with the respect implied by the term care. Before she came to the clinic she felt a sameness to others; not special, not different, just a mature, capable adult. But now there is a sense that she feels somewhat less than this; less than intelligent, less competent and less able. She does not have a sense of equality anymore only of being judged as having less value than before.

Van Manen (1990) speaks of being in the world as to be with others which provides relevance to people's experiences through their actions and deeds. This relevance is given context when Moira tells of being in the care of a radiologist. With this individual, she feels as same as any other patient. The experience is unremarkable. Moira goes where she "*normally goes*" within the clinic and describes her time with the radiologist as "*fine*", a subtle word which implies a sense of simple everydayness. Her words tell of being unaware of her age or of being different in anyway. She is just ordinary here. She then points to once again becoming aware of the receptionist. As she leaves, she tells of noticing the receptionist's gaze, "*the receptionist sort of looked at me as we came out*". She speaks of interpreting the attitude of the receptionist as again diminishing her as before. The receptionist reiterates "*You didn't have an appointment today*" but Moira only hears, "you should not have been here" and she tells of feeling like an intruder as though she had deliberately come here when not invited. There is even a sense of dishonesty as if having somehow jumped a queue when she says "*It made you feel as if you had been wrong in being there and you weren't supposed to be there in the*

first place and you go out feeling pissed off". The normality and ordinary everydayness she felt with the radiologist is interrupted and replaced with suppressed resentment.

Heidegger informs that it is only through reflection of an experience that one is able to uncover some of the hidden meanings of an encounter (Inwood, 2000). As Moira later reflects on feeling diminished by the receptionist, she speaks of annoyance. There is a sense that this is directed less toward the receptionist but more at the choice she had made to remain silent. *"No, I'm not going there (to speak out) because I'm going to get really mad"*. In choosing not to confront the situation she speaks of feeling forced to compromise. By passively complying, she feels she has silently condoned the receptionist's behaviour and contributed to a scenario she will likely have to repeat. *"You want to cringe and you don't want to go back again. But you need to go back. You go because you have to not because you want to"*. She points here to feeling powerless, both now and in the future, and for giving tacit approval to be treated in this way, as if she was of little importance. It is in a sense, becoming emotionally disabled. Moira speaks of feeling devalued by the receptionist's conduct and she points to being complicit in her own diminishing. There is a sense of impotence and that she is beginning to devalue herself through feeling ineffectual.

Being diminished and having feelings of lesser value than others speak of being different and Moira points to being old as the reason for being

different. She gives voice to some of her feelings as she interprets the manner in which older people at the clinic are differently viewed with the words, "*here comes another one*" and "*on its last legs*". The use of the term "it" demonstrates her sense of being treated like a "thing"; an object rather than a living breathing human being. She tells of her value as being relative to age. She indicates through the words "*you get thrown into the too hard basket*", a sense of disposability and of simply being too much trouble to bother with when old.

Experiencing the inability to change a given set of circumstances seemingly promotes a sense of powerlessness. It is a sense of ineffectuality and a loss of control over one's destiny. Moira's story speaks of being diminished through feeling powerless and of being treated almost like an intruder in her own experience. This story demonstrates the interactions of the players within an encounter and exemplifies van Manen's (1990) description of an individual's experiences being inseparable from those around them.

To have an expectation of how one will experience others in the future may sometimes not turn out to be what has been anticipated. Even in situations when there has been a pre-existing familiarity and an open and interactive dialogue, feeling diminished can stem from encountering an unexpected sense of not being listened to.

Jan's story tells of experiencing a sense of diminished value at not being heard when trying to convey her health concerns to her longstanding General Practitioner (GP) and former colleague.

“As someone who is reasonably fit as an older person, I want to keep that way and almost on a daily basis, I think hell, I hope I don't get cancer like my family and for me it's impossible to get that ongoing preventive investigation. My mother was one of eight children. Every single one of those children died of cancer. My father died of cancer. My brother died of cancer. For me, psychologically that's terrifying. I'm meant to be having regular tests. Well that doesn't happen now. Once you reach 69 you're no longer considered a priority and you have to actually push with your General Practitioner to even have a preventative-type investigation done. So that really distresses me personally. The examination that I was thinking of that really, really distressed me was related to some medical problems that I believed required investigation. That investigation required what's called a colonoscopy. I went to my G.P. and he said “You're too old. They're not going to be interested in looking at you just because you think you've got something wrong with you”. And I said, “But my family history! Every single person in my family has had cancer. What say I've got cancer”? He said “Well you know, we just have to live with that”.

Then he said “Oh, well”, he said “If I could find something extra I could send you off for a laboratory test and for example we could find some blood or something. They might look at that”. So we duly organized a blood test,

The next thing, I get a phone call from him, from my G.P. and he says, “Don’t panic, don’t panic, but your tests were positive”. So I’m freaking at this stage and he says “No, no, don’t worry, a lot of people have it”. And I said “Yes I know but this is me. This is me”! “No, don’t worry about it”. He says “But at least, the good thing is that at least we’ve got something that can recommend that you have your test”.

So I had the investigation, which ultimately found that I had other things but I didn’t have any tumors, so they said. But I found that whole experience quite, quite frightening that no one actually gave a stuff that I could have cancer and that I was lying awake at night thinking, when is somebody going do anything about this? They didn’t care. I was old and they didn’t really think it was a priority.

Jan already has a sense of being different from others as she recalls *“I’m meant to be having regular tests. Well that doesn’t happen now. Once you reach 69 you’re no longer considered a priority”.*

She tells of her value as a person being bound to her age. She is aware of the need to be vigilant with her health especially in light of her family

history but feels disempowered due to being old. It is a sense of abandonment which rouses fear for an uncertain future and can be heard in the words, *“for me psychologically, that’s terrifying”*. Jan points to the fear of seemingly losing control over her own destiny. The means by which she could prevent illness have become unavailable she believes, simply because of her age.

The feeling that age now defines her becomes highlighted for her with the GP’s words *“You’re too old. They’re not going to be interested in looking at you”*. Jan hears in these words that no one cares and that her worth is measured by her years. She has a sense that the GP does not hear her concerns and by highlighting her maturity has only diminished her self-esteem further.

The sense of not being listened to compounds her uncertainty. *“But my family history! Every single person in my family has had cancer. What say I’ve got cancer”*? There is a sense of growing desperation and a feeling that the ability to protect her future is slipping away.

She points to a lack of empathy and of being fearful, alone and not mattering with the words *“They didn’t care. I found that whole experience quite, quite frightening that no one actually gave a stuff”*. This tells of being marginalised. She feels little compassion, no sense of connectedness or understanding. That someone would merely listen to and acknowledge her concerns would help show that she retained some relevance and that her experience mattered. She again points to her age to rationalise the lack of connectedness *“I was old and they didn’t really think it was a priority”*.

To her becoming older is to be slipping backward in life's queue. It is a feeling of expendability and insignificance. Again there is a sense that one's worth is somehow intrinsically tied to age.

These participants' stories provide examples of the emotions of fear and anger and moods such as feeling devalued and of low self-esteem.

Heidegger differentiates between moods and emotions in that, emotions are directed at someone or something whereas moods are directed at the world (Inwood, 2000). Being diminished when viewed in the context of a mood has the capacity to cast a pall over the manner in which one may experience being in the world. Thus, an older person who feels diminished may view their lives as an existence which has lost its attraction and become dull or unimportant. Indeed, to interpret Heidegger's concept of moods could suggest the existence for the participant has become as diminished as they themselves feel to be.

Conclusion

Being diminished for the older people in this study was uniquely different and at the same time very similar with catalysts for their feelings ranging from the overt suggestion of others to benign complacency. The antithesis of experiencing being in the world for them may have been a failure to be acknowledged and a sense that they had been separated out; no longer having a place.

Being diminished changed the context in which the participant's world was experienced. It placed in doubt, their self-worth and the manner in

which they believed their value to others to be. To feel diminished was, for these individuals, to be marginalised and made to feel different.

The sense of being left behind may present yet another expression of the lived experiences of older people and their health providers. The next chapter examines this more closely in the theme of being forgotten.

Chapter five

Being Forgotten

How would it feel to live a full life and have no one remember it, to have no one remember the extraordinary things you accomplished, even if it was just waking up every day and finding the courage to get out of bed?

— T.J. Klune, *Into This River I Drown*

Introduction

This chapter presents stories that resonate with the theme of having been forgotten. The term forgotten conveys different meanings, such as an unintentional omission or an accidental oversight. It may also imply being willfully neglected. The root of the term is sourced from the old English word “*forgieten*” of approximately 900 A.D. “*For*” had the meaning “*away*” or to be “*amiss*” and “*gieten*” to get or grasp. (Dictionary.com, n.d). Thus “*forgieten*” is to un-grasp or to be lost from the mind. The negative connotation associated with being forgotten is drawn from a deliberate act of being removed from one’s thoughts as if not be taken notice of or disregarded. Most importantly it points to the feeling of not having a presence or of being excluded from an experience.

In these participants’ stories, the context in which forgotten becomes apparent also speaks of a sense of being ignored and treated as though invisible. The terms, ignored and invisible, share many connotations with being forgotten and when examined, they exemplify some deeper

implications of the word. For example, to be ignored is a sense of being neglected or overlooked. Phenomenologically speaking it could imply feeling not present as if rejected by others and made to be in some way, apart. The term, ignore stems from the Latin root “*ignorare*” meaning not to know or to disregard (Dictionary.com, n.d.). It implies as does the active version of “*forgieten*” a deliberate omission with the intent to exclude from one’s mind. Similarly, the word invisible shares this sense of being forgotten. Originating from the Latin “*visibilis*” meaning “seen” and “in” meaning “not” thus, it is not to be seen or in other contexts, acknowledged (Dictionary.com, n.d.).

“Being forgotten” was chosen as this theme as it embodies these various expressions and describes best the sense within the following stories that one’s presence simply means little. It tells of feeling unimportant and not appearing to matter or of having any influence.

Neville relates his feelings upon arriving at a hospital and of being excluded from what is occurring around him. He tells of a sense of feeling shut away from others:

“When I arrived at Auckland hospital it was hours, or what seemed hours in a little alcove you know? Being shoved in there and the blinds pulled and waiting there. When I eventually did see someone I can remember feeling relieved that I was actually dealing with somebody instead of being shut away. Obviously there are a lot of people that were shut away behind their curtains and a

minimum of staff because they all seemed to be rushing around in every direction. It wasn't calm like with the ambulance because hospitals fill me with terror. Not terror but unreasonable apprehension on my part I suppose; going into hospital with knowing that basically that there's going to be an operation at the end of it or something like that perhaps. I've had a lot done: every time I've gone in there I've lost a bit of the body. They always end up chopping a bit off whether it was toes, or feet, or a leg.

I can remember the surgeon at one stage really blowing up someone on his work team because the epidural had come out of my back halfway through the operation. And that didn't put me in a good frame of mind you know. Nobody informed me what was going on and I can remember thinking, my God, you know, what are they doing to me? But not caring much at that stage. Not caring what they did to me as long as it didn't hurt. Their attitude was cool and calculating, quite a "business as usual", yeah. You know, carrying out their job in other words, you know I might as well as have been a piece of cardboard or something they were going to chop up."

Neville uses the word "shoved" and describes being put into an alcove. The literal expression of shoved is to be pushed rudely, or jostled with force (Dictionary.com, n.d.). This indicates the value Neville feels himself to have here. It is a sense that, for at least at present, he is not worth any

consideration or of being treated with a sense of compassion. In a busy environment such as the hospital, currency is measured in time and he has been afforded little if any. He describes; “*the blinds being pulled and waiting*”. The blinds being pulled for him are an act of disconnection; of separation. It is a physical barrier that has been imposed. He was not consulted or asked if he needed privacy but simply put here until someone else chose to include him. Neville is describing through the term “*shoved*” the way he considers an inanimate item with no feelings is treated. He depicts in these words being objectified as if he were something to be shelved or stored away; unseen until it was decided if he had a use. There is a feeling that the needs of all others are more important than his and he will be attended to when he is deemed important enough to be awarded some time. When he talks of “*being shut away*”, he points to the sense of being not only detached but alone. His sense of being invisible is to be out of sight and out of mind.

This story speaks of experiencing exclusion and of feeling segregated as if different from others. He says “*nobody informed me*”, this tells of a deeper need than merely communicating and sharing; it is of making the unknown, known. There is a need to be included in his own experience. It is almost as if this encounter is happening without him and he is being deprived of the simplest consolation which comes from simply being with other people. It is the sense that he must again wait; wait till others are ready to invite him back to the world, and wait is what Neville does. In the temporal sense he describes his perception of time passing slowly for

“*what seemed like hours*”. The impression of time passing is very much a subjective experience; time passes quickly when busy or enjoying an activity and slowly when bored or during an unpleasant situation. His experience of time passing slowly is expanded by his solitude and Neville’s aloneness becomes an arena in which to consider his past hospital encounters. He is no longer distracted as he was when interacting with the ambulance crew; he is now alone in the isolated environment of the little alcove with time to think.

Heidegger describes how in the process of being there, elements of an encounter are inconspicuous while they are occurring (Inwood, 2000). With time to reflect it is almost as if Neville is interpreting his experience as it transpires, elevating his anxiousness as he waits. He tells of the sense of relief he experiences when eventually being seen by a clinician, “*I can remember feeling relieved that I was actually dealing with somebody instead of being shut away*”. Here, Neville points to a respite from being alone, it is a reprieve from separation to once again have human contact. He uses the term “*somebody*” to tell of a sense that his relief could have come from anyone. This has the feeling of being liberated, and at least for now he is able to commence the process of regaining some small sense of value.

It may not always be that the presence of others diminishes the sense of being alone. To be amongst others and still feel alone may even exacerbate feelings of isolation. Neville points to another experience of

being alone whilst still in the presence of others. He becomes aware of a surgeon reprimanding colleagues during an operation. He points to not feeling present to those around him. He is being spoken about but not to. He is corporally present amongst others and the physical focus of the medical team but apart in an emotional sense. The term care is often given positive connotations of wellbeing and being looked after but in reality it may also be about worry, anxiety and fear. Neville indicates these emotions with the words *“my God, you know, what are they doing to me”*? For Neville, his humanity seems to have been forgotten by the medical team elevating his anxiety through overhearing the surgeon’s comments. As in the little alcove, his words point to feelings of uncertainty, vulnerability and a sense of helplessness. He still feels alone even though surrounded by people. Neville uses the term *“something”* to describe himself rather than someone, which speaks of becoming blinded to his own humanity and objectifying himself. He describes himself as *“a piece of cardboard or something they were going to chop up”*. This is his belief of how the medical teams view him; as an object rather than a person. Neville tells of relinquishing even these feelings as he succumbs to a sense of helplessness when he says, *“But not caring much at that stage; not caring what they did to me as long as it didn’t hurt”*. He speaks of not having control or even influence in his own fate; it is easier to simply acquiesce. By detaching himself and shutting out what is occurring to him he tells of surrendering emotionally and in a sense becomes as invisible to himself as he feels he is to the medical team. Feeling forgotten from this

story portrays uncertainty and anxiety however, in a different type of encounter, when one is not expecting to experience being forgotten it can very quickly alter one's sense of place in the world.

John describes transitioning from a sense of feeling valued to that of being forgotten when he speaks of waiting for test results from his doctor whom he has known professionally for many years:

“It was getting the results of the angiogram that was another frustrating experience. I contacted my GP, this is the GP I had a relationship with, and I said “Have you got the results”? I had sent him an email. “Have you got the results of my angiogram and my consultation with the second specialist “? And I got a one line reply saying “Yes, they arrived on Monday”. Well I was ropable because there was no, “The results are here. Would you pop down and see me. Or I’ll get my practice nurse to have a word with you”. It was just blatant, and it was out of character totally for this guy. I said to Anne “what do we have to do now”? So she said, “Send him another email saying that you were only asking for the results and were they good or bad”? So that’s exactly what I did, I sent him an email an hour later saying “you’ve got the results, should I be worried, are they good, bad or indifferent? Shall I come and see you”?

The angiogram test arrived a week after talking to the GP which meant that it had taken six weeks for that result to come back. I

was sent a copy but it's written medically and I don't totally understand the various technical terms that they are referring to and I still don't know where I am. There's this thing where they are limited to an appointment time and I would always like to get more time to actually talk about my condition and where they think we may be going but there always seems to be a need if you like to terminate a particular appointment. In other words they haven't got all afternoon for me. If I could make one recommendation it would be to take more time with the patient.

John is describing the initial sense of anxiety through being forgotten by his GP. He implies a confidence in the doctor through the feeling that there had existed a rapport between them which would provide him some small consideration. He describes the initial unexpected feeling of frustration and points to a trust that this person he has known for many years would have had a somewhat more empathetic approach and an understanding of the anxiousness he might be experiencing. It is not that John feels that his value or need is greater than other patients but that his value to the doctor was slightly special in view of their prior history. There is a sense here, as he begins to grapple with the idea of being ignored, that he may have misjudged his own value. Frustration gives way to anxiousness when addressing the doctor; *“you've got the results, should I be worried, are they good, bad or indifferent”*? John's tells of not only seeking information important to him but also of a need to be recognised. His experience of waiting has been a vigil which he feels the doctor has

the power to address but somehow chooses not to. John goes on to tell of confusion and of not understanding his test results. *“I don’t totally understand the various technical terms that they are referring to and I still don’t know where I am”*. He feels that no one seems to care whether he understands the outcome of his tests. These are his test results and this is his health which the doctor does not allow sufficient time to explain to him. John points to feelings that his physical needs have been forgotten and his emotional needs ignored. He provides a sense of not being worth the doctor’s time. *“I would always like to get more time to actually talk about my condition but there always seems to be a need to terminate a particular appointment. In other words they haven’t got all afternoon for me”*.

Van Manen (1990) describes experiencing the world in the corporal sense and of the manner in which we interpret the signals and messages around us. These may be conveyed through actions such as attitude or mannerisms or indeed as in John’s story through inaction.

The ability to empathise with another’s experience becomes all important to making the individual feel connected. In an epilogue to these stories, Neville has provided the sense that even though one can feel alone whilst still in a crowded room; perhaps one of the loneliest experiences, what a difference can be made should but one person show empathy and a sense of understanding.

“It was in one of those operations (amputations), I can remember a nurse when I wasn’t put out, but just with an epidural; a nurse holding onto my hand and stroking my head, stroking my hair and talking to me. And saying you know, “You’re doing fine and everything’s going so well and you’ll be right”. It felt so good to have someone talking to me. It made me feel like a person; one of them and not just a hunk of meat lying on my back like most of the time. It didn’t happen with anyone else at any other time, you know, just this particular time”.

Neville speaks here of remembrance, of being one of them and a human. He tells that one person who, in this one encounter does not view him as an object and gives back some of his humanity through sharing his experience. This story illustrates how Heidegger describes experiencing the world as Dasein and the notion of being with others. It is not important to know who is there, why they are there or what they look like. It is sometimes sufficient that they are simply there, and as with Neville, that they understand.

Conclusion

These stories tell of the different experiences of being forgotten. Each tells of the more troubling psychological aspects; the objectification and segregation, with or without others present and the interpretation of self-value through the actions of others. There is a sense of a resilient undertone which in its own way helps to mitigate many of the physical

challenges endured. Still, the stories speak of fear, uncertainty, surprise and aloneness. In contrast to these there is an example of kindness and understanding which exemplifies how for the participant empathy dramatically influenced the lived experience. Viewing the world through an everydayness provides a different manner of experiencing the world. A manner which affords resilience and may sometimes unshackle the burdens associated with being diminished or forgotten. The next chapter examines stories from the perspective of people who view their experience of the world through a lens of resilience.

Chapter six

Being Resilient

When we learn how to become resilient, we learn how to embrace the beautifully broad spectrum of the human experience.

— Jaeda DeWalt

Introduction

This chapter presents stories which embody a sense of resilience or an ability to rebound from encounters that have the potential for adversity. It also shows how some participants attributed importance to different events as they were experienced. Standing out in these stories is the way in which the challenges encountered when seeking healthcare, irrespective of nature or magnitude, are approached with a sense of typicality or simply as being an everyday experience. The stories speak of this resilience and reveal a pliability and an ability to absorb challenging events. By demonstrating how such issues were experienced by the participants, the stories reveal that rather than choosing to be affected adversely they may take from the experience a motivation which may even prove to enhance their lives.

What is also notable is the sense that the health events involved appear to be of greater concern to the clinicians than for the participants themselves. Bringing these stories together begins to reveal how resilience is reflected in different individuals through their actions and their words.

The term ‘resilient’ first appeared in the early to mid-17th century and stemmed from the Latin “*selire*”; to rebound or jump back. The prefix *re-*

having the meaning, again and again, thus to rebound repeatedly and speaks of individual, durability and adaptability. (Dictionary.com, n.d.). Resilience may range from adopting an action which directly responds to an adverse situation, to merely having an intrinsic capacity for deflecting unfavorable encounters. This may be viewed as an inverse situation to some individuals who experience difficulty when facing similar situations, indicating that the nature of being human is that there is no absolute. Margaret speaks of events which present her attitude and the manner with which she proportions importance when having received healthcare.

“Well, I’ve kept good health mainly all my life and I’m eighty-two at the moment. Years could go by before I went to a doctor and then I did break my shoulder at the op-shop actually and ended up in North Shore Hospital. I was living in Devonport then and that seemed to go quite smoothly, though they did lose me in their computers but that could happen at any age.

They eventually found me and it was quite good because they hastily kept giving me appointments for checkups and I didn’t have to wait at all. After that I had to go to my own doctor a couple of times for checkups. Everything seemed to go smoothly and there were no problems and then when I moved here and got the flu. I didn’t cancel Devonport but enrolled with another Medical Centre and I really had no problems there except when I went because of diabetes. My uncle had apparently a rare form and his doctor said

“keep on being checked”. I got checked when they had the diabetes week and they got very concerned about but my blood pressure, it was too high. Frankly that’s about the only time I go to the doctor; every three months to top up my high blood pressure pills.

It’s a busy place they have. I think you can make appointments in the morning but I don’t worry I just go. I take my glasses and a book if they’re busy. I sit down and have a nice relaxing time reading. One doctor there sends me to the lab about once a year or six months to be checked out. Once when they were very, very quiet he tested me for my heart, lungs and everything I think he wanted a new patient. But it didn’t work. All he could tell me was, “You’re very healthy”. When I do go I’m quite interested in what happens. I’m not worrying because I’m more interested in seeing what’s happening and what they do. It’s all a new experience for me”.

In this story Margaret talks of being lost in a medical centre computer system. She dismisses age as contributing to this and her words tell of an absence of feeling singled out. She is seemingly like others, in that anyone could also have had this experience. This is not personal and she chooses not to refocus the event as being about her age. By not personalising this experience her words say that it is merely an occurrence, an event that simply happened. Her resilience in this instance may stem from not giving

the incident importance or a power to influence her feelings; thus, she easily absorbs and moves on from the episode.

Rather than reflecting on the feeling of being lost in the medical centre system Margaret instead chooses to view herself as receiving special treatment; *“They hastily kept giving me appointments for checkups and I didn’t have to wait at all”*. She tells of feeling a measure of significance. She is distinctive and stands out for special attention and becomes the focal point in her story rather than the event itself.

As Margaret speaks she uses the word *“smoothly”* throughout her story. Defining smoothly as a flow or transition, free from interruption; her use of this word points to a leveled approach within herself when having experienced such events as breaking a shoulder, having high blood pressure or diabetes. It is almost as though the health events were only footnotes to her story rather than the focus. This in itself provides a sense of how Margaret appoints significance in her life.

Margaret also demonstrates resilience through simply going along with how things are. When Margaret speaks of visiting with her GP, it is treated as though almost recreational; *“I think you can make appointments in the morning, but I don’t worry, I just go. I take my glasses and a book if they’re busy. I sit down and have a nice relaxing time reading”*. There is a sense of tranquility to Margaret’s approach and her resilience allows her to maintain calmness of attitude whilst waiting for care. The GP’s waiting room is a place for her to have a break; almost a recreational space.

Margaret describes it as a “*busy place*” and she understands that there may be more important issues to which the practitioners have to attend. She hints that she is comfortable with the practitioners’ attitudes and is as confident here as in any other place, filling her day and being happy to just wait. On an occasion in which she describes the clinic as “*very, very quiet*” she tells of an impression that the doctor is providing extra attention to her health. She has been accommodating when the clinic has been very busy and now she feels her patience is rewarded through extra special attention. Margaret alludes to doctors and clinicians making appointments and checking various indicators of health and her words underpin her relaxed approach. She tells; *I’m quite interested in what happens. I’m not worrying because I’m more interested in seeing what’s happening and what they do. It’s all a new experience for me*”. Here Margaret speaks to us of a belief in the skills of the people who look to evaluate her health and she trusts that their attitude toward her is correct and proper. Her words demonstrate resilience through trust and self-confidence. She matters here and thus is able to step away, any anxiousness giving away to curiosity.

Apparent throughout Margaret’s stories is sense of liberation through having an attitude of confidence and self-assurance. Other stories show resilience differently and tell of an ability to rationalise and accept events of the past that may have influenced the present. These stories also point to not giving these events the power to dominate the present or the future. Trevor tells us of such an attitude when dealing with skin cancer.

“I’ve had an op to remove a melanoma; yeah nodes, that’s right. GP picked it up. Yeah, it’s a bit of a nasty isn’t it? But you know, it’s there and they’ve discovered it and they’re going to take it off. I’d had bits of it off before. I did a lot of running, saw a lot of the sun and I’d had bits burnt off for years now, it’s sort of part and parcel. It’s too late to do anything about it now. You just have to accept what’s coming. No point in getting into a panic. I had this one done last year with radiation treatment and everything. That was described as a “nasty”, but they got onto it quick and got it out quick.

My only problem was high blood pressure on the day of an operation, kind of thing. But you’re feeling confident in yourself and fully relaxed. They did all the work one day ready to go and after the final check had to stop everything and send me home. Not good. Not good for them you know, the whole team lined up to do the job.

The clinician’s attitude was a very common sense one. They told you what was going on and spoke to you directly it was a very pleasant thing. The hospital experience was much like the GP; yes I can’t believe it. Yes. that attitude of professionalism it’s a big thing. I have a lot of confidence in them. Well, you’re in good hands really. Nothing you can do about it yourself, you’ve just got to go along with it. Follow the rules. No, honestly I was amazed.

It's a difficult job they've got. I always go in there feeling they're all doing their best. You've got to along and work with them, get along with them.

I think a lot of people go in thinking "nasty", you know? It's going to be horrible. And when you get that attitude you can find fault with everything can't you? Whereas with the older age you just accept what's coming, relax and go with it; it's a different attitude".

Trevor speaks of an attitude toward having skin cancer surgery due to his exposure whilst running when younger. *"I saw a lot of sun. It's too late to do anything about it now. You just have to accept what's coming. No point in getting into a panic"*. He conveys a sense of resilience through acknowledging the past but being firmly situated in the present. Through reflection, this becomes an opportunity for him to make a change in his future health and make peace with what the future has in store for him. His words suggest that he is looking ahead and above all he is telling of being self-assured. *"I have a lot of confidence in them. Well, you're in good hands really. Nothing you can do about it yourself, you've just got to go along with it"*.

Trevor's resilience seemingly stems from being made to feel that he has value. He speaks in the story of being *"fully relaxed"*, and an *"attitude of professionalism"*, which tells us of a deeper trust in the clinician's skill and his sense of significance. His resilience is apparent through being able

to just go along with the process and speaks of experiencing positive attitudes from his encounters with clinicians.

His resilience is such that it permits him to not only manage feelings surrounding his own encounters, but to also feel a sense of empathy for the clinicians. Trevor tells us of an understanding of the difficulties experienced by the clinicians when a procedure he is about to undergo is cancelled. *“Not good for them you know, the whole team lined up to do the job. It’s a difficult job they’ve got. I always go in there feeling they’re all doing their best”*. Empathy involves the ability to imagine what another may be experiencing (Collins Dictionary and Thesaurus, 1988). In what may appear to be almost a reciprocal care role, through his words he places himself amongst the medical team, working with them. This has become a shared experience which he describes as not only occurring to him but also to them. Trevor’s resilience, blended with empathy, permit him to deflect his own concerns toward the medical team.

Trevor goes on to consider age in a manner which holds self-benefits as he attributes his capacity to deal with challenging situations to his maturity. *“I think with older age you just accept what’s coming, relax and go with it; it’s a different attitude. I think a lot of people go there with a negative attitude; looking for faults”*. Here Trevor points to his age as becoming an asset in helping manage challenges arising from becoming older. There is a sense of tolerance and having learnt to appreciate his experiences for what they are.

When examining the experiences of these participants a relationship in the meanings begins to emerge. German hermeneutic philosopher and historian Dilthey, used the term “*erlebnis*” to describe a form of unity and pattern of meaning (van Manen, 1990). The encounters, though manifesting in differing ways, point to an underlying sense of experiencing life in a similar manner. It is a life that is undefined by age or illness which demonstrates resilience here and is supported by the professional attitude of healthcare practitioners.

Conclusion

In the context of the diversity of health practitioners’ attitudes, it is possible to distinguish through these stories the different ways in which being resilient is revealed. With both participants, there is an awareness of feelings of trust and of having confidence. There is a trust placed not only in those to whom healthcare is abdicated, but also an intrinsic belief in oneself. As in other themes there is a sense of temporality; of past, present and future with a view or expectation of one’s future self. However, in difference to other themes, for those who experience greater resilience, the view of one’s future appears not to be significantly affected.

Resilience, as previously defined, is the ability to rebound. For Margaret, the events surrounding the experience of seeking healthcare appear secondary to her normal life. She is curious and tells us of feelings of significance and alludes to little or no disruption to her normal living routine. Trevor experiences resilience through pragmatism, by

empathising with the clinicians and through recognising that elements of his life grounded in the past are now part of his present and likely future.

Though these individuals' encounters both embody the same values of adaptability and durability which define resilience, they have told us of quite different expressions from their own lived experiences. Furthermore, they tell of the manner in which the participants have chosen to interpret the attitudes of the health practitioners they encountered. There is an underlying sense that they have been made to feel that they are in competent hands and that professionalism surpasses any biases such as age and that they are at least as important as everyone else.

Chapter seven

Discussion

Empathy is the ability to step outside of your own bubble and into the bubbles of other people. Empathy is the ability that allows us to be useful creatures on this planet. Empathy is the ability that allows us the perception of things around us, outside of ourselves; so a person without empathy is a limited human being, someone who will only live half of a life.

— C. JoyBell C.

Introduction

As age progresses one may become increasingly aware of maturity and events which are associated with becoming older (Levy, 2003). Van Manen (1990) tells of “lived experience gathering hermeneutic significance” (p. 37). Through a reflective process of thoughtfulness, individuals assign meaning to living. Should encounters repeatedly signal feelings of low worth or unimportance, this is likely to influence how living in the world is viewed overall. This aligns with the notion of priming which suggests that one’s attitude to life and the downstream implications on health in later years maybe instilled through the way the world is experienced as people age (Levy et al., 2000).

Much research on the attitude of healthcare providers has concentrated on the experiences of older persons domiciled in retirement facilities, institutionalised age care environments, or from the perspective of clinical providers. Such studies tend to be of a quantitative nature, rather than

dealing with the interpretations of elders experiences. As such, the gap this study aimed to address was to uncover older New Zealanders' lived experiences of healthcare providers' attitudes. The use of hermeneutic phenomenology as the methodology was particularly suited to this task as it allowed for deeper meanings within the participants stories to be revealed.

The experience of being older provides a context in which a population often viewed as more vulnerable may have a differing sense of self and perception of their place in the world as they age (Levy, 2003). Using the themes uncovered by the interpretation process, a scan of literature was made to determine if any other articles of relevance could be found in order to situate this study's findings within the literature.

Summary and discussion of the findings

Insight was achieved into elders' experiences and how the attitudes of health providers had influenced the participants' feelings of self. Three emerging themes from the interpretation were those of feeling diminished, being forgotten and being resilient. Both the first and second themes aligned with notions of being treated differently and that one's value was less than others.

The third theme, being resilient, exposed experiences which embodied a sense of the positive and pragmatic. The lens through which the participants viewed their encounters appeared to be less self-central and more generalised in their approach to living in the world. There was a

sense of being a part of the world and the experience rather than being separated out from it.

Across the two themes of feeling diminished and being forgotten common notions became apparent such as feeling marginalised, ignored and invisible. Two major impressions were revealed from these; firstly, that of the effect of objectifying, which spoke of reducing one's humanity to that of an article or thing. It presumes a disposability or even obsolescence, ignoring the richness of feelings and emotions that is the hallmark of the human condition. Secondly, there is the impression of being judged which has connotations of hierarchy and that someone else has prevailing control. It is a sense of powerlessness and loss of control of one's own providence.

The notion of a power differential between some healthcare providers and older people is not new and was examined in a study, which investigated the attitudes of nurses to older people in acute care (Higgins, van de Riet, Slater & Peek, 2007). The study found that older persons had a sense of prevailing control by nurses, resulting in feelings of reduced capacity. The nurses themselves described this as being a form of oppression of elders. The study, however, presented only hypothetical examples containing positive and negative elements of treatment toward older patients instead of drawing from actual experiences. Furthermore, the age of experience of nurses interviewed ranged from 30 years to only 2 years

indicating a significant difference in the clinical expertise of working with older people.

The hierarchical structure of the healthcare provider and patient relationship has the potential to lead to reflectivity, introspection and an altered view of the older person's place in the world (Doyle, 2014). This Australian study utilised in depth interviews with participants ranging from 55 to 91 years of age and though the opinions of participants were still valuable the range of ages might also suggest a significant difference in the nature of the experience encountered. From this study, however, Doyle (2014) suggested that induced feelings of forced compliance had silenced the voices of older people who believed this response was necessary to ensure continued assistance from caregivers. This situation was comparable to the experience of one participant in this study who believed that no choice was available other than "*to put up with it*".

Consistent across the themes of feeling diminished and being forgotten was the impression of not being heard or listened to. There was a sense from the participants that there was insufficient time allocated for older people from some health providers, and a lack of understanding of the participants daily needs. This is comparable with research which showed similar emergent feelings of not being heard in addition to a sense that doctors always felt they knew better (Ward, Barnes, & Gahagan, 2012). Ward, Barnes and Gahagan (2012) supported the notion of overt power differentials and the feeling by older people that they were not being

included in the decisions surrounding their own wellbeing. Thus, feelings of somehow being marginalised may be due in part to the seeming unwillingness of some healthcare providers to give time to older people; a situation which may be exacerbated when viewed in the context of busy healthcare situations. This was reflected in the words of a participant who felt constrained by ridged consultation times. *“There always seems to be a need if you like to terminate a particular appointment. In other words they haven’t got all afternoon for me”*.

The third emerging theme of being resilient contrasted to the experiences discussed in the previous themes. There emerged the sense of an ability to deflect negative connotations and to view an experience from different perspectives. Those participants who represented being resilient portrayed a sense of trust, confidence and respect for the providers’ professionalism. By choosing to trust there may be the retention of a sense of control over one’s own encounters and is the antithesis of the participants’ powerlessness experienced in the previous themes.

Retaining a sense of essential identity and maintaining influence over the events of life in old age was put forward by McCann-Mortimer, Ward and Winefield (2008), who examined attitudes toward healthcare which promoted successful ageing. Participants in their study highlighted the importance of maintaining a degree of autonomy over their lives, extending this ultimately to how they chose to die. Furthermore, being able to select a care provider and then maintaining a close relationship

was found to be of great importance to older people (Troutman-Jordan & Staples, 2014).

Congruent with this study's findings, research suggests older people may develop strategies, such as developing familiarity with a healthcare provider, to help manage age related changes (Pejner et al., 2015). Of interest, in the earlier themes the ability to choose or establish a rapport with a doctor did not guarantee a satisfactory encounter. In this current study, despite having selected one's own doctor and maintaining a long standing, familiar relationship some participants still experienced being diminished. In contrast, Neville's encounter involving "*feeling like a person and one of them*", illustrates the power of empathy provided by someone he did not know or who did not know him. This may indicate that a much deeper understanding of the interactions between clinicians and older patients has yet to be established.

In the final theme of being resilient the stories demonstrated an ability to adapt to different circumstances. Coping with change and maintaining a positive attitude to adverse situations whilst maintaining a sense of humour and taking one day at a time was emphasised by older persons as being a major contributor to successful ageing (Troutman-Jordan & Staples, 2014). This same philosophy was reflected within the stories of the participants who demonstrated an attitude of being resilient.

The way participants in this study interpreted their role in the encounters with healthcare providers relates to Heidegger's assertion that being in

the world allows for a choice of the way to be in it (Inwood, 2000). For example, it may not be possible to change the circumstances of an encounter but participants in this study who exemplified resilience demonstrated it was possible to choose how to experience it.

Limitations and strengths of this study

The methodology used in this study was new to the researcher and the process of learning the interpretive process, whilst developing an understanding of hermeneutic phenomenology was challenging. Thus, the level of experience through the data collection and interpretive process developed over the course of the study as an emerging skill. This evolving learning may have been a limitation in the gathering and interpretation of the findings.

The participants were all from reasonably affluent areas of the greater Auckland region. Given the significant geographical size and diversity of New Zealand's older adult population, data gathered from a wider cross section of areas and socioeconomic groups may have yielded different experiences.

None of the participants from this study identified with any particular cultural group; all being considered as New Zealand European or Pakeha. Volunteers were all sourced from the Age Concern organisation and tended to be from similar environments which may have contributed to the limited diversity of the participants. Data sourced from people from

other cultures may have presented unique insights into the experiences of other older person's encounters of health providers' attitudes.

The strength of the study was sustaining full and open transparency throughout the research process by outlining the initial pre-understandings, and making clear the researcher's own experiences and what this brought to the project. Furthermore these pre-understandings also outlined how these influences informed the lens through which interpretation was later carried out. Transparency of process was also important to ensure the participants remained fully informed throughout the progress of the study. More importantly, however, was the full and open disclosure of the transcripts and obtaining the participants' approval of the stories as they were carefully crafted to fully represent their experiences.

Trustworthiness/Rigour

Trustworthiness in interpretive research is achieved through carefully following a phenomenological process (Tobin & Begley, 2004). To appraise the trustworthiness of this study, four criteria as outlined in Annells (1999) model of evaluating phenomenological research are used. Firstly, the descriptions used to present the experiences should be in clear but simple terminology which matches the methodology being used Annells (1999). As phenomenology attempts to capture hidden meanings, the writing of the interpretations in this study have attempted to render into everyday language the meanings with clarity and openness.

Secondly, in presenting “an understandable inquiry process” (Annells, 1999, p 10), it is important when outlining the methods utilised within the study that the process may be easily followed by the reader. The process should be presented in sufficient detail as to be easily understood, should this is not be the case it is likely that insufficient information has been presented for the reader to adequately follow the methods (Annells, 1999).

In outlining the final two criteria of Annells’ (1999) model, it is best to engage these in reverse order for utmost clarity. Next it should be determined if the philosophical and methodological approach chosen was best suited to the task. What is “the congruency of the approach to the research question” (Annells, 1999, p 11). For example, phenomenology asks “What is an experience like?” or “How does the experience feel?” but avoids asking “why” an experience may have occurred (Wright-St Clair, 2015). The purpose of the methodology is not to determine a causal relationship but to explore reflectively what lies beneath a lived experience. This study engages the phenomenological “how”, when exploring the underlying feelings of how older people experience health providers’ attitudes. Furthermore, the study utilises the Heideggerian approach of acknowledging the lens through which it describes how the researcher’s own lived experience have provided influence.

Finally, it should be determined that the product of the study has a function through outlining implications for future research or professional

practice (Annells, 1999). In line with these criteria for methodological rigour the study provided new insights through the better understanding of the effects on older people of attitudes by healthcare providers, and of the participants' attitudes to their individual experiences. The implications of these form the basis for the recommendations for both professional practice and research.

Hermeneutic phenomenology, being the interpretation of experiences is distinct from merely describing an event. In satisfying Annells' (1999) mode of enquiry and to maintain methodological integrity during data collection for this study, methods such as rolling recruitment occurred concurrently with text analysis, allowing for interpretation to evolve as meanings were revealed. This iterative process assisted in a deeper understanding of the data as the interviews progressed. However researcher inexperience particularly in the initial phases of data collection may have precluded exploring notions as effectively as they could have been.

The research design for this study, such as the age criterion, was chosen to align with relevant literature and the recruitment methods selected were all in keeping with accepted ethical criteria. The interviews, being free from structured questions ensured that the voices of the participants were captured allowing full and free expression of lived experiences.

Implications drawn from this study

The ability of health providers to have meaningful communication with older people may provide a mechanism to assist those less resilient to better relate when seeking healthcare (Troutman-Jordan & Staples, 2014). Some participants in this study spoke of not having enough time to discuss their health fully or of not understanding medical terminology used by practitioners. Research is therefore needed which examines how health providers may better create a more supportive environment when managing the complex needs of an older population. Research into the efficacy of including undergraduate or post graduate training in working with older people may help healthcare providers present a more compassionate approach to their care and should look to inform and provide an understanding of the potential negative and positive effects of their attitudes towards an older population. Communicating in a manner which helps the older person better understand implications associated with their health may not only affect their approach to health but also convey a sense of empathy or interest in them by the provider.

Future research into the experiences of older persons and the attitudes of healthcare providers could explore regional differences such as those from lower socioeconomic areas. Similar research involving different cultures would further provide a more comprehensive picture of the encounters as had by older members within these cultures. Addressing

these gaps in knowledge may help advance understanding in an under researched area of human experience.

Conclusions

This study's findings uncovered a deeper understanding of how the participants involved experienced their healthcare providers' attitudes. It suggests that the way in which one chooses to experience life may affect one's encounters. It is possible for some individuals when confronted with challenging health provider attitudes to effectively maintain an outlook of simply taking things one day at a time or as they come. However, the nature of being human and experiencing the world is different for each individual and an attitude of resilience should not be solely relied upon to provide a satisfactory, humane experience. A more considered approach by healthcare providers may serve to promote a more affirmative outlook encouraging more positive or resilient attitudes whilst minimising the likelihood of feeling diminished or being forgotten.

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Appendices

Appendix A

12 February 2013

Peter Simunovich
10 Burnsall Place
Avondale
AUCKLAND 1026



Private Bag 92006
Auckland 1020, NZ

T: +64 9 921 9999
www.aut.ac.nz

Dear Peter

ST1087643 Peter Simunovich

Master of Public Health - Thesis topic and Supervisor confirmation

Thank you for submitting your PG1 Research Proposal application. Your proposal has been reviewed and approved by the Faculty of Health and Environmental Sciences Postgraduate and Research Committee 26 January 2013 meeting. Details are:

Topic:	Older persons and the New Zealand health system: A user's perspective of service provider attitude.
Primary supervisor:	Valerie Wright. St Clair
Start date:	4 March 2013
Expected completion date:	20 February 2015
Enrolment:	Part-time thesis enrolment

You will see processes for progress within the thesis paper are laid out in the *Postgraduate Handbook*. If you do not have a copy of this booklet please contact the Executive Administrator on (09) 921 9999 extension 7020.

The AUT website for forms and handbooks is:

<http://www.aut.ac.nz/study-at-aut/current-students/postgraduate-support>

Please feel free to contact me with any questions or clarification you may require.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Erica Hinckson'.

Associate Professor Erica Hinckson
Associate Dean (Postgraduate)
Postgraduate and Research Office
Faculty of Health and Environmental Sciences

Cc Primary supervisor Valerie Wright. St Clair

A p p e n d i x B



A U T E C
S E C R E T A R I A T

18 June 2013

Valerie Wright-St Clair
Faculty of Health and Environmental Sciences

Dear Valerie

Re: **13/137 Older persons and the New Zealand health system: A user's perspective of service provider attitude.**

Thank you for submitting your application for ethical review. I am pleased to confirm that the Auckland University of Technology Ethics Committee (AUTEC) has approved your ethics application for three years until 10 June 2016.

AUTEC suggests a larger font and the provision of a land line contact number on the Information Sheet in view of the participant demographic.

The committee noted that recruitment through Grey Power may not lead to a fully representative sample and suggests that wider recruitment sources be considered in order to increase diversity.

As part of the ethics approval process, you are required to submit the following to AUTEC:

- A brief annual progress report using form EA2, which is available online through <http://www.aut.ac.nz/researchethics>. When necessary this form may also be used to request an extension of the approval at least one month prior to its expiry on 10 June 2016;
- A brief report on the status of the project using form EA3, which is available online through <http://www.aut.ac.nz/researchethics>. This report is to be submitted either when the approval expires on 10 June 2016 or on completion of the project;

It is a condition of approval that AUTEC is notified of any adverse events or if the research does not commence. AUTEC approval needs to be sought for any alteration to the research, including any alteration of or addition to any documents that are provided to participants. You are responsible for ensuring that research undertaken under this approval occurs within the parameters outlined in the approved application.

AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to obtain this. If your research is undertaken within a jurisdiction outside New Zealand, you will need to make the arrangements necessary to meet the legal and ethical requirements that apply within their.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all correspondence with us. If you have any enquiries about this application, or anything else, please do contact us at ethics@aut.ac.nz.

All the very best with your research,

A handwritten signature in black ink, appearing to read 'Madeline Banda', is written over a light blue horizontal line.

Madeline Banda
Acting Executive Secretary
Auckland University of Technology Ethics Committee

Cc: Peter Simunovich masteryoda@xtra.co.nz

**Are you 75 or older and have consulted
with a medical professional in the last
year?**

**We are looking for volunteers for a research project
exploring how older people experience
communication with health professionals.**

If you are:

- **Aged 75 or older**
- **Live in the greater Auckland metropolitan area**
- **Have visited a doctor or other health professional
in the last 12 months**
- **Live in the community**

Then we would love to hear from you.

For more information please contact: The Researcher. Peter

Simunovich

AUT

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Appendix D

Participant Information Sheet

**Date Information Sheet Produced:**

14th May, 2013

Project Title

Older persons and the New Zealand health system: A user's perspective of service provider attitude.

An Invitation

My name is Peter Simunovich. You are invited to participate in a study, the purpose of which is to determine the attitude of health providers to older persons seeking health care in New Zealand. This research is part of a Masters degree in Public Health and at some point in the future may form a contribution to a conference paper or academic journal.

How was I identified and why am I being invited to participate in this research?

You are receiving this because you have acknowledged yourself as a potential participant in one of three ways; through the person based research centre at AUT University, from information circulated through Grey power or from someone you may know who is aware of the research. I am seeking women and men aged 75 years and older who live independently in the community and who have had contact with health services such as doctors, nurses, physiotherapists, etc in New Zealand over the last twelve months. If you are able to communicate comfortably in conversational English I would like you to tell me the stories of your health care encounters.

What will happen in this research?

Once you have consented to participate, we will hold an informal interview at a venue in which you are comfortable with such as your home or other location you

choose. The interview will be voice recorded and would take between one and two hours of your time.

What are the discomforts and risks?

No risk is anticipated; however you may recall details or events of an uncomfortable nature which could cause some discomfort

How will these discomforts and risks be alleviated?

No risk is anticipated however should any issues raised cause you distress recording will cease and the you will given time to compose. You will always have the option to stop the interview at any time. Should you continue and later feel you would like to discuss any issue raised during the interview, referral to counselling services through AUT University will be made available to help resolve any of your concerns.

The free counseling, for participants who require it, will be provided by our professional counselors for a maximum of three sessions and must be in relation to issues arising from their participation in this research project.

To access counseling services:

- Drop into our centres at WB219 or AS104 or phone 921 9992 City Campus or 921 9998 North Shore campus to make an appointment.
- Let the receptionist know that you are a research participant and provide my contact details to confirm this.

You can find out more information about our counselors and counseling on our website: http://www.aut.ac.nz/students/student_services/health_counselling_and_wellbeing

What are the benefits?

It is expected that your contribution to this study will serve to provide feedback to clinicians, on the manner in which they may improve their interaction and/or services toward older clients. Additionally it is hoped that as a participant you will feel some benefit from sharing your experiences.

How will my privacy be protected?

The only person who will know your identity will be myself and a support person of your choosing should you desire to have one present. You will not be identified in any way in the study and you will be invited to select a pseudonym to be used in the study should you wish to further ensure your anonymity. Your information will be stored in a secure facility at the university.

What are the costs of participating in this research?

It is expected will take approximately 90 minutes to 2 hours of your time for the interview and should you incur any travel costs a \$10 petrol voucher will be provided to offset these expenses.

What opportunity do I have to consider this invitation?

I would appreciate if you would register your interest in becoming a participant within four weeks of receiving this information.

How do I agree to participate in this research?

If you are interested in contributing to this study, simply phone or email me and you will be sent a consent form which you may read, sign and return in the self addressed and stamped envelope. I will contact you by the means you have chosen to arrange a suitable time and location to conduct the interview. If you do not wish to participate simply take no further action. Participation is completely voluntary and should you choose to participate you have the option to withdraw from the study at any time up to the completion of data collection should you desire. Your decision will not advantage or disadvantage you in any way.

Will I receive feedback on the results of this research?

Yes, a summary of the research findings will be delivered to you at the completion of the study.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Valerie Wright-St Clair

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEK, Dr Rosemary Godbold, rosemary.godbold@aut.ac.nz , 921 9999 ext 6902.

Whom do I contact for further information about this research?***Researcher Contact Details:***

Peter Simunovich, email; masteryoda@xtra.co.nz, Mobile 0274 830 510

Project Supervisor Contact Details:

valerie.wright-stclair@aut.ac.nz (09) 921 9999 ext. 7736, Mobile 021 773 738

Approved by the Auckland University of Technology Ethics Committee on *18 June 2013*, AUTEK Reference number *13/137*.

Appendix E

Participant Consent Form



Project title: *Older persons and the New Zealand health system: a user's perspective of service provider attitude*

Project Supervisor: *Dr Valerie Wright-St-Clair*

Researcher: *Peter Simunovich*

- I have read and understood the information provided about this research project in the Information Sheet dated 23 May 2013.
- I have had an opportunity to ask questions and to have them answered.
- I understand that notes will be taken during the interviews and that they will also be audio-taped and transcribed.
- I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.
- If I withdraw, I understand that all relevant information including tapes and transcripts, or parts thereof, will be destroyed.
- I agree to take part in this research.
- I wish to receive a copy of the report from the research (please tick one): Yes No

Participant's signature:

Participant's name:

Participant's Contact Details (if appropriate):

.....

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Date:

Approved by the Auckland University of Technology Ethics Committee on 18 June 2013, AUTEK Reference number 13/137.

Note: The Participant should retain a copy of this form.

Confidentiality Agreement

Support person



Project title: Older persons and the New Zealand health system: a user’s perspective of service provider attitude.

Project Supervisor: Dr Valerie Wright-St Clair

Researcher: Peter Simunovich

- I understand that all information is confidential.
- I understand that the content of the interviews meetings or material can only be discussed with the researchers.

Support person’s signature:

Support persons name:

Support person’s Contact Details (if appropriate):.....

Date:

Project Supervisor’s Contact Details (if appropriate):

Dr Valerie Wright-St Clair

Valerie.wright-stclair@aut.ac.nz

(09)9219999 ext.7736

Approved by the Auckland University of Technology Ethics Committee on 18 June, 2013, AUTEC Reference number 13/137.

Note: The Support person should retain a copy of this form.