Hope Surfacing: An investigation into documentary modes for telling the stories of families who support a family member who has experienced mental distress

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This thesis (an artefact DVD and exegesis) is submitted to
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Abstract

This work is a creative production PhD project that consists of a documentary artefact and an exegesis. The documentary project entailed investigating ways to create a process of working ethically with sensitive material and in doing so has integrated two significant inquiries. The first relates to the designing of protocols for working ethically with sensitive material and vulnerable people.

The second is the design of a documentary called *Hope*, that captures the stories of six families who are supporting a family member with a mental illness. This situation can leave such families isolated, under stress and often experiencing stigma and discrimination. Because very little training is available to families in these circumstances, the documentary captures personal narratives so that certain issues in common can be identified. This is achieved while simultaneously acknowledging the unique and authentic nature of individual family experience.

The result is that these stories contain information about caregiving that is seldom discussed and in so doing the documentary provides observations that can be of assistance to others.

Acknowledgements

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[1] Auckland District Health Board
[2] Waitemata District Health Board

Services, Maraingi Bay) for their support and encouragement.

I am indebted to many professionals in completing this artefact and exegesis.

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The poem extract that forms part of the title sequence on the documentary is from the poem *Hope* by Emily Dickinson.[3]

Finally, I would like to thank the AUT University, School of Education, the School of Communication Studies research committee, and Television and Screen Studies for support with production and post-production resources used in the development of my documentary and this exegesis.

Ethical approval

This research was subject to AUT University ethics approval granted by the Auckland University of Technology Ethics Committee (AUTEC) on 17th September 2010.

Ethics Approval Number: 10/170
All research was conducted in keeping with the regulations and guidelines of the approval.

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[3] The Poems of Emily Dickinson: Reading edition, Ralph W. Franklin, ed., Cambridge, Mass.: The Belknap Press of Harvard University Press, Copyright ©1998, 1999 by the President and Fellows of Harvard College. Copyright ©1959, 1955, 1979, 1983 by the President and Fellows of Harvard College.

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All images are those of the author unless otherwise indicated.

Attestation of Authorship

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

Eileen Lavranos

Date

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Chapter 1: Introduction

This chapter introduces the project and in doing so it discusses:

- My motivation and interest in mental health issues
- Positioning myself as the researcher
- Thesis structure
- Exegesis
- The project.

When loved ones become mentally distressed and are diagnosed with mental illnesses it is devastating for their families. People seldom speak about mental illness and families become isolated and withdrawn, fearing stigma and discrimination when disclosing their circumstances. I became interested in mental health issues when my son, then aged 17 became unwell, was admitted to a psychiatric hospital for observation and was later diagnosed with schizophrenia. The family was given some generic information about medications that were available and their side effects, but medical staff were reluctant to discuss outcomes. Friends, on hearing that our son was ill, were disbelieving and empathetic but could offer little support or help. Their reactions and my family's experiences constituted the inception of this research project.

The thesis is about storytelling using documentary modes, capturing authentic narratives about human experience, and using stories as a way to inform others. It has involved collecting sensitive stories and using them in ethical ways to create a documentary artefact.

Initial exposures

Finding out about mental illness was difficult. No one spoke about it. I recalled how in South Africa, a good friend whom I saw regularly, had been diagnosed with bi-polar disorder. She was a high school teacher and we visited one another frequently with our children. One day her husband rang me up from work and asked me to stay with her during the day because she was unwell, and couldn't be alone. She was very disturbed, repeating over and over how people in the street shouted out and called her names in the night. After a short hospital stay she was well again but she and her husband never

discussed the episode. Years passed and she continued teaching history. Looking back on those times it seemed she managed her situation well. But I often wondered why they didn't feel confident speaking about it.

I realise in retrospect that if I had had the vision and knowledge of what my friend and her family were experiencing in the long term, I might have been of far greater assistance to them and our friendship would have been enriched. There are benefits to hearing how other people manage their situations and sharing experiences can help everyone involved. It is not a question of gossip but of touching the emotions of another. Alice Walker (2005, p. 223) described it this way:

> It is from our stories that we will remake the world. Also, there is an easy distrust of 'information'. There is too much of it. Knowledge supplies the facts, stories give sensation to the heart.

The professional realm

Most of my experience as a professional and independent filmmaker has been in making programmes for television. I have worked in drama, documentary and other non-fiction forms and had explored ways of storytelling using this medium. But television work is driven by budgets, tight timeframes and production standards acceptable to the paying client; the broadcaster. This allows little time for reflection. As Horrocks and Perry (2004) have noted, broadcasters in competing commercial situations tend to push the boundaries and create controversy in their storytelling to make sure programmes score high on ratings. The more provocative the story, the higher the ratings.

However, Rabiger (2009) suggested that documentary directors, if they invest time in significant research, may get close to a subject and be able to portray something of the "quality and justice of human life" (p. 4). Also by viewing an issue in an unusual way, an audience may be invited to confront the subject matter from a unique perspective. This may influence them to change their attitudes or act on a concern they may have hitherto dismissed. As most compelling stories about human activity centre on development, in watching people struggle with some dilemma an audience can be left with some feeling of hope in humanity.

Before beginning this project, it seemed to me that few documentaries existed on mental illness, perhaps because people are reluctant to speak about it, and hearing about it is not a subject that many wish to pursue.

Support and insight

Because of my son's illness, attending support groups for families caring for mentally ill members became a regular occurrence for me, and I started to learn from other people's situations. Invited speakers to these groups would discuss valuable information on specific issues, but I also heard and learned from families about information related to problems, fears, coping with stress, legal matters and how to handle difficult situations. These were all relevant issues but families in these circumstances had little experience of recovery and most were coping with the here and now, while wondering fearfully about the future. Stories about recovery were seldom if ever mentioned.

Reading about mental illness was informative, but I needed to know how families reacted and how they managed situations. I reached a turning point in my attempts to understand the nature of mental illness when I was introduced to a middle aged man who was living with schizophrenia. He had become ill in his early thirties but had recently studied for a qualification in health sciences, got married and was working in the health services in peer support. I am indebted to him for sharing his story with me because it changed my understanding and gave me hope. He had fought with the mental health system for years and one day he had what he described as a religious "epiphany" that changed his attitude. From that day he had moved forward. He began to engage with the mental health services, and as his recovery progressed he increasingly interacted with people, became less isolated, made friendships and met his wife, a social worker. The inspiration of his story was that it showed that people's situations can change and improve with support and if they have the motivation.

It seemed that if people diagnosed with schizophrenia (one of the most debilitating mental illnesses), receive good assistance and on going clinical support then they can improve their situations. Harding and Zahniser (1994, p. 140) suggested:

> …worldwide data shows over more than 50 per cent of patients
> significantly improve or recover. We will be there to walk with you on this

journey toward recovery. This new message keeps a small spark of hope alive. Hope provides the self-healing capacity inherent in any recovery process for any illness.

DeSisto, Harding, McCormick, Ashikaga and Brooks (1995), in comparing long-term rehabilitation over three decades in Maine and Vermont, have shown that with supported community life, those labelled with schizophrenia can become rehabilitated. In Vermont the rehabilitation strategies have included providing community residences, work options and effective case management, with support focused primarily on maintaining a continuity of care.

A number of personal stories I encountered at this time also confirmed that people could make a recovery from severe mental distress. Saks (2007) described her experiences of becoming ill with schizophrenia while studying at Oxford. She subsequently returned to the United States of America, graduated from Yale and became a Professor of Law, Psychology, Psychiatry and Behavioural Sciences at the University of Southern California. In contrast Deveson (1991) gave an account of the difficulties she had in attempting to support her son and her attempted interventions to get him into a treatment facility in Australia. Hers was a harrowing narrative about a young man who had very little insight and did not accept his diagnosis of schizophrenia. Accordingly, he constantly ran away from assistance. Although he needed treatment she could not get him admitted into a facility and his health slowly deteriorated. In her story I recognised a very familiar pattern.

Porter's (2002) historical analysis also provoked me to pursue recording what was to become a series of video interviews. He said the following about the phenomena of mental distress:

> … mental illness must be understood not as a natural fact but as a cultural construct, sustained by a grid of administrative and medico-psychiatric practices. The history of madness properly written would thus be an account not of disease and its treatment but of questions of freedom and control, knowledge and power. (p. 3)

What Porter highlighted was the fragility of all of our lives when examined on a spectrum of wellness. Statistics in New Zealand show that one in five adults will make use of mental health services in their lifetime (Mental Health Commission, 2012). My experiences have shown that there is a gap between institutional care, and the administration of community services. I have also seen that family care and communication between families and medical services widens with poor communication.

I realised that if families were to become the caregivers in the community, finding out how they perceived their roles and how some successfully coped with their family member, might be of value to others. I thought that making a documentary that reflected participants' involvement with caregiving for a family member could perhaps articulate how families were being affected. A DVD that was entirely made up of the voices of those dealing with, and connected to a situation might provide an authentic and useful resource.

1.1 Positioning myself as the researcher

I was born in South Africa and I grew up in Durban in a multicultural environment. From childhood I had an interest in theatre and I studied drama at the University of Natal in Durban. My mother was a nurse specialising in orthopaedics, working with children with physical disabilities and my father started life as a horticultural labourer, then he studied horticulture at Kew Gardens and eventually became an eminent Parks Administrator in South Africa. As a student I became involved in the anti-apartheid movement through student organisations, and I found that this opened up an awareness of human rights that has remained and influenced my decisions ever since.

While studying psychology in the final year of my BA degree, I was taken with the other students by bus to Fort Napier, a psychiatric hospital near Pietermaritzburg. We sat in a lecture room and psychiatrists in white coats brought forward a number of patients and talked about their symptoms and illnesses. One had had a lobotomy, another was a paranoid schizophrenic and had killed his wife. All black men, they stood silently while their lives were discussed in front of young white students. There was no sense of

privacy, or concern that these men might be sensitive to this information; they were presented as speechless, deaf exhibits. The memory of this terrible experience demonstrated to me the attitude of the authorities at that time. Mentally ill people were perceived as having no significant sensitivity to people or their surroundings. The episode has haunted me ever since.

After graduating, I started my working life as an actor, touring and performing dramas in high schools. Through this I became interested in Theatre in Education (TIE) in England when I saw the possibilities of how this medium was being used with children and young adults. As a consequence of this, I was asked to start a youth company and children's theatre group for the state organised Cape Performing Arts Board in Cape Town.

However, I became increasingly frustrated by the limitations of what we were able to achieve within the formal restrictions of the school and apartheid systems. Gavin Bolton and Dorothy Heathcote, from Newcastle University, England, visited South Africa in the late 1970s giving workshops, expanding on their philosophy and educational approach. Taking part in these workshops I observed and participated in discovering how children could become involved in the decision making process of an unfolding story or drama and it radically changed my approach. Dorothy Heathcote's work was developed over years of her practising as a teacher and I was introduced in a practical workshop to her method of learning, which she called the "Mantle of the expert". The mantle she referred to placed the pupil at the centre of learning, and enclosed them like a cloak (Heathcote & Bolton, 1994). In this approach, the teacher consciously positions the student as a co-constructor of the learning.

At that time I was running children's drama workshops part-time at a Community Centre in Woodstock, an impoverished area in the inner city. In this multicultural environment I found working with these methods was particularly effective in involving the children so that they felt part of the development of the drama. I was offered an opportunity to take up a scholarship to study overseas and enrolled at the London International Film School (LIFS).

While at LIFS I had my third direct contact with mental illness and psychiatry. The school was approached by the Canterbury Health Authority to make a video that would

assist them in recruiting psychiatric nurses. Called *Somebody Cares* it was shot within the walls of the Victorian built Canterbury psychiatric hospital. This institution was set in the bucolic countryside outside the city. It was a formidable building, built with huge stone walls. It was 1981 and Britain's mental health policy of closing down their archaic psychiatric institutions had begun. Patients were being discharged after short stays in hospital and were being treated in Community Day Centres. The only patients we saw were in the distance, sitting alone. We filmed nurses in training sessions interacting with "patients" played by nurses in role-play situations, and nurses in meetings discussing patients at staff changeover. This video was made from a medical perspective and showed the routine of the psychiatric hospital. I accepted this point of view without question, as it seemed humane and sensible. The nurses on the wards were smartly dressed in their crisp uniforms. However, *Somebody Cares* was created from an approved constructed script and was made to serve the Health Authority, and it followed a biomedical treatment model.

Documentary films on television in South Africa in that period had been restricted to highly controlled versions of Government propaganda, what the National Government called "current affairs". Alternatively, they were informative items of general interest narrated with the voice of authority. As a result all programmes were politically sanitised. Despite the repressive regime it was still possible to capture or tell stories about people who were different, who came from *other* economic, cultural or religious parts of the world. Acquiring these skills in filmmaking was a privilege as film could be exploratory; it could capture new experiences and provide a purpose to meet and communicate with different people. It could also reach a wide and growing audience that was seeking information and looking towards a different future.

I returned to Cape Town. The Xhosa television service was about to go to air and I became involved in working on projects for that community. I also got married and my life changed.

Apartheid kept communities apart geographically and socially and it was a revelation to be part of a new communication system, making contacts within the African township areas and building up a rapport with members of the different communities. Setting up personal networks with teachers and educators and physically travelling into township

areas was a new experience. It was exciting to develop a number of children's programmes, a concept that was unfamiliar for Black audiences. In these I incorporated some of the techniques and approaches I had learnt in theatre practice. Most African children only speak their native tongue so although children's programmes were airing on South African Television (SATV) in English and Afrikaans, children's programmes based on South African culture and the African township community were unknown. Working with two writers and a lecturer in Xhosa from the University of Stellenbosch, I devised and directed a children's educational drama series *Aphaya Naphaya.* Each half-hour episode involved a drama in which an African professor and his three assistants needed to find out some information that would help them solve some difficult situation. When these went to air we became aware of how influential this medium was becoming and how it was opening up the world to isolated communities. The theme song was being sung in taxis and the actors were mobbed in the townships. During the second series of filming I became pregnant with my daughter Zoë, and I managed to complete the edit of the final half-hour episode only a few weeks before she was born.

I continued making educational television programmes on primary health care and other community based issues and became involved in a training project sponsored by the Swedish government, the New Africa Theatre Project, when my son Alexander was about a year old. The aim of this initiative was to provide training for disenfranchised youth whose education had been broken by the school riots in the 1980s. Many of these young people wished to become educators or actors. We devised programmes on AIDS education, sponsored by the local health boards that toured to township schools and communities. The success of these community touring programmes led to my being commissioned to create educational theatre programmes on voter education before the first democratic general election. These productions were mounted on the back of a truck and visited all the townships outside Cape Town and surrounding villages in the hinterland. The student actors were sponsored by the Black Sash, The World Council of Churches and the African National Congress (ANC) in exile. These became significant moments as they marked the changing political landscape and I believed these activities could make a small contribution to that. It was challenging and demanding, but my family also took part the children becoming involved in some of the drama classes and street carnival parades.

We immigrated to New Zealand in 1997 after the first South African General Election. My experiences in professional mainstream theatre, TIE, television and community theatre all made me wish to continue working in an educational field and I began teaching screen production at AUT University. I had always been conscious of representational issues on screen and in South Africa I had taken special care to observe differences of values and culture when working with students at the New Africa Theatre Project.

When my son became unwell I became increasingly aware that people held many different attitudes to mental illness and expressed a considerable amount of unconscious prejudice. When he was locked in an intensive care unit (ICU), we would sit feeling powerless and alone waiting in the institution for a visiting room to become vacant so that we could see him. It was often difficult to tell the staff from the service users. I felt helpless while a senior staff member, dressed in casual clothes just like one of those in care, locked us in and then out of doors wielding a large bunch of keys. The nursing staff were kind and empathetic. However, they only knew our son as the person presenting to them at that moment, and they had no knowledge of what he had been like, his personality, enthusiasms, achievements, and how articulate he had been. He was in a silent closed-off world of his own and he could not be reached. So began this journey.

The development and design of the documentary *Hope* has been a process of digging deeply into tacit knowledge and past experience. Sela Smith (2002), described this as that "internal place where experience, feeling, and meaning join together" (p. 60). With this thesis therefore, I have drawn upon diverse social and cultural experiences, bodies of knowledge and professional and creative histories. It is from this collective experience that I am positioned and from this state I have moved forward. The title of the documentary, *Hope,* was suggested by Emily Dickinson's poem:

> "Hope" is the thing with feathers
> That perches in the soul
> And sings the tunes without the words
> And never stops at all.

1.2 Thesis structure

This thesis is in two parts; the first is a documentary artefact titled *Hope* made up of six narratives and the second is this exegesis in which the context, research design and critical concepts underpinning the work are discussed.

The purpose of the exegesis is to critically unpack the making of the documentary, which captures the narratives of family caregivers who are supporting a family member who has experienced mental illness. Reviewing the process and the completed documentary, the exegesis reflects my engagement with production practice that situates the creative work within my personal development, as a practitioner and teacher. It also describes how I considered and dealt with issues around ethics, production, families and caregiving.

Scrivener (2000) has noted that creative practice theses should begin with a "reflection on past practice" (p. 8). They should also situate the work as research, that is a response to issues and concerns in society. This research can also contribute to human experience.

1.3 Exegesis

The exegesis is divided into six chapters.
In Chapter One, I describe why this project is important. I disclose and position myself in relation to the topic, and describe the thesis structure.

In Chapter Two I review contextual knowledge impacting on the inquiry.

In Chapter Three I discuss how the creative process and research design have been brought together in the thesis. I explain the nature of this work, the theoretical underpinnings and the methods used in the project.

In Chapter Four I discuss issues that impacted on and shaped the project

In Chapter Five I provide a critical commentary on the work. Here I explain the processes, problems and procedures I followed to complete the project.

In Chapter Six I reflect on the project and consider its contributions to knowledge.

1.4 The project

Hope is a ninety minute documentary. It is designed so it can be shown as a single text. However, it can also be subdivided into discrete sections for use in workshops or training sessions. In this regard each interview is a self-contained portrait, but in composite, participants' reflections suggest certain common experiences and framings of care. The work is designed for families who care for a family member, health practitioners, mental health counsellors, medical practitioners, students and those interested in mental health care. It is intended to be viewed in private circumstances at home or with a counsellor.

The creative work is the primary site of research in this doctoral project.

Chapter 2:   Review of contextual knowledge

This chapter is a review of relevant contextual knowledge and works that have influenced the design of this project. It is divided into three sections.

- Section One: Community care
- Section Two: Representation: screen media and mental illness
- Section Three: Documentary and capturing the real.

Section One: Community Care

2.1 Introduction

In New Zealand as in many other countries, Government policy relating to mental illness advocates a policy of family inclusiveness in a family member's care. This was described by the Mental Health Commission in 2012:

> There is a need to optimise every opportunity to build and strengthen consumer and family/whānau[4] engagement. Engagement and healthy respectful relationships with consumers/service users are key factors of successful outcomes for people and must be at the heart of every interaction. Holding hope and optimism, expecting recovery and recognising personal strengths, uniqueness and the impact of trauma on a person's life all contribute to building stronger engagement. (2012, p. 48)

This is a statement of intent and it explains in principle how individuals should be addressed and how families could be supported. It is a positive document but it would seem that financial cutbacks are not always supporting its implementation in significant, concrete outcomes. In embarking on this research I knew little about mental health institutions and what I did know was largely gleaned from the media.

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[4] An extended family group of three to four generations, forming the basic unit of Māori society.

2.2 Living in the community

The closure of psychiatric institutions for long-term care for the mentally ill in the 1980s in New Zealand and other countries, has mostly had a positive effect (Cowan, 2008; Torrey, 2001) but the decision has created tensions in care for individuals. These have been difficult to resolve and have meant a complete reorganisation of mental health services. The effects on individuals who have lived in mental asylums and hospital institutions are many layered (Goffman, 1961). One overwhelming aspect of institutionalisation was that in order to leave the hospital a mental patient had to acquiesce to accepting the institution as a place of treatment and in doing so accept a role of subservience to those who controlled it.

Appraisals of the effects of these institutions have had a powerful impact on shaping public discourse surrounding their demise (Foucault, 2007; Goffman, 1961). This move towards deinstitutionalisation has had direct implications for social policy and the management of community services. Foucault (2007) gave a vivid description of how society came to think about organising the treatment of those it labelled as mad. From the perspective of a social psychologist he gave a chilling account of how society has organised itself to both protect and be protected from those deemed mentally unwell. He claimed that a cultural image of madness has been perpetuated since Hieronymous Bosh's painting *Ships of Fools* (1498). This work shows the insane gathered together sailing their ship in search of sanity; the occupants of the boat being outcasts of medieval society both literally and in reality. Porter (2002) suggested that during this period in England the mad were either cast out of society, beaten, and forced out of the cities to beg, or locked up to rot. After leprosy died out as an illness, he notes, the former leper institutions became places of treatment and later institutions of incarceration for those deemed mad. Thus one form of inhumane abuse followed another.

It has been suggested by writers like Cowan (2008) that the closure of psychiatric asylums in New Zealand has created an era of community neglect and this idea is reflected elsewhere in the world (Torrey, 2001). The shift towards deinstitutionalisation has meant that people whose illness does not need acute clinical monitoring can receive treatment living in the community. They can live in their own homes or accommodation and become integrated into the community, gain employment, become involved in

community activities and develop a social life. Secker and Platt (1996) argued that the media has a role to play in public attitudes as closure of major mental hospitals in the United Kingdom and elsewhere indicated that community care policies can be successful only if community attitudes are not hostile to people. The media's fuelling of negative fears about mental illness raises unjustified fears, and potentially also has an impact on community attitudes.

Perron (2002) suggested that successful recovery has also been achieved for mental health consumers because of advances in the development of more effective neuroleptics. These work towards improving the positive and negative symptoms for schizophrenia and other serious mental illnesses. As a result mental health consumers have reduced the amount of time needed for acute care as hospital inpatients. With health care systems being stretched by financial constraints, Perron (2002) advocated that families could provide some of the best support for their loved one. Cross (2004) applauded the restoring of the mentally ill to community care arguing that it eased long-term pressure of incarceration on individuals. This view stands in contrast to the notion that psychiatric care has to contend with deeply ingrained perceptions that the mentally ill pose a dangerous threat. Cross further noted that restoring the mentally ill to community care is a less expensive option for governments. However, Cowan (2008) has argued that the upshot is that generally some patients have been left to fend for themselves.

Lawn, Walsh, Barbara, Springgay and Sutton (2013) have argued that service providers have little understanding of what it is like for families to care for a family member with mental illness. Family caregivers do not choose this as an occupation, they receive no training and subsequently they are generally ill prepared for the role. They also have to provide continuous support seven days a week. Lawn et al., (2013) have suggested that family caregivers can be more effective because they know more about the person they care for, and have had a longterm experience of knowing them, while health professionals usually only have a brief knowledge of the individual. They note that health workers are frequently repositioned within the system and this results in poor empathy for families, because they become removed from the impact of experiencing a situation where there is no continuous care.

Studies (e.g. Cowan, 2008) show that ten years after discharge from asylums, some people who were traditionally under institutional care were living in inadequate accommodation, boarding houses or with parents. In these cases, minimal support was available for caring family members who were left to cope as best they could. This problem is not a local one. In the United States of America, Torrey (2001) noted that often living facilities for discharged patients are so poor that professionals concerned with discharge are put in an ethical dilemma, regarding the relative merits of hospital care over what is offered in the community. Today, the policy in New Zealand is to provide psychiatric hospital wards for short-term stays that average two weeks in duration. (N. Te Pania, personal communication, January 20, 2012)[5]. The expectation is that the acute patient will recover with appropriate medication and be discharged. The hospital administrator plans for the patient's discharge as soon as possible after admittance to a hospital ward.

The dilemma this poses was well portrayed in the New Zealand feature film *The Insatiable Moon*, (Riddell, 2010). This film, based on a realistic scenario, depicted the situation faced by occupants of a shabby boarding house in Ponsonby, Auckland, that was about to be taken over by property developers. The tenants, some of whom were mental health clients, faced eviction and some of them who were acutely unwell were about to become homeless. Without this accommodation there was nowhere for them to go but the streets.

2.3 Uncovering Hope

The concept of "recovery" in mental illness is complex and confusing for mental health consumers and family caregivers. Recovery refers to a person's restoration to normal health and survival from a serious or long-term condition that could dominate their life. In effect, suggested Jacobson and Curtis (2000), recovery is more of an expectation than an actuality. The idea of recovery is the basis of mental health policy in New Zealand, but there are few clear definitions. A view expressed by Cowan (2008) suggested:

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[5]Family Adviser, Mental Health, Waitemata District Health Board, Auckland.

> … recovery is the process a person diagnosed with mental illness undergoes to make sense of their experiences and learn how to make their life work for them, living fully integrated into the community, as an active participant in their treatment, and a citizen of a democracy, using the resources of family, society and the mental health services. (p. 22)

The mental health consumer philosophy of recovery is described as,

> … achieving the life we want in the presence or absence of mental distress. The right conditions for recovery are the strength and interrelationships of our self-determination, personal resources, supports, therapies, and our social and economic opportunities. (Mental Health Advocacy Coalition, 2008, p. 19)

Deegan (1988), who described herself as a mental health survivor, was diagnosed with schizophrenia, and suggested that it takes more than going through a rehabilitation process to become well. What is needed is for someone to "experience themselves as recovering a new sense of self and of a purpose within and beyond the limits of the disability" (p. 56). She pointed out that the problem with rehabilitation processes is that they force a person to participate and confront possible failure. Working through this and having the support of those who believe in a person's progress is essential. Deegan (1988) said:

> We do remember that even when we had given up, there were those who loved us and did not give up. They did not abandon us. They were powerless to change us and they could not make us better. They could not climb this mountain for us but they remained hopeful despite the odds. Their love for us was like a constant invitation, calling us forth to be something more than all of this self-pity and despair. (p.56)

Barnett and Lapsley (2006) argued that the rebuilding of family relationships is crucial for someone's recovery process. Family caregivers have to take on a wide range of caregiving situations to make sure that their family member embraces a cohesive approach to becoming well, including ensuring that they adhere to a medication regime. This can have a negative effect on relationships if the family member does not believe

they have an illness, refuses medication or does not wish to connect with support services. However, Cowan (2008) suggested, as many family caregivers find themselves becoming vigilant monitors of a medication regime or symptoms, there is a tendency for them to become a "clinician-in-situ" (p. 117), which should arguably be the focus of a clinical team and not the family. Cowan (2008) has suggested that an overly vigilant approach can prevent the unwell family member from taking responsibility for their own recovery (thus enabling them to make progress), and can encourage them to hold on to an invalid status. She said this is because, "The person's self–concept is dominated by the illness rather than by their hopes, dreams and efforts to succeed in living well" (ibid.).

Many families believe that once their loved one has been discharged from hospital they will be well, but this is not necessarily the case (McCann, 2002). For those not directly experiencing a mental illness it is difficult to comprehend the debilitating nature of severe depression or psychosis. Psychiatric rehabilitation is a many-layered process. On a practical level rehabilitation involves assistance in planning, so that individuals can receive the basic necessities of money, food, accommodation, employment, making friends, and receiving medical care (Amador, 2007; Cowan, 2008; Torrey, 2006; Watkins, 2007). Expectation (or hope) is shown to be the main motivation that assists people to move forward (Cowan, 2008; Torrey, 2006). For Deegan (1988) it went further. She argued:

> Recovery does not refer to an end product or result … we find that our personal limitations are the ground from which spring our own unique possibilities. This is the paradox of recovery, i.e. that in accepting what we cannot do or be, we begin to discover who we can be and what we can do. (p. 56)

However, a major concern is that stigmatisation and discrimination form barriers for people seeking appropriate help. These attitudes also suggest that people who need help are a risk to the community. A strategy for nursing staff described as one that enhances "motivation" and develops "pathways" to wellness has been suggested by McCann (2002) and supported by Cowan (2008). Both writers have advocated that in practice a goal, plan, and vision have to be shaped by the client and not imposed by mental health staff or family. A further hindrance identified by McCann (2002) is that, as community

attitudes are sometimes negative towards the mentally ill, there is often community reluctance to assist those who have a mental illness. People somehow feel that the mentally ill deserve less assistance than people with other disabilities.

Many people experiencing mental distress refuse treatment and avoid mental health services when they are not really well enough to make that choice. These people believe that they do not have an illness, or that they do not need treatment (Amador, 2007; Torrey, 2001). This can be for different reasons, including denial, or anosognosia (a lack of insight). Problematically, the compulsory treatment of people against their will can be damaging as it can make their recovery and progress difficult (Amador, 2007). Although conditions in some hospitals have changed and seclusion is no longer regular practice, clients are now given the option of assistance when in acute stress by the use of a sensory modulation environment. However some are still haunted by experiences of the past. As Cowan (2008) described:

> … they discuss the terror of being physically overwhelmed and injected
> with mind-numbing medications. They may have been locked alone in a
> small room, which seems to confirm that they have lost the right to belong
> to society. This happens when they are already distressed with the effects of
> the mental illness. (p. 113)

My experience in the last few years suggests that some of these situations still occur within the current system.[6]

2.4 Family caregivers and emotional management

When a member of a family is diagnosed with a mental illness the impact is profound. Riebschleger, Scheid, Luz, Mickus, Liszewski and Eaton (2008) noted that family experiences include "stigmatized social interactions, high levels of stress, and on-going caregiver burden" (p. 120). They also found that there are predictable moments in the

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[6] After a visit to my son in an intensive care unit (ICU) he attempted to prevent his father from leaving by reaching out and catching his cardigan at the wrist. Within seconds he was restrained by a nurse, while another injected him. Sedated, he was bundled into a room in the secure unit. It was shocking and emotionally disturbing, even though from the nurses' perspective my son appeared to be becoming agitated and needed to be restrained.

unfolding of a person's illness, as there are with caregivers in parallel careers. Karp and Tanarugsachock (2000), in examining the emotional management of family caregivers, found that "every person interviewed felt the emotions of fear, confusion, hope, compassion, sympathy, love, frustration, sadness, grief, anger, resentment and guilt" (p. 8). Often, while families are coming to terms with a family member's illness, and before they receive a firm diagnosis, they can experience what might be called emotional anomie or social isolation (Karp & Tanarugsachock, 2000). Confusion and a medical diagnosis generally lead to a medical framework that clarifies the situation and provokes feelings of hope, compassion, and sympathy. The initial optimism that the mental illness can be "fixed" can give way to a sense of its "likely permanence" (ibid p. 8). This frame of permanence coupled with doubts about the ill person's ability to control their odd or objectionable behaviour can lead to negative feelings of anger, resentment, and even hate. The family may eventually conclude they can't change things, and this can lead to a form of acceptance.

Pirkis, Burgess, Hardy, Harris, Slade and Johnston (2010) argued that "caregiving is associated with a relatively high degree of emotional and psychological burden, in the sense that mental disorders and psychological stress were found to be linked to being a carer" (p. 935). Their research reported that a lack of recognition from others of the carer's position added to their difficulties in the role. In addition, they noted, families can incur financial burdens and have poor work productivity due to taking days off to manage the additional responsibilities. They suggested that family caregivers should be assisted by "strategies designed to alleviate some of the emotional pressure associated with care-giving, and that these strategies might have flow-on societal benefits" (p. 936).

Wynaden (2007) suggested there is a flow-on effect in tracing the emotional stages that caregivers go through. She found that family caregivers were often overwhelmed by the role and this state Wynaden conceptualised as a social psychological problem called "being consumed". She described this state as "a bewildering sense of preoccupation, absorption and engrossment with what was happening to them, the ill family member, and their family" (Wynaden, 2007, p. 383). In managing the experience of "being consumed", she noted, carers engaged in a social psychological process, called "seeking balance", where carers eventually transitioned to a state where their commitment to the ill family member was more balanced and proportionate to other areas of their lives.

Wynaden's research showed that discovering that the emotional reactions families experienced were common to others, led carers towards acceptance and this made the situation more bearable. She also found that the amount of time these phases take varied, and in many instances families sought out a variety of groups for education and support.

Research suggests that the realisation that a family member's illness may never go away is a crucial turning point in the caregiving experience. This is because it forces the caregiver to come to terms with the reality that the expectations, aspirations and hopes that they had for their family member are unlikely to be realised (Torrey, 2001; Watkins, 2007; Wynaden, 2007).

Not only do findings like these provide health professionals with a valuable insight into caring, the research suggests that the need to decrease the stigma directed towards people with a mental illness is an important factor in facilitating a person's integration into the community and the maintenance of a cohesive level of family life (Jacobson & Curtis, 2000; Vaughan & Hansen, 2004).

Riebschleger, et al., (2008) have noted that in medical education, little attention is given to family caregivers, because the curriculum contains little concerning family crises planning, needs, or how carers experience stigma. The researchers noted that as relapse and remission are common in mental illnesses, family caregivers need education and emotional support. They also need training in how to observe signs of remission occurring and ways of knowing what, if anything they can do about it. The researchers also reported family members feeling the social stigma of mental illness, and expressing feelings of being isolated, ignored, blamed, and criticised by family, friends, neighbours, colleagues and in some circumstances, mental health providers. These families' additional, ongoing caregiving responsibilities, the researchers found, contributed to their sense of having a "family burden' and they reported 'relationship strains', as well as feelings of grief, loss, sadness, anger, frustration, shame, and guilt" (p. 120). Their research raises significant questions about curriculum objectives and the ability of physicians to work with families of individuals with mental illness.

However, Peterson, Pere, Sheehan and Surgenor (2004) suggested that a significant cause of discrimination can actually stem from family dynamics. Families, they found,

sometimes do not acknowledge a person's civil rights, and often try to conceal a person's hospitalisation when they are mentally ill. Some family members see mental illness as contagious, or display a lack of interest in mental illness by avoiding the topic. Their research showed that adults are sometimes treated as if they are children, or as less than competent. In their research, persons with mental illness reported being rejected by family and friends, called names, seen as incapable or incompetent, and found that other family members tried to control their lives.

2.5   Recovery and family caregivers

Dixon, Adams and Lucksted (2000) have noted that some families have successfully created self-help groups and organisations to help fill inadequacies in support. They suggested it is important that family psychoeducation should remain as part of best practice guidelines and treatment recommendations. Peer-led family education programmes clearly have a special role to play when a client is unwilling to work with medical professionals but this requires investment in time and interaction from family members. Jacobson and Curtis (2000) argued that building rapport and trust are important factors when working to meet family and consumer needs without the structure of formal family psychoeducation programmes.

Lucksted, Medoff, Burland, Stewart, Fang, Brown, Jones, Lehman and Dixon (2012), suggested that families taking part in Family-to-Family peer-led groups (FTF), sponsored by the National Alliance for the Mentally Ill (NAMI) in the United States of America,[7] experience a reduction in prolonged stress. This leads to better communication and increases ability in problem solving, coping and empowerment. The skills learnt through peer-led family experience, in training and supporting others suggests that over time family relationships can improve and potentially lead to more positive outcomes for the family member.

There is little research as yet on the efficacy of online support for caregivers, however Perron (2002) suggested that, like traditional face-to-face groups, people develop helpful online relationships. Online activity can provide opportunities for caregivers to describe their lives, their emotional journey, and discuss traumatic events. Through their writing,

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[7] These groups are run by trained volunteers who teach one another.

participants can get the opportunity to share anonymously with others. People can respond and continue a conversation when they feel ready to do so. This does not necessarily occur in a face-to-face group.

Dyall's (1997) research showed that Maori are over represented in mental health statistics, although no specific reasons or causes are given. The Maori health model that has been developed emphasises the importance of wellbeing of whanau (family), to ameliorate discrimination. Cowan (2008) suggested that poor outcomes for mental illness conditions have severe consequences for indigenous people in colonised countries; and she emphasised the need to address Maori mental health from a Maori cultural perspective, as well as the need to identify the concept of "recovery" from a Maori perspective. However, Peterson et al., (2004) have suggested that the most common reporting of discrimination is seen to be from whanau (family) and friends. The experience of a family is not always positive and discrimination can become complex when it is experienced on grounds of both mental illness and of race. The same applies to Pacific Island and Asian Communities, and is evidenced in the development of agencies in Auckland to meet their needs.

A study by Corrigan, Edwards, Green, Diwan and Penn (2001) on prejudice and social distance suggested that prejudicial attitudes influence discriminatory behaviours towards the mentally ill. It was found that those who rejected an authoritarian attitude toward mental illness, or believed that the mentally distressed should be taken care of by authorities, were likely to maintain social distance from the mentally ill. This seems to confirm that negative views on mental illness lead to negative behaviours towards people with psychiatric disabilities. Conversely, another negative effect is "benevolence". This is "the view that persons with mental illness are childlike and need to be watched by a compassionate caretaker" (Corrigan, et al., 2001, p. 223). Such attitudes can lead to positive behaviours through helping someone, but they can concurrently promote perceptions of irresponsibility, and assumptions that people with a mental illness cannot be responsible for their actions.

Concerning attitudes towards recovery, Perron (2002) suggested that while in good periods families believed that their loved one was getting well, this view could be quickly overturned when their loved one's mental state deteriorated and they needed

acute psychiatric care. In these instances, family attitudes can often turn rapidly to feelings of despair with an on going cycle.

2.6　Young people and mental illness

My family experience has shown that it is very difficult to get admittance to hospital and state funded mental health services. Many young adults do not access the mental health service (Barnett & Lapsley, 2006) and many miss out on receiving help at an early stage because they lack the ability to negotiate their way in unfamiliar territory while they are ill. In addition, Barnett and Lapsley (2006) have noted that young women with a non-psychosis diagnosis such as depression, anxiety, post–traumatic stress disorder, self-harm and maternal health issues are under catered for in the New Zealand system. The researchers reported that recovery for young people was seen as progress towards reaching some goals and finding meaning and gaining independence in their everyday lives. They also noted that research in New Zealand showed that young people were very clear about what helped them and what hindered them. Barnett and Lapsley (2006) spoke of the need for support that included:

> … someone to talk to, safety, respect, hope, friendship, work and careers, family support, meaning and purpose in life, independent housing, community participation, and the provision of holistic, recovery-oriented treatments and supports. (p. 85)

In New Zealand, at the current time, services are stretched and underfunded and a person needs to be in an acute state of mental distress to gain hospital admittance. Often, a first admission occurs when someone's odd behaviour becomes the focus of police attention. The reality is that people not needing hospitalisation or being in an acute state are normally returned to the community and live with their families or in subsidised housing.

2.7   Summary

Community living for those who have experienced severe mental distress is difficult, but if supported with professional and family assistance a positive transition into community life can be achieved. Families are often the best people to support a person who has experienced mental illness but are often disadvantaged as caregivers because they need education and training (Torrey, 2001; Cowan, 2008).

Recovery and the uncovering of hope was seen by Deegan (1988) as a key factor in a recovery journey. Mental health consumers need to find self-motivation and a focus to become independent while being supported by their families. Families and those who experience mental illness need support as they both experience stigma and discrimination (Riebschleger, Scheid, Luz, Mickus, Liszewski & Eaton, 2008). As the situation is ongoing there is a need for continual emotional management to cope (Karp & Tanarugsachock, 2000) as families can become consumed and preoccupied with their caregiving journey. However, over time families can eventually learn acceptance and realise that the illness may never go away (Pirkis, Burgess, Hardy, Harris, Slade & Johnston, 2010; Torrey, 2001; Watkins, 2007; Wynaden, 2007).

The effects of stigma are far reaching. Barnett and Lapsley (2006) noted that many young people miss out on support and assistance from the mental health services because they are afraid of stigma and discrimination.

These issues indicate that educated and informed family support and caregiving play a crucial role in the recovery journey of a family member. Utilising educational resources pertaining to their role as a support person can assist families. Therefore the making of a documentary DVD that contains family stories as a resource for families, might provide information in a way that is dynamic because it discloses personal narratives from which other families can learn.

Section Two: Representation: Screen media and mental illness

2.8 Representation of mental illness in nonfiction screen media

Diefenbach and West (2007) argued that watching television influenced viewers negatively in their beliefs and understanding about mental illness and its causes. Their study of prime-time television in the United States of America indicated that people with mental distress are disproportionately portrayed as violent criminals, having a negative impact on communities. Viewers in their study suggested that others could be affected and develop negative attitudes but were reluctant to admit that they were influenced. Klin and Lemish (2008), in considering a number of studies of television entertainment programmes, suggested that public perceptions showed that those afflicted with mental disorders were perceived by the public to be dangerous, violent, of low intelligence, poor at communicating, lazy and unproductive members of society. Diefenbach (1997) argued that viewers saw people with mental illness portrayed on television as being aggressive and significantly more violent than other kinds of characters. They were also portrayed as having a "quality of personal life which is more negative than violent criminals" (p. 300). Such findings become significant in the light of research by Stout, Villegas and Jennings (2004) that suggested that many people have little or no contact with those who have a mental illness and rely on media information to form their social constructions and attitudes about them.

A desire for profit, suggested Wahl (1995), is another prevailing attitude impacting on the tendency to distort media images of mental illness. In an environment where mass media is in fierce commercial competition, audiences are attracted to phenomena that are dramatic and intriguing. Public titillation sells media, and stories about homicides and violence that include mental illness are very popular. In analysing television entertainment programmes in Australia, Pirkis, Blood, Francis and McCallum (2006) concluded that viewers are frequently shown negative images of mental illness in fictional films and television programmes and that this can affect people with mental illness. As a consequence they may not seek assistance with their illness for fear of stigma and discrimination. They suggested that collaboration between the mental health sector and the television and film industries might assist in educating and informing the public as well as entertaining them.

Stout, Villegas and Jennings (2004) have also discussed the socialising effect of television and argued that people accept what they see on the screen as being a true reflection of society. Philo, Secker and Platt (1994) suggested that the study of the content of press and television showed that two-thirds of media references to mental health related to violence and that these negative images tended to be shown as headlines in the press, while the more positive items were shown on the back page, the health page, or letters and problem pages. This kind of coverage has an impact, as it encourages people to associate serious mental illness with violence.

Documentary films historically have been created on what can be achieved technically in the moment of capturing an event, and film-makers pursue the most strategic way they can to achieve their aims. The uses of documentary forms, suggested Austin and de Jong (2008), in reality TV programmes in the early 1990s showed that utilising these production methods in recording the intimate areas of participants' lives is both popular and entertaining. This has made documentary television highly commercial and competitive, and as a result it reaches large audiences. This has also had an impact on commercialising programming and coercing people to expose their situations in the hope of commercial gain (Winston, 2005).

Stastny (1998) suggested that the history of screen depictions of mental illness is clouded by images that show people with mental illness as being shabby and unkempt. These images that have existed through the centuries show torn garments, long tangled hair and wild eyes, suggesting that a relationship exists between community beliefs and madness that can be traced back to antiquity (Gilman, 1988). Historically, many depictions in art from Bosch, Goya and Munch show that the mad look different (Cross, 2010; Cross, 2004; Stastny, 1998; Wahl, 1995). Cross (2004) argued that a key factor in the public perception of the appearance of the mad is melancholia and dishevelment, and these representations of "wild unkempt hair and tattered clothing have long provided influential visual signs of madness" (p. 199). Hence assumptions that one might know a lunatic when one sees one have become a concern for those managing and treating the mentally ill.

As many of these negative attitudes have prevailed over the centuries and across cultures, it might be argued that ideas about mental illness and madness are carried down

through prevailing community perceptions. Cross, (2010) has noted that beliefs about the nature and treatment of a range of illnesses which remain mysterious to the observer, and which cannot be understood by an outsider, are in time perceived as facts. In examining relationships between traditional iconographies of madness and images of mental illness utilised by British documentary makers in the last decade, Cross (2004) noted an adoption of a paradigm of "danger" when describing mental patients living in the community. He contended that in revealing details of the lives of schizophrenics, readings often concentrated on showing changes within communities of psychiatric care, from institution to community care. He suggested there is a complex relationship between culture and madness that goes back to antiquity. The idea that "madness is, as madness looks" (Cross, 2004, p. 197) is highly influential in communities that seek to identify madness in their midst.

As Cross (2004) and Foucault (2007) observed, many images of the mentally ill represent conceptualisations of people that have been around for centuries. The idea of moral lapses as precipitants or causes of mental illness was prevalent in the Middle Ages in Christian countries (Stastny, 1998; Wahl, 1995). People with symptoms of mental illness were considered to be possessed by the Devil or they were understood as having committed a grave sin. At the time of the Inquisition, loss of reason denoted a sign of possession by demons and was perceived to follow the violation of natural or conventional behaviour; it was also seen to be related to immorality, vice and filth. In attempting to represent an unobservable mental phenomenon, artists created their own interpretations. While dishevelment became a key icon of madness, other external features of "melancholic people" (Wahl, 1995, p. 117) depicted characteristic poses that included downcast eyes and muscular tension. Hippocrates had introduced the idea that melancholia could be seen in a tendency to be dark in complexion, because melancholia was believed to be the result of an excess of black bile that lent darkness to the appearance.

Wahl (1995, p. 117) also suggested that "Muscular tension and an arched back were added to dishevelment in depicting frenzied madness". He argued that the idea of mental illness being "dangerous" comes from the sixteenth century, where the madman and hermit became blended, and the concept prevailed that a madman was like a forest beast, primitive and savage. It was also believed that insane people would never recover but

would "grow steadily worse until they were so incapacitated as to be little more than animals" (p. 119). Such people were often kept in cells, and for a small fee the public could view them, with no realization that these visits might disturb the incarcerated even further. It was also believed that these animal-like, dangerous people, had no appreciation of their surroundings, and if left could run amok and destroy a community.

Wahl (1995) noted that hospital superintendents would often exaggerate the dangerousness of their patients to add to their authority. This gave staff permission to use restraints, and supported claims that hospitalisation was necessary, as these people were potentially violent (Cross, 2010; Wahl, 1995). Stastny (1998) has shown that such descriptions of psychiatric disabilities led to a history of "exploitation, objectification, and even annihilation" (p. 68).

In the twentieth century the Chancellor of the Fuhrer commissioned the production of documentary and feature films "aimed at illustrating the supposedly useless and burdensome existence of persons with a variety of disabilities languishing in German institutions" (Stastny, 1998, p. 74). These films were shot in over twenty institutions and were reportedly shown to Hitler's associates in July 1939. They were used to support an order to exterminate all inmates of psychiatric institutions in August 1939. Fortunately however, this did not happen.

Despite this negative representation of mental illness in historic screen media it appears that a newer more positive attitude is being promoted through community efforts. In New Zealand, television programmes such as *The Nutters Club* (Maori Television, 2012, 2013) and *Attitude* (TV One) have shown some stories of people with mental illnesses living well in the community. But these programmes are arguably nominal when one considers the negative representations on television schedules and the wider media. Community programmes such as the *Like Minds Like Mine*,[8] a positive advertising project, are shown at irregular intervals on television. Vaughan and Hansen (2004), in evaluating this campaign with Pacific peoples, suggested that showing positive scenarios

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[8] The New Zealand Mental Health Commission in 1998, created a de-stigmatisation programme, *Like Minds, Like Mine*, that promoted the education of community groups and the public at large, not the individual family. It employed a range of media including television. People have, since the institution of the campaign reported less stigma and discrimination in a range of organisations (Vaughan & Hansen, 2004).

revealing personal interactions on television was seen to be having an impact on people's attitudes, which indicates that such interventions can impact on public perceptions.

Documentaries such as *Stephen Fry: the secret life of a manic depressive* (Wilson, 2006) in which he discussed his bipolar disorder, help to highlight some of the stereotypical versions of this condition. Collectively however, Harper (2008) suggested that programmes like this could form part of a positive celebrity following that promotes mental distress. It singles out and distinguishes those who have successfully come out of their situations in a "If they can do it so can I" scenario, which is seldom the case for most people. Depictions of gender issues in these scenarios and the neglect of Black and Asian experiences of mental distress have caused Harper (2008) to argue for further research. He posited that many depictions have been supported by pharmaceutical companies and show a decided leaning towards a biomedical approach to recovery.

2.9 The impact of stigma and discrimination on families

The shift towards deinstitutionalisation has meant that people whose illness does not need acute clinical monitoring can receive treatment while living in the community, but lack of assistance and support means that these measures cannot always be met.
One reason that such people are neglected is because of stigma and discrimination.

Jorm, Korten, Jacomb, Christensen, Rodgers and Pollitt's (1997) research into public attitudes about mental illness suggested that most people receive their information from screen media, and partly because of this people have an inability to identify and recognize mental disorders. They also have certain understandings or beliefs about causes; ideas about self-help treatment and attitudes towards appropriate treatment and how to gain information. This general lack of knowledge, Jorm (2000) has suggested, has contributed towards negative attitudes as these are often based on incorrect beliefs. As an extension of this, Wahl (2011) noted that fear of stigmatisation inhibits those who need help from seeking it. Recent research in New Zealand that explored the basis of discrimination, identified three areas as its source, "mental health services; extended family and whanau; and societal norms including media stereotypes and general social milieu" (Barnett & Barnes, 2010, p. 11).

I would suggest that fear and stigmatising effects produced by the media, need to be addressed by the media. Nairn and Coverdale (2005), in their study on print media in New Zealand, found that very few self-depictions of psychiatric patients were conveyed in this medium. When these did occur they were regarded as being successful when subjects were portrayed as ordinary everyday people and "they were not to be defined or limited by the disorder with which they lived" (Nairn & Coverdale, 2005, p. 286). A study of television drama in New Zealand using intertextuality, showed how meanings were drawn from known sources and experiences of the viewer, which contributed to the current generation of meanings of what is viewed. Wilson, Nairn, Coverdale and Panapa (1999) analysed the interrelationships in television dramas and showed how associations between mental illness and dangerousness were created in sequences and across sequences in drama through the technical codes of lighting, sound, framing and music, as well as the appearance of the character, and the settings selected. They believed that "in showing how dangerousness is constructed, the basis of such stereotyped portrayals and their attendant contribution to the existing stigma can be better understood" (ibid., p. 247). They suggested that for attitudes to change, both producers and mental health professionals need to be educated about the effects that negative media messages have on audiences' perceptions, this being one way that stigma can be alleviated. These changes need to occur in the concurrent education of media professionals.

Krahn (2009) argued that public perceptions of mental illness can be shifted by encouraging critical discernment fostered through educating audiences via feature films and discussion panels. This may create a critical awareness of what values actually exist in society around issues of mental health. He proposed creating a film series and panel discussion from experts in ethics to work with the public in general. In this way audiences could assess how their perceptions were being shaped by popular drama.

Cutliffe and Hannigan (2001) suggested that beliefs and attitudes towards causes and treatment of mental illness are important in that they reveal underlying attitudes to people diagnosed as mentally ill. They noted that media practitioners, as well as psychiatric and mental health nurses, needed to become more aware of the wider socio-political implications that are perpetuated in the media. This is because the stigma that is inherent in prevailing attitudes can influence representations and subsequent government positioning and policy concerning the care of people with mental health problems.

Although there is evidence of some damaging representations in mass media, there is also evidence of some positive images within public service media campaigns. Despite empirical evidence that indicates a decline over the last 40 years in the number of homicides carried out by people identified as suffering from mental health problems, the current mass media continue to use representations of mental health service users that appear to "emphasize violence, dangerousness and criminality" (Cutliffe & Hannigan, 2001, p. 320).

2.10 Documentary and health education

If screen narratives can be negatively persuasive they can also reveal messages that are favourable. Nicolaides, Curry and Gerrity (2005), evaluated Nicolaides' (2002) documentary on family violence, arguing that this is an effective medium that can record complex human situations. Their study indicated that personal testimony could be used to inform others about circumstances of intimate personal violence. After viewing the documentary, clinic workers significantly changed their approach to patients. They reported that this practical method of giving information on intimate personal violence, which was survivor informed, created greater empathy and understanding towards patients. It also resulted in an improved way of referral for patients requiring specialised care.

This has been further substantiated by the use of patient narratives in medical education. As Kumagi (2008) suggested, the importance of patient narratives is that they create empathy and assist medical students by giving them experiences of lived situations, "forging emotional links with the other, stimulating self-reflection through cognitive dissonance and eliciting resonance of similar, fundamental emotions in the learner" (p. 657). In this way students develop a greater understanding of the implications of treatment in their training and how people react to it.

Parrott (1996) posited that media messages could be helpful in enhancing health information. She observed that narrative visual case studies worked well with young students and these implicitly or explicitly offer conclusions in different health situations. She made a distinction between health communication, health care and health education and highlighted the need for different approaches and awareness of the ways of

interacting between doctors and patients. She noted that individuals seeking care from formally organised health systems bring with them all of their knowledge and experience gained from news, media, entertainment and commercial messages, sources of television and other media. Patients may gather information from the Internet and other sources and more or even newer information than the health care professional. Trends are emerging demonstrating that people seek media information from the media and choose one process over another and will avoid some medical activities "for their belief in positive outcomes being associated with activities that health practitioners deem to be imminently harmful" (Parrot, 1996, p. 275).

Hodgetts and Chamberlain (2003) pointed out that television documentary is a mediated forum where those in control negotiate meanings about health issues. They noted that perceptions of the medical profession in lower socio-economic communities showed that far from being perceived as the "caring professional", the doctor is also seen as "medical entrepreneur" or "bungling quack" (p. 3). Participants in their New Zealand study were drawn from diverse local communities. In viewing documentary coverage, the participants not only questioned certain diagnoses and options for treatment, but issues were also raised about the doctors' motivations. These motivations related to decisions concerning private and public treatment of patients. They observed that the wider implications of medical health policy and provision of health care in the community were also under scrutiny in these programmes. The authors concluded that lay views were derived from a number of different experiences where their viewing of mass media coverage and their personal experiences became combined. This had an impact on both potential patients and families' views of health professionals.

In 2002 Nicolaides constructed a documentary from personal testaments on intimate personal violence, using video case records. The documentary coupled qualitative research with documentary production. She found that the outcomes revealed much greater comprehension and recognition of symptoms in situations when the participants' personal testimony was added to the traditional expert driven interventions. The information on the documentary was beyond what was being presented in the immediate consultation with a client, and contained sensitive information, which patients would not wish to disclose for fear of retaliation from a partner. The documentary used drawings and animation to visualise the narrative and also explored common themes and patterns

in behaviour before patients sought help. It provided a tool whereby physicians could learn from the voices of their patients.

Another body of research undertaken by Lupton (1999) considered how the mass media operates as an important source of information about medicine and health matters. She concluded, "Mass media portrayals contribute to the creation or reproduction of knowledge about illness and disease, doctors and other medical workers and medical treatments" (p. 260). She further suggested that the media tends to portray people as either "innocent victims" or as "deserving of their fate" (p. 260). Other depictions present patients being subject to authority in a "partnership" with the medical profession, or as "helpless" (p. 260) until medical intervention arrives.

In considering documentaries that deal with real life situations that purport to reflect "lived experiences", Kendrik and Costello (2000, p. 16) questioned the ethics of using participants who were in vulnerable situations. They argued that the camera only captured the framed moment, not what came before or after, and this potentially distorts meaning. They believed that the camera's presence "deserves moral scrutiny" (ibid., p. 16) when filming takes place in areas that should provide a haven for people in a time of vulnerability. This is particularly pertinent in health care situations where the basis of consent ensures that the participant gives their consent freely and without any coercion to either participate or abstain from doing so. Kendrik and Costello (2000) suggested that participants should be allowed to give their consent as part of an ongoing dynamic not as a one-off process. This is because, they argued, the nature of illness is unreliable and this may create a situation that quickly becomes out of control. Scenes that might be seen as permissible under the healthcare screen could, without that context be considered as voyeuristic or pornographic. The camera can demystify healthcare delivery but compromises occur when programmes are made that dehumanise someone. In telling a story, when determining clarity and attempting to create realism, overt exposure of an individual should not interfere with compassion for that person as a subject. They suggested that:

> … programme makers must ask how their skills can be used to reflect the
> meaning of suffering, as well as the experience of illness. The conceptual
> differences between these two themes would certainly challenge the art

and craft of those who make socio-documentaries. When such

programmes concentrate on capturing dramatic 'snapshots' they fail to

address either the meaning of suffering or the experience of illness.

(Kendrik & Costello, 2000, p. 21)

Hodgetts and Chamberlain (1999) noted that there is a tendency in television health documentary depictions that seek to inform the public, to depict lay people as being both "active consumers" and "passive patients" (p. 330). These two versions of approach, they believed, are frequently shown to be interdependent. The relationship of the subjects to treatment, ailments and interactions with health professionals, is generally used to illustrate treatment and recovery from a medical point of view. Audiences are given statistics and medical examples to back up these stories, but the functions of lay people are not the focus of research in these stories; what we receive is a narrative that is mediated, medical, and professionally oriented.

Lupton (1999), in considering how the mass media influences public perceptions, suggested that what is most frequently depicted is the hierarchy and practices of public medical healthcare. The wider social issues such as political and economic factors that lie behind healthcare decisions are generally not shown. Corner (1995) argued that the complexity of a health topic requires a perspective where order and evidence are selected and through editing this is made into a cohesive narrative. To create some clarity for an audience, a narrative structure needs to be imposed upon the story with a beginning that sets up the situation and places it into a context that draws attention to its worthiness as a subject. When a presenter is used he or she tends to lead the viewer through the narrative, persuading or convincing viewers about the facts of the situation. This creates an investigation around events and leads to conclusions from a narrative of cause and effect.

2.11 Summary

The literature suggests that families as well as service users are affected by stigma and discrimination and much of this stems from incorrect information or sensationalised representations of mental illness in the media. Watching television has a negative effect on people's perceptions of mental illness, as people with mental illnesses are frequently

portrayed negatively as being violent criminals (Diefenbach & West, 2007) or unproductive members of society (Klin & Lemish, 2008). These depictions reinforce existing, negative public perceptions because most people never come into contact with someone with a mental illness, and they rely on media information to inform their attitudes (Stout, Villegas & Jennings, 2004).

Historically, in visual and screen media, the representation of mental illness has been extremely negative (Cross, 2010; Stastny, 1998; Wahl, 1995). Popular entertainment tends to distort images of mental illness as audiences are drawn to stories and images that are dramatic and unusual. This approach makes stories about mentally ill or "mad" characters interesting. Consequently the character constructions have a negative effect and people with mental illnesses tend not to seek treatment for fear of stigma and discrimination.

Families are affected by stigma and discrimination (Jorm, et al., 1997) which can result in them not coming forward for treatment, or ignoring or mistreating their family member who is experiencing mental distress. Changes in public attitudes may be alleviated by educated media professionals who can pass on well informed approaches and information through their productions (Wilson, et al., 1999). It is possible to change public perceptions by media representations that positively reflect realistic situations (Krahn, 2009; Cutliffe & Hannigan, 2001).

Documentary narratives have been successfully utilised as a means of portraying family relationships in the area of family violence (Nicolaides, 2005) and these can have an influence as visual case studies that may inform medical students and physicians (Kumagi, 2008; Parrott, 1996).

Filming participants in vulnerable situations who are unfit to give permission or consent was identified as an issue by Kendrik and Costello (2000). Most frequently depicted in medical or health documentaries is the biomedical model and hierarchical practices that exist in public health care, (Hodgetts & Chamberlain 2003).

The literature would seem to indicate that positive screen depictions of individuals and families who have experienced mental illness can be illuminating for members of the

public who might carry prejudicial views. Such depictions may also be enlightening for families who are experiencing crises. Positive, realistic depictions may reduce stigma and discrimination and assist people in coming forward for assistance and treatment. They may also help them in coming to terms with their illness.

Section Three: Documentary and capturing the real

2.12 Introduction

As descriptions and definitions of documentary have shifted and as practice changes, so has theory grown, and technological changes have expedited new ways of capturing, recording, and editing film and digital video material. Bruzzi (2000) suggested that it is best to accept that documentary can "never be the real world, the camera can never capture life as it would have unravelled had it not interfered, and the results of this collision between apparatus and subject are what constitutes a documentary" (p. 7). As a result documentaries give us "views of the world" in a way that is enjoyable and engaging as no other medium can (Nichols, 1991 p. ix). As new documentary hybrid forms emerge, new forms of television programming surface where editorial gatekeepers hand over their role to communities. These communities produce unique forms of representation.

Bruzzi (2000) has suggested that a new approach to traditional techniques is needed and that existing theoretical texts about documentary relate to past iterations of the media form. She argued that we need to find alternative ways of discussing documentaries. Referring to Nichols (1991) and his discussion of documentary modes, she suggested that his definitions create limitations on possibilities of what can be achieved. She disputed his view that technical and cultural developments work as a kind of Darwinian evolution. This view she suggested, imposes a false sense of importance on what can be seen to be innovative. As an example she noted that expository forms of documentary, being the media form's earliest mode, are didactic and outdated, yet in practice they are being used more and more. She has also argued that although "fakery" is easily achieved with new desktop technology, it has always been part of filmmaking and it does not invalidate documentaries as a medium.

Corner (1995), in discussing a wider audience in the United Kingdom, stated that with the popularisation of documentary production these developments in production and editing in practice give documentaries a wide public appeal because they involve

observation, interview, dramatisation, mis-en-scène[9] and exposition. However with greater popular appeal community issues are often oversimplified. Corner (2005) further suggests that the erosion of the public service ideal of television can be interpreted as an erosion of public discourse. This erosion has meant that minority issues, seldom represented on television, are being increasingly relegated to broadcast slots such as a Sunday morning, late night, or are disappearing from the schedules altogether (Horrocks, & Perry, 2004).

2.13   Documentary modes

Choosing how to work with documentary modes has played a central role in planning the development of this thesis. Modes or production styles have evolved as the purpose of documentary making has progressed into different ways of communicating with an audience. McLane (2012) argued that the pioneers in documentary making were motivated by Grierson's belief that "collective effort, cooperation and understanding could lead to a better world" (p. 77). Grierson saw the camera as a kind of pulpit and a way of influencing social and community mores. Nichols (2010) suggested that through Grierson's influence a number of conventions in production were developed based on historical precedents that stemmed from institutional requirements, sponsorship and ownership. These he suggested are still in accepted use today.

Grierson (1933, p. 8) described the documentary form as follows; "Documentary, or the creative treatment of actuality, is a new art with no such background in the story and the stage as the studio product so glibly possesses". His phrase "the creative treatment of actuality" has been frequently quoted as a description of documentary and a way of working in this medium. The early documentary pioneers accepted that elements of art were involved in the filming and editing of images from actuality into a coherent work. They also believed that this work would encompass a perspective or an argument on an issue (Australian Film commission, 2004). Grierson worked with Flaherty (1922) who had made feature length documentaries living amongst the people he was filming. As McLane (20012) argued, what distinguishes these texts is that Flaherty worked to tell a story about what he saw was happening, as opposed to Grierson who believed in writing a script with a preconceived point of view. These opposing views still remain in

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[9] Everything that appears in the framing of a shot; art direction, actors, lighting.

production practice and both have become accepted ways of working with a subject. Flaherty was not adverse to romanticising or dramatising a lifestyle,[10] as evidenced in his documentary *Nanook of the North* (1922). The controversy surrounding this work partly lies in the view that the public accepts what it sees on the screen as a real event.

Working in the expository mode was common practice in early nonfiction narratives (Nichols, 1991), where a commentary explained and guided the viewer towards a point of view.[11] Commentaries were primarily recorded using a male voice, and this was termed the "Voice-of-God" style. This selection of spokesperson or authorial voice firmly placed interpretation in the hands of the producer.

The use of an expository voice also provides new content and, as suggested by Nichols (1991), represents the dominant ideology so that "topical issues can be addressed with a frame of reference that need not be questioned or established but simply taken for granted" (p. 35). The way in which commentary can be used has changed with contemporary production practice. Bruzzi (2000) has argued that narration is a direct way of addressing an audience by simultaneously being all present and intimate and that narrations assist an audience because they:

> … set out an argument (thus implying forethought, knowledge, the ability
>
> to assimilate): they possess a dominant and constant perspective on the
>
> events they represent to which all elements within the film conform; they
>
> offer a solution and thereby a closure to the stories they tell. (pp. 42-43)

Bruzzi (2000) asserted that a documentary is the construct of the director. However, Nichols (2010) has suggested that the role of institutional factors and their influence on production are as far reaching. Many documentary productions have evolved through institutions that pursued specific goals with budgetary constraints, or socially delineated aims that have particular criteria defined by the group membership. He believed that documentary represents the historical world and not the imaginary world of fiction,

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[10] Flaherty asked his main subject Nanook to go out fishing on the ice and build an ice dwelling to create his story. Winston (2005) argued that this so called collaboration between Allakariallak (Nanook) and Flaherty was one that ultimately served to misrepresent the Inuit. In reality Allakariallak lived a contemporary modern lifestyle and it was his father's generation that had lived in these settings.

[11] Grierson's influence in the Commonwealth and English-speaking world was wide, as he travelled extensively though the British Colonies making productions, theorising and teaching about documentary.

albeit filmmakers in this area share common interests in the use of equipment and stylistic techniques. They also share similar difficulties in the distribution of films whether for theatrical or television and broadcast outlets. This has created further institutionalised practices reflected in professional organisations and distribution festivals (Nichols, 2010). The sense of a common purpose in providing a platform for discourse is perhaps what makes documentary practice a constantly evolving process. In this dynamic, over time, innovation becomes accepted practice.

Nichols (1991) said that in defining documentary as a practice, there is no fixed territory of what is encompassed, because the term does not define a set of practices, issues, style or modes. He suggested documentary form might be considered in "terms of the film-maker, the text and the viewer" (p. 12). He questioned any definition that describes documentary in terms of the relationship of power roles between filmmaker and subject. This he suggested ignores the social constructs of power in relationships where one group is disadvantaged. It also raised issues of consent and the consent a participant gives to a filmmaker in terms of the knowledge they contribute to the final product. Other problems he raised relate to how the filmmaker gains sponsorship, who retains ownership and distribution of the documentary and the end use of the work.

However, Nichols' (1991) theory of documentary describes a series of modes that distinguish different approaches. He described observational film as being the most authentic approach, as the non-intervention of the filmmaker allows for exploration of the world of the participant through the camera lens. However, he suggested that this can also be the most deceptive mode, as the image can be manipulated through editing, framing and camera placement. The rationale is that the filmmaker should be unobtrusive and it presumes the participant or subject of the film is not influenced by the camera's presence. The story is told without narration and is an attempt to present life as it is.

The participatory or interactive mode described by Nichols (1991) is commonly used in television documentaries, and largely revolves around edited interviews and observational footage that are used to create a representation of a situation. The viewer is a witness to this historical text as represented by the social actor whose testimony is spoken as one who has experienced a particular situation. This becomes an expectation

for the viewer, who is seeking information situated around personal or social experience. This practice highlights the power relationship that exists between subject and filmmaker. It also emphasises the hierarchy that exists in class difference and decisions around who is selected to be a representative or spokesperson in a film. The viewer is aware this is a reconstruction as pieces of interview testimony are assembled together creating a narrative or argument. This mode allows for the participants to speak for themselves and their testimony provides the narrative, which builds up the argument or point of view. This approach can be used with oral histories or testimonies as the person involved is viewed. It is also seen as a mode where personal perspectives or recollections are used to build up a story. Nichols (1991) emphasised the visible presence of the subject or social actor as one that assumes a monologue to the audience that comments, describes and gives impressions as an evidential witness to a situation. This presence can be further enhanced by the use of graphic information, intertitles to emphasise or clarify, and commentary, and these are ways a director can intervene and express a point of view. In so doing the participatory approach may emphasise the hierarchical interaction of the director's influence.

In practice, documentary practitioners view the changing formats and technologies differently. Rabiger (2009) suggested that for many, documentary is concerned with uncovering dimensions to actuality that may not have been perceived by others. Many stories too, provoke social criticism through their imagery of unfamiliar social situations and cultures. The viewer may be invited to rethink the status quo through experiencing the narrative. They may also confront moral and ethical questions inherent in the selection and interpretation of material. This observation suggests that the documentarian can unwittingly manipulate the narrative to create a positive outcome.

2.14 Examples of documentaries that influenced my research

Films about mental illness

The changes in public perception of mental illness are slowly being recognised and can be seen in in Philibert's (1997) observational documentary, *Every Little Thing,* which shows inpatients at Le Borde (The Clinic), a psychiatric rehabilitation centre in France, participating in rehearsals for a play by surrealist playwright Gombrowicz. This film portrayed the inmates with empathy and with openness to what is happening. Both

patients and staff are participants within the institutional space. This quasi-ethnographic approach allowed for observation over a period of a few days. It enabled the audience to follow daily life and it illustrated instances of a group living within a treatment situation. As most of this took place in the open air the documentary allowed opportunities for discreet observation by the camera.

There have been some notable films in the last decade about mental illness that have influenced my perceptions. In general these attempted to capture the world as perceived by the person experiencing mental distress. Negroponte's *Jupiter's Wife* (1995) is an observational documentary about Maggie Cogan living in Central Park, New York. Negroponte captured her over a two year period in the park, and interacts with her as she describes her connections with the god Jupiter. His intervention when Cogan is evicted from her shack in Central Park is controversial as it takes the viewer away from the observational nature of the piece. What it brings home to the viewer is Cogan's mistrust for society and the impact this has on her homeless state. This is a problem that many mentally ill people confront daily.

Marbrook's (2002) documentary *Dark Horse* is an observational film about Genesis Potini who suffered from bipolar disorder. It followed him in his exploits of teaching chess to young people in the Gisborne district of New Zealand. He is observed discussing his acute psychotic behaviour with other clients in a group meeting that reveals a great deal about Potini's experience of psychosis. Marbrook followed this documentary[12] with *Mental Notes* (2012). This offered an historical account of mental asylums as they existed in New Zealand that followed up with interviews with ex-patients and staff who reflected on their experiences. This second work brings home the realities of how the asylums had been perceived by some patients, and the documentary highlights individual cases. Stylistically it uses a combination of interviews with former inpatients, and actuality footage as individuals revisit the now defunct institutional buildings. The film's approach to removing the interviewer's presence from the final text was influential in my decision to adopt a related method. This choice was made because, by removing the visual presence of an outside party, a more in depth and focused emphasis can be drawn to the carer's narrative.

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[12] The documentary was made for cinematic viewing.

This work may be contrasted to a documentary shown on New Zealand television as part of Inside New Zealand, TV3, *Just a Little Mad?* (Bruce, 2008). Bruce created a narrative that juxtaposed re-enactments using an actor playing a schizophrenic with news footage of convicted killers with a psychiatric history to create authenticity and credibility, but at no time in the work did he delineate clearly between what was fact and what was fiction.[13] Although Bruce used extensive interviews with mental illness consumers throughout the documentary, the main character who is schizophrenic and experiencing a psychotic state was played by an actor. The story was neatly tied up with a positive ending and the schizophrenic was "cured" and working in a full-time job within a year. Bruce (2008, para. 7) stated:

> I realised when I was directing *Inside New Zealand: Just a Little Mad?* that the whole business of making a television documentary is in a sense an illusion. Nothing is really 'real' on TV, for as soon as you film it, reality becomes a captured fantasy.

He argued that this gave him "the licence to blend fact and fantasy into a story which has an ending you won't believe" (Bruce, 2008, para. 8).

For those hoping to learn more about schizophrenia, Bruce's handling of a sensitive story of an acute schizophrenic is disconcerting. Even though the programme contains interviews from people who have experienced psychosis, the techniques of blending real interview situations with role-play and re-enactments blurs authenticity and problematises the work. News footage of criminals with mental illness blended with the enacted hallucinations of the story's protagonist created further complexities about the illness. By juxtaposing schizophrenia and news footage of violent schizophrenics the film may arguably reinforce prevailing attitudes of danger and stigmatisation. The story presents a simplistic view of experiences that families go through, both in its suggestion of a short time span and in proposing redemption at the end of a year. Although worthy, the story shows an over-simplified view of family experiences both in terms of time and in the implicit over-promising of a redemptive ending.

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[13] The audience were notified at the beginning of the film that some re-enactments would occur but it was not made clear where these were.

Cadigan's film, *People Say I'm Crazy* (2003), was made over a period of a decade and offers a more realistic, "insider" perspective. In this work he filmed his own experience of schizophrenia concentrating on the emotional relationships and his ambitions with his artwork. The documentary is unusual in that Cadigan traced his life after being diagnosed with schizophrenia and his interactions with the people who remained his friends and supported him in his art. Cadigan began making the work a few years after he was diagnosed with schizophrenia and while he was studying at art school. He learnt to use the camera and directed the film himself.

In 2010, Dudding made a film called *Asylum Pieces* that was released at the New Zealand Film Festival in the same year. The work began as a film about asylums and in particular Porirua Asylum in New Zealand. In an interview with Gnanalingam (2010, para. 2), Dudding said that "research in the subject led me to discover major concerns such as the lack of care for mental health patients post-deinstitutionalisation and the adverse side effects of anti-depressants SSRI's". Dudding's film showed how official attitudes to mental illness are reflected in the changing architecture of New Zealand psychiatric institutions. The film used voice over and poetry to convey the human suffering and hopelessness of those sent back to live in the "community". It was slow paced and contained lengthy shots with strong content and voice overs that were poetic, complex and emotionally gripping. In viewing the film I realised the strong impact an authentic voice can have when narrating a personal story.

Costa Botes' documentary about writer and poet Michael Morrissey, *Day Tiger*, was launched at the New Zealand Film Festival in 2011. This observational work traced a period of time where Morrissey was manic. Morrissey refused to take medication as he felt it destroyed his creativity. I found the documentary difficult to watch, the raw emotion and mental battering his wife Anna endured filled me with despair. In many ways it was an interesting film because it showed the experience of an acute manic state, but on the other hand it produced an unsettling sense of voyeuristic invasion into someone's darkest moments. One can only feel compassion for a wife who so loyally endures this level of verbal abuse. This may be a reality of the experience but it is a hard one to witness. The film is centred round Morrissey, and his wife is viewed as a passive victim. To survive and support Morrissey she could not have been a victim, but would

have to have been courageous and strong-minded. This aspect of her behaviour was barely portrayed in the film. The observation of Morrissey's mental distress made me realise that there is a fine line to draw between a voyeuristic albeit realistic portrayal, and one that offers reflection and insight into a situation. I wanted to capture the latter.

These documentaries are all notable examples of filmmaking that are centred around the subject of mental illness and are available to the general public. However, what they do not show is the family experience of mental illness, or how families communicate with a family member who is attempting to manage the condition.

Videos for personal viewing

In seeking out online resources dealing with families supporting members with mental health issues, a few publications came to light. On SANE Australia's website,[14] there is a series of video resources in the form of podcasts for families, in which family care and different relationships are discussed. In short interviews, approximately two minutes in length, people talk frankly about their relationships with the person they support, and some key issues are mentioned. I was deeply affected by hearing these short snippets that showed strong interpersonal relationships between caregivers and family members. These recordings stood in contrast to what our family was experiencing.

In 2009, Carer's Australia made a DVD that dealt with the experiences of Australian families who were supporting a family member with depression. In it families speak about their experiences. Two of these interviews, one by a well known Australian television personality, have been placed on their website[15]. These works led me to explore in depth, day to day situations and relationships in New Zealand.

An Internet site set up in 2009 by the actress Glenn Close, *Bring Change 2 Mind*, was devised as Close's response to supporting her sister who has bipolar disorder.[16] The main function of the site is to talk about mental illness and set up conversations that might reduce stigma and discrimination. While Close's family are named and their story is told, most other contributors to this website are anonymous.

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[14] www.sane.org
[15] http://beyondblue.org.au.
[16] bringchange2mind.org

These works have impacted on my research project as they highlighted that most of the work described how individuals behaved when unwell. Very few of them show interactions of support and there is very little information available on carer narratives.

Video models with established international success

Employing interviews and visual sequences to create a story is not new. The technique was used notably by Field (1980) in *The Life and Times of Rosie the Riveter.* Field interviewed women who had been working in the armaments factories in America during WW11. These interviews were interspersed with documentary footage of factory workers, advertisements for the war effort, American war propaganda, and archived depictions of women working in the factories during the period. The interviews were conducted in 1980 with women who had taken over men's jobs. In these they reflected on what factory work had been like as an appreciated undertaking during the war years, prior to their suddenly being made redundant when men returned from combat.

Fyfe (2003) described a model similar to this used by Gaylene Preston in her 1995 documentary, *War Stories Our Mothers Never Told Us*. Preston's work recorded oral testimonies and stories of the everyday lives of New Zealand women during World War 11. Fyfe (2003) argued that traditionally war has been viewed as a male domain and although the war had re-shaped the lives of women at the time, what women had contributed was seen as of peripheral importance. Preston selected a small group of women to interview on camera whose experiences were not only representative of the war in general but were "also distinctively their own" (Fyfe, 2003, p. 296). Stories were created from both audio and video recordings. Fyfe (2003) noted that she and Preston did not start with a particular premise but with a series of questions that encouraged the women to express whether this had been the best or the worst time of their lives, or whether it had been an interesting or insignificant time. In selecting participants they tried to assemble a diverse group from different socio-economic backgrounds who had unique wartime experiences. A peremptory literature review suggested themes they might explore. Over ninety interviewees were chosen for the project, and their stories have been archived in the Alexander Turnbull Library, Wellington. Seven of the interviews were then selected and developed into stories for the feature length film. The strength of these stories Fyfe (2003) contended, is that they "give a voice to those previously denied the chance to contribute to the recording of history" (p. 300).

In developing this documentary, the filmmakers first assembled a chronology of events and milestones of national and international importance and considered how these had impacted on the participants' lives. This gave an opportunity for Preston to look at relevant letters and photographs, and establish other archival material that could be useful in building a visual story. Preston's film relied heavily on interviews conducted in a studio where women were talking about experiences that occurred over fifty years ago.

Unlike Preston's film, the stories collected in *Hope* are ongoing and primarily situated in the present. However, there are other fundamental differences to Preston's film. The first is that there is very little historical footage or individual family footage added to the stories I have presented. The stories in *Hope* have to rely on the power of personal testimony, because I wanted to focus on the immediacy and presence of caregivers' stories. Second, my work is not supported by re-enactments; everything is a testament of the moment. Finally, I did not interview the carers in a studio. Instead I have filmed them in their homes and the surrounding environs to provide a context and establish their relationships with family members.

2.15   Summary

The many threads of this review of knowledge have provided a context for the film *Hope*. Documentary forms continue to evolve, yet in this evolution traditional techniques are still being used albeit with greater technical sophistication and clarity. What is evident is that production practices are now being used in different ways to engage audiences. The expository mode described by Bruzzi (2000) and Nichols (1991) demonstrates how a director can control the script content and the writer's narration is used to guide the viewer towards the director's point of view. Considering this mode has enabled me to work through ways to combine what Nichols (1991) described as participatory/interactive and observational modes in the planning of my documentary in which interviews selected as narratives are edited together to build up a conversation. These I believe may offer an arguably more authentic way of conveying family stories because the family becomes the personal narrator and influences the flow and content of the storyline.

A number of feature documentary films have influenced my approach, but most of these are observational and not suitable for the task of capturing the narratives of families. However, observational sequences have influenced my decision to record family members interacting. Using narration and dramatic re-enactments was not an area I wished to utilise as the literature revealed that family interactions were complex and unique, and the individual characteristics of each family story needed to be clearly portrayed without unnecessary artifice.

The review of contextual knowledge has taken me into new areas and has opened up diverse avenues of information but, most importantly, it has provided a context to develop interview questions for the participants. In addition this review has considered a realm of knowing in which the thesis can be situated and a range of provocations that have been instrumental in the realisation of the project.

The next chapter considers the Research Design of the thesis and discusses how methods employed emanated from the nature of a heuristic inquiry.

Chapter 3: Research Design

3.1 Introduction

This thesis comprises an exegesis and a creative production artefact[17] in the form of a documentary called *Hope*. To explicate the documentary project I developed a research design that addresses creative and logistical aspects of the project. This chapter therefore offers a consideration of the following ideas:

- Philosophical underpinnings

- Creative practice as research

- Methodology

- Methods.

The purpose of this thesis has been to find a way of capturing and presenting stories within ethical guidelines that afford respect and allow participants to narrate experience in a relatively authentic manner, and to provide support for others in similar situations. Here data is collected and reconstituted as a documentary that has been designed to be accessible and relatable to situations that other caregivers might experience.

From these considerations an initial research question was developed. It asked:
How can an ethically robust documentary process be developed that effectively captures the experience of supporting a family member who has experienced a mental illness?

This question surfaced from my awareness that telling stories as documentary practice is currently in a state of evolution. As technology has become more sophisticated, more accessible and easier to use, practitioners have increasingly been able to carry lightweight equipment and capture real life events as they are happening. However as Rabiger (2009) noted, what is captured through the camera lens is only a partial view of reality. It is in effect a construction, framed and selected to provide a view that is an interpretation of a live event. How a director selects an image to shoot and edit, depends

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[17] In using this term I refer to Scrivener's (2000) essay on art and design PhD research projects. In this, he noted that such research produces an artefact that "can be described as a response to a set of on-going issues, concerns and interests … usually rooted in the cultural context." These artefacts "contribute to human experience. This being the case, the creative production … is more important than any knowledge embodied in it" (p. 5).

on both explicit knowledge of the craft of film production as well as tacit knowing that allows her to reflect on and enrich the construction of information.[18]

Thus, in this thesis I have sought to reach beyond the creative construction of an artefact as a discrete object. I have also considered ethical processes underpinning its realisation. Accordingly the project has required a research design that is both analytical (able to review and synthesise contextualising knowledge and feedback on emerging iterations of the work) and intuitive (able to generate ideas and heuristically sense my way through a range of emerging questions and creative responses).

3.2 Philosophical underpinnings

Paradigmatically this thesis project may be understood as qualitative in nature and concerned with creative production. As such, it has been developed in response to a need to consider ways in which people interpret their experiences of caregiving. The documentary has been designed to communicate six discrete yet thematically linked personal narratives. Accordingly, I have employed a phenomenological approach to data gathering (collecting the stories).

Titchen and Hobson (2005) suggest phenomenology, is "the study of lived, human phenomena within the everyday social context, in which the phenomena occurs from the perspective of those who experience them" (p. 121). They further differentiated between phenomena that can be "*directly* researched by exploring human knowing through accessing consciousness, and *indirectly* by investigating human *being*, through accessing the senses and shared background of the phenomenon" (ibid.). Because I have been concerned with the ontology (or essence) of the subject, I have also explored the epistemological perspective (or way of knowing) that was being presented. In so doing I have used a phenomenological approach to data collection that has provided me with indepth and reflective information. Husserl (1913/1982) identified "Eidos", and the perception of the essence of an object and suggested that this was a process of intuition.

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[18] For this project I have been the producer, director, editor and researcher. Accordingly, in the following discussion I refer to my role as director/researcher.

He suggested, "The Eidos, *the pure essence*, can be exemplified for intuition in experiential data—in data of perception, memory and so forth" (p. 11). However it was Heidegger (1953/1996) who identified "Dasein" (being), which is a way of understanding and interpreting the world through experience, and this became my predominant way of looking at my data. My understandings or experience, assisted my dasein in drawing out this interpretation that was often buried in my unconscious (Heidegger, 2005). As both the gathering of the information in the recorded interviews and editing were an exploration of caregiving, intuitive reflection and tacit knowing formed part of the process of story capture and the refinement of the design.

3.3 Creative practice as research

Aims and Purposes

Hope was developed as a documentary that might usefully contribute to human experience and reflect on cultural issues. However, although Scrivener (2000) has suggested that artefacts produced in such research are themselves more important than the knowledge embodied in them, the ways in which this creative production has been developed have been as important as the interpretation of human experience that is contained within it.

In designing and constructing this documentary I have been motivated by four aims.

- Firstly, I wanted to work on an issue of which I had personal, lived experience. The intention was to investigate the potential of qualitative interview techniques to examine how documentary might be used as a form of indepth inquiry into an issue.
- Secondly, I wanted to create an artefact that would bring knowledge together in a way that would be useful for a specific audience, because it would widen their experience.
- Thirdly, I wanted to work collaboratively with interviewees and crew to see if we could develop ethical protocols that might preserve participant safety while allowing each person to contribute an authentic narrative of lived experience.

- Finally, because I was personally involved in a similar family situation, I hoped to learn from the stories of others.

Relationships between phases of the inquiry

Although before beginning the practical project certain questions about caregiving and the effect it had on families were identified, the outcomes of the research were unknown. My proposed framework suggested qualitative interviews, and reflection-in-action through a collaborative model that involved both participants and crew. I understood from the outset that the research design would need to be flexible enough to accommodate changes or problems that surfaced during the documentary's production. The creative working process of the director/researcher and camera crew, the collaboration with the participants, the critical reflection on the content, and the editing and addition of music and graphics comprised the production elements of the project. These created a distinctive workflow illustrated in Table 1.

The project began with a small crew operating as an integrated unit. This team worked collaboratively with participants. Initial recordings of interviews were made and these were assembled in draft form as a documentary. After viewing the first edit the documentary focus was changed, and was edited into six discrete stories. Following feedback and advice from each participant on this draft edit, additional shoots were undertaken.

Encompassing the entire workflow are considerations of ethical approaches to establishing parameters and protocols for the project.				
PREPRODUCTION Meetings with participants. Crew discusses the implications of and approach to the project (director/researcher camera, sound). Core concerns, parameters, implications and experiences are discussed.	PRODUCTION Individual stories are recorded on camera.	POST-PRODUCTION Edited into one documentary. Individual stories are re-assembled as six initial edits.	FEEDBACK First edits are fed back to participants as a rough cut for critical reflection, advice, required changes and forward planning for additional shoots. Edits shown to professional counsellors for comment. If participants wanted to add or subtract anything this was decided at this stage, otherwise the original was left as it was.	PRODUCTION Further shooting where necessary (over a period of 18 months). è
FEEDBACK Feedback sought from relevant professional parties.			POST-PRODUCTION A fine edit completed. Titles developed. Additional music/visuals added to enhance the documentary's atmosphere.	FEEDBACK The proposed documentary is fed back to participants for approval. Participants receive a copy of the work before it is submitted for examination.

Table 1*: Workflow showing integration of production elements.* With each version of the documentary I returned to the participants as we collaboratively developed and refined their stories. Finally a fine cut edit was produced with additional music, environmental footage and sound. The project was then distributed to the participants for approval.

3.4 Heuristics

Methodologically the thesis project may be broadly described as a heuristic inquiry (Douglass & Moustakas, 1985; Hubka & Eder, 1996; Ings, 2013; Kleining & Witt, 2000; Moustakas, 1990; Sela-Smith, 2002). Ings (2011, p. 227) suggested that such inquiries relate to "the ability to find knowledge, patterns or a desired result by intelligent, informal questioning and guess work rather than by applying pre-established formulae." As a form of inquiry he suggested that heuristics employs "sophisticated levels of informed subjectivity and tacit knowledge to solve complex creative problems" (ibid.). Although the project engaged periods of objective analysis and critical review,

its primary concerns were with discovery and inquiring into how a process and artefact might be developed when one is sensing one's way forward.

Moustakas (1990, p. 11) in referring to origins of the Greek word "heuriskein" (ευρισκω—to discover or to find) described the heuristic process as a way of using knowledge to gather together a combination of intuitive and conscious processes. His description that "Whatever presents itself in the consciousness of the investigator as perception, sense, intuition, or knowledge represents an invitation for further elucidation," caused me to question my work deeply.[19] However, heuristic inquiries are also unpredictable (Douglass & Moustakas, 1985), and the research focus can change as the study evolves (Griffiths, 2010). While sometimes destabilising, this tendency for change can also produce serendipitous discoveries or unanticipated results (Ings, 2013). Thus the project became a system of inquiry in which perceptions, self-discovery, dialogue and the research question came together. The emphasis was on the investigator's frame of reference. I used intuition and indwelling to work my way through accumulating data (Douglass & Moustakas, 1985; Moustakas, 1990; Kleining & Witt, 2000). My family experience with its specific problems functioned as an accompaniment to the inquiry. Both the research question and data emerging from it were absorbed into the self (Sela-Smith, 2002) and I worked my way forward without a formula but with a growing recognition and emerging comprehension.

The role of tacit knowing

Pivotal to this process Moustakas (1990) suggested is tacit knowing. Polanyi (1983) identified tacit knowledge as knowledge gained from experience that discloses both the self and the elements of perception that need to come into research. He stated "I shall reconsider human knowledge by starting from the fact that we can know more than we can tell" (p. 4). He suggested that tacit knowing combines different kinds of knowing, that are a combination of functional and phenomenological aspects, because we may know something without being able to specify its details.

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[19] These outcomes, Borgdorff (2009, p. 21) suggested, may broaden and shift our perspectives and horizons. He says such research, "is about constituting and accessing uncharted territories. It is about organised curiosity, about reflexivity and engagement. It is about connecting knowledge, morality, beauty and everyday life."

Mead (2007), in discussing Polanyi, described "tacit intimation" as a kind of intuition, or "trained capacity" (p. 303) that evolves from acquiring competency through years of scholarly inquiry, (and not as some mystical or subjective phenomena). This knowledge, he suggested, is made normative or reliable by being acquired in educational situations and through scholarly traditions. Mead (2007, p. 303) said:

> It is from our experience of such sustained, disciplined, and collaborative immersion, or indwelling, that we come to sense that we are located within a "heuristic field" and (to use another Polanyian phrase) are proceeding along a "gradient of discovery" that guides us—though not infallibly, still for the most part reliably, fruitfully, and therefore in the right direction— for achieving deeper and more comprehensive understanding (or 'comprehension') and discovery.

Moustakas (1990), in developing Polanyi's concept, suggested that the search for knowledge is exploratory, open-ended and self-directed. Tacit knowledge, he argued, is "the deep structure that contains the unique perceptions, feelings, intuitions, belief, and judgements housed in the internal frame of reference of a person that governs behaviour and determines how we interpret experience" (p. 32). Our experiences can produce something that fits together with earlier experiences creating a new whole, which over time develops the core of a person's knowledge. The researcher continues to compare new knowledge with the inner knowledge core and evaluates these to match new experiences with what they already know. In this way he suggests, knowledge expands.

Douglass and Moustakas (1985) have described the heuristic process as, "a search for the discovery of meaning and essence in significant human experience" (p. 40). They argued that, it requires a personal exploration that is probing, and that requires the effort of refinement and illumination of what is being investigated.

Tacit knowing has played a significant role in my analysis of the information captured in the video interviews. Polanyi (1983, p. 6) argued that tacit knowledge and the creation of a body of work could be described as "the active shaping of experience performed in the pursuit of knowledge". He saw this shaping or integrating as a manifestation of "the great and indispensable tacit power by which all knowledge is discovered and once

discovered, is held to be true" (ibid.). In this way knowledge gained and combined with intuition, was interpreted and became part of the final artefact.

My approach to interpreting data relied on tacit knowing, and I used my accrued experience as a starting point. Tacit knowing enabled me to "sense my way forward" with the inquiry (Moustakas, 1990; Ings, 2011). I was able to discern homologies and correlations in recorded material (Kleining & Witt, 2000), select these intuitively, and weave them into cohesive strands of narrative.

Tacit knowing is deeply embedded and not explicit. I found my lived, subjective experience of the caregiving role influenced me considerably. In interviews, tacit knowing emanated from my encounter with a related situation and caused me to appreciate certain homogeneous situations when they arose, even when my family experiences were not identical to scenarios that participants described. In this regard the research was experienced on both a cognitive and emotional level and finding ways to navigate and manage this was challenging (Ings, 2011). This was partly because I often found myself in a state of unknowing and the shared experience of listening to another person navigating a caregiving situation without a roadmap was emotionally very moving.

The protean question

In a heuristic inquiry, when capturing data Moustakas (1990) noted, one seeks "to obtain qualitative depictions that are at the heart and depths of a person's experience-depictions of situations, events, conversations, relationships, feelings, thoughts, values and belief" (p. 38). Working heuristically demands that the researcher remains open to new concepts in an investigation and is aware that the topic may change as more knowledge is gained about the subject (Kleining & Witt, 2000). These writers suggested that in heuristic inquiries, data should be taken at different times, in different situations, and with different respondents. The subsequent analysis of data should place emphasis on the discovery of similarities.

Accordingly this research project was not a linear journey but one that took me down many different avenues of understanding and through processes that were re-evaluated and continually processed. As both Ings (2011) and Sela-Smith (2002) have noted,

heuristic research can lead one into unfamiliar and unstable forms of investigation, where the researcher must surrender to the inquiry and let it take her into new territories. These inquiries are generally navigated by a form of interior orientation.[20]

Sela-Smith, in her 2002 critique on Moustakas' method (1990), suggested that in his writing on heuristic inquiry he had failed to emphasise the feelings and internal orientation that heuristic research must maintain. She stated, "The experience of life may be turned upside-down when there is surrender to feeling (p.80). Even so, she suggested that a relentless inward focus can lead to a "greater self understanding, self-transformation, and reconstruction of a hindering worldview." (p.80). This was true on quite deeply felt levels for me while developing the project because I was often hearing occurrences and anxieties articulated that I had also experienced, but had hitherto been unable to give expression. These caused me to draw what I was finding back into myself (and by extension, into the protean research question as an indwelt phenomenon).

Sela-Smith suggested that without self-understanding, a researcher when receiving external feedback can end up applying critique to the artefact and restricting its focus instead of connecting it to the tacit knowing that created it. However, it has been noted that the researcher who has substantial personal experience can draw on such feedback for critical decision-making by absorbing it back into the question being considered and this enables her to maintain a focus on the purpose and wider dimensions of the inquiry (Ings, 2011).

When beginning this thesis project, my only certainty was that the documentary would be constructed from depictions of lived experiences, stories, photographs and images, and these would be edited into an artefact that could elucidate life experience.

In researching *Hope,* the themes that significantly shaped the documentary's final form (home as a sanctuary, chaos and order, nature as a metaphor, understanding recovery, diagnosis and treatment, and giving and receiving care) were not coded or examined analytically. Instead, they gradually emerged through the descriptions of the participants' lived experience. Thus, the themes were not identified at the outset of the

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[20] By this I mean a form of intuitive sensing of homologies and connections between data as I experiment with it in the design of the documentary both in its field work and post-production.

project but surfaced as a natural consequence of its protean development. The emergence of knowledge that changes the emphasis of an inquiry is indicative of heuristic research and as Kleining and Witt (2000) suggested, such changes may be taken as evidence that the research is working effectively.

3.5 Methods used in the creative process

Interviewing participants

Although methodologically the research project employed the tenets of a heuristic inquiry, distinct methods were employed in its explication. Because I was capturing life stories, I worked with qualitative research interviewing techniques as described by Kvale and Brinkman (2009) who suggested an exploratory way of interviewing that uses questions that are open ended. The interviews were structured to enable participants to be clear about the purposes and the "why" of the study. I also identified the "what" of the study by first discussing what was possible to disclose in a video interview that could become public. Even with the greatest care being taken, I could not be absolutely sure that information spoken would be entirely confidential as I was working with a team of people. What I aimed to achieve was information that Kvale and Brinkman, (2009) suggested might be "descriptive and seek to chart key aspects of the subject's lived world" (p. 106). In planning the "how" of the interview, I was aware that it was necessary to maintain an overview of the complete investigation. In identifying the themes and asking questions, the experiences of caregivers were my primary consideration. I was sensitive to the trust being placed in me so I endeavoured not to guide or direct participants into what they selected to disclose. My questioning technique was open ended and responsive, acting as a catalyst to draw stories to the surface in a manner that was neither intrusive nor disorienting. My approach was normally to question only if necessary and to link questions to information that was already surfacing through the flow of the participant's narrative.

I was also careful to constantly reacquaint all parties with the purpose of the documentary. The project was not seeking to expose emotional distress. Instead it was attempting to draw to the surface experiences that might be useful to viewers who might find themselves in similar situations.

In selecting specific locations for the recordings I chose settings that might reveal something authentic about the participants and their way of life. I was aware that I would be questioning them about historical events so I endeavoured to avoid the situation Rabiger (2009, p. 481) described in his critique of television interviews where,

> People speak in the past tense about events already concluded. They
> face an interviewer and give—or resist or deny—what the interviewer
> seems to want. The limitation is obvious, that it's interviewer centred
> and at some level inherently adversarial.

Rabiger suggested in these instances that the director is setting up an argument for discussion that will be answered on screen. This was not the purpose of the interviews in *Hope.* My intention was to collaborate in a discussion that explored the experience and assisted the interviewees through questioning that might help them to explain their point of view. [21]

Finding volunteer families who were willing to tell their stories presented some personal challenges. During this period I had taken part as a volunteer in a university research project on caregiving and when being interviewed I had found myself becoming anxious, tearful and overwhelmed by talking about events. This alerted me to the vulnerability of my potential subjects and made me cautious, both in approaching them to take part, and in explaining the possible consequences of telling their story in public.

The practitioner working with reflection-in-action

Although the methodology employed in explicating this project may be broadly described as heuristic, within this I constantly reflected on my practice while interviewing and more significantly, when writing (editing and constructing) the final text. Reflective practice is described by Schön (1983) as an ongoing process that can be examined at different stages. He identified working through a process of reflection-in-action that can proceed to knowing-in-practice and back to reflection-in-action. As the documentary content and production processes were integrated, his description of

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[21] In designing the approach to the documentary, early on, I decided to edit my questions out of the final narratives so the focus of the work would remain solely on the participant's stories.

reflection-in-action and practice resonated as a means of following the working progression. In commenting on the notion of reflection-in-action for the practitioner, Schön (1983) conceded that knowing is tacit, and implicit in the way the practitioner works with the material in a progression that matches the action. He identified a series of questions that formed a progression for practitioners in reflecting on the course of action in progress (Schön, 1983, p. 50)

These were:

- What features do I notice when I recognize this thing?
- What are the criteria by which I make this judgement?
- What procedures am I enacting when I perform this skill?
- How am I framing the problem that I am trying to solve? (ibid.)

Schön distinguished between knowing-in-action as the basis of practical knowledge and reflecting-in-action, which is recognising thinking about something while doing it. He suggested that phrases such as "thinking on your feet", "keeping your wits about you" and "learning by doing" show that we can think while doing and this process occurs in sports, music or any performance (ibid. p. 54). This process of reflection also occurs while we are creating something. Working with video is inherently a process of reflection-in–action as the preparation and planning can never be exact when working with human subjects, who are responding dynamically to an ongoing situation.

Also inherent within this reflection is the fact that through errors and bewilderment comes surprise, and it is this element of surprise that generates a new understanding. Schön (1983, p. 68) noted:

> … the practitioner allows himself to experience surprise, puzzlement, or
> confusion in a situation which he finds uncertain or unique. He reflects
> on the phenomena before him, and on the prior understandings, which
> have been implicit in his behaviour. He carries out an experiment which
> serves to generate both a new understanding of the phenomenon and a
> change in the situation.

I encountered numerous examples of spontaneous surprise when shooting, editing and designing *Hope.* For example, when I asked Tupuna about how he had been supported in

caring for Shirl he spontaneously revealed that being Maori made a significant difference.

Figure 1: Tupuna explaining how being Maori supports him. His revelation surfaced naturally from the flow of his narrative about caring, but at no time preceding this discussion had I raised the issue of the couple's bicultural relationship.

> Me being a Maori is of great importance in whanau (family), so tikanga and all that sort of thing does … it helps in some ways, but it doesn't always help because you have the old beliefs and you've got what's happening now right there in front of you. And you know Maori talk about mataku and all that curse and that's the reason a person is the way she or he is, but you know being brought up in a Pakeha world in a sense has taught you not all of it is that way, you respect what your elders are saying or your tupuna has said, but you also have to look at it in an another light, yup. Deal with it how it is right now (Tupuna, 2011. Transcript: 01:00:17:00-01:01:48:00).

When I revisited Tupuna some months later his niece was putting away a guitar when we arrived. On the front lawn they had been practicing a waiata[22] to perform at an upcoming meeting. Shirl allowed us to capture her practicing while Tupuna accompanied the women on the guitar.

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[22] A waiata is a song or chant where words and expressions normally preserve the wisdom and knowledge of ancestors in Māori culture.

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Figure 2. Tupuna playing his guitar in accompaniment to the waiata.

Figure 3. Shirl and Tupuna's nieces practising a waiata on the front lawn after we arrived for an additional day of shooting.

In the process of reflection in practice I experienced a form of dialogue (or backtalk) with the material I was capturing or editing. Yanow and Tsoukas (2007, p. 1348) noted that a phenomenological view of reflection-in-action is dependent on this "backtalk" that leads the practitioner to a response or reaction that is improvised.[23] In their discussion of how reflection in practice works, Yanow and Tsoukas (2007, p. 1348) emphasised that "backtalk" is not the same as feedback but is unplanned and non-rational.[24] The authors said "one needs to respond in the moment: scenes are built out of successive layerings of backtalk".

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[23] Schön (1987, p. 5) defined improvisation as being able to deal with unique cases marked by "uncertainty, uniqueness and conflict," describing it as 'inventing, and testing in the situation strategies of (one's) own devising". He presumes that a professional practitioner has gained a set of practices, has rehearsed information and has a fund of knowledge to draw from.

[24] The authors use the example of acting improvisation and theatre techniques where a group of actors working together after hours of practice in improvising, learn to understand one another's way of thinking and can work from each other's spontaneous reactions.

Working with feedback

When drawing accumulated interview data together into coherent narratives, I found that I looked for authenticity, connectedness and relationships. Moustakas (1990) suggested that what I was trying to do was to ensure that the "research participants remain visible in the examination of the data and continue to be portrayed as whole persons" (p. 39). My focus was to recall their lived experience and to recreate it in a manner that preserved the unique nature of each account of caring for a family member with a mental illness.

After the first edit I gave all of the participants a DVD copy of the rough-cut of their story so they could view and comment on it. At the same time I gave rough-cut copies to family counsellors at Supporting Families in Mental Illness (SFMI) Auckland, who viewed the first cuts as a group and provided me with feedback. This seeking of external feedback became important in the design process. This is because I had become personally very involved with each family story and I was finding it difficult to maintain an objective stance. I was reminded in this process of Gray & Malins' (2004) assertion that, "In seeking the views of others which will inevitably be subjective, we can develop inter-subjective views, which are less likely to be one-sided" (p. 23).

The following example illustrates this process of feedback altering the content and emphasis of the final documentary. It relates to concerns Emma raised regarding the choice of language she had used in the interview.

> ... when we were kids we didn't know anyone else with a mental illness and so you just didn't talk about it, you just pretended everything was fine. We lived with Dad but we went to Mum on the weekends and sometimes she was completely nuts and we didn't tell anyone, and that's not healthy ... (Emma, 2011. Transcript: 00:01:30:00-00:01:31:08)

When viewing the first cut of her interview Emma was initially worried that she was being callous about her mother's ill health when she had used the words "completely nuts". However when we talked through the issue, she concluded that within the context of the discussion of her writing the book *David's Story* (excerpts of which were included

in the interview), the reason for her emotional framing was revealed and on reconsideration she felt that the statement was appropriate because it avoided reducing the language to clinical terminology. She came to the conclusion that her comments had been motivated by a desire to allow young children the opportunity to express their feelings about their parents in an authentic manner.

Figure 4. Emma explaining why she wrote David's Story.
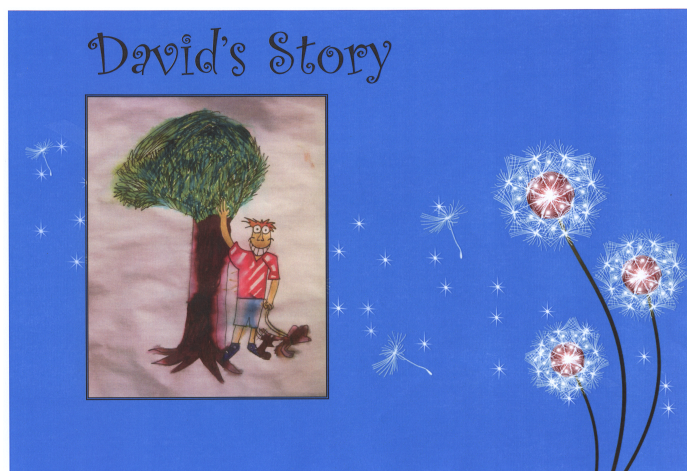

Figure 5. Illustration from David's Story.[25]

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[25] *David's Story* is an electronic book for children aged 6 to 12 about a young boy living with a mother who has Bipolar Disorder. David describes his family, his mum and her illness, and who he stays with when his mum is sick. The book can be accessed at:
www.copmi.net.au/resources/search/rsults.html?site=3

In the final edit a visual sequence of Emma writing on her computer is intercut with illustrations and text from the story. This serves to place her comments within the context of her reflections on her childhood.

The Reflective Journal

Throughout the research process I kept a reflective journal. Such journals have a long, educational and professional history in art and design research (Mäkelä, 2007; Newbury, 2001). They are useful because they integrate elements of "the real 'inner drama' of research, with its intuitive base, its halting time-line, and its extensive recycling of concepts and perspectives" (Marshall & Rossman, 1995, p. 15). In this thesis the journal facilitated the research process through recording observations, impressions and questions as they occurred. As such, it provided an "ongoing developmental dialogue" with data as it was being collected (Schaltzman & Strauss, 1973, p. 94).

From my first interview with participants I made entries that were written up after each meeting. I continued recording these when shooting, and reflecting on how the interview had gone (from both my perspective and the interviewee's). These notes assisted me when re-examining the transcripts because I had noted down when participants were emotionally stressed and recorded how it had affected members of the team and myself. This process of recording reflections on the context of the shoot was useful when deciding which areas needed expansion in later interviews. The reflections also helped to maintain my focus on anxiety levels around the project as it moved through various iterations. It was particularly valuable during the first few shoots as I had been nervous and tentative and felt concerned about being invasive in my questioning. However, after a few sessions, and as I got to know the participants, it became easier, particularly as I found that participants were keen to talk and took advantage of the opportunity to do so.

3.6 Summary

In this chapter I have discussed how the research design of *Hope* was influenced by the philosophical underpinnings of a phenomenological approach to data gathering, based on an understanding and interpretation of the world through lived experience (Heidegger, 2005). The purpose of the inquiry was to use my personal experience as a starting point

from which to investigate the potential of qualitative interview techniques in developing an indepth inquiry into an issue. As an extension of this I wished to use the project to develop a set of protocols for working with participants who, when contributing to a documentary, might be placed at risk when exposing personal stories.

Central to the research design was the use of an heuristic approach. This heightened the chances of discovery in the project because the research remained flexible and responsive to emerging data. The heuristic approach enabled me to find knowledge and patterns through a process of insightful questioning, guess work and feedback from collaborators. It validated the subjective nature of the inquiry where I drew heavily on tacit knowledge to solve complex problems.

Heuristic inquiries draw on tacit knowing and a substantial amount of this emanated from my professional background as a documentary maker, and my lived experience as a family caregiver. As the project developed, these experiences operated as "an internal frame of reference" (Moustakas, 1990, p. 32). Because I was dealing with unknown stories I was unable to predict trajectories through the inquiry. Accordingly, I worked collaboratively with participants and crew to establish a form of inquiry where open-ended questions and feedback enabled me to draw to the surface (and have agreed upon), the content, emphases and eventual design of the participants' stories.

As the project progressed I reflected on my actions through the use of a journal and an ongoing dialogue with emerging data. The use of feedback loops with participants and professional organisations enabled me to constantly re-evaluate iterations of the documentary and remain attentive to participants' perceptions of their recorded material.

While it is impossible to offer a clear cut methodological approach, this chapter has highlighted the application of the research design underpinning the development of the documentary *Hope.* Having done this, I will now consider significant issues that impacted on the development of the project.

Chapter 4: Issues impacting on the project

4.1 Introduction

Many considerations shaped the design of the documentary *Hope*. However there are three significant issues that relate to the area of experience that it encompasses. This chapter offers a discussion of these concerns and how they impacted on the structural and ethical resolution of the project. They are:

- Narrative structure and emphasis
- Subjectivity and reliable storytelling
- Ethical issues relating to documentary production.

4.2 Narrative structure and emphasis

The design of *Hope* is distinctive and it has been developed after considerable reflection on the potentials and implications of different narrative structures. Bandura (1995) suggested that sharing personal life stories with others can produce a sense of self-efficacy and this can have an empowering effect on the storyteller. This process was important for me, because in constructing the documentary, I made choices about what to include and what to exclude, and the feedback from participants was insightful, constructive and affirmative of certain decisions I made. But I was acutely aware that when editing the participants' stories, I was shaping their narratives. In this regard, I was constantly reminded of Buckingham's (2009) observation that, in making an artefact it is naïve to believe that as the director/researcher one is not shaping it.

Most of my working life as a practitioner has involved developing fictional or non-fiction material creatively into stories for the theatre and screen and I drew on this knowledge to construct the narrative for *Hope*. Todorov (1981), in defining story structure, described it as a process of gradual shifts in the events occurring in the narrative, that are shown through a character's development. A story begins with the main character in a state of equilibrium, then disruption or conflict occurs; there is recognition, an attempt towards action, and a new found or created equilibrium returns at the end. This structure underpins a great deal of documentary material designed for television viewing. This is because, as de Jong, Knudsen and Rothwell (2012, p. 100)

have noted, documentary makers often adopt a basic structure drawn from Western storytelling practice because it is what audiences recognise and expect.

De Jong, Knudsen & Rothwell's model is illustrated in Table 2.

INTRODUCTION	POINT OF ATTACK	MAIN BODY OF THE FILM	WRAP UP	EXIT SEQUENCE

Table 2. *De Jong, Knudsen & Rothwell's (2012) documentary structure.*

In this model the authors described:
- The *introduction* that provides the main characters, the theme, and the framing of the story.
- The *point of attack.* This introduces interviews, sequences and an exploration of the topic.
- The *main body* of the film. This develops these areas, leading to a "wrap up" or climax.
- Finally, the *exit sequence* explains the changed reality of the main characters. (ibid., p.100).

In constructing a documentary story this way, an assumption is made that the narrative is historical, it can be plotted out before shooting begins, and a script can be clearly drawn up. However, the stories I captured delved into the unknown; they were about feelings, recalling emotions that could be ephemeral and disturbing and might not be possible to articulate. Accordingly, I was unable to determine the potential nature of the storylines.

Rabiger, (2009) has suggested that shaping a story is more complex than considering cause and effect. He suggested that implying a thematic and interpretative approach will reveal changes in characters that lie inherent in the story. He argued that identifying an effective structure is dependent upon looking at the footage and the director/researcher determining how she will handle "time". Next, she must decide in what order "cause and effect or any dramatic advantages" (Rabiger, 2009, p. 422) will be affected by changing the natural sequence of events. Rabiger (2009) believed that the most satisfying stories

are about change and the need to deal with it. In this dynamic, the development of characters he believed, must be central to each story.

I had envisaged that, in constructing *Hope,* the capturing of accounts of experiences would create knowledge for people in related situations. Concurrently, I hoped that participants, when viewing the narratives of other interviewees, might strengthen their understanding of themselves because they might recognise common themes and experiences. I was aware that each situation and story was different but there were some common threads surfacing though the interviews.

I was also aware of Czarniawska's (2004) observation that the different ways in which we tell stories about ourselves are integral to understanding the content. This is because people tell stories to entertain, or they use them as a way of teaching and learning, or as metaphors when interpreting an issue, or as a way of describing action to give meaning to a situation. All participants when interviewed about their life experiences interpreted circumstances in their own particular way and this gave clear insight into their unique role as a caregiver or support person.

Bruner (2002) suggested that we study stories as a way of making sense of occurrences in our lives and these stories make experience meaningful. This is because we are constantly constructing and reconstructing ourselves to fit situations we encounter. Our dialogue with ourselves tells us about our present and what is past. It also gives us reasons or explanations for the actions we take. Bruner (2002, p. 66) said:

> Self-making is, after all our principal means for establishing our uniqueness, and a moment's thought makes plain that we distinguish ourselves from others by comparing our accounts of ourselves with the accounts that others give us of ourselves.

In this way our stories about how we interpret events become an important part of how we rationalise experience and gain perspective on situations. In this sense the scientific and narrative ways of knowing are different. This is because with science, the truth is what is being sought, but with narrative we are seeking to evaluate experience and meaning.

Essentially, my approach to the narrative of *Hope* was based on a decision to let stories and themes surface through the data as it was gathered. I quickly realised this material was neither linear in its recounting nor redemptive in its nature. Within these two features I believed lay the potential to construct a documentary that placed discrete narratives alongside each other so the related accounts of the six participants might provide insight into caregivers' stories as individual narratives that in composite, suggested related experiences.

4.3 Subjectivity and reliable storytelling

The design of *Hope* was underpinned by extensive research. For some years I had been attending regular support groups such as Supporting Families in Mental Illness (SFMI) and the EQUIP Family Education Group. I had also been attending public lectures and practical workshop sessions, such as those run by Amador on how to work with and understand a person who has experienced psychosis. In addition, I had my own experience on which to draw. However, these efforts to learn about mental illness had led me to realise that very little is known, and that families can become isolated in learning how to cope.

Being aware of this, I also spoke with members of organisations such as the Mental Health Foundation. I attended conferences organised by SFMI on family education in Auckland and Wellington, and I listened to a wide range of topics related to the care of the mentally ill. The experience of searching for relationships that lay under my son's condition was worthwhile but time consuming. In the midst of this searching I was reminded of Moustakas' (1990) assertion that such searches in heuristic inquiries, because they are felt subjectively, can be difficult but rewarding. He said, "In the process of heuristic search, I may challenge, confront, or even doubt my understanding of a human concern or issue; but when I persist in a disciplined and devoted way I ultimately deepen my knowledge of the phenomenon" (p. 11).

In developing the project I was aware that there was a possibility of unreliability in what I was requesting from the participants and that the storytelling process can be deceptive. Bruner (2002) has noted this in his discussion about how we translate our memories of self to contend with new circumstances. These memories he noted, can become a fiction.

Stories also become problematic when they are constructed too well, often with complex metaphors that move them beyond simple recollection. Although story is a common way of documenting experience, people have a tendency to embellish and create when recounting lived episodes. As Bruner (2002, p. 7) said, "the worlds of good stories are peopled with free-willed protagonists of idealized courage or terror or malevolence who have to cope with obstacles to their desires that are preternatural, even preternaturally ordinary" It is for this reason that the telling of stories can be both compelling and unreliable.

This situation is problematic when one is pursuing high levels of authenticity and it poses very complex challenges to filmed documentary as a "reliable" account of lived experience. I cannot claim to have solved the complex problems an individual's communication of their experience poses, but I was able to talk with participants about the value of simple, direct narration. Because such recounting can be very difficult emotionally, I also discussed with them the need for time to reflect on whether or not they would take part in the project.[26] We discussed the implications of making their feelings known and I asked them to think about the experience in terms of what they believed others should know and could benefit from.

Although I was aware that such approaches cannot mitigate against distortion, I was able to give each person the opportunity to set certain considered parameters around what they were prepared to divulge.

4.4 Ethical issues relating to documentary production

As Stastny (1998) has noted, the history of filming psychiatric disabilities has often been negative and destructive. However, Nichols (1991) observed that certain documentary practitioners, in exploring more interactive and reflexive ways of working with personal issues, have created distinctive changes in approach. Stastny (1998) said that when dealing with the subject of mental illness, certain documentary makers have attempted to "explore their relationships to the subjects and thus become one, if not the central subject of the film" (p. 83). This approach has opened up the relational aspect of filming where

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[26] In most cases this was about a month.

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subjects become participants and are not objectified. As director/researcher I sought in this project to enable participants to exert some control over how their stories appeared on screen. This meant developing distinctive ethical approaches to recording and processing the stories they shared.

Ethics and the discrete interview

In approaching the project I was concerned not only with ethical issues surrounding participant disclosure, but also with subsequent effects of disclosure of these experiences on family relationships. I was also aware that disclosure might impact on individual family members, and revealing information not previously articulated could affect those disclosing it to the public gaze. Bishop (1996), in considering "participant–driven" research (which is particularly relevant to the experience of families who are caregivers), placed strong emphasis on ethical considerations and the involvement of participants in being able to explain and theorise their own lived experience. He emphasised, in relation to cultural sensitivity and cultural differences, the need to bring "research participants together, in a dialogic manner, who are developing the explanations in terms of the cultural contexts of participants, rather than that of the researcher seeking themes and patterns" (p. 55).

However, I had decided early in the development of the project, not to bring the participants together, but to reflect individually with them on their contributions and allow each to discuss the content further in follow up interviews if they wished. There were five reasons for this decision.

- First, I did not wish participants to feel the need to disclose personal information by being unduly influenced by others.
- Second, I was concerned with protecting privacy and confidentiality. This is because I was aware of the high probability that some participants would want experiences and feelings they related removed from the final documentary.
- Third, I was aware of the need to keep individual perspectives as stylistically authentic as possible. This meant not "infecting" how each person constructed their experience with other people's narratives and approaches to storytelling.

- Fourth, I needed to build a trusting relationship with participants in their home environment. The place they spoke from needed to remain as undisturbed as possible.[27]

- Finally, I was aware that each of these people was giving up their time to assist me with my thesis project and as they were all strangers I did not wish to impose on them by requesting relocations to a studio, when their primary concern was the care of their loved one.

Devising a way of working with participants was more than an issue of gaining consent from those who took part, it was also predicated on building trust, a collaborative environment, and ethically managing the practicalities of the different stages of production

Ethics and collaboration

When interviewing family participants about their experiences I was seeking their views, and not those of medical practitioners or health workers. The intention was to avoid being didactic so that audiences might respond to the interviews in a more intimate and familiar manner. This I hoped might occur through the way participants spoke about their experiences; what they said, and how they chose to interpret their own narratives. Each story revolved around a specific family and its approach to supporting a loved one. The six stories, when combined, were designed to create a wider view, showing different aspects and situations of caregiving. These stories can be interpreted as a response to what Mäkelä (2007, p. 160) described as a "dynamic relationship between the research content, question, method and audience".

Arguably, the thesis has enabled me to contribute something useful to the way we think about documentary making in ethically respectful ways. As the artefact was a response to an issue and concern in society (Scrivener, 2000), it held a central position in the research. While the documentary was the embodied result of the research it was also, as Mäkelä (2007) suggested, a "method of collecting and preserving information and understanding" (p. 158) of a situation. Thus, the process of making was connected to the end result.

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[27] This was important because I realised that in later interviews I would bring in a camera crew and I was concerned at the potential loss of intimacy this might produce.

Because there were issues of confidentiality in this production, gathering data about ethically sensitive issues needed careful consideration. Although this issue is discussed more fully in the next chapter it is useful to illustrate before this discussion, an example of the kind of complex issue the project faced.

An illustration of this occurred when I considered the final cut of *Eileen, Wally and Simon's* story. I decided that although the narrative was primarily concentrated on how Simon's parents had managed to support him, his point of view might be useful in providing a fuller picture of the story. Simon (as with a number of other people) had become more confident and involved with the community during the course of the project and I wished to record this change in him. He had lost weight and was managing his situation with greater independence. In the early stages of the research I had interviewed Simon and he had viewed the rough cut version. His comments were confident although hesitant, and he was keen to enlarge on his earlier interview. He said,

> Now that I am living alone I'm master of my own destiny and I find … um … I make sure all my … my needs are met … (Simon, 2014. Transcript: 04:00:20:46:00-04:21:03:00).

> Since being independent I've learnt strategies of handling an odd uh … foible and when one comes up … reminding myself I'm a person and I'm doing the best I can at the present moment. (Simon, 2014. Transcript: 04:00:20:46:00-04:21:03:00).

Figure 6. Simon preparing lunch during the filming of additional footage.

This development in Simon's health led me to asking to film him while making his lunch. This demonstrated his capabilities in organising his daily needs. Thus the filming of episodes with consent became not only documentary in nature but also affirming. I had not anticipated that the project would have such dimensions, or carry such responsibilities. One could not remain objective because in dealing with recorded stories I realised I was also reinforcing journeys into identity and providing affirmations of wellness.

Responsibility and consent

Mental health organisations have their own regulations to protect their clients on issues relating to privacy and confidentiality (EQUIP, 2008), but these do not normally extend beyond their own organisations should clients voluntarily give information or participate in a documentary. To date no specific standards have been set in New Zealand for documentary makers by either broadcasters or the film industry with regard to ethical procedures. Most debate about ethics revolves around discussion about the completed film (Sanders, 2010), not around practice leading up to its resolution. Pryluck (1976) has noted that in filming, material may be shared that the participants may not wish to have widely known. However, procedures used to obtain content are often not discussed, and it is in this area that many concede problems can arise (ibid.).[28] Nichols (2010) suggests that the documentary film industry has historically drawn on ethical procedures from print journalism. Beyond guidelines that these may offer, behaviour in production has tended to rely on individual judgement, guidance from television executives and discussions with other filmmakers at film festivals (Nichols, 2010).

Aufderheide, Jaszi and Chandra, (2009, p. 1) have identified three conflicting areas of responsibility noted by practitioners, "to their subjects, their viewers, and their own artistic vision and production exigencies". What they suggested is that responsibility lies with the documentary maker and her/his attitude towards participants and her/himself.[29]

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[28] For example, in the United Kingdom, a panel organised by the British Royal Television Society on the ethics of documentary making, focused on ideas about lying, privacy and the vulnerability of interviewees (Bell, 2005). During this discussion, questions of payment, and the tension between informing and entertaining were highlighted.

[29] The authors cite a research project in the United States, where forty-five prominent documentary makers were interviewed. Their anonymous comments indicated that there is "a need for a more public and focused conversation about ethics before any standards emerging from shared experience and values can be articulated" (2009, p. 1).

They suggested the director must ask:

- To whom am I accountable?
- To whom am I loyal?
- What is my assignment?
- What truth do I want to tell? (Aufderheide, et. al., 2009, p. 4)

These questions are predicated on an understanding by a director that she/he creates a point of view when developing a story and this narrative is shaped and editorial control is constructed and maintained as a subjective engagement with other people's experiences.

Ruby (2005), has argued that filmmakers, along with anthropologists have "ethical, political, aesthetic, and scientific obligations to be reflexive as well as self critical" (pp. 211-217) and he has suggested that three moral issues are intrinsic in documentary making. These are:

- Firstly, that the image maker's personal moral contract is to produce an image that is a "true reflection of the intention in making the image in the first place."
- Secondly, that the producer has a moral obligation to the subject.
- Thirdly, that there is also an inherent moral obligation to the potential audience.

As Winston (2005) has noted, most individuals are not aware of the consequences of being seen at a future date by the public, work colleagues, or relatives. Any assertion by the filmmaker that all will be okay, (the "consent defence") they believe should not justify the little distortions or omissions that are used to entice someone into participating in self-revelatory narrative. He further suggested that the responsibility lies with documentary makers when lay people are asked to give consent. Winston argued that the consent defence which is frequently used as being sufficient, applies even if participants never have second thoughts about their participation, if they benefit or suffer from being viewed, or just wish they had never taken part because of the consequences. He suggested that it behoves the documentary maker to explain carefully to participants what is entailed and his thinking was influential in my consideration of ethical approaches to the making of my documentary.

In producing *Hope,* my approach to participants was based on something more than gaining consent and a signed release form. Discussions and decisions about the project oscillated between the participants and the director/researcher. Specifically this was before shooting began and before the second interview shoot, in which we discussed any new material, and whether or not the participants were satisfied with the content of the rough cut. The initial footage was approved or removed from the narrative, and participants were able to ask for material to be re-edited if they believed my interpretation misrepresented their story.

4.5 Summary

In this chapter I have considered how three significant issues have impacted on the planning and creation of the project. The first was planning the narrative structure and emphasis of each family story. Although the stories in *Hope* contained some historical content, most dealt with recent experiences that were neither linear in content, redemptive, nor concluded. In shaping the stories I considered knowledge outside of the participants' immediate experiences, which I felt might be useful to others. However, what dominated in my selection of material were stories that would enable the participants and other carers to strengthen their self-knowledge in recognising the common themes and experiences of others.

The second issue of subjectivity and reliable storytelling became less important with the increasing knowledge I gained both from first hand experience and from attending support groups for families. I was aware that participants might have a tendency to distort their own experiences in contending with new circumstances (Bruner, 2002), but I felt confident that, after initial discussions with them, they could be relied on to evaluate and set their own parameters around what they wished to disclose.

The third issue relating to ethical issues around disclosure of family circumstances and relationships was complex and I needed to devise a way to develop trust with the participants. The ethical issues were not only about the completed film, (Sanders, 2010), but also as Pryluck (1976) noted, related to the lead up, obtaining, and capturing of content. As a result my approach was to ensure that the participants were well informed

before they agreed to participate and I planned the production so that stages could be approached in a manner that maximised opportunities for deliberation, feedback and rewriting.

Having now discussed the influence of narrative structure and emphasis, subjectivity and reliable storytelling, and ethical issues relating to the production of *Hope*, in the next chapter I will consider the outcomes of my practice.

Chapter 5: Critical Commentary

5.1 Introduction

This chapter offers a critical commentary on the making of the documentary *Hope*. In this regard it offers a discussion of the following issues:

- Ethics in practice
- Collaboration
- Structure
- Audience
- Thematic considerations
- Style.

The documentary *Hope* was designed to capture the stories of families who are caring for or supporting a family member with mental illness. The focus of the documentary's content is on the role of the support person or persons in the family. In many instances the interviews also include reflections from the person who is being supported. Accordingly, the documentary provides insights into circumstances that, while common to such situations, are rarely revealed. Families who are in the middle of a crisis often attend support groups for advice, but in these situations what is normally heard are stories of distress, fear and anxiety. Distinctively, its narratives suggest that recovery is a quest, and progress towards living well is an aspiration. People achieve progress in different ways, in their own time, and the individual stories although situation specific, all reflect this.

My original plan when approaching this project was to make a single documentary that could be viewed in small group situations. I envisaged that the text might contain a range of narratives of families from diverse cultures and ethnicities describing and showing how they provided support. Stories would be intercut to make up a discussion or series of points around mental illness that described how families handled different circumstances relating to the care of their family member. However, what evolved was something very different.

5.2 Ethics in practice

A number of factors influenced both the research inquiry (as a process) and the final form of the documentary. These factors arose from the nature of the project as a practice-led thesis. Arguably, the most profound and formative of these were issues related to the ethical treatment of participants and their stories.

Setting up, telling experiences and creating a permanent record
Filmmakers generally work with a crew and maintaining ethical practice in this environment demands that clear parameters are established, discussed and observed. Pryluck (1976) has noted that confidentiality is difficult to maintain in the production phase of documentary making because ethical concerns have traditionally focused on what is contained in the final product rather than with what occurs while material is being recorded. Broadcasters are concerned with the legalities of consent and whether or not a programme exceeds norms of public taste and decency. Setting up protocols in practice to protect participants, without inhibiting what might be captured is seldom achieved. Such protocols involve negotiation, defining boundaries and being aware of the implications of disclosure.

Before contacting potential participants I obtained formal ethics approval for the project from the University's ethics committee (AUTEC). I then advertised the research inquiry in the monthly publication for Supporting Families in Mental Illness (SFMI) in Auckland. In the advertisement I explained the nature of the research and asked for volunteers who might consider contributing their experiences.

The intention of the project was to capture some of the long-term experiences that occur in relationships between life partners, or a parent and child, because the dynamic changes from that of caregiver to a support person. Accordingly, I stipulated that participants needed to have been in a caring situation for about ten years. I discovered when discussing the proposed documentary with groups at a mental health family support meeting, that people often don't initially consider the implications of being involved in such a project. Repeatedly, after supporting the project enthusiastically, potential participants tended to withdraw because they were reluctant to speak about situations where their relationship with their loved one might be compromised. Other issues that heightened their anxieties around being interviewed concerned their

relationship with Mental Health Services or other family members. I became aware that the project contained a number of challenges and an environment of trust, understanding and clarification had to be developed. I also realised that there were hidden issues surrounding the care of family members with mental illness that needed to be shared and the proposed project increasingly appeared to be a way of addressing this situation in a positive and affirming manner.

Finding participants continued to be problematic as the advertisements I placed with the Supporting Families in Mental Health and Mental Health Consumer Movement newsletters drew no response. In a second attempt to find people who might share their stories, I spoke at a number of family support group meetings, and to managers at Supporting Families in Mental Illness and EQUIP Family Support groups. A few months passed and it seemed that the project would not progress as only one family had volunteered. Tentatively I began filming this participant's story and continued speaking about the project at every available opportunity with friends and colleagues. I followed up the earlier phone and email contacts with personal visits and had meetings with the mental health family liaison representatives of the Auckland District Health Board and the Waitemata District Health Board. I also met with representatives of the Maori, Pasifika and Asian mental health support services who informed their networks about the research and gradually others came forward. The personal contact and disclosure of my motivation assisted this process.

To manage the safety of the families who volunteered to be part of the project, the filming progressed in stages. After making initial phone contact I explained the project in greater detail and disclosed my personal circumstances[30] and why I was interested in the subject area. I confirmed that the proposed documentary was part of a research project. It was not for television broadcast and it would only be shown in specified (and mutually agreed) circumstances.

At the first face-to-face meeting I gave prospective participants an information sheet explaining the nature and extent of the project, my intended approach to recording their

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[30] Explaining my motivation and family circumstances assisted me in forming a relationship with those I proposed to interview. They responded to the research protocols of the project and this added to their reassurance that I would be handling their stories with respect and insight.

stories, and where what they told me would be used. I was careful to point out that this was a thesis research project and the content was from the point of view of families. I further explained that the project was not being funded or sponsored, nor was it associated with any pharmaceutical company, medical department, health board or specific organisation. I also asked that consent be obtained from the person they cared for before we continued with further discussion.[31] Only when this had been clarified and agreed, did I invite them to collaborate with me in creating the documentary.

I discussed with participants the practicalities of shooting; I explained that the process would probably be slow and that I would return to shoot on more than one occasion. I requested that they keep this in mind when agreeing to take part. I hoped that participants, when viewing the narratives of other interviewees might benefit from hearing how other families shared common themes and experiences, and realise they had much to share.

In this initial meeting they told me their stories, and with permission I made some notes, recording useful dates and sequences of events. I didn't probe in depth as I wanted to ensure that the filmed interview could be reasonably spontaneous and reflect the deeply felt emotions of the participants. Once the caregivers and person being supported had consented to participate, I allowed them a month to reflect on this decision before arranging the video recording. This proved invaluable as family situations changed quite quickly; for example, I had initially planned to interview a caregiver and her partner who had a diagnosis of schizophrenia. With his partner's support he felt he was making a good recovery. He had made plans for his future and had been attending a course in farming methods with hopes of becoming a farmer. He had also acquired a regular farm job and they were planning to get married. The man was enthusiastic about participating and wanted to explain how his partner had supported him through some difficult circumstances. But months of discussions came to nothing as he became unwell and left the district.[32]

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[31] Prior to the formation of the film crew I discussed the confidentiality requirements that were needed in participating with potential members and talked them through the confidentiality conditions of the ethics approval I had obtained. With their agreement they joined the team.

[32] Giving participants time to reflect on whether or not they wished to continue working with the project, and to withdraw if they were uncertain was also invaluable in planning the production. It allowed me time to assess whether or not the family member was well enough for the story to be told, and to determine if they could realistically give consent.

Personal safety of participants

For those who required personal support, Auckland University of Technology's counselling services offered three, free counselling sessions after the interviews. Supporting Families in Mental Illness, Auckland also offered the use of their phone in services during filming. Each participant was given a fact sheet outlining the project's parameters and the services they could draw upon before shooting began. Some of these services were successfully utilised. This became evident when I re-visited the interviewees for follow up filming a few months later.

Careful thought went into putting a crew together and I chose initially to work with an all-female crew. As the majority of family caregivers were women (Cowan, 2008), I wanted to try this grouping to see if it might make people feel more comfortable.[33] At my first production briefing with these collaborators I discussed the importance of working ethically and made it clear that these sessions were confidential. They were made aware that the participants trusted us to keep to this agreement. All of the crewmembers signed confidentiality agreements and the participants were informed that this had occurred. This production briefing was very valuable and one experienced crewmember said she wished all projects had such clear clarifications of expectations before filming commenced.

Because I was aware that family participants less familiar with camera interviews might find being recorded particularly difficult, a week before each shoot I gave each family a list of open-ended questions that were based on the information they had given me in the preliminary discussions. This served to illustrate the potential parameters of the interview. These they could discuss and reflect upon. I did this because I wanted them to feel comfortable with what they wished to reveal. Before shooting, I rephrased each question so that it became spontaneous and would serve to open up a conversation. I further discussed with them that these interviews would not be available to be broadcast, nor would they be available for internet posting on websites.

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[33] However, this plan became impractical when shooting was delayed, participants became unwell, or crewmembers got other jobs. In these circumstances the team was reorganised, although I was careful to explain before each shoot, the importance of confidentiality and the sensitive nature of the project.

Safety during the production phase

Before each shoot I gave the crew a brief explanation of the family situation so they could work flexibly if anyone became stressed or anxious. On one occasion a participant felt claustrophobic, causing us to move to an outside location after we'd spent some time setting up indoors. On other occasions when participants became emotional we stopped the camera and discussed whether they would continue.

I realised from the first day that it was going to be difficult to film any spontaneous events that might occur. The ethics agreement on observational filming stipulated that this could only occur with permission, so I made a point of asking ahead of time if I could film any action but would refrain if any sensitive issue came up. This participants and crew agreed upon. I also explained that if they felt uncomfortable, tearful or emotionally stressed in any way I would switch off the camera. One of many examples of this occurred while Emma spoke about "recovery", and she suddenly realised while speaking that it was "an ongoing process for your whole life and your family's whole life and that's the hardest thing". (Emma, 2012. Transcript. 01:38:10:00-01:38:21:00).

I could see while she spoke that she was becoming overwrought, but she finished the sentence and we stopped the camera, had a break and discussed the situation with her before resuming. When she felt composed we looked at the footage and she asked to continue with the interview.

In preparing to shoot the interviews I had initially been cautious about disclosing too much of each family's location, but with careful selection of imagery I was able to utilise certain public areas of the city that provided a recognisable context but did not reveal the residential location of the participant. When working with a residential location I made it a procedure to take the crewmembers into the home and introduce them to the family before bringing in the gear and setting up.[34] I would also explain each person's role and what we planned to do. While setting up I talked to the participants and explained the focus and purpose of the interviews and reminded them that if at any time they felt uncomfortable we would stop. Each situation had its own tensions and I was

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[34] Arriving with film gear and crewmembers who are strangers can be intimidating, so I endeavoured to establish a relationship between family members and crew before setting up. I found it was useful if family members knew who each person on the crew was, understood their job, and were aware of their background.

aware at times that the interview content was having an effect on the crewmembers. To alleviate stress on the participants and crew I captured the interviews as half day shoots. I found that shooting in the morning generally worked best for the interviews. For all the interviews I did not wish to make the interviewees feel they were being hurried, as on occasion I needed to spend some time discussing what I was hoping to achieve with them that day, and to make sure they were agreeable. I found the mornings to be more productive as individuals were fresher, positive and often very hospitable in inviting us to stay and take refreshments with them.

Before shooting began at each location I asked crew members to make certain that their phones were turned off, so that there would be no disruptions. This is normal professional practice, but even more important to adhere to in this case because of the sensitivity of the material and the necessity to ensure an uninterrupted flow for the participants relating their experiences.

All of the participants voluntarily gave permission for their first names to be used, and I took this to be an indication of trust in the project and their confidence in what they disclosed. After filming each interview I transcribed, logged and made a rough edit of the footage.

Feedback and advice

Because I saw *Hope* as a collaborative undertaking, I also asked for comment from the counsellors at SFMI. This I did with permission from the participants. Five counsellors reviewed the edited stories and gave their feedback to me as a group. Spontaneous, positive comments were made about the visual context that "normalised" each family situation. They also confirmed that they wanted to utilise the videos in their support group sessions and could use some of the rough-cut footage immediately. This I refrained from doing for contractual reasons. My original agreement with the participants included showing the video to support groups but I had assured them that this would only occur once they had seen the completed project and were happy with the final assembly.

Participants were given the opportunity to give me feedback after this first roughcut edit. If they had any concerns I had explained that I could edit out or insert replacement

material. I was concerned at this early stage, that any issues of vulnerability in exposing a family story to other people should be carefully considered by the participants (Ruby, 2005). Enabling participants to see that they had a say in what was included was a priority. This was because I was acutely aware as director/researcher, that how I selected material for the edit was dependent on my analysis and that this could be biased.

Issues impacting on inclusion

Based on my past experiences I was aware that family circumstances could be fluid and unpredictable. I identified with what Wynaden (2007) described as a familiar pattern of reactions experienced by other caregivers who were trying to understand and come to terms with, behavioural changes in a family member. These reactions ranged from guilt to acceptance.

The participants in their interviews raised a number of difficult situations that had created confusion when realising their family member was becoming unwell. The recording and depiction of these issues needed to be negotiated on an individual basis. How participants dealt with mental health services for the first time and in subsequent episodes of mental distress was a recurring theme, as a person has to be acutely unwell before they get assistance from the mental health services or a place is found for them in a hospital ward (Barnett & Lapsley, 2006). A family member's involvement in a violent situation, illegal action or with police was discussed, and it was agreed that these facts would only be disclosed if agreed to and volunteered by the participant.

The implications of a Compulsory Treatment Order being served on a loved one are also complex and after discussions, I decided not to specifically acknowledge or disclose if family members were under a Court Order. My decision was cognisant of the fact that the family member would not want others to know they were under the Mental Health Act (Compulsory Assessment and Treatment Order, 1992). This is because they could be embarrassed by this action, they might disagree with a court judgement, or their families might feel guilty that they caused this situation to happen (Barnett & Lapsley, 2006). In New Zealand, the Privacy Act (1993) prohibits the disclosure of personal information from one agency to another without consent, so often families are not informed about someone's condition if the client does not wish them to know it. This had become familiar to me in my family's experience. I was aware that disclosure would be difficult

and I also did not wish to encourage people to make public any areas of concern that they believed could be detrimental to their family or loved one in the longer term.

Ethical approaches to editing and representation

The participants were aware that their interviews would be edited and that the editing would create what Nichols (1991) described as a conversation. This was to ensure an open exchange between interviewer and interviewee without attempting to arrive at a predetermined outcome. They had to trust my interpretation of what was important in their interviews, and giving them the roughcut of what I was proposing to utilise in the final story assisted them in assessing my approach. At all times I asked for their approval when selecting interior locations and I explained why I needed to shoot exterior sequences or include additional visual material to develop their stories.

Questions arising from viewing recorded material

The first breakdown of the recorded interviews involved a process of analysing, embracing and understanding the essence or characteristics of caregiving. I selected and edited the material into different aspects of the caregiving experience, choosing issues to highlight difficulties and successes that families were encountering. From this first breakdown of material a script was constructed that raised issues, themes and suggested answers. In many ways this method of constructing a dialogue was a clear description of Nichols' (1991) "interactive-participatory" mode. The material showed that participants were contributing to a debate and revealing uniquely positive and negative answers to related situations. Through this process I could see a story emerging. Initially I clustered the problems, perceptions, fears and ideas about recovery together. However, on viewing the roughcut draft, the nature of each relationship became buried in the arrangement. The stories about individuals, about how they communicated with one another, what assisted them, and how they came to accept and work harmoniously within their unique situations were no longer intact and the proposed focus of the documentary had changed.

Accordingly, I returned to the transcripts of the recorded material and reflected on the overall tone, emphasis and attitude of each family. Then I reselected a storyline based on the cohesive nature of each person's interview. Ethically, I was concerned that the over-fragmentation of the narratives deflected from the context of each caregiver's lived experience. In an attempt to find a documentary based on similarities, it had become

evident that the initial pattern had overpowered the cohesiveness of each family story. The flow of narrative had become lost. This seemed ethically problematic as each story had been shared as a trusted and discrete reflection and my pursuit in identifying themes had overpowered (and lost) something of the integrity of the nature of this contribution.

When reconsidering the material to find a more consistent method of shaping the story, I returned to the notes I had written after each day's interview. These assisted me in making more effective decisions around the stories because they contained reflections on the emotional and cohesive nature of each interview experience. Considering the material through a Heideggerian (2005) view and interpreting the interview data from pre-understandings gave me a richer and deeper description of events. Here, the gathering of information to substantiate the research direction informed my decision making process. I was able to determine a series of questions and additionally an approach to organising and planning additional days of shooting. From this reflection I was able to decide where to expand or develop visual sequences to support the interviews.

It was after this second version when I had restructured the material into separate, participant-focused stories, that I gave each participant a roughcut DVD of their interview. After receiving feedback I discussed the next step with each family, and we agreed on a plan for filming follow up sequences.

Over this period, some time passed, in some instances more than nine months. Personal circumstances changed in some instances and when we discussed what had been recorded participants often decided that their stories needed further explanation. At this time I decided to ignore any physical changes that had occurred with the participants. In particular, Shirl had been upset at her untidy hair when viewing her appearance on the roughcut and had subsequently cut it. Rosser had also grown a beard. Although I realised that these decisions might disturb the continuity of their composite interview, I decided to preserve the authenticity of the recorded experience. It seemed artificial to ask participants to groom themselves for the "look" of the documentary. If time had passed in the recording process, then I decided not to hide it.

Reflection on the material I had recorded also raised ethical questions relating to portrayal and identity. Participants when seeing their narratives in recorded form, often became aware of emphases or were sensitive about the context of their comments. Because I had established a loop for viewing and feeding back on iterations of the documentary, we were able to work through such concerns on a case-by-case basis until they were happy with what was presented. The following example serves as an illustration.

After viewing the rough cut Emma and I discussed the content of her interview and whether or not to include parts of it in the final edit. A particular issue related to the following recollection:

> Having the support of a partner has changed everything for me … when we had our Civil Union, Jay had no idea what it was going to be like marrying into this family. Within a few months various members of the family had got very sick ... and I'd be outside screaming on the phone to my sister and she'd be screaming back and I'd come and I'd scream at Jay and it was awful, and he said "this isn't going to work out very well. Let's go to couple counselling?" What man in the world actually says let's go to couple counselling and we did … and it changed everything and now I don't yell anymore because I came from a family where there was always strife and you always yelled and you didn't work out anything and Jay came from the opposite type of family. (Emma, 2012. Transcript. 01.02.20-01.53.10)

Feedback from the counsellors from Supporting Families in Mental Illness suggested that this comment and Emma's discussion of going to "couple counselling" and the effect this had, might not be appropriate for them to disclose. They were concerned that Emma and Jay might regret it later as people generally do not disclose such information. However, after discussing the issue with Emma and Jay they were adamant that the recollection should be included, because they wanted to encourage others and inform them of how important it was to get professional help when needed. In so doing they wanted to emphasise that they weren't afraid of stigma associated with mental illness.

Emma's adult life had been influenced by her childhood experiences and because her support role was ongoing, her desire to encourage other families to discuss their problems with professionals was understandable. Riebschleger et al., (2008) note this situation when they discuss how families of mentally unwell members often feel stigmatised and are forced to discretely manage "high levels of stress, and ongoing caregiver burden" (p. 120). The anxieties they feel are rarely discussed in an overt way with others outside of the family unit.

Ethical treatment of the final documentary text

At the end of the documentary making process all participants were given a copy of the final DVD. As *Hope* is not designed for a public audience there have been limitations placed on where it can be shown. An embargo will be placed on it at the Auckland University of Technology library, so it cannot be accessed online through Scholarly Commons. A separate agreement will be made with the participants about further distribution. Transcripts of the interviews have not been included as an appendix to this exegesis as they contain sensitive material that should not be disclosed. However, all quotes included in the exegesis have been used with permission.

5.3 Collaboration

Collaboration occurred during the project's refinement on several levels. These included the participants, family mental health advisers, mental health counsellors, and technical support. Collaboration was developed not only to increase the usefulness of the documentary, but also its production values and integrity as a designed text.

Collaboration with participants

When participants first saw the edited rough cut DVD of their interview a number registered shock at seeing themselves on screen. Many families had not realised the strength of their own stories or the intensity of what they had experienced. By instituting this feedback loop not only was the work able to be guided by greater levels of authenticity and engagement but, I was also able to work through with participants, the impact of seeing themselves on film. In this respect I was able to make adjustments in response to how people saw the construction of their identities and lived experience.

Collaboration with external bodies

Showing parts of the edited version to research peers was also helpful. Their comments, understanding and empathy for the subject were not only insightful, but also reassured me that the material was interesting and useful to those outside of the recorded situations.[35] These appraisals brought another perspective that assisted with reflecting on and maintaining a certain level of objectivity when I was editing the work.

I made a joint presentation with Emma at a documentary conference in which we showed some excerpts from the work in progress and discussed the relationship between director/researcher and participant in filming and editing ethically sensitive material.[36] This presentation prompted some lively discussion about ethics, authenticity and mental health issues. This was beneficial in that we discussed the implications for Emma in revealing these aspects of her background, which assisted her in accepting what had happened in the past. We were both very surprised when a significant number of people came up to us privately afterwards and said how much they appreciated the discussion as they had experienced similar circumstances, but had felt that they could never discuss them. They all believed that issues related to mental health and family dynamics needed to be aired.

With the permission of participants, in 2012, I also showed excerpts of the documentary at a conference in Melbourne,[37] and feedback from mental health, social workers and others involved in the field was validating and practical. It was at this conference that I was challenged by a mental health worker regarding a participant's point of view about recovery. She felt the participant was misinformed and she should read further and educate herself on the subject. This I found interesting as it raised questions about the aim of the research and its emphasis on the family perspective. I was reminded that I was selecting material because it reflected the experiences and beliefs of those taking part. Accordingly the participant's recorded material remained in the documentary.

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[35] The research involved me emotionally. As Gray & Malins (2004, p.23) suggest, "keeping a critical view of your research at all times is essential".

[36] *"Sometimes I hate them". In what ways do identity and subjectivity currently influence forms of documentary expression?* Expanding Documentary Conference, 5-6 Dec. 2011, Auckland University of Technology, Auckland, New Zealand.

[37] *Documentary and carer narratives; providing an opportunity for participation.* Social participation: Knowledge, Policy and Practice Conference. 28-29 Nov., 2011. La Trobe University, Melbourne, Australia.

I also (with permission) showed different sections of the documentary at *The Arts in Society* conference in Budapest in 2013.[38] Here I gained some insightful feedback from colleagues about related experiences of Alzheimer's disease and suicide. The resulting discussions suggested to me that the interviews were communicating to a broader audience and had the potential to raise wider issues.

Collaboration with technical experts

Hope was also a collaboration technically and artistically. This support came in the form of camera operator,[39] and sound recordists.[40] It was also necessary to work with others in post-production, as there were certain specialist skills I did not have. I collaborated with an online editor[41] in the final stages of editing and he assisted with tightening sequences and also provided an independent, external eye on the overall piece. We made small changes, assembled the narratives into a timeline and constructed a menu so viewers could select how they wished to view the stories. The last technical phase was executing the audio mix with a sound mixer,[42] refining the audio tracks and adding in additional sound effects and music.

I collaborated with a graphic designer for the design of the titles and the artwork and layout of the DVD cover.[43] He viewed the work and we discussed the aims and audience for the project. Then we co-constructed a brief to determine various design concepts and typographical choices. We discussed the possibility of intertitles and ways of using words to add information to each story. However, these were eventually removed, because once the final cut had been completed, the opening introduction to each story made each situation clear to the viewer. Additional graphic elements tended to "over explain" what was already evident. This paring back of extra material was in keeping with my original approach to let the views of each family member unfold for the audience and to refrain from external commentary. It was when creating the title sequence that the designer suggested I might add the quote from Emily Dickinson's poem, *Hope*.

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[38] *The Arts and Disability: representation of mental illness in video.* The Arts and Society Conference, 24-26 June, 2013. Eötvos Loránd University, Budapest, Hungary.
[39] Mairi Gunn, with additional camera work from James Nicholson and Christian Jones.
[40] I worked with a range of sound people including Shani Bennett, Rosie Bohling, Calvin Samuels, Tom Levesque, Esther Jeong, Britney Hazeldene and Elizabeth Hoyle.
[41] Roger Grant
[42] Paul McGreal
[43] David Sinfield

Collaboration with a Director of Photography

I chose to use High Definition video (HD) and to work with a director of photography (DOP) Mairi Gunn, who was very experienced and liked to work in the field. This gave me the assurance that when shooting I could focus on and listen to the interviewees, allowing me to follow up with questions when necessary. Mairi and I discussed a visual approach to the stories that was naturalistic. This meant working without additional lighting and creating a specific look for each family that would add a sense of normality to situations that were potentially filled with tension. This approach wasn't always successful because with natural lighting the sun moves in and out from behind clouds. This meant that the flow of certain shots was sometimes disrupted and we had to stop and start the interview. At times I decided to ignore these lighting changes, as I preferred not to interrupt the flow. On a practical and aesthetic level the decision did achieve the natural effect we were looking for, and we were able to set up quickly. It was less intimidating without lights and cables and this lowered tensions around the interview and cut down on set up time that can often be tiring for participants.

Before starting to shoot I discussed the framing and focus of each story with Mairi. She followed the conversation as closely as possible, keeping the interview on a medium close up and slowly zooming into a close up when the discussion became intense. This was a rather broad instruction but I was unable to communicate with her while the camera was rolling without disturbing the concentration of the participant.[44] After viewing the first rushes we could see that briefing her on the focus and discussing the context of each interview had produced an effective mode of recording.

We chose to keep the framing tight and used closeups extensively. Each interview was also shot with an establishing mid shot or medium closeup. I chose to include these with establishing shots that revealed the location and gave a context for each individual's story. I kept the camera at the subject's eye level and I sat as close to the lens as possible so that a conversational tone was sustained, with the eyeline directly towards me, and slightly off camera. This was done so I could position the documentary's audience in such a way that they felt part of the conversation. It also meant that I was sitting close to the interviewee and we could continue talking with a conversational tone with Mairi and

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[44] I was fortunate to work with someone who was both empathetic to the subject content and a very good listener.

I positioned closely together as a tight knit team. At times I was worried that we were might be framing too closely, but in editing I chose to use these closeups as they depicted a rawness and sincerity of inner feeling. The viewing format for the documentary is either a television or computer screen. The audience is therefore likely to view *Hope* in a small space, or as part of a group in an intimate environment. The close-ups and tight mid-shots were used to draw the audience into the conversation. The closeup shots were tightly framed, with the intention of drawing attention to facial expressions and fleeting emotional changes.

Sound

The interview recordings depended on good sound and I used a microphone and boom because they gave the best quality recording. However, using several different sound operators and working under different conditions, the inevitable changes created problems that affected the overall quality. When recording *Tiffiny and Gael,* due to technical problems we changed from the boom to lapel microphones after the first few minutes. The sound levels in the early part of the recording are not matched evenly but the material recorded was important and was used in the final edit, despite the drop in sound quality, which we had to re-engineer in the final sound mix.

When recording *Rosser and Sharon,* the sound of cicadas in midsummer was very loud, so the first interview was recorded indoors with the windows firmly closed. After a short while Sharon felt claustrophobic so we continued filming in an outside location. This created difficulties in editing, and to even out the sound, an audio track of cicadas was laid over some sequences to smooth out the sound transitions between the interview segments.

Music

I approached Toi Ora Live Art Trust, an organisation that provides training and facilities for mental health consumers, to find a composer who might wish to create original music for the project. I discussed the project with Robert Hamp, who was working at the Trust. We viewed the roughcuts and, based on his impressions of the stories, he volunteered to work on the music composition. He composed in a classical style and created his own arrangements. We discussed how incidental music could be used to develop a mood and he created some short pieces that reflected his impressions and interpretation of the interviews. From these I chose to use music at the beginning and end of each story to set

the tone. I also used music sparingly throughout the interviews to support periods of emotional storytelling.

While filming *Eileen and Wally* I became aware that Simon's daily practice session on the clarinet reinforced how important music has been in his recovery, and he was happy for me to use his clarinet playing as linking music in his family's story. After shooting the first interview he thanked me profusely for recording him playing the piano and being interested in listening to him play. He explained that being filmed by the crew had been a very enjoyable experience for him. It was a surprise to me that he had been so touched by this, as he was a proficient clarinet player and had taught himself the piano while in recovery. He explained that playing the piano assisted his concentration, focus and emotional state and he practised every afternoon in the church hall. It was a stark reminder of his earlier ambitions, as he had studied music at postgraduate level and had intended to become a performer, and his thwarted ambition continued to preoccupy him. For this reason I used his playing to accompany his family's story.

Emma and Jay's story has music selected from a copyright free source. I had originally edited it without music, wanting to keep it simple and not impose a mood on the interview. But later, music was added as the storytelling carried many strong themes, and the music assisted with both slowing the pace and tempering the mood of the interview.

5.4 Structure of the DVD and DVD menu

The DVD can be viewed as a full-length feature composed of a series of six shorter pieces. Each of these is approximately fifteen minutes in duration. Alternatively, a viewer can select from the menu and play whatever story they wish. The end credits are a separate menu item. On the inside of the DVD case is a short description of each item.

I called the DVD *Hope* after the edit was completed. It was only after viewing it in total that it became clear that all the stories carried strong expressions of this concept, but each showed different experiences and contexts.

The overall structure begins with an adult remembering how she as a teenager had responded to her mother's experience of mental illness. From her adult perspective she realises how her developing communication skills assisted her relationship with her mother.

This narrative is followed by the story of a married couple who adapted to the circumstances of what became a long-term illness. They describe how learning about the illness and finding acceptance developed a strong relationship between them, so that they now lead more fulfilled lives.

The third story concerns parents who have supported their son over many years of mental illness. He was originally living at home. Then he moved into boarding houses and rented accommodation. Finally, with medical treatment and support he progressed into accommodation with three flatmates. He is now living independently with the support of mental health services and his family.

The fourth narrative is about a young adult who continues to support her mother. In an effort to educate other young people she has written a children's story about the experiences of being a child that supports a parent. Her motivation has been to encourage young people to communicate their concerns and experiences to others.

The fifth story tells of the experiences of a mother who has three adult children, and supports her son. He has spent some time in a locked ward in a forensic institution but at the time of the interview he was working towards living in a rehabilitation centre, before moving into the community.

The final story is about a husband who has supported his wife through many phases of acute illness. His encouragement has enabled her to restore family bonds. She has also been successful with tertiary study and maintaining a fulfilling career. They have struggled against prejudice and have now managed to bring the whanau together as she has progressively moved forward in her recovery.

5.5 Audience

The target audience for the documentary is private families or people who might meet in a support group setting. This might occur out of a common interest in wanting to know more about issues that concern families who are supporting a family member.
The views expressed are those of the participants and are not those of mental health professionals. The stories reflect the way these special families interpret their world and circumstances. The DVD can also be used as an educational resource in a teaching seminar, discussion group or home situation. It is also designed to be utilised by small groups of mental health students, counsellors, doctors, psychiatric nurses and those interested in mental health issues.

5.6 Thematic considerations

A number of themes suggested themselves while I was constructing the edit. These surfaced from recurring ideas situated in each family story. In constructing visual sequences, I used these themes as a way of drawing attention to underlying concepts and creating continuity across the documentary. The themes were:

- Home as a sanctuary
- Chaos and order
- Nature as a metaphor
- Understanding recovery
- Diagnoses and treatment
- Giving and receiving care.

Home as a sanctuary

In editing, visual sequences were selected that portrayed the importance of the home environment. The isolation families feel was expressed several times by participants and the individual care they took in making the home environment a hospitable and comfortable place was always evident. Each story opens with an establishing sequence that describes the "lived context" of each carer's story. Thus we see Tiffany and Gael cooking (Figure 7);

Figure 7. Tiffiny and Gael baking and discussing food preparation.

and we establish Shirl and Tupuna in their garden (Figure 8).

Figure 8. Tupuna and Shirl sit on their front steps admiring Shirl's roses. Shirl found that working in the garden brought her high levels of satisfaction and she felt that Tupuna's physical assistance brought them together.

On other occasions I took participants to public areas they often visited together (Figure 9).

Figure 9. Sharon and Rosser walk on a beach.

While shooting I also looked for spontaneous events that might provide interior sequences, such as when Eileen carefully laid the table for her guests and Wally worked on turning metal in his shed. These images showed domestic calm and a sense of order. Sequences in which I took people out of their home environment were chosen for their personal significance to the participants, for example, Simon practising the piano in the church hall, and Sharon feeding the wild ducks in a nearby park. These images all support the idea of home, neighbourhood and community operating as a sanctuary that is important in maintaining equilibrium.

Chaos and order

Many scenarios in *Hope* describe the tensions between chaos and order. Each family talked about how one chaotic situation changed into others and they all discussed strategies they devised to find a working equilibrium. Emma explained how as a child she would spend weekends with her mother tidying the kitchen and emptying the rubbish. This desire to create order through care has prevailed into adulthood. She was filmed at home in her front yard tidying up the leaves and putting the garden in order (Figure 10).

Figure10. Emma sweeping her garden into an orderly state.

By establishing order, chaos is minimalized and the family can interact and relate to one another in a more stable manner. All of the families expressed this desire for order in different ways. It normally surfaced as a long-term aim or a tentative hope that might be maintained.

Nature as a metaphor

I observed that most of the families interviewed worked hard in their gardens and that for them, growing and nurturing plants was an important part of their lives. As an extension of the theme of home as a sanctuary and the balance between order and chaos, in the documentary I use seasonal changes in plant life. Often these operate as a visual metaphor for the passing of time (Figures 11 and 12). The use of plant life gives the documentary a contemplative tone and serves to move it away from expectations of crisis, abnormality and sensationalised storytelling. By emphasising the beauty of nature, I have tried to subtly reinforce ideas of recovery being transitional and the naturalness of family experiences shared in the work.

Figure 11. Janita's house is framed with a spring flowering kowhai

Figure 12. The transition of time in Janita's story showing a koru.[45] The plant shows new growth, and the beginning of the fern's life cycle. This serves as a metaphor for what is occurring in her son's life at the time. There is a suggestion of motion in the round shape that curls backwards and inwards and seems to be growing in on itself.

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[45] Te Ahukaramū Charles Royal says, "The koru therefore symbolises the way in which life both changes and stays the same" (Royal, C. 'Mâori creation traditions - Common threads in creation stories'. Te Ara – the Encyclopaedia of New Zealand. http://www.TeAra.govt.nz/en/photograph/2422/the-koru).

Figures 13, 14, and 15. Autumn leaves. The transitions between the positive expectations talked about in Tupuna and Shirl's life in the present, and how Shirl describes her darkest moments of being in hospital respite and returning to the outside world, are laid over with autumn and winter imagery showing leaves on a tree, then decaying, and falling on to the ground to rot.

Figure 14. Autumn leaves dropped on earth.

Figure 15. Autumn leaves on grass as dew catches the light

Understanding recovery

Recovery is experienced differently because each family situation is unique. For families there is no fixed measurement or outcome that can determine if a person is recovering from a mental illness. The notion of 'recovery' was one each family interpreted from their own experience. How families see recovery is very different from views expressed by mental health workers and from those who have experienced mental distress. This is an important issue and it is pivotal to helping families in their own recovery (Deegan, 1988; Cowan, 2008; Barnett & Lapsley, 2006; Watkins, 2007).

This may be illustrated in Eileen's reflection on what she had thought was going to happen during her son's recovery. She said:

> It's a long slow recovery and I think we all expected it to be a quick fix, like taking a pill and it's gone. That doesn't happen, it's long and slow with ups and downs. It's like a roller coaster (Eileen, 2011. Transcript. 00:44:37:00-00:44:56:00).

Having lived her life knowing only the erratic behaviour of an adult parent, Emma saw recovery differently.

> Recovery's a very good word but I think with serious mental health issues it's a farce. I have this feeling mental health services are just like everybody else who have key performance indicators, that you have a certain amount of people on your books and you get them to a certain stage and you get them off your books. But actually it's an ongoing process for your whole life and your family's whole life … (Emma, 2012. Transcript. 00:01:37:50-00:2:06:00).

Rosser's interpretation of recovery indicated a belief that circumstances dictate the family's perceptions, and that a one policy description cannot describe all types of situations.

> The idea of a recovery journey sounds really interesting, but means two fifths of sod all because I'm naturally quite cynical, wary of anything described as a journey … because that has all sorts of implications about starting points and

destinations and one thing I was quite aware of in the last ten years is that there are people who are never fortunate enough to get to the end, they get to a point perhaps, where they are able to function to a degree (Rosser, 2011. Transcript. 00:22:15:00-00:22:43:00).

These interpretations demonstrate some of the differences that families experience. As a consequence the documentary is designed to allow each story to surface its own reflection, with the evident theme being "the concept of recovery is experienced in diverse and sometimes contradictory ways".

Diagnoses and treatment

Many of the family members expressed frustration at being patronised by medical professionals. Some found that medical professionals in the mental health field were not forthcoming with information about the implications of a diagnosis. Family caregivers were also unclear as to whether or not treatment offered for their loved one would have a positive outcome. This increased the stress experienced by family members.

Rosser explains how he reacted to Sharon's quest in securing a diagnosis.

> My main feeling was just how inexact the whole process was, and how difficult it must be for people who were in even worse situations than we were in terms of trying to get a sense of naming something, getting a sense of what that meant, getting a sense of how to deal with it, and it was probably also for me a fair degree of frustration and anger in terms of the amount that Sharon had to do herself to get that … (Rosser, 2011. Transcript. 00:09:26:00-00:10:04:00).

Another area of frustration related to the time it took to secure an accurate diagnosis.

> At that point it was overwhelming relief, really mostly because I could see how absolutely frustrating it had been for Sharon … getting to a point where we thought we had a label we thought we had a set of symptoms … treatments and then found out that wasn't necessarily the right treatment and I also felt … a fair degree of frustration and probably anger myself because in the end it took a lot of

work on Sharon's part to actually get that sorted ... (Rosser, 2011.Transcript.
00:04:52:00-00:05:04:00).

Eileen and Wally expressed relief when decisions on treatment were taken out of their hands and professional assistance took over. This was because their health had begun to suffer through stress.

I think we were quite pleased that someone else had taken over the problem at that stage because we weren't well enough. We couldn't sleep because we were worried what he was doing at night walking around (Eileen, 2012. Transcript. 00:16:26:00-00:17:02:00).

For many of the carers, the lack of a diagnosis meant their families were uncertain about where to find support. They were not sure what the support could mean and were relieved and enlightened when they eventually got in contact with a support agency.

You think you've got the whole lot on your shoulders and it's just terrible, it can't be… and you go to Supporting Families and there are other parents there and their situation is worse than ours and that's when you go on to appreciate, learn and listen to their problems, and you think that yours is not so bad, (Wally, 2012. Transcript. 00:07:14:00-00:07:46:00).

As with the theme of recovery, the documentary allows each story to present its unique experience of diagnosis and treatment. Thematically we encounter experiences that range from relief to frustration.

Giving and receiving care
In the documentary I have also drawn attention to issues related to giving and receiving care. Family members perspectives of caregiving tended to centre on practicalities, planning and motivation. However, this was shown to be quite different when viewed from the perspective of someone being supported. For some of these people, recognition of support being given provided a sense of hope.

Well he was my caregiver, when I wasn't functioning, when I needed caring and I needed a lot of caring, so the relationship (pause) that became part of our marriage. I think we redefined what marriage is because of the illness and the illness redefined it for us and we had to accept it if we were to stay married, rather a catch twenty two (Sharon, 2011. Transcript. 00:51:53:00-00:52:26:00).

For some, hearing about how those being supported felt about the care they had been receiving, was an experience that drew on deep emotions.

Tupuna taught me a lot, from being a person who you know, didn't even know who I was, or didn't understand myself, had a lot of issues, that helped keep me unwell I suppose, to showing me different ways of being able to deal with a situation and look at things in a different light as well, and that's really helped me in staying well (Shirl, 2011. Transcript. 00:03:01:00-00:03:40:00).

Emma expressed how she felt about being supported by her husband, Jay.

Jay best supports me by being able to listen to me, and remind me that there are other things in life … You don't have to be caught up in this every single day and that you're allowed to have your own life, and there have been times when I've completely forgotten that … (Emma, 2011. Transcript. 02:01:51:00-02:02:20:00).

Tupuna saw support as something surfacing from wider cultural and community acceptance.

I think it's a lot to do with whanau concept, whanau concept of having people that accept that you're part of the whanau, nothing else counts, just making people understand that this happens to everybody … even in my whanau we've got people with a mental illness and yeah, and just accept the person for what they are, not what they do and all the things they get up to, it's about what they are, their whole being (Tupuna, 2011.Transcript. 00:03:40:00-00:05:10:00).

Janita felt that a wider view needed to be embraced for those being supported by their families and mental health services. The isolation that families felt was even more strongly experienced by her loved one, who needed additional help in integrating with others:

> When you become mentally unwell, when that happens over time you know, and he's been in the system quite a long time, so much what other people may take for granted, like friendships and, you know, a sort of pattern and life in the community, breaks down and you have to start at the beginning and rebuild those things. You have to learn how to make friends (Janita, 2011.Transcript. 00:02:10:00-00:02:31:00).

Janita also commented on the effects of a long stay within an institution, which can happen after extended hospitalisation. She believed that family members and mental health staff need to understand the nurturing and support required in integrating back into the community:

> From my perspective the demands on that relationship from me are … I see it as kind of acting ethically to make myself available to him in the same way if I was in his situation I would want to be in a relationship with somebody who made themselves available to me (Janita, 2011. Transcript 00:06:35:00-00:07:22:00).

Another issue that surfaced in several families was the frustration that occurs when trying to get support from mental health professionals in an emergency. Being left to cope with a crisis alone was seen as devastating. Tupuna described it like this:

> I haven't had good support and I think if you talk to most people that have a family member that has a mental illness, they will say the same thing. You don't really get support … You get better support from your neighbours from your friends, not from the authorities. The crisis team, like I said, hopeless, just hopeless because they go by the book and that's the problem (Tupuna, 2011. Transcript. 00:32:10:00-00:33:59:00).

Tupuna's experience was spoken with marked frustration and grief, and this is conveyed in the visual framing. The repetition of the words "hopeless, just hopeless", makes it a striking moment in the interview.

5.7 Style

Hope has a distinctive though understated style. In general I used special effects sparingly so the audience can concentrate on the power of each story. However, a few distinct decisions are worthy of consideration.

Lighting

Natural lighting (using sunlight) was the first choice for all of the shoots. However we were forced to add diffused light in the interview with *Tiffiny and Gael* because the sky became overcast and the interior darkened as the afternoon progressed. This had the effect of reducing natural shadows, but at the same time it brought out the warmth of colour in the background (Figure 16).

Figure 16. Tiffiny and Gael lit by soft diffused light that evens out shadows.

Working with natural lighting reinforced the lack of artifice in the documentary. In everyday conditions, light as we experience it is variable. Accordingly, instead of the controlled, uniform lighting scheme of a studio, we often catch subtle, unexpected highlights. These often occurred because participants became so focused on their stories

and relationships that the presence of the camera and crew became secondary (Figure 17).

Figure 17. Tupuna turns to kiss Shirl

Structuring the storylines.

I developed the storylines for *Hope* after recording the second follow-up interviews. From the way in which situations were described I discerned what appeared to be the most important aspects of each family experience. I created a story outline that covered a coherent timeline and included aspects of each narrative that I thought might be helpful to others. I was aware that in constructing the storylines I was imposing my interpretation on the data, but I endeavoured to remain as close as possible to the original intention described in the interviews. Once I had assembled the primary narratives I edited out any repetitions, considered each story in relation to others in the documentary, and made further edits. Originally, each story was around thirty minutes in length, but I edited them down to approximately fifteen minutes each, so the core ideas were more evident.

 I was aware that the presence of the camera and crew had been disconcerting for some of the participants. I was also aware, as Bruner (2002) suggested, that when explaining or telling stories about ourselves we tend to change our interpretations of circumstances

to suit each situation. He described it this way:

> We constantly construct and reconstruct ourselves to meet the needs of the
> situations we encounter, and we do so with the guidance of our memories of the
> past and our hopes and fears for the future. Telling oneself about oneself is like
> making up a story about who and what we are, what's happened, and why we're
> doing what we're doing. (Bruner, 2002 p. 65)

Interviewees had told their stories in different ways, some as a monologue, and some as
a three-part discussion. In framing participants for the camera I allowed them to sit
together or apart, choosing what they felt was comfortable. For example, Rosser and
Sharon on our initial meeting discussed the past in different ways, so I chose to
interview them separately, while they listened to the other person's interview. By editing
their interviews as an interwoven discussion, and in bringing them together at the end, I
emphasised how they had managed the worst times as a supportive unit.

Janita's interview was originally planned as a discussion between her son and herself. At
first he wanted to participate in the story, and we discussed ways of filming him so that
he wouldn't be identified. He said he felt embarrassed by his past actions and wanted to
disassociate himself from them. Eventually he decided to withdraw but was happy for
me to continue interviewing his mother.

Eileen and Wally spoke together and then separately so that they could discuss different
circumstances within different locations. Their son Simon was living independently, so
he was interviewed in the church hall and at the house that he shares with flatmates.

After each story was set up and situated within its location, the major themes in each
case were explored. As each story unfolded I edited it to include an ending that
described the present circumstances and considered how each carer described their
relationship in the present. Each story was also given a title, taken as a quote from the
main storyteller. This quote introduced the main focus of the discussion.

For example, Tiffiny and Gael's interview title is *"The only thing they really need is to
feel loved"*. The story tells of a daughter supporting her mother through depression. The

themes of unconditional love, communication within families and doing things together dominated the discussion. The opening sequence of the mother and daughter working together in the kitchen reflected this.

> She always wanted to spend time with me and I think some people when they have depression want to be on their own, whereas in my case it was actually good for me to have somebody around, who made me laugh or was silly, or gave me a hug, just sort of lifted me out of myself. (Gael, 2011. Transcript: 00:11:56:00-00:12:08:00).

Eileen, Wally and Simon's sequence is titled **"We want him to be self-sufficient."** It opens with a discussion of how difficult they had found it as parents to understand what was happening to their son. This discussion is overlaid with the sound of Simon practising his clarinet.

> It was quite a shock to us because he was a different Simon to what he'd always been and it was quite difficult to cope with. We tried our best. (Eileen, 2011. Transcript: 00:26:05:00-00:26:15:00).

Janita's title is *"He's got a life".* As her son was in a forensic institution at the time of the interview, Janita's world revolved around his home visits. Her son worked a few days a week in a community garden and brought home the vegetables he'd grown. These are seen on her table, as his contribution to the family.

> At the moment in my son's life because he's been in an institution for a long time that, he gets family leave and that gives him the ability to move freely in the community and if I didn't make myself available for him to do that, it means he would spend more time within an institution and I see that as a very unhealthy thing, (Janita, 2011. Transcript. 00:05:56:00-00:06:12:00).

Rosser and Sharon's title is, *"Hanging on to hope".* Their sequence opens with a scene on a West Coast beach where they frequently take their dog for a walk. In the interview,

Rosser looks back on the past ten years.

> Whenever anyone you love gets sick, then, well certainly for me I think,
> probably for a lot of people, one of the key things is you just want to focus on
> what you can do to help them, (Rosser, 2011. Transcript: 00:01:35:00-
> 00:01:5:00).

The quote from Emma and Jay's sequence is "*Being able to listen and remind me there
are other things in life*". Theirs is a story dominated by Emma's bewilderment about her
mother's behaviour when she was a child. She refers repeatedly to the extent in which
mental illness occurred in her family and the impact it had on her family relationships.
The sequence begins with a visual of the outside of her present home. Her opening
words emphasise the dislocation she felt:

> When I was a child and my mother was diagnosed with what was then called
> manic depression and is now called bipolar. No-one gave us any information, no-
> one ever explained anything (Emma, 2011, Transcript. 00:28:05:00-00:25:20:00).

Tupuna and Shirl's relationship is summed up in the quote, "*This is what counts, the two
of us.*" Their sequence discusses the importance of neighbours, friends and whanau
(extended family) in recovery. The visuals shown of their neighbourhood and street are
overlaid with Tupuna's words:

> A lot of people used to hide people away with a mental illness, and I think being
> open, and I don't mean you go out and tell everybody in the whole wide world
> you have a mental illness, it's just being part of that group of people where you
> live. (Tupuna, 2011. Transcript. 00:12:08:00-00:12:23:00).

Editing

Finding a pace and rhythm to the editing of each interview depended on how each
interviewee told their story. The pace of each narrative was determined by taking into
consideration if the speaker was confident, nervous or hesitant. I completed an initial
edit developing the thematic arguments that had emerged and worked on discussions

concerning family attitudes to recovery, the importance of diagnosis, getting treatment, professional and ongoing assistance, and how families have to adjust to their changing circumstances.

I constructed each story with its own beginning, middle and end. What became clearer in examining each narrative was that no family circumstances were the same, and each family had its individual way of working with and communicating with their loved one. Preserving this uniqueness while constructing a cohesive documentary was a major challenge in the design of the project. It became clear that certain attributes of empathy and resilience enabled caregivers to keep a possible vision of a future in sight. These were the keys to families finding equilibrium and acceptance, but they were all realised differently. There was no uniform pattern. A brief comparison between two stories serves to illustrate divergent editing approaches.

Janita's narrative has fragmentary ideas and as she speaks she leaps towards different philosophies and concepts. In editing her story I built up a visual picture that included fragmentary images of her surroundings that complemented her manner of storytelling. In contrast, Tupuna and Shirl were very considered and continually complemented one another as they spoke. Accordingly, the cutting was less pronounced. We see a fluidity and exchange through a series of two shots and interfacing close ups. Overlaying their discussion are visual sequences of them gardening, entertaining and cooking in their home. This was included as a response to the intimacy and mutual support evident within their relationship.

5.8 Summary

In this chapter I have unpacked some of the production and design issues underpinning the project. The first consideration was setting up ethical practice protocols that would protect the personal safety of the participants and develop trust between them and the director/researcher during the production process, editing and creation of the final documentary text. Also explored are the ways in which collaboration between participants and the director/researcher, as well as with external bodies were considered. An integral part of this process is the acknowledgement of the expertise and technical

support of working with a director of photography and sound recordists, a music composer, a graphic designer, and an online editor and sound mixer.

Building an atmosphere of trust resulted in the recording of profound insights and personal experiences. This occurred because I established a safe and unhurried environment. Briefing crew and participants, setting up practical protocols and discussing the research outcome enabled participants to decide how much they wished to reveal and the context in which it would be presented. Because I refrained from coercing participants, and made them feel that their views were important, many became more confident and outspoken as the filming progressed.

Thematic considerations that include perceptions of home as a sanctuary, chaos and order, nature as a metaphor, understanding recovery, diagnoses and treatment, and giving and receiving care, form the conceptual composition of the work. Stylistic choices related to lighting, editing and story structure have been used to draw these ideas together into cohesive threads that permeate the documentary.

Having now offered a critical commentary on the making of *Hope*, the final chapter offers some reflections on the project and discusses its contributions to knowledge and future research.

Chapter 6: Conclusion

6.1 Introduction

This chapter offers a reflection on the project. In so doing it summarises:

- Ethical considerations impacting on the construction of the documentary
- Contributions the thesis makes to knowledge and understanding
- Considerations for future research.

In closing it offers a thesis conclusion.

Rabiger (2009) described documentary as a construct and this research has accepted that what is on screen is the director/researcher's version of events. However, what I have tried to achieve is an authentic account, by developing an approach to documentary making that is both empathetic and collaborative in its process.

Hope tells the stories of six families but each is only a fragment of a much larger lived experience of caring for someone with a mental illness. Because interviews were conducted in a concentrated time frame, much has been left unsaid so more remains to be revealed about the complexities families face when working towards the recovery of a loved one.

This thesis project has involved recording and designing the stories of others into an integrated text that also affords discrete separation of individual narratives. The project has led me to confront some challenging situations. Professionally I have encountered complex and dangerous circumstances in the past when filming, but the challenge with this project has been to provide a "method for making" that enables participants to tell their stories in their own way. I directed and synthesised the facts and storylines I was given and encouraged the participants to express issues in their own words. By excluding voice overs or extra-diegetic introductions, intertitles and conclusions, the narratives are expressed entirely in the participants' original words. This has been used as a way of minimalising distortion and retaining a sense of authenticity and continuity in each story.

6 .2 Ethical considerations impacting on the construction of the documentary

In making *Hope,* I drew up production protocols for practice, and found that by disclosing the rationale for making the documentary, participants understood what was being aimed for and they generously collaborated with the process. At first the project was unnerving as I wasn't sure if families would discuss their experiences freely. However, in an atmosphere of trust in which ethics were a central concern, the featured participants continued to give feedback and we were able to discuss if material should remain or be edited out.

Rabiger (2009) notes that, in general, directors look for participants who will come across well on camera, and have an engaging or distinctive personality. In such instances the final outcome and its impact are normally prime considerations (in contrast to concerns over how participants may be affected). Volunteers who took part in *Hope* were not selected for their screen presence; those who came forward fitted the criteria, which was that they be mentally well, have been supporting a family member and had been involved with mental health issues for about ten years and were willing to appear on screen.

In this thesis I argue that consent to participate in a documentary should be more than signing a release form; the use of personal stories needs to be carefully explained and negotiated. I propose that cultural as well as personal vulnerability must be recognised if people are stressed, unwell or wish to withdraw personal information. Participants also need to be made aware of the future use of any recorded material, and it is imperative that a director/researcher underscores the fact that it may not be possible to control where digital based material is viewed in future. As the project progressed, considering carefully how much value there is in people exposing their innermost thoughts and feelings became an ongoing consideration. I knew the participants' revelations could have long-term effects if people could be held up to ridicule, become victims of voyeurism or suffer criticism for speaking out.

I found that working through careful protocols before filming created an environment of trust, and contributed to the collaborative process. This is because the process reduced the divide between who is in control and who is taking part. Disclosing my personal interest and family experience of mental health issues enabled me to appreciate what I was being entrusted with. It also heightened my ability to empathise and alerted me to the need to remain as unobtrusive as possible in my questioning. The result produced some unique, indepth information that explored areas of difficulty in relationships, and conflict between mental health consumers and mental health professionals. It also revealed certain achievements where different agencies have worked together successfully. The dynamics of viewing people explaining their situations, and disclosing their pathways was illuminating and moving.

6.3 Contributions the thesis makes to knowledge and understanding

The documentary *Hope* provides new knowledge and understandings of human experience through the stories of families who were interviewed in a manner that enabled them to recount situations that rarely make an appearance in the public domain. I suggest that the thesis makes four useful contributions to knowledge or understanding.

The first relates to the design of useful ethical protocols when recording the experiences of vulnerable participants. Facilitating the recording of these personal stories heightened my awareness of the responsibilities a researcher/director needs to consider. This enabled me to construct certain protocols for ethical practice. These protocols I suggest, may be transferable or adapted to other situations where a researcher/director is working with documentary as a tool of inquiry. These protocols include:

- Clarifying and explaining the reason for and aims of the inquiry.
- Establishing clear, agreed parameters for the way interviews will be conducted.
- Clarifying and discussing the rights of participants within these guidelines.
- Openly declaring one's subjective/lived relationship to the field of inquiry.
- Understanding that a camera may be an intimidating device and mitigating against this by maintaining small, discreet, ethically guided crews who use minimal rigs.

- Explaining and maintaining a collaborative feedback loop where participants have significant control over what is included and how it is portrayed. This feedback loop is initiated at the first scoping interview, activated after the initial cut of the first interview and exercised through subsequent follow-up interviews and new versions of the documentary.

The second contribution of the thesis relates to evidence of shared experiences arising from the recorded stories. Of the six families I interviewed, all, independently felt that communication between them and mental health clinicians could at times be very difficult. Many felt they were not being listened to, and found meetings difficult to attend as they were arranged during working hours. This is an area that needs addressing, as clinicians often determine what happens to family members and families need to feel secure that their point of view is being recognised. Poor communication was evidenced through accounts of the Privacy Act being invoked and information not shared, being ignored, or families feeling patronised. Conversely some interviews indicated that there were families who received knowledgeable assistance and support. This range of experience suggested that communication with, and support for families can be erratic. There were some instances of the graphic recounting of diagnoses not being carefully explained, and explanations of information about recovery being contradictory and vague. Hospital inpatient units for some participants were described as places to fear and brought back strong memories of stress and trauma.

These stories suggest that families need assistance and education in how to behave with their family member and help in supporting them towards recovery. The stories suggested that this was seldom being provided. What became apparent was that Non-Governmental Organisations (NGOs) provided support through group and individual assistance in times of crises but more training for families was needed. The interviews additionally suggested that the police need training in mental health issues because they were often called in during critical events. While I accept that the six families contributing these stories represent a small sample of those caring for a family member with mental illness, their experiences contribute to understanding about how families can experience the wider mental health treatment scenario.

The third contribution the research makes relates to the impact of such findings on pedagogical approaches to teaching documentary making. Working on location, in unique circumstances with this project has changed my approach to capturing personal stories. The experience has also caused me to rethink how I teach students about ethical issues, and prepare them to consider the implications of what their decisions can have for ordinary people. Camera and sound recordings create a permanent record. The choice to encourage others in exposing personal issues might make effective television but I would argue, if this serves no long-term purpose then it is exploitative. With the stories in *Hope* a great deal has been left unsaid. I learnt that words expressing grief and the restraint with which people describe their feelings are in combination, very powerful, and watching overt displays of emotion are not the only prerequisites for feeling empathy or understanding another's suffering. Documentaries like *Hope* suggest a more restrained approach to storytelling where authenticity of narration rises above the desire for dramatic peaks of "captured" emotion. Here continuity and the absence of extra-diegetic commentary afford a comparatively subtle kind of storytelling that reveals authentic experience while allowing participant's the right to control the levels of intimate revelation they choose to contribute. Pedagogically such approaches serve to widen considerations of the role and nature of documentary making among emerging filmmakers and the thesis helps such considerations because it examines findings in the context of practice.

Finally, the research contributes something to how we might develop documentary processes in constrained circumstances. Working with a small production team, researching, directing and editing the videos, enabled me to become very familiar with the content. Establishing collaborative approaches to story construction where participants and informed groups are able to feedback into the process has demonstrated how, on a restrained budget, it is possible to create documentary processes that are highly responsive and participant-focused. Such approaches engage a heuristic methodology because they are arguably systems of discovery and collaboration.

This kind of documentary making forsakes emotional provocation and micro-managing and respects the need for privacy and informed restraint in storytelling. Yet, with all of these constraints in place, one can produce deep and arresting documentary material that offers profound insights into lived experience.

6.4 Considerations for future research

A doctoral-level project can never cover all of the complexities and potentials of either documentary process design or subject content. Future research may extend the potentials of working with a combination of observational film and interview footage. This approach may offer distinctive insights into little considered aspects of family interactions when there are no outsiders present. Teaching participants to use a camera so they can record their version of situations as they occur may be helpful in providing further reflective data both for personal and institutional consideration.

It may also be interesting to follow up on these families in a few years and record their progress. While working with this project some family members became unwell again and in one family their family member had passed away. Considering such inquiries not as discrete inquiries, but as on going documents of lived experience, change and adaptation over extended periods of time, may offer a deeper consideration of the non-redemptive nature of caring for and supporting people with mental health issues.

Another area that I am considering in terms of the research is documenting siblings' experiences of growing up with a brother or sister with mental illness, and the role reversal that occurs when they become the caregiver of a parent. Children who are now adults take their experiences into the next generation and need assistance with learning further about family relationships.

The current project will benefit by a broadening of participants, especially the documenting of stories of culturally diverse families such as Maori, Pasifika, Asian and other ethnic minorities in New Zealand. I approached many organisations representing a range of cultural and ethnic groups without success and it is hoped that this video might stimulate useful discussions in these communities and lead to a higher level of engagement in future projects.

Another potential trajectory for the project is recording the opinions and stories of those diagnosed with schizophrenia. In doing this we might better understand how support is most effectively achieved. This process would be challenging both ethically and physically, but documentary material that records how managing the lived experience of

"hearing voices" would be of great assistance to both caregivers and those living with schizophrenia and other psychotic disorders, as it is information that needs to be shared.

While interacting with these six families I noted how important gardening and growing plants were to their wellbeing. Further investigation into the affect of gardening and working with the soil on families involved with mental health issues, could be an important area of research.

6.5 Final personal reflections

Directing *Hope* has involved a balancing process of consistent reflection and heuristically sensing my way forward. Although such inquiries bring with them high levels of instability and "unknowing" (Kleining & Witt, 2000; Ings, 2014), they can result in considerable growth for the researcher. As a consequence I have experienced considerable development in perception that has produced a deeper questioning of my professional practice.

This research has benefited from continual reflection on the importance and implications of what people wish to communicate about their situations. Acquiring in-depth knowledge of some of the deep-seated prejudices that have existed historically, and examining the influence of contemporary screen media on people's attitudes to mental illness, have assisted me in realising how much care is needed in designing an ethical approach to recording the stories of people who care for the mental health of parents, partners, children or siblings. In developing the project a wide range of people have had to be considered; families, service users, mental health workers, hospital staff, counsellors, psychiatrists and community mental health workers. All have been formative in developing both the documentary and the processes that brought it into a tangible form.

As researcher, director and editor I acknowledge that I edited out material the participants might have wanted to include, but it was done with consideration for their overall narrative and I endeavoured to maintain the full scope of each story. There is a limited time a researcher/director can spend with participants without becoming an

invasive personality and in meeting families I became a recorder of what occurred, and I attempted to ensure that filming did not provoke or manipulate false interactions.

Finding out about a diagnosis or knowing about treatment options is only a part of the process of recovery. For many family caregivers, witnessing that recovery is possible is a strong motivating force, as is seeing how supportive relationships assist those in recovery towards living independently. Most important, *Hope* demonstrates that families are not alone; others are struggling with the same situations and the participants' experiences can assist others in gaining greater levels of perspective. I believe that projects like this thesis can make a useful contribution to reducing stigma and discrimination. The capturing of stories on video has meant that the project can speak both to the academy and to the world of the research participants and those like them.

Families need training and education in how to communicate with and support the work that professionals are doing. The stories in this project revealed that many families are not aware that support groups exist or that they can get assistance with mental health issues. Most of the families interviewed found assistance by chance, or had never been given family support. Fear of stigma and discrimination had prevented them from discussing mental illness with others because it is a subject that is seldom talked about in the community. Families are often left to work through their grief silently and alone.

Editing this project while our family was experiencing some difficult times gave me hope that it was possible to move successfully through these patches and that with persistence and patience we can learn acceptance. Knowing that some people do succeed was a strong impetus to keep on learning about how to cope and provide support. I feel I am moving in attitude from being a carer to being a support person and that brings hope.

Through this research project I have learnt humility and I have gained strength from those I interviewed.

This has greatly enriched my life.

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