What Matters to Me?
Photovoice with people living with severe mental illness

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Contents

Tables

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Abstract

In 2018 the report of the government inquiry into mental health and addictions, He Ara Oranga, was published following 'remarkable' engagement with stake holders including, service users, their families, health and other service providers, community organisations, and researchers. The report was commissioned due to widespread concerns for mental health services within the sector, and within communities and concluded that a paradigm shift was required, making recommendations across 12 broad areas as to how this needed to happen.

One area was that the voices of service users needed to be stronger across all levels, including governance, planning, policy, and service development, with genuine partnerships building recovery focused services. Additionally, people need to be placed at the centre and acknowledged as active participants in their care rather than passive recipients of that care. This research aimed to engage with long term services users with severe or serious mental illness whose voices have traditionally been silenced to add to the growing body of knowledge as to how these identified gaps can be addressed.

Four participants who attend a day service were issued with cameras and asked to photograph 'What Matters to Me?' in their everyday life. The question was a deliberate attempt to usurp the medical dialogue 'What is a Matter?' Participants were issued with disposable cameras and the photographs formed the basis for individual interviews. Thematic analysis from a descriptive methodology identified themes which were discussed through the lens of the recovery framework CHIME (Connection, Hope and optimism, Identity Meaning, Empowerment).

Findings illustrate that participants identified home, and homemaking, the things they do and the people in their life as what matters. Contrary to much of the literature participants articulated multiple positive identities viewing an illness identity as only a small part of self. Access to occupations and the importance of narrative and narrative continuity appear to be important aspects of recovery aligning well with the occupational therapy concepts of occupational justice and 'doing with'.

Terminology

Many terms are used to describe people who access mental health services, including, clients, consumers, services users, survivors, and people with lived experience. Many terms also exist to capture the collective labelling of mental illness, mental distress and psychiatric illness or disorder. More recently individuals with lived experience are reclaiming the term madness. This project uses the term service user, and serious/severe mental illness (SMI).

Acronym	**Meaning**
OT	Occupational Therapist or Therapy
PT	Physiotherapist/Physiotherapy
ECT	Electro Convulsive Therapy
NGO	Non-Government Organisation
PSW	Peer Support Worker
CHIME	Connectedness, Hope and optimism, Identity, Meaning and purpose, Empowerment A conceptual framework for recovery
SMI	Severe or serious mental illness
OTNZ-WNA	Occupational Therapy/Whakaora Ngangahau Aotearoa
PAR	Participatory Action Research
LSF	Living Standards Framework
CA	Capabilities Approach
PIS	Participant Information Sheet
PSO	Presbyterian Support Otago
POP	Pan Occupational Paradigm
OPH	Occupational Perspective on Health
SHOWeD	What do you See? What is Happening? How does this relate to Our lives? Why does this situation concern us/you? What can we Do about it?

Chapter One : Introduction

Introducing the Researcher

OT, PT, ECT, Cup of Tea

It was with fear and trepidation that I first approached the austere and imposing entrance of Horton Asylum as an occupational therapy (OT) student in 1986. Opened in 1902, its capacity peaked in 1971 with 1438 patients and its doors closed for the last time in 1997. Little did I know the impact it would have on my life and the compassion I would still carry for the patients I met 35 years later. How cruel society can be and how blind and indifferent the system.

I remember the blank staring faces, the repetitive movements of tardive dyskinesia, the shuffling gait and the language of 'care' that lacked all compassion: 'burnt out, chronic, hysterical.' I remember wards so filled with smoke it lingered below the ceiling and travelled home on my clothes, as lack of volition, and a belief that smoking helped collided to create a nicotine culture. I remember too, the discharged 'patients' returning daily from their community homes to sit instead on park benches throughout the expansive grounds of their former home. First, we locked them up, then we locked them out.

When I qualified a year later, I knew there was only one area I wished to work and quickly found work at a long stay and rehabilitation hospital. All modern and ready to change the world, it soon became apparent that with many of the patients and staff having transferred from decommissioned asylums, it would take more than a new building to change the institutional culture.

I saw a patient 'frog marched' to OT by two nurses, only to leave immediately when we refused to contain her against her will. I regularly observed another one so institutionalised that he walked the corridor on time everyday chanting "OT Cup of Tea" all the way. I witnessed taunting and provoking of patients by staff for their own entertainment and I sat in ward rounds where patients were diminished by the sheer number of people in the room, all talking about them and at them, yet not been allowed to voice an opinion. Days were passed marking time by OT, PT, ECT, smoke time, mealtime, meds time, bedtime just to do it all again tomorrow.

Deficit, Goals, and Outcome Measures

At first glance the past may seem irrelevant, such a long time ago, however, not only has it shaped me, but I now work with people who lived through it. People who have spent time in institutions, rehabilitation wards, day hospitals and community homes. Days full of OT, PT, ECT, smoke time, mealtime, meds time, and bedtime. We travelled different paths through the same system of care, a system that appeared not to care. I recognise its cruelty in the name of caring and wonder if we are ever going to get it right.

I am reminded regularly of the continued discrimination in our communities, as I am told "*People stare at me all the time, and say mean things, what should I do?"* or*, "One day you wake up and realise all your friends are service users."*

This then is my view of the care system we have created, a system that maintains itself and is more concerned with deficit, goals, and outcome measures, than people, kindness, and compassion. A system that is on top rather than on tap and places blame and responsibility on individuals, disregarding the role society plays in 'othering', discrimination and the socioeconomic realities people endure.

I am still an occupational therapist and I have worked in the field of mental health for close to thirty years, including acute wards, day hospital and rehabilitation services. My current position is manager of a mental health day service, 'A Place to be Me' (pseudonym) and is the setting for this research project. I believe the people who attend look for nothing other than acceptance and kindness, not much, yet everything, things which they demonstrate in abundance. We could learn a lot from listening.

Introducing the Research

The recovery movement, a grassroots movement of service users demanding to be valued, heard, and empowered has roots in deinstitutionalisation and Care in the Community policies of the 1980's. The movement challenges the medical model dominance of mental health service delivery and demands that people with lived experience of mental illness be valued as experts in their own care. To be partners in service provision from government policy level, through to delivery, and to be accepted and treated as people with a valued place in society, to have a voice and to be heard. Recovery was adopted into New Zealand policy as far back as 1998 and is now widely accepted as the only way to deliver mental health services (Mental Health Commission Blueprint, 1998). Yet more than twenty years after adopting recovery as a policy, the recent government inquiry into Mental Health and Addictions in New Zealand reported that medical services continue to dominate the lives of individuals.

> *"People with lived experience are too often on the periphery; they should be included in mental health and addiction governance, planning, policy and service development. Consumer voice and role should be strengthened in DHBs, primary care and NGOs."*
>
> (He Ara Oranga, 2018 p.13)

'A Place to be Me' is an activity-based day service funded by the District Health Board (DHB) for people with severe mental illness (SMI). The service has a philosophy of acceptance for who you are, and a belief that there is a place for everyone. Criteria for entry is simply that you wish to belong and adhere to one simple rule. Be Nice or Leave. Biomedical approaches and medical terminology are rejected along with formal assessments and treatment planning. Goals are set and achieved but are nurtured organically through collaboration and discussion between staff and service users.

This research is concerned with the voices of long-term mental health service users who attend 'A Place to be Me' and asks participants 'What Matters to Me?' in a deliberate attempt to usurp the medical dialogue 'What is the Matter?'

The Structure

In Chapter One, I have introduced myself as the researcher, outlining my journey to this point, and my view of our approach to mental health services. I have briefly outlined the mental health landscape within New Zealand and introduced the research setting and question.

Chapter Two will review the literature of recovery, relevant government and occupational therapy policy, and recovery frameworks, along with voice and partnerships, and the barriers to achieving these goals. The role occupational therapists can play and the relationship between occupational therapy and recovery is explored. The review will consider current research, gaps within it and build justification for the research question.

Chapter Three will explore in greater detail, the aims of the research and the research question. It will outline the methodology, including the choice of research method, ethical and cultural considerations, participant selection, data collection and analysis, and rigour.

Chapter Four presents the findings from participant photographs and semi-structured interviews. Direct quotes are used to facilitate voices to be heard in their entirety.

Chapter Five uses the recovery framework CHIME as a lens to explore the findings in relation to the literature, policy, and occupational therapy.

Chapter Six will conclude with learnings, particularly for practice, future research suggestions, limitations, and personal reflections.

Chapter Two : Literature Review

Introduction

This review considers the New Zealand government inquiry into mental health and addictions, (He Ara Oranga, 2018) along with earlier New Zealand government and mental health commission publications. Data bases were used to access published literature alongside the grey literature, including that of service user groups and advocates obtained from online presentations, support groups and media releases.

The review begins with a synopsis of the recovery movement, its origins and mission, including current models and frameworks, in particular the framework CHIME (Connectedness, Hope and optimism, Identity, Meaning and purpose, Empowerment). It goes on to consider a critical view of recovery before discussing the broader concept of mental health and illness within the context of wellbeing.

The correlation between recovery and occupational therapy is explored including models and frameworks, policy, and current research, with emphasis on the role of occupation or 'doing' in recovery. As the research takes place within a day service the relevance of day services within the recovery movement is given due reflection, before concepts of service users voice, peer support and partnerships between service providers and service users, are explored.

Recovery History

Recovery is essentially concerned with a shift from a medically based deficit approach to services to ones which support people to live a meaningful life (Pincus et al., 2016). In 1998 the Blueprint for Mental Health Services New Zealand (Mental Health Commission, 1998) acknowledged a need for change, placing emphasis and responsibility not only on individuals but on the part services and wider society play in assisting (or impeding) recovery. It stated that the concept of recovery could be applied to biological, psychological, social, and spiritual aspects of mental illness, and was readily compatible with the holistic model of health, Te Whare Tapa Wha (Durie, 1984). It made clear the expectations of a recovery approach to service delivery, empowering service users, and allowing them increased control over their mental health and wellbeing. It did not go so far as to refer specifically to consumer or service user voice/s.

Our Lives in 2014, (2004) was prepared by 20 mental health service user leaders in consultation with large numbers of service users to guide the Ministry of Health's plan by describing a vision and pathway for the proceeding ten years. This document reported growing support for a fundamental shift in how society and services respond to mental illness. A shift from a biomedical framework of disability, to a recovery focussed approach supporting people to regain personal power and a valued place in society.

Definition of Recovery

Over ensuing years as recovery has continued to be the focus of mental health policy and services, definitions, models, and assessment tools have been developed and debated. An absolute definition of recovery remains elusive, in part due to the individualised and personal nature of it (Shanks et al., 2013). Concepts usually centre around personal responsibility, rebuilding life, developing roles, engaging in meaningful activity (Lloyd, e tal., 2014) and more recently inclusion and citizenship (Davidson & Roe, 2007). Originally perceived as linear, it is now agreed to be a nonlinear journey with no endpoint rather than a destination (Davidson & Roe, 2007). The following definitions of personal recovery are considered and highlight the historical nature of the concept.

> *"a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness."*
>
> (Anthony, 1993 p.527)

> *"the extent to which a person with mental health problems regains or attains a meaningful life with or without symptoms"*
>
> (Pilgrim, 2017 p.153)

Repper and Perkins (2003), point to the fact that as mental illness affects so many aspects of life then people need to recover from many things including symptoms, effects of treatment, disempowering services, discrimination, and social exclusion. O'Hagan (2010), service user, leader, and past New Zealand Mental Health Commissioner (2000-2007) believes recovery has evolved beyond its institutional roots when it related to an individual's journey, to now include recovery workforce and recovery services.

Considering people with severe or serious mental illness (SMI) Davidson and Roe (2007) propose two recovery concepts: 'recovery from' and 'recovery in' mental illness.

Studies show that approximately 25% of people diagnosed with SMI will 'recover from,' as consistent with 'cure', or re-establishing life as it was before illness. 'Recovery in' then refers to those for whom symptoms and effects of illness persist, thus making hope, aspirations, autonomy and control in life, the desired outcomes despite illness. Thus 'recovery in,' requires individuals to (re)build a positive sense of identity beyond that of patient and is seated in small acts of everyday living (Davidson & Roe, 2007). Davidson and Roe also discuss the possibility that 25% of people with SMI are not in recovery. They suggest various reasons for this, including the notion that illness overwhelms personal resources making ineffective even the best efforts to cope. Peyser (2001 cited by Morrow & Weisser, 2013) agrees claiming some people with SMI are simply unable to engage in the recovery process. People at this extreme end of the illness spectrum find themselves relying on services to survive (Davidson & Roe, 2007). This notion contrasts markedly with advocates who claim that anyone can recover, defined as having the ability to live a meaningful life in the community, provided they have the support of recovery services (Myers et al., 2016).

CHIME

Confusion around definition has led people to believe and think differently about recovery, and therefore service delivery is inconsistent. To create order and build clarity Leamy, Bird, Le Boutillier, Williams, and Slade (2011), completed a systematic review and narrative synthesis of the literature. The review identified three parts to recovery: recovery journey, recovery process and recovery stages. The acronym CHIME (Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment) was developed to represent the five measurable domains in the recovery process.

Connectedness refers to relationships with others, including professionals and peers, support groups and the wider community. Hope recognises the need for people to be able to envisage a positive future self, having dreams and aspirations that facilitate motivation to change. Identity refers to the overcoming of negative illness identities and rebuilding multiple positive identities, recognising the need to overcome stigma to achieve this. Meaning is about making sense of the illness experience and rebuilding a life that includes meaningful roles and relationships. Empowerment is strengths-based and refers to personal responsibility, autonomy, and control in one's life (Leamy, et al., 2011).

Six papers included in the original systematic review considered recovery from the perspective of ethnic minority groups, including a qualitative study with New Zealand Māori. These papers were analysed, and all five components of CHIME were found to be relevant. However, the analysis also found that experiences and influences of stigma and spirituality were more pronounced, as were the presence of traditional therapies and faith healers. A more collectivist approach to illness was also evident, which for some had the positive effects of increased hope and support, while for others it increased perceived levels of stigma as 'shame' was reflected on the wider family (Leamy et al., 2011). Table 1 illustrates the domains of the recovery process.

Petros, Solomon, Linz, DeCesaris, and Hanrahan (2016), issued video cameras to people with SMI who had completed a recovery course and asked them to record their experiences. The data was analysed using CHIME leading Petros et al., (2016) to argue that the goal-orientated and unidirectional instruction associated with the framework was in danger of reinforcing a deficit approach. Going on to claim that the framework failed to consider the contribution people with SMI can make to society, it recommended that reciprocity of relationships and contributing to the community need to be included within the connectedness domain.

A systematic review of literature by Stuart, Tansey, and Quayle (2017) exploring recovery experiences for people with SMI also used CHIME as a framework to analyse the data. It recommended the framework be expanded to CHIME-D (Connectedness, Hope and optimism, Identity, Meaning, Empowerment, and Difficulties) to acknowledge the difficult realities and circumstances of living with SMI.

According to its authors, the framework CHIME provides clarity around the recovery philosophy, recognises the individual nature of recovery and is a tool to inform research and practice rather than a rigid model (Leamy et al., 2011). To date, the literature has primarily focused on its use in research to analyse data (Petros et al., 2016; Stickley, et al., 2018; Stuart et al., 2017), and there is a paucity of literature concerned with its use as a framework for practice. In New Zealand, CHIME has been incorporated into the mental health champions training programme Rakau Roroa as an evidenced-based model of wellbeing (Like Minds Like Mine n.d.).

Table 1 : Domains in the Recovery Process

Connectedness
• Peer support and support groups • Relationships • Support from others • Being part of the community
Hope and optimism about the future
• Belief in the possibility of recovery • Motivation to change • Hope-inspiring relationships • Positive thinking and valuing success • Having dreams and aspirations
Identity
• Dimensions of identity • Rebuilding/redefining positive sense of identity • Overcoming stigma
Meaning in life
• Meaning of mental illness experiences • Spirituality • Quality of life • Meaningful life and social roles • Meaningful life and social goals • Rebuilding life
Empowerment
• Personal responsibility • Control over life • Focusing upon strengths

Narrative

As personal recovery is a journey of self-discovery, guided by the narrative of the person with lived experience (Chandler & Hayward 2009, cited by Cameron & McGowan, 2013), it requires those engaged in the process to know their own identities (Mutasa, 2017). Illness dominated identities need be replaced with multiple positive identities (Mancini, 2007) enabling a strong sense of self from which to build the voice, autonomy, and agency necessary to sustain recovery (Baldwin, 2005). As the key to identity is our narrative, providing opportunities for dialogue and storytelling, facilitates recovery by enabling people to maintain and build their own narratives (Baldwin, 2005; Barker & Buchanan-Barker, 2004).

The Tidal Model is one example of a model that puts the stories of those with lived experience at the centre of care, emphasising the importance of listening to a person's story, claiming that people are their stories, and using the tides as a metaphor for our constantly changing stories with endless possibilities (Barker, 2002; Brookes, et al., 2008). Using a narrative approach all professionals working in mental health can be the trusted co-authors in service user's narrative requiring them to consider narrative continuity (does the story makes sense), ensuring narrative agency (the service users input into the story), countering meta narratives (the stories told by others about us), and paying attention to small stories (Baldwin 2005). Whereas life histories attempt to organise narrative over long periods of time, small, often fragmented stories are collected in chit-chat and play a vital part in building identity (Bamberg, 2004 cited by Baldwin, 2005).

Recovery, Colonisation, and Rejection

A growing body of literature is critical of the individualistic nature of recovery and recovery models, claiming that experiences such as hope, and empowerment germinate from complex relationships between individuals, their environment and society (Edgley, et al., 2012: Morrow & Weisser, 2013: Price-Robertson, et al., 2017: Slade et al., 2014:). Price-Robertson, et al., (2017) suggest that for recovery to survive as an approach to service delivery the notion of an individual as an isolated unit must be rejected, and interdependence needs to be acknowledged. Relational frameworks that recognise the complex synergies between individuals, families, communities, and society need to be developed (Price-Robertson, et al., 2017).

The service user movement ‘Recovery in the Bin’ is also critical of the individualistic nature of recovery. The movement accepts some of the core principles of recovery, but also claims ‘unrecovered’ as a valid definition of mental health. It further claims that services have become politicised, using recovery as a form of coercion, imposing conformity, and failing to acknowledge ‘impossible and intolerable’ social and economic conditions. The most extreme misuse of recovery is that people with mental distress are labelled as ‘recovered’, considered work-ready and services are then reduced as part of austerity measures (Morrow & Weisser, 2013; Perkins & Slade, 2012; Recovery in the Bin, n.d).

Others have highlighted the colonisation of recovery by professionals and policymakers, accusing them of seizing control and transforming it from a personal journey of discovery to one of service provision (Hamer, et al., 2014). When models are defined and directed by health professionals the true origins of recovery are ignored, services models become prescriptive and have little or no value to service users, instead serving the needs of service providers (Perkins, 2013; Thomas, 2015). Services built on the concept of professional knowledge perpetuate an individualistic view of problem definition and recovery while overlooking the social and economic factors or upstream determinants of health (Perkins & Slade, 2012). Interventions focus on medical and behavioural factors and marginalise or neglect factors such as poverty, or stigma, consequentially, individuals are blamed and are left dependent on services (Morrow & Weisser, 2013; Reid & Alonso, 2018; Thomas & Knight, 2018).

Morrow and Weisser (2013) discuss the outright rejection of recovery, claiming it perpetuates psychiatrization which nurtures sanism, a form of oppression that values rational thinking and socially acceptable forms of behaviour. Others believe that recovery implies illness, illness from which people need to recover. A change of dialogue from recovery to ‘discovery’ is required, discovering what the problem is, and discovering how to put it right (Bullimore & Carson, 2012). ‘Discovering’ the problem from the perspective of the service user requires a fundamental shift in the user/provider relationship. This project aims to provide an opportunity for the perspectives of long-term services user to be considered with a view to informing such a shift in relationships.

Reclaiming Place /Wellbeing

Recovery advocates now claim further rejection of the deficit-based medical model is needed. Mental distress or 'madness' needs to be reclaimed as a full and legitimate human experience positioning people in recovery on the wellbeing spectrum as part of the general population (Mad Pride, n.d; Morrow & Weisser, 2013; O'Hagan, 2010). Durie, (2012) agrees, calling for Māori to reject the deficit model of disease and take ownership of health and wellbeing, developing policies that empower whanau to control their personal narrative, and for services to reflect Māori culture and values. An example of such a service, is Mahi a Atua, a narrative-based programme where diagnosis and psychiatric treatment are secondary to finding cultural meaning and honouring Te Ao Māori or Māori world view (Rangihuna, et al., 2018).

The living standards framework (LSF) is a tool to apply a wellbeing approach across government policy and decisions making (The Treasury, NZ. 2019). The underlying concept of the LSF is the capabilities approach (CA), which is concerned with what people can do and be, and the opportunities such as education or relationships that are afforded to them to realise wellbeing (Robeyns, 2005). The LSF defines wellbeing as when 'people are able to lead fulfilling lives with purpose, balance and meaning' which it then considers across twelve domains such as housing, social connectedness, and health. Mental health is positioned under the health domain alongside categories such as loneliness, housing quality, trust, and material wellbeing. In all the categories within the health domain, people who have accessed mental health services score lower rates than the general population (The Treasury NZ. 2019). Subjective wellbeing, defined as, feeling good, or having positive emotions such as happiness, contentment, and enjoyment, functioning well, having positive relationships, control, and purpose in one's life is also one of the twelve domains.

Positioning mental illness on the wellbeing spectrum aligns recovery with civil rights, and disability rights, reclaiming space to live in a safe, dignified, and meaningful way, demanding social inclusion and self-determination regardless of the severity of symptoms (Davidson & Roe, 2007; Repper, 2011). Such a shift has implications for service delivery and practice which occupational therapy is well placed to respond given it has long recognised wellbeing focus rather than health as the desired outcome (Christiansen, 1999).

Occupational Therapy and Recovery

Occupational Therapy New Zealand Whakaora Ngangahau Aotearoa (OTNZ-WNA) position statement for mental health and addictions (2016) supports a recovery-focused approach to mental health practice. Advocating the use of an occupational framework to encourage motivation, strengthen competence and sense of self, promote inclusion, citizenship, and community participation. The position statement was written within the scope and context of the Ministry of Health and Mental Health Commission strategic publications and aligns practice with recovery. A client-centred holistic approach which values occupational performance and participation means occupational therapy is well placed to support recovery and help to change the dialogue from 'what is the matter' to 'what matters' (OTNZ- WNA 2018).

One guiding concept of occupational therapy is the occupational perspective on health (OPH) which considers that engaging in occupation, or 'doing', provides the opportunity for being, belonging, and becoming. Doing is the purposeful, or goal-orientated aspect of activity, and through 'doing' we achieve, being, becoming and belonging (Hammell, 2004; Wilcock & Hocking, 2015). Being is about the present time, contemplation, reflection and (re)discovering self. Becoming is the idea that we can imagine our future self with all its possibilities, and belonging is our connection with others (Hammell, 2004). In this way, occupational therapists understand the relationships between occupation, health, and wellbeing, and recognize that what we do forms our identities, in other words, we are largely what we do (College of Occupational Therapists, 2007). Occupations, or doing are not only key to being a person but to being a particular person creating and maintaining identity (Christiansen, 1999). Occupational therapists can therefore demonstrate the absolute necessity of occupation in building identity, a key component of recovery. Further, the Pan Occupational Paradigm (POP) illustrates how therapists can use the concepts of doing, being, becoming, belonging when engaging individuals and communities in occupations to facilitate movement along a continuum of illness to wellbeing (Hitch, et al., 2018). Occupational therapists are therefore well placed to integrate recovery into their everyday practice (Lloyd, et al., 2014) as the belief that occupation is vital for wellbeing is common to both (Rebeiro Gruhl, 2005).

However, Hammell (2004), points to the divergence of purpose and meaning in occupations arguing that classifications of selfcare, productivity and leisure are political and values based, leading to overemphasis on selfcare and productivity. Further, Doroud, Fossey, and Fortune, (2015) claim that although studies have demonstrated that occupation plays an important role in recovery, engagement in work or employment has received most of the attention and further study is required into engagement in social and recreational occupations. By engaging with service users to ask what matters it is anticipated that understanding the role social and recreational occupations play in recovery will be better realised.

Day Services

Occupational therapists working in mental health may be employed in a variety of settings, including inpatient units, residential services, community mental health teams, and day services (OTNZ-WNA, 2016). As this research is placed in a day service, attention to the position of such services within recovery is warranted.

Originally conceived in the 1990s as a bridge between institutions and care in the community, day services are controversial within the recovery movement. Supporters value them as a safe environment for social interaction, occupation, and routine, claiming that a sense of self can be fostered and developed, and links made to the wider community. Critics maintain that segregation denies full inclusion and therefore employment along with inclusion in mainstream activities has dominated the recovery dialogue (Beresford & Bryant, 2008; Bryant, et al., 2010). However, supporters point to discriminatory social and work environments and a lack of discretionary finances and resources necessary to engage in social activities and networking. According to supporters if day services are to be condemned, it would be in direct conflict with the voices of the service users who access them (Beresford & Bryant, 2008).

There is a paucity of research involving people with SMI who attend day services which is concerning considering the characteristics of this group. Recognised as a vulnerable group, they have higher mortality rates, higher levels of poverty and trauma and comprised physical health (Davidson & Roe, 2007). They commonly live alone, have lower levels of education and greater levels of unmet needs than those who access specialised mental health services (Eklund & Sandlund, 2012; Milbourn, et al., 2014).

Approximately 25% of people with SMI require support to manage their illness necessitating services that focus on promoting self-determination while ensuring safety, comfort, and dignity (Davidson & Roe, 2007). The five principles of self-determination are: freedom to decide how you wish to live, authority or control over services available, a network of support, including family and friends, responsibility for own actions, and confirmation or validation. Efforts to engage this group are challenged as levels of agency, autonomy, and identity, may have been eroded by long term service use (Hamer, et al., 2014).

Placing this research within a day service aims to give voice to those who attend. Failure to address this tension between recovery voices demanding employment and inclusion in mainstream activities, and those who value day services potentially leave those most vulnerable again subject to the voice of others.

Service User Voice, Participation, and Barriers

Where agreement does exist in the recovery dialogue is the value of obtaining service user views and developing genuine partnerships between health professionals and service users (Pilgrim, 2017). These partnerships are needed at all levels of service planning, policy, and delivery (Funk, et al., 2006; Rapport et al., 2010) and are beneficial to service providers and service users (Scholz, et al., 2017). Service user involvement can be considered at a micro level, referring to the individual planning and implementing of treatment and care, or macro level, referring to policies, service models and service delivery (Lloyd & King, 2003). The benefits or potential positive results of service user involvement have been identified in five areas across the three domains of, individual, service, and societal. These five areas are: person-centred approach, informed decision making, advocacy, obtaining service user feedback and views, and working in partnership (Millar, et al., 2015). However, these underlying concepts of recovery in service delivery, are yet to be fully understood, and the extent to which they influence services are still developing and remain inconsistent (Pincus et al., 2016). Few services are operating a recovery-focused approach, and services incorporate recovery into the policy and planning without practising it (Cameron & McGowan, 2013).

Incorporating recovery concepts such as service user voice necessitates a fundamental shift in the attitudes of professionals who have traditionally been in a position of power, and maintained service users as passive recipients of care, hence a new and collaborative learning process is required (Millar et al., 2015). It is advocated that professionals must recognise and value the knowledge of lived experience, and accept that service users know more about planning, developing services and the management of their own care than anyone else. As mental illness can disempower and undermine confidence and autonomy, then professionals need to value lived experience as part of the recovery process rather than something to be ‘fixed’ and assist service users to develop the skills and confidence needed to be active participants in the relationship. Through genuine partnerships, a cycle of empowerment, hope, independence and recovery can occur, and services that provide the opportunity to develop confidence, decision making and social connections replace those that reinforce hopelessness and dependency (Lloyd et al., 2014; Lloyd & King, 2003). Most of the research into service user voice or leadership has focussed on consumer-run organisations, leaving a gap as to involvement within the mainstream services (Scholz, et al., 2017).

Research exploring the reasons behind this apparent attitude behaviour gap has identified many individual and systemic barriers. Systemic barriers include tokenism, restricting the amount of power and influence afforded and deliberately engaging those who are compliant (Meagher, 2011) along with stigma, resistance to change and an over-reliance on the medical model (Gee, et al., 2016; Linhorst, et al., 2002).

Individual barriers include fear of reprisal or censorship (Happell & Scholz, 2018), cognitive impairment, lack of confidence and skills, and difficulty understanding the language (Jansson., et al. cited by Magnusson & Lützén, 2009). Cameron and McGowan, 2013 suggest that overtime as people feel unheard or not listened to, they may become silent. People with SMI frequently demonstrate a passive approach to situations, waiting for guidance before responding and adapting their response accordingly (Erdner & Magnusson, 2011). While some examples do exist in New Zealand of effective co-design, more often one person is employed as a 'voice' or 'representative' with varying amount of resources and influence, having very little effect (He Ara Oranga, 2018).

This research will consider the agency, confidence and trust required to speak after prolonged silence, by exploring photovoice as a method to strengthen the voices of service users in order to better understand what matters and inform ways to build genuine partnerships.

Summary and Conclusion

Government policy and reports, research, and published literature along with service users all agree that a fundamental shift in approach to services is both essential and overdue. This project asks the question 'What Matters to Me?' of long-term mental health service users who attend day services to add to the growing body of knowledge aimed at informing change. As the complexity of different voices begin to be heard it is important that space is provided for those living with SMI whose recovery journey and service needs may differ from those experiencing mild to moderate illness.

Chapter Three : Methodology

Introduction

The following chapter discusses planning and implementation, the research question, and the method used. Participant selection and recruitment, along with inclusion and exclusion criteria are discussed, and the process followed is recorded. The chapter also explores the ethical and cultural issues anticipated, and as they arise, and how these were addressed.

The research aimed to gain an understanding of 'What Matters to Me?' while facilitating space for enactment of agency by utilising a qualitative descriptive with photovoice methodology. Purposeful sampling was used to select four members of a day service, within a large urban centre, funded by the district health board for people with SMI.

Methodology

Qualitative descriptive research is a method commonly used in health and social sciences to describe a phenomenon, and is concerned primarily with why, how and what. It is a useful method to gain first-hand knowledge of a subject or experience. While generalisation of results is not appropriate it can be used to explore a deeper understanding of a phenomenon (Sandelowski, 2010). Qualitative descriptive research follows traditional qualitative research methods but uses descriptive rather than interpretive data analysis to provide a rich description of the participants (service users, professionals or family) experience or view, by 'staying close to the data' and reporting it in the language of the participants (Sandelowski, 2010; p.8; Bradway, et al., 2017). As this research is concerned with hearing the voices of those previously silenced or marginalised, it is important to use methods that facilitate voices to be heard.

Method

Photovoice is a method of data collection developed for listening and learning with a focus on improving the health of communities, by empowering and hearing the voices of those who are not usually heard. It was originally conceived as a tool for participatory action research (PAR), as a method to engage with marginalised groups presenting information to inform change. The data collected may not be new information but using photovoice it can be presented in new and engaging ways that create dialogue (Wang 1999).

This project uses a qualitative descriptive, rather than a PAR methodology, meaning the use of photovoice could be more accurately named photovoice-as-method, or photo-elicitation (Baigent, 2014). Methods of data collection in qualitative descriptive research can be varied, but typically involve individual unstructured or semi-structured interviews or focus groups (Neergaard, et al., 2009).

Using photovoice as a tool to facilitate dialogue the project aimed to create space for this ‘difficult to engage’ group and add to the body of knowledge to inform how service users and professional can partner to build recovery services. Photovoice was selected as the preferred method of data collection as it allowed the participants to define and shape the discussion by the taking of and interpretation of photographs, opening the opportunity for dialogue of issues that can be difficult to articulate. Participants were able to control the narrative and capture otherwise difficult to express issues, ensuring their voices are not obstructed or taken over, as could happen with other methodologies, such as interpretative descriptive.

Research Design

This research is built on the belief that people who have accessed mental health services over an extended period are vulnerable to the needs and control of the system and the people who work within it. This learnt compliance is both the reason for, and the difficulty within the research, and requires full consideration during research design. The question ‘What Matters to Me?’ aimed to allow participants to become aware of the objects, events, people and places in their daily life that have meaning, both positive and negative to them, and to further explore these in interviews.

Research Setting

A Place to Be Me is a community-based day activity service in a large urban area funded by the district health board, for mental health service users. With an open-door policy, acceptance of who you are and the importance of belonging, are paramount. Recognising the longevity of SMI and the socio-economic realties of people’s lives it is common to find members who have accessed the service for many years. Welcoming members of the wider community the service strives to be acknowledged as a community service or facility, achieving integration rather than segregation. Staff, volunteers, community members, students and mental health service users all contribute to planning, decision making and executing activities. Only on rule is stated and applies to all, ‘Be Nice or Leave’.

As manager of the service I supervise two part time support staff, John, who has worked there for five years and Fran, a peer support worker (PSW) who has worked there two years. Both staff were actively engaged in participant selection, making the initial approach to potential participants on my behalf, and supporting participants through the research process. Fran was invited to and attended one participant interview.

Ethics

Ethics approval was granted from Presbyterian Support Otago PSO in June 2019, and Otago Polytechnic Ethics October 2019 (Appendix 1).

All research needs to consider the potential to do harm to participants, or others, throughout the research process and the following areas were considered to mitigate against this.

Researcher / Participant Relationship

The longevity of researcher participant relationships was an important consideration planning this project. Long term relationships are vital to building trust when working with people who experience mental illness (Thomas, 2015), and trust is considered beneficial when considering the advantages and disadvantages of researcher membership in a group (Mcdermid, et al., 2014). Trust has further been identified as particularly important when engaging into research people who are socially excluded (Emmel, et al., 2007). I have established relationships of between 4 and 16 years with the participants, which was pivotal in ensuring place and space where participants felt safe to engage in the research process. At the end of the project I took participants out to dinner to thank them for their involvement and to mark the closure of the project while maintaining our ongoing relationships. During this time participants were asked informally for their feedback about their involvement and gave consent to use this in write up. When asked if they would have participated with a researcher who was unknown to them, I received an immediate and unequivocal ‘no’ from two participants. A third said probably not with only one believing he still would, as he likes to be a ‘*helpful bastard*’. All participants said they had agreed to participate to help me.

Consent Process

As my role was both researcher and manager of the service particular consideration was required to alleviate the possibility of coercion. While voluntary participation may seem straight forward, people may feel powerless to decline due to coercion, peer pressure, or fear of retaliation. Potential participants were approached first by staff members other than me to explain the project. Emphasis was placed on the voluntary nature of participating and the fact that it had no bearing on continued involvement in the service. Participant information sheets (Appendix 2 & 3) and consent forms (Appendix 4) were deliberately issued for people to take away and complete in their own time giving them space to reflect, discuss with others, consider the implications of participating and ask questions. The voluntary nature was repeated at each contact and participants were given opportunity to withdraw, although it was explained that should they withdraw more than forty-eight hours after their individual interview information from their interview may be included in the write-up. For some participants, such as Susan, this consent process occurred over time. She approached me on several occasions to discuss or ask questions, agreeing each time to participate but delaying the start.

Narrative ethics

If we accept that we are essentially narrative beings and that people with SMI are compromised in their ability to construct a recognised coherent narrative arguably ethics becomes about which narrative we choose to attend to and how we choose to tell it. To maintain narrative ethics consideration needs to be given to narrative continuity, narrative agency, countering meta-narratives and giving attention to small stories (Baldwin, 2005). Having a long-term relationship and knowledge of participants assisted narrative continuity such as when Mike talked about respite care, or Susan talked of her recent trip to Gisborne. Narrative agency was maximised by allowing participants to talk freely throughout their interviews, leading the discussion by controlling the order and timing of photographs. As researcher it was imperative to be aware and challenge meta-narratives or narratives told by others. This included being aware of my own meta-narratives that I might hold about participants, something addressed through a reflexive diary and supervision. Valuing small stories or chit-chat is recognised as an important sense of self and valuable in building stories in the here and now.

Group Members Feel Ostracised

Consideration was also given to the fact that group members who were not invited to participate may feel disappointed or ostracised. This was to be managed by explaining the nature of the research project, the selection process, and the reasons for a limit on numbers to anyone who raised this concern. In the event it was not necessary. All service provision continued as usual.

Managing Participant's Distress

Consideration was given to the fact that during interview a participant may become distressed or upset, and time was allocated to interviews allowing for this to be dealt with immediately. Options considered to manage this were, closing that area of discussion and removing it from the data before continuing, stopping the interview, and continuing later, or leaving the research entirely. Such a situation would necessitate the researcher having to change roles from researcher to health professional, prioritizing the welfare of the participant over the research (Gelling, 2015). Having an established relationship means I have information about the participants support network and could make provision to help the participant access this support if necessary. Although planned for, this situation did not arise. However, when asked about her experiences in institutional care Susan became silent staring at the floor in front of her. Having a long-term relationship with Susan immediately alerted me to the fact that this is extremely unusual behaviour for this chatty engaging lady. I immediately asked if she would like to move the discussion to something else which she responded to by nodding before re-engaging in the interview. Susan had invited the peer support worker (PSW) into the interview and when she became restless accepted the offer a short break asking the support person to go with her.

Negative or Abusive Comments

I was cognisant of the fact that comments about the service, other services or people may arise that were negative or concerning. To deal with this I planned to draw attention to it, give the participant the option of closing that discussion and removing it from the data before continuing. Or, choosing to stop the interview, address the issue, then either continue later or leave the research entirely. If this caused the participant to become distressed then further support could be offered, either with the researcher, or other, by liaising with participants' extended support network. Again, in this situation the welfare of the participant would be prioritized over that of the research (Gelling, 2015). This situation did not arise.

Participant’s Anonymity

During write up and throughout the process I used initials to identify participants, their family, friends, and staff. Prior to publication participants were given the time to choose a pseudonym for write up. The names of family, friends, staff, and places were also changed.

Photographs Identify People

Thompson et al., (2008) did not allow photographs of people to be included in a photovoice project exploring the experiences of those living with SMI, due to the ethical considerations of identification. Results indicated that this prevented participants from including the most important interactions with other people in their life, leading the authors to recommend that future studies allow photographs of people for the purpose of the discussion and write up but not for reproduction or publication.

Ethical consideration when taking photographs, choosing the appropriate time and place, and asking for informed consent were discussed individually with participants and consent forms for this were issued (Appendix 4). Ways to take photographs that do not identify individuals, such as not seeing their face, were explored, although only one participant used this method taking a photograph of her partner’s chair. During the interview one participant talked about having asked if she could photograph her friend who declined, and this request was respected.

All participants took photographs that clearly identified people, while not necessarily completing the information and consent form. These photographs were used in interview and write up but not in publication, as informed by Thompson, et al., (2008).

I had not anticipated that participants would have photographs of themselves, which three did. One was a reflection as Susan photographed her glass door, Peter was stood beside his car and talked about the importance of it, while Mike was unable to identify where and why a photograph of him had been taken. Verbal consent was given at the start of the interview process to include these in discussion. Participants were also given the time to remove any photographs they did not want reviewed, therefore giving them an opportunity to action physical consent.

Data Storage and Protection

Interviews were recorded on i-phone, transcribed, and stored on a laptop, both of which are password locked. Interviews and transcripts were shared with the research supervisor via Otago Polytechnic email. Two sets of photographs were developed so participants could keep one copy, the negatives and the second research set of photographs were stored securely by the researcher at the premises of PSO along with consents. At the end of the research, transcripts, recordings, photographs, and negatives were destroyed except one copy that will be stored at Otago Polytechnic for 7 years and then destroyed.

A reflexive diary and supervision were both used to consider ethical issues as they arose from the discussions and data.

Literature Review

A review of the literature was carried out, using electronic databases including CINAHL, ProQuest, Nursing and Allied Health Science, and Google Scholar, using a variety of terms including, but not limited to, mental health/illness, recovery, occupational therapy, service user voice, identity, and narrative. Publication dates were considered along with reference lists which were reviewed for further relevant literature. Books, online discussion forums, lectures, media releases and interviews were searched pertaining to service user groups and mental health advocacy. Database searches were then narrowed to focus on Aotearoa New Zealand, and Māori mental health. Literature pertaining to Māori mental health and the use of photovoice as a research tool within Māori populations were considered to inform the method and cultural safety. The literature and resources accessed have influenced and informed the choices and decisions made throughout the research process.

Participant Selection and Recruitment

After introducing the research to staff members at the service I asked that they contribute to selecting four participants. Four had been identified as a suitable sample for the project size, and to enable individual voices to be heard. Both staff members asked for a copy of the research proposal and we agreed to meet in three days having given time to consider and reflect. Maximum variation purposeful sampling techniques considering ethical and cultural background, age, gender, levels of literacy and levels of support (Neergaard, et al., 2009) were then discussed along with a person's mental health and likelihood of remaining engaged through the project.

Inclusion Criteria

Potential participants had to be attending the day service on a regular basis and be diagnosed with a severe mental illness (SMI). SMI includes conditions such as depression, bipolar disorder, schizophrenia, and psychosis (Kessler et al., 2001), defined as severe when they have a significant negative effect on everyday life, including, employment, relationships, housing, education, and physical health. No time frame was placed on length of contact with the service.

Exclusion Criteria

People accessing acute medical services, as either inpatient or outpatients. Anyone potentially lacking the ability to understand the implications and engage fully in the consent process. Anyone whose physical health was compromised or created limitations to participating fully.

Selection Process

Staff members suggested people I had not initially considered, and I recognised that my thoughts were tending towards those with whom I have a stronger relationship. For example, I had not considered Peter, as he attends only the woodwork group, so I spend little time with him. To provide opportunity for a Māori worldview to be included in the research a group member who identifies as Māori and was selected to approach.

Following the meeting staff members approached identified individuals to explain the project, allowing time for discussion and questions. If potential participants were interested participant information sheets (Appendix 2 & 3) and consents to participate were issued for people to take away and consider (Appendix 4). The voluntary nature of participation was emphasised. All four participants agreed and returned the necessary consents so further selection was not necessary.

Table 2 : Participant Characteristics

Participant	**Age**	**Gender**	**Ethnicity**	**Living situation**
Angie	59	F	NZ Eurpoean	Living alone. Own home
Susan	55	F	Māori	Living with partner, supported housing
Peter	58	M	NZ Eurpoean	Living alone. Own home
Mike	64	M	NZ Eurpoean	Living alone, council flat

I then approached people individually to reiterate the purpose of the research, offer the opportunity to ask questions and arrange a convenient time to meet. Initially, a meeting of all participants was planned but when one participant, approached me asking questions it felt natural to allow the discussion to progress. Reflecting that the participants attend the service at different times it seemed an inconvenience to them to bring them together. I realised that by meeting participants individually I could tailor the discussion towards an individual's level of interest and understanding, allowing as much space as necessary for questions, and eliminating any potential influence they may feel by knowing who else had been approached and the questions and thoughts they shared. This change in procedure was discussed and agreed with my supervisor.

The first meeting included instruction on camera use, the practicalities of taking a camera and using it in daily life, privacy and consent when photographing people or places, (Appendix 5). Participant rights and expectations were restated. The question 'What Matters to Me?' was placed on the back of the camera as a reminder for participants.

Disposable cameras were selected as everyone had the same predetermined number of photos (23) to use and eliminated the possibility of unmanageable amounts. I considered that digital cameras had the potential for difficulties around use, such as, maintaining battery charge. Some participants would have the skills to look and edit photos, potentially altering the results. At $25 each it was also achievable to issue one camera to all participants at the same time and to quickly replace any if lost or damaged.

All participants were given flexibility about when they felt ready to start. Peter and Mike turned down the opportunity to take more time deciding opting to start immediately. Mike was quick to reassure me he understood the question and mentioned things he might want to photograph, then very carefully repaired the damage I had done to the cardboard box the camera was in, before placing it in his pocket. Although I was conscious to take more care when issuing the other cameras none of the other participants were observed to be concerned in this way.

Angie approached me and was eager to sign the consent but deferred starting until the following week. I did not question her delay for fear of this being perceived as coercion. Angie was interested in knowing more about my qualification and motives for doing the project, and we discussed the broader issues of mental health services, something that despite a 8 year relationship we have obviously never had occasion to discuss.

Although agreeable, Susan was cautious and asked for the discussion to be deferred, then later initiated discussion directly with me, a pattern that was repeated. She eventually took away the camera and consents, 2 months after the first approach. This individualised approach was accepted as part of respecting participants ways of engaging and as a means of maintaining their own control and involvement in the research.

Interviews

It was anticipated that 2 weeks would provide enough time for participants to complete the photography while still feeling actively engaged with the process. Two participants completed within this time frame but two took considerably longer. Despite his initial enthusiasm, Mike took 4 weeks to return his camera and had only used 8 shots. Photographs were developed within 24 hours and interviews organised as soon as convenient to maximise recall and capture data in the present time.

All participants were given the option of meeting at the service, home, or a neutral place specified by them, and all chose the service. They were then asked about a suitable day and time, one choosing to meet after her regular session, following which I drove her home, two selecting the time during their regular attendance and one choosing a day she does not attend. In this instance, transport to and from the interview was offered and accepted.

Susan invited the PSW Fran into the interview, including her by explaining new situations that she knows I was aware of due to our long history, making sure Fran saw the photographs, and inviting her to speak. At one point she spoke directly to Fran seeking knowledge about her history and relationship with mental health services. When I asked Susan if she would like a break she deferred to Fran, then invited her to go on the break. Despite having a long-term relationship with Susan the invitation was not extended to me illustrating a different type of relationship despite both being staff members at the service.

Susan brought her own digital camera to the interview and was dismissive of the photographs taken on the disposable camera. To enable Susan to engage and be heard in her way of choosing and maintain congruence by addressing the question it, was agreed to view first the printed photos and then her digital camera. The digital camera contained over 600 shots, which were flicked through in sections, with Susan choosing when to stop and include one in the discussion. She then gave permission for some to be printed into the findings.

Table 3 : Photograph and Interview Information

Participant	**Number of photos**	**Duration of interview**
Angie	24	59.16
Peter	17	1.05.24
Mike	8	40.26
Susan	11 (plus 600)	19.06 break 30.46

Participants were the first to view their photographs and given time at the start of their interview to review, remove or destroy any they choose; this remained an option throughout the entire process. I planned to use SHOWeD[1] (Wang, et al., 1999) as a framework discussion but at the first interview Angie immediately began leading,

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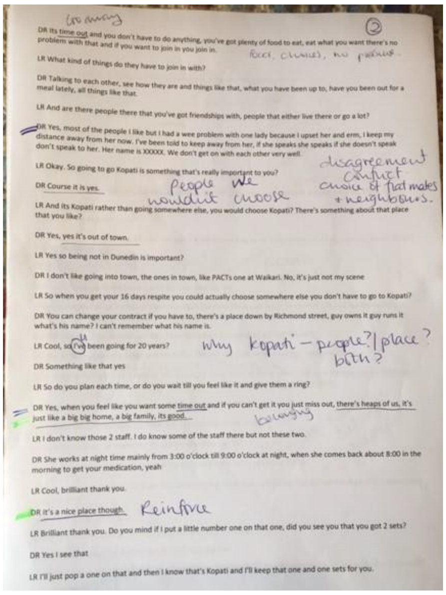
[1] What do you See? What is Happening? How does this relate to Our lives? Why does this situation concern us/you? What can We do about it?

talking freely and openly about her photographs. I followed her lead, only interceding to affirm, reflect, and explore further. This style was adopted for the remaining 3 interviews and is consistent with allowing the service user voice to be heard.

Interviews were recorded on a password protected i-phone and transcribed with Word dictate, all transcripts were shared with the first and second supervisors.

Data Analysis

Thematic analysis (Braun & Clarke, 2012 p. 47) was used within a qualitative descriptive framework to describe and represent the phenomenon rather than interpret or analyse allowing shared meanings and experiences to emerge into themes and subthemes. Transcripts were read independent of each other and initial thoughts and responses written as key words, such as, people, opinion, cost in the margins. This was repeated with the photographs alongside. This was initially a difficult process, as a new researcher, but with repeated reading and reflection commonalities and differences began to reveal themselves.



Go away ②

DR Its time out and you don't have to do anything, you've got plenty of food to eat, eat what you want there's no problem with that and if you want to join in you join in.

Food, clothes, no pressure

LR What kind of things do they have to join in with?

DR Talking to each other, see how they are and things like that, what you have been up to, have you been out for a meal lately, all things like that.

LR And are there people there that you've got friendships with, people that either live there or go a lot?

DR Yes, most of the people I like but I had a wee problem with one lady because I upset her and erm, I keep my distance away from her now. I've been told to keep away from her, if she speaks she speaks if she doesn't speak don't speak to her. Her name is XXXXX. We don't get on with each other very well.

disagreement conflict choice of flat mates + neighbours.

LR Okay. So going to go Kopati is something that's really important to you?

DR Course it is yes.

People we wouldn't choose

LR And its Kopati rather than going somewhere else, you would choose Kopati? There's something about that place that you like?

DR Yes, yes it's out of town.

LR Yes so being not in Dunedin is important?

DR I don't like going into town, the ones in town, like PACTs one at Waikari. No, it's just not my scene

LR So when you get your 16 days respite you could actually choose somewhere else you don't have to go to Kopati?

DR You can change your contract if you have to, there's a place down by Richmond street, guy owns it guy runs it what's his name? I can't remember what his name is.

LR Cool, so I've been going for 20 years?

Why Kopati – people?/place? both?

DR Something like that yes

LR So do you plan each time, or do you wait till you feel like it and give them a ring?

DR Yes, when you feel like you want some time out and if you can't get it you just miss out, there's heaps of us, it's just like a big big home, a big family, its good.

belonging

LR I don't know those 2 staff. I do know some of the staff there but not these two.

DR She works at night time mainly from 3:00 o'clock till 9:00 o'clock at night, when she comes back about 8:00 in the morning to get your medication, yeah

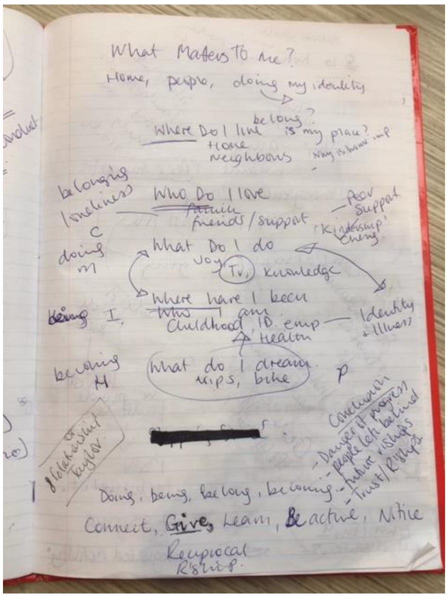
LR Cool, brilliant thank you.

DR It's a nice place though. Reinforce

LR Brilliant thank you. Do you mind if I put a little number one on that one, did you see you that you got 2 sets?

DR Yes I see that

LR I'll just pop a one on that and then I know that's Kopati and I'll keep that one and one sets for you.



What Matters To me?
Home, people, doing my identity

Where Do I live belong? is my place?
Home
Neighbours Why is home imp

belonging loneliness
Who Do I love
~~Family~~
friends / support
— Peer Support 'Kindership' Cheng

C
doing m
What Do I do
Joy (Tv,) knowledge

being I.
Where have I been
~~Who~~ I am
Childhood, ID emp — Identity + Illness
Health

becoming H
What do I dream
trips, bike
P

[redacted]

8 Wilcock Hitch
Taylor

Conclusion
– Danger of progress
– people left behind
– future r'ships
– Trust / R'ships

Doing, being, belong, becoming
Connect, Give, Learn, Be active, Notice
Reciprocal R'ship.

Illustration of pen and pencil analysis

Table 4 : Example of Margin Notes

Quote	Margin Notes
“.....laptop all set up....”	Connection with the outside world
“....something I took at my flat.....”	Home
“...we had a family reunion...”	Family

A supervisor researcher discussion then took place, following which I felt more confident considering the initial themes of friendship, loneliness, home, interest, employment, money, health, childhood, and identity. Further supervision led to themes been condensed and organised into themes and subthemes, Home, Love and loneliness, Hobbies and interests, Life journey, A different Life. Findings were written up under these headings and sent to second supervisor with all transcripts for deliberation.

A meeting with the researcher and both supervisors resulted in the following.

Table 5 : Evolving Themes

Theme	**Sub theme**
Where Do I Live?	• Home • Homemaking • Neighbours
What Do I Do?	• Hobbies and interests • TV • Sharing knowledge
Who am I?	• Health • Childhood memories • Employment • Family
A Different Life	

At this stage I had originally planned to meet with all participants as a group, to share photographs and discuss emerging themes. Due to Covid 19 restrictions this did not go ahead, and instead participants were contacted by telephone for member checking. The findings were discussed, and participants were given clear direction that they were under no obligation to agree before been asked a series of questions which informed some alterations (Appendix 6). Home and homemaking were combined, employment moved from identity to doing, A Place to be Me was introduced to categorise what participants had said about the service and a different life became Hopes and Dreams. The themes were then finalized as illustrated in table 6 within the findings chapter.

Table 6 : Themes

Theme	**Sub-theme**
1. Where do I Live?	1.1 Home and Homemaking 1.2 Neighbourly
2. What Do I Do?	2.1 Joy of Life 2.2 Sharing Knowledge 2.3 Employment
3. Who am I?	3.1 Sharing Memories 3.2 Health 3.3 Family
4. A Place to Be Me	
5. Who Do I Love?	5.1 Family 5.2 Friends (and cats!) 5.3 Supportive relationships
6. Hopes and Dreams	

Rigour

Rigour is the extent to which research is carried out systematically and to a high standard.

Cultural Considerations

The Treaty of Waitangi signed by representatives of the British Crown and Māori Chiefs in 1840 plays a major role in informing policy in New Zealand, and all research must consider the implications for Māori. This is important as disparities in health are two to three times higher in Māori than non-Māori populations, including mental health (Durie, 2011). The connections between culture and health are well documented (Durie, 2011), yet the New Zealand approach to mental illness is built on western political, social and cultural systems that fail to acknowledge relationships, meaning, values, beliefs and cultural practices that are important to Māori (Rangihuna, et al., 2018).

Photovoice as a method to explore Māori patients' perspectives on health has been evaluated concluding that it can be suitably adapted to Māori-voice, to include Māori cultural values and practices such as collectivism and storytelling in the research (Mark & Boulton, 2017). By using qualitative descriptive methodology, keeping close to the data during analysis and involving the cultural advisor at PSO, means data was managed in a way which supported not silenced a Māori world view. The involvement of the cultural advisor assisted with clarifying my understanding of Māori concepts and enable participants to use Te Reo. The research proposal was sent to Office of the Kaitohutohu Māori Research Consultation for feedback prior to commencing on the project (Appendix 7 & 8).

Congruence between Research Aims and Design

As a methodology within PAR photovoice (Wang, 1999) recognizes the knowledge of the participants and has been used successfully to give voice to marginalized groups. It assumes that people can best identify and represent their own realities and reflect on what they see as significant (Wang, et al., 1998). Occupational therapy and photovoice value narrative to understand perspective and meaning (Cottrell & Langzettal cited by Andonian, 2010), and photovoice has been used successfully to inform occupational therapy programs, and outcomes (Andonian, 2010). Utilizing this method gave participants opportunity to take a transportable easy to use piece of equipment to capture the essence of ‘What Matters to Me?’ allowing them to record their own life and experiences and giving them the tools to define and frame the discussion. It was selected as a method that is particularly useful with difficult to articulate issues, does not demand literacy skills, and promotes dialogue that increases both participant and researcher understanding (Andonian 2010). A review of articles considering photovoice within mental health parameters confirmed its value for collecting in depth information about an individual’s experience of illness (Han & Oliffe, 2016).

Dependability

I transcribed the interviews verbatim to enhance the richness of the data by capturing paralinguistic information, such as speed, volume, pitch, providing a further layer of context and meaning. The transcripts were read and reread by the researcher and notes made in the margin as to initial response. The supervisor read all transcripts, and regular discussions took place between the supervisor and researcher as part of the decision-making process. A second supervisor was consulted during thematic analysis and prior to final write up. Member checking back to all participants also helped ensure that themes reflected participant experiences (Appendix 7).

Reflexivity

In qualitative research, it is acknowledged that the researcher is not objective but is very much immersed in the research, and the position and views held by the researcher, and the researcher's relationship with participants is of utmost importance. Potential relationship or outcome bias needs to be considered and addressed throughout all stages to achieve transparency (Mcdermid et al., 2014). Transparency was promoted by the keeping of a reflexive journal (Baille, 2015) considering any assumptions, expectations, behaviour or emotional reactions and unconscious responses (Finlay 1998, cited by Baillie, 2015) and through supervision. The following is an excerpt taken from my journal after interviewing Angie illustrating my preconceived expectations and reflecting on a new understanding and relationship.

> *"I feel like our relationship has been strengthened even further and I have gained another layer of understanding into Angie's life. I don't think it is as harsh as I perhaps imagined, in fact I would suggest that she is perfectly happy or would be if she could access Sky sport. I feel enormous gratitude to her for doing this and trusting me so much with her emotions. It feels like an honour."*

Credibility

Credibility refers to how accurately the representation of participants experiences are to those they describe. Allowing participants to choose the photographs to be discussed, in the order and pace set by them, maximised the ability for them to use their own voice. Participants were supported to speak freely to the photographs throughout the interview with guidance to explore and answer 'What Matters to Me?' At the end of each interview, I summarised and reflected what had been heard allowing the participant to respond accordingly. Transcribing the interviews, along with supervision and member checking further strengthens credibility.

Summary

This chapter has outlined the process and decision making throughout this project, including application for ethics and the methods implemented to increase rigour. The primary aim is to facilitate the voices of those who have traditionally been silenced, use the information to inform practice evaluation in line with developing recovery focussed services and to explore photovoice as a tool to achieve this aim. The next chapter presents the findings in the form of photographs and dialogue from semi-structured interviews.

Chapter Four : Findings

Photographs taken to represent what matters to me were used as the basis for individual interviews. Participants were given the photographs and after removing any they wished, used them as a tool to facilitate discussion, controlling the direction, flow, and pace of the interview. Interviews were recorded and thematic analysis was used to develop the following themes and sub-themes as presented in Table 6: Themes.

Table 6 : Themes

Theme	**Sub-theme**
1. Where do I Live?	1.1 Home and Homemaking 1.2 Neighbourly
2. What Do I Do?	2.1 Joy of Life 2.2 Sharing Knowledge 2.3 Employment
3. Who am I?	3.1 Sharing Memories 3.2 Health 3.3 Family
4. A Place to Be Me	
5. Who Do I Love?	5.1 Family 5.2 Friends (and cats!) 5.3 Supportive relationships
6. Hopes and Dreams	

1. Where Do I Live?

All participants had taken photographs to represent home, which are considered under the subthemes of, home making and neighbourly. Ten of the eleven shots Susan had taken on her disposable camera were taken in and around her flat, with many shots on her digital camera also representing home. She shares her flat with her partner Chris and cat Garfield, one of 5 properties in a small, supported living complex and describes it beautifully as "*the center point of my life*"

'I love it, yes I love it"

Mike has a history of homelessness and housing insecurity and recently moved into his council flat from a more expensive private rental. He had taken one photograph to represent his flat, which was the view from the window. While sharing his pleasure about the new flat he also shares some of the difficulties associated with living alone.

> *"Yea. um it can get lonely, but I just go, and go do something, like go and clean something to take my mind off things. It's hard but it's all good, I'm happy and it's cheap."*

"Oh, I love it I like it,"

Mike's first photograph was of 2 staff members at a residential facility offering respite care which he describes as *"my favourite place that I live, I like living there."* Prompting revealed Mike accesses respite frequently and has done so for over 20 years. Before introducing the next photograph, he takes the opportunity to reinforce his sentiments.

"It's a nice place though"

1.1 Home Making

All participants spoke about tasks associated with managing or maintaining their home, and for Susan this was a recurring theme, with rich descriptions giving insight into what matters. She had a photograph of a rug and furniture in her lounge, the condition of which concerned her.

> *"… we're gonna have to get new furniture one day, ours is just bloody, it's wrecked. It's ruined. Our leather couch, it's got scratches on with the cats. The leathers peeling off Chris' one, oh, we need to get a new lazy boy, new couch, new sofa. The one sofa that we've got beside him goes down deep and the springs are broken yeah"*

> *"...that's one of our rugs on the floor. We got it from the Persian rug store about 4 years ago and the state of it now, when we first got it was lovely and clean. The state of it now, it's got marks all over it. I've used everything I can think of to get the marks off, some of them have come off but not all of them. I've got this stuff at Goods to Go for $5.50, erm, stain remover for carpets, and I tried the deodorizer, vanish, I've tried everything."*

She was pleased with her makeover of the plant pots

"that was our pots before I did a, what do you call it, um a makeover"

Angie took a photo of her front garden leading from the front door to the gate, talking about the tension between having a nice garden but 'hating' gardening, and the help she gets from her sister to maintain it.

"Now this is something I hate, I hate gardening, ...I really like flowers, but I hate gardening, but Mary helps me. Mary has been helping me that last few times so that's good. I do like a nice garden, I just I just I can't see how anyone likes weeding, I think weeding is horrible."

11 of 17 photographs taken by Peter were in and around his home including one of the basement showing a well-stocked and organised 'blokes shed.' Despite the impression this gave, and the fact that he photographed what mattered, when asked if he spent much time in it, he said *"No, ...not really... I Erm... No not really now and then..."*

"Yeah, I got it sorted out now... I sort of got all the basement sorted out now... and I've painted all this recently"

1.2 Neighbourly

This subtheme considers participants' photographs and dialogue about home in the broader context of neighbours and neighbourhood.

Susan portrayed a sense of belonging within the immediate community of the supported living complex as something that mattered to her and photographed her neighbour's house.

"… because it's the neighbour's house it's a neighbourly house"

When asked if she visited her neighbour she responded in her usual cyclical manner, using repetition for emphasis

> *"yep, yep, yeah. I like it. I like it. It's nice and Pam likes where she is too, so yeah, I like to pop in now and again for a smoke. We sometimes lend each other smokes."*

She illustrated her immediate community with a photograph of letterboxes representing the people and her connection to them which she readily talked about.

"That, that's Pam's letterbox, and the other two belong to Bruce and erm… there's Alan, Mark and Bruce, another Bruce, me and Chris, Pam and Karen"

Describing how *"yeah, we all get on,"* she also highlights the tensions of living closely together

> *"except the other day Mark next door was asking my sister for money and asking Tina if she could drop him off and I said, Mark, you do not ask her anything right, no money, no cars, she doesn't come here to see you, she comes here to see me, I blew him up and he was scared...oh hell he was stunned, he walked off and that was it. Oh, he comes over to our place all the time I'm sick of it."*

Tension was similarly highlighted by Mike when talking about a resident in respite care

> *"Yes, most of the people I like but I had a wee problem with one lady because I upset her and erm, I keep my distance away from her now. I've been told to keep away from her if she speaks, she speaks, if she doesn't speak don't speak to her... We don't get on with each other very well."*

and of his immediate neighbour

> *"... we had a bit of an argument, disagreed with each other and we aren't talking to each other now."*

Angie's immediate neighbour is the daughter of her friend and she visits regularly when Jo is there and offers support.

> *" I go next door and see the baby...they are nice wee girls and sometimes I babysit them in the holidays"*

However, she did not have such a connection with other neighbours

> *"I don't have much to do with her, she's a bit strange really."*

Relationships with neighbours can provide opportunities such as visiting the baby and connecting with pets, opportunities that have shared meaning and create occasions for giving such as babysitting or sharing smokes. However, suspicion and tension were also substantiated as mattering.

Home is more than the place we live and can mean different things to different people. A place of memories, a place of safety, control, and comfort, a place for activity, connection, and dreams. Whether owner-occupied, or rented, or respite care, whether living alone or with others, home was a strong theme when asked what matters.

2. What Do I Do?

This theme begins by considering the images participants had taken to represent the things they chose to do, and the enjoyment and knowledge they derive from this. The second part considers references to past employment which was not represented by any photographs but was discussed by three participants.

2.1 Joy of Living

Angie is deliberate in her approach to interpreting the question 'What Matters to Me?' correctly. She carefully goes through all her photos and tears up 4 that she is not happy with due to poor picture quality then presents them in a predetermined order. She has 9 photos of sport on TV and chooses to start with one of the cricket.

"I really enjoy my sport, I really do and I really enjoy cricket and it means a lot to me and erm, I just really enjoy the competitiveness' of it and if it is a close game it really gets me going. If it's a really close game...you sort of get like an adrenaline rush... that was really good I was really thrilled about that...."

She is animated when talking about sport and her passion for it is evident in all her verbal and nonverbal communications, her face comes alive when asked about her photograph of the All Blacks doing the Haka.

"I like the Haka. I like the Haka, I like the Haka."

Unable to afford subscription fees she relies on free to air TV and radio to keep up to date, identifying the TV as something that matters a great deal.

"I'd be lost without telly I really would be; I know I shouldn't be I should find more things to do but if there is nothing on telly I think what am I going to do, what am I going to do."

When asked about extending her interest beyond watching on the TV and attending a sporting event she replied,

> *"I'd like to do it, it's just with not having a car, and getting down there, just getting down there, it's out of the way a bit now."*

She also talked of anticipated future barriers to accessing sport through technology,

> *"....but I think cricket is going to be on Spark and that's really annoyed me cos I haven't got the App and I'm not very good at how to do it, put the App on my computer to get the App for the cricket..."*

Peter also appears to take the task of answering the question earnestly, talking deliberately, and candidly about each photograph. His intellect and curiosity make for an engaging sparring partner, with politics and religion been his chosen subjects. He introduces the subject by sharing a photograph of his lounge from the viewpoint of his favourite chair and talks about *"following the American political situation, Trump, the current Trump impeachment,"*

"... so that's how I spend a lot of my time, following the American political situation,...it's just really interesting ***...****It's interesting, it's intriguing, but its enlightening,..."*

For Peter, doing, was not limited to researching his favourite subjects online, he photographed two sets of golf clubs, a recently purchased electric bike, along with his basement workshop, his car, and a reading book by his bed. The stories he told through his photographs painted a picture of someone who values learning, physical activity, and new experiences. Yet despite his resources and tight control of his budget,

> *"....that's my running tally of my current account basically so I like to know exactly how much I've got."*

Peter still identifies cost as a barrier to doing, such as joining a golf club and having a drink after a round of golf.

> *"…it started out 300 and something and it's gone to 500 and something and next year it will be 700 or so which is nuts…I was just fed up with it cos…you know the price of beer was not going down. I couldn't afford it really on a benefit."*

His material, physical and intellectual strengths and resources contrast with the known characteristics of people who access day services, such as Mike whose limited resources seem to restrict his doing to walking the streets, visiting friends and reflecting on life.

"…that's my favourite street I like walking up…sometimes I'll go and see um, a friend. Yeah, it's good…just memories that's all. I used to play soccer on the ground up there when I was a young boy. I go up there and sit and look out onto the gardens, I love it. I like my bush I like the bush the sound of birds"

2.2 Sharing Knowledge

Participants often elaborated on the photographs in this theme, giving context, demonstrating knowledge, and embracing the opportunity to share their passion, as illustrated by Peter.

> *" …they haven't done a damn thing, they haven't passed a single piece of legislation since the Dems, since they have held the house,they have got a drug funding policy sitting there ready to go, and they got the Mexico Canadian free trade agreement sitting waiting to be signed off but Nancy Polosi and co are too busy trying to impeach the president."*

Angie shares not only her extensive knowledge of sport, but informed opinions and memories of games and results.

> *"It was a day game; it was a day game between NZ and England. I'm not sure who won but we both won two games and they won two games and the third game was a draw and it was a draw on the last over and they had to have one over to decide. It was a mad over so England got 18 runs and we had to get 19 runs to win but England won."*

> *"He's an Otago player, he played for the Highlanders, he was more or less dropped from the All Blacks in Japan. I felt sorry for him, he's a world-class player and Steve Hanson dropped him. Only gave him one test I think, but he is going to France now."*

"….. that's Casey Kapua,… boy did she play her heart, she played really well".

On these occasions it felt like participants were the experts in their chosen field imparting their knowledge and opinions, recalibrating the power dynamic, enjoying being listened to, *"not everyone else wants to hear my views on the world"* and feeling proud, *"… you can get lost, but I don't get lost I know most of the tracks."*

2.3 Employment

Although none of the participants took photographs to represent employment it was included as a subtheme as three participants talked about past employment. Angie and Peter indicated that employment had mattered in the past, but illness had created a *"broken work history"* making work unattainable and unsustainable. Despite this the benefits of past employment were still present, for Angie in the form of lasting friendship and for Peter achieving a level of material comfort. Mike listed numerous jobs he had had but gave no indication as to the value and meaning in his life.

3. Who am I?

This theme captures the stories participants told about their past and present self in subthemes of memories, health, and family. Susan captures how important this is to her and is explicit in her desire to make others understand.

> *"I wanted to be known, I wanted my identity to be known and I wanted my friends to know that it is not just one-sided"*

She is the only participant who identifies as Māori , something which she expresses throughout her interview, referring to someone as *"another Māori lady"* and explaining why she could not gift Chris a hat with the marae logo on *"I thought Chris wears that everyone will think he's Māori , I said no I better not get him one of those.*

3.1 Sharing Memories

Photographs were often the catalyst for participants to share memories. A photograph of a cricket game on TV led Angie to share part of her story, contributing not only to her own sense of self and identity but to a greater understanding for others about who she is, highlighting the possibilities of photovoice.

> *"I remember one game, rugby game, this is going back a few years, me and Mary went. I think she took the afternoon off work and Otago were playing the Springboks and it was teaming down with rain and the students were walking round in diving suits and flippers and it was so funny and we actually beat them, and we were the only provincial side in New Zealand to beat the Springboks.... it was at Carisbrooke and they put out a T shirt Bok Buster...it had a picture of a deer or something and all the Otago players signed it at the back and Mary gave one T-shirt to me and my brother for Christmas and I've kept it."*

Mikes photograph of the park was the catalyst for him to share childhood memories and reveal his view of himself as 'special' and being segregated from his peers.

"I wish I wasn't kept there, but that used to remind me of when I was younger, when I was very young. I was in hospital when I was a kid, the one where St James is there. There used to be an old house there when I was a young boy, a boarding house for special people and we used to live there and go to the school, drive to the school around town we used to go to, that's when I was very young."

Limited literacy skills and difficulty expressing himself verbally are a part of Mike, and the quote is the longest he made without prompting, again highlighting the possibilities of photovoice. While he continued to share information about his school memories, this was in response to questions leading to short truncated answers.

3.2 Health

All participants have a long history of mental illness and service use and although Angie was the only participant to take a photograph to represent health all participants referred to it intermittently throughout the interview. It was as if illness had travelled along their journey with them, a part of who they are, but not the sum of who they are.

"...this is my medication. And that means a lot to me....I know if I don't take them I will get sick, so I've got to keep taking them"

Peter acknowledged the long-term impact mental illness and medication has on health

> *"...yeah but bipolar sort of buggered me up on a fairly regular basis,...another tooth fell out, so I've got a great big bloody gap now, you know two adjoining teeth gone and this is all, all this dental stuff is all medicine related. All the oral meds that I take for bipolar and heart disease and stuff. I got about 8 pills at night and it dries your mouth out so the saliva doesn't clean your teeth"*

Angie shared how health impacts daily life, talking about her experiences shopping at Pak n Save

"...I find grocery shopping quite stressful... I go to Pak n Save and food is important, you got to eat and I never know what to get. I'm not as bad as I use to be but I used to find it quite stressful... it's knowing what I want, knowing what I want is the most stressful part"

Having photographed the rest home over the boundary fence and using it to discuss someone she knew Susan was adamant in her reason for never having visited, a reason perhaps rooted in her experiences of institutions.

"I don't like hospitals"

(Researcher) "It's a retirement home"

"Yeah well, it's still like an institution though"

When I attempted to explore this further the chatty engaging person, I had known for so long was replaced by one I did not recognize. Diminutive and silent, averting her eyes to the ground, nodding, and shaking her head in place of verbal responses. At no other point did Susan or any of the participants answer questions using only body language. Her silence was taken as a clear signal that she did not wish to revisit this part of her life.

3.3 Family

Angie is one of four siblings born to Irish descendants on both her mother and her father's side. Her pride and connection weaves through her narrative, showing a strong sense of self.

"Yes, that's dad there and that's my grandparents.... and that's my mum....We did have a family reunion in 1980 we had a big get-together but that was a long time ago and we put out a family tree and it was really good, it was really beaut...I don't know much about dad's side of the family, but mum was a C, and of course dad was a G, and C is an Irish name too. It sounds English but is actually Irish."

Among the myriad of photographs on Susan's digital camera were a collection of photographs taken on her recent trip to Gisborne with her mum and sister. She used one of these photographs to deliver her mihimhi[2], expressing her cultural identity and connection to her whakapapa[3].

> *"Yes, moms is on her side and dads is on his side, because both of the maraes, ones on a rise, one on the other side, the mounts up there. There's a big mountain you can go and see but you can't walk up it, you have to be a climber to get out there. Me and Tina tried to get as close as we could, take some photos of Mount Hikurangi, you might have heard of that mountain in Gisborne erm Waiapu which is our River our tribe is Ngati Porou, yea, a few things anyway."*

Expressing a sense of self and connection to the past did not come easily to Mike and gentle prompting for more information often led to brief one-sentence answers which occasionally dissolved into mumbling and unclear speech.

> *"no, mom, mom yes it was only my sister she's only a couple of years older, couple of years younger than me my sister a couple or three (mumbling, unclear)."*

Despite appearing to make attempts to answer and never showing any irritation or annoyance to questions in due course he did say of his father

> *"...how I was treated yeah that's why I don't like talking about it, he's out of my life"*

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[2] [1] Mihimihi, introduction or speech usually done in a round, when people traditionally stand to share a little bit about where they come from and who they are, often sharing parts of their whakapapa or *genealogy*).

[3] Whakapapa, a line of descent from one's ancestors; genealogy.

Peter did not have a photograph to represent his family but during the discussion talked about a bike ride with his sister and time spent caring for his parents. He did have a photograph of a collection of English decorative plates called “Country Crafts” and when asked what it was that appealed about them, he replied

> *“Well they are just lovely old English things really and I guess that is my heritage.”*

Concerned about the quality of the photograph, the next time I saw him he brought all 6 plates in for me to photograph, perhaps indicative of the importance he places on them, or maybe the importance of participating in this project.

4. A Place to Be Me

This theme considers what matters to the participants about the service where the research was completed. I had anticipated an overt reference to the service given the level and duration of participants involvement, however, while some direct reference was made most of the connections were subtle requiring a deeper exploration of the dialogue.

For Mike, we see how he recognises the service as a place which provides practical support and problem solving when asked about his new flat.

> *"Oh, I love it, I like it, but I need some curtains um."*

Getting curtains is important to him and he has the certainty that this is something he will receive assistance with at the service.

Items donated to the service, are sold to people who attend for a nominal charge, giving them access to affordable clothing and household goods. Susan had photographed various items in her flat that she has 'bought' at the service and referred to throughout the interview.

> *......I bought it here yes.... bought here, ...I bought that here years ago...when I got from here..."*

"....the mats I got from here which is outside now

Angie demonstrated the connection between home and the things made at the service even though she did not perhaps feel as included in the making process as she could have or would like to have.

> *"This one here is a birdfeeder I made...I made that with John, but John did most of it, I just sort of painted it, he sort of hung it up..."*

Important implications for OT in the experience of engaging from the client's perspective.

Susan photographed a doorstop made at the service many years earlier painted to represent her cat Garfield. She had originally made two to represent both her cats and she was adamant that this photo had to be used in the discussion. As a result of the fate of 'Chardie doorstop' she now keeps 'Garfield' in her bedroom.

".... When Chardie died I put her one in front of her stones but then the rain washed it away and it didn't last long...."

Discussed above are the practical ways activities and support can be accessed through day services but, participants also talked about relationships with others, including staff, one who had left the service some 8 years earlier. Susan had photographed a staff member and gave a rich insight into what about the relationship matters to her.

> *"I chose this one because Elizabeth is very official and very therapeutic and very practical and very smart very down to earth and a nice person to know and to get on with and get to know and erm happy to help whenever she can, erm she makes people better she makes people feel worth, worth it and says all the right things that you need to hear for your own dignity."*

Mike is more succinct but no less compelling about what matters

> *"It's my second home, I love going there, it's the people, it's the people around you."*

While overt reference to the service was not made connections to the staff and group members, along with activities and practical support were some of the way's participants highlighted what about the service mattered.

5. Who Do I Love?

This theme considers relationships and connections to others in the subthemes of family, friends, and supportive relationships such as those within services. For Susan, much of her dialogue was about the people (and cats) in her life, something she articulates by proposing that she is not going to let anyone get away from her

" ..everyone packed in a tight box and none of them can escape"

5.1 Family

Angie talks often about her sister leaving us in no doubt that Mary matters, really matters to her

"She means the world to me Mary. She's very good to me. She can be
big bossy sister at times, but she means the world to me."

Susan talked naturally and openly, about her brothers, sister, parents, and extended family members, even though contact is compromised by the physical distance between them. Regarding her sister Tina she talks of things they have done together, and gifts that she has received from her, one of which she photographed and wants to keep as an "*heirloom."*

Susan is the only participant who does not live alone, she describes the presence of her partner Chris with obvious affection.

"This one here is about Chris' life in his chair, the life and soul of the party is when
he sits in the corner of his chair. Sleeps in it, rocks in it,...It doesn't get moved.
That's the only one he likes, loves, and that's probably the only one he will have..."

However not all family relationships are positive, as we see when Mike talks of his father and a relationship fraught with tension

> *"dad was a violent man to me…The way I treated… most of my life the way I was treated by my father."*

For Mike perhaps respite care is family

> *"there's heaps of us, it's just like a big big home, a big family, its good."*

5.2 Friends (and cats!)

All participants talked about the importance of friends and two gave insight into our relationship with pets.

> *"And this is a friend of mine, and her wee dog and they both mean a lot to me. Her name is Jo and that's her wee dog and she's a chihuahua something cross, but she just loves to sit on my knee like a cat… Its just so nice…the dog comes running up to me and just won't leave me alone and will just sit on my knee and sit on my knee, she just loves to sit with me she just won't leave me alone. She didn't to start with she would bark and bark and bark, but she's got to know me now."*

We also gain some insight into the emotional connection and empathy in the relationship with Jo.

> *"God if she moves, she's going to lose that flat, … she's going to lose the flat next door and she's going to uproot the kids, terrible. Jo is worried sick."*

Susan expresses empathy and a desire to invest in a relationship when she talks about her friend who is in hospital long term, using the interview as an opportunity to ask for assistance maintaining the relationship.

> *"well I don't see her very much and it's sad to know that she's up there all the time, it would be nice if we could go and see her one day for an afternoon tea if she wants up there, if she's well. I've got a card for her, I was going to get her a present but because I never saw her at Christmas time I had to leave that and just get her the card but I'd like to make her something or buy something for her for Christmas because she made all those lovely pictures and those wee ornaments she gave me remember? So, could you maybe arrange with this staff to go and visit her again one day that would be good."*

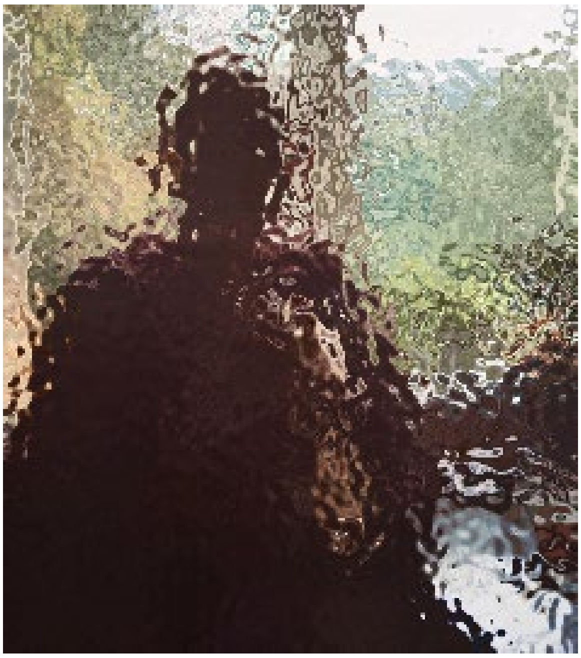
Although Susan talked about friends, family and Chris her frequent references to her cat Garfield left no doubt as to how much Garfield matters, mentioning cats more than ten times in her one-hour interview, her present cat Garfield, previous cat Chardonnay and past and present cats of her Mum and sister.

"... that's my cat Garfield.... the cat, and Garfield......In the middle is Garfield of course (laughs).... that's Garfield no that's not Garfield. (Its a doorstop of Garfield)....When Chardie died... that's the cat flap,... that's Garfield's scratcher...., that's Garfield..., that's his bare plate... "

5.3 Supportive Relationships

This sub-theme primarily considers relationships between service users and paid staff, but also acknowledges supportive relationships that can exist with family and friends and the benefits of caring for other people and animals as well as being cared for.

Two participants photographed staff members and highlighted the trust, support, and level of connection in the relationship.



" And what I like about her, we can talk to each other and it stays there and she's helped me a lot...she's an amazing person. Not scared of anything, don't seem to worry it too much, I like her as a friend... I just feel happier...you know she listens to you. She's an amazing lady" [image obscured]

Angie talks with compassion about her sister and the efforts she makes to support her

"But no, she hasn't been very well, so I don't want to bother her...it was just hopeless, ...And I said well why don't you go and see Dr S, she said I will...she can't go on, she can't go on."

She also cares for the birds that visit her bird table

"I try and feed the birds every day.... that means a lot to me because the birds get hungry."

Too often people who access services are viewed as passive recipients of care and denied the right to give back, care and do things for others. Giving is vital to creating equitable relationships and maintaining health and wellbeing, we see evidence that participants do care for others and express a desire to give. Peter clear that he participated because he likes to be a "*helpful bastard*"

6. Hopes and Dreams

Occasionally participants hinted at a different life, one perhaps that they had hoped for, or still do hope for, and the chance to get away, to change a routine or to leave town.

> *".... if I'd gotten mechanical minded I wouldn't have minded being a mechanic yes things, like that enters my head...Yea I'd have loved to have been doing up cars yeah."*

"... I was taking a photograph of the house on the hill, ... I haven't got the money for that... heck yeah, heck yeah,"

A weekly lotto ticket is an experience Angie shares with her sister Mary, the ticket sits under the lucky leprechaun, and occasionally they share dreams of winning, looking at houses on the internet.

> *"It's just bit of fun really but if we win it, we'd be oh my God, if we won it, we'd be oh my God... , this would be a nice house when we win lotto, when we win lotto this will be a nice house when we win lotto, she gets on the computer, this will be a nice house."*

A car affords Peter opportunities often denied those with more limited resources.

".... well I love my little car... I got a tow bar put on it....
so, I can sling bikes on the rack and go places."

Many of these hopes and dreams seem beyond the control of individuals, even "*.... erm, trips we go on each year...*" and "*payday when we get our smokes*" are dependent on external factors. When mental illness is viewed through an individualistic lens, we fail to acknowledge these external factors and allow for the possibility that *".... people live hand to mouth and can't see further than next week".*

Summary

The findings chapter reported the things participants shared about what matters and presented them in six themes. 'Where do I Live,' explored the part home and neighbours played in the lives of participants. 'What Do I Do,' looked at how participants choose to spend their time, while 'Who am I,' considered their journey through life and their identity. 'A Place to Be Me' is the day service common to all participants and this theme looked at the different ways' participants referred to the service for meaning and support. 'Who Do I Love' examined the relationships participants have with family, friends, professionals, and pets, while 'Hopes and Dreams' captures desires for a different life and wistful comments.

The next chapter will discuss the findings predominantly through the lens of the recovery model CHIME (Connectedness, Hope and optimism, Identity, Meaning, and Empowerment) and consider how this relates to occupational therapy.

Chapter Five : Discussion

This chapter discusses the findings, predominantly through the recovery framework CHIME (Connectedness, Hope and optimism, Identity, Meaning and Empowerment) but also considers literature and voices that both align and contrast. Implications for practice and recommendations for future consideration and research are made, along with limitations.

Where Do I Live?

Critics of CHIME claim its individual stance fails to fully acknowledge the wider social and economic factors influencing recovery (Petros, Solomon, Linz, DeCesaris, & Hanrahan, 2016: Stuart, Tansey, & Quayle, 2017), which is immediately apparent when home emerges as a strong theme. The living standards framework (LSF) recognises housing as a component of health including it as a measure within the health domain (The Treasury, NZ. 2019) and literature argues that decent stable and safe housing is a prerequisite to recovery (Cheng et al., 2009) acting as both an anchor and a base from which to develop identity (Clements, 2012). As a resource, the home provides a safe place to explore hobbies and interests, make rules and decisions and develop routines, enabling personal growth, hope, meaning and agency (Borg et al., 2005; Doroud, Fossey, & Fortune, 2018). From an occupational perspective, private and stable housing, or 'being in place' is necessary for supporting the interconnections between being, belonging and developing a sense of normalcy (Townley, Kloos, & Wright, 2009).

All participants were in stable housing at the time of interview (although for one this was a recent development), and a sense of 'being in place' was apparent as participants had photographs of activities, people and possessions connected with home. Two had photographs that were a direct representation of home. Mike often struggled to articulate 'what matters' but did not hesitate when asked about the photo of his flat "*Oh I love it"* and Susan describes it poetically as "*the centre point of my life."*

As a material resource, home enables immaterial meanings such as emotional comfort, security and self-esteem and provides a stage for the 'little things' in everyday life (Borg et al., 2005), such as watching TV or feeding the birds. In this way, a home may be vital for maintaining a sense of self, and contrasts markedly from the controlled way of institutional life (Borg et al., 2005).

Homemaking or transforming spaces into meaningful places, and houses into homes

(Borg et al., 2005) was illustrated in the findings. Susan talked about her desire to upgrade her furniture, rugs and flowerpots, and Peter talked about renovating his basement and roof. While for some these activities seemed welcome for others, they were a chore "*... this is something I hate, I hate gardening, ...*"

Within the characteristic connectedness, CHIME points to being part of the community as a determinant of recovery, and while relationships with neighbours are often more superficial than those with family and friends they are no less important for building a sense ofbelonging and position within the community (Jody, et al., 2008). However, Petros, et al., (2016) are critical of CHIMEs unidirectional view of community proposing that people need the opportunity to contribute or give back to the community to feel a sense of belonging. Safe healthy neighbourhoods with access to services and green spaces facilitate healthy lifestyles and routines, conversely neighbourhoods where residents feel unsafe or stigmatised have negative impact on health (Doroud, et al., 2018).

Susan is the only participant to live in a multi-resident supported living complex and her sense of belonging was evident in her photos and dialogue, *"... it's a neighbourly house.., I like to pop in now and again...*" Angie had a strong relationship with her immediate neighbour, going next door to see the dog and babysit but this was perhaps due to a historical friendship connection as much as about the neighbourhood. Of her other neighbour she said, *"I don't have much to do with her, she's a bit strange really."* Mike and Susan both talked of the tensions that can arise living closely to others "*I blew him up and he was scared." "we had a bit of an argument, disagreed with each other."* These findings reflect those in *He Ara Oranga* (2018), that there is an atmosphere of disconnection and mistrust within our communities. This needs further investigation if we are to succeed in the goal of moving from "Big Psychiatry to Big Community" (O'Hagan, 2017) and building environments that enable individuals to lookafter their own and each other's wellbeing.

What Do I Do?

Occupational therapists working in mental health use activity or occupations to improve, maintain and restore health and wellbeing (OTNZ-WNA, 2016). The overarching goal is for maximum control over one's life (Hitch et al., 2014). Using the Pan Occupational Paradigm (POP) occupational therapists value doing as a way of achieving being, becoming and belonging, concepts that can further be attributed to promoting the characteristics of CHIME (Hitch et al., 2018). All participants talked of activities that they chose to do and the meanings they attach to them. For Angie much of doing is watching sport on TV or listening on the radio, occupations that provide opportunity for social connection, personal growth and forming identity, which facilitate being, as she reflects and develops sense of self.

> *"I really enjoy my sport, I really do and I really enjoy cricket and it means a lot to me and erm, I just really enjoy the competitiveness' of it and if it is a close game it really gets me going."*

When asked about the haka Angie smiles broadly, her connection and belonging to her national identity is evident in her response.

> *"I like the Haka. I like the Haka. I like the Haka."*

The activities people chose to do provide meaning, nurture positive identities, and promote empowerment through independent decision making, facilitating recovery as viewed through the conceptual framework CHIME. For people with SMI building identity beyond that of a service user is seated in small everyday acts of living (Davidson & Roe, 2007) such as walking, feeding the birds, or watching TV as described by participants.

The solitary nature of these activities is also apparent, resonating with findings that people with SMI spend long periods of time alone engaged in solitary activities such as watching TV and smoking (Milbourn, et al., 2017). This study also found that people with SMI have limited opportunity and choices for doing, so while it appears what people choose to do matters to them, questions remain as to whether or not they are satisfied with the opportunities and choices for doing afforded to them.

When a person's ability to participate in occupations and do the things they need to do is compromised then mental health is compromised, as people measure their health and wellbeing by the things that they can and can't do (OTNZ-WNA 2018). When engaging in meaningful doing is acknowledged as a vital part of wellbeing then occupational therapists must concede meaningful doing is no longer a treatment but a right. Thus, occupational therapists no longer have a right to focus on individual deficits and treatments but are duty-bound to address systemic causes of occupational injustice. This necessitates less time and resources are spent on measuring deficits and more attention given to capabilities, strengths, and resources (Hammell, 2015). Capabilities are the things people want to do and be, while also considering the opportunities, or resources available to them (Robeyns, 2005). Capabilities across the 4 participants vary markedly. Homeownership, a university education, a car, sports equipment, and a laptop offer Peter multiple opportunities for doing, yet he still identifies barriers to increasing his activity. Angie loves her sport, but quickly identifies barriers to increasing her participation. For Mike, unstable housing, limited literacy skills, and a lack of transport or discretionary finance all play a part in limiting his options for doing to walking the streets and visiting friends. Both worthy occupations but insufficient to provide occupational balance.

None of the participants had taken photographs that were a representation of employment (productivity) although work was referred to by three participants. Angie spoke of work having been important in the past but the stress it created, and managing her illness made work continuity unattainable. Similarly, Peter talked of '*a broken work history*.' For these participants, the value now afforded to past employment was about the financial reward having contributed to the current standard of living and resulting friendships that remain today.

Current health systems are provider centred (He Ara Oranga, 2018 p.159) and occupational therapist may therefore find themselves obligated to predetermined expectations (Reed & Field, 2017), such as goal-orientated outcome measures that satisfy the needs of the funders not the service users (Perkins 2013; Thomas, 2015). Thus, occupations or doing for meaning rather than purpose or productivity are often overlooked as self-care, and productivity are traditionally perceived to be more important (Hammell, 2004). Occupational therapists are expected to 'address the topic of productivity, have a frame of reference for work evaluation, and understand the factors that interrupt the work process' (Gibson & Strong, 2003 as cited by Chodhoury et al., 2015, p.268). While there is an association between meaning and purpose the two are not interchangeable and studies show purposeful occupations or activities are of value only when they are personally meaningful (Vrkljan & Miller-Polgar, 2001). By neglecting meaningful activity in favour of self-care or productive activity it could be argued that occupational therapists have inadvertently promoted ableism and been a voice for the state (Reed & Field, 2017), reinforcing views that devalue those who are deemed to be unproductive. Services need to focus on outcomes that are related to a person's ability to participate in occupations, something that is increasingly neglected due to an over-emphasis on talking therapies at the cost of doing therapies (OTNZ-WNA, 2018).

The implication that occupational therapists may inadvertently be neglecting meaningful occupations for a focus on productivity is consistent with a critical view of recovery. The service user group, Recovery in the Bin, believes that recovery has been colonised by professionals, Thomas and Knight, (2018) agree reporting that interventions are increasingly politicised with therapies such as 'pyschocompulsion' being used to force people into being work-ready in a bid to reduce benefits and increase employment rates.

Who Am I?

Loss of identity is at the centre of mental illness, with studies reporting that people who access mental health services believe the ascribed mental illness identity becomes dominant subsuming other positive identities they previously held (Fleming, et al., 2009; Hamer, et al., 2014; Ørjasæter, et al., Stickley, 2017). The recovery journey is one of self-discovery and requires those engaged in the process to know, rebuild, and redefine a positive sense of identity (Leamy et al., 2011; Mutasa, 2017). This aligns with the occupational therapy research in mental health that addressing identity along with healing, self-discovery, and community participation are the most effective interventions (Wimpenny, et al., 2014).

All participants have a long history of mental illness which was acknowledged by them at various points during the interview,

> *"…this is my medication. And that means a lot to me…I know if I don't take them, I will get sick,"*
>
> *"….I get silly thoughts in my head but that's all controlled by the tablets…"*
>
> *"…..yeah but bipolar sort of buggered me up on a fairly regular basis."*

However, in contrast to the literature, an illness identity did not present as dominant, and for one participant a historical institutional identity was one she refused to return to, falling silent and disengaging when asked about it. No answer is an answer.

Occupational therapists understand the relationships between occupation, or doing, and health and wellbeing, recognising that what we do forms our identity. Through doing and being we achieve becoming or who we wish to be, our future self, building hope, and through belonging we achieve connection to people and place (Wilcock, 1998; Hammell, 2004) therefore we are what we consistently do (Christiansen, 1999). For Peter following American politics and Christian Apologetics online revealed something of his political and spiritual identities, but he also spoke often of the physical sports and activities he participated in, including golf, skiing, kite surfing, and cycling, revealing a physically active motivated identity.

Not everyone views identity through an occupational lens, maintaining that we are essentially narrative beings, our Self is the stories we tell ourselves and others, and the stories others tell about us. As stories continue over time our future is influenced by the past, necessitating narrative cohesion, integrating past and future events in stories creates some form a meaningful whole out of the different phases in one's life (Baldwin, 2005). Difficulty constructing positive and meaningful identities through narrative maybe due to cognitive impairment caused by the illness and or by the reactions of other people leading to a loss of narrative cohesion and sense of self (Baldwin, 2005). Striving for coherence narrative theory may impose meta-narratives on fragmented or chaotic stories causing stories to be lost (Stone, 2004). The findings illustrated how words often overflow from Susan resulting in slightly fragmented and chaotic stories, such as when using her photograph of a mountain to deliver her mihimihi. Using a narrative approach professional working in mental health are the trusted co-authors in a service user's narrative (Baldwin, 2005). This requires consideration for maintaining narrative continuity and agency, countering meta narratives (stories created by others as a means of understanding) and paying attention to small stories to engage with identity in the here and now. Participants used photovoice to share their stories, a concept that has possibility for integrating into practice and could be adapted to use existing photos or objects to facilitate storytelling and collecting (Baigent, et al., 2019).

Illustrating this Angie uses a photograph of the rugby to share a small part of her story and herself '*this is going back a few years'* which connects her with family '*me and Mary went…Mary gave one to me and my brother*' Reflecting on the experience '*it was teaming down with rain'* and the enjoyment *'it was so funny and we actually beat them'* she is speaking from a positive identity, engaging in the here and now, '*they put out a T-shirt Bok Buster…. I've kept it*' and demonstrating narrative continuity.

Angie reveals herself as a daughter and a sister in a "*sports mad"* family, something which she has clearly adopted and integrated into her present sense of self. Similarly, Mike shares memories of car meetings he attended in years gone by but still identifies his present self as a car enthusiast. "*I love my car racing; I love my cars"*

Susan is a sister, a daughter, a Māori lady, a cat lover, a partner, and a homemaker, while Peter revealed himself as a brother, a son, a person of faith and spirituality, a sportsman and a friend.

The occupational therapy concept of 'doing with' provides opportunity for therapists to engage in chit-chat collecting stories that promote the development and maintenance of self. Helping people with mental illness make meaning of their stories by recovering their voice is the philosophical approach of the Tidal Model (Barker, 2002) which claims people are their stories, change is constant and simply spending time together is the ‘midwife of change’ (Barker, 2002; Brookes, et al., 2008).

Whether we are defined by the things we do or the stories we tell does not alter the fact that all participants revealed multiple positive identities and paid only cursory attention to an illness identity. A finding seemingly contradicting the literature (Fleming, et al., 2009; Hamer, et al., 2014; Ørjasæter, et al. 2017).

A Place to Be Me

While not the focus of the research given the setting, it was almost inevitable the service would play some part in the discussion. The longevity and strength of the participant researcher relationship was an important consideration in the planning of the research, with trust been identified as particularly important when attempting to engage into research people who are socially excluded (Emmel, et al., 2007; Mcdermid, et al., 2014). Opinion is divided as to the value of day services (Bryant et al., 2010) and participants in this research seem to agree with the supporters, reporting that the connection to people, and the things they had made or bought at the service mattered. Two participants had taken photographs of staff members and were unequivocal about just how much they mattered

> *“...she's an amazing person... I justfeel happier...She's an amazing lady.”*

Angie talked about a bird table she had made at the service and how much it mattered, but she also reflected on the fact that the staff member had done most of the work, valuable feedback about the tension between ‘doing with’ and ‘doing for.’ The former providing opportunities for chit-chat, fostering confidence, building skills, and strengthening relationships, the latter potentially undermining these and fostering helplessness and dependency. Thus, photovoice provided Angie with the opportunity to engage in genuine service evaluation.

If the cornerstone of recovery is the voice of service users, then it could be argued that condemning day services is in direct conflict with service user wishes and voice (Beresford & Bryant, 2008) as Mike leaves us in doubt as to how much the service matters to him.

> *“I love it, I love going there, it’s the people, it’s the people.”*

This view echoes those reported in the recent government inquiry that people want resources to move from DHB's to community where people can stay connected, while receiving the help and support they need (*He Ara Oranga*, 2018). Reflecting on a capabilities approach to achieving wellbeing, we need to consider not only a person's level of functioning but their opportunities for realizing them, opportunities that can be restricted by many factors including stigma and a person's socio-economic environment (Sylvester, 2011). Day centres can play a vital part in increasing opportunities by providing place, and resources for being and doing, promoting the characteristics of CHIME for personal recovery and wellbeing. Susan and Angie had photographed things made or bought at the service, highlighting how opportunities and resources impacted on home life. Mike used the opportunity to ask for practical help and Peter recognised the value of our relationship by continuing the dialogue in the weeks following bringing things he knew would be of interest to me. In this way participants used photovoice as a tool to articulate what is important to them about the service and provide feedback for evaluation and development. Given people with SMI who attend day services, may potentially be overwhelmed by illness, and unable to 'recover from' (Davidson & Roe, 2007) photovoice could be developed as a method for engaging them in genuine partnerships. Further investigation could consider if such engagement would facilitate a cycle of empowerment, hope, independence, and recovery as suggested in the literature (Lloyd, et al., 2014).

Who Do I Love?

Connection is well documented as an important part of recovery (Leamy et al., 2011; Williams et al., 2012) and maintaining mental health (Jody et al., 2008). A study of service user views reported that recovery was only possible in the presence of 'kindership': when other human beings — friends, family, and staff— care about you (Cheng et al., 2009). The findings in this project align with this as all participants had taken photos of family, friends (including cats) and staff that were important to them.

However, it is also well documented that people living with SMI have fewer social relationships, other than family, outside of services (Andonian, 2010). The reasons for this include symptoms and effects of illness creating difficulties such as anhedonia, or social anxiety, stigma and self-stigma and practical considerations such as transport and cost (Andonian, 2010; Davidson, et al., 2004) all impeding opportunities for connection.

One participant talked about loneliness, which is not about the number of people in a person's life but the need to feel you are sharing something with the other person that is meaningful to you both, that you are ‘in it together.’ (Cacioppo, p.83. cited by Hari, 2018). People may belong to and participate in social groups and activities yet still feel loneliness (Meltzer et al., 2013). Loneliness, therefore, is not the physical absence of others but the sense that you do not share anything that matters with anyone else (Cacioppo, p. 83. cited by Hari, 2018). This concept of giving and receiving support and reciprocity in relationships has been discussed in the recovery literature and highlighted as an important aspect of recovery, decreasing social isolation, and increasing self-worth (Petros et al., 2016).

Angie shows reciprocal caring sharing her concern about her sister’s health and the plight of her friend who she supports by listening and expressing empathy about her daughter’s situation. She also provides practical support to her neighbour by babysitting. Susan talks frequently about caring for her partner and her cats and asks about going to visit a friend in hospital.

> *“I don't see Shirley very much and it's sad to know that she's up there all the time, it would be nice if we could go and see her one day if she's well.”*

The concept of reciprocity is pertinent when considering that two of the participants had taken photographs of staff at three different services. The essence of a professional relationship is meeting the needs of the service user and does not readily allow the opportunity for reciprocity. Service users need to be supported to develop opportunities within services and the wider community that provide an opportunity for reciprocity. When discussing the theme ‘What Do I Do’, participants appeared to appreciate the opportunity to share or reciprocate dissemination of knowledge. The motivation to engage in this study was seemingly driven by a desire to reciprocate or give something back as all participants said they did so for me and Peter demonstrated it further by bringing his plate collection for me to photograph.

Loneliness and Barriers to Inclusion

In New Zealand, one in three adults report feeling lonely some of the time, and 77% of people with SMI experience loneliness and social isolation (O’Hagan, 2017; Badcock, 2016). Loneliness and disconnection create an aversive state with feelings of insecurity linking directly to anxiety (Cacioppo, p.78 cited by Hari, 2018). In a photovoice study Erdner, Andersson, Magnusson, and Lutzen (2009) described ‘existential loneliness’ due to a lack of personal contacts creating mistrust in others and exacerbating symptoms of illness. In New Zealand, the strong association between rates of loneliness, mental health and socioeconomic status is recognised in the LSF (The Treasury, NZ 2019). While short term loneliness may act as a catalyst driving people to make changes, prolonged loneliness is recognised as detrimental to health (Mann et al., 2017; He Ara Oranga, 2018). Reported detrimental effects are multiple and include loss of pleasure, disordered thoughts, and impairment of cognitive functions (Badcock, 2016). Feelings of loneliness prevent people from being able to appreciate themselves (e.g. negative self-concept) and contribute to mental illness (Panazzola & Leipert, 2013). Loneliness and social isolation also impact negatively on physical health both directly and indirectly due to increased levels of inactivity and smoking (Shankar, et al.,2011). Only one participant discussed loneliness, possibly due to the stigma associated with it creating a reluctance of people to report it (Mann et al., 2017) but all participants discussed barriers to inclusion. Given such reported prevalence and such far-reaching negative implications, loneliness and social isolation are worthy of attention for those working with people with mental illness.

Individual interventions may address cognitive and social skills, and individuals may develop strategies to manage loneliness, "*.... it can get lonely, but I just go and go do something like go and clean something to take my mind off things....*" but systemic barriers to participation also need to be explored. Susan values her relationship with her friend Shirley, who lives in a hospital based rehabilitation house but clearly needs assistance with the practicalities of maintaining their relationship *" ...So could maybe arrange with the staff to go and visit her again one day that would be good."* Poverty plays an important role in assisting or impeding relationship building and failing to recognise this means social withdrawal is often interpreted as a symptom of SMI (Topor, et al., 2016). Both Angie and Peter point to financial constraints limiting opportunities for inclusion, Peter talking about the escalating cost of golf club membership and Angie the cost of Sky TV and getting to live sports games.

Many programmes and interventions are developing in the general population across various communities to address loneliness, but to date, there is a paucity of research to support them (Mann et al., 2017). 'Campaign to End Loneliness (UK)' aims to 'inspire everyone to connect and bring communities together' suggesting a collective rather than individual problem and solution. However, in a meta-analysis of interventions to reduce loneliness those targeting maladaptive social cognitions such as addressing negative thoughts and stress management proved to be more effective than those focusing on increasing social interaction or social support (Masi et al., 2006 cited by Meltzer et al., 2013). According to Mann et al., (2017) there is no clear ownership of the problem and professionals working in this area need to recognise the role of the individual, the community and society. The intersectionality of loneliness, social support, housing, income levels and transport along societal attitudes and education is well documented (Mann et al., 2017; Stephens, et al., 2010) and therefore, multiple approaches and interventions are required.

Peer Support

Peer support workers (PSW) may be well placed to facilitate social inclusion offering support networks for socialisation and friendship, using their own experiences to provide information, emotional support, and putting things into perspective (Cabassa et al., 2013). The value of peer support and its role in recovery is well documented, with peers been seen to have higher levels of trust and credibility than health care professionals (Cheng et al., 2009: Cabassa et al., 2013: He Ara Oranga, 2018). In studies participants have described PSWs as people who 'have been there,' 'have walked in the same path,' and have 'street knowledge' (Cabassa et al., 2013), claiming that this lived experience helps in recovery, by enabling them to be 'teachers' and 'philosophers' (Cheng et al., 2009). CHIME acknowledges the part these 'inspiring' relationships have in building hope and optimism about the future (Leamy et al., 2011). Mike seems to concur when he describes fran, the PSW as "*... an amazing person...*" Susan invites Fran to the interview sharing knowledge with her, seeking her approval and opinion, and asking about her own experiences with services.

Considering the role of PSW in an acute inpatient unit Lloyd, et al., (2017) suggest that including PSW in assessment, individual and group work, and discharge planning provides opportunity for occupational therapists to affect change towards recovery orientated services. Findings in this project suggest they also have a valuable part to play in day services.

Hopes and Dreams

Hope is defined as the expectation or desire for positive events in the future (Hayes, et al., 2017) and is considered essential to recovery (Schrank, et al., 2012) promoting overall wellbeing and quality of life (Young & Ensing, 1999). The more meaning, hope, and sense of direction that someone has the more likely they are to problem solve, plan and be an active participant in their recovery (Buckley-Walker, et al., 2010). Hope is directly related to having control over our own destiny, and when people do not feel in control, they lack hope (Chandler cited by Hari, 2018. p.137). Little is known about the determinants of hope and strategies or interventions to improve them (Schrank et al., 2012).

Due to a lack of symptom control, some people with SMI have lower levels of hope than the general population, making recovery difficult, which has implications for the amount and types of support offered to them and their families (Hayes, et al., 2017). Many recovery models fail to acknowledge this implying that recovery can be achieved and by implication that hope can be restored independent of the level of symptoms an individual experiences (Hayes et al., 2017).

Very little reference was made to hope and future self during these interviews other than aspirations that were beyond the control of the individual such as winning lotto, living in the house on the hill, or going on trips organised by services. Even '*payday when we get our smokes*' is beyond Susan's control. We cannot assume the absence of presence of hope, without further investigation. It could be the interpretation of the question did not lead people to include hope or the future, or as Peter observed it could be that,

> *"When people live hand to mouth, they can't see further than next week"*

This would resonate perhaps with the belief that an individual's reality and socio-political environments may make hope unattainable, and that interventions aimed at building effort, positive attitude, and a commitment to a better future fail to acknowledge this (Thomas & Knight, 2018).

> *"While leaving people under-resourced, we promise the panacea of hope."*
>
> (Cheng et al., 2009)

Acknowledging the importance of hope in recovery Schrank et al., (2012) completed a systematic review of the literature, suggesting that interventions worthy of further consideration to improve hope centre around, illness management, relationships, peer support, self-directed realistic goals, and increased self-esteem and efficacy. These individual interventions fail to acknowledge the fact that the recovery movement was borne out of service users feeling disempowered in the face of omnipotent services, and that a recent government inquiry (He Ara Oranga, 2018) into these services concludes that little has changed. The assumption that hope, or lack of, can be accredited to an individual without considering the wider socio-political environment needs challenging, with further investigation into the factors that nurture or impede hope for people living with SMI is required.

Summary

By engaging with long term mental health service users this research attempted to discover what matters and view the results through the lens of the conceptual framework CHIME. Participants verified that connection to others, including staff members, past and present, was important to them. Underlying this was a suggestion of loneliness, and limited opportunities for social inclusion due to systemic barriers. The presence of hope was lacking, but the reasons for this would need further exploration. Contrary to the literature participants were not overwhelmed by a negative illness identity and expressed multiple positive identities. The day service and home provided opportunities for meaningful activity although limited options and the solitary nature of the activities engaged in at home is perhaps concerning and requires further investigation. Participants conveyed a sense of empowerment and determination in their everyday life, but also talked of situations over which they had little control.

Some findings lay outside the framework of CHIME. All participants indicated that home was important to them, which the literature acknowledges as imperative to providing a base from which to develop or recover. Building a home and housing security like the components of CHIME all need to be considered in the wider socioeconomic environment in which a person lives. Perhaps these results align with the suggestion that CHIME could be improved by the addition of Difficulties (CHIME-D) to remind those working with people in recovery of the difficult realities of their lives (Stuart et al., 2017).

Implications for Practice

Occupational therapists working in mental health, need to recognise the importance of place and 'being in place' especially home as a platform from which to engage in recovery, and recognise homemaking as a meaningful activity. By working with service users to engage in meaningful occupations, occupational therapists can facilitate recovery through developing the characteristics of CHIME. However, it is important to recognise the limitations of engagement in occupations within a service environment and occupational therapists need to work with people in recovery to explore barriers to inclusion, engaging with family and communities to address these limitations.

The occupational therapy concept of 'doing with' is useful for collecting stories in chit-chat, stories that are valuable for developing a sense of self, positive identities, sharing knowledge, and building narrative cohesion, aiding an individual’s recovery. However, this process needs to be done over time, and requires the skills and awareness necessary to maximise an individual’s narrative agency and counter meta narratives. Photovoice or elicitation can be an effective tool in for engaging people with SMI, providing opportunity for narrative agency and building narrative identity cohesion.

By acknowledging lived experience and the limitations of professional knowing occupational therapists can play a critical role in supporting and advocating for service user voice and the role of PSW in providing recovery-focused services. This may require therapists to explore methods such as photovoice to enable those most vulnerable to find their voice, be given a platform to use it, strengthening partnerships and informing service evaluation and development.

Occupational therapists need to be mindful that while adhering to a client-centred approach means they will inevitably incorporate recovery into practice, service provider and role expectations may compromise the extent to which this can truly be achieved.

Finally, participants illustrated ‘doing’ is important but also illustrated barriers to increasing their opportunities for ‘doing’. Occupational therapists can utilise frameworks such as Capabilities Approach (CA), Pan Occupational Paradigm (POP), and Occupational Perspectives on Health (OPH), to advocate for occupational justice, and the role it plays in wellbeing articulating meaningful doing as a right not a treatment or intervention.

Future Research

Further research could explore any number of issues highlighted in this project, for example, barriers to inclusion, reciprocal relationships and how professionals promote or impede them, or the role occupational therapists can play in promoting service user voice. Utilising POP research into occupational justice and the right to meaningful doing, could provide valuable insights into the future possibilities for occupational therapy as policy moves from deficit to wellbeing. Further research could also consider occupational therapy and recovery in the context of the socioeconomic environment that impacts on wellbeing, questioning hope, and the individualistic approach to services. Photovoice as a tool in participatory action research (PAR) would create a cycle of participation and action making it ideal for evaluating and informing change, in areas such as developing services, building community involvement, and engaging peer support.

Limitations

This research engaged four participants to explore and understand their experience of what matters. The small sample size selected from one day-based service where participants attend severely restricts transferability of findings. Being the manager of the service and having considerable prior knowledge about the participants the brings into question impartiality. However, the strength and longevity of the research participant relationship created the trust required to ensure full engagement and honest reporting and dialogue. As a Masters' project, this was the first time I had engaged in research increasing the likelihood of oversights or misinterpretation. Both these issues were addressed through a reflexive journal, documented decision making and supervision.

Chapter Six : Conclusion

Recovery demands that the lived experience of illness is respected and that people, not professionals are the experts in their own life. This requires that the voices of those accessing services are heard and services are built and delivered on partnerships between professionals and service users. The recent report into mental health and addictions was unequivocal in its findings that despite the long-held expectation for recovery services, a biomedical approach remains dominant, and service users feel powerless (He Ara Oranga, 2018).

This project 'What Matters to Me?' set out to discover what matters to people with SMI who attend day services and aimed to create space for this 'difficult to engage' group and add to the body of knowledge to inform how service users and professional can partner to build recovery services.

Photovoice provided participants with the opportunity to lead the dialogue in semi-structured interviews where photographs were considered at a pace and order dictated by them. Commonly photographs were a direct representation of what matters, such as a photo of a friend, home, or the neighbours letterbox. Other times gentle prompts and questions allowed further exploration of issues, and dialogue moved away from the photographs. For example, three participants talked about past employment, but no one had taken any photos to represent this experience in their past.

Identity is believed to be at the centre of the recovery experience, with literature suggesting that for people who access services an illness identity is dominant. Recovery then, involves people rebuilding positive identities. All participants talked of the things they do that have meaning to them and used storytelling, sharing, and chit-chat to reveal multiple positive identities. A sports fanatic, a sibling, an animal lover, a TV addict, so much more than a service user, aspects of a life journey, some aspects to share, some quite deliberately sealed in the past. Whether these identities are created by 'telling' or 'doing' or a combination of both we may never know, but occupational therapists working in mental health have a role to play in exploring opportunities for meaningful doing and in gathering stories and helping people make meaning from them.

From American politics to the captain of the Silver Ferns, from feeding the cat to walking the streets, ways of 'doing' and 'being' were evident. To maintain wellbeing people, need opportunities of doing that offer, choice, meaning, satisfaction, and achievement. Opportunities are extended or diminished by factors such as, income, gender, stigma, and literacy skills. While participants in this project gave insight into what they do there was a solitary nature to many of these activities and the barriers that exist to developing new occupations, especially ones that facilitate connection, were also referred to throughout the discussion.

Love, friendship, family, belonging, however we choose to label or define them does not detract from the overwhelming evidence as to the value of connection reported by participants. However, how we measure connection does matter, as it is the quality, meaning and reciprocity of those connections or relationships that count.

The findings were considered through the conceptual framework CHIME and while some of the characteristics of CHIME were revealed discrepancies were also evident. Services and our approach to mental health, including recovery, continue to view health and wellbeing from an individual stance. It, therefore, comes as no surprise that we continue to fail to acknowledge the part housing or other socio- environmental factors have on health. Home or 'being in place' was a strong theme, and while the connection between mental health and the social environment is recognised (He Ara Oranga, 2018; Reid & Alonso, 2018) there seems to be a disconnect between literature that proves this and services. Services reinforce individualistic responsibility perpetuating the notion that individuals are themselves responsible for their situation and wellbeing, neglecting the importance of social, political, and economic context (Thomas & Knight, 2018). If we continue to seek and promote individual recovery while neglecting the impact of socio-political factors, we will continue to fail those we are tasked with assisting.

Current systems may restrict the role of occupational therapists working with people in recovery to focusing on individual solutions, and productive doing. 'It is the occupation of governments to develop policies that drive occupation within populations' (Wilcock & Hocking 2015. p. 148), and as meaningful doing is a vital component of wellbeing, occupational therapists must advocate for occupational justice. Access to meaningful doing is no longer a treatment but a human right. Occupational therapists have the skills to work with communities to help people build reciprocal relationships, increase opportunities for meaningful doing, and foster hope. Working to achieve these may conflict with the socio-political environment and the expectations of the organisations who employ them (Frantse & Kerns, 2007 cited by Buckley-Walker, et al., 2010) necessitating systemic change. Systemic change is critical because systems don't care, people do and it's time to put human back into human services (Deegan, 2017).

Personal Reflection

Reflecting on the research

> *"All Kiwis want is someone to love, somewhere to live,*
> *somewhere to work, and something to hope for."*
>
> Norman Kirk, New Zealand Prime Minister 1972-1974

In my introduction I boldly concluded that people who attend A Place to Be Me look for nothing other than acceptance and kindness. Over all participants confirmed this portraying a life of meaning, shared with people they love, and demanding little, if anything, in return. However, I see how the socio-economic environment maintains a reliance on services, and limits among other things, opportunities for meaningful doing and building reciprocal relationship. Throughout this project, as participants talked about home, relationships and doing, Norman Kirk's words returned to me often. I believe they still resonate today and align well with occupational therapy values and philosophy.

Occupational therapists need to help people in recovery build genuine reciprocal relationships, including re-examining and redefining our own professional relationships. We must challenge discrimination and help create communities where care and compassion flourish. While we cannot build houses for everyone experiencing homelessness, or housing insecurity, occupational therapists can recognise the necessity of home as a platform for recovery and facilitate homemaking as a legitimate activity with meaning and purpose. We can broaden the concept of work, challenging the notion that value and contribution in society is synonymous with productivity and advocate for access to meaningful doing in a bid to address occupational injustice. We must recognise the importance of hope, and point to the socioeconomic environment that stymies hope, acknowledging that for some people intolerable living conditions are a reality and mental distress a legitimate and valid human reaction.

So occupational therapists working with people in recovery might do well to consider that, all Kiwis want is someone to love, a place to call home, something meaningful to do, and something to hope for.

Reflecting on my professional journey

I became an occupational therapist more than 30 years ago due to my joy of doing and a desire to share this joy. When I started work, I quickly realised that like people with SMI occupational therapy was struggling with stories others told about us, stories of baskets and bunnies. The profession worked hard to counter this identity, focusing on quality of life, independence and productivity, meaningful doing got left behind.

Sixteen years ago, when I accepted a job at A Place to Be Me, doing was at the centre of the service, yet while the content looked tolerable the delivery was not. Institutional life was evident everywhere, the staff were omnipotent, the doing prescriptive rather than meaningful, and the service users compliant. I embarked upon a journey of change, and with a limited understanding of recovery, I simply did what felt right. I had never heard of Pat Deegan yet somehow, I knew she was right, "*recovery is rooted in the simple yet profound realisation that people who have been diagnosed with a mental illness are human beings*" (Deegan, 1996. p.92).

One sunny day in those early years we were sitting outside when Tony looked at a dent in the back of my car and told me to buy some black matt paint. The following week he turned up with the tools of the trade and began work eliminating that dent. A small group gathered around to watch him work and share stories of crashes, dents, and love affairs with cars. I knew I was taking a risk, crossing professional and ethical boundaries, but I did it anyway. A few weeks later when all evidence of the dent was gone, Tony's mana[4] continued to thrive.

As my understanding of recovery grew and we continued to collect and share experiences and affect change we quietly began weaving our stories together. While some people were there at the start, others joined later or passed through weaving their threads into our collective journey. When I started this project, it was to document our journey, and to weave a final thread about facilitating the voices of those living with SMI. What I discovered was the magnitude of building meaningful long-term relationships with people with SMI if we are to be allowed the privilege of hearing their voices and weaving our stories together. Voices are present if we create the space for them, and photovoice proved a useful tool to facilitate this, but I wonder about its value without trust borne of longevity. All four participants engaged fully and actively, all four participants said they did so for me.

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[4] Respect, authority, presence, or prestige

Reflecting on those sixteen years, I see all the things I did, the decisions I made and the risks I took make sense. I was sharing responsibility and building reciprocal relationships. I realise now that reciprocity is fundamental, both the foundation and an integral part of recovery. Tony died a few years ago, and I am proud of the decision I made. I share with you his narrative of a kind considerate man, and skilled panel beater, defining him as much more than a service user. We are indeed the stories we tell, and the stories others tell about us, stories that can extend beyond the grave. Occupational therapists are well placed for collecting these stories when doing with and facilitating those living with SMI to build narrative cohesion and positive identities.

I realised that my rudimentary belief as a neophyte is at least partly true, there is joy in meaningful doing, but more than that, meaningful doing is a necessity and a right. Completing this project has given me the knowledge and the language to articulate and champion meaningful doing, reciprocal relationships, and the need for empowering and resourcing communities. More importantly it has proven the power of service user voice and owning our own narrative. And yes, I did learn basket weaving at OT School but that does not make me a basket weaver.

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OTAGO
POLYTECHNIC
Te Kura Matatini ki Otago

4 October 2019

Louise Roberts
c/- School of Occupational Therapy
Otago Polytechnic
Dunedin 9054

Dear Louise

Re: Application for Ethics Consent

Reference Number: 826
Application Title: *What Matters to me?*

Thank you for your application for ethics approval for this research project.

This letter is to advise that the Otago Polytechnic Research Ethics Committee review panel has approved your application, following the minor amendments made in response to feedback.

We wish you well with your work and remind you that at the conclusion of your research to send a brief report with findings and/or conclusions to the Ethics Committee.

All correspondence regarding this application should include the project title and reference number assigned to it.

This protocol covers the following researchers: Louise Roberts, Rita Robinson, Mary Butler.

Regards

Richard Humphrey

Richard Humphrey
Vice-Chair, Otago Polytechnic Research Ethics Committee

Appendix 2 : Participant Information Sheet 1

For more information please contact
Louise Roberts 027 686 9866
louiser@psotago.org.nz

Dear

This sheet contains important information about the research project "What Matters to Me?" that you are invited to participate in.

The project will be carried out by Louise Roberts, Occupational Therapist, as part of study towards a Master of Occupational Therapy at Otago Polytechnic (OP), with oversight from Rita Robinson and Mary Butler OP.

Ethics approval has been granted by the ethics committee at OP and Presbyterian Support Otago ethics committee.

Please read the information carefully, ask questions and take time to consider whether you wish to take part.

The recent government inquiry into mental health and addictions was established to consider how to promote mental health and wellbeing for everyone. Among the nine recommendations it made was the need to place people who use services at the centre of care and decision making, this means finding ways to allow their voices to be strengthened and heard.

While this might sound easy, identifying what is important to you and having the language and courage to speak up can be very difficult. This project has been designed to help people begin to identify and verbalise what really matters to them.

Photovoice is the research method used and everyone who chooses to be involved will be issued with a disposable camera and asked to take photographs that represent "What mattes to me?" Cameras will be returned when full or at the end of a two-week period.

Two sets of photographs will be developed, one set is yours to keep and the other is for the research project. You will be the first person to see the photographs and you will be given the opportunity to remove any that you wish for whatever reason.

You will then meet with Louise to discuss the photographs you have taken; this meeting will be recorded. Later you will be asked to join a small group of up to four members to share ideas and photographs that you choose to. This discussion will be recorded and then written about. Louise will be at this group and at the beginning we will talk about respecting each person's views and about confidentially.

You will have full access to the discussions, results, writing and your own photographs. Remember you will not be in the photographs so it will not be possible for people to identify you from them although it may be possible that you can be identified by the photographs you to take. You will be given the opportunity to remove photos when they are printed, and you can withdraw entirely at any stage up until write up without giving a reason if you wish. The research will be written up and some of the things you say could be available publicly, such as in articles or essays, but you can choose a different name for the write up of the project so you cannot be identified in any writing.

Taking photographs of people and places will be discussed in greater detail at the start of the project. If it is something you wish to do you will need to ask permission, explain what it is for, and ask them to sign a consent form. We will discuss this further if you join the research.

It is important that you understand taking part is completely voluntary and has no impact on your continued attendance or services you receive at Presbyterian Support.

Should you choose to participate your safety and wellbeing is important to me, therefore I will be available to answer questions or discuss should you need and will assist you to access further supports if necessary.

Appendix 3 : Participant Information Sheet 2

For more information please contact
Louise Roberts 027 686 9866
louiser@psotago.org.nz

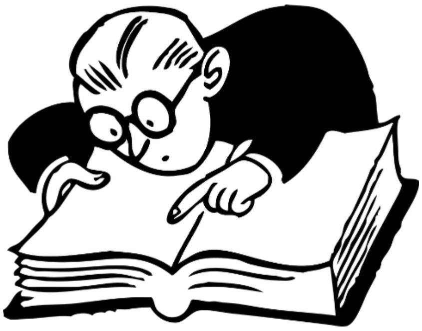
I can choose whether to do this

I take photographs of "what matters to me"

I will talk to Louise about my photos

I can remove photos that I don't like

Louise will write about the things I said



I can look at the photos and the writing about my photos

Appendix 4 : Consent to participate

For more information please contact
Louise Roberts 027 686 9866
louiser@psotago.org.nz

Participant Consent Form

- I have read or listened to the explanation on the information sheet and I understand what is involved.
- I have been given the opportunity to ask questions.
- I am choosing to do this; I do not have to if I don't want to.
- I understand that some photographs of my community and homelife may reveal my identity even if I am not pictured in them, and that such photographs may be used for publication or presentation.
- However, I also understand that I can remove any of my photographs if I want to.
- I know that I can change my mind at any time until 2 days after I get my photographs and talk about them.
- I know that when I talk about my photographs it will be recorded.
- I know that I will be asked to meet with Louise and other people at 'A Place to Be Me' who are doing this to talk about some of the photographs.
- I can choose a secret name for the project so people who see it will not know it is me.
- I know that the photographs and interviews will be kept securely at Otago Polytechnic for seven years before they are destroyed.

Name________________________________

Signed_______________________________

Date_________________________________

Appendix 5 : Consent to take a photograph

For more information please contact
Louise Roberts 027 686 9866
louiser@psotago.org.nz

Consent for taking and using my picture

I consent to be photographed by ____________________________ as part of a research project "What Matters to me?"

I understand that

- This research will be carried out by Louise Roberts as part of her study towards a Master of Occupational Therapy at Otago Polytechnic (OP).
- That ethics approval has been granted.
- ________________________ will be given one copy of the photograph to keep.
- A second copy will be used as part of an interview for the research.
- The photograph will not be used in publications, presentations or displays without further consent.
- My name will not be used in the project.
- On completion of the research the photograph will be stored at OP for seven years before been destroyed.
- I can contact Louise Roberts at Presbyterian Support Otago, or on 027 686 9866 to view the photograph or for further information.

Name ____________________________________

Signed ______________________________ Date _________________

Contact details ____

Appendix 6 : Member Checking Questions

Member checking questions

1. When you talked about your furniture/garden/workshop/ curtains I understood that your home and looking after it is important, yes?
2. The things that you do, walking/sport/watching TV are meaningful to you?
3. You told me that the people in your life are important to you, is that correct?

3a. You talked about caring for other people and cats, what does this mean for you?

4. When you shared with me stories from your past you were telling me who you are/how you want to be known?
5. We talked about work, but I didn't feel that you attached much importance to it other than enabling you to save money/meeting people. Would that be correct?
6. You shared a lot of knowledge with me about......was it important to you to share this? Did you want me to know what you knew; did you enjoy sharing this knowledge?
7. You occasionally used the photos to change the conversation, are somethings better left in the past?
8. You talked about your health; do you see this as a big part of who you are?
9. You expressed concern about the quality of your photos, why did this matter to you?
10. You did not talk much about your plans or hopes for the future, was there a reason for this?

Appendix 7 : Letter to Office of the Kaitohutohu Māori Research Consultation

Kia ora koutou,

As a member of the post graduate school I have submitted an ethics application for research focusing on the voice of long-term mental health service users, voices that over time have become lost or unheard. I plan to use Photovoice to ask members of a day service provided by Presbyterian Support Otago for long term service users in Dunedin, “What Matters to me?”

Photovoice was developed by Wang in 1998 and has since been used successfully as a research method to give voice to groups who are marginalised.

I would like to ensure that my research plan is sensitive, beneficial, and relevant to Māori and I have considered Māori models of health care and the how these relate to mental health recovery. I have also considered MāoriVoice (Mark and Boulton 2017), which explores how Photovoice can be adapted to better meet the cultural needs of Māori, and I have consulted with the cultural advisor at Presbyterian Support Otago.

We would now like to consult with the rūnaka as part of this application process and look forward to discussing this further and participating with you in this consultation process.

A copy of our ethics application is attached.

Nga mihi,

Louise Roberts
Rita Robinson

Appendix 8 : Response from Office of the Kaitohutohu Māori Research Consultation

Whāia te pae tawhiti kia tata. Whāia to pae kiā maua.
Persue the distant horizons so that they may become your reality.

Office of the Kaitohutohu Māori Research Consultation Feedback

Date: 6 November 2019
Researcher name: Louise Roberts
Department: Occupational Therapy
Project title: What matters to me.

TAIAO: Achieving environmental sustainability through Iwi & Hapū relationships with the whenua & moana	
Mātauraka Māori: Exploring Indigenous knowledge	
Hauora: Improving health & wellbeing	The applicant has undertaken a literature scan of how her research topic links with Māori-voice and cultural practices. She also is working in consultation with the Presbyterian Support Otago cultural adviser. Her research design is aimed to highlight Māori voice, enable te reo Māori to be used, appropriate feed back loops and whānau tautoko. You may wish to consider how you could disseminate this information in a way that reaches your target audience, including iwi. An invitation to the four local rūnaka may be one way to approach this. We wish you all the best with your research Louise.
To Live as Māori: Kaitiakitaka to ensure Māori culture and language flourish	

Unlocking the innovation potential of Māori knowledge, resources and people.

Name: Kelli Te Maihāroa

Position: Tumuaki: Rakahau Māori | Director: Māori Research, Otago Polytechnic