

School of Nursing and Midwifery

Mental health: The way forward
A grounded theory on the experience of mental health consumers
living in the Western Australian community

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgement has been made. This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Signed:

Date:

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ABSTRACT

Many people with a mental disorder are desperate to improve their situations. It is therefore timely that a substantive theory on what it means to live with a mental illness in Western society is developed that explores a way forward for them. This study goes back to the grassroots and finds out from the people diagnosed with major depression, bipolar disorder or schizophrenia what they say helps them. Although many studies have been carried out on the impact of mental disorders, the voice of mental health consumers has not featured prominently. This study aims to redress this in reporting on what they identify as their main concern and on how they resolve it.

This thesis presents the substantive theory of *transforming oneself and society to resolve life being a struggle*. It is based on interviews with 35 mental health consumers living in the Western Australian community. Relevant national and international literature is also included as additional data. This study used the grounded theory method to identify a commonly shared pattern of behaviour in how participants resolved their main concern. The main concern, called the basic social psychological problem of *life being a struggle*, was brought on by eight *disempowering conditions*, which disempowered participants in both personal and social spheres. Participants then engaged in a personal struggle, including identifying their intrinsic value as a person, and their struggle with relationships. This culminated in the struggle with getting through daily life.

Participants resolved the basic social psychological problem of *life being a struggle* through the basic social psychological process of *transforming themselves*. This process consisted of two stages separated by a turning point. In the first stage, participants found that neither withdrawing nor trying to get on top of having a mental disorder was successful in dealing with basic social psychological problem of *life being a struggle* despite their best efforts. In their powerlessness at making a difference to their lives they reached a breaking point, which became a turning point, where they were forced to confront their hopeless situation. The successful confrontation, or turning point, marked the change from their hitherto powerless

position into one where participants had some power for the first time. They pinpointed this as the beginning of their transformation.

In stage two of the basic social psychological process of *transforming themselves*, participants built up their power by deciding to tackle the struggle to identify their intrinsic value as a person first rather than focusing on trying to get on top of having a mental disorder. By refocusing on getting better as a person, participants managed to gain a new perspective, which in turn allowed them to learn new strategies and take action that made a difference in their lives. This second stage was fulfilled when participants felt at peace.

However, as participants pointed out, being at peace remained fragile because the *disempowering conditions* that had brought on the basic social psychological problem of *life being a struggle* were still operating and therefore these conditions also had to be changed. *Empowering conditions* could achieve this in given participants sufficient power or influence and authority so that the *disempowering conditions* could be countenanced and then banished on a permanent basis. Participants' lives would then no longer be a struggle and they could live in peace. Participants suggested that enacting these *empowering conditions* would amount to *transformation of society*, where society treated people with a mental disorder with justice and provided effective help. In accord with other identified theories and models, the substantive theory of *transforming oneself and society to resolve life being a struggle* established that *the transformation of society* was the way forward to improve the situations of people with a mental disorder and relieve their desperation.

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CHAPTER 1: INTRODUCTION, BACKGROUND AND PROBLEM STATEMENT OF THE STUDY

1.1: Introduction

Historically, people living in Western society with a mental disorder commonly suffered ill treatment (Herman & Green, 1991) and social exclusion (Morrall & Hazelton, 2000). Before the 19th century most people with a mental disorder were left to fend for themselves, often leading a life of destitution (Herman & Green, 1991). In the 19th century management methods changed and tens of thousands of people with a mental disorder were moved into asylums built on the outskirts of cities (Millon, 2004). In the mid 20th century, advancements in pharmacological treatment (Frisch & Frisch, 2006; Lewis, 1988) and a philosophical paradigm shift in the care of people with a mental disorder (Mechanic & Rochefort, 1990) allowed governments to close the once-prized asylums and to move patients into the community (Millon, 2004).

Despite the fact that most people with a mental disorder now live in the community they largely remained hidden (Groom, Hickie & Davenport, 2003) and silent for fear of experiencing discrimination (Stroman, 2003). Until recently, those who spoke out against their treatment and against community attitudes were often regarded with condescension because "what the mad said was no better than meaningless babble" (Porter, 1987, p. 2). According to Porter (1987), history has been written in the main from the perspective of the establishment, such as family members or health professionals. This thesis aims to redress this imbalance and report on the experience of mental health consumers diagnosed with major depression, bipolar disorder or schizophrenia and living in the Western Australian community, from their perspective. The term 'mental health consumer' or 'health consumer who has a mental illness' is used in Australia to describe people who use or have been using mental health services (Olsen & Epstein, 2001). They will be referred to as 'consumer' in the rest of the thesis.

The experience of consumers has only recently been recognised as valuable. Internationally, the United Nations (1991) emphasised the rights of consumers in the *Resolution on the Protection of Rights of People with Mental Illness and for the Improvement of Mental Health Care*. In Australia, the experience of consumers has been taken into account in the *National Mental*

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Health Strategy documents (Australian Health Ministers, 1992a, 1992b, 1992c, 1998, 2003, 2009a, 2009b), particularly in the policy document entitled *Mental Health Statement of Rights and Responsibilities* (Commonwealth of Australia, 1991). This policy document emphasised consumers' right to contribute to decision-making regarding their treatment, care and rehabilitation. Furthermore, the *Fourth National Mental Health Plan 2009-2014* (Australian Health Ministers, 2009a) continues to urge politicians, policy-makers and service providers to treat people with mental disorders as equal partners when deciding on matters affecting consumers' quality of life.

However, government reports have not been influential enough to change society's largely negative view of consumers. As most consumers are now living in the community after the closure of many psychiatric hospitals (Burdekin, Guilfoyle & Hall, 1993; Department of Health and Aging, 2005b) they are often confronted with the hostile reaction of the public. This hostile reaction has been documented in studies from Australia, Europe and the USA and ranges from discrediting consumers professionally (Joyce, McMillan & Hazelton, 2009) to discriminating against them daily (González-Torres, Oraa, Arístegui, Fernández-Rivas & Guimon, 2007) and attacking them physically (Marley & Buila, 2001).

The experience of consumers living in the Western Australian community is the focus of this study. It is hoped that the findings will make a significant contribution to the understanding of this experience in the 21st century. This chapter will explore the background of the study by first providing definitions of mental health terms that will be used in the thesis. The number of people affected, i.e. the prevalence, will be described as well as the changing focus of mental health care. In addition, the chapter will detail the need, significance, purpose, objectives, and assumptions the researcher considered prior to commencement of the study. It will close with an overview of the organisation of the thesis.

1.2: Definition of mental disorder

According to the World Health Organisation (2001) mental disorders are defined as conditions affecting mental functioning "characterised by alterations in thinking, mood (emotions) or behaviour associated with personal distress and/or impaired functioning" (p. 21). The Department of Health and Aging (2005b)

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refers to a mental disorder as "a clinically recognisable set of symptoms (relating to mood, thought, or cognition) or behaviour that is associated with distress and interference with functions (that is, impairments leading to activity limitations or participation restrictions)" (p. 7).

A person is diagnosed with a mental disorder by conventions used in psychiatry. These conventions dictate Western society's understanding of mental disorders. Sadock and Sadock (2003) explained that a person is diagnosed with a mental disorder when their presenting signs and symptoms compare with the diagnostic criteria published in one of the two world-wide classification systems, the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM-IV-TR) or the International Classification of Diseases, 10th edition (ICD-10). The DSM-IV-TR is used more in the USA and the ICD-10 in other countries such as Australia.

Specific clinical manifestations have to be present for a diagnosis to be made (Sadock & Sadock, 2003). Where appropriate, associated features can also be included such as age of onset, gender related factors, prevalence and incidence, course, complications and familiar pattern. However, theories of causation and treatment methods are not covered in the two classification systems. The definitions and descriptions of mental disorders are still evolving and will change with future editions (Aldhous, 2009).

The term disorder is used when the cause of a disturbance of a body system or mental function has not been identified, in contrast to the term disease where a specific pathogen or biochemical or physiological dysfunction has been found (Meadows, 2001). The term disorder is used in this study when an actual psychiatric disorder, that is major depression, bipolar disorder or schizophrenia, is referred to (see Appendix A). The term illness is used when relating the consequences of the disorder on the affected person in terms of impairment, disability and functioning.

1.3: Prevalence

Extensive surveys have been carried out (Slade, Johnston, Oakley Browne, Andrews & Whiteford, 2009; The World Health Organisation, 2001) measuring the number of consumers. These surveys all use the Composite International Diagnostic Interview (CIDI) as a tool to measure prevalence. The CIDI consists

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of a comprehensive interview for adults assessing the symptoms of mental disorders and their impact on daily life according to the criteria of the IDC-10 (Australian Bureau of Statistics, 1998).

The World Health Organisation (2001) identified that worldwide 450 million people have a mental disorder by estimating the prevalence of depressive disorders, schizophrenia, substance use disorders, dementias and epilepsy. The point prevalence, or the prevalence at one point in time, for adults is 10% and the lifetime prevalence is 25%.

In Australia, the *2007 Australian National Survey of Mental Health and Wellbeing* (Slade et al., 2009) in a national, representative household survey estimated that the 12-month prevalence of anxiety, affective and substance use disorders in adults is 20%. Anxiety disorders account for 14.4%, affective disorders such as various types of depression, mania and bipolar affective disorders, for 6.2% and substance use disorders for 5.1%. Twenty-five percent of affected people reported that they had more than one disorder. The same survey found that 13% of the general population had suicidal thoughts during their lifetime, with 4% saying they had a plan and 3.2% had attempted it (Johnston, Pirkis & Burgess, 2009). Furthermore, only one third of the population who admitted to mental health problems were in contact with health services (Slade et al., 2009).

Jablensky et al. (1999) looked specifically at psychotic disorders as part of the *National Survey of Mental Health and Wellbeing* conducted by the Commonwealth Department of Health and Aged Care in Australia. They defined psychotic disorders as those disorders characterised by distortions of thinking, perception and emotional response. Examples are schizophrenia, bipolar affective disorder and delusional disorder. They found that these disorders account for 0.47% of adults who are in contact with mental health services in a one-month period (Jablensky et al., 1999). Worldwide, the lifetime prevalence for schizophrenia alone is 0.4% according to Saha, Chant, Welham and McGrath (2005) who reviewed 188 studies from 46 countries.

1.4: Burden of disease

The impact of a disability is measured as burden of disease, which measures the gap between years lived with a disability and those that could have been free of

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disease and disability, according to the Department of Health Statistics and Informatics at the World Health Organisation (2008). Its *Global Burden of Disease 2004: Updates* put the years lost due to disability as a result of depression, bipolar disorder and schizophrenia worldwide as 13.6 % for males and 18.3 % for females. This survey also estimates that depression alone will move up from its third position in 2004 to become the leading cause of disability globally by 2030. In Australia, mental disorders are identified as the largest source of disability and the third largest source of burden of disease, after heart disease and cancer (Department of Health and Ageing, 2005a).

The importance of the burden of disease is reflected in the cost of care for consumers. The original *Global Burden of Disease Study* (Murray & Lopez, 1996) equated the level of disability of living with schizophrenia and depression to the level of disability of living with quadriplegia and paraplegia respectively. Andrews, Issakidis, Sanderson, Corry and Lapsley (2004) put the direct cost of a disease management program dealing with anxiety and depression at \$15,000 to \$20,000 and that of schizophrenia at \$200,000 annually. Direct costs are expenses related to the management of symptomatology, suicidality and self-harm, and associated personal disability related to everyday self-care (Carr, Lewin, Neil, Halpin & Holmes, 2004). In addition, indirect costs are estimated to be at least five times higher (Andrews et al., 2004). Indirect costs are associated with impaired social and occupational functioning related to lack of education, unemployment, and subsequent income and family support (Carr et al., 2004). Both direct and indirect costs highlight the enormous personal, social, financial and economic burden associated with mental disorders (Robinson & Pennebaker, 2002). As major depression, bipolar disorder and schizophrenia are severe mental disorders the personal and social burden is high. People diagnosed with these disorders have therefore been selected for this study.

1.5: Changing focus of mental health care

As early as the 1960s the high cost of looking after people with mental disorders had already been recognised worldwide by most governments (Mechanic & Rochefort, 1990). As a result the focus of service delivery of mental health care moved from an inpatient to the community setting through a process called deinstitutionalisation. Although many participants in this study had not

personally gone through the process of deinstitutionalisation they were experiencing the repercussions from this service delivery policy change. How deinstitutionalisation was achieved, its philosophical underpinnings and the Australian government policies determining how community care should be carried out will now be discussed.

1.5.1: Deinstitutionalisation

Nothing has changed the environment for people living with a mental disorder more in the last 50 years than the process of deinstitutionalisation. It has therefore been described as the "single most important issue" with regards to service delivery (Rich, 1987, p. 114). Deinstitutionalisation was achieved by discharging large numbers of patients into the community (Sadock & Sadock, 2003). Fewer admissions and readmissions (Stroman, 2003) and shorter lengths of stay (Coffey, 1994) also contributed. Globally, as a result of deinstitutionalisation, the provision of mental health care in the community continued to expand (Mechanic, 1987). Modern community mental health care, supported by legislature, aims to maintain the consumer in the community by providing treatment, rehabilitation, housing and support services at a local level.

As early as 1990, Mechanic and Rochefort (1990) examined the ideological, judicial and economic reasons for deinstitutionalisation. Ideological reasons were based on the belief that institutions were detrimental to the well being of patients because they fostered dependency and a sense of hopelessness and helplessness (Goffman, 1961). Living in the community was seen as a way for consumers to live a more 'normal' life and maintain connections with society (Newton, Rosen, Tennant & Hobbs, 2001).

Judicial reasons for deinstitutionalisation were based on the human rights movement in the 1960s, which demanded increased recognition of the rights of consumers (Herman & Green, 1991; Mechanic & Rochefort, 1990). This culminated in the United Nations' (1991) resolution entitled *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care*. This resolution laid down 25 principles for the equal rights of people with mental disorders incorporating their right to live and be treated in the community, and their freedom from discrimination. It also covered the right to

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adequate standards and access to treatment, and the right to high quality surroundings in mental health facilities.

Economic reasons for deinstitutionalisation, argued Mechanic and Rochefort (1990), were based on the high cost of psychiatric hospital care, which could be reduced by transferring care into the community, and hence onto the family (Wynaden, 2002).

Deinstitutionalisation in Australia occurred because it was found to be too expensive to provide modern care for the ever-increasing number of patients in institutions (Lewis, 1988). To reduce the number of inpatients, the intellectually impaired, the elderly and those with alcohol dependence were moved into non-psychiatric facilities such as community homes overseen by social services, nursing homes and drug and alcohol treatment centres. In addition, large numbers of patients with mental disorders were released into the community. The advent of medication able to reduce psychiatric symptoms allowed for early discharge and the maintenance of consumers in the community. The beginning practice of patient rehabilitation carried out in the community aided the reshaping of services. This reform process reduced the inpatient population of psychiatric hospitals in Australia by 86% between the 1960s and 1992 (Burdekin et al., 1993) and a further 59% subsequently (Department of Health and Aging, 2005b). The rate of reduction in public hospital beds plateaued in 2001 (Department of Health and Ageing, 2007).

1.5.2: Community care

Whereas services for patients in segregated institutions were provided in the one place, the delivery of services in the community proved to be more complex (Australian Health Ministers, 1992b). To facilitate the organisation of services in the community in Australia the government introduced the National Mental Health Strategy (Australian Health Ministers, 1992c). This strategy ushered in the modern era of mental health service delivery in Australia by providing for the first time a national agenda for mental health reform. This reform was called a "standard for other nations" (Betts & Thornicroft, 2001, p. 15) and its associated policies were formulated nearly a decade before the World Health Organisation (2001) report, *The World Health Report 2001: Mental Health: New Understanding, New Hope*. The World Health Organisation (2001) report

recommended that establishing national policies and programmes was important for achieving significant and sustained action in the delivery of community based mental health services. Now 18 years old, this strategy is still used as the basis for the delivery of mental health services in Australia. Rosen (2006) laments the "loss of momentum" of reforms that has occurred and puts this down to a "failure of governments to continue to drive and fund them adequately" (p. 81). Even though 10 % of submissions to the National Health and Hospitals Reform Commission (2009) report were concerned with mental health issues there is no implementation plan and, quoting the health minister, mental health reform remains "unfinished business" (Mental Health Council of Australia, 2010, no pagination).

The principle aim of the still current National Mental Health Strategy (Australian Health Ministers, 1992c) was to improve the lives of consumers with a focus of transforming mental health services previously based in institutions to services primarily provided in the community.

Initially four policy documents made up the National Mental Health Strategy (Australian Health Ministers, 1992c) with another two added later, each one dealing with a particular aspect of service delivery (Multicultural Mental Health Australia, 2006). The National Mental Health Policy (Australian Health Ministers, 1992b) gives broad aims and policy directions to guide the establishment of services in the community. The four National Mental Health Plans (Australian Health Ministers, 1992a, 1998, 2003, 2009a), each spanning five years, provide an action plan to implement these policies. The *Mental Health Statement of Rights and Responsibilities* (Commonwealth of Australia, 1991), based on the United Nations' (1991) resolution on human rights for people with mental disorders, determines the rights and responsibilities of consumers and service providers. The *Medicare Agreements* (Office of Legislative Drafting, 1992) allocate funding for the plans.

Several evaluations and reviews of the national strategy were carried out (see table one for an overview of the national policy documents, evaluations and reviews). Selected aims of the national strategy, important in the context of this study and articulated in the policy documents and plans, will now be discussed and compared with actual achievements found in the evaluations and reviews.

Table 1: Overview of the documents contained in the *National Mental Health Strategy*, evaluations, and reviews, with the date of release. References are given in the text.

National Mental Health Strategy, commenced in 1992				Evaluations and reviews
Policy documents	National Mental Health Plans	Funding arrangements	Additional policy documents	
National Mental Health Policy, 1992	National Mental Health Plan, 1992	Medicare Agreements, 1992 onwards	Mental Health Statement of Rights and Responsibilities, 1991	Burdekin Report, 1993
			National Standards for Mental Health Services, 1997	
	Second National Mental Health Plan, 1998		Learning together: Education and Training Partnerships in Mental Health, 1999	
			National Action Plan for Promotion, Prevention and Early Intervention for Mental Health, 2000	International Midterm Review of the Second National Mental Health Plan, 2001
	Third National Mental Health Plan, 2003			Out of Hospital, Out of Mind, 2003
				Dare to care? SANE Australia Mental Health Report, 2004
				Not for Service, 2005
				Ninth National Mental Health Report: Summary of Ten Years of Reform, 2005
National Mental Health Policy, 2008	Fourth National Mental Health Plan, 2009			Tenth National Mental Health Report: Summary of Twelve Years of Reform, 2007

1.5.2.1: Human rights

It is postulated that enhancing the quality of life for consumers rests on basing government mental health policies on human rights principles (Gostin, 2004). To this end the Australian government released its policy documents *Mental Health Statement of Rights and Responsibilities* (Commonwealth of Australia, 1991) and the later *National Standards for Mental Health Services* (Mental Health Branch, Commonwealth Department of Health and Family Services, 1997). Both are based on the United Nations' (1991) resolution entitled *Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care* (Groom et al., 2003). The *Mental Health Statement of Rights and Responsibilities* (Commonwealth of Australia, 1991) provides the philosophical foundation for the *National Mental Health Strategy* with its aim of trying to "redress inequalities in Australian society by way of social justice strategies" (p. 3). It explains that social justice is concerned with "equal access to health care, housing and education, and equal rights in civil, legal and industrial affairs", being "free of prejudice" and living in a "caring, just and humane" society (p. 3).

The *National Standards for Mental Health Services* (Mental Health Branch, Commonwealth Department of Health and Family Services, 1997) provides standards for service delivery with regards to the application of human rights and when introduced was used as a yardstick to measure the level of human rights consumers receive. There were two additional inquiries exploring the state of consumers' human rights in Australia, both using widespread community consultations. The first inquiry was a report by Burdekin et al. (1993), called *Human Rights and Mental Illness: Report of the National Inquiry into the Human Rights of People with Mental Illness*, also referred to as the *Burdekin Report*. It found that consumers "suffered from widespread, systematic discrimination and were consistently denied the rights and services to which they were entitled" (p. 908).

The second inquiry, a report entitled *Not for Service: Experiences of Injustice and Despair in Mental Health Care in Australia* was conducted by the Mental Health Council of Australia and the Brain and Mind Research Institute in association with the Human Rights and Equal Opportunity Commission (Mental Health Council of Australia, 2005). It was published 14 years after the *Mental*

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Health Statement of Rights and Responsibilities (Commonwealth of Australia, 1991) and eight years after the *National Standards for Mental Health Services* (Mental Health Branch, Commonwealth Department of Health and Family Services, 1997). It identified that inadequate access to quality health services was the most frequent complaint received, with the lack of respect for consumers, poor resources and inadequate facilities also highlighted. It concluded that "after 12 years of mental health reform in Australia, any person seeking mental health care runs the serious risk that his or her needs will be ignored, trivialised or neglected" (p. 14). Furthermore, it found that systemic weaknesses were also evident in a "failure to provide basic medical and psychological health care" (p. 14). It concluded that there had been few advances in human rights since the *Burdekin Report* (Burdekin et al., 1993), and that many aspirations expressed in the *Mental Health Statement of Rights and Responsibilities* (Commonwealth of Australia, 1991) had not been met.

1.5.2.2: Focus on the consumer

The World Health Organisation (2001) purported that consumer involvement in service delivery would bring about an improvement in meeting their needs. The *National Mental Health Strategy* (Australian Health Ministers, 1992c) stated that the perspective of consumers was of central importance. In line with this statement, the *Third National Mental Health Plan* (Australian Health Ministers, 2003) set about strengthening consumer participation. Consumer participation was defined as consumers taking part in decision making "at all levels of policy, planning and treatment" (Australian Health Ministers, 2003, p. 24). The *Ninth National Mental Health Report* (Department of Health and Aging, 2005b) outlined that consumer participation could be achieved by establishing consumer advisory groups set up to provide direct consumer input into the formulation of mental health policy and the development of services. It found that 83% of mental health services had established some form of consumer participation. However, just two years later, as reported in the *Tenth National Mental Health Report* (Department of Health and Aging, 2007), consumer participation had declined to just over two-thirds. The findings of the *Not for Service* (Mental Health Council, 2005) report also established that in the parts of Australia where

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consumer advisory groups were operating, there was often a lack of meaningful consultation with consumers.

Consumer participation also became an important feature of the education and training of health professionals, as laid down in the policy document entitled *Learning together: Education and training partnerships in mental health* (Deakin Human Services Australia, 1999). Consumer participation in the education and training of health professionals meant that consumers were to be actively involved "in all aspects of the education and training process, including curriculum development, teaching and learning programs, and accreditation" (Epstein & Rechter, 1999, p. 22). However, the *Not for Service* (Mental Health Council, 2005) report found that this policy had had little effect as consumer participation had not been enacted. Many consumers were still confronted and treated with disrespect in an undignified manner by health professionals on a daily basis. In addition, health professionals in the *Out of Hospital, Out of Mind* (Groom et al., 2003) review were seen to be functioning in an institutional framework, dominated by authoritarian ways, rather than focused on implementing models orientated towards consumer participation. The National Health and Hospitals Reform Commission (2009) found it necessary to reiterate calls for establishing "more effective mechanisms for consumer... participation and feedback to shape programs and service delivery" (p. 26).

1.5.2.3: Organisation of services

To further the interests of consumers, health services had to be reorganised. Ideas such as mainstreaming, integration, interagency links and service mix became the dominant policy principles.

To avoid treating consumers separately, mainstreaming mental health services was advocated (Australian Health Ministers, 1992b). Mainstreaming meant that mental health services were part of the mainstream or general health sector. It was envisaged that only a small number of consumers would still require the services of a separate psychiatric hospital. As reported in the *Tenth National Mental Health Report 2007* (Department of Health and Ageing, 2007), this was achieved when 84% of acute psychiatric beds were located in general hospitals by 2005. Integration between services would ensure continuity of care

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to prevent consumers "falling between services" (Australian Health Ministers, 1992b, p. 8).

For consumers to successfully live in the community, a range of social services needed to be available as well. The *National Mental Health Policy* (Australian Health Ministers, 1992b) addressed this problem by setting up interagency links between mental health services and other services providing housing, financial support, domiciliary care, employment and training opportunities. In addition, the service mix between different types of consumers had to be ensured. The *National Mental Health Policy* (Australian Health Ministers, 1992b) identified that a comprehensive mental health service needed to cater for consumers requiring short-term and long-term care. However, consumers reported that the working together of services remained sporadic and fragmented and there was often little follow-up on discharge from the hospital into the community (Groom et al., 2003). The National Health and Hospitals Reform Commission (2009) still recommends that people with long-term mental illness should be able to access "a single primary health care service to strengthen the continuity, coordination and range of multidisciplinary care available to meet their health needs" (p. 19), including the provision of stable housing, access to training opportunities and support in their employment.

One way of assessing the success of the new organisation of services was to track government funding. The *National Mental Health Strategy* (Australian Health Ministers, 1992c) made funds available for each of their five-year national plans through *Medicare Agreements* (Office of Legislative Drafting, 1992). These determined that mental health funding were part of mainstream health funding while still remaining identifiable as a source for mental health services. The *Tenth National Mental Health Report 2007* (Department of Health and Ageing, 2007) stated that spending on mental health had increased by 85% in real terms since the inception of the *National Mental Health Strategy* (Australian Health Ministers, 1992c) in 1993. This accounted for six point eight percent of total expenditure on health care. However, the proportion of spending in comparison with general medical services has remained stable, as there has been a concomitant increase of spending on general medical services (Department of Health and Ageing, 2007). Furthermore, 49% of mental health money is still

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spent on hospital-based care instead of on community-based services (Department of Health and Ageing, 2007).

In conclusion, Australia's *National Mental Health Strategy* (Australian Health Ministers, 1992c), when commenced in the 1990s, was praised as an "international exemplar for mental health policy" by Betts and Thornicroft (2001, p. 22). These authors asserted that "no other nation on earth has taken the time to focus its intellectual and political capital to develop such an extensive, measurable plan" (p. 15). Despite this praise they recommended that more work needed to be done to fully implement these plans, and that mental health needed to remain a national priority for government policy and funding. Since that time, a slippage of mental health policy from the national agenda has occurred as documented in the *Dare to Care?* report released by SANE Australia (2004). This report found that despite more than a decade of reform "mental health services were in crisis to varying degrees all around Australia" (p. 1).

1.6: Life in the community

Despite deinstitutionalisation, a less restricted life in the community and many favourable governmental policies consumers received a negative reception from society. Society's view of people affected by having a mental disorder as being irrational and having impaired mental functioning affected their status in society and how they were treated. The already negative attitude of the community towards them intensified. For example, Phelan, Link, Stueve and Pescosolido (2000) assessed the reaction of members of the public to the same vignettes noting their attitude to people with various mental health disorders in 1950 and 1996. They found that the fear and stigma directed towards people with severe mental disorders had increased in the 50 years since deinstitutionalisation began. In fact, for consumers stigma has become the greatest barrier to living a normal life in the community (Sartorius, 1998). They are disliked, rejected (Alexander, 2001; Wright, Gronfein & Owens, 2000) and perceived to be dangerous as shown in studies from as far a field as Australia, the USA and Israel (Hazelton, 1997; Penn, Kommana, Mansfield & Link, 1999; Spitzer & Cameron, 1995). Groom, Hickie and Davenport (2003) found that barriers to the community understanding mental disorders remain high and cited consumers calling for a concerted effort to reduce the level of stigma directed towards them.

As a consequence of stigma many consumers remained marginalised within their communities. They experienced disadvantages with regards to employment, housing, health care and access to support services (Stroman, 2003). For example, in a longitudinal study by Link, Struening, Rahav, Phelan and Nutbrock (1997) 84 male American consumers reported that 50 % of employers refused to hire them because of their disorder even when they displayed few symptoms and were able to function reasonably well. These disadvantages often lead to poverty, lack of opportunity (World Health Organisation, 2001) and, in some cases, homelessness (Herman, Susser, Jandorf, Lavelle & Bromet, 1998) and perpetuated consumers' disenfranchisement.

Due to stigma and discrimination not all consumers are able to take advantage of the freedom of residing in the community. Although some consumers enjoy making their own decisions and exercising some control over their lives (Newton, Rosen, Tennant & Hobbs, 2001) many found that they were not able to take effective action to improve their quality of life. Their sense of mastery was undermined by mental health symptoms and unmet needs in housing, food and leisure activities (Bengtsson-Tops, 2004). In addition, although most consumers had identified goals, only a small minority were able to accomplish these goals (Hodges & Segal, 2002). Qualitative studies showed that consumers tried hard to gain hope (Landeem, Pawlick, Woodside, Kirkpatrick & Byrne, 2000; McCann, 2002; McCann & Clark, 2004) and develop resilience (Geanellos, 2002). Participants in Humberstone's (2002) study felt their difficulties with daily difficulties were a matter of life and death. They tried to survive psychosis, alienation, basic daily requirements like shelter, food and physical safety, and health services. Other consumers gave up on these difficulties and decided to end their life because they were overwhelmed by seemingly unsolvable problems and felt they had no future (Neale, 2002).

1.7: Need for the study

Research into the experience of consumers is needed because such a large number of people are afflicted by a mental disorder and the burden of disease associated with particularly major depression, bipolar disorder and schizophrenia is high. Moreover, current treatment methods only reduce 13% of the burden of disease with, for example, schizophrenia (Saha et al., 2005) and

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even with the best treatment scenario about 75% of the burden remains (Andrews et al., 2004).

Jorm, Griffiths, Christensen and Medway (2002) found that stakeholder groups, consisting of academics, health professionals, consumer and carer advocates, want more research into what can make a difference to the daily lives of consumers. These stakeholder groups want priorities set on depression and suicide, on prevention and promotion of mental health, psychological and social treatments, the evaluation of health services and the education of health professionals. In order to make a difference to the daily lives of consumers Groom et al. (2003) and the Mental Health Council (2005) quoted Australian consumers calling for a concerted effort for more research based on their experience because current management methods were seen as not working.

Jorm et al. (2002) identified in their report on gaps in Australia's mental health research that further research can play an important role in easing the suffering of consumers, reduce the burden of disease and the costs to the community. Moreover, consumers in the *Out of Hospital, Out of Mind* (Groom et al., 2003) review called for the development of a new holistic model of care that would be responsive to their needs and appropriate to their present life situation in the community.

This study aims to fulfil the above requests in a comprehensive and coherent way by formulating a substantive theory on the experience of consumers living in the Western Australian community. The experience of consumers is explored from their standpoint so that their views can be heard and greater insight gained into what concerns them and how they resolve these concerns.

While many studies have been carried out on aspects of consumers' experience, for example on their relationships with other members of the community (Alexander, 2001) and with health professionals (Forchuk & Reynolds, 2001), on coping strategies used at work (Alverson, Becker & Drake, 1995), on quality of life (Corring, 2002) and on improving health and social functioning (Hannigan, Bartlett & Clilverd, 1997). More studies have been conducted on selected groups of consumers, for example women (Chernomas, Clarke & Chisholm, 2000), young people (O'Toole et al., 2004), people with schizophrenia (Boydell, Gladstone & Volpe, 2003; Davidson, 2003) or

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depression (Egan, Gridley, Hood & Brew, 2003). It is postulated that only a substantive theory is able to pull together all strands of this experience. Studies producing substantive theories dealing with selected topics such as mental illness stigma (Link, Struening, Dohrenwend, Cullen & Shrout, 1989) and suicide (Aldridge, 1998, Durkheim, 1887/1952, Joiner, 2005) provide important information. These theories, however, by dealing only with a selective topic, may have missed vital aspects of consumers' experience. This study, by taking a broad approach, aims to present insight into all facets of the experience important to consumers.

1.8: Significance of the study

A substantive theory on the experience of consumers living in the Western Australian community is necessary to discover how they resolve their main concern in a multi-dimensional and comprehensive way. This theory should help affected individuals by extending the knowledge on and providing innovative understanding into key issues and important strategies used by consumers to manage their experience of living in the community.

In addition, this substantive theory will provide the general population an increased understanding of consumers' experience so that the hostile social environment could be reduced. The developed substantive theory will also provide a significant conceptual advance in the field of mental health care. It should guide the formulation of new policies and the design of more effective health services that will meet the needs of consumers so that they can be helped to move towards wellness. The increased understanding can also lead to the development of best practice standards in mental health management. It could contribute to the development of a theoretical base for health professions and would be a useful guide in clinical practice. In addition, the developed theory will open gateways for further research to consolidate the study and to develop a deeper understanding of the social, psychological and interactional experiences of a person with a mental disorder.

1.9: Purpose of the study

The purpose of this study is to formulate a substantive theory to obtain a multi-dimensional insight into consumers' experience of living in the Western

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Australian community and significantly advance the understanding of that experience. It is hoped that it can improve their lives and make an important contribution to mental health care nationally and internationally.

1.10: Objectives of the study

In order to achieve the above purpose the objectives of this study are to:

- Explore and explain the experience of consumers living in the Western Australian community;
- Identify conditions, or factors, that influence this experience;
- Develop a substantive theory that explains consumers' common shared experience.

1.11: Assumptions underlying the study

Prior to commencing this study the researcher held several assumptions about the experience of living with a mental disorder. Based on her qualifications and experience as a mental health nurse, general nurse and midwife, as a senior lecturer in Nursing including teaching the mental health units and as a result of her Masters of Science on the experience of young adults living with a mental illness these were:

- Consumers have difficulties living with a mental illness.
- Health services are inadequate to address these difficulties, whether carried out in hospitals or in the community.
- The concerns of people with a mental illness are central to improving the quality of their life.
- An increased understanding of the experience of consumers has the potential to enhance outcomes for consumers, carers and services.
- A substantive theory on the experience of consumers can make important contributions to mental health education.

1.12: Summary

As most consumers now live in the community they have to be able to manage life outside the organised confines of an institutional setting. Life in the community exposes them to a hostile social environment. As their view has traditionally been ignored it is important to describe their experience from their

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point of view in a coherent and comprehensive manner. This study identified patterns that explained what is going on as consumers resolve their main concern. Uncovering these patterns explains the common shared experience of consumers, which as yet has not been fully explored.

1.13: Organisation of the thesis

The first chapter contains the introduction, background and problem statement as well as the need, purpose, objectives and justification for the study. Chapter two describes the use of the grounded theory method and the application of this method in this study.

Chapters three to six detail the substantive theory, resulting from interviews with consumers. Chapter three explains the framework and explores why participants' main concern has occurred. Chapter four presents their main concern. Chapter five details what participants did in order to resolve their main concern. Chapter six delineates what society can do in order to ameliorate the main concern of participants.

Chapter seven focuses on the discussion by comparing the substantive theory of this study with other theories and models, and chapter eight examines recommendation, limitations and further research and delivers the concluding statement of the thesis.

CHAPTER 2: METHODOLOGY - THE GROUNDED THEORY METHOD

2.1: Introduction

This chapter describes the methodology used to explore consumers' experience in the context of the Western Australian community. It explains the grounded theory method as espoused by Glaser and Strauss (1967) and Glaser (1978, 1992, 1998, 2001, 2003, 2005, 2007), details methodological steps, defines key terms and outlines a description of participants. The researcher identified two concepts to be central to the grounded theory method: induction and conceptualisation. These will be used to analyse the origins of the grounded theory method, the divergent methods of Glaser (1992) and Strauss and Corbin (1990, 1998) and the differences between the grounded theory method and other research methods. The data collection method and data analysis will also be included in this analysis. Data preparation and how the thesis was written up along with definitions and terminology used in the thesis will then be outlined. Criteria for evaluating the grounded theory method will also be explained. The chapter concludes with a brief overview of the developed substantive theory.

2.2: General overview of the grounded theory method

The grounded theory method is a systematic approach to generating theory from data (Glaser, 2001) by following clearly set out procedural steps (Glaser, 2005). The grounded theory method is based on the implicit assumption that human societies are socially organised and that latent but recurrent patterns in this organisation can be uncovered (Glaser, 2001). It asserts that these patterns "drive and organise behaviour and its social psychological aspects" (Glaser, 2001, p. 13). The grounded theory method aims to identify and explain these latent patterns (Glaser, 1978), especially in how people resolve their main concern (Glaser, 2001). It organises the complex and possibly confusing nature of the pattern of behaviour around a core category to "reduce the confusion to an integrated complexity" (Glaser, 2003, p. 168). In addition, factors or conditions that vary the pattern of behaviour are identified whereby the pattern may be maximised, minimised or otherwise changed (Glaser, 1978).

Two essential features of the grounded theory method are that it is inductive and conceptual. The inductive feature of the theory ensures that the

research focuses on the concerns of participants and on trying to understand the patterns of behaviour from their perspective (Glaser, 1998). The resulting theory is, therefore, not based on any pre-existing or preconceived theories, models, paradigms or frameworks. It develops its own abstract model or framework based on the analysis of the data alone (Glaser, 1992, 2001, 2003, 2005). Glaser (2005) argued that applying preconceived ideas to the analysis is "diametrically opposed to the goal of grounded theory" (p. 102). He explained that preconceived ideas would distort or bypass the participants' main concern and instead just confirm the researcher's own perspective, which is often not the real problem relevant to participants (Glaser, 1998). The method is therefore called grounded, that is, the generated theory corresponds to or is grounded in the experience of participants and not in extant ideas (Glaser, 2003). Once the theory has been inductively developed it is set into the context of existing scientific literature.

The second essential feature of the grounded theory method requires that the fundamental pattern of behaviour be explained conceptually and not descriptively (Glaser, 2003). Conceptualisation means identifying concepts involved in the pattern of behaviour, which elevates the theory to an abstract level that is abstract of time, place and people. The grounded theory method thereby does not record the particularistic voices of participants but identifies their common shared pattern of behaviour and explains the reasons behind this behaviour (Glaser, 2003). It "transcended the boundaries" (Glaser, 1978, p. 101) of describing specific people in a specific place at a specific time. The resulting theory, which arises from a substantive area of research, can then be "fully generalisable as abstract processes" (Glaser, 1978, p. 101) and applied to other research fields (Glaser & Strauss, 1967).

2.3: The origins of the grounded theory method

The two essential features of the grounded theory method identified above were already evident in Glaser and Strauss' (1967) first book on the grounded theory method, entitled *The Discovery of Grounded Theory: Strategies for Qualitative Research*. In this work they described how they "discovered" (Glaser & Strauss, 1967, p. 1) the grounded theory method while doing research on dying patients in hospitals (Glaser & Strauss, 1965, 1968). They believed that their new method

would be more relevant and applicable than other research methods because it was able to interpret, explain and predict behaviour relevant to real life. It would give affected people, whether laymen or professionals, an increased understanding on what is going on in their social sphere and subsequently allow them some control over their situation. In addition, theories could be formulated where none previously existed or when a new perspective was called for. They claimed that basing theory formulation inductively on data gave it credibility and endurance over time.

To ensure the generation of a theory from any type of data, qualitative or quantitative, Glaser and Strauss (1967) devised a set of systematic analytical procedures, which were further explained by Glaser in two other books: *Advances in the Methodology of Grounded Theory: Theoretical Sensitivity* in 1978, and *Doing Grounded Theory: Issues and Discussions* in 1998. Glaser (2003) stated that some of the analytical procedures formulated in these books were based on other research methods. For example, Glaser (1978, 2005) explained how he took the procedure of how to generate concepts from data from Lazarsfeld's concept-indicator model in survey research analysis, a quantitative method on the conceptual coding of a set of indicators (Lazarsfeld, 1958, 1959, cited by Glaser, 1978). This yields concepts that are linked to data and therefore produce an inductive theory (Glaser, 1978). Merton (n. d., cited in Glaser, 2005) supplied his idea of substantive and theoretical coding-conceptualisation to grounded theory's coding procedures.

While Glaser's background was in quantitative research, Strauss had been trained in qualitative methods, particularly in symbolic interactionism (Glaser, 2005). The term symbolic interactionism was first coined by Blumer (1969) and was based on the work of Mead (Meltzer, Petras & Reynolds, 1975). According to Blumer (1969), the term symbolic interactionism signifies that human beings attach meanings not only to objects in their daily life but also to their social interaction with other people. Individuals interpret these meanings and shape their behaviour on the basis of this interpretation. However, symbolic interactionism, according to Glaser (2005), should not be seen as dominating the grounded theory method's origins to the exclusion of other inspirations.

The arrival of the grounded theory method 40 years ago was described as turning traditional research methods upside down in that it advocated using data to create theory instead of testing it (Rennie, 1998). Since its inception it has become very popular in many fields of research and has now been described as a global phenomenon (Cutcliffe, 2005). The success of the grounded theory method has been marred, however, by the divergence in the writings of its originators in the 1990s.

2.4: The divergence in the writings of Glaser, and Strauss and Corbin

In 1990 Strauss, with his co-researcher Corbin, published a new book, entitled *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*, which sought to present the procedural steps in the grounded theory method in an easier to understand format for the beginning researcher. Strauss and Corbin (1990) introduced a new framework or model, called conditional matrix, to integrate the core category with specified conditions, actions, interactions and consequences. They stated that "the researcher needs to fill in the specific conditional features" (p. 162, bold font in the original version) such as time and place. To emphasise the necessity of using their model, they warned: "Unless you [the researcher] make use of this model, your grounded theory analysis will lack density and precision" (p. 99). In order to accommodate their model, Strauss and Corbin (1990) introduced an additional step in the analysis, which they named axial coding. In axial coding the specified conditions, actions, interactions and consequences were to be explicated (Dey, 1999) by directing predetermined questions at all concepts and categories in the data (Stern, 1994). Strauss and Corbin (1990) told readers: "With such category relating questions in mind, we then return to our data and look for evidence, incidents, and events that support or refute our questions" (p. 108). This statement indicates that their version of the grounded theory method model is deductive, not inductive. They insisted that all studies had to verify their model.

Glaser wrote a reply to Strauss and Corbin in 1992, in a book called *Emergence Versus Forcing: Basics of Grounded Theory Analysis*, in which he explained in detail that Strauss and Corbin's method forced their preconceived model onto the analysis, whether relevant or not. In contrast, Glaser (1978, 1998,

2005) only gave examples of theoretical frameworks in order to sensitise the researcher to a palette of possible models. He insisted that these were not prescriptive. In fact, he encouraged researchers to devise their own, new theoretical framework if the analysis called for this. The original grounded theory method is purely inductive with data only used to illustrate the theory (Glaser, 1998) whereas Strauss and Corbin (1990) made verification of their framework from the data an explicit goal (Charmaz, 2005).

Glaser (1992) called Strauss and Corbin's (1990) model conceptually descriptive and denied that it was compatible with the original and, according to his judgement, only true grounded theory method. Glaser (2001) explained that conceptual description consisted of identifying a concept and then describing it fully. Strauss and Corbin did not directly reply to Glaser's (1992) stance but mellowed their assertion that their theoretical model "needed" to be used (Strauss & Corbin, 1990, p. 162) and instead went over to suggesting its use (Strauss & Corbin, 1998).

The divergence in the writings of Glaser, and Strauss and Corbin divided grounded theory researchers into Glaserian and Straussarian schools (Stern, 1994). Although this divergence has complicated the choice for an appropriate research method this choice hinged on whether an inductive or deductive theory is sought. An inductive theory can contribute to uncovering new phenomena, whereas the deductive version verifies Strauss and Corbin's (1990, 1998) model. As this study aimed to generate an inductive theory the researcher chose the original or Glaserian approach, from now on called the grounded theory method only.

2.5: Rationale for choosing the grounded theory method for this study

The grounded theory method was chosen for this study because it enabled the objectives to be achieved. Objective 1 and 2 were to explore the experience of consumers living in the Western Australian community and to identify conditions and factors that influenced this experience. The grounded theory method was especially suitable for exploring participants' concerns from their perspective. Adherence to the procedural steps in the grounded theory method resulted in the formulation of an inductive, conceptual substantive theory, the third objective.

Other reasons for choosing the grounded theory method for this study were its suitability to manage qualitative data (Glaser, 1978), its promised relevancy (Glaser, 2003) and immediate applicability (Stern, 1994), in this case to other consumers, their families, the general population, governments and health professionals. In addition, the theory could be generalised to other substantive areas.

Explaining the grounded theory method in detail by examining how its two essential features, induction and conceptualisation, were applied to the data collection and data analysis in this study will now be proceeded with.

2.7: Data collection

Induction in this study was achieved in the way data were collected, how data were sampled, how participants were recruited for the study, how interviews were conducted and how literature was selected. The grounded theory method is able to handle qualitative and quantitative data (Glaser & Strauss, 1967; Glaser, 2003), however, for this study qualitative data in the form of open-ended interviews were used as primary data. Qualitative data were chosen as primary data because they were most suited to inductively accessing participants' own accounts to learn about their experiences (Morse & Richards, 2002). Quantitative data were then added as part of the literature review.

2.7.1: How data were sampled

The sampling method used in the grounded theory method is called theoretical sampling. According to Glaser and Strauss (1967) theoretical sampling searches for concepts that address the theoretical purpose and relevance of the study (Glaser & Strauss, 1967). Glaser (1978) explained that "the initial decisions in theoretical sampling are based only on a general sociological perspective about a substantive area within a population" (p. 36) and therefore this initial sampling is also referred to as purposeful sampling by some authors (Coyne, 1997). The concepts were identified from interviews with people who had experience with the phenomenon under study, that is, what it was like to be a consumer living in the Western Australian community.

A central characteristic of theoretical sampling is induction. Induction is achieved through the application of the constant comparative method. The constant comparative method consists of continuously comparing new data with concepts that have already emerged from previously collected data and which have been found to be important to the evolving theory. Glaser (1978) described the constant comparative method as the joint collection of data, concept identification and analysis. Further data are then collected based on these concepts and the developing analysis. This ensures that "data collection is *controlled* by the emerging theory" (Glaser, 1978, p. 36, italics in the original text) indicating its inductiveness.

Induction through the use of the constant comparative method during data collection was achieved in the following way in this study. In the open-ended interviews the researcher invited participants to tell her anything they liked usually by opening the interview with the following open-ended statement: "Tell me about yourself" to prompt them to talk. Some participants did not even need this prompting and started to talk about what was important to them straightaway. Some other prompts used are included in the open-ended interview guide in Appendix E.

In order to be able to encourage participants to talk freely the researcher tried to establish rapport and an atmosphere of trust. She achieved this by listening to what participants had to say with interest and by emphasising the importance of their contribution, upon which this study is based. This rapport and trust also helped her to "capture the nuances and meanings" (Glaser, 2001, p. 177) of what participants were saying, enabling the identification of initial concepts. These concepts and an early discovery of relationships between them were then used in the following interviews as the basis for follow up questions after participants had exhausted what they had wanted to say. These concepts directed the researcher to what type of further data to sample in subsequent interviews (Glaser, 1978). To further ensure induction, she also reviewed the interviews to see whether all follow up questions had been open-ended and whether any leading questions had been present, which had unduly influenced the response of participants. Glaser (1978) pointed out that any topics that were

not mentioned by participants were deemed unimportant and had to be left out of the evolving theory.

To be able to explain the patterns of behaviour under diverse conditions consumers with a wide range of experiences were interviewed. These experiences ranged from consumers with three different primary diagnoses, diverse professional and economic backgrounds, males and females of all age groups above the age of 18 with outliers in their twenties and seventies years. Responses to the experience of being a consumer were also diverse, with outliers either isolating themselves from society or being highly visible consumer activists. The researcher also chose two other people with a different perspective to consumers to increase the conceptual scope, or variation, of the theory (Glaser, 1978, 2001; Glaser & Strauss, 1967). Excerpts of interviews of one family member who looked after an adult son who had a mental disorder and a health professional who treated patients with mental disorders who had come forward were therefore also included. Other negative cases, such as people who shared some aspects with consumers' experiences but had not been diagnosed with a mental disorder, were sourced from the literature and included as more data.

2.7.2: A description of the characteristics of participants

Thirty-five people who were or had been consumers participated in this study. Their ages ranged from 22 to 77 years, with a nearly equal number of participants being in the thirties, forties, fifties and sixties age groups. Two thirds were female. Seven (20%) participants were degree qualified, some of them as health professionals, adding to their knowledge and experience of mental illness. Eighteen (51%) had worked in well-regarded jobs, two were studying, one of them at postgraduate level, and one was working full-time when interviewed. Seven (20%) participants were working part-time and three (9%) were doing voluntary work. Five (14%) had unwillingly retired early. Most (93%) participants had never used illicit drugs.

Twenty (57%) participants reported some form of abuse in childhood and/or adolescence; two thirds of these were characterised as severe. Seven (20%) mentioned a happy childhood and the remainder did not comment on their upbringing. Eighteen (38%) participants were members of mental health

support groups or daycentre organisations. Six (17%) had become consumer activists using their extensive experience and insight to contribute to a greater understanding of being a consumer. They had been or were members of government advisory groups, had made submissions towards improving state mental health plans, lobbied politicians and health care managers, featured in newspaper articles furthering the cause of consumers, were leading members of support groups, and had given guest lectures at universities on their experience as consumers.

All participants identified themselves as having been diagnosed with a mental disorder. Nine (26%) participants had been diagnosed with major depression, 21 (46%) were diagnosed with bipolar disorder, six (17%) with schizophrenia and four (12%) with a combination of a mood disorder and psychosis. At the time of their interview, no participants were in an acute stage of their illness and had no florid signs and symptoms present. Medications were taken by 33 (94%) participants and the same number was using mental health services. Twenty-nine (83%) participants had thought about suicide with 13 (37%) reporting actual attempts. Some participants had only recently been diagnosed but many had used mental health services for up to 40 years with both treatment in the community and extended time in mental hospitals including being in locked wards. The mean length of having lived with their mental disorder was 20 to 40 years, with up to 60 years in some instances. Even the participants in their twenties reported having had signs and symptoms already in childhood or adolescents and the onset of their disorder could not be precisely dated. Participants were highly educated about their mental disorder and very knowledgeable about a large variety of treatment options, including medications.

People who had come forward to be interviewed and identified that they did not have major depression, bipolar disorder or schizophrenia were excluded from this study.

2.7.3: How participants were recruited

Recruitment occurred through advertisements placed in 16 community newspapers, through invitations at support groups and a drop in centre as well as through announcements about the study on a community radio station.

2.7.4: How interviews were conducted

When a potential participant was identified the researcher initially contacted that person to arrange a time to meet up, usually by telephone. During these conversations the researcher explained the objectives of the study and how the interview would be conducted. If the potential participant met the inclusion criteria and agreed to participate, the researcher arranged to meet them in a mutually agreed location. The most common meeting place, 60%, was in the participants' home, with the remainder taking place in public places such as cafes, parks and community centres. All participants were interviewed separately. Privacy was assured during all interviews by making certain that no one else was close enough to understand what was talked about.

Interviews were conducted between November 2006 and February 2007. The average length of time for the interview was about one hour, with the shortest being 13 minutes and the longest five hours, which was split into two sessions. Interviews were audio-recorded with each participant's permission.

2.7.5: How field notes were written

In addition to open-ended interviews, some data were generated through the use of field notes (Streubert Speziale & Carpenter, 2003) where the researcher noted down what she observed and her early analytical thoughts, complementing the data obtained in the interviews. The field notes contained information on the environmental setting and the ambience during the interview. The following is an excerpt from a field note:

Excellent interview! I think I have identified the main concern as struggling. I need to explore from now on in other interviews whether this is correct. The participant said prior to the voice recorder starting that she wants to do further education in social studies to help other people affected by a mental illness. She was teary twice during the interview but recovered from that within a short time. Just before I left she said that the interview had inspired her to do some more consumer advocacy work, meaning that she felt better and the interview had helped her. (Field note 7)

2.7.6: How literature was selected

Induction is achieved in the literature review by completing it in three stages. The initial review focuses on the background and significance of the study only

and outlines its contribution to existing knowledge (Chenitz, 1990). In this study, it was carried out for the writing of the proposal and identified that a substantive theory on the experience of consumers was absent. The second literature review establishes the background and context of the study and reviews readings on the grounded theory method. Literature on the substantive area, however, is not reviewed at this stage to avoid influencing the analysis and ensure induction.

The third literature review is carried out once the analysis is nearly complete and concentrates on literature relevant to the substantive theory (Glaser, 2001). This literature is "woven into the theory as more data" (Glaser, 1998, p. 67). Therefore it is grounded to concepts sourced from the data and inductive. In this study, both technical and non-technical literature was used. Technical literature, or refereed literature, consisted of reports of other research studies and theoretical writings, and non-technical, or grey literature, was comprised of non-refereed writings such as autobiographical accounts. Literature was also chosen from other population groups. This choice contributed to the density and scope of the theory (Glaser, 1978).

2.7.7: How data saturation was reached

Saturation means that no additional data are found to add new concepts (Glaser & Strauss, 1967) and the same concepts indicating a recurrent pattern in behaviour are detected (Glaser, 2001). Glaser and Strauss (1967) explained that saturation does not depend on the number of participants or how often a concept occurs but on how many diverse concepts are identified. They explained that the diversity of concepts determines the density of the emerging theory. Interviewing is therefore stopped when saturation is reached and this occurred after 35 interviews with consumers in this study. On gaining feedback from 16 participants, even after they read the draft no further concepts were identified by participants.

2.7.8: How data were prepared

In this study, all interviews were audio taped and transcribed verbatim by the researcher. Although Glaser (1998) strongly advised against taping and transcribing interviews because of the time involved the researcher found it

useful as it allowed her to go back over the exact statements given by participants and extract the correct concepts.

Data were prepared by placing the text of the transcripts into one column and the concepts into a second column. The concepts were then collated into categories. Further sorting was done until initial relationships between these concepts and the categories were fully explored. Concepts were then combined under higher order categories, which were further related to one another and finally assembled into the theory. Once a draft of the whole thesis was ready editing occurred.

2.7.9: Conclusion to data collection

Using grounded theory the data collection for this study abided by the essential feature of induction. It was based on sampling participants who were exposed to the experience of being a consumer. The concepts identified from the interviews then directed further concept identification in the following interviews. Field notes and literature were included only when relevant to the theory. Obtaining deductive data that were not based on concepts obtained from the interviews was thereby avoided and the inductive nature of the grounded theory method ensured.

2.8: Data analysis

Data analysis is based on the second essential feature of the grounded theory method, conceptualisation. Conceptualisation is achieved through the application of the constant comparative method (Glaser, 2003) at all levels of data analysis. In contrast to the application of the constant comparative method during data collection, where induction is the aim, its use during data analysis facilitates conceptualisation. The constant comparative method here allows conceptualisation by constantly comparing differences and similarities between theoretical concepts and the data at each step of the analysis. For an overview of the data analysis see table two.

Table 2: Overview of the data analysis

Coding procedures:	Identifying increasingly abstract conceptual levels	Applying the constant comparative method	Writing notes (memoing)	Outcome: conceptual codes and theory
1.Substantive coding: a) Open coding	Identifying incidents in data; Lower level concepts; Categories and their properties; Core category	Comparison of incident with incident; Comparison of incidents with categories and their properties	Writing notes on concepts and categories and their properties and the relationship between them	1.Substantive codes: patterns relating similar incidents and categories and their properties
b) Selective coding	Focusing only on the core category and related categories and their properties (delimiting)	Reducing the categories and their properties to those related to the core category only; Saturation	Writing notes on how categories and their properties were reduced and saturated	
2.Theoretical coding		Comparing the core category with related categories and their properties	Writing notes on the relationship between the core category and other categories and their properties	2.Theoretical code: abstract model or pattern of how substantive codes relate to each other
		Comparing the core category with the theoretical code	Writing notes on how the core category integrated with the theoretical code	Theory: integration of the core category with the theoretical code

2.8.1: Coding procedures

Glaser (1998) defined coding as assigning concepts to incidents in the data. He explained that incidents are noticed in a phrase or a sentence in interviews. These concepts are then grouped as categories at a higher level of abstraction. Coding is carried out in two steps: substantive coding and theoretical coding.

2.8.1.1: Substantive coding

Substantive coding deals with concepts close to the substantive data or the actual behaviour of participants (Glaser & Strauss, 1967) and these codes are regarded as hypotheses or "probability statements about the relationship between concepts" (Glaser, 1998, p. 134). Substantive coding is divided into open and selective coding.

Open coding is ascribing concepts to all incidences in the data (Glaser, 1978). Glaser (1978) used the term "open" in open coding to refer to "running the data open" (p. 56) or coding incidents into as many categories as possible. Open coding lifts the data from a descriptive level to a conceptual level. It concludes with the selection of a core category, which is how participants resolved their main concern. This core category is easily recognised because participants constantly talk about it, as it is "the prime mover of behaviour" (Glaser, 2001, p. 49). The core category in this study was found to be *transforming oneself and society to resolve life being a struggle*. The identification of the core category marks the end of open coding and the start of selective coding (Glaser, 1978).

In selective coding, the coding focuses only on the core category. This process is called delimiting (Glaser, 1978). In delimiting the large number of categories and their properties are reduced into a smaller set of those related to the core category only (Glaser & Strauss, 1967).

In line with the constant comparative method, incidences are compared with other incidences, followed on by comparing concepts with incidences. These concepts are then compared with emerging categories and their properties and then to the core category (Glaser, 1978). This process results in theoretical completeness (Glaser, 1998). Theoretical completeness is defined as covering as much variation in the behaviour with as few concepts and categories as possible,

also referred to as scope and parsimony (Glaser, 1978). All conceptual thoughts on the analysis are recorded in memos and then placed into a memo fund ready for sorting in the last stage of the coding procedure, theoretical coding (Glaser, 1978).

2.8.1.2: Theoretical coding

Theoretical coding refers to how the substantive codes are organised or related to each other (Glaser, 1978, 2003) in an overall abstract model or framework, called the theoretical code (Glaser, 2005). While in open coding the data are taken apart, in theoretical coding "the fractured story is weaved back together again" (Glaser, 1978, p. 72). This weaving back together is achieved by linking all substantive codes together through a theoretical framework or code and results "in a unified whole" (Glaser & Strauss, 1967, p. 108). The integration of the core category with the theoretical code constitutes the theory (Glaser, 2005).

How the coding procedures are arrived at the final integrated substantive theory from the raw data through the application of the constant comparative method is summarised in table 2. It was adhered to in full in this study.

2.8.2: Conclusion to data analysis

The identification of concepts at ever-higher levels of abstraction and the exploration of their relationships through the constant comparative method fulfilled the essential characteristic of conceptualisation in the grounded theory method.

2.9: Reducing bias

To conclude the section on data collection and data analysis, how researcher bias is reduced through induction and conceptualisation will be briefly explored. Bias is any influence that brings about a distortion in the data collection and analysis (Polit et al., 2001). The grounded theory method handles bias by regarding it as just another factor to consider (Glaser, 1998). If not relevant it is revealed as eccentric (Glaser, 2003) and corrected for by theoretical sampling, the constant comparative method, memoing, focusing on the core category and saturation (Glaser, 1992). In addition, two other factors reduce undue influence that would

distort data collection and analysis by further assuring induction and conceptualisation: reflexivity and theoretical sensitivity. How these two factors were adopted in this study to reduce bias will now be explained.

2.9.1: Reflexivity

Reflexivity refers to "the degree of influence that the researcher exerts, either intentionally or unintentionally, on the findings" (Jootun, McGhee & Marland, 2009, p. 42). As the grounded theory method requires the grounding of the developed theory in the data only, and is thereby inductive, the researcher in this study had to ensure that she did not unduly influence the developing theory through her own experience and attitude towards participants and the kind of life they described.

Jootun et al. (2009) highlighted two components of reflexivity. The first component deals with the personal and professional relationship between the researcher and participants. In this study, this relationship was limited to a brief conversation when arranging to meet up and to the duration of the interview session. The researcher did not previously know the participants. This brief relationship limited any undue influence of the researcher's values, preconceptions or personal beliefs on the response of participants.

The second component of reflexivity addresses the influence of the researcher's values, preconceptions or personal beliefs on the response of participants and the interpretation of the data (Jootun et al., 2009). In this study, the researcher undertook a personal journey during which her values and worldview changed. As she had no personal experience of being a consumer her values and worldview at the beginning of the study were seeing consumers largely as patients. At the end of her personal journey she had moved to seeing them as complex human beings. She realised both the depths of participants' predicament and their enormous strengths. The researcher started to fully realise how difficult participants' lives had been and what their struggles were. It also emerged that far from being people drowning in a never-ending sea of difficulties, they had taken the initiative, learnt new skills and found the resources to resolve their problems. This inspired admiration. Participants also told of the many positive examples of how people had helped them and that had

given them comfort. This left the researcher with a hopeful outlook for the future, contrasting the early gloomy picture.

2.9.2: Theoretical sensitivity

The second factor reducing bias and distortion on the data collection and analysis is theoretical sensitivity or the ability to think in theoretical terms (Glaser & Strauss, 1967). Glaser (2003) advised that the researcher should "stay engaged with the data totally and let the abstract patterns emerge through constant comparisons" (p. 69). In order to broaden the researcher's theoretical perspective, Glaser (2003, 2005) recommended studying the some different theoretical codes in other grounded theories unrelated to the substantive area.

Glaser (2003) was confident that most researchers are able to suspend their knowledge of other ideas until the completion of the data analysis and to stay open to the patterns identified from the data (Glaser, 2005) thus avoiding forcing other ideas onto the data (Glaser, 1998).

The researcher followed Glaser's recommendations and achieved theoretical sensitivity by applying the principles of data collection and data analysis already described and by being reflexive. She also looked at the over 50 theoretical codes in Glaser's (1978, 1998, 2005) writings and at other theoretical codes in other studies. She also guarded against being unduly influenced by models prevalent in the substantive area, such as the disease model or models on suicidal behaviour. In addition, the researcher decided not to use any medical terminology in the write-up unless used by participants in order to help the reader also avoid any undue association with other ideas.

2.10: Writing up the theory

Glaser (1998) stated that a basic tactic in writing up a grounded theory is to place theoretical statements and concepts at the beginning of chapters, subsections or paragraphs and then illustrate them with examples that include direct quotations from the interviews. These illustrations are used to persuade readers of the usefulness of the theory and of its correspondence with the data (Glaser & Strauss, 1967). A second tactic crucial to writing up is to use concepts that carry forward, the "carry-forward notion" (Glaser, 1978, p. 136). The carry-forward

notion highlights the importance of the identified concepts. If a concept does not carry forward it is possibly irrelevant to the developed theory.

In addition, the original wording used by participants in this study was maintained so that the participants' voice could be heard despite the use of some unorthodox language. Other points are as follows:

- Each participant in this study received a code number, for example P1, to preserve his or her confidentiality. P represents consumer participants, HP the participant who was a health professional, and FM the participant who was a family member.
- Italics denote major conceptual terms, those that carried forward.
- Square brackets [] used in direct quotations indicates information added by the researcher.
- Asterisks * denoted omissions of identifying features of participants and other people and organisations, including the names of health facilities, to protect their identity.

2.11: Definition of terms

The following terms used in this study:

- Health professional: Any professional giving health care to consumers. Health professionals referred to in this study were nurses, doctors, psychologists, occupational therapists, social workers and counsellors.
- Mental health services: Services the consumer had used or sought out from health professionals and/or community clinics and hospitals.

2.12: Criteria for evaluating a grounded theory study

The grounded theory method uses "fit", "workability", "relevancy" and "modifiability" as a criterion for evaluating research (Glaser & Strauss, 1967). Fit means that categories are derived from the data and, according to Glaser (1978), this criterion is automatically met by adhering to the method. Workability refers to the power to explain the pattern of behaviour (Glaser, 2003), or that the "theory should be able to explain what happened, predict what will happen and interpret what is happening" (Glaser, 1978, p. 4). Both fit and workability combine to produce a theory relevant to affected people in the substantive area

(Glaser, 1992). To test the theory in this study for fit, workability and relevancy the theory was discussed with 16 participants who provided feedback and with other people not taking part in the study who had experience with the phenomenon of being a consumer. Lastly, according to Glaser (1992), a grounded theory should also be modifiable, or able to be easily altered, by being able to integrate new concepts as they come to hand. Modifiability was achieved in this study during the third literature review where further concepts were added.

Glaser and Strauss (1967) gave some additional criteria for evaluating a grounded theory, namely logical consistency, clarity, parsimony, density, scope and integration. As part of the process of checking the developed substantive theory for these criteria, critical reviews from academics and non-academics were sought out by the researcher. Feedback was also sought from all participants still contactable, 31 out of the initial 35, and received from 16. These whole-hearted endorsed its contents and made comments such as: "At last someone is actually tackling the whole of life and the real issues behind mental illness" (30), "[It is about] where I have come from, where I am and where I am going" (P27), "It describes me to a T" (28). One participant expressed his gratitude to the researcher for the "diligence and commitment you have made to help the needy and suffering in your pursuit of mental health" (P9).

2.13: Ethical considerations

Ethical conduct needs to be part of all research activity and has to be evident in every step of the study from the recruitment of participants to writing up the thesis (Aita & Richer, 2005). The *Belmont Report* (National Institutes of Health, Office of Human Subjects Research, n.d.) established three fundamental principles, which had to be adhered to when conducting research on humans: respect for autonomy, beneficence and justice. How this study adhered to these three principles in the Australian context, that is, in accordance with the National Statement on Ethical Conduct in Research Involving Humans (National Health and Medical Research Council, 1992) will now be explained.

2.13.1: Respect for autonomy

The first principle, the respect for autonomy, addresses issues of participants' informed consent. Autonomy means that participants have a right to be informed on the advantages and disadvantage of the research they are consenting to (Christians, 2005).

This study conformed to the principle of respect for autonomy when, with regards to participants with a 'mental impairment', consent was obtained "whenever the person is sufficiently competent and, where the impairment was temporary or recurrent, at a time when the impairment did not prevent the person giving or refusing consent" (National Health and Medical Research Council, 1992, p. 26). None of the participants in this study were in an acute episode of their mental disorder during the time of the interview as assessed by the researcher, a qualified and experienced mental health nurse. They also had to be over 18 years old to give legal consent without a guardian and be proficient in English so that no interpreters were needed. Participants' competence and willingness to consent was recorded in the field notes.

Participants in this study were informed both verbally and through an information sheet about the study. On initial contact the researcher explained the purpose of the study and how the interview was to be conducted. On meeting participants for the interview, she again outlined the study. Participants were given an information sheet (see Appendix B) that explained the type and purpose of the study and the voluntary nature of their participation. They were given time to ask questions before signing the consent form (see Appendix C). All participants signed the consent form prior to commencing the interview and were given a copy of it and the information sheet.

2.13.2: Beneficence

Beneficence deals with the benefits and risks of a study to participants and other stakeholders (Aita & Richer, 2005). It is concerned with the welfare of all involved parties (Aita & Richer, 2005). The majority of the participants in this study expressed that they were able to air their concerns and get relief by talking about their problems during their interview, which had been beneficial.

Furthermore, no participant in this study was exposed to harm or experienced distress during the interview. Some participants displayed some minor discomfort at times but were able to complete their interviews without distress. During these times of discomfort the researcher offered to cease the interview or change the topic. This offer was always denied. The researcher was also careful in the choice and phrasing of questions so as not to probe for unpleasant experiences the participants did not want to talk about (Babbie, 2007). The information sheet and the copy of the consent form given to all participants carried the researcher's contact details and those of her supervisors if participants wanted assistance after the completion of the interview (Polit et al., 2001).

The safety of the researcher was also an important consideration. As a standard precaution employed when conducting interviews with strangers, some interviews, especially with males, were conducted in a public place. At no time did the researcher feel unsafe in the interview situation.

2.13.3: Justice

The principle of justice covers fair and equitable treatment of participants (Polit et al., 2001) particularly regarding privacy and confidentiality (Christians, 2005). In this study, each participant was allocated a code number, which could only be linked to him or her by the researcher. Only the code number was recorded on the audiotape and transcribed interview. The information obtained during the interviews was stored in an appropriately referenced form in accordance with the Data Storage and Retention Guidelines outlined in the National Health and Medical Research Council (1992). All transcribed interviews are kept securely for five years after completion of the study and then destroyed. No other person had access to the data. Ethics approval was obtained from the Human Research Ethics Committee of Curtin University of Technology (see Appendix D).

2.14: Overview of the substantive theory

The substantive theory in this study consisted of the core category of *transforming oneself and society to resolve life being a struggle*. The main concern was *life being a struggle* for those people who had a mental disorder and

lived in the Western Australian community. They resolved it by a social psychological process entitled *transforming oneself* that revealed in two stages how the main concern was overcome. Two sets of conditions were identified: *disempowering conditions* and *empowering conditions*. The substantive theory will be presented in chapters 3, 4, 5 and 6 of this thesis.

2.15: Summary

This chapter analysed the use of the grounded theory method as outlined by Glaser and Strauss (1967) and Glaser (1978, 1992, 1998, 2001, 2003, 2005, 2007) by using two of its essential features, induction and conceptualisation. In this study, the data were obtained from interviews on the experience of consumers living in the Western Australian community, from field notes taken at the time of the interviews and from relevant literature. The constant comparative method of analysis along with the coding procedures led to the emergence of the core category of how participants resolved their main concern and the conditions influencing this. A brief outline of the theoretical framework will be presented first followed by a detailed presentation of the substantive theory.

CHAPTER 3: THEORETICAL FRAMEWORK AND DISEMPOWERING CONDITIONS

3.1: Introduction

This chapter firstly presents the theoretical framework of the substantive theory called *transforming oneself and society to resolve life being a struggle*, which explores and explains the experiences of consumers who had been diagnosed with major depression, bipolar disorder or schizophrenia and were living in the Western Australian community. Secondly, this chapter contains the first part of this theory.

3.2: Theoretical framework

The main concern for participants in this study was called the basic social psychological problem. It was identified as *life being a struggle* and many participants spoke of their *life being a struggle* explicitly as a problem: "The focus [is]... on the world being really difficult and that life is a struggle" (P31). Other participants concurred, for example in the simple statement of "I struggled" (P7), or in a more expansive form: "It is a daily struggle" (P18) and: "[I am] struggling with everything in this life" (P11). Struggle was defined by the Macquarie Dictionary as a "hard contest... against any adverse agencies or conditions" (Delbridge et al., 1997, p. 2102), and by the New Shorter Oxford English Dictionary as "a strong effort under difficulties" (Brown, 1993, p. 3104). Those participants not directly articulating that their life was a struggle provided many examples that typified the similarities of the experience for them.

It emerged from the data that in order to be able to explain the basic social psychological problem of *life being a struggle*, it was first necessary to explore the reasons why this life was a struggle. These reasons were identified as conditions and contained specifically the negative conditions influencing participants' lives. Glaser (1978) called this type of framework or theoretical code a causal-consequence model. The conditions were the "cause" and the basic social psychological problem the "consequence". The conditions in this study were called *disempowering conditions*, as they revealed how they disempowered participants and thereby led to their *life being a struggle*. They were the foundation for the rest of the thesis and were therefore placed ahead of the basic

Theoretical framework and disempowering conditions

social psychological problem as part one, covered in this chapter, with the basic social psychological problem following in part two in chapter four.

The third part of the theory in this study, explored in chapter five, consisted of the pattern of behaviour, or the basic social psychological process, by which participants resolved the basic social psychological problem. This basic social psychological process was called *transforming oneself*. Participants *transformed themselves* from being someone who had no power in dealing with their *life being a struggle* to someone who had gained sufficient power to be able to gain a new perspective about who they were as a person and their place in society, learn new strategies and take effective action. *Transforming themselves* delineated two stages participants went through in making these significant changes to themselves. These stages were separated by a turning point. The basic social psychological process of *transforming oneself* concluded by participants *being at peace*, which signalled that their life had turned from being a struggle to one of peace. It was the completion of resolving the basic social psychological problem of *life being a struggle*.

Despite participants' engagement in the basic social psychological process of *transforming themselves*, its resolution was fragile as they often remained exposed to the *disempowering conditions* that had given rise to the basic social psychological problem of *life being a struggle*. To put the resolution of participants' *life being a struggle* on a solid foundation the *disempowering conditions*, especially the ones related to participants' social sphere, also needed to be changed significantly. How society could be changed in order to alleviate the possibility of participants' *life being a struggle* from reoccurring was identified as *empowering conditions*. These *empowering conditions* formed the fourth and last part of the theory in this study and were presented in chapter six. They outlined participants' suggestions for the creation of an equitable society. This required a transformation of society. By presenting these suggestions, participants anticipated that the negative experiences in the *disempowering conditions* could be countered and they hoped that, if the suggestions were implemented, life would not be a struggle any more and they could live in peace.

3.3: Disempowering conditions

In the first part of the theory of this study, participants revealed that *life was a struggle* because they were disempowered. To disempower is "to deprive of power, authority, or influence: make weak, ineffectual, or unimportant" (Merriam-Webster's Online Dictionary, 2008, no pagination). Whereas participants in this study were fully aware of the disempowering influence of these conditions, either as an antecedent to their mental disorder or as a consequence of it, they said that it was doubtful whether many members of society were cognizant of the devastating effects their disempowering views, values and behaviour had on them.

The possibility has to be emphasised here that many experiences described by participants under the *disempowering conditions* may be very upsetting for the reader, especially the category of *having been abused in childhood and/or adolescence*. Some conditions related to participants' social sphere could also be seen as perturbing and even confronting, such as those pertaining to the organisation of health services, to clinical treatments and to the attitude and behaviour of health professionals. They could be seen as confronting because the general population, including health professionals, regarded them as normal and the right thing to do. However, participants insisted that it was important to fully expose their experiences, so that the *disempowering conditions* they described could be addressed: "[People] need to know" (P35).

Disempowering conditions occurred in participants' personal and social spheres.

3.3.1: Disempowering conditions related to participants' personal sphere

Three conditions were identified: 1) *having a mental disorder*; 2) *wanting to be dead*, and 3) *having been abused in childhood and/or adolescence*. Each of these conditions will now be presented.

3.3.1.1: Having a mental disorder

Participants in this study explained that *having a mental disorder*, referring to the experience of signs and symptoms during an episode of illness, disempowered them because they lost the ability to control their mental faculties. They said that

Theoretical framework and disempowering conditions

at times that their loss of control was so severe that it could be likened to a terrible evil force that had taken hold, disempowering them to such an extent that it had taken away or "stolen" (P33) their "birthright to be a viable, alert person" (P33). They described the various ways in which they had lost control over their lives, which occurred irrespective of diagnosis:

I was screaming and throwing things around and accusing them [other people] of... destroying my life.... I was trying to stop myself, I kept telling myself, 'Stop it, * [name of participant]... just get back to normal'.... But I couldn't. I couldn't control it.... I KNEW the things I was saying were untrue, and I knew it but I couldn't stop myself. (P7)

The loss of control also affected participants' thinking during an episode. They described how they had not been able to control their thoughts and they could not decide which events were real and which were not: "I didn't have the filter in my brain that filtered out what might be real and what might not be real" (P12). Other participants spoke of being unable to control their emotions. Yet others said that they were unable to depend on their own perceptions over their physical surroundings to tell them what was happening: "Nothing... the things you see, the things you hear, the things you feel are not real... when you are having an episode" (P16). At this time the loss of control was so great that participants said they felt like they had changed to someone they hardly recognised:

I remember I went shopping with my son and I was just... out of control. I mean literally out of control. I was like yelling at shopkeepers and this is... not my nature, not at all. I'm not an aggressive person. (P21)

Another participant described how her loss of control due to *having a mental disorder* had overridden her better judgment and turned her from being a law abiding and family orientated person into someone who smashed expensive items against her will because a voice in her head told her to: "At that time [during the episode] someone, I wasn't myself, someone was controlling me totally.... But it wasn't I. Someone was telling me, 'Today you want to break this... [item]'; then I go and break it" (P10).

The inability to take control was so disempowering that participants really thought what they experienced was real:

You totally believe that's it [that is reality]. You don't question it... because to you it's logical.... You can't sit back and say, 'Hey, hang on a minute,

that's wrong'. You don't think that way. You're thinking that [other] way, so it must be right. (P18)

These experiences are classed as hallucinations and delusions by mental health professionals.

Participants pointed to possible physical changes in their brain to account for the disempowering inability to exert control over their behaviour, thoughts, emotions and perceptions of surroundings and they began to use physical terminology to describe what was happening with them. For example, they compared the start and end of an episode to a switch in their head that turned on and off. Others likened the physical changes to bubbles popping in their brain: "It feels like... bubbles inside your head here. It is like, 'click, click, click', like air bubbles [popping]" (P26). They explained that after these physical changes had occurred something akin to a festering wound had been opened up, which never healed and left them susceptible to the occurrence of further episodes of illness.

Affirming the theory of a physical origin, participants pointed to the genesis of their mental disorder as either something that had just sprang up as a mutation, or as being genetic, naming many other family members who were also affected. Importantly, participants could remember that they already had signs of the developing disorder in childhood or in their early teenage years: "I knew from very early... there was a woeful problem" (P26). They described what ranged from being "miserable" (P25) and being "very absent minded and... [unable to] concentrate" (P3) to having hallucinations and delusions: "I used to have these electronic or radio discharges going on in my head then. The whole works, the vision, and I was only a five year old kid" (P16).

Other consumers in autobiographical writings have also reported that they were not able to control the signs and symptoms of their mental disorder: "I cannot will control of my mind" (Moore, 2001, p. 199). They indicated a loss of control over their emotions: "[They were like] blazing fires that I could not put out" (Molta, 2002, p. 98) and their perceptions over their physical surroundings: "Horrible images flickered through my brain that I could not stop" (Hensley, 2002, p. 418). A grounded theory study of 38 men in England also revealed that they were convinced that physical changes in their brain had occurred (Ridge & Ziebland, 2006, p. 1043). Other consumers were quoted as talking of "air

bubbles... hitting me... from every side" (Repper & Perkins, 2003, referring to a consumer cited by Kitzinger & Perkins, 1993, p. 19). Shattell, Starr and Thomas' (2007) study with 20 adults with a mental illness living in the community uncovered that they also had had signs and symptoms since childhood: "I've had these visions since I was a little girl" (p. 279).

3.3.1.2: Wanting to be dead

The second *disempowering condition* related to the personal sphere was expressed by participants as a wish of "wanting to be dead" (P35). Many participants experienced this condition at some time during their life and one participant described it as being a generalised feeling: "I just wanted to die. I was totally happy just to die" (P23). Other participants said that this generalised feeling had already been present since their childhood: "It's like [a] vivid memory. I mean you can't really remember much when you are five but it's really vivid, this feeling of wanting to be dead.... It is obviously something you are born with" (P35).

The intensity of participants' feeling of *wanting to be dead* disempowered them to such an extent that they had no control over the feelings when they occurred: "I couldn't stop [it]. It [the feeling] was continually in my head all the time. [I] couldn't get rid of it... [It] just [went] on and on and on" (P23). The feelings were so intrusive and constant that participants experienced them as innate, or "in me anyway" (P20). They explained how the feelings had come "uninvited into my brain" (P12) without prior warning or any initiating situations: "I can just... wake up in the middle of the night and think, 'I don't want to be here'.... I'll just think, 'I wish I would die.... I wish something would happen to me and I would die'" (P29).

For many of the participants the generalised feeling of *wanting to be dead* then progressed to specific thoughts about committing suicide. They said that these thoughts were so powerful that they seemed like they were being pushed to kill themselves for no reason. Those participants who had a religious faith believed this was the presence of an awful force that precluded any free will. For instance, suicidal thoughts could appear during completely innocuous activities like walking along a road: "I'd be walking my kids to school and be walking home across the bridge... and I'd stop and contemplate... jumping off" (P29). The

following participant likened the power of these unexpected and uninvited thoughts to being swamped by a king wave that suddenly appeared in a calm sea:

They [the suicidal thoughts] come in waves, and it's like when you are swimming.... You are quite happy swimming along and then you get hit by a wave of these thoughts. And you come up for air and you get hit by another wave.... It was horrid, absolutely horrid. (P12)

The same disempowerment also occurred when seemingly forced to make plans for how to commit suicide: "I was at the level, all the time of... wanting to do things [committing suicide]. [There] was always... a plan. I always had a plan going.... I would work it through in my head every day, all day" (P23). Making plans became so pervasive that it was incorporated into everyday activities such as driving along a highway: "I would drive everywhere wanting to drive into everything I saw. I'd be driving down Reid Highway wanting to hit all the pillars on the road" (P23).

Participants in this study were then just as disempowered when it came to exerting any control over stopping their actual attempts to take their life. These attempts were sometimes performed nearly every day: "I just walked into the room, simple as that, shut the door, locked the door, put all my pills into a glass, filled it up with water and just glug, glug, glug [swallowed them all]" (P18). This loss of control led to their suicidal behaviour becoming habitual at times: "I just kept taking tranquilizers, [I] just kept wanting to black out, continually just taking them, overdosing" (P20). As these attempts occurred so frequently participants began to view them as natural or normal. They concluded that the disempowering wish of *wanting to be dead* had reduced the threshold between a desire to stay alive and *wanting to be dead* to such a degree that there was little difference between the two: "Sometimes there is only a fine line between life and death itself" (P26). Consequently, it did not take much to tip participants over the edge into wanting to go through with suicide, as will be revealed again later in the study.

Other consumers have also spoken in publications about their wish to be dead: "I... wished I was dead" (Lovejoy, 1984, p. 810). Like participants in this study, they told of the intensity of this wish and the lack of control they had over it: "I obsessed about dying" (Michael, 1999, p. 414). They also indicated their disempowerment in attempts to take their life: "I was driven on many occasions

to attempt suicide" ('Gina', 2007, p. 56). Other research also supported the same disempowerment associated with suicide. Durkheim (1887/1952) reported in one of the first extensive studies on suicide that suicide was a "vague aptitude" (p. 103), an "irresistible impulse" or an "irresistible force" (cited in de Boismont, n.d., p. 65). He wrote that due to this vague aptitude, no particular reason for the wish to commit suicide and therefore no explanation for its occurrence could be found: "*I have no reason to kill myself*" (Durkheim, 1887/1952, from de Boismont, n.d., italics in the original text, p. 65). Joiner (2005) also concluded, in his substantive theory on the factors influencing suicide based on accounts of several hundred people contemplating suicide, that suicidal acts were certainly not "impulsive" nor "'spur-of-the-moment' decisions" (p. 185). He stated that his informants habitually thought about suicide, as did participants in this study. Durkheim (1887/1952) stated that "there is nothing which cannot serve as an occasion for suicide" (p. 300).

3.3.1.3: Having been abused in childhood and/or adolescence

The third *disempowering condition* in participants' personal sphere related to the severe physical and emotional abuse many participants in this study experienced as children and/or adolescents. For these participants this abuse left a lifelong legacy and became the defining part of their life: "See, when you have 15 years of hell, it leaves its scars" (P18). Participants linked the abuse directly to the occurrence of their mental disorder. Whether the abuse was a cause, a magnifier or a trigger, participants were convinced that their mental disorder was an inevitable consequence of this abuse: "If people have those kinds of things in their lives [the abuse] they are doomed basically.... No wonder I had a mental illness" (P30). Participants could easily explain the link between the abuse and the occurrence of the mental disorder because they were certain that severe trauma had permanently altered the chemicals in their brain: "[It] locks in a pattern in your brain" (P35).

Having been abused in childhood and/or adolescence was such an important factor in disempowering participants because it took away the capacity to build a satisfying, enjoyable life and left participants feeling fragile and insignificant. They described how the abuse ranged from neglect to brutal attacks: "We lived in a house of horrors" (P30). They elaborated that neglect

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consisted of living in "dysfunctional" (P33) and "non-nurturing" (P20) families where participants were left uncared for in every way: "My mother totally neglected me" (P23). In some families there was no physical affection shown between participants and other family members: "She [my mother] didn't want anything to do with me. So she just ignored me basically" (P23). In some instances, participants' parents also had a mental disorder and consequently they left participants to care for themselves from an early age:

My mum was never physically or emotionally there; she was so mentally ill. She died emotionally and mentally at a young age. When you have a good look at photographs of her when she was young, you could see there was nothing there. She was just like a cut off person; she was cut off from the world. (P30)

Other participants described the brutality of their family life: "Very abusive and very nasty" (P23). They relayed how the sexual abuse consisted of abhorrent acts of rape: "I was sexually abused as a kid... before the age of three... up to God knows how long, years" (P30). Several participants told of how they had been passed around to several other people for further sexual exploitation: "He used to auction me off to his mates as well" (P34). Furthermore, they recounted how the physical abuse, which manifested itself through savage beatings, was sometimes so severe that participants believed they would be killed: "Their [the abusers'] definition of punishment was, you had to be black, blue and bleeding.... They forced me to strip off and just start working on me... and there wouldn't be a piece on me that wasn't bleeding, black and blue" (P18).

Psychological abuse, as remembered by participants, referred to threats: "I remember my * [abuser] threatening to castrate me" (P9) and prolonged attacks on participants' dignity and self-respect. Acts of humiliation were common, as in the example provided by the following male participant: "She made me dress in a woman's dress; sit on a stool... with a dummy in my mouth, nursing a doll. I was 14 [years of age]" (P18).

In the literature, other people who had been abused also characterised this abuse as "brutal" (O'Gorman, 2009, p. 221). Female child abuse survivors thriving in adulthood described their home as a "nightmare house" or "hell" (Thomas & Hall, 2008, p. 154). Erdmans and Black (2008) found that 27 young mothers in their study who had been sexually abused in their childhood made

"direct connections" between their abuse and the development of mental health signs and symptoms (p. 86). The prevalence of the abuse in childhood and/or adolescence was demonstrated by a study from Sweden, which revealed that 51% of women using mental health services had been abused (Nilsson, Bengtsson-Tops & Persson, 2005). In the USA, the prevalence of abuse ranged from 48% for males (Swett, Surrey & Cohen, 1990) to 98% for females (Ford & Fournier, 2007).

In summary, the *disempowering conditions* in this study that were concerned with participants' personal sphere consisted of *having a mental disorder*, where they had no control over their behaviour, thinking, emotions and perceptions of their physical surroundings during an episode; of their compelling feeling of *wanting to be dead*; and of the abuse suffered in their childhood and adolescence that became an antecedent to their mental disorder. These were, however, compounded and then overshadowed by the disempowerment they encountered when confronted with society.

3.3.2: Disempowering conditions related to participants' social sphere

These conditions arose from the views, values and actions of society. Society can be defined as "the aggregate of people living together in a more or less ordered community" and their "system of customs and organisation" (Brown, 1993, p. 2931). In this study, society consisted of families, friends, workmates, employers, health care professionals and organisational systems, such as the judicial system and mental health system. Participants emphasised that their disempowering relationship with society was of primary importance in bringing about *life being a struggle*:

Society [is a]... major, major disabling factor.... That would be great if it's put somewhere in there [in this study] in big letters.... The mental illness itself... could be easily dealt with if it wasn't for all these other [social factors]. (P30)

Repper and Perkins (2003), by drawing on the accounts of many people with a mental disorder and their own experience as consumers, concurred: "The specific cognitive and emotional difficulties that led to a diagnosis of mental health problems are usually less disabling than the discrimination and exclusion that accompany them" (p. viii).

The five *disempowering conditions* in the social sphere in this study were: 1) *society did not believe what consumers said*, 2) *society devalued and dehumanised them*, 3) *society was not willing to help*, 4) *society mistreated them* and 5) *society let perpetrators get away with their misdeeds*. These conditions ranged from society's view of consumers, where they did not believe what participants said, to their attitude changing from devaluation to dehumanisation. This attitude then laid the foundation for society's reaction in not wanting to help and justified mistreating consumers. They also fostered an atmosphere of letting perpetrators get away with their misdeeds.

3.3.2.1: Society did not believe what consumers said

This *disempowering condition* reflected society's view of people who have a mental disorder. Participants were thought of so unreliable and dishonest that they were not believed. Not being believed was such a pervasive factor underpinning their disempowerment that it affected most of their interactions with society.

Participants identified that *society did not believe what they said* for two opposing reasons. On the one hand, participants were not believed when they told other people that they had a mental disorder: "A lot of people... out there still think... that you are making it up" (P35). Even experts in the mental health field dismissed some participants' reports about their illness, as related by one participant who had been living with his mental disorder for 60 years: "[They think that] you don't know what you are talking about" (P25). On the other hand, participants were not believed for the simple reason that they had a mental disorder. However, once their illness was confirmed, everything they said was disbelieved, even when it had nothing to do with the illness. For example, a technical suggestion put forward to his professional organisation by a participant was not considered valid despite his long and distinguished career within the area: "Being a professional * [name of occupation]... no one takes me for my word. They think I'm a nutcase" (P16). The same happened to other participants when they put forward suggestions to improve health services.

A consequence of *society not believing what consumers said* was that issues brought up by participants were brushed aside and their interests disregarded on a daily basis: "Nobody would take any notice of you" (P25).

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Decisions on vital matters directly affecting them were made without taking into account what they wanted. Furthermore, participants' comments as official consumer representatives at government-sponsored meetings were ignored: "You'd be on the minutes [of meetings] having said something and they [other members of the meeting group would] never follow it up. They never do it. It's just shit; all that stuff" (P30).

Supporting literature also reported that consumers were not believed. Other consumer-writers noted that what they said was consistently brushed aside and ignored (Leete, 1989). A study based on focus groups with 18 people diagnosed with schizophrenia found that they had "not [been] seen as an important party for receiving information or being included in the decision-making process regarding treatment" (González-Torres et al., 2007, p. 17). Another set of focus groups with 249 consumers stated that their goals and choices were routinely disregarded (Brody, 2008). Moreover, Cutcliffe and Happell (2009), in their examination of power relationships between consumers and nurses, came across examples where nurses insisted on making decisions about consumers' best interests.

Another consequence revealed in this study of *society not believing what consumers said* was that other people were not interested in wanting to understand them and to gain any knowledge on mental health matters: "They need to learn, and that is something [they are] not doing.... [They say,] 'Oh, you've got the problem, deal with it'. Well, you need more than that. You need some understanding" (P27). Of great concern to participants was encountering similar sentiments amongst health professionals: "If you went to talk about something they'd stop you.... They didn't want to know" (P30). Participants pointed out that this led to a grave lack of understanding: "I realised that the medical profession were woeful in understanding mental health" (P26). Despite ample education in mental health theory health professionals, according to participants, did not comprehend the "intricacies and the depth of mental illness" (P28) nor did they understand some common signs and symptoms: "[Health professionals described dissociation as] 'indecisiveness, poor memory'.... I mean don't they understand that you dissociate because there is something so bad there [such terrible experiences, such as the abuse in childhood and/or adolescence]" (P30). Other consumers also told of health professionals who were disinterested

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in understanding them: "[They make no] effort trying to get to know exactly where you're coming from" (Happell, 2008, p. 126).

Participants in this study pinpointed why health professionals were not interested in understanding them. They thought that health professionals were unaware of their own lack of knowledge even though they had ample contact with consumers. Participants explained that health professionals only knew the mental health theory they had learnt during their studies. This theory is based on contemporary psychiatry focusing almost exclusively on identifying signs and symptoms for diagnostic purposes without seeking to find out what precipitated these signs and symptoms. Participants explained that many health professionals' knowledge of mental health matters was divorced from their patients' real life experiences. Participants had the impression that health professionals were confident in their abilities to practice, despite the apparent dissonance between contemporary psychiatric theory and how patients presented: "The * [health professional] kept saying she knew everything but she spoke as if she knew nothing" (P25).

Participants in this study also came across health professionals who persisted in treating them although, in participants' eyes, they were not equipped to do so: "I think some of them do take that task on perhaps without having the right background and skills to do it" (P28). Alongside participants in this study, Van Der Tillaart, Kurtz and Cash's (2009) study found that consumers were disempowered by not being listened to.

The last consequence of *society not believing what consumers said* was blaming them for *having a mental disorder*. Participants said they felt blamed by both the general population and health professionals because they were viewed as weak and incapable or because they were thought of as possessing "bad morals" (P7). Due to this blaming, participants pointed out, society was free to argue that it was incumbent upon participants to get over their mental disorder and saw them as failures if they did not succeed: "Think differently. THINK differently is the big thing. Don't think like that" (P23). Feeling blamed for *having a mental disorder* was also voiced by participants in Humphreys and Thiara's (2003) thematic analysis of 20 interviews with female consumers.

3.3.2.2: Society devalued and dehumanised consumers

This second *disempowering condition* in participants' social sphere followed on from *society not believing what consumers said*. It reflected society's values towards people who have a mental disorder. These values were so widespread and severe that participants reported that they were not accepted as being equal members of society, which was disempowering for them: "The present system prevents people [with a mental disorder] reaching their proper place in society. Society reviles them" (P22). How devaluation consisting of degrading misconceptions progressed to condemnation and prejudging participants will now be explained.

To devalue a person is to see them as lower in status, as not worthy of consideration and respect, and not important enough to ask for their counsel or their opinion. Consequently, a devalued person can be easily dismissed as inconsequential and irrelevant. Participants in this study described how they were devalued by broadly circulating misconceptions that were not only wrong but also degrading: "There's... a lot of misconceptions about * [the person with a mental disorder]" (P1). Common misconceptions that participants came across were beliefs that mental disorders could be controlled by a person's willpower. Therefore simplistic ways of how to overcome these disorders were advocated, possibly in the belief that they would help participants, such as: "You just need to pull your socks up and... get on with it" (P26). As participants were not able to follow through with these admonitions they were regarded by others as irrational cases beyond comprehension. Participants' failure in this regard then resulted in them being singled out as stupid and helpless creatures with no value. It was then all right to attach the most demeaning terms to them, for example: "Crackers or... loony" (P25) or: "Some sort of freak" (P18). In line with general society's adoption of devaluing misconceptions, some participants encountered health professionals who harboured the same misconceptions. They treated participants as if they were stupid, for example when participants asked for assistance: "They basically treated me like I was stupid. They just said, 'we don't deal with people [like you]'" (P23).

The devaluation of consumers was consistent across other parts of the world. Lundberg, Hansson, Wentz and Björkman (2007) reported from Sweden about the devaluation occurring amongst the 200 people with mental disorders in

their study. Connor and Wilson (2006) quoted consumers living in Northern Ireland who were confronted with similar derogatory terms. They were called names such as "'headbin', 'loony'... and 'monsters'" (p. 466). Those in Spain were called "lazy or overdramatic" (González-Torres et al., 2007, p. 170). Read and Baker (1996) found in their English study that families of consumers urged them to "pull themselves together" (p. 16) and displayed the same lack of understanding as participants had experienced in this study.

Condemnation was then added to devaluation: "Of course mental health has always been that, the condemnation. There is something weird; there is something wrong with you" (P27). It was now easy to see how all consumers were viewed as being the same and prejudging them became such an effortless option that it happened automatically and became ingrained. For example, participants said they were prejudged to be untrustworthy and seen as guilty whenever they came in contact with the law.

Health professionals also prejudged consumers. Participants in this study met some who were, in their opinion, even more judgemental than other people in society: "I felt at the time and still do that health care professionals are often the most judgmental of [people with a] mental illness. I think more so than... the general community" (P28).

Devaluating people with mental disorders then progressed to dehumanising them. Dehumanising is to "deprive of human attributes; make impersonal or machine-like" (Brown, 1993, p. 621), or "to deprive of human character" (Delbridge et al., 1997, p. 569). To dehumanise someone is to see them as a depersonalised object rather than as a human being. Consequently, people who are dehumanised are not regarded as equal to other human beings. People do not wish to identify with them and do not want to connect with them on an emotional level. Participants in this study described being dehumanised because the demonised attribute of *having a mental disorder* came to be seen as the only attribute that was important in interactions with others. All of their other attributes and qualities became invisible, along with their societal rights and powers. How dehumanisation occurred both amongst the general population and in the general health service and how it was then applied in the mental health field will now be explored. Both resulted in a distorted view of consumers.

Amongst the general population, dehumanisation changed the demonised attribute of *having a mental disorder* into a stigma. Stigmatisation is the attachment of discrediting labels on a whole group of people (Link & Phelan, 2001), in this case on those with a mental disorder. Participants explained that stigmatisation occurred because mental disorders could not be scientifically explained and therefore society's "bigoted, narrow-minded" (P18) view endured. They realised that stigma could easily defame them because they remained an enigma as human beings and were not understood in how they led their lives.

In this study, this was the point at which the public's attitude changed from broadly devaluing consumers towards only seeing the demonised attribute of *having a mental disorder* in them. This turned consumers into one-dimensional figures. In this study, participants of all ages, whether they were in their twenties or seventies, said that they were affected by stigma, where they were marked out permanently as non-persons who were not part of the human family. The following participant dismissed the view that stigma against consumers had decreased and said that, according to her experience, stigma had actually increased in her lifetime: "That stigma... has disappeared, no. It is actually totally well entrenched.... We... [have] got to be kidding ourselves. It is a myth to say that, 'Oh, everything is changing'. It is not; it is far... worse" (P30).

Participants pointed out that stigmatisation was not only wielded by individual members of society but also beset the general health system: "Of course stigma and discrimination... hasn't gone when you've got a [health] system that uses it really well... [and where it has become] systemic... ingrained" (P30). Participants could point to instances where the stigmatising attitude of the health system had infiltrated health professionals. This was particularly disturbing to participants because these health professionals seemed to see themselves as stigma free but displayed these attitudes nevertheless without, perhaps, being aware of them: "There is a stigma attached to mental health.... I just felt it stronger and more pigeon holing [with health professionals] in the health care system" (P28). This was evident when participants overheard health professionals calling consumers by derogatory names, such as "loopy and loony and punters" (P30).

That consumers are vulnerable to stigmatisation has also been reported in many other studies. In Australia, 80% of surveyed consumers reported being

stigmatised (SANE Australia, 2004). A survey of 778 consumers in England confirmed participants' suspicion in this study that stigmatisation had increased and that attitudes towards consumers are "ingrained, entrenched and debilitating" (Read & Baker, 1996, p. 4). Sartorius (2002), along with participants in this study, stated that health professionals also stigmatise consumers.

Dehumanisation in the mental health field occurred differently. Here the demonised attribute of *having a mental disorder* was transformed into a list of signs and symptoms. As psychiatry focused on this list, participants saw this focus as a way of dehumanising them: "I have experienced a psychiatrist... whose attitude towards me was basically, 'you're nothing but a bunch of symptoms. You are not a human being, you're a mental illness, you're a bunch of symptoms'" (P12). Some mental health professionals saw participants as mere objects, or as "a block of wood" (P30). Other studies described similar consumer experiences. Malins, Oades, Viney and Aspden (2006) found in 33 interviews to elucidate consumers' views on health services that they were not treated "like a person" (p. 200). Lilja and Hellzén (2008) talked to 10 former patients in Norway who also reported being only seen "as a disease" (p. 281).

As a result of the dehumanisation of consumers society formed a distorted view of them. The distorted view amongst the general population was that consumers were dangerous. Participants in this study spoke of a deep-seated fear in the public: "People just brand you.... They are frightened of you" (P18). Participants said that people were frightened because they were convinced that participants would just go out and hurt or even kill other people, and their merely owning a power tool produced fear in others. Participants explained that this very pernicious one-dimensional public-held view, where society mistook rarely occurring manifestations of *having a mental disorder* as the norm, had become the only yardstick by which they were judged. According to participants, this view was widespread: "That's what you get when you got a mental illness" (P18).

Participants found that this distorted view of consumers as dangerous was then reinforced in the media: "People just have this misinformed information about people that are mentally ill through the media and it makes them scared" (P35). Participants pointed to how consumers were depicted in newspapers and chat shows as the worst kind of person, usually reserved for sordid fantasy novels: "Mad, axe wielding maniacs" (P18). According to participants'

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experience, these exaggerated, unrealistic media representations inevitably led to calls for all consumers to be locked up: "What they [the media] are trying to say to society, 'This nutcase did this; lock him up'; him or her; 'Lock him up... because... he's got a mental illness. So, lock him up; he doesn't deserve to be loose'" (P18). In participants' eyes, what made these representations in the media even more hard-hitting was that the public believed that the depictions were correct: "Society looked at it and said, 'Oh, well... there must be some truth to it'" (P18).

As with participants in this study, consumers in other studies came across portrayals in the media of consumers being "killers" (Connor & Wilson, 2006, p. 466) and calls to lock them up were encountered: "'Crazies' must be locked up and drugged for their own good" (Brody, 2008, p. 27).

A distorted view of consumers also occurred in the mental health field. Participants in this study said that this view was "twisted [and] distorted (P30)" because, by focusing solely on signs and symptoms, the background of what had happened to them was not recognised as important: "I am viewed from a scientific gaze that has no thread attached to my life" (P30). Participants explained that this scientific gaze had been put forward to justify the objectivity of the mental health theory, which was aimed at "minimalising" (P30) their experiences. As a consequence, even the most traumatic and blatant abuse predating the mental disorder was blacked out by mental health professionals as if it had never happened and had had no effect on participants:

I didn't just arrive here all of a sudden in a psychiatric unit. I had a world way before I had arrived.... [I was] a... wounded soul.... My wounded... soul was... wounded way before I got to your units... and you couldn't see that.... That doesn't show... 'cause it is something that is not seen. (P30)

Participants realised that this blacking out led to mental health professionals believing that these underlying terrifying causes of mental disorders did not exist:

They [health professionals] got no idea what was going on inside me. They got no idea.... No idea. (Participant is crying.) Every day you've been raped as a child (pause) and they write shit things like that.... I've looked at these [writings] and I tell you, they are disgusting. (P30)

Participants concluded that they were not the ones to see reality in the wrong way here but that a distorted view of consumers was inherent in and promulgated in the mental health field: "Who's got the distorted lens? I don't think I have" (P30). Other consumers quoted in Connor and Wilson's (2006) study also stated that their "life experiences were never taken into consideration" (p. 469). Humphreys and Thiara (2003), in their study on consumers with a history of domestic violence, concurred: "The 'mental illness' becomes the treatment focus reified from the abuse context" (p. 217).

A consequence of the distorted view in the mental health field was revealed in the way psychiatry operated. Participants identified that their signs and symptoms were not recognised as such if they did not exactly fit those described in psychiatry's manual. This had happened to the following participant whose mental health signs and symptoms had not been recognised for many years: "All the doctors missed it" (P26). Moreover, participants' normal emotions and behaviour were mislabelled as pathology because they looked similar to those in the manual:

Some people who work in the mental health field... are always looking for everything that you do to link it to your mental health... to pathologise you.... If you cry, 'Oh, maybe that is a sign of your depression', or if you laugh, 'Oh, are they manic again?' (P12)

Participants said they especially encountered this type of mislabelling when they were angry about how they were treated: "It's like as though you... shouldn't be angry.... So they [health professionals] then take that for being my * [mental disorder]. 'Let's give her some more pills, up the medication'. That's what they said" (P30).

Other mislabelling resulted in making a mental health diagnosis where no signs and symptoms were present. The following participant related how she got diagnosed with a mental disorder merely as a consequence of some of her statements when she pleaded for help after her childhood abuser had moved into the neighbourhood:

I went to a psychiatrist and I walked in and I said, 'Look... I am a nutcase. I sit in my corner. I can't leave my house 'cause I don't want to run into him [the childhood abuser]. Someone's at my windows every night scaring the shit out of me.... I don't know what to do.... I am paranoid, but I am justifiably paranoid'.... That's what I said to him. He goes, 'All right, you

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are paranoid schizophrenic' and he put me on this medication for being a paranoid schizophrenic. (P5)

Due to the distorted view promulgated in the mental health field, participants concluded that it was based on false premises: "The very theories that psychiatrists base their treatments on... are false" (P22). Participants had even come across mental health professionals who did not seem to quite understand how to apply this theory: "They are confused themselves" (P30). However, despite this confusion, participants said that mental health professionals were so dominated by the distorted view perpetuated by psychiatry that nothing was seen outside its framework: "They just have their worldview and... you can see when you are talking to them, they don't get it [understand what you are talking about]" (P30). Therefore, any acknowledgment of its failings was impossible. It was accepted and even encouraged by the public, highlighting again the power of society over consumers: "It is socially sanctioned political power over [consumers]" (P30).

3.3.2.3: Society was not willing to help

In this third *disempowering condition* pertaining to participants' social sphere, participants felt barred from being helped. Due to the devaluation and dehumanisation of consumers as laid out in this study it was no surprise that society's reaction to consumers was often not to give them any help: "They don't... want to help" (P22). These people were family members, friends, employers and work colleagues, and members of governmental departments. Participants also referred to some health professionals who were not willing to help although their whole vocational ethos was based on helping others. Participants recalled how they did not even receive help on the most basic level from them but were left to fend for themselves:

I used to turn up at the * [community clinic] for my appointments, and I used to walk up the bloody highway in the middle of the summer or rain or whatever.... I was quite... grubby and dishevelled and... obviously very unwell... [but] nobody like said, 'look, look, come' and sat me down and tried and... assist me. (P3)

Likewise, participants in Brody's (2008) study on first hand experiences of 249 consumers in California called the society's unwillingness to help a "help

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vacuum" (p. 21). In this study, *society is not willing to help* was manifested in two ways: people were not willing to support participants and they did not want to care for them.

One way of *society being unwilling to help* was to not support consumers. Participants remembered how unsupportive family members had not wanted to talk about mental health issues with them and had decided to switch off instead when the topic of mental health came up. They also did not visit them in hospital when they were sick. Consequently, when crises occurred in participants' lives they were left on their own. Even life-shattering experiences were not acknowledged and dealt with. The following participant recalled how her family had not wanted to support her after she had been raped: "Mental health wasn't discussed. The rape was very much buried under the carpet by my family and so there was no police involved, no medical treatment, no discussion about it at all. It was just shut off" (P7). Other consumer-writers also remembered how their mental disorder was ignored by their family members: "My mental illness became the elephant in the living room - unmistakably present, yet totally ignored" (Steele & Berman, 2001, p. 24).

Participants in this study voiced some reasons why other people did not want to support them: "You are in the too hard basket" (P5). They decided to cut off contact instead and told participants this bluntly and without any false pretences: "You can see the ten-foot barge pole just about that they put between you and them.... People never look at you the same. People won't talk to you. People won't let their kids near you" (P35). Some family members did not allow participants back home after their first hospitalisation and some employers terminated participants' employment: "I got sacked from my job" (P7).

Other people chose to get rid of participants in this study by indirect means. For example, they did not make participants welcome, they did not include them in conversations as if they were not in the room, or they left them out of social activities: "[They] didn't want anything to do with me" (P25). Participants were even not taken any notice of when they were suicidal: "She said, 'Fuck off and stop being a drama queen' and hung up on me" (P17). Often underhand tactics were deployed, such as choosing to cut off contact at those times when participants could not protest: "He [husband] went to court when I was in hospital.... He won the battle [and] got the kids" (P4). Some family

members took even more drastic steps by trying to get participants locked up in mental health institutions. The following participant related how her family member sought advice from his doctor on how to get her admitted to a psychiatric hospital when he was angry with her:

He got cross with me... [and] his psychiatrist said, 'If she is getting under your feet and annoying you, ring the Psychiatric Emergency Team'. So, he did, and I ended up in * [mental hospital], please. Yeah, [you] got to be very careful in this State [of Western Australia]. A spouse can do that. You didn't know, but they can. (P8)

Participants knew that this was a good way of getting permanently locked up: "I know that my relatives... want to make me totally, no sorry, permanently incarcerated so they will never have to see me or hear from me again" (P22). They had encountered fellow consumers who had been left in these mental health institutions because no one supported them.

Cutting off contact with consumers was also a common theme in studies conducted in the USA (Brody, 2008), Canada (Van der Tillaart et al., 2009) and England (Read & Baker, 1996, p. 17). Furthermore, 34% of consumers interviewed in Read and Baker's (1996) study were dismissed or forced to resign from their jobs.

Another way of *society being unwilling to help* was to not care for consumers. Not caring for another person meant not to feel concerned for them and not be bothered with helping them out, whether directly or through institutions. Participants in this study had the impression that many individuals of the very professions whose reputation was built on caring for other people, did not care: "[The health professional] was the pits.... He couldn't have been worse. He didn't care at all" (P25). Nurses with a mental disorder taking part in Joyce et al.'s (2007) study conducted in New South Wales, Australia, also reported on health professionals who did not care: "I found them [health professionals] mostly uncaring" (p. 377).

However, participants in this study singled out elected governments for not caring for those of their citizens who happened to have a mental disorder: "The state doesn't [care]. I proved that" (P22). Participants were clear that governments did not care for consumers' welfare because the services they set up "write human beings off as beyond help" (P22) and this left consumers

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languishing in "appalling conditions, which no one should have to bear" (P22). This uncaring attitude of governments was puzzling to participants because they were convinced that Western governments had the wherewithal to set up services to care for them adequately but for some unknown reason chose not to: "[The statistics are] yelling. Surely... the government can hear... that" (P32).

To participants, governments' unwillingness to care for them was encapsulated in the deficiencies of the mental health services. Participants stated that these services, often referred to by them as the mental health system or merely as "the system" (P3), were "shocking" (P34) and "terrible" (P25). Participants emphasised that the uncaring attitude found in the mental health system had been especially disempowering because it was a major factor in bringing on *life being a struggle*: "The mental illness is bad and it is disabling but the mental health system is the most disabling factor in it" (P30).

Governments' uncaring attitude is revealed in the violation of human rights, in the way they allocate funding and in the deficiency of organisational regulations. With regards to human rights, the formulation of internationally recognised human rights is supposed to pressure governments to safeguard the basic rights and freedoms of all their citizens and protect the individual against "undue coercion" (Richardson, 2008, p. 246). However, participants in this study realised that they were obviously not included as such citizens because, according to their experience, the proclamations on human rights in the mental health field were often only empty statements: "They [consumers] are... starved of everything enjoyed by most people as their human right" (P22). Other consumers had also noticed how their human rights were disregarded, for example in the focus groups set up by Brody (2008) in California.

Participants in this study referred specifically to the human right to make one's own decisions. They said that this human right had been taken away by the state when governments passed acts of parliament that gave health professionals the legal authority to override participants' right to make their own decisions, disempowering them profoundly:

There is a book put out by the Mental Health Law Centre giving the rights of mental patients. Well, I say put it in the rubbish bin. They have no human rights, none. No rights at all because every time they want something a psychiatrist just has to say, 'No', and then they haven't got it. (P22)

Participants in this study pointed to two groups of consumers who were especially at risk of being disempowered by having their human rights violated. Those on Community Treatment Orders, who received psychiatric treatment against their will whilst living in the community if this treatment was deemed necessary by psychiatrists, have no right to decide what they want, especially over whether they want to take potentially poisonous medication:

People [with a mental disorder] have got no control once you've got a Community Treatment Order [in place]. You've got to do anything they [health professionals] say. They can force drugs down you that are like totally toxic, can kill you. I mean, that's [violating] human rights. (P30)

Those consumers residing in locked wards of mental hospitals were also at risk of having their human rights violated: "I cannot forget the terrible injustices I have witnessed in * [name of mental hospital] and other places like it, where man's inhumanity to man is at its worst" (P22). Participants had either personally experienced or had seen first-hand the injustices other consumers were subjected to in these locked wards. They compared the conditions as being "stuck in... dreadful human cages" (P22), where the lack of human rights to make one's own decisions was entrenched: "They don't have freedom" (P22). Participants described how they had come across instances where consumers were denied the right to make decisions with regards to how much water they wanted to drink despite the compulsory administration of medications that produced excessive thirst, and how much they wanted to eat. They were denied their right to decide upon how they wanted to spend their own money, for example, whether they wanted to pay a lawyer who would help them to get out of the hospital. They were also prevented from deciding whether they wanted privacy as they were constantly watched, or whether they wanted to smoke cigarettes as blanket bans on smoking on hospital grounds had been implemented.

Other consumer-writers also reported on the injustice when in these hospitals and commented on the denial of their basic rights: "All your rights are no longer yours" ('Joe', 2007, p. 65). Short (2007), another consumer-writer, also thought it worth mentioning that the lack of privacy was undesirable: "Having someone in a room watching your every movement was uncomfortable" (p. 24).

Another area where governments' uncaring attitude was manifested was in not providing adequate funding for services or a misallocation of available funds, resulting in insufficient services: "There's not enough services and... it's just all crumbling" (P32). Other authors also pointed to a "reluctance to invest resources into mental health care" occurring in other countries, for example in Europe (Sartorius, 2007, p. 810).

Participants in this study said that a misallocation of funding saw high profile acute services prioritised and low profile services that would help participants in the long-term left neglected. Hence both a lack and misallocation of available funds led to insufficient access to services. Participants found that access to general practitioners, specialist services, hospitals, non-medication focused treatments and community services was so restricted that often the only possibility of getting any health care was at the hospital emergency department. Although access problems also existed for patients with general medical conditions, participants thought that it was far worse in the mental health system, underscoring the neglect of these services by governments.

3.3.2.4: Society mistreated consumers

In the fourth *disempowering condition* in the social sphere participants explained that few other groups of people were subjected to such disdainful treatments as they were: "It is the worst treatment of human beings in peacetime" (P22). At the same time they realised that, as the devaluation and dehumanisation of consumers was so ingrained, this mistreatment often did not register as such: "Human beings can be so cruel... and maybe they don't even know" (P22).

Most mistreatment that participants in this study encountered was not against the law but was ethically incompatible with generally agreed values of how to treat other people: "Nobody is trying [to] treat these people [consumers] with how they themselves would like to be treated. Isn't that what they call the golden rule?" (P22). Corroborating this rule, other consumers in other studies also defined the generally agreed values of how to treat other people as "common sense, just treat them the way you would want to be treated if you were in the same situation. It's not rocket science, it's just basic human values" (Connor & Wilson, 2006, p. 467). Two types of unethical actions were identified in this

current study: The first was due to other people feeling superior and the second concerned mental health treatments.

The first type of unethical action occurred because other people, both members of the general population and health professionals, thought themselves superior to participants. In feeling superior, they automatically lowered participants' status to an inferior position and thus disempowered them. Members of the general population, participants recounted, believed that they had the right to tell participants what to do: "The trouble is, you see, once people know that you had a breakdown, they feel very important, and they [think that they] can tell you [what to do] and they treat you like a complete absolute idiot" (P19). Furthermore, participants said that these people thought that they knew better what participants' needs were and that they were in a better position to determine how participants should conduct their life: "They try and run your life.... They... don't just leave you be. They got to run your life how they reckon you should live" (P18).

Participants recalled how some members of the general population, in feeling superior, then felt justified in taking advantage of participants financially and that it was perfectly all right to tell lies because lying to consumers did not matter: "He tells lies because... he thinks... it is all right to lie" (P22). Consumers in other studies also reported being taken advantage of. For example in Browne, Hemsley and St. John's (2008) study on housing following discharge from hospital reported being "vulnerable to being exploited by unscrupulous people" (p. 406). Participants in González-Torres et al.'s (2007) study on stigma and discrimination mentioned being lied to by family members.

In this study, participants found some health professionals also thought themselves superior to participants. Participants said that, to them, it seemed that these health professionals felt superior even more so than the general population in that they believed that patients were "subhuman" (P22) and that they had a right to dominate them:

They [health professionals] are the superior almighty gorgeous people. You [as a consumer]... are human rubbish. That's how you are made to feel and treated.... 'WE are the bosses and WE, we'.... They enjoy feeling superior. There is no doubt about how, because of how they behave towards people [consumers]. 'Oh, we are the superior ones. We are going to be dominating... all these human inferior beings'. (P22)

Participants regarded this belief of health professionals that they were superior as an abuse of power: "Abuse of the first order" (P30). Power confers authority, influence and control over people and the abuse of power applies this authority, influence and control in harmful ways. Participants noted that the abuse of power was so widespread in the health industry that it was found in the whole gamut of professionals starting at the top of the hierarchy down the ranks to those dealing with consumers on a daily basis: "The Minister of Health... [has] got the wrong attitude. So has everybody down the line. If the top is wrong, everybody is wrong" (P22).

Participants identified some reasons why this abuse of power occurred in the health industry. They speculated that health professionals possibly saw it as the right thing to do because they made no attempt at concealing it: "[They] do not disguise their hatred and condescension.... They don't try to hide that" (P22). Furthermore, participants suspected that many health professionals even regarded the abuse of power as beneficial because they were not aware of what they were doing: "Maybe they are not aware" (P22).

Health professionals thinking of themselves as superior and regarding people with mental disorder as "being the underdog" was also identified in Johansson, Skärsäter and Danielson's (2006) Swedish study on the health-care environment on a locked psychiatric ward. Consumers in Northern Ireland witnessed other patients being treated "like cattle" (Connor & Wilson, 2006, p. 469). In an article on the process of recovery Spaniol, Wewiorski, Gagne and Anthony (2005), consumers speculated why health professionals abuse their power: "The power of having power over another person goes to their heads" (p. 89).

Participants in this study described the following tactics used by health professionals to display their superiority and abuse their power. Withholding information and not giving education was one tactic. Participants said that they were not told important facts, such as what diagnosis they had been given or what type of medication side effect to expect: "As if it was none of my business" (P22). They also did not receive education on their mental disorder: "[That was] frustrating on top" (P29).

Undermining participants' self-worth was another tactic used by health professionals. Participants had been told: "'You are absolutely no good. No

good" (P30). Other examples pertained to how participants had been belittled, how they had been told off like naughty children and how they had been threatened with chastisement if they failed to comply. Then the display of power was matched with the concomitant behaviour: "People can sink to terrible depths of behaviour" (P22). For example, participants' most desperate pleas for help were fobbed off in the coldest way as if they were not worth anything:

I'd be... highly suicidal, and my * [health professional] would say, 'Oh, we'll change you onto this medication, go home'.... I'd... lie on the floor in her office... and... say, 'You can't send me home.... I'm going to kill myself, I just feel so desperate'.... She goes, 'Sorry, I can't talk to you now, I've got another patient coming'. (P7)

Participants concluded that health professionals abusing their power were "brutal, bullying, abusive, and totally wrong for such work" (P22). Participants insisted that their own suffering was perpetuated by this abuse and that it was therefore not surprising that they were driven to attempt suicide. However, even with regards to suicide, participants said that health professionals treated them with derision as the following participant related: "A * [health professional] actually said to him [another patient]... 'Well, do you want me to get the gun for you, mate, and show you how to pull the trigger?'" (P7). Participants therefore questioned the whole purpose of health care, whether it was to help them or to create an environment to keep health professionals in powerful positions: "Because after all our [health professionals'] livelihoods depend on keeping people [consumers] under subjugation" (P22).

In similar research, other consumers also described similar tactics used by health professionals. In an interpretive phenomenological analysis of hope and first episode psychosis Perry, Taylor and Shaw (2007) mentioned the lack of information given before and during time spent in hospital. Likewise, participants in Agar-Jacomb and Read's (2009) New Zealand study on what consumers needed when in crisis and in Malins, Oades, Viney and Aspden's (2006) study on consumers' views of Australian mental health services identified that they were not once told what their diagnosis was or were given information about medications. As participants in this study, other consumer-writers described health professionals as "rude and unapproachable" (Short, 2007, p. 25), "military-like, with no compassion or understanding" (Norwood, 2007, p. 43)

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and displaying "bossiness... bullying [and] verbal abuse" (Connor & Wilson, 2006, p. 470). Other authors also identified the disempowerment in how consumers were spoken to (Cutcliffe & Happell, 2009). Johansson et al. (2006), in their study on the Swedish health-care environment on a locked psychiatric ward, concluded that health care was not about treatment but about control: "A health care environment that was overshadowed by control.... [and] attempted to [be] maintain[ed]... by means of rules, routines, coercion and pressure" (p. 245).

The second type of unethical action mentioned concerned mental health treatments. Participants especially singled out how they had been damaged by the treatment with medications and with electro-convulsive therapy (ECT), and during their stay in mental hospitals.

Participants gave many examples of how they had been "damaged" (P7, P19, P22, P30, P33) by these treatments: "Psychiatry has never, in my experience, and I've seen hundreds of... [people being treated], done any good whatsoever, only the opposite. It destroys every aspect of a person's life" (P22). Participants especially singled out the treatment with medications. They explained how they had been damaged by being prescribed medications when they were not warranted or were not the right ones, the latter happening sometimes for decades. Participants recalled that many medications had such severe side effects that they interfered with participants' lives to the point of debilitating them: "So he gives me some tablets and just turned me into a donkey" (P26). Being debilitated by medications occurred in all areas of life: physically, leaving participants with gross weight gain, life threatening organ damage and permanent disabilities; mentally, often adding other signs and symptoms to their mental disorder or making it impossible to think: "Like a lobotomy" (P7); and socially, where they could not fulfil their wish to have sexual relationships due to side effects. Participants described that many medications were so damaging that they prevented them from functioning even on the most basic level: "[I was] dumbed down with medication that was absolutely useless, damaged my whole physical well-being and my psyche, and wrecked me for years" (P30). Participants therefore did not like the heavy emphasis on treatment with medications, which often neglected the use of non-medication focused treatments that they considered as being much less harmful.

The psychiatrists Sebastian and Beer (2007) documented the same damage wrought by mental health medications. Other consumer-writers, such as Francell (2002), explained that some of the side effects of medications were so serious that they "become the primary effect of the medication" (no pagination).

Some participants in this study also singled out the administration of ECT as damaging. They recounted that when all possible medications had been tried and found to be unsuccessful they were offered the last resort treatment, ECT, touted as the only hope left to improve their signs and symptoms. However, instead of improving these, ECT often made life worse: "I reckon it damaged my brain" (P15). Participants complained of severe headaches during treatment and prolonged and permanent memory loss: "I couldn't remember that we'd got a third child. I couldn't remember that we'd moved house" (P25).

Despite these treatments with medications and ECT, participants said that the core problems still had not been addressed because the causative events of their mental disorder, such as *having been abused in their childhood and/or adolescence*, were still ignored. For example, when participants reported that they could not sleep well due to the haunting memories of their abusive experiences, health professionals thought that this could be treated by merely increasing the sedative medication.

Participants also detailed how they had been damaged whilst being a patient in a mental hospital. Many participants, although living in the community at the time of being interviewed, had been in a mental hospital at some point in their life, some for extended periods. They reported that the physical surroundings of some of these mental hospitals were not conducive to healing but, on the contrary, would induce anguish in anyone: "I've been there, in those things [mental hospitals]. Like rabbit [warrens].... The only thing missing from those things is the bars at the windows.... They are disgusting places. They are just about the grossest" (P30).

According to participants, much of the treatment in these hospitals mirrored the prison-like surroundings: "Psychiatry is the only branch of medicine where punishments are part of the treatment" (P22). The impression was given that punishment was meted out just because participants had a mental disorder: "Ah, mentally ill, do something to punish that" (P22). This something, as experienced by participants themselves and also witnessed by them in other

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patients, was the administration of an undue amount of medication for the purpose of subduing them and thereby transforming them into helpless individuals:

They punish her [the patient] with drugs. I've seen her drugged too much. She's been unable to get up off the ground, unable to speak coherently, unable to sign her name and she gets diarrhoea all the time. She was vomiting. I think it's disgusting.... She's been victimised. (P22)

Participants reported that this level of damage experienced in mental hospitals disempowered them and other patients like them to such a degree that it left them as near empty shells without the wherewithal to conduct a meaningful life, even when they were discharged: "[A stay in a mental hospital] deprives people of what they might have got out of life.... [It] ruins any chance of normalcy in what's left of their lives, if and when they get out" (P22).

Consumers in other studies also said that they perceived their stay in a mental hospital as being in prison-like surroundings. They used terms such as "being 'banged up'... [to] convey the sense of imprisonment" (Perry et al., 2007, p. 785). They also had the impression that the treatment they received was meant as punishment: "Those were the ways they used to punish me" as recorded in Hughes, Hayward and Finlay's (2009, p. 156) study on patient's perceptions of the impact of involuntary inpatient care on self, relationships and recovery. An Australian study on nurses diagnosed with a mental disorder quoted them as describing their stay in hospital as "an overwhelmingly counter-therapeutic experience" (Joyce et al., 2007, p. 377).

Up to date, most unethical actions of *society mistreating consumers* were legal and completely within the realm of behaviour acceptable to society because participants had been thoroughly devalued and dehumanised and thus disempowered. However, there were actions that were criminal in nature, in addition to the abuse participants had been subjected to as children and adolescents.

These criminal actions, according to participants' experience, were not as common as the unethical ones. Nevertheless, participants realised that they were more at risk of becoming victims than non-consumers because they thought they were seen as vulnerable and considered easy targets. Participants were sure that

certain members of the population were even attracted to them as they smelled blood as from a wounded animal: "[They] turn on the traumatised" (P30).

Participants recounted that the criminal actions perpetuated on them included theft and physical attacks or threats of such, including threats to rape them. These occurred in everyday life situations such as at workplaces. For other participants physical attacks occurred in their marriage when they got violently assaulted by their spouses. Participants had even encountered criminal actions being perpetuated in mental hospitals. They reported that despite the constant surveillance they had come across instances of theft and rape: "I know a guy got raped while I was there" (P12).

That people with mental disorders were more likely to be victims of crime has also been established in other countries. In the USA, rates of adult physical and/or sexual assault on consumers have been reported as high as 67% (Jacobson & Richardson, 1987). In Sweden, the numbers were 46% for women, compared to 25% for women in the general population (Bengtsson-Tops & Tops, 2007, the latter number referring to a study by Lundgren, Heimer, Westerstrand & Kolliokoski, 2001). In agreement with participants in this study, Marley and Buila (2001) also found in their survey of 234 consumers sourced from two support organisations in the USA that they were "singled out for victimisation because of a specific characteristic" (p. 123). In addition, criminal actions occurring in hospital have also been reported elsewhere. For example, Happell (2008) mentioned in her study from Victoria, Australia, on how a consumer had been assaulted. Steele (Steele & Berman, 2001), a consumer-writer, was gang raped in a mental hospital. In all these instances, the perpetrators were other patients.

3.3.2.5: Society let perpetrators get away with their misdeeds

In this fifth and last *disempowering condition* pertaining to the social sphere, participants in this study realised that those people who had abused them, either as children or adolescents, or had mistreated them as adults through unethical or criminal actions, got away with what they had done: "[They are] getting away with it" (P30). This was made possible because *society did not want to believe what consumers said, society devalued and dehumanised them and society was not willing to help them.*

Society not wanting to believe what consumers said provided a foolproof way for perpetrators to get away with almost any awful act they dreamt up: "Many people use this fact to safely perpetuate all sorts of cruelty and injustices... knowing their victim will not be believed. The more bizarre the abuse... the easier [it is] to get away [with it]" (P22). As a result of not being believed because they had a mental disorder participants in this study felt utterly disempowered because they could not claim any credibility and therefore the perpetrators were listened to in preference to them: "They have taken his word [over mine]" (P30). Participants said that they were not even believed when they reported grave matters such as ongoing assaults, and their accounts of life threatening situations were given no credence:

They don't check out [the information].... Is this person [the abuser] she [the participant] is charging [in court] really like what she says he is 'cause he's got a house full of guns and he's... a dangerous man? He put a gun to my head, radi-radi-ra.... They were just like pretty much under the impression that it was all in my head. (P5)

As a result of participants not being believed about perpetrators' actions participants could easily be blamed for the very acts that had been perpetuated against them. Being blamed for *having a mental disorder* was now extended into blaming them for what had happened to them: "It is your own fault" (P23). The habit of blaming them for any misdeeds perpetrated by other people led to participants being treated as scapegoats for the awful behaviour of others. The following participant explained how this had played out in her family: "I lived in a very domestically violent abusive relationship and that [the mental disorder] was a big crowbar and a lever for him to be even more so" (P30). She said that using the excuse of her mental disorder as a crowbar and lever the abusive family member justified victimising her. He accused her of being irrational instead of admitting that she acted in her own best interests.

Families using their relatives who had a mental disorder as scapegoat also occurred in other studies, for example in a survey of first-hand experiences and perspectives on stigma and discrimination (Brody, 2008) and in an examination of life trajectories of female child abuse survivors thriving in adulthood (Thomas & Hall, 2008). Humphreys and Thiara (2003), in their study on domestic violence, noted:

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Part of the repertoire of threats used against women by the abuser is that 'she is crazy'. Her referral to mental health services can act as confirmation of this verbal abuse, supporting his distorted perceptions and deepening her sense of disempowerment and loss of self-esteem. (p. 219)

Society devaluing and dehumanising people who have a mental disorder was also replayed here, which set the general population, the person in the street as well as its institutions, up against consumers: "Society seems to have it against you" (P18). Participants in this study realised that due to their devaluation and dehumanisation perpetrators were more highly valued by society than participants would ever be. As a consequence, perpetrators could easily make up excuses for their behaviour, which were readily accepted by society: "They make these weak excuses" (P30).

One of these weak excuses was used to paint the abuse and mistreatment of participants as being all right and to see them as ordinary, even normal events: "[The perpetrators] have been doing it for so long, their brutality is regarded as normal" (P22). Weak excuses were then used to justify the actions of perpetrators at all levels of society. For example, participants had uncovered that excusing the abuse and misdeeds of perpetrators was instigated right at the top of the political system influencing people in many lower positions: "[It is] systemic.... Parts of the system are rotten and that filters down into... what * [others] can get away with, in behaviour and stuff" (P7).

Lastly, *society not being willing to help* contributed to *letting perpetrators get away with it*. Participants said that society, in not being willing to help, aided the perpetrators in that nobody demanded that perpetrators behave with any sort of integrity. Participants said that integrity was not upheld because organisations responsible for holding perpetrators to account were tainted with the same values as the perpetrators and had been set up to protect this behaviour: "The world is highly politically set up to foster the perpetrators" (P30).

Participants gave examples of two governmental departments that were not willing to help and thereby, in their eyes, *let perpetrators get away with it*. Participants were convinced that proceedings in the justice department had been stacked up against them due to the court responding to the fears of the general population with regards to consumers:

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Their [consumers'] trials are always a formality, whose outcomes are decided beforehand, by the press, the public and all concerned with the trial. Their trials are not real trials, since people's irrational fear of the mentally ill prevents them from being able to see, or wanting to know, the truth about the nature of the person and what happened. (P22)

Participants explained that therefore the outcome of many trials was unfair in that many perpetrators were acquitted and others goaled for only short periods of time not befitting the horrific acts they had committed. Evidence that crimes were not reported to the judicial system at all appears in Agar and Read's (2002) study on what happens when people disclose their sexual or physical abuse to staff at a community mental health center. Erdmans and Black (2008) found, when interviewing young women with a history of child sexual abuse that only very few that were reported were prosecuted.

Participants in this study reasoned that the unfair outcome of trials lay in how judgments were made. They thought that, at the best of times, they were made so arbitrarily that they seem to depend on pure luck: "One man [the judge] making a decision, maybe it is like 50:50 [how the judgement goes]. It's Russian Roulette [him] making that decision" (P26). However, participants knew that most of the time the judge's decision was a forgone conclusion because it usually went in favour of the perpetrator: "He [the judge] would tend to err on the side of caution. As soon as he hears mental health, 'Oh, well, we have to give the other [party] the benefit'" (P26). Participants were therefore justifiably worried that malevolent people would take full advantage of these unfair proceedings because of the near certainty of acquittal. Humphreys and Thiara (2003) also found that in order to discredit a person with a mental disorder during, for example, custody cases, contact with mental health services was brought up in court appearances.

The other governmental department that participants pointed to with regards not helping and in *letting perpetrators get away with it* was the mental health system. They implicated the mental health system because it came across to them as standing by and letting criminal acts happen without taking a stand on participants' behalf. They remembered instances where the mental health system had brushed aside the existence of the terrible assaults on participants without helping: "He bashed me up through the whole house... and the bed went flying across the room and I had another snapped head and black eyes.... The mental

health system ignored all those things" (P30). Participants went further in accusing the mental health system of becoming complicit in the crimes committed against them because health professionals knew of the abuse and let it happen:

They [health professionals] actually allowed him [the perpetrator] to [continue with the assault].... They are culpable for going along with it [the abuse].... They are perpetrators as well because they go along with these people [the perpetrators].... I've seen it, I've seen them; they still do it. (P30)

Rice (2009) concluded, in her study on why health professionals in the USA did not take any action in response to the abuse and mistreatment reported by patients, that health professionals came to accept this violence. She reckoned that this amounted to the patients being "forsaken" (p. 846). In comparison, participants in Joyce et al.'s (2007) Australian study on the experiences of nurses who had a mental disorder explained bluntly the reason for health professionals letting perpetrators get away with their misdeeds: "If someone's being kicked, everybody joins in, that's the way the culture [in the health service] is" (p. 376).

Due to the perpetrators not being brought to task by the legal system, and participants in this study seeing the mental health system as standing by and not being responsive when criminal acts were committed, participants knew that they had nowhere else to go: "I had no redress" (P18). In fact, they feared that their situation might get even worse if they complained: "The poor victim knows what's going on but if he tells anyone... he will end up in a far worse situation, locked up for years in a mental hospital" (P22).

The *disempowering conditions* in participants' social sphere in this study consisted of *society not believing what consumers said*, leading on to *society devaluing and dehumanising them*, which in turn was used to justify both *society not willing to help them* and *society mistreating them*. The *disempowering conditions* were completed by *society letting the perpetrators getting away with their misdeeds*.

3.3.3: Summary

Conditions were those factors that influenced the core category. The conditions in this section were named *disempowering conditions* because they

Theoretical framework and disempowering conditions

disempowered participants to such a degree that they were not able to be in charge of their affairs and therefore their life was a struggle. Those conditions that disempowered participants in their personal sphere were related to factors in the participants' own life. These were *having a mental disorder, wanting to be dead and having been abused in childhood and/or adolescence*.

The *disempowering conditions* in participants' social sphere were concerned with society's role that explained why participants' life was a struggle. These were *society not believing what consumers said, society devaluating and dehumanising them, society not wanting to help* and *society mistreating them*. The last *disempowering condition* detailed how society let perpetrators who had abused participants, either as children or adolescents, or had mistreated them as adults get away with what they had done.

As the context of *the disempowering conditions* is now set, the exploration of the second part of the theory, which explained participants' main concern of their *life being a struggle*, can be proceeded with.

CHAPTER 4: THE BASIC SOCIAL PSYCHOLOGICAL PROBLEM OF LIFE BEING A STRUGGLE

4.1: Introduction

The second part of the substantive theory of *transforming oneself and society to resolve life being a struggle* presents the basic social psychological problem of *life being a struggle* as experienced by consumers living in the Western Australian community. Whereas the previous chapter detailed the *disempowering conditions*, this chapter identifies how these conditions impacted on participants' life. That these conditions imposed the basic social psychological problem of *life being a struggle* was illustrated by one participant who recalled how the *disempowering conditions* had followed her around and had haunted her all her life: "You never escape from [them] [disempowering conditions].... [They've] been like a shadow permanently, just a permanent shadow" (P30).

The basic social psychological problem of *life being a struggle* was identified as participants' main concern as it was found to be fundamental to their experience of being a consumer. Why the struggle occurred and how it was fought are significant elements in this theory. As will be shown, the unremitting struggle left participants without power to take charge of their personal and social life by making them feel unimportant and ineffectual. The basic social psychological problem consists of three components: *the struggle within oneself*, *the struggle with relationships*, and *the struggle with getting through daily life*. These components occurred simultaneously and constituted the sum total of the basic social psychological problem.

4.2: The struggle within oneself

This first component pertained only to what participants experienced within themselves and excluded anything referring to a relationship with other people. It explored the following three aspects: 1) *the struggle to identify any intrinsic value in oneself as a person*; 2) *the struggle with having a mental disorder*; and 3) *the struggle with staying alive*.

4.2.1: The struggle to identify any intrinsic value as a person

This aspect played a central role in the basic social psychological problem of *life being a struggle*. Participants asked themselves whether they had any intrinsic

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value as a person. They identified one reason why they had no value, namely the signs and symptoms as explored in *having a mental disorder*: "When I first had that breakdown, I described that like being kicked in the guts, like just being kicked in the stomach.... I am just knocked down" (P29). Being knocked down by the occurrence of the disorder had such a dramatic impact on participants' sense of value that they felt crushed by it: "It knocks you flat" (P16). They compared it to having the lifeblood drawn out of them when they had no pleasure, enthusiasm or passion left for living: "I lost my zest for life" (P6).

A second reason for *the struggle with having no intrinsic value as a person* was induced by *having been abused in childhood and/or adolescence*. They described this impact as having every part of their self-worth eliminated:

When you're told that you are nothing, you are a piece of garbage etc., etc. over that many years; you believe it... especially when you are only this high [a small child] and I believed all of that, you see.... I never thought I was worthy of anything. (P18)

The third reason for *the struggle to identify any intrinsic value as a person* was brought on by *society devaluing and dehumanising* participants, in particular by society viewing them as non-persons and sub-human: "I just felt like a useless piece of dirt" (P35). Participants regarded themselves as only fit to be discarded: "I felt like I was a blotch on society that had to be removed. It was very awful" (P23).

The struggle to identify any intrinsic value as a person left participants without any power: "I felt like this totally pointless, purposeless... individual" (P9). They said their self-worth was zero, they had no self-esteem; they believed that everything they stood for was wrong and that they were completely inadequate:

I felt like everyone had value. Everyone else's opinions mattered. Everyone else's lives mattered but not mine. It was difficult to think that anything I said would be true or right. Everything I thought, every one of my thoughts I felt was faulty. My feelings felt like they were invalid. They weren't to be listened to. (P23)

Even those participants who had been capable and self-assured people at one time had lost their self-reliance and doubted their judgement, ability and authority. They experienced a profound loss of self-confidence with feelings of insecurity and a premonition that things were slipping from their grasp.

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As part of *the struggle to identify any intrinsic value as a person* participants struggled with finding meaning in life: "There is absolutely nothing in life.... I don't feel I've got a life" (P15). As part of this struggle they asked themselves the question why it had been them who had been struck down by a mental disorder and why their life had been so completely annihilated by it. Some fell back on religion to find an answer: "I've suffered from * [mental disorder] for over 40 years, if not a lifetime.... So, I say to Him [God], 'Look, why... me? Why are you doing this to me?'.... What... was the purpose of it?" (P16). They struggled with the answer because in adding up the positives and negatives in their lives the positives always outweighed the negatives:

I can remember weighing it up like a business, thinking... if you had a business and it was going to go bankrupt you wouldn't keep putting energy into it. You wouldn't keep putting money in it.... There is no point in it and I had to get to look to my life like that. (P9)

Other consumers similarly struggled to identify any intrinsic value in themselves as a person. For example, Deegan (1997), a consumer-writer, considered herself as having "no value" (p. 16). Other studies also linked *the struggle with identifying any value as a person* to the same *disempowering conditions* as in this study. For example, a participant in Browne et al.'s (2008) study on consumer's perspective on recovery mentioned: "Having a mental illness knocks your confidence about and you end up having a low opinion of yourself" (p. 406). Participants in a study on childhood abuse in Swedish female users of psychiatric services linked the low value they had in themselves to *having been abused* (Bengtsson-Tops & Tops, 2007). Likewise, female child abuse survivors mentioned confidence destroying societal messages that they struggled with (Thomas & Hall, 2008). An introduction to ideas about recovery for people with mental health problems by Perkins (2007) also asked "'Why me?'" (p. 12) and participants in a grounded theory study on 38 men in England wondered" "'What am I doing in the world?'" (Ridge & Ziebland, 2006, p. 1049). Likewise, other people saw suicide as an answer to the worthlessness of themselves and their life, as documented in Aldridge's (1998) and Joiner's (2005) substantive theories on suicide.

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4.2.2: The struggle with having a mental disorder

This second aspect of *the struggle within oneself* was so important to participants in this study that the term 'struggle' was often used euphemistically for 'having a mental disorder': "When I was not so good [had symptoms] I'd be struggling" (P26). Participants identified that *having a mental disorder* led directly to their *life being a struggle*: "[The] struggle with mental health" (P26). They said that they were struggling due to *having a mental disorder* because these were terrible disorders to have: "[It is] one of the cruellest sicknesses that you can get" (P4). The following participant expressed his despair at having been affected: "When you are * [sick] they may as well shoot you" (P25). Some participants were struggling so hard that they called it a battle: "Battling with my * [mental disorder]" (P12). Participants were battling because they thought that, by chance, they could overcome it but they felt powerless to prevail over its impact.

Supporting these sentiments, other consumers also described their *struggle with having a mental disorder*, as expressed directly in the process of recovery from schizophrenia by Spaniol et al. (2005): "Struggling with mental illness" (p. 88). Rowe (Rowe & Rowe, 2005), a consumer-writer, also called it a battle. Some referred to their mental disorder a "hell of the condition" (Connor & Wilson, 2006, p. 464) and to getting it as "a catastrophic and life-changing experience" (Repper & Perkins, 2003, p. 46). As participants in this study, they felt powerless to prevail over its impact, as reported in a study on consumers' views of Australian mental health services (Malins et al., 2006).

Participants in this study said that they were powerless in *the struggle with having a mental disorder* for two reasons: They were left helpless and they could not make sense of what was happening.

Participants felt that they were left helpless because their life had been taken over by the mental disorder and because they had lost control over most of its facets: "It [the mental disorder] just takes... over and you feel that you have... lost control of your life" (P31). They also felt helpless and powerless in the face of the disorder and likened it to the lack of control over getting cancer: "You can think as positive as you like but if it is going to get you, it is going to get you" (P29). Likewise, they compared the way their disorder advanced with the course many cancers took because they felt that the mental disorder was inexorably eating away at them inside:

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When the process [episode] starts... whatever path it takes is completely independent of me. Whether it's just going to be a little... stumbling... in my path or whatever or whether it's going to be a complete fall is... not up to me.... It is not up to my doctors and it is not up to... any decision that we make. It's... either going to happen or... it's not. (P32)

As a result of their powerlessness they found that they had been unable to act any differently when ill: "I can honestly say that... there is nothing I would have been able to do differently" (P7).

Feeling helpless was further exacerbated by not being able to make sense of what was happening: "I got into quite a state with everything just going kaput and it was like I didn't know what was happening" (P23). They said they could not make sense of what was happening when their disorder first appeared, as to why symptoms occurred, what caused those symptoms and what treatment was about. Not being able to make sense of what was happening was also frequently mentioned by other consumers, such as in a study on the perspectives of young consumers (Boydell et al., 2006), in a study on people with a first episode of psychosis (Perry et al., 2007) and by a consumer-writer ('Joe', 2007).

As a result of being left helpless and not being able to make sense of what was happening participants in this study were frightened: "It was the most frightening time of my whole life and I'd been through a few things" (P9). Other consumers also recalled how they had been frightened by the appearance of their signs and symptoms, for example in a study by Connor and Wilson (2006) on consumers' experiences in Northern Ireland.

Participants in this study were also intensely worried. Those participants who had children were first and foremost worried about their children also getting a mental disorder due to a possible genetic influence and them having to go through the same struggle: "It's pretty strong in the bloodline, which makes me worried about my children" (P35). They were also worried for themselves with regards to their disorder getting worse and about it progressing to other even more serious conditions. This worry about their own future was at times so intense that they thought it was not worth living any more: "I thought [that] as I got older I'm going to be worse and worse and worse. I used to always be praying that, 'Good God, let me go home in my sleep'... [to] cancel out [end my life]" (P26).

4.2.3: The struggle with staying alive

This aspect of the basic social psychological process of *life being a struggle* was directly brought on by *the disempowering condition of wanting to be dead*: "It was a real struggle... to stay alive" (P7). It appeared at every turn and added a terrible burden to everything else. Participants said that staying alive was a struggle because it was a hard fight against the disempowering force of *wanting to be dead*. Although participants felt the strength of this force, they were terrified of the prospect of having to bring about their own death and just the thought of suicide was "too much to bear" (P12). The struggle with these contrasting forces between *wanting to be dead* and *staying alive* tore participants apart and left them powerless to choose between them: "You feel in between a rock and a hard place. Your brain is saying, 'It is all too hard. Why don't you just end it?' And the other part of your brain is saying, 'But, no, you can't'" (P12).

A struggle "against a desire to give in to suicide" was also mentioned in a review of studies on suicide (Lakeman & FitzGerald, 2008, p. 124). Substantive theories also relayed how people who were suicidal described a sense of powerlessness (Aldridge, 1998) and explained how difficult it was for suicide to be carried out (Joiner, 2005).

The struggle with staying alive in this study occurred along a continuum. At one end there was certainty about wanting to commit suicide and at the other end uncertainty about whether it was the right thing to do. Over a period of time that was sometimes as short as a few hours, participants were swinging from one end of this continuum to the other: "You think, 'Yeah, I want to finish it all', and later on you think, 'Gee, to even think that way was really stupid'.... The next time you think, 'Oh, I want to end it again'" (P29). Five points along this continuum were visited by various participants.

The first point was at the certainty end of the continuum. Here participants were certain that suicide was the right thing to do: "It [was] the right thing to do... the only thing to do" (P17). They were "desperate" (P21) to end it all and could not see any merit in wanting to survive: "I had NO hope or even consideration of surviving. I just really, really wanted to kill myself" (P7). To help them with the struggle in reaching this heart-wrenching decision they thought of "logical" (P34) reasons for wanting to go through with it: "That was

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the only way I could handle trying to get rid of myself" (P9). Participants explained this logic as follows: Suicide was the right thing to do because it was not only beneficial to themselves but also to other people. They argued that other people would be able to lead a happier and more productive life if participants were not around any more as they were only a burden to them:

I actually have these thoughts that are going, 'You know, what? If I wasn't here, I wouldn't be so much of a drain. I wouldn't have my brother worrying about me. I wouldn't have my mother worrying about me.... My partner would be free to go... and actually find somebody who is sane and who is together.... My friends would be ok with it and... they'd be happy not having to worry about me.... I would no longer be on the dole [and]... therefore I would be less of a strain... on the economy'.... It all makes sense, it does. (P17)

People contemplating suicide in other studies also thought along the same lines. For example, interviews with 30 child abuse survivors revealed that they thought suicide was the right thing to do because it was not only beneficial to themselves but also to other people (Harper, Stalker, Palmer & Gadbois, 2008). Joiner (2005) found that people thought of themselves a burden to others and therefore wanted to be dead.

Those participants in this study who adhered to this line of thinking were determined to go through with suicide: "There was no going back" (P7). To make sure they achieved their aim they made detailed plans with safeguards in place so that they would not be caught out:

I was determined not to let... [this] time [of attempting suicide] have it go wrong. I booked myself into a hotel and said, 'I've been travelling all night and I don't want to be disturbed'. Having gone round to all the doctors the day before I had a lot of tablets and I just took them all. (P4)

When participants were then saved by circumstances beyond their control they were very angry. They were either angry with themselves because they had messed up their plans inadvertently: "I was so angry, 'Urgh, urgh [growling noise], [I] can't even do this properly'" (P34) or with the other people who had interceded:

I was really angry at everybody.... I was angry at * [family member] first, [for] finding me. I was really angry at the doctors for... keeping me alive. They had to put me on life support, and it was sort of quite bad. (P7)

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The second point along the continuum was characterised by an emotional kind of thinking about suicide: "The emotional kind [of thinking is] where you are really sad or you are really sort of angry and, 'That's it, I am going to kill myself'.... It's all sort of in the heat of the moment" (P17). Those participants who were at this point said that here it was easier for some doubt to creep in about the merit of carrying out the suicide than with the calculated logic employed at the first point. They were therefore prepared to call someone who was in a position to "talk me down" (P17) before proceeding.

Those participants who were at the third point along the continuum between certainty and uncertainty were ambivalent. They saw the two ends of certainty and uncertainty as being equally valid and regarded suicide as a credible "alternative" (P20, P31) to the "miserable" (P35) life they were leading. They were hesitant about wanting to die and were weighing up the pros and cons of staying alive: "I didn't particularly want to die. It was a horrible thought of having to do something" (P9). Yet even here, being dead was preferable to staying alive, as "the thought of living was more painful than the thought of dying" (P9). This was reflected in how participants planned their suicide. They started with half-hearted attempts of self-harming before becoming more serious about contemplating going all way:

It just started off as... not an intention to kill myself but as it progressed I'd... be really aggressive about it and say... 'If I die I don't really care'.... Trying... not set out to kill myself but if it happens it is a bonus. (P5)

At the fourth point along the continuum between certainty and uncertainty more doubt over the merit of committing suicide became apparent. Those participants who were at this point had doubts about whether the available methods were reliable and whether they would survive the attempt: "What if you didn't actually kill yourself? What if you just got back in hospital and you were still alive?" (P23).

However, the greatest amount of doubt appeared at the fifth, or last, point along the continuum, identified as uncertainty. Here participants considered that they might make a mistake in committing suicide because of the possibility of a somewhat happier life in the future:

What if you were making a mistake and something was going to change down the track? Or what if... you were going to miss out on something later

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in your life that you would have really enjoyed and you wouldn't have the chance? 'Cause I knew it was very final and I had it in my mind, 'It's final, it's final'. So, I had to make sure.... There was always that little tiny 'What if, what if' right at the end of it all the time that was holding me back. That was the only thing that was holding me back [from committing suicide]. (P23)

Those participants at this fifth point therefore engaged in a prolonged time of contemplating the merits of proceeding: "I am going over things in my mind and thinking, 'Oh, well... maybe I should.... What would happen if?'" (P31). This was also the point at which they were least likely to contemplate going through with their suicidal wish. That people who were suicidal were at times ambivalent and carefully weighed up the reasons against dying was also emphasised by Joiner (2005) in his substantive theory on suicide.

The struggle to identify any intrinsic value as a person, the struggle with having a mental disorder and the struggle with staying alive was then compounded by having to face the most complex of struggles; that with relationships.

4.3: The struggle with relationships

The second component of the basic social psychological problem of *life being a struggle* in this study pertained to participants' relationship with other people. Relationships between participants and other people were the focus of interviews: "I struggle now with the social aspect of it all" (P23). Participants regarded relationships with other people as very significant because they desired nothing more than to be friends with others. This was also the case in interviews with 71 people around the United Kingdom, which found that "the dominant theme... was the role and value of relationships with other people" (Faulkner, 2000, p. 1). Participants in this study classed having good relationships with other people as a struggle because members of society largely refused to reciprocate their great desire to be friends with them:

I spent my life [wanting good relationships], and [it was] a struggle, a daily struggle [to get them].... You want to talk to people, you want to make friendships, you want relationships, but you can't [because] people shy away from you. (P18)

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Therefore, the most significant part of participants' lives, good relationships with other people, had turned into the worst: "I find the worst thing is relationships for me" (P20). *The struggle with relationships* added to the already difficult struggle within themselves and made participants' lives even harder. Four aspects of the struggle with relationships were identified: 1) *the struggle with responding to the impact of having been abused*, 2) *the struggle with establishing credibility*, 3) *the struggle with having been let down by the mental health system*, and 4) *the struggle with maintaining normal relationships with individuals*.

4.3.1: The struggle with responding to the impact of having been abused

This aspect was concerned directly with the relationship with participants' abusers. Those participants who had been abused as children and/or adolescents related that *the struggle with responding to the impact of having been abused* came about because that impact had been enormous: "This... abuse.... had a huge impact on my life" (P11). They said that the memories of these "traumatic" (P13) events were extraordinarily painful: "Like being in hell" (P9). They were also so enduring that they affected participants for the rest of their lives.

Participants explained that *having been abused* had turned their life into a struggle because their right to grow up in a safe and secure environment was absent and the foundation on which to build a satisfying and enjoyable life had been destroyed. In addition, participants found that their trusting, loving, carefree nature as children had been eviscerated: "Like everybody else is 14 and... confident and going to cricket... and you are all sort of lost and mixed up and it is all too much" (P13). Likewise, their hopes and aspirations for a bright future had been shattered, as the following participant expressed ironically: "I distinctly remember thinking, 'Well, I'm going to grow up and be the world's best prostitute'" (P13). Participants reported that their sense of personhood was torn apart: "When you get abused... it does something to your psyche or something; it just does something to you" (P13).

Other people who had been abused, whether they had developed a mental disorder or not, also felt that they had been robbed of their innocence and childhood, such as 27 young mothers with a history of childhood sexual abuse (Erdmans & Black, 2008). Herman (1992), in her substantive theory on trauma

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and recovery, also reported that people who had been abused had no plans for the future. Participants in Perry et al.'s (2007) study with people after their first episode of mental illness described that their "personality" had been "shattered" by the abuse (p. 785).

Participants in this study recounted that the impact of the abuse had been both physical, as in permanent physical damage, and also emotional. They said that they struggled particularly with the emotional impact: "So that's why it's been a struggle, I've had all these emotions... sitting... [there] over the years" (P18). They explained that these emotions made them feel powerless because their abusers had captured them emotionally: "They [the abusers] are so powerful all the time over you.... You will always [be] captured by them because if you start breaking away they put it on you" (P30). One participant compared this way of being emotionally captured with Stockholm Syndrome, a term coined in connection with adult hostage taking. In these situations hostage-takers intimidated hostages so much that they were prepared to do anything to avoid further abuse and showed signs of loyalty and obedience that was controlled with being emotionally captured. Participants in this study described how their loyalty and idolatry of their abusers continued despite not wanting it to: "Even to this day.... when I think of him [the abuser] I still can't get this... idolising thing out of my head" (P34).

As a result of *the struggle with responding to the impact of having been abused* participants explained that they were living in fear. They recalled that this had overshadowed any possible joyful experiences they might have had as children and/or adolescents: "I've observed children. Now children who are free can express their feelings. They scream with joy; they yell in the park. I never got to do that as a child. I always lived in fear" (P13). As this fear remained in adulthood it added a second layer to the fear experienced in their *struggle with having a mental disorder*.

Furthermore, participants were blaming themselves for having been abused. The feeling that they had to blame themselves was so complete and internalised that participants utterly believed that it was their fault that they had been abused: "How many years did I put it on myself that I was the one who was the problem. I did; it was constant. It was me; I was at fault; it was me who was the cause of it all" (P30). They were aware that they blamed themselves because

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they had fully adopted the degrading values the abusers had inculcated in them. Those participants who put it into a spiritual context reasoned that they had adopted these values because the abusers' sinfulness had infiltrated their mind: "Their evilness or their bad spirit comes into you and... goes into your mind" (P13).

Participants were also blaming themselves for having been abused because they did not want to shatter the revered image they had built up of their abusers. They told how they had put their close family member on a pedestal to be worshipped, and instead of shattering this revered image by blaming the abuser they blamed themselves:

Rather than recognising that it is the * [close family member] who is... doing the abuse it is better for the child to be blaming themselves or thinking they are the ones [at fault]. Because to... realise... that the * [close family member] is the one who is at fault... is... so devastating. (P30)

As a result of blaming themselves some participants felt so ashamed that they did not tell anyone of the abuse. This left them feeling desolate as they could not see a different future free from abuse: "It was just like a nightmare" (P9). Consequently some participants entered into a series of self-injurious activities: "[I] just grabbed a razor and slit my wrists.... I did it for years" (P5). Others went further and actually tried to carry out suicide as *the struggle with responding to the emotional impact of having been abused* was too much to bear.

Other people who had been abused went through similar struggles. In studies concerned with abuse they felt "trapped and caged by the abusers' strategies of control" (Humphreys & Thiara, 2003, p. 215), lived in constant fear (Nilsson et al., 2005) and blamed themselves: "I've been raped, beaten and humiliated since I was a little boy.... This doesn't happen to everyone - it's got to be something wrong with me" (Bloom, 1997, p. 118). Moreover, Van der Kolk, Roth, Pelcovitz, Sunday and Spinazzola (2005), in their study on an empirical foundation of complex adaptation to trauma, found that 36% of people who had been abused in childhood idolised their perpetrator. The risk of suicide also went up in a variety of publications (Agar & Read, 2002; Aldridge, 1998; Bengtsson-Tops & Tops, 2007; Bryer, Nelson, Baker Miller & Krol, 1987; Erdmans & Black, 2008; Fergusson, Boden & Horwood, 2008; Harper et al., 2008; Joiner, 2005).

4.3.2: The struggle with establishing credibility

In the second aspect of *the struggle with relationships* participants found themselves powerless in the face of the overwhelming impact of *society not believing what consumers said, how society devalued and dehumanised them and how society mistreated them*. Participants struggled with responding to this impact with valiant attempts to establish their credibility as trustworthy and honest citizens: "First you've got to prove that you are not a crackpot" (P13). Participants knew that this was hard because even illicit drug users' standing in society was higher than their own: "It was almost better to be assumed that it was marihuana or this and that [illicit drug] when people think you are not all here today [display signs of a mental disorder]" (P26). Participants felt ashamed at being regarded as dishonourable and improper and explained that this had taken a terrible toll on them.

Participants responded in *the struggle with establishing credibility* in two ways: They tried to reason with other people and they tried to defend themselves. They first tried to reason with other people to convince them that they were worthy of being believed and what they were saying was true. When they tried to explain that their mental disorder was not different from a physical disease they put forward what they thought were rational arguments that it was indeed a real illness: "It [the mental disorder] is not a visible ailment but it is still an ailment. Just because you can't see diabetes, you can't see internal bleeding... it's [still] there" (P17). They knew that physical diseases were acceptable because of the scientific proof, which was lacking with mental disorders.

Furthermore, in reasoning with other people, participants used supporting evidence that would prove that what they were saying was true. For example, in the interviews conducted for this study they showed samples of their work, provided documents such as character references, letters and even x-rays to back up their statements: "Just to show you that it's not all hokum-pokum" (P9). They provided witnesses to the police to back up the credibility of their statements as to what had happened to them to counter the view that they had invented certain events: "My sister was a witness to that, and my cousin" (P5).

Secondly, participants tried to defend themselves. In particular, they tried to defend their reputation against what they regarded as false and demeaning

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accusations. The following false and demeaning accusations were particularly grating and participants felt insulted by them. The first was being blamed for *having a mental disorder*: "People don't chose to be like that" (P25). The second referred to other people's belief that participants were not trying hard enough to overcome their mental disorder. Here participants asserted that episodes of illness did not disappear just because they wanted them to and that it was impossible to get better by willpower alone. They also stressed that their mental disorder could not improve by merely changing the negative thoughts to positive ones as advocated by society because negative thoughts were not the root cause of the disorder: "[To] change your thinking doesn't change the way you feel" (P23). However, despite knowing that willpower alone was not effective in overcoming the mental disorder, participants emphasised that they were not malingerers who did not want to help themselves: "Because, quite honestly... I [am not able to] try any harder [to get better]" (P15). Participants emphatically stated, in defending themselves, that they were the ones, more than anyone else, who looked desperately for a cure and would take advantage of any treatment that showed the slightest prospect of helping them.

The third false and demeaning accusation, however, was the most offensive for participants. It pertained to the accusation that they were dangerous people and should be locked up: "That's how it is a struggle every day" (P18). Corrigan et al. (2002) concluded in attitude questionnaires of 213 people from the public and in drawing from research over four decades that the belief that people with mental disorders are dangerous was "perhaps the most pernicious of the stigmatising attitudes about mental illness" (p. 303). Participants in this current study were especially offended by the portrayal in the media of consumers as violent killers because it affected their reputation directly: "It's [television] shows like that that give people like me [a bad reputation].... It might sell the movies but it doesn't do anything good for the * [person with a mental disorder]" (P18). Participants tried to defend their reputation by pointing out the truth that many consumers were generally "passive" (P1, P18) and that they would rather harm themselves than anyone else:

The reality is... a lot of people who struggle with mental health... wouldn't normally deliberately want to inflict any harm on anyone.... At the end of the day they would harm themselves but they wouldn't go and hurt no one.

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And a lot of people don't, normal people don't think like that. They think it is the other way around. (P26)

These three false and demeaning accusations affronted participants' self-worth and increased their *struggle to identify any intrinsic value as a person*.

Participants also tried to defend themselves by standing up for themselves, in particular, against the injustice of mistreatment. They thought that by standing up for themselves their credibility would be increased. For example, they tried to defend their right to decide what was best for them and what their needs were in response to the unethical actions detailed in *society mistreated people who have a mental disorder*. Participants were particularly aghast at the injustice of getting blamed for the misdeeds of others when they had been innocent: "It is not their [consumers'] fault. It is the society's fault" (P22). Furthermore, participants insisted that members of society had to take the responsibility for treating them in a shocking way: "Is it my responsibility to change the way I do things? What about the bloody abuser? Excuse me, why should I change? Isn't it the perpetrator who should be changing? Excuse me!" (P30). Participants asked themselves who was really crazy here, people who had a mental disorder and did not want to harm anyone, or those people who mistreated them and in so doing violated ethical standards and criminal laws and got away with it:

This is why it is such a crazy world we are living in... We are called the crazies. There are more crazies that walk past * [the mental hospital] than there are in [there] now. I tell you. Because it is the crazies out there who put us in * [the mental hospital]... and they don't lock them up. They lock the ones who are driven crazy by the crazy world; they lock them up. They lock us up. (P30)

Despite participants' best efforts at trying to reason with other people and in trying to defend themselves, the disempowerment of the conditions related to participants' social sphere was so great that no matter what arguments and defences participants put forward they could not make any difference. This powerlessness increased the feeling of being left helpless in *the struggle with having a mental disorder* and further deepened *the struggle with responding to the impact of having been abused*: "All the parasites [perpetrators] were trying [to] use you... and they wouldn't take 'no' for an answer. They just kept at you until you go down" (P18). Participants pointed out the stark reality that society

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was winning and that consumers had lost out in their efforts at leading a decent life in peace. Many participants had therefore come to the conclusion that their lot in life would always be unjust and that they would always be seen as disempowered "second-class citizens" (P20).

As a result of losing *the struggle with establishing credibility* participants had become afraid of being further exposed to the misdeed of others. This was the third layer of fear, in addition to the previous two layers of being frightened in the *struggle with having a mental disorder* and living in fear in *the struggle with responding to the impact of having been abused*. They also realised that they had become totally isolated: "The sheer isolation of it and the ostracism" (P30).

Participants in Read and Baker's (1996) survey of the stigma, taboos and discrimination experienced by people with mental health problems also spoke of their loneliness and isolation because they were "shunned" by society (p. 17). Participants in this current study realised that the isolation and ostracism imposed by society had caused them a lot of suffering, permanently affecting their mind, referred to by them as "brain bruising" (P30). This suffering and brain bruising often culminated in suicidal acts: "See, that's why a lot of people with mental illness end up killing themselves. Because of the way they've been treated" (P18).

4.3.3: The struggle with having been let down by the mental health system

Participants' powerlessness in this study in establishing any credibility was further deepened by being let down by the mental health system. This third aspect of *the struggle with relationships* dealt with the impact of the mental health system. Participants said they were struggling with having been "let down" (P22) because they had difficulties with coming to terms with their deep disappointment over what they thought was the most important source of help for them. Participants in Connor and Wilson's (2006) grounded theory study in Northern Ireland also expressed the same sentiments: "I am sure most people have felt let down [by the mental health system], I know I have" (p. 467). Participants in this current study found that they had been "written off" (P5) by the way the system was organised, by the way they were clinically treated and by the way many health professionals abused their power.

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Participants recounted how *the struggle with having been let down by the mental health system* had occurred. Initially they had put all their faith in the ability of health professionals: "I put all my faith and... my life in their hands" (P7). They had put them "on a pedestal" (P22) and they had truly believed whatever they said or did: "I remember sitting there, just totally believing him" (P7). Participants recalled that their faith in health professionals was due to declarations that they were the profession with all the solutions. However, participants described that they slowly came to realise that what many of these health professionals said was not what they practiced and that they were, in fact, just pretending to want to help: "[Health professionals] are such hypocrites" (P22). Participants felt let down by this hypocrisy and started to distrust what they said. Consumers in other studies also related how they had lost trust in health professionals, for example, in a study on determining the effectiveness of mental health services from a consumer perspective (Happell, 2008). Vassilev and Pilgrim's (2007) treatise on risk, trust and the myth of mental health services explained that "'trust' and its betrayal" had arisen from "routine care and its corruption" (p. 355).

As a result of *the struggle with having been let down by the mental health system* participants in this study were angry. The depth of this anger was reflected in the strong expressions used: "There's things that happen in the mental health system that really piss me off" (P12). Participants were angry at how the mental health system was organised, at the way clinical practices were conducted, and at the attitude and behaviour of health professionals: "I just got so mad with the * [health professionals]" (P5). Despite this anger many participants realised how powerless they were to exert any influence to change anything in the mental health system for the positive and that, in fact, they had been made helpless by this powerlessness. Their feeling of being made helpless increased their feeling of being left helpless as part of their *struggle with having a mental disorder*. It also further undermined their *struggle to identify any intrinsic value as a person*.

As a consequence of being made helpless by the mental health system participants felt trapped. They felt trapped because they had nowhere else to go to get help. They also felt trapped because there were no alternatives to the use of damaging medications and because they could not see any way to escape the

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abuse of power by health professionals. They found themselves in a no-win situation. This feeling of being trapped increased being emotionally captured in those participants already subjected to *the struggle with responding to the impact of having been abused*.

A second consequence of being made helpless by the mental health system brought on a terrible fear. This added a fourth layer of fear, in addition to being frightened as part of *the struggle with having a mental disorder*, living in fear in *the struggle with responding to the impact of having been abused* and the fear experienced in *the struggle with establishing credibility*. This fourth layer of fear appeared when merely thinking of finding themselves helpless, for example, by an admission into a mental hospital and by treatment failing. A further consequence of having been made helpless was losing hope of ever escaping from the mental health system, especially from the clutches of the locked wards: "Horrid. They do people for unlimited years" (P22).

In response to having been let down, participants regarded themselves as deserted by the system: "[It] felt... like... abandonment" (P7). This feeling of abandonment added to the isolation and ostracism already occurring in *the struggle with establishing credibility*. Participants also felt increasingly mentally wounded: "It is a very wounding experience" (P30). They said that instead of finding hope and a healing experience, the mental health system had had the opposite effect. They, therefore, held it responsible for being a major contributor to both their pain, which was already severe as a result of *the struggle with responding to the impact of having been abused*, and to their suffering, imparted under *the struggle with establishing credibility*. For these reason, participants turned to well-established behavioural patterns because they could see no way of ever getting better: "I just thought, 'I'm just going to live in hell for the rest of my life. I'll be better off dead'" (P7). This was the second reason identified by participants why their life was like living in hell.

Participants in other studies mentioned similar impacts of *having been let down by the mental health system*. They were angry, as presented in a report on research evidence and implications for practice on the process of recovery from severe mental illnesses (Spaniol et al., 2005). They also expressed their powerless in an article on consumers' views of Australian mental health services (Malins et al., 2006) and felt trapped in an interpretive phenomenological

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analysis of hope and first episode psychosis (Perry et al., 2007). Fear (Connor & Wilson, 2006; Holst, 2005; Norwood, 2007; Vassilev & Pilgrim, 2007) and a feeling of having been abandoned (Hughes et al., 2009) were also common in the literature.

4.3.4: The struggle with maintaining normal relationships with individuals

This fourth and last aspect of *the struggle with relationships* was the hardest to bear for participants in this study. They had already been hit hard by the many ways in which the conditions related to participants' social sphere disempowered them so far, but they were "devastated" (P7) by the fact that *society did not want to support them*, particularly the lack of support they received from their family members: "That is all I ever wanted" (P30). By not being supported they felt "neglected, abandoned and ignored" (P25) and so hurt that they thought that there was no reason for going on with life without this support: "If she's [family member] not going to be there... it's just no point, I can't survive without her" (P7). Again they sought to commit suicide: "I tried to commit suicide, not once but three times" (P4). In another study, other consumers also felt abandoned by their families (Spaniol et al., 2005) and wrote about how very hurt they were (Steele & Berman, 2001).

As a result of not being supported, participants in this study *struggled with maintaining normal relationships with individuals*, where normal relationships were characterised as those found in most families and between friends. In this struggle, participants tried to identify who was responsible for normal relationships breaking up. They weighed up the reasons for and against their own culpability. They knew that they were obviously not at fault in some instances, for example, when their parents had abandoned them as children. However, doubts about their own responsibility surfaced in less clear cut cases. To help them identify whether they had been responsible, they remembered instances that would absolve them. For example, they asserted that they had never been a danger to anyone, particularly not to their children: "I have never beaten them, never thumped them or anything like that" (P25). However, despite this, doubts remained in their minds as to whose fault it was, especially when participants remembered some of their behaviour that was not conducive to maintaining

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normal relationships. They stressed that this behaviour had solely occurred as a result of *having a mental disorder*, and over which they had no control over.

As a result of doubts over responsibility participants questioned whether they had been good enough at maintaining relationships: "I struggle with feeling like [I am]... a bad deal" (P33). They suspected that they had been a bad deal because they had been unable to live up to their family members' expectations: "I've been a failure at relationships" (P35). Caswell (2005), a consumer-writer, expressed similar feelings: "I began to believe that I was undeserving and unworthy of meaningful relationships with others" (p. 131).

As a consequence of not being able to maintain normal relationships participants in this study felt utterly lonely. This loneliness was described as the worst part of *the struggle with maintaining normal relationships*: "It's the being alone that I find the killer really" (P15). This deep sense of loneliness came on top of the isolation and ostracism already experienced as part of *the struggle with establishing credibility* and the abandonment in *the struggle with having been let down by the mental health system*. Self-blame again plagued them: "[I] was the crazy mixed up father who messed everything up" (P25). Whereas blaming oneself here for relationship break-ups was not all encompassing, it still amounted to increased feelings of self blame experienced by those participants who were *struggling with responding to the impact of having been abused*.

The recurring theme of blaming oneself, however, had two sinister consequences in this context. The first was participants' willingness to become scapegoats: "I was willing to be the scapegoat for the dysfunction in my family" (P33) and to take on the burden "for making it better" (P33). As a result they thought that it was incumbent upon them to put things right: "The responsibility for making it [relationships with family members] better [was mine]" (P33). This ready willingness to accept the scapegoat-role played further into the hands of *society letting perpetrators getting away with their misdeeds*, as explained in chapter four.

A second consequence of blaming oneself was the feeling of "enormous guilt" (P7) of having been a "torment to my family" (P16). In feeling guilty for having failed at relationships and regarding oneself as a torment to one's family, participants got further embroiled in *the struggle to identify any intrinsic value as a person*. It revealed their powerlessness at being able to maintain the most

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significant part of their lives, that of maintaining normal relationships with individuals.

4.4: The struggle with getting through daily life

This third component of the basic social psychological problem of *life being a struggle* occurred due to an accumulation of the previous two components, *the struggle within oneself* and *the struggle with relationships*. Participants described how they struggled with just getting through the day: "Trying to survive through... daily life" (P26). Daily life referred to the mundane, in contrast to the existential matters in *the struggle within oneself* and *the struggle with relationships*, where participants grappled with who they were as a person and their standing in society. However, even in this participants were proved powerless as *the struggle with getting through daily life* testified.

A contextual study of daily living strategies of five consumers, which observed the daily tasks and ask questions about strategies, also noted consumers' "struggles of daily living" (Gioia, 2006, p. 1217). One consumer-writer described how that was for him: "I began to struggle to put one foot in front of the other, to make it through each and every day" (Steele & Berman, 2001, p. 5). In this study, *the struggle with getting through daily life* involved the struggle with working, with being brought down by stress and with being incapacitated.

Participants in this study emphasised the importance of their struggle with work: "My biggest struggles are at work, always" (P33). They explained how important work was for them by pointing out that they wanted to feel fulfilled in life through work and also wanted to support themselves financially, just like other people: "They [others] have to understand, we are also people. We also need to earn money to live" (P10). Despite the great importance of work, participants said that they struggled because their work performance was adversely affected by various symptoms that did not allow them to do their work in the way they would have liked. Participants recalled that the quality of their work suffered to the point where even simple requirements were hard to meet: "It was a real mess" (P29).

The struggle with working was then further reinforced by the treatment participants received from their colleagues and employers. Even with their best efforts to get on with other people at work and overcome the shortcomings due to

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having a mental disorder they were powerless at avoiding trouble with these people: "I work very, very hard at my jobs and [despite that] manage to somehow get myself into big, irreconcilable conflicts" (P33). Despite having had a great passion for their work, which they loved doing, as a result of this struggle with work, it had turned into a nightmare: "It was just living hell for me" (P29). This was a third reason why life was compared to being in hell.

The struggle with working was also a theme in other studies, such as that on nurses with a mental disorder who reported on their work environment (Joyce et al., 2009). A survey of 556 people conducted by The Mental Health Foundation in England (Bird, 2001, in Repper & Perkins, 2003) also remarked on the bullying occurring at the workplace.

In this study, the struggle with working became part of being brought down by stress: "If there is any stress, stress will bring me down. That's one of the worst things on me" (P20). Participants explained that even minor stressors "absolutely threw" (P27) them. However, by looking at the whole basic social psychological problem of *life being a struggle*, these minor stressors were able to absolutely throw participants because participants were already weighed down by all the other aspects. Therefore even minor stressors seemed like major ones to them: "Any little thing... [can turn into] World War III. I can assure you" (P11). Being brought down by stress further deepened *the struggle to identify any intrinsic value as a person* because participants had accepted the explanation given by health professionals of why they were so easily affected. This explanation pointed to participants having a "narrower allowance" (P13) for stress and this made them out to be weaklings: "You are weak because you haven't been able to handle... what life has chucked at you" (P23).

With even minor stressors having such a disruptive impact on participants' day-to-day living they were not far from being incapacitated, which completed participants' powerlessness. They described how they struggled with wanting to do things but were unable to due to a lack of energy. This lack of energy was compared to having a flat battery, which did not have enough charge to start an engine: "The battery is absolutely flat, rrrh, rrrh (making a sound of an engine not starting). You want to go and it won't go" (P25). Participants indicated that the lack of energy affected whatever they wanted to do, from making simple

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decisions to doing household chores and cooking: "I was ending up eating baked beans and bits of bread every two or three days" (P3).

Being incapacitated further deteriorated to a point where participants were unable to do anything at all. They described how they were sitting in a room for extended periods of time without doing anything: "I sit in a dark room, the last time for three days and three nights" (P4). They likened it to being paralysed, both physically and mentally. Physically they were unable to move: "I'm talking about literally not moving unless I had to go to the loo" (P13). Mentally they were unable to talk or even hear and it seemed to them as if there was "nothing in my head" (P16). Deegan (2005a), a consumer-writer, described her own incapacitation as a feeling of being "among the living dead" (p. 60).

As a consequence of *the struggle with getting through daily life* in this study participants' mental disorder was made worse: "It got me down and I had a nervous breakdown" (P15). Moreover, *the struggle to identify any intrinsic value as a person* was further compounded. Participants felt a loss of value by not being able to do even simple chores and their self-esteem plummeted: "[I] felt inadequate" (P29).

Those participants who had lost their jobs grieved over the loss of value that work had bestowed on them. Being retired against their will "floored" (P16) them as they realised the value of their work capabilities had permanently been assigned to the scrap heap. In addition, some participants, in having lost their jobs, had to resort to social security benefits, which left them without sufficient financial means to get by. They often did not have enough money to buy healthy food or live in decent accommodation: "My living conditions are like being back in the Boys' Scouts and camping" (P25). Living in circumstances of poverty, participants felt ashamed and guilty that they were no longer able to work and had to draw on welfare. This shame and guilt deepened the already felt shame in *the struggle with establishing credibility*, and guilt experienced when they blamed themselves in their *struggle with maintaining normal relationships with individuals*. In addition, they now found themselves under a regime of frequent reviews for welfare eligibility, fostering a sense of fear and insecurity with regards to the provision of lodgings and their daily bread and butter.

Participants in this study who had lost their jobs were not alone. Marwaha and Johnson's (2004) review found that in most Western countries only 10 to

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20% of people with serious mental disorders were employed. Borg et al. (2005) also identified, in examining the role of material resources in recovery from severe mental illness, that poverty and substandard living conditions were among the "major struggles" consumers faced (p. 243). Spaniol et al. (2005) highlighted the importance of financial security to people with mental disorders: "Dealing with poverty was a greater challenge than dealing with mental illness" (p. 92). As did participants in this study, Caswell (2005), a consumer-writer, talked about the guilt he felt when he was unable to get a job.

The last consequence of *the struggle with getting through daily life* in this study consisted of its contribution to *the struggle with staying alive*. Participants felt that their life had come to a standstill, that it was dead and devoid of everything, and that they were virtually decaying: "I just lay there all day, rotting" (P25). In this situation participants asked themselves: "What's the point of... struggling with everything in this life?" (P11). They came to the conclusion that they did not care anymore about anything, particularly about keeping their life together: "Let everything fall apart" (P29). Therefore suicide was again an obvious choice: "One night I sat down and carved myself up [with a knife].... [I] just sat there, and blood was going everywhere. I was too weak to move. I lay on the bed, too weak to move for a week" (P18).

4.5: Summary

The basic social psychological problem of *life being a struggle* presented participants' account of why they struggled and how they struggled. This struggle left them powerless. In *the struggle within oneself*, they struggled with *identifying any intrinsic value of oneself as a person*, which was central to the basic social psychological problem of *life being a struggle*. They also struggled *with having a mental disorder* and *with staying alive*.

In *the struggle with relationships*, the basic social psychological problem of *life being a struggle* consisted of *the struggle with responding to the impact of having been abused*, *the struggle with establishing credibility*, *the struggle with having been let down by the mental health system* and *the struggle with maintaining normal relationships with individuals*.

Both *the struggle within oneself* and *the struggle with relationships* culminated in *the struggle with getting through daily life*. The powerlessness

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brought on by the impact of the *disempowering conditions* seemed complete, with one exception: anger. As will be seen in the next chapter, anger was the only emotion that contained within it the seeds for spurring participants on to resolve their *life being a struggle*.

CHAPTER 5: THE BASIC SOCIAL PSYCHOLOGICAL PROCESS OF TRANSFORMING ONESELF

5.1 Introduction

The third part of the substantive theory of *transforming oneself and society to resolve life being a struggle* explains how the basic social psychological problem of *life being a struggle* was resolved by those consumers of mental health services who were living in the Western Australian community. It was resolved through the basic social psychological process identified as *transforming oneself*. Transforming referred to making considerable change. Due to the suffocating and seemingly insurmountable basic social psychological problem of *life being a struggle*, participants' *transforming themselves* was a feat that was very difficult to achieve as the obstacles to overcome were so great and there was no plan, according to participants, on how to proceed. This feat was therefore highly admirable for its originality and power of execution. The psychiatrist Bloom (1997) agreed: "I feel compelled to state that we have treated some of the strongest and bravest and cleverest people we can ever hope to meet.... [They are] tough, resilient and often ingenious" (p. 140).

In *transforming themselves* participants in this study changed themselves from people being helpless and powerless to people being confident and assertive and in charge of who they were and how they ran their lives. They compared *transforming oneself* to a metamorphosis, such as the metamorphosis of a caterpillar to a butterfly. A caterpillar appears unseemly and is unable to take to the air but after a long incubation period breaks out of its cocoon and emerges as a fully-grown butterfly. It displays beautiful wings and is free and able to fly off to wherever it desires:

I am almost that, coming out of the cocoon and the butterfly has broken out and it is just ready to flutter its wing. Its wings are just in the stages of getting dry. The colours are all coming [out]. (P13)

The term transformation was also used by Spaniol et al. (2005) in describing how consumers overcame their difficulties. Coleman, a consumer consultant and trainer, described his own transformation as going from "victim" to becoming a "victor" (Coleman & Smith, 2007, p. 2). He also identified that at "its very heart [is] the reclamation of personal power" (Coleman, 2004, p. 45).

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Participants in this study likened the basic social psychological process of *transforming oneself* to a "journey" (P30). They compared it to traveling along an arduous road that took a long time to negotiate, ranging typically from between 20 to 50 years.

The basic social psychological process of *transforming oneself* consisted of two stages: *trying to deal with life being a struggle* and *getting better as a person*. They were separated by *the turning point*. Although interviews were only conducted at one point in time, it was possible to identify the two stages and *the turning point* because participants described what they had done at earlier periods in their lives. In addition, analysis also revealed which stage participants were positioned in during the time of the interview. For example, some were still in stage one, whereas others had just emerged from *the turning point* into stage two. Only a few participants had gone through the full process. This is not a value statement as to participants' ability to go through these stages because the process discovered in this study was not readily identifiable to those in an earlier stage. Despite trying their utmost, these participants could not have known how to proceed along the journey towards fully resolving the basic social psychological problem of *transforming oneself* as it typically took decades to learn how to navigate through its entire length.

Literature on people who did not have a mental disorder will also be included as additional data in this chapter. This will show that the basic social psychological process of *transforming oneself* is common to both groups, people with and without a mental disorder.

5.2: Stage 1: Trying to deal with life being a struggle

Entry into the first stage of participants' basic social psychological process of *transforming oneself* occurred with the advent of *the struggle with having a mental disorder*. Two phases were identified: 1) *not wanting to deal with anything* and 2) *trying to get on top of having a mental disorder*. Participants' movement between these phases was not necessarily sequential and they could return to the previous phase at any time.

5.2.1: Phase 1: Not wanting to deal with anything

Participants in this study bluntly stated that in this first phase they did not want to deal with anything in their life: "Not have to deal with anything" (P29). They said that this phase most often occurred at the beginning of an episode, especially in the first few years of an illness, and when stress became too much to handle. In their powerlessness due to the cumulative nature of aspects of the basic social psychological problem of *life being a struggle*, participants turned to the only strategy they could think of and employ at this point of *not wanting to do anything*, that is, to withdraw.

Participants indicated that this act of withdrawal was instinctive: "Something flicks inside, 'withdraw'" (P11). They explained that the purpose of withdrawing was to be "taken out of circulation... [to] get out of here" (P33). The most prominent reason participants gave for wanting to withdraw was the fear of being exposed to *society devaluing and dehumanising people who have a mental disorder*: "People are going to look at me funny and they are going to laugh at me and they are going to point and I can't deal with it" (P17). The shame participants felt at being someone dishonourable and improper also contributed to not telling anyone about their illness and deciding to hide away instead: "You grow up... a closet person... because of the shame of it" (P26). However, participants gave a second, deeper reason for wanting to withdraw in that they did not want to deal with *the struggle with having a mental disorder*. Participants did not want to admit to themselves who they really were, namely someone afflicted by one of those demonised mental disorders.

Supporting this study, other consumers gave similar reasons for withdrawing. Aldridge (1998), in his substantive theory on suicide, noted that his participants concealed the fact that they had a mental disorder because they were ashamed. Repper and Perkins (2003), drawing on many consumer accounts, recognised that many were frightened and that they did not want to deal with their mental disorder because they wanted to "reject the images of themselves as dangerous and incompetent" (p. 99).

The first way that participants in this study withdrew was from the knowledge of *having a mental disorder*. They thought that it was easier to pretend that it was not there, to "ignore it" (P32) and deny its existence: "That's a part of the denial because so long as you can keep yourself well out of mental

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illness and the knowledge of it, it's like you haven't got it" (P30). They said that as part of this denial they also stayed clear of mental health professionals: "A lot of people [with mental disorders] think, 'oh, my goodness, if I see a psychiatrist I am really mental'. So they don't want to deal with that" (P31). Thinking along the same line, they also convinced themselves that medications were not necessary as they regarded themselves as being all right and therefore thought it was pointless taking any.

Corroborating these feelings, Boydell et al.'s (2006) analysis of the perspectives of young people with mental disorders also found that these young consumers had decided to "try and forget about it [the mental disorder]. That was my way of dealing with it!" (p. 57). Likewise, Brody (2008) recorded in focus groups on the first-hand experiences and perspectives on stigma and discrimination that consumers often did not seek treatment.

The principle goal of the other ways of withdrawing in this study was to not have to deal with *the struggle with relationships*. The second way of withdrawing was therefore to remove oneself physically from associating with other people: "I... just disappeared off the face of the earth" (P7) or locked themselves in their home, not answering the phone nor opening the door to anyone.

The third way was to withdraw mentally within oneself. Those participants in this study who had not been abused in childhood and/or adolescence withdrew mentally behind a façade: "You can joke and you can... look happy and people think you are ok but you are not.... Sometimes the worse you feel the more you [withdraw behind]... a façade" (P29).

However, those participants who were faced with *the struggle with responding to the impact of having been abused* withdrew mentally within themselves to a much larger degree. This was necessary because withdrawing mentally behind a façade was not sufficient because the impact of the abuse had been too great. These participants therefore needed other ways that were realistically achievable for them. They described how they withdrew from the memories of the abuse by burying them deeply within their minds and putting a seemingly secure lid over them, described as "a trap door" (P30), so that they could hopefully be forgotten forever.

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Some participants withdrew mentally even further. They created a fantasy world into which they could remove themselves from the intolerable, hellish, real world: "My * [abusers] made my life so unbearable, so intolerable and for so long... that I left the real world. Not deliberately. It just happened. There seemed no [other] way out. I started to fantasise" (P22). This fantasy world that participants created was concerned with living, albeit fleetingly, in a realm where this abuse did not occur and where they could dream of being loved and cherished. In some instances this fantasy world was then peopled by "imaginary friends" (P11). The following participant described how an imaginary friend appeared as part of her fantasy world who offered to shield her from *the struggle with responding to the impact of having been abused* by making it possible for her to *not want to deal with anything*:

She [the abuser] belted the daylight out of me.... So, I went running outside... and I just lay down... in the mud, just lay there. I could feel the rain on me. [I] don't know what happened. It just felt like as if my mind had shifted to a different dimension.... I saw this child, probably a little bit older than myself, dressed in very old fashioned clothes, saying to me... 'When * [name of abuser] does these things to you, you just come to me'. Whenever these things were happening, I couldn't stop them but I just sort of went into another realm with this person. (P11)

With this participant, the imaginary friend kept his promise and assisted her in *not having to deal with* other highly stressful situations. This safety mechanism that appeared in the form of an imaginary friend was so valuable that the participant refused to take mental health medications for many decades because these medications took the imaginary friend away from her.

However, other consumers reported that not all 'people' in their fantasy world were as benign and friendly as the one encountered by the participant in this study. For example, Steele (Steele & Berman, 2001) described his 32 years with voices that were relentlessly menacing, threatening and deprecating: "Hang yourself. The world will be better off. You're no good, no good at all" (p. 1).

Some participants in this study went even further than living in a fantasy world and retreated completely behind a protective barrier that had the function of cutting them off from the real world. This protective barrier was described as a mental "brick wall" (P30). This mental brick wall was far more solid than the façade put on by those participants who had not been abused. Participants

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explained that behind this mental brick wall they felt that they were somewhere else instead, somewhere undefined: "Like I wasn't really here" (P23). They said that this perception of not really being here and being cut off from the real world had already occurred in childhood: "I've got a photograph of me when I was... probably about 8 [years old].... You can see I am completely cut off.... It's this look that... nobody's at home.... I always felt like that, cut off from the [real] world" (P30). This feeling of being cut off from the real world then continued into adulthood, especially at times of great distress: "It was like... being in the corner of a room watching and listening to all this stuff happening [to me]. You are just not [there]. I know that it was me sitting there but it just didn't feel like me" (P34).

In order to assist participants to stay behind that mental brick wall but still be able to get through daily life, they operated 'on automatic'. They achieved this by using an outside persona that was separate from their inner true selves, which stayed behind the mental brick wall:

I did it [things in daily life] as a task that I knew had to be done correctly.... It didn't matter what I was feeling inside I knew I had to behave a certain way.... It was on a level that was outside of me. It wasn't really from me. It was just what was meant to be [done]. (P23)

Ridge and Ziebland (2006) quoted similar statements from their participants in a study on how people give meaning to recovery following depression. Their participants also mentioned that they had "built up a very good high brick wall and nothing came in or out" (p. 1042), that they had "put on a front" and were "functioning like a machine" (p. 1044).

Participants in this study further explained that they separated the outer persona from their true inner selves to such an extent that it led to a feeling of being split between an outer world, which was represented by the outer persona, and an inner world, dominated over by their inner true selves. This feeling of being split became so great with some participants that there was no true interaction between the outer and inner worlds anymore. Participants described feeling split as turning into two different people who were able to feel and display two different, vastly contrasting emotions. For example, the outer persona was presented as a false frontage that seemed to manage fine, whereas the inner true self was so desperate that it was ready to commit suicide: "I split

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into two people.... This one person who just put on this act that everything was ok and that I was really enjoying myself... [and this other person who was] just really determined to kill [herself]" (P7).

Participants found that the feeling of being split, or dissociated, was a very effective way of withdrawing from the reality of the abuse they had suffered: "I'm trying to dissociate myself from that childhood event" (P13). The reason it was effective was that the outer persona was shielded from being overwhelmed by the destructive influence emanating from the inner true self. This reality of being split was then translated into actual physical experiences: "I used to have these blackout episodes [and] I used to get these smells... and... all of a sudden my hands would look like shrunken" (P30).

Other consumers also reported that they dissociated, for example in a study on what survivors traumatised by child abuse need from community-based mental health professionals in Canada (Harper et al., 2008). Van der Kolk et al. (2005) established that dissociation occurred in up to 80% of people who have been abused before the age of 14 years and 59% with late onset abuse. It is defined as a "compartmentalization of experience" (Van der Kolk, Van der Hart & Marmar, 1996, p. 306). Bloom (1997), in her substantive theory on the experience of trauma, explained that when traumas in life cannot be resolved, "then we must find a way to turn off the emotion. That is when we dissociate" (p. 42). Furthermore, exploring the experience of trauma Van der Kolk, Van der Hart et al. (1996) stated that people experiencing dissociation lose "an integrated sense of self" (p. 306) and can "leave their bodies... and observe what happens from a distance" (p. 307). Van der Hart, Nijenhuis and Steele (2005) reasoned that dissociation allowed the affected person to function in daily life.

The fourth and last way of withdrawing in *not wanting to deal with anything* in this study was through suicide. Both groups of participants, those who were *struggling with responding to the impact of having been abused* and those with secure and non-abusive upbringings, were united in their realisation that they could enact this way of withdrawing once and for all: "The thoughts of suicide and... wanting to escape, wanting to get away... feeling trapped and wanting to get away" (P32). That suicide was an option to escape was also commented on in a review by Lakeman and FitzGerald (2008) on how people lived with suicidality.

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Participants in this study described withdrawing through suicide as being highly attractive to them and were relieved in their realisation that it was available. They saw it as an obvious way to proceed. Although it formed the last rung in a line of thinking about options to withdraw, the decision to choose it was often reached very fast:

I wanted to withdraw. That was the beginning and then you just lock up your hat. You don't talk to anybody [and] you don't want to see anybody.... In my case I'd probably think that, 'Oh, well... my kids won't talk to me; my parents didn't love me... may as well just die. I 'm going to die anyway'. That's how I used to think... 'Well, I will die anyway. So I may as well go now [die] and get away from everything'. (P11)

Some literature on people without a mental disorder will now also be included here. Surprisingly, a selection of only a small number of studies, including autobiographical writings, on people who either had been abused in childhood and/or adolescence but had not developed a mental disorder (Erdmans & Black, 2008; O'Gorman, 2009), had various chronic physical conditions (Aujoulat, Luminet & Deccache, 2007; Stamm *et al.*, 2008) or suffered from a terminal illness (Denz-Penhey & Murdoch, 2008) found that many facets of *not wanting to deal with anything* explored in this study also occurred in these people. Ways of withdrawing, including not wanting to accept one's illness and ignoring it instead, mentally withdrawing by going behind a façade, burying memories and operating 'on automatic' were also reported by them. A synthesis of seven studies on people in chronic pain established that suicide became an option for them to escape an "intolerable situation and ... despair" (Skuladottir & Halldorsdottir, 2008, p. 897).

Withdrawing in order *not to deal with anything*, as revealed in this study, despite its seeming ineffectiveness, had advantages as it allowed participants to survive: "That's how you kind of... survive" (P30). They pointed out that they were able to gain space and time, where they could rethink their lives, get back on track and start again on a better footing. They mentioned that life was also made tolerable because facing the fear and shame associated with *the struggle with relationships* and the fright and the worry related to *the struggle with having a mental disorder* were avoided. Deegan (1988), a consumer-writer, concluded that the denial that one had a mental disorder was "a normal reaction to an overwhelming situation. It was a way of surviving" (p. 13).

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However, *not wanting to deal with anything* by withdrawing also brought disadvantages because withdrawal was eventually recognised as a deferment only: "It [the mental disorder] doesn't respond well to being denied" (P32). Withdrawing mentally within oneself by separating the outer persona from the inner true self prevented participants from feeling like a whole person. They said they did not feel "altogether" (P13) because their emotions did not belong to a unified individual inside them: "I never felt right; I never felt like I was a complete person. I always felt like there was a conflict with what I was being and what I was feeling. There was always a very definite conflict" (P23). With this loss of feeling like a whole person, participants explained that any coherent identity of whom they were meant to be disappeared: "I didn't know who the dickens I was... and who I was supposed to be" (P23). Instead their identity became "jumbled. I couldn't figure out who was me out of it all" (P23). The lack of a coherent self-identity was so strong that it persisted even in the face of achievements participants had made in life. As a result they regarded themselves as "a nobody" (P30). This loss of a coherent self-identity reinforced the loss of value in *the struggle to identify any intrinsic value as a person* with demoralising effects: "It was just the most disastrous thing" (P30).

Due to the disadvantages of *not wanting to deal with anything* mounting up, participants reached a point where this way of trying to resolve the basic social psychological problem of *life being a struggle* was no longer viable. For the following participant that point came when he left school and had to find employment: "All of a sudden life, the reality of life, was staring me so hard in the face that I sort of couldn't retreat into that fantasy world anymore" (P9). For other participants, the loss of their job or their role in the family, the loss of an important support person or another episode of mental illness unraveled their hitherto protective ways of withdrawing: "It was... all encompassing. I was drowning in it" (P32). At this point participants realised that it had become detrimental to use *not wanting to deal with anything* because it made the basic social psychological problem of *life being a struggle* worse. Participants noticed that they had entered "a vicious cycle" (P31) because they had not developed better ways of dealing with situations. In order to find these better ways they entered into phase two.

5.2.2: Phase 2: Trying to get on top of having a mental disorder

In this second phase of *trying to deal with life being a struggle* participants were looking at all possibilities as to what to do "to try and get on top of it [having a mental disorder]" (P29). Despite being aware that *having a mental disorder* was only secondary in importance to *the disempowering conditions* related to participants' social sphere in bringing about *life being a struggle*, participants came up with reasons why they wanted to focus on *having a mental disorder* now: "[The] focus on the [mental] illness... was... huge" (P11). It was huge because participants wanted nothing more than to get over it. They also thought that dealing with this one *disempowering condition* the other ones, with the exception of *having been abused in childhood and/or adolescence*, would then also be resolved as it was believed to be the reason for their occurrence. Furthermore, resolving *having a mental disorder* was heavily emphasised by society. Therefore, participants' focus now changed from *not wanting to deal with anything* by withdrawing to *trying to get on top of having a mental disorder*.

Participants said their overall goal of phase two was to be normal. They explained that normal referred to being free from signs and symptoms. Participants wanted to be able to organise themselves, have sufficient mental energy and stay symptom free without having to resort to taking medications. In addition, they wanted to get back to what they considered a normal lifestyle with a steady job, a positive outlook on life and not to be "the odd one out" (P17). Some participants in Ridge and Ziebland's (2006) English study on how people give meaning to recovery following depression also mentioned that they "just wanted to get back to how life was before * [the mental disorder and] feel 'normal'" (pp. 1042-1043).

Participants in this study thought long and hard about what strategies they could devise to achieve this goal. They tried to find a "quick fix" (P5) with the central aim of finding happiness, which they thought would lead to a temporary relief from their misery. For example, they went to nightclubs, drank alcohol or smoked marijuana: "Because if I felt sad, I would just smoke that and forget it and feel happy" (P12).

When happiness was not found, participants said that they scaled their aim back to finding mere relief from their misery, described as "almost like feeling good" (P9). Participants here used band-aid measures, which helped to

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superficially gain some relief from their misery without resolving it entirely. In this they were more successful. For example, they said that they got some relief from simply crying or from finding anything that would provide them with some comfort, such as eating "comfort foods" (P29). To have a short time each day where some form of comfort was found turned out to be so important that it became the focal point of their life in this part of phase two.

However, participants eventually found that all their own efforts at *trying to get on top of having a mental disorder* were futile. This sapped their mental energy and they remained powerless in resolving any aspects of the basic social psychological problem of *life being a struggle*.

Participants now turned to the second strategy of *trying to get on top of having a mental disorder*, where they sought out advice from outside sources. They had now abandoned not wanting to know about *having a mental disorder* from phase one and were keen to comply with everything in this advice, including taking all the various medications available: "You need to take this'; 'ok'. 'You need to do this'; 'ok'" (P34). Participants went to great lengths to seek out education. They attended all the therapeutic sessions and workshops, and consulted all the books they could lay their hands on, sometimes for many decades: "You name it; I've done it" (P33). Cognitive therapy was also tried with the same diligence: "I've tried that for years and years and years" (P15). Furthermore, participants turned to alternative ways, which were not strictly medical but had been recommended nevertheless. For example, they started to exercise as they were told that exercise increased endorphin levels in the brain, a neurotransmitter that was linked to increased mood levels.

Other consumer-writers also remembered how they had been keen to comply with all advice (Lovejoy, 1984). In Coleman's (2004) words, he had become a "good schizophrenic" (p. 11). However, participants in this study found that complying with all this advice ended in disappointment, as none of it eased *having a mental disorder*: "It wouldn't help" (P29). This left them as powerless as they had ever been.

Therefore, participants were left with the last strategy of *trying to get on top of having a mental disorder*, the use of extreme measures. In having failed to make headway so far, participants now reasoned that they could at least gain some power over other aspects of the basic social psychological problem not

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pertaining to *having a mental disorder*. These measures were classed as extreme because participants turned to them as a last resort. They felt they had no other options left. For example, some thought that the only thing over which they could still exert any form of power in *the struggle within oneself* was their weight so they stopped eating. To gain some power in *the struggle with relationships* other participants tried to express their need for other people's attention to their plight by "smashing things" (P13). Another sought to gain some power over getting help from health professionals by setting the hospital ward on fire: "It was a cry out for help, basically" (P2).

However, the consequences of this last strategy were disastrous because participants damaged both themselves and the relationship with other people. They damaged themselves by, for example, weakening themselves physically, by again turning to self-harming practices, by being put into straightjackets and by getting criminal records. They damaged their relationship with other people when "everything turned into a fight" (P33). The greatest damage, though, was to the *struggle to identify any intrinsic value as a person* because participants thought that it must be their fault that they were not able to *get on top of having a mental disorder*: "You think... 'What is wrong with me?'" (P29).

Due to all these strategies failing, participants realised that they had come to the end of the road in *trying to get on top of having a mental disorder*: "I don't know what more I can do, quite honestly" (P15). In their failure to make any progress participants now became convinced that it was beyond their reach and that there was nothing else they could do: "I'd just got to a point where I'd just couldn't deal with anything any more" (P5).

As a result of not being able to deal with *life being a struggle* participants in this study became "resigned" (P12) to their situation. They did not know what else to do. Becoming resigned, though, brought with it further stress in the form of grieving over the seemingly permanent loss of any power to make meaningful changes. So some participants in this study therefore went back to revisit the first phase and started to withdraw again.

Other participants, however, continued to be determined to *try and get on top of having a mental disorder*. They said that they were resolute and willing to fight until their mental disorder was under control: "I will fight this thing to the end.... [I am telling myself] 'You are going to fight this. You are going to win'"

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(P29). This fight required the expenditure of large amounts of mental energy and a "never-ending effort" (P31). As a result, they became so worn down that they were "constantly exhausted and flat" (P6). Their powerlessness to effect any positive changes further worsened to the point where they characterised their life as being in "turmoil" (P3). In the face of this turmoil they concluded that they "didn't have that strength to continue" (P23) and that giving in to not fighting any more was much easier: "If I had a [gun] next to the alarm clock like probably 20 [or] 30 percent of the days in the year I'd pick it up and go, 'shh' [making a shooting sound] 'cause it is just too hard to go on" (P26).

Participants now realised that they were stuck in a loop, from which they could not escape and they capitulated: "I've had it" (P5). They had reached a desperately low point that became a breaking point for them: "I was... ready to... explode" (P29). At this point of total powerlessness they were forced to confront their hopeless situation. This was the moment when they started to advance through *the turning point* into stage two.

In summary, stage one of the basic social psychological process of *transforming oneself* consisted of two phases. In the first phase, participants *did not want to deal with anything* and withdrew. When withdrawal was no longer a viable option, participants progressed to phase two where they wanted to engage in better ways of dealing with their situation. Now they wished *to get on top of their mental disorder* but despite their best efforts this resulted in failure. They either made further attempts, some even going back to phase one, until eventually they reached a desperately low point, at which time they entered *the turning point*.

5.3: The turning point

The separation between stage one and stage two of the basic social psychological process of *transforming oneself* was the *turning point*. A *turning point* was defined as "a point at which decisive changes take place; a critical point" (Delbridge et al., 1997, p. 2279). Participants turned from being powerless at *trying to deal with life being a struggle* despite their best efforts, to discovering ways to gain personal power over what to do. This theory found that a *turning point* was necessary in order to achieve the transformation that ultimately turned

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participants' *life being a struggle* into a life of *being at peace*. The *turning point* was either precipitated by a crisis or brought on by *empowering conditions*.

5.3.1: Turning point precipitated by a crisis

The majority of participants entered *the turning point* through the first possibility of experiencing a crisis. A crisis occurred either suddenly due to the appearance of one major event or as a result of a slower accumulation of many smaller events coming to a head. The major event was likened to a "cyclone" (P12), such as getting an especially devastating episode: "I completely lost it" (P16). However, more typically, several smaller events built up and accumulated over a period of time to the same intensity as the single major event. An example produced by one participant described the many smaller events as consisting of her deteriorating mental health, her seemingly permanent stay in hospital from which she could not escape and the associated abuse of power by health professionals: "They treated me horrifically, really badly" (P2).

Whether the crisis occurred due to a sudden major event or due to an accumulation of smaller events coming to a head, it resulted in participants experiencing a hopelessly low point in their lives: "I was very, very desperate" (P7). Participants said they knew that there was no one left in the world able to help them, that they had nowhere else to go and no viable options left. Participants also realised that they only had two pathways left in front of them: "I had to actually make a decision within myself, either I was going to... kill myself and that was that, or I would... try again" (P7).

The decision to try again was the critical break-through point where participants broke out of the vicious cycle of the unsuccessful first stage that had merely served to increase their powerlessness. This break-through point signalled to them that something had changed inside them and this something was a change in their attitude. They realised that a change in attitude led them beyond thinking they were stuck at the desperately low point. It made them realise that they were able to take "ownership" (P34). This ownership was epitomised by participants stating that they themselves now had to determine what to do: "I thought, 'Screw it, no one else is going to help me; I'll have to do it myself'. So I did" (P5). Participants described this as the point at which they started to gain some personal power for the first time and pinpointed it as the beginning of their

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transformation: "I felt like I was completely different person" (P7). With this realisation came a sense of great relief: "I sobbed deep within" (P9) and a glimmer of hope surfaced indicating to them that they had the capacity to get through the desperately low point after all.

In the literature, *turning points* are described as permanent disruptions or deflections in the life course trajectory, for example by Wheaton and Gotlib (1997) who examined concepts and themes of trajectories and turning points over the life course. Other consumers also told of similar *turning points* to participants in this study: "To remain as I am is impossible. I must die or be better" (Lincoln, 1841/1953, pp. 229-230). Furthermore, the critical break-through point resulting in an attitude change, which depended on a decision to change, also happened to other consumer-writers (Lovejoy, 1984), as was taking ownership (Coleman, 2004). Taking charge was an important theme in Borg and Davidson's (2008) study on the nature of recovery as lived in everyday experience.

Turning points were also described as occurring in the lives of people who did not have a mental disorder. Those with a history of childhood abuse explained how they making a "big decision" was *the turning point* for them (O'Gorman, 2009, p. 129). *Turning points* could be "precipitated by exceptionally severe events... or cascades of disasters" (Wethington, Cooper & Holmes, 1997, p. 48). Participants in a study on what it was like to live with a terminal illness described how they had taken charge of their lives (Denz-Penhey & Murdoch, 2008) and those with paraplegia highlighted the importance of hope: "Hope was all you had" (O'Connor, Young & Saul, 2004, p. 210).

5.3.2: Turning point brought on by empowering conditions

A minority of participants in this study went through *the turning point* with the help of *empowering conditions*. Although it may seem premature to introduce *empowering conditions* here it is important to fully examine how this type of *turning point* was brought on. The *empowering conditions* mentioned gave participants some measure of power directly, again for the first time. Three *empowering conditions* were identified.

The first *empowering condition* prompted participants to realise that they were able to make their own decisions. It consisted of getting correct knowledge on what was wrong with them, which, in turn, spurred them on to finding out

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more about their disorder and what they could do about it. This was so important that it "helped spare my life" (P26). Participants also put getting a clear head to think with in this category. They described how due to the prescription of effective mental health medications they could now think sufficiently clearly so that they could make decisions of what they wanted to do in life: "I sat down one night and thought, 'right, come on, let's think this out.... I've got my life back on track thanks to the little pills.... So, how about doing something with yourself for a change?'" (P18).

The second *empowering condition* gave participants sufficient confidence to think that they had the capacity to make positive changes. It consisted of affirmations, which were strong assertions or statements aimed at improving their opinion of themselves. Participants recalled how these affirmations helped them when they recited them over and over in their minds: "They become... part of who you are" (P13). Getting other people's confirmation that participants were people who were valued also lifted their self-confidence. They called it being validated, meaning that they were believed in and that their experience was understood as being valid: "Being believed and validated... changed my attitude.... Not in a theoretical mental illness lens. Understanding me from my experience of the world and my experience from my whole life, as a human being" (P30).

The third *empowering condition* that brought about the *turning point* assured participants that they had not been totally abandoned and that they indeed had the strength to continue. Participants characterised this as a religious experience. They described how they had felt a presence coming into their lives: "I didn't hear an audible voice but it was like a strong thought came up" (P9). They sensed that this presence was something other-worldly: "The presence of whatever it was... I now believe was angels or the Holy Spirit; I'm not sure" (P9). Those participants who had this experience indicated that this was the moment from which they started to pull through: "From that point on I started to recover" (P16).

The importance of these *empowering conditions* was also reflected in the literature. For example, male consumers living in a rural area of Queensland talked of their *turning point* gaining correct knowledge (Gorman et al., 2007). Other consumer-writers emphasised being put on the right medications (Steele &

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Berman, 2001) and the importance of affirmations (Lovejoy, 1984). A review of studies on how people live with or get over being suicidal mentioned the importance of being validated as facilitators for their *turning points* (Lakeman & FitzGerald, 2008). People who had been abused in childhood and did not have a mental disorder also spoke of a religious experience being "an absolute pivotal moment", a turning point" for them in a study on how they thrived in adulthood (Thomas & Hall, 2008, p. 161).

After having gone through the *turning point*, whether it was precipitated by a crisis or facilitated by *empowering conditions*, participants in this study realised that despite the pain involved, this transition had been necessary and that it had been worth it: "It [was] a blessing" (P12). They also understood that without it they could not have moved into the second stage of the basic social psychological process of *transforming oneself* where they were now able to make fundamental changes to themselves and their life. Having gained a small amount of power during *the turning point* participants now acknowledged that they could start on a new trajectory, a trajectory on which they were finally able, step-by-step, to build on this power in order to resolve the basic social psychological problem of *life being a struggle*.

In summary, whether *the turning point* was precipitated by a crisis or was brought on by *empowering conditions*, it allowed participants to gain a small amount of power for the first time upon which they were able to build.

5.4: Stage 2: Getting better as a person

Participants started on a new trajectory by taking the most important lesson learnt in stage one to heart, namely that they could not *get on top of having a mental disorder*. They now realised that they had to take a much broader view by going "far beyond the boundaries of mental illness and the biomedical model" (P30). They had to change their focus onto what was central to the basic social psychological problem, that is, *the struggle to identify any intrinsic value as a person*, and resolve that first. They said that this redirection of their focus led them to a "deeper understanding" (P30) that they could only resolve the basic social psychological problem of *life being a struggle*, and correct some of the errors they had unwittingly made in stage one, if they concentrated on this central

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aspect first. They therefore decided to *get better as a person*: "I know I can't get better [with my mental disorder] but as a person I want to get better" (P35).

Getting better as a person had a personal and a social dimension. The personal dimension was illustrated by the following participant: "I want to get stronger. I want to be able to cope better" (P35). The social dimension pertained to participants' *getting better as a person* in their relationship with other people: "The only thing that makes a person better or worse is [this]: you are better if... you can do good things like helping other people and you are worse if you do bad things like hurting other people" (P22).

The necessity of changing the focus away from *trying to get on top of having a mental disorder* by "minimising... [its] significance [and] relegating... [it] to a small and insignificant corner" was also recognised by other consumers (Repper & Perkins, 2003, referring to an anonymous contributor, 2001, p. 96). Likewise, the consumer-writer Steele (Steele & Berman, 2001) identified that *getting better as a person* was important, both in the personal and social dimensions. In a study by O'Connor et al. (2004) people who lived with paraplegia also insisted on refocusing away from their physical condition towards "a broader conceptualisation of self" (p. 211) because "focusing on the medical could be particularly damaging" (p. 210).

Participants in this study realised they had to find their own ways of how to accomplish *getting better as a person*: "Nobody taught me" (P11). They said that they could find their own ways because of the insight they had gained from their own experiences to date: "These are the benefits of being pushed through the grid mesh" (P26). Three steps, embedding both the personal and social dimensions of *getting better as a person*, were identified: *gaining a new perspective*, *learning new strategies* and *taking action*. Steps differed from phases in that, by and large, one step built upon the last and participants did not go back to previous steps unless they wanted to deepen their accomplishments further.

5.4.1: Step 1: Gaining a new perspective

Through refocusing away from *having a mental disorder* onto *getting better as a person* participants in this study found that they were able to gain a new perspective. Arising from both recognising and accepting what had happened, a new perspective was consequentially created.

5.4.1.1: Recognising what had happened

Here participants looked anew at who they were as a person. In having gained sufficient power during *the turning point* it now became clear to them that they had attributes that did not belong to the disempowered picture drawn up by society and which they had so completely adopted in *the struggle to identify any intrinsic value as a person*. They realised that these attributes, hitherto obscured, indeed belonged to them and could be used to lay the foundation to build an identity that was positive. Participants said that they gained this realisation through becoming self-aware. Some used creative writing and visual arts to this end: "You find yourself in creativity" (P30).

Becoming self-aware of who one was as a person and one's place in the world was also found to be important by participants in Ridge and Ziebland's (2006) study. Likewise, Leete (1989), a consumer-writer, thought it imperative to recognise positive attributes in oneself because these attributes were "the tools for rebuilding our self-image and thus our self-esteem" (p. 199). Secker, Spandler, Hacking and Shenton (2007), in their study on empowerment and arts participation for people with mental health needs, also emphasised how doing art had empowered participants in their study "especially with regards to gaining a new perspective of who one is as a person" (p. 19).

Through *recognising what had happened* participants in this study discovered three significant attributes in themselves: the ability to make choices, self-reliance and determination. According to participants the ability to make choices went far beyond the thinking of and acting on the dead-end possibilities in stage one: "I just [used to think], 'Do as you are told'.... So... realising [now] that... you have [the ability to make] choices" (P13). Understanding that one had the ability to make choices brought with it some further measure of power, for example the power to analyse complex situations. One participant gave an example of how she analysed in depth the complex ethics around choosing whether to take her abuser to court.

As a result of participants' realisation that they had the ability to make choices, they recognised that they could now decide with whom they wanted to spend time. This freed them from much of the terror of having to associate with people who mistreated them and straight away eased a large part of *the struggle*

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with relationships: "You suddenly realise you don't have to mix with people that make you unhappy" (P19). They also found that it even extended to the power of making a choice over whether to commit suicide: "That [committing suicide] is something I can do because that is my choice" (P20). This simple realisation already eased *the struggle with staying alive*.

Self-reliance was the second attribute that led to a positive identity. Participants regarded self-reliance as consisting of being materially independent of other people, ranging from being financially independent and earning one's own living, to having secure housing and owning a car. Participants explained that self-reliance was important as it allowed them to gain the power and freedom to "run their own life" (P22). As a result of an increase in self-reliance they noticed an immediate improvement with regards to *the struggle with getting through daily life*: "Things have just got so much better" (P2).

The third attribute was determination. Although participants had a lot of determination in stage one they now realised that to be effective in their determination this time, they had to redirect it towards *getting better as a person*. Associated with the ownership they now felt was also the determination to take full responsibility for who they were and what they wanted to do in life: "Now I take... responsibility" (P29).

However, participants also realised that the ability to make choices, self-reliance and determination could only be utilised if sufficient mental energy was available. A participant pointed to the large amount of mental energy that was necessary to resolve *the struggle with staying alive*: "It was taking sometimes all my energy just to stay alive" (P26). Participants found that a sense of inner strength was underpinning mental energy. They explained that it took an extraordinary amount of inner strength to escape from the memories of being emotionally captured in *the struggle with responding to the impact of having been abused*: "Otherwise you're... trapped by the past and it's got you in bondage" (P13).

Participants now also found that they could harness the mental energy that came from being angry. Anger, the one positive emotion that emerged from the basic social psychological problem of *life being a struggle*, gave them the inner strength and hence the power to stand up to those people who had not believed them and who had devalued, dehumanised and mistreated them. The strength

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garnered from anger became in some instances so great that participants considered prosecuting their abusers:

I [have now] got the strength to stand up in court and look at him [the abuser] one day and say, 'Look, I am not doing it from revenge. I am doing it because... I am a strong person'.... And he can lie to my face and... [deny] it... [but] then I might get [even] more angry. (P13)

Anger, not as a symptom of the mental disorder but as an energising force, was also recognised by the consumer-writer Deegan (1997). She emphasised that anger is a "very sane response to the situation you are facing" (p. 19) and that it "moves [people] into action to change... injustice" (p. 5). Participants in Lucock, Barber, Jones and Lovell's (2007) study on consumers' views of self-help strategies in the United Kingdom also found that this kind of anger brought empowerment.

Participants in this current study found that their mental energy needed to be sustained and some participants found it helpful to utilise physical exercise. The positive effect from physical exercise increasing their mental energy contrasted with its lack of effect on lifting mood levels in stage one. Participants in Crone and Guy's (2008) study on understanding consumers' experiences of sports therapy also found that they had more energy. Moreover, they reported that they felt mentally more positive with greater self-esteem when exercising because exercise gave them a sense of accomplishment and well-being.

Participants in this current study had now achieved a major part of the personal dimension of *getting better as a person* and they were becoming much stronger. This strength enabled them to proceed with recognising what had happened: they were now ready to face up to who they were as a person in relation to *having a mental disorder*. Where they had previously rejected this part of themselves, they now realised that they could not ignore and deny their mental disorder any longer:

I have been in that framework... 'Oh... you just need to walk away from it'. But when we walk away from things [the mental disorder] we are running away from ourselves. We are running away from our own selves, a part of who we are. (P30)

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They completed the difficult task of destigmatising their mental disorder and began to regard it like any other physical disease rather than as a demonised condition: "It's no worse or no better than any other illness that we have" (P27).

With this awareness that the mental disorder was like any other physical disease, participants came to understand that it had to be looked after like any other disease: "So... I am diabetic. So, I've got to look after my diabetes. [So, I am mentally ill. So,] I've got to look after * [the mental disorder]. That's how I see it" (P11). Looking after the mental disorder involved managing or containing the signs and symptoms so that they would no longer control all aspects of their lives: "You must control it [the mental disorder], because it will just control you otherwise. You must find... some way to control it" (P11).

Participants recognised that, after having tried to deal with their mental disorder unsuccessfully for so long, controlling it in some way involved agreeing to receive treatment. Therefore, treatment had to be destigmatised as well and regarded just like any other type of medical treatment: "I need to take my [mental health] tablets like some people need to take their heart pressure tablets or their vitamin pills" (P16). The same attitude was projected onto being hospitalised. Hospitalisation during an episode was now seen as just a minor disturbance in one's life and not as a major setback: "So what if I have to go into hospital for a few weeks at a time. I'll look at it as being an interruption. It's just an interruption [because]... I'll be coming back out again" (P4). Viewing the mental disorder and the associated treatment as just another part of life, participants finally started to make sense of what was happening. They were no longer frightened and worried to the same degree. It also reduced participants' helplessness by giving them sufficient power to move towards resolving the previously all encompassing and dominating *struggle with having a mental disorder*: "It is a small, small part of my [life now]" (P11).

Furthermore, recognising what had happened also pertained to who participants were as a person in relation to *having been abused in childhood and/or adolescence*. They knew they had to face the fact that the abuse had happened: "Unfortunately that event [the abuse] is my reality" (P13). This contrasted sharply from the first phase in stage one where they felt they had had no other option but to hide their memories under a trap door, withdraw into a fantasy world or split themselves into an outer persona and an inner true self.

Participants explained that looking the abuse in the face could be taken further by taking the abusers to court, thereby looking them literally in the face: "My... fix was... taking my * [abuser] to court, and being able to stand up... look him straight in the face... and say my piece" (P5). Participants said that this feat gave them a huge amount of power, irrespective of the outcome of the trial: "I got all of my powers back" (P5). Furthermore, they now saw the connection between the abuse and their mental health symptoms, which took away more of the helplessness associated with not making sense with what was happening in *the struggle with having a mental disorder*: "These outward symptoms that are manufactured from the trauma and the abuse... I am [now] recognising them coming from the trauma and the abuse" (P30). Connecting the signs and symptoms to the abuse that had occurred in childhood had also been important to participants in Harper et al.'s (2008) study on what survivors traumatised by child abuse need from community-based mental health professionals.

5.4.1.2: Accepting what had happened

After having recognised what had happened in the process of gaining a new perspective, participants turned to accepting it. For example, with regards to *having a mental disorder* they now accepted that they had one: "I accept it. I've got it. I accept it. I can't help that" (P11). To aid them with this acceptance, participants thought of three proofs that demonstrated to them that this was true. The first proof consisted of becoming aware of certain telltale symptoms that a mental disorder was present: "Something triggered that it could be right" (P23). This was especially pronounced when participants had come out of an episode and looked back at how they had been when sick: "Really, it was only in hindsight that I look back and think, 'You couldn't do that without being sick.... You couldn't be like that without being sick'" (P23).

The second proof was provided when the taking of medications had reduced or even got rid of their symptoms: "I don't attempt suicide anymore and... I don't have this * [symptom] I had before.... So I must have the illness. It's the only way I can look at it" (P18). However, for those participants who did not feel any different when on medication, the third proof came when they had gained sufficient trust in health professionals to believe them when they told them that they had a mental disorder.

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Alongside the acceptance that they had a mental disorder, participants were now also ready to accept that it was unlikely to go away despite the easing of symptoms when on medication: "At times in my life I am going to be * [a person with symptoms].... I must accept that" (P12). With this acceptance achieved they could also move onto accepting that they had to have treatment, and that this treatment had to consist of taking medications: "Unless there is some magic way of dealing with it, medication is the way that... [I am] going to be helped" (P31). However, participants had to find the right medication that made a difference to them without side effects that were too damaging. Once participants had found it, some by changing health professionals, others by widely consulting consumer forums on the Internet, they were glad that this medication existed: "When the medication kicked in it was like seeing in colour for the first time" (P35). Furthermore, participants came to the conclusion that medications were not an optional extra but had to be taken long-term so that they would not go "downhill" (P31) again. They now realised that their previous argument for going off medication, namely that the mental disorder had gone away because the signs and symptoms had improved, had been erroneous:

[I used to think it was] like taking antibiotics, take it for the infection and it's gone.... I used to believe that and go off them all the time and that was the worse thing I ever did. [You] must never, ever go off your medication. (P11)

This realisation turned them into dedicated medication takers: "It's... absolutely necessary for me" (P32). Participants said that they were now also willing to put up with some of the unpleasant side effects because they realised that the benefits of taking the right medication outweighed the drawbacks: "If the medication doesn't agree with you, tell the doctor, but put up with it because in the end, it is doing you good" (P16). Likewise, ECT was welcomed by those participants for whom it worked: "It's done the best for me. It's done wonders" (P2).

Acceptance also occurred in relation to *having been abused in childhood and/or adolescence*. Participants were now ready to accept that they had been traumatised in this way: "I am feeling some very deep-seated loss and grief that has been etched into my psyche from my earliest experiences. And I have accepted this" (P30).

Other consumers also uncovered the value of acceptance. In Ridge and Ziebland's (2006) study on how people give meaning to recovery following depression consumers stated that they had accepted themselves, "warts and all" (p. 1048). The consumer-writer Deegan (1996, in Spaniol & Gagne, 1997) noted that delaying the acceptance that one had a mental disorder until this time was wise because now one had "the resources to deal with it" (p. 76). As did participants in this study, other consumers then also accepted that taking medications was necessary in a study by Van der Tillaart et al. (2009) on voiced realities of women living with a mental health diagnosis.

5.4.1.3: Creating a new perspective

Participants in this study were now ready to create a new perspective with regards to the value they had as a person. They achieved this by comparing themselves with what they called other normal people. Participants said that in many respects they were like other normal people, meaning that they had the same needs and aspirations: "When you say normal, I eat, I drink, I breathe, like everybody else" (P22). They also had the same ambitions to further themselves in life, to be able to work like other people or to just go traveling with friends. Most of all, they wanted to stay in their own home and not be locked up in a mental hospital.

However, despite having many things in common with other normal people, participants also knew that they were not like them: "I am not like other people" (P22). They did not feel like other normal people because they had a mental disorder: "Basically my whole life I have never felt normal" (P35). The previous view of what normal meant in stage one, which referred to participants' wish to be free from their signs and symptoms, had gone. Likewise, they now realised that their previous goal of getting back to what was considered a normal lifestyle was unattainable: "That's what they [consumers] think can happen but it doesn't" (P11).

Participants said they were also not like other normal people because they held different ethical values. The ethical values held by many other normal people, according to participants' experience, were a readiness to go out and harm others, leaving all ethical norms of how to treat other people behind:

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There are so many people that... can throw their morals and... their... integrity out [of] the window... as if it is something of no value... and be as evil as you can possibly imagine.... I mean, that is just normal. That is just ordinary people. (P22)

Participants did not consider themselves normal in this sense: "I'm not as evil as it is normal to be. That's what it is" (P22). They said that their different set of ethical values consisted of treating everyone as equals. They maintained that this was the true yardstick one should be judged by: "That's... how I grade people" (P22). By comparing themselves with other people using this yardstick, participants found that they were not of lesser intrinsic value. They were not non-persons or sub humans, as many sections of society had made them out to be, but qualified as human beings: "I finally realised I was a human being" (P30). The consumer-writer Deegan (1996) agreed: "The goal... is not to become normal. The goal is to embrace our human vocation of becoming more deeply, more fully human" (p. 92). In this study, this insight resolved most of *the struggle to identify any intrinsic value as a person*.

Participants in this study also created a new perspective with regards to *the struggle with responding to the impact of having been abused*. Participants realised, by looking at the long time that had elapsed between the abuse and the present time, that they had indeed survived: "I am still here" (P13). Being still here also proved to them that they were now safe and that they did not have to live in fear any longer: "No one is going to hurt me [any more]" (P13). In creating this new perspective, participants were able to reduce the feeling that they were split between an outer persona and an inner tormented self. They said that although the dissociation still "pops its head up at times" (P13) their wish to have a whole and intact sense of personhood was almost realised: "I wanted the two [the outer persona and the inner true self] to be together so that I knew who I was and how I felt" (P23). To further reinforce the feeling that they indeed consisted of one person, participants said they had to constantly remind themselves of this fact: "I am still looking at the mirror... [and] just touch my hand" (P13). They found that through these reinforcements the periods of time where the disassociation happened grew fewer and shorter: "[It] is getting less and less" (P13). They now realised that by "get[ting] that congruence so that I

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felt [as] one person, not two" (P23) the wounds inflicted by the abuse had started to heal.

In the literature about people who did not have a mental disorder similar accounts were relayed. In examining gender, contexts and turning points in adults' lives Clausen (1995) stated that people questioned who they were. Wethington et al. (1997) looked at turning points in midlife and described how people had gained awareness and new insights into themselves and into situational factors. Wheaton and Gotlib (1997) explored trajectories and turning points over the life course and identified the occurrence of a transformation of identity.

Those writers who had been abused told of how anger had empowered them: "As the time passed and I faced honestly and openly what had happened, I got angry. And that anger became outrage. And outrage drove me forward with purpose and a new clarity" (O'Gorman, 2009, p. 168). Those with chronic physical conditions described how they had gained a new perspective in relation to their illness in a study from Perth, Western Australia (Denz-Penhey & Murdoch, 2008, p. 400). A Victorian study on how young women with type 1 diabetes manage turning points and transitions included the acceptance of their illness (Rasmussen, O'Connell, Dunning & Cox, 2007).

5.4.2: Step 2: Learning new strategies

In order to act on the new perspective participants in this study knew that they had to learn new strategies: "A lot of it was strategies" (P34). They devised four new strategies: formulating new goals, having a plan ready, using constructive ways of dealing with problems, and developing new skills.

5.4.2.1: Formulating new goals

The first new strategy started with "wiping... my slate clean" (P7). Participants reasoned that new goals were necessary so that the new strategies could reflect them. These goals had to be realistic: "Something that you felt that you could cope with" (P23). They had to be tangible, or within easy reach, such as losing weight. In addition, they had to be short-term, at least initially, as participants felt that planning for the long-term was not yet feasible for them. Having realistic

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goals and focusing on small daily tasks was also advised by Repper and Perkins (2003).

Participants in this study found that these new goals were suitable to implement gradually and in small increments: "You just take the tiniest of steps... all in your own time" (P7). Furthermore, to make sure that participants did not overreach themselves they "set [themselves] boundaries" (P30). Sticking to the new goals within the boundaries they had set themselves gave participants further power and they no longer felt overwhelmed by the many tasks required to resolve the basic social psychological problem of *life being a struggle*.

5.4.2.2: Having a plan ready

The second new strategy was to have a plan as to what to do ready for when another episode loomed. Participants stated that being proactive in this way reduced the helplessness experienced as part of *the struggle with having a mental disorder*. Having a plan ready consisted of increasing medications oneself straightaway before accessing medical help. Many participants also made sure their plan included having support people in place, such as family members and friends, so that they could be used when things deteriorated: "You have to have some key figures... [to act as] security blanket... [so that you can] mobilise the troops" (P12). These key figures could then take over in case participants were temporarily left helpless in case *the struggle with having a mental disorder* recurred by, for example, arranging immediate access to treatment.

The necessity of having a plan ready, often referred to as advanced directive, was also recognised by other consumer-writers (Coleman, 2004; Mead & Copeland, 2005).

5.4.2.3: Using constructive ways of dealing with problems

The third new strategy in this study was to use constructive rather than destructive ways of dealing with problems. Using constructive ways prevented the disastrous consequences of using extreme measures that had damaged both participants and their relationship with other people in *trying to get on top of having a mental disorder*. For example, participants explained that a constructive way to deal with problems was to ask for help from empathetic people rather

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than turning despair onto oneself: "Now I ask for help instead of [self-harming]" (P2).

Other constructive ways were employed towards resolving the struggle with working. Despite the great importance of work, participants' wish to find any kind of job, whether suitable or not, had now passed and they had learnt to be more discerning. They said that they were looking for jobs that were beneficial to them as a person, providing job satisfaction and contributing to meaning in their lives. Getting a living wage was also important: "It has to be something viable and profitable" (P26). Due to the difficulties in finding employment like this, some participants had decided to work for themselves. They had been fortunate enough to find a niche in the market place where they could work according to their own schedule, yet be productive, earn money and bring pleasure to other people at the same time: "Out of it all I've discovered a niche" (P4). This was one way of moving towards resolving the lack of value in participants' lives that was part of *the struggle to identify any intrinsic value in oneself as a person*. In the absence of suitable work, some participants opted to do voluntary work, despite the lack of remuneration, as they were aware that it also would give them an enhanced feeling of value.

5.4.2.4: Developing new skills

The fourth new strategy in this study was to translate the different goals and constructive ways of dealing with problems into skills: "The skills that we need to live" (P27).

An important skill was deciding how much to analyse problems. Participants knew that not all problems had to be analysed too deeply but that merely acknowledging them and then deciding to move on was often sufficient. This pertained especially to simple problems. In contrast, complex problems could not be skimmed over. For these, precipitating events and reasons for their occurrence had to be identified. If at all possible precipitating events had to be avoided: "Try and stay away from anything that will cause you unnecessary grief" (P26). If precipitating events could not be avoided participants had to learn to tolerate them. Participants found that slowing down, reducing the number of activities and sticking to a daily routine helped. This way of managing precipitating events was often used to resolve the struggle with being brought

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down by stress: "I have to be very careful of my stress levels" (P12). Lucock et al.'s (2007) study on consumers' views of self-help strategies had also organised their life around daily routines. Other consumer-writers also mentioned that it was important to be careful about stress levels (Leete, 1989).

Being vigilant about precipitating events was also used as part of resolving *the struggle with having a mental disorder*. Participants in this study explained that by becoming aware of precipitating events, warning signs that symptoms might return could be pinpointed. They now knew that even on the right medications symptoms could come back at any time and therefore they had to be watchful in an ongoing way: "I could crash again in a major way" (P32). Participants said that warning signs ranged from innocuous ones: "My main warning sign... is if I wake up in the morning and think, 'Oh, my goodness, not another day'" (P21) to alarming ones, such as thought processes starting to change: "I get these irrational thoughts" (P14). Learning what these warning signs were and not ignoring them was vital: "Notice warning signs. Don't ignore [them. They are] there for a reason. [They are] telling you something" (P30). However, even when an episode recurred, participants now saw it, for the first time, as something positive as it told them to be careful about those aspects of their lives that were not conducive to living with a mental disorder: "So, instead of pushing the door on it [ignore it] and then keep carrying on, like you have been doing.... say, 'Ok, come for a visit'" (P30).

Being vigilant about precipitating events as part of resolving *the struggle with having a mental disorder* and heeding warning signs were also used by other consumer-writers (Leete, 1989; Mead & Copeland, 2005). A participant in Ridge and Ziebland's (2006) study on how people give meaning to recovery from their mental disorder explained that he had also changed aspects of his life that were not conducive to living with a mental disorder to reduce the likelihood of getting another episode: "It's rather like having a dream which is telling you something. I take no notice so it returns and recurs until I do" (p. 1046).

Another important skill learnt by participants in this study was to wait for problems to pass. They realised that many problems in life did not last very long and passed sooner or later without any intervention. For example, symptoms and even whole episodes passed on their own accord: "[I] just have to wait it out.... I just have to let time takes its course until it's better" (P29). Participants therefore

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decided to "just keep breathing through it [until the symptoms] eventually... diminish" (P32). They were now confident in the knowledge that many problems were only temporary: "Life is a roller coaster, it goes up and down and up and down.... Even when it's really low, you know it's going to go up" (P17). Some suicidal thoughts were also treated that way:

I made a deal with myself. In three days time... if I still felt like this [suicidal], and I was still so sure that it was all sane and it all made sense and it was all very logical, then I would start putting a plan into action, and to do away with myself.... Of course by three days later... I wasn't feeling like that anymore. (P17)

Furthermore participants identified the skill of how to handle problems. Participants said that this entailed, initially, learning what they could handle and what was too much: "I have learnt over the years now that... I've got to do what I can only mentally, physically, financially do" (P27). This necessitated dealing with one problem at a time and not letting them build up as participants had done previously. They also started to prioritise them. Lastly, they stood back from problems and put them into perspective: "Being able to stand back from what is happening and... looking at yourself from outside and seeing what different things are" (P28). Putting problems into perspective made it clear to participants that many small problems were not really large and important after all. Participants in Ridge and Ziebland's (2006) study also used the same skill of putting problems into perspective.

Putting problems into perspective was also utilised in resolving *the struggle with having been abused*. Participants in this study were now able to stand back and realise that, on a global scale, many other people had also been subjected to similarly traumatic situations and had managed to survive: "I realised, 'So, these things have happened. Wars have happened, people have had to struggle and live and survive'.... My... circumstances are just like another little bit in history.... You realise, it's no different from other people" (P13). Furthermore, participants noticed that other families also had problems and that they had chased an unrealistic and unachievable dream of living in a perfect family. This awareness finally absolved them from blaming themselves for *having been abused* and contributed to giving them further power that freed them from being imprisoned by the haunting memories.

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In addition, putting problems into perspective was employed towards resolving *the struggle with staying alive*: "I just think... 'Oh, well, really in the big scheme of things... it is more important that I should be here', and I know that" (P11). By putting this aspect of the basic social psychological problem of *life being a struggle* into perspective participants could now see that what they previously thought as logical had been flawed: "I can see how, even though that's logical [at the time of feeling suicidal] it is illogical to think like that" (P34). Coupled with their stronger willpower participants were now able to convince themselves that suicide was not right and was "not what you want to do" (P28). They were also surprised at being glad that they had not succeeded in killing themselves previously, in contrast to having been angry when they had been saved: "First you are angry. But when you feel good and you come home again [from hospital], you think, 'Ah, look'" (P11).

By putting problems into perspective participants in this study now felt more detached from them and therefore were able to take each day as it came without being overwhelmed: "I just take each day as it comes now and whatever happens; happens" (P26). Going about life this way, they realised that not everything needed to be solved and all that was required was doing the best one could within the realm of what was achievable: "For me, when I really struggle... I just do whatever I can" (P26). Twomey (2005), a consumer-writer, had similar ideas: "Whatever I accomplished, however small, would be enough" (p. 328). This freed participants in this study from much of the self-blame experienced in many aspects of the basic social psychological problem of *life being a struggle* including the guilt at not being able to handle *the struggle with getting through daily life*.

The last skill participants in this study learnt was how to deal with their thoughts. For example, they now countered or opposed voices in their head by sternly talking back at them: "I started controlling my head, 'I cannot talk; I shouldn't talk to anybody'" (P10). Tormenting thoughts were discredited, knocked down and not succumbed to, such as the urge to carry out self-harming activities: "I haven't given in. I don't intend to give in" (P17).

However, the most widely used skill in dealing with thoughts was to actively try and change the length of time negative thoughts occurred. Participants had another look at the technique of positive thinking that they had

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tried to use unsuccessfully in stage one. They realised that they now had enough power to shift the balance away from the previously overpowering negative thoughts towards having some positive thoughts instead: "Tell yourself to think [of] a better scenario" (P19). Participants said that the secret of thinking positively lay not in expecting that every thought would now be positive but in changing the balance in small ways: "Not going over the top positive thinking" (P19). Occasional positive thoughts could then be increased in number gradually so that they occurred more frequently until they began to outweigh the negative ones. With this progressively increasing level of control over negative thoughts participants came to appreciate that the positive thoughts, although sometimes few in number, especially to start off with, were very valuable. The ability to think in a positive way, even if only transiently, then helped with making changes in behaviour: "If one changes one's way of thinking... you can behave in a different way" (P31).

Changing one's thinking from being less negative to more positive was also applied to reducing the times when the tormenting memories of *having been abused in childhood and/or adolescence* were overpowering participants. However, this was much harder to achieve: "What happened to me as a child was a very traumatic and overpowering event.... Consequently the mindset that I took on was very strong and overpowering" (P13). Initially, participants brought out the tormenting memories about the abuse cautiously from under the trapdoor where they had been stored. Then they forced themselves to identify some pleasant events that had happened in their childhood and/or adolescence also and to focus on remembering these instead: "If you really sift through all the bad things, you can find good things. Think about the day * [abuser] took you to see Santa. Not the day she belted you" (P11). Participants found that gradually the length of time in which the abusive events were remembered diminished and the pleasant thoughts became more numerous: "Think about the positive and skim over the bad parts.... I used to think about it [the abuse] all the time... [and] dwell on [it].... [It] used to just... crowd my mind. I don't do that any more" (P11). Participants could now see that life was made up not only of the many tormenting memories but also of good ones:

In my experience, most people... that have had hard lives will think about the real bad experiences they've had.... [They]... see the thorns on the rose

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bush but don't see the rose. You got to look at the rose, too, because it's [life is] a whole package deal. (P11)

Finally, participants were ready to start letting go of the tormenting memories: "You've got to let go. Let go of the past" (P11). The following participant described leaving the bad memories behind, like leaving troublesome baggage behind at a railway station: "Being able to... dropping the baggage off... saying, 'You are left at that station. And I am not picking you up again'" (P30). Letting the baggage go changed the previously ingrained train of thought that had been full of the awful memories onto a new and different track. This way the scars left by the abuse slowly faded.

At the end of learning new strategies participants felt that they had now *got much better as a person* in the personal dimension and they were able to "cope" (P35) much better.

In *learning new strategies*, people without a mental disorder also learnt to put their life with an illness into perspective, for example those with type 1 diabetes (Rasmussen et al., 2007). Those who had been abused learnt to deal with their memories by "choosing not to dwell on horrendous episodes [of abuse] but to hold on to [positive] memories" (Thomas & Hall, 2008, p. 162). In addition, they spoke of "reprogramming" themselves, as described in Herman's (1992) substantive theory on trauma: "I'd consciously impose other powerful images on the feeling (of the father abusing her) - like seeing a waterfall. If they can put SM (somasochism) on you, you can put waterfalls there instead" (p. 203, referring to Saphyre in Bass & Davis, 1988). Like participants in this study, O'Gorman (2009), in his autobiography, had also realised that he had, in fact, survived and stopped blaming himself for *having been abused*.

5.4.3: Step 3: Taking action

After participants in this study had gained a new perspective and learnt new strategies they took action. This consisted of adjusting one's lifestyle, acting to protect others and oneself, helping others and facing other people head on.

5.4.3.1: Adjusting one's lifestyle

The most immediate action was concerned with taking care of oneself, such as eating a balanced diet and getting enough sleep to reduce the possibility of getting another episode and keeping busy. Participants explained that the purpose of keeping busy was to ward off loneliness and to keep one's spirits up, helping with opposing the loneliness experienced as part of *the struggle with relationships*. Keeping busy to "keep my mind off myself" (Twomey, 2005, p. 328) was also important to other consumer-writers.

5.4.3.2: Acting to protect others and oneself

Action to protect others from getting hurt was at the top of the agenda for participants. This achieved part of the social dimension of *getting better as a person*. The most important group that participants said they wanted to protect were their children. They emphasised that they were determined to protect their children with all their powers from any possible abuse by guarding and nurturing their carefree nature, including their sexual innocence: "You are determined... that they are not going to suffer what you've suffered" (P23). In addition, participants pointed out that detecting any possible signs of a mental disorder in their children early would also ensure their ongoing good mental health and happiness: "I am actively watching out for it [signs and symptoms of a mental disorder] because I would like to nip it in the bud so they [my children] don't have to go through [the same as me]" (P35). Through protecting their children in this way participants reduced the worry experienced as part of *the struggle with having a mental disorder*.

Protecting one's children was also important in a study with fathers who had a mental disorder (Evenson, Rhodes, Feigenbaum & Solly, 2008) and in studies with people who had been abused but who had not developed a mental disorder (Aujoulat et al., 2007; Erdmans & Black, 2008; Thomas & Hall, 2008).

However, most of all, participants in this study wanted to protect other people from the terrible hurt and shame they would experience if participants were to commit suicide: "I mean, my kids would be... beside [themselves]" (P4). Therefore they vowed never to go through with *wanting to be dead*, almost completely resolving the doubt about whether it was the right thing to do: "I think of my son then and what it would be like for him when I'm gone. So that he

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keeps me here" (P20). Protecting others in this manner also included other family members and friends: "[They] would all be completely devastated" (P12). Joiner (2005), in his substantive theory on suicide, also quoted someone who said "I couldn't do that to so-and-so" (p. 119) and found that that was an important reason for not committing suicide.

In this study, some actions were also directed towards protecting oneself. Participants found that they had developed a thick skin over time that protected them, for example, from giving in to the compelling force of *wanting to be dead*: "I feel like I'm... bullet proof with regards to suicide... because I had to contend with it all the time" (P26). However, participants most commonly sought to protect themselves from getting hurt in *the struggle with relationships*. This was utilised especially by those who had been battered so severely that they were not willing to take any further pounding. For instance, participants decided against any further attempts to keep in contact with family members after they had yet again been hurt by their rebuffs. The same applied to work: "I never want to work in a situation with bosses or people who are going to treat me like dirt [again]" (P29). Some participants went as far as choosing not to interact in a personal way with anyone at all because all their attempts at not getting hurt, as documented in *the struggle with relationships*, had come to nothing:

I have shut off from everybody.... I just don't want to know people. I don't want to know society.... That's the only way I can resolve the daily struggle [with relationships]... to keep everybody at arm's length. That's the only way I can do it. (P18)

This way of protecting oneself by deciding to shut oneself off from other people differed from the withdrawing in stage one, as the latter had been instinctive. The shutting oneself off here, in contrast, was implemented as a wise measure to protect oneself after long and careful deliberation. It was no longer seen as a negative but regarded as something of value.

Shutting oneself off in this way also applied to the interaction with some health services. Those participants who had no positive encounters chose never to go back: "I gave up on them" (P26). Likewise, damaging treatments were discontinued "because I burned my ass" (P25). Likewise, a decision to "stay away from anyone who has anything to do with the mental health system" was

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taken by a participant in Spaniol et al.'s (2005, p. 87) study on the process of recovery from a mental illness.

Through these protective actions, participants in this study gained power in a quiet way. They found that they could now bypass the fear, shame and self-blame previously associated with *the struggle with relationships*.

5.4.3.3: Helping others

According to participants, another essential action in *getting better as a person* in the social dimension was to help others: "I do feel like I have things to give and I'd like to be able to give them" (P33). Participants realised that they possessed the qualities required of a good helper, such as being kind and compassionate. They also found they were able to understand what other people went through. In the case of other consumers, participants said that they were now able to "appreciate" (P29) them, in contrast to their view when they were still struggling with making sense with what was happening: "Before... you think, 'Oh, people [with a mental disorder] are mad'... but it is not mad[ness]" (P10). This included the understanding that consumers should never be blamed for their behaviour: "When they [consumers] do something wrong it is not their fault" (P10).

Having these qualities set participants up to find people who needed and appreciated their help. These were people who had been disempowered just like them: the infirm elderly, those who had a physical disability and those who, like participants, had mental issues in some way: "There have been a lot of people on the way who I know struggle, too" (P26). Participants helped these people through simple acts like encouraging them in whatever they wanted to do. They also tried to talk to them about how to resolve *the struggle with staying alive*: "I sat up with him to three in the morning" (P11). They endeavoured to help those consumers who were still in mental hospitals to stand up for their rights, thus giving them a boost in power to get through *the struggle with establishing credibility* and *the struggle with having been let down by the mental health system*. Other participants helped other people by setting up support groups: "[I had] the desire... to reach out and help other people" (P27). This ability and capacity to help others then provided participants with a purpose in life: "I kind of think that's what I'm here [for]" (P33). Thereby they had found another way of finding meaning in their life, further progressing towards fully resolving *the*

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struggle to identify any intrinsic value as a person. The same happened to other consumers. They said that helping others gave their life purpose and meaning in studies from Northern Ireland (Connor & Wilson, 2006) and Australia (Edward, Welch & Chater, 2009).

The corollary of helping others was accepting help for oneself. Participants in this study finally realised that there were people out there who were willing and able to help, that it was possible to contact them and that it was important to take up their offer: "Listen to [them], they are trying to help you" (P16). However, in contrast to stage one, participants did not accept this help without any critical analysis as to its benefits. To this end, they attached two provisos. The first proviso concerned the demand to be attended to: "It is important to be pushy... push for help" (P20). The second proviso was to be selective as to the right type of help and the qualities of those who provided this help. The right kind of help consisted of being accepted and treated as the people they were, that is, as human beings who were to be valued equally. Participants were also looking for the right qualities in the people who wanted to help such as being interested in and having a willingness to understand them. Being taken seriously and having the best interests of participants at heart were also important. Participants felt that these individuals, displaying true empathy, could be trusted and followed their advice to the letter: "Have faith in them.... Do what they say you [should] do" (16).

As a result of being helped, participants were very "grateful" (P26). In being grateful they emphasised that they now wanted to "turn it [the help] back" (P26) in some way. Participants in other studies felt the same, for example a participant from a Canadian study said: "I am not just a person here on earth meant to take, take, take, but I have something to give" (Kirkpatrick, Landeen, Woodside & Byrne, 2001, p. 50).

Participants in this study explained that returning the help they had received meant meeting their obligations to society. They saw these obligations as not being a "burden" (P28) to others, where a burden was defined as relying too much on others for help. For example, not being a burden to individuals involved not exposing one's problems unduly so that they did not become worried. Not being a burden to society meant not relying on the government for too much financial help: "So I can carry my weight if that is possible.... That's

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my desire" (P26). By helping in these ways, participants' life gained further meaning, which added to resolving *the struggle to identify any intrinsic value as a person*.

As with participants in this study, other people who had been abused but did not have a mental disorder also "felt compelled to give something back" by helping others (Thomas & Hall, 2008, p. 157). They said that the fact that they had been abused enabled them to provide this help and this gave their life meaning (Burke Draucker & Martsof, 2008).

5.4.3.4: Facing other people head on

This last action was reserved for those people who did not believe them, who devalued and dehumanised them, who were not willing to help them, and who had abused and mistreated them. Another way of *the struggle with relationships* was to show power openly. Participants proclaimed who they were, namely someone with a mental disorder, because they did not care any more about being known as such: "I really don't give a shit. It is like, 'This is who I am. If you don't like it, too bad'" (P12). Any shame they had previously felt had gone. Likewise, participants no longer feared the expected adverse reaction from others and were, in fact, unconcerned with resolving *the struggle with establishing credibility*:

If people can't handle it, honestly, they are not worth knowing. I've come to that point... If someone doesn't like it and they treat me horribly I just say, 'Well, you know where the door is. Hopefully it doesn't bang you on the bum on the way out'. (P35)

Furthermore, assertive behaviour was now also employed in insisting on being treated well in the health field: "I've actually had to sit them [health professionals] down and go, 'The way you are treating me is not helpful. It's making me feel worse'" (P7). Participants no longer accepted health professionals' reasons for abusing their power: "They... have all the justification under the sun but I make them accountable" (P7). As a last resort participants made their concerns known to the top of the mental health hierarchy, often after years or even decades of being mistreated by the system. They were not afraid to challenge the whole the system when they decided to publicise its failings: "[I am] not going to let them get away with it" (P30). Participants had now finally succeeded in gaining sufficient power to counteract being made helpless in *the*

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struggle with having been let down by the mental health system, and they no longer felt trapped, afraid and without hope. Other consumers took a similarly assertive stance towards the health system, as in a study with 38 men in England (Ridge & Ziebland, 2006). The consumer-writer Coleman (Coleman & Smith, 2007) insisted that "to be assertive in your relationship with the services... is your right" (p. 7).

Lastly, participants in this study undertook the most difficult task, that of sending their perpetrators packing by facing them head on:

I looked straight at him, and I said, 'No, I want you to hear this and look at me.... What I want you to do is just go and get out of my life altogether. Go, get out'. And that's the last I ever heard from him. (P30)

5.5: Being at peace

The conclusion to the basic social psychological process of *transforming oneself*, encapsulated as *being at peace*, signalled to participants that the long journey towards resolving the basic social psychological problem of *life being a struggle* was complete: "There is no doubt about it, it has been a struggle... [to have got] to that resolution and peace" (P30). *Being at peace* was described by participants as *being at peace* with the fact that they had a mental disorder, with their place in society, and with who they were as a person.

5.5.1: Being at peace with the fact that one had a mental disorder

"I am at peace with it now" (P11) meant that participants had finally resolved *the struggle with having a mental disorder*. They now felt in tune with it: "I am very much... in tune with my illness" (P11). As a consequence, participants were finally liberated from its disempowering grasp: "I am not trapped any more" (P33). They had taken power away from *having a mental disorder* in that it no longer ruled their life as it had previously done: "Normally in the past it [an episode] would have stopped me absolutely [from] functioning completely, and I can't let that happen. It's still sad and I still feel it but I have to carry on" (P30). Participants also realised that they did not have to fight *having a mental disorder* any longer, as they had done in stage one. They said that this had become irrelevant and was, in fact, counterproductive: "Fight[ing] against it [having a mental disorder]... doesn't work. Fighting against it... pushes more at you" (P30).

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Other consumers felt similarly. In a Canadian study with 10 participants they expressed that they were now able to exert sufficient power so that they were no longer controlled by *having a mental disorder*: "You don't have to let your illness run your life" (Kirkpatrick et al., 2001, p. 50). Likewise, in an English study on how people give meaning to recovery from their mental disorder, they also did not consider it helpful any longer to see the mental disorder as an enemy that needed to be fought (Ridge & Ziebland, 2006).

Participants in this study now fully understood that *having a mental disorder* could not be banished as they had tried to do so strenuously in the past. Instead they had come to terms with it: "I've learnt to live with it" (P32). Learning to live with it meant enduring it as it was part of life. Enduring it entailed tolerating being incapacitated while an episode lasted although they knew that this incapacitation was not nearly as severe as it had been during *the struggle with getting through daily life*.

As a result of *being at peace* with the fact that they had a mental disorder participants said they felt calmer in themselves, their thinking processes had become clearer and their "negative, fatalistic thinking, that was with me constantly.... went away" (P7). They found that the new strategies they had learnt largely worked and kept them relatively safe from any unwanted, uncontrollable, catastrophic slide back into *having a mental disorder*. They said that they had now become content with how they handled their life: "I have to manage how I am living. And that's... all I can do. And that's all anyone can do" (P20).

Some participants stated that if they had known at the beginning how long and arduous the journey of *transforming oneself* turned out to be they would definitely not have chosen to take it. Others doubted that it had been worth it: "If I could have it over again... I don't know that I'd do it. I don't know [if]... that was worth it" (P32). However, most participants who were now at peace could see that resolving *the struggle with having a mental disorder*, although it had taken a terrible toll on them, had also had a good side. For example, it had given them strengths and capabilities they might otherwise not have had. They also knew that they were in a special position to help other people: "[You] know where they [other people] are coming from... and so... there is actually some great positives in it [in having a mental disorder]" (P26). This insight taught them that their suffering had not been in vain: "I am not going out of here, with this suffering

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and crap, for nothing.... It's got to be worth something.... That's how I've got to look at it" (P30). They pointed out that this realisation made them feel that they were in fact lucky to have a mental disorder as it provided them with a richness that they could not have gained otherwise, richness, not in a material sense, but in a spiritual one: "That's richness, isn't it? How rich can you be in your soul and spirit? We are so lucky. I am lucky.... You might feel mad but we are very lucky" (P30). This realisation made them rejoice: "I am glad I've got a mental illness actually. That's all I can say... 'Hurray, I've got a mental illness!'"(P30). Caswell (2005), a consumer-writer, also commented on the richness of his present life: "I'm now experiencing a richer, fuller life that is better than I could have imagined" (p. 140).

5.5.2: Being at peace with one's place in society

Being at peace also referred to being at peace with one's place in society: "I am [now] at peace with the world" (P30). Participants in this study had finally resolved *the struggle with relationships*. They were now confident in their dealings with others. They also no longer felt responsible for and, by extension, did not blame themselves, for relationships failing. They knew they were far more astute in judging others and had become more cautious about whom to trust. At the same time, they realised that they were capable of holding down long-term, loving relationships. However, some had become reconciled to the fact that they would remain on their own and had gained "peace and quiet" (P18) that way. Many had adopted animals instead of mixing with people as animals never failed to appreciate them.

5.5.3: Being at peace with who one was as a person

For participants, *being at peace* with the fact that they had a mental disorder and with their place in society, now coalesced into *being at peace* with who they were as a person. Participants' realisation that they had positive attributes had given them a positive identity. By cementing this to the fullest they had found meaning in their life, which fully resolving *the struggle to identify any intrinsic value as a person*. They knew they were capable people and their self-esteem had taken root and grown. Participants were astonished at the transformation they had achieved, from the terribly low points when they had been powerless, a "nothing"

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(P30), to now being someone who could influence and have authority over how to act and what to do: "[It] took me a long time to actually believe that you can get somewhere... from nowhere" (P5).

At the same time, participants had succeeded in preserving their humanity, meaning that they had not gone down the path of adopting the same values and ways as those people who had not believed them, who had devalued and dehumanised them, who had not given them any help and who had abused and mistreated them. In addition, they found that by refusing to take part in maintaining the existing power structure of society, they had preserved their integrity. Despite all the horrible experiences in their lives and the great struggles they had had to endure their decency and honesty as human beings had been left intact. They knew that they could be proud of themselves and hold their heads up high. This was possibly their greatest triumph and contributed most to their "sense of inner peace" (P31).

Participants in this study were now ready to go out and do all the things they had wanted to do: "Wanting to do things in life, 'I want to do this, 'I want to do this, I want to do this, I want to do this'. So, I want to make up for lost time" (P13). They were now able to engage in pleasurable activities, such as gardening, swimming, bush walking, listening to music, writing literature, painting or doing craft work. Although their life was still far from perfect they could readily see improvements and this made them change from being pessimistic about the future to someone who was more hopeful: "I became a glass half full person. Whereas previous to that I had always been a glass half empty [person], a pessimist" (P35). However, participants remained cautious as they were aware that *being at peace* was fragile and that it could revert to *life being a struggle* at any time with the advent of any further disastrous experiences: "I've actually passed the stage where life is a struggle. Right now I feel I am sitting on the top of that mountain, [but it] could go either way... I could be pushed right back down to square one [again]" (P22).

Other consumer-writers similarly described how they were now at peace with who they were as a person (Twomey, 2005) and how they could now "rejoice at my good fortune" despite having gone through many hardships (Rowe & Rowe, 2005, p. 173). This also included people without a mental disorder who

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had been abused. They described that they had reached "a point of peace and life satisfaction" (Thomas & Hall, 2008, p. 156).

As with *having a mental disorder*, participants in this study knew that *wanting to be dead* still lingered and would never go away. However, they had now learnt to live with it: "It's a struggle living but I've got used to it" (P20). Although sometimes, when life became hard, committing suicide remained an option because it also brought peace with it and therefore participants regarded it as the right thing to do on the odd rare occasion: "I just want to be able to rest and relax and... be at peace" (P6).

Lakeman and FitzGerald (2008) also found in their review of 12 qualitative studies on how people live with suicidality that "struggling against a desire to give in to suicide... did not diminish in time" (p. 121). Aldridge (1998), in his substantive theory on suicide, cited a consumer who thought he could achieve peace through committing suicide: "All I wanted was peace" (p. 153).

5.6: Summary

The basic social psychological process of *transforming oneself* mapped out the journey participants took to change themselves from being helpless, powerless, and, in their eyes, worthless individuals, to being confident and assertive persons who knew who they were and what they wanted, and who had the mental energy and strength to achieve what they had set out to do, to resolve all aspects of the basic social psychological problem of *life being a struggle*.

Participants in this study had travelled along this journey in two stages, which were separated by a turning point. In the first stage, entitled *trying to deal with life being a struggle*, participants started out by *not wanting to deal with anything*. When this became no longer feasible they decided to *try to get on top of having a mental disorder* as this seemed to be the most obvious difficulty in their life. However, despite enormous efforts they could not get on top of it and were left powerless. This plunged them into an abyss of despair, from which the only viable exit was *the turning point*.

The turning point was identified as providing the transition into stage two. It was precipitated either by a distinct crisis or brought about by *empowering conditions*. These enabled participants to take matters into their own hands and

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for the first time feel they had any power. This was the springboard that catapulted them into stage two.

In stage two, participants in this study decided to start afresh and refocus their attention away from *trying to get on top of having a mental disorder* to what was central to the basic social psychological problem of *life being a struggle: the struggle to identify value as a person*. They identified this as *getting better as a person*. *Getting better as a person* had a personal and a social dimension. Both were attained in three steps: gaining a new perspective, learning new strategies and taking action. Stage two was fulfilled by participants *being at peace*. By *being at peace, life being a struggle* had finally been resolved.

Importantly, a selection of literature showed that people who did not have a mental disorder but whose life also was a struggle because they had been abused in childhood and/or adolescence or were suffering from chronic physical health conditions were using many similar ways to participants in this study to deal with their lives. This revealed that how participants went about dealing with *life is a struggle* was not "maladaptive" (Harper et al., 2008, p. 367) but was also used by many other people.

However, having largely resolved the basic social psychological problem of *life being a struggle* participants in this study were cognizant of the fact that *being at peace* could easily be broken with the advent of any new disasters. Participants realised that a *transformation of society* also had to occur. This *transformation of society*, as will be explored in the next chapter, would then make the deep inroads needed to countenance and then banish once and for all the basic social psychological problem of *life being a struggle*. However, participants realised that it was not under their control to change these *disempowering conditions* and that other people have to step in to advance a *transformation of society*.

CHAPTER 6: EMPOWERING CONDITIONS - THE TRANSFORMATION OF SOCIETY

6.1: Introduction

The fourth part of the substantive theory of *transforming oneself and society to resolve life being a struggle* contains conditions that also empowered participants. Empowerment here meant allowing others sufficient power or influence and authority so that they are "equal" (P22) in value and standing to other people. Participants in this study explained that they could only become equal in value and standing to others if the existing power relationship between them and society was rearranged. Participants maintained that in order to achieve this rearranging, society also had to be transformed, or changed significantly, so that it perceived and treated consumers as fellow human beings: "That is what it is all about, humanness" (P30).

The transformation of society was significant in this study because it had the capacity to directly influence or even prevent the *disempowering conditions* from occurring. If a *transformation of society* were accomplished, the basic social psychological problem of *life being a struggle* would not be brought on and resolving it through the basic social psychological process of *transforming oneself* would not be necessary. To a minor degree, they also positively influenced the basic social psychological problem of *life being a struggle* and the basic social psychological process of *transforming oneself*. *The transformation of society* therefore showed the way forward to improve the lives of consumers.

Other consumers concurred and they too wanted to be seen as a "fellow human being" (Shattell et al., 2007, p. 280). Deegan (1996) pointed out that to achieve this required a change in society.

Participants in this study said that their vast experience, their "career of being mentally ill if you can call it that" (P22), put them in the driving seat for knowing how a *transformation of society* could be achieved. They identified two conditions to this end: 1) *treating consumers with justice* and 2) *providing effective help*.

6.2: Treating consumers with justice

With this first condition, participants asserted that treating them with justice would uphold principles of fairness and give them the rights and opportunities to

be equal citizens. *Treating consumers with justice* would particularly address *the disempowering condition of society letting the perpetrators getting away with their misdeeds*. Participants would get justice or "redress" (P18) for the abuse and mistreatment perpetuated against them. Being treated with justice was so important to participants that they called it a basic human need: "Human beings have certain needs and one of them is to be treated... with justice" (P22).

To participants, *treating consumers with justice* means to apply laws equally to everyone, irrespective of whether someone has a mental disorder or not. As an example, they pointed to the principle of regarding everyone as innocent unless proven guilty. They insisted that this principle has to be enforced with regards to consumers also: "The public should be protected from dangerous people whether they are mentally ill or mentally well, but the law should protect the innocent, and therefore harmless, which many mentally ill suspects are" (P22). Participants made the point that it is important to enforce this principle because to them the presence of any illness is irrelevant to whether someone is guilty as charged or not: "Using the state of the person's health, mental or otherwise, to judge [someone in a law court]... is like using eye colour or length of hair. It's irrelevant" (P22). Other consumer-writers agreed: "[We] need to be accountable for our behaviour - just like everyone else" (Mead & Copeland, 2005, p. 326).

Furthermore, participants in this study said that the attitude of judges has to be impartial so that the outcome of trials is fair. They explained that this would largely prevent perpetrators of criminal acts and those who had abused participants as children and/or adolescents *getting away with* what they had done. In addition, participants emphasised how important it is for any new laws to enshrine equality. They gave the example of a relatively new law in Australia at the time of the interviews that gave both parents equal responsibility for their children after a separation or divorce. The principle of equality portrayed in this law was vital to participants because many had lost custody of their children or felt threatened of losing this custody due to *having a mental disorder*: "To me it [equal responsibility for children guaranteed by this law] should be mandatory" (P26).

Beyond the legal system, the concept of justice encompasses social justice. The importance of social justice was stressed by other consumer-writers

(Deegan, 1997). Social justice in this study is concerned with discrimination or unequal treatment. Participants especially mentioned discrimination with regards to housing, where neighbours often protest if housing for consumers is to be provided nearby. At the workplace, participants did not want to be discriminated against by being dismissed from their jobs on the basis of *having a mental disorder*. They asked for equal opportunities with regards to being employed and promoted.

Both legal and social justice could be fostered by changing society's attitude towards consumers to counter *society not wanting to believe what consumers said, society devaluing and dehumanising them* and *society not willing to help them*, as detailed in chapter three: "Minds need to be changed here. They need to be. Plenty of minds need to be changed" (P22). For instance, participants maintained that if society's mind were changed, discrimination at the workplace would be reduced because employers would gain an understanding of the fact that participants might need to take a few days off work when sick with their mental disorder. Furthermore, employers would become more flexible to accommodate sick days by allowing work to be done at home or by allocating some of it to colleagues. Participants also pointed out that discrimination with regards to housing could be overcome if the community's mind is changed about consumers moving into their neighbourhood.

Participants proposed ways of how people's minds could be changed. For them, the first and most important way is through a scientific discovery of the cause of mental disorders so that these disorders are seen just like any other medical condition: "That will be the biggest breakthrough ever" (P23). They hoped that this scientific breakthrough would include tests, such as blood tests or brain scans that would prove the existence of mental disorders. Participants explained that only through these scientific discoveries would mental disorders lose the stain of stigma and be acknowledged as legitimate and valid physical illnesses. Moreover, their disorders would no longer be regarded as mere 'mental states' indicating that they were just 'in the head' and made up, as in 'mental state assessment', a term used in the assessment of consumers: "Then you will get people acknowledging an illness instead of a mental state" (P23). Participants believed that by finding the cause or causes of mental disorders, including

impartial tests, *society not wanting to believe what consumers said* would largely be obliterated.

Another way of changing people's minds was through increasing public awareness. Participants hoped that increasing public awareness would decrease *society devaluating and dehumanising consumers*. They said that the general population should be made aware of how many consumers are living successful lives amongst them. They pointed to prominent people who had come out in public with the fact that they had a mental disorder, proving that leading a successful life was possible: "[They] have done more for mental health in that one action than... many [other] people can achieve" (P12). Participants argued that even less prominent people who had a mental disorder could play a valuable role in increasing public awareness by also telling others about it: "There's doctors, nurses, there's lawyers, I mean, there's people from all walks of life [who have a mental disorder], which, perhaps, they should let people know that" (P3). Participants in Malins et al.'s (2006) study, which was part of the Consumer Evaluation of Mental Health Services project in Australia, agreed with participants in this study in pointing to the usefulness of educating the public on "what it is like to experience a mental illness" (p. 200).

Moreover, participants in this study said that the fact that consumers are fully able to lead successful lives should be emphasised by the media, for example in documentaries and chat shows: "If they [the media] show people [consumers] that are integrated into what everyone perceives as normal, it [living with a the mental illness] won't be seen as such a bad thing" (P35). Most importantly, they said that the media has to increase awareness about the fact that most consumers are not dangerous people. This would counteract the deep-seated fear in the general population: "The hysteria often whipped up in the public mind [through the media]... should be outlawed. The reporting is false and does enormous damage [to consumers]" (P22). Participants suggested that guidelines have to be introduced and enforced through anti-defamation laws with attendant penalties to prohibit the depiction of consumers as dangerous. They explained that this could be done if, instead of concentrating on the few criminal acts of a small percentage of consumers, the media put these into perspective and show the real facts. These real facts are that, although a small number of consumers have been involved in unlawful actions, they are vastly outnumbered by healthy

people who commit crimes: "But... the media just don't make that obvious" (P35). Furthermore, participants pointed out that, although a few people with mental disorders have committed crimes, all others should not be seen in the same light:

The public is led to believe that because one mentally ill person murdered someone, all the mentally ill are capable of murder. It is a big mistake to think that there is any connection between one mentally ill person and another [in this respect]. They are as different from each other as the mentally well are. (P22)

The depiction of dangerousness and its representation in the media was also a daily occurrence for other consumers (Repper & Perkins, 2003, referring to Rose, 1996). However, evidence that the label of being dangerous was made up and not based on fact, as participants asserted, came from a number of extensive studies. For example, in England and Wales The Confidential Inquiry into Homicides and Suicides by Mentally Ill People chaired by Dr William Boyd (1994, cited by Crepaz-Keay, 1996), called the Boyd Inquiry, found that of 2000 homicides in the three-year reporting period only 34 were committed by people who had been in contact with mental health services. Nine percent of these, or only three cases, involved killing a person unknown to them. Most of the perpetrators with a mental disorder had taken their medication and had received adequate mental health care. The *Boyd Inquiry* concluded that it was therefore unclear whether the homicides were due to a mental disorder or due to other causes.

Other research into the dangerousness of people with a mental disorder found that only a small subset was violent (Link, Andrews & Cullen, 1992). On closer inspection only those subjected to certain psychotic symptoms were identified. A study in Israel (Link, Monahan, Stueve & Cullen, 1999), where 4914 people with a mental disorder were interviewed on whether they had been involved in fighting or had used a weapon, found that some people with a mental disorder felt so threatened by other people, due to their psychosis, that they thought it was justified to defend themselves in a violent manner. Others had been prevented by their psychotic thinking from applying internal controls over any violent behaviour. For example, they believed that God had commanded them to kill someone. Based only on a small subset of consumers being violent,

Link, Monahan et al. (1999) conclude that the public's fear of people with a mental disorder remains unjustified and that the stereotype of dangerousness is not based on fact. They point out that if society wants to exclude people on the grounds of dangerousness they should be looking to exclude men, teenagers and people with low educational levels. Rosenman (1994) writes most poignantly that "argumentative drunks, sedative-abusing adolescents and wife-beating men pose greater risks and dangers than the average mentally ill person" (p. 561).

As participants in this current study noted, the view that people with a mental disorder are dangerous is then enhanced in the media. For example, Williams and Taylor (1995), in analysing 83 Australian newspaper articles with a subject matter of mental health, found that people with a mental disorder were stereotypically perceived as violent. A distorted image was created of those with a mental disorder. Moreover, the Glasgow Media Group (Philo, 1996) showed that 40% of the general public had been influenced by the media to believe that schizophrenia was associated with violence. The influence of the media was even overriding belief systems gained from direct experience with non-violent consumers.

Participants in this study asserted that if the general population became aware of the real facts, the devastating effects of the public's disempowering views, values and behaviours on consumers would be revealed. For example, *wanting to be dead* would then be taken seriously: "You know the facts yourself that every seven hours someone checks out [in Australia]... and they are no different from me because I could have or should have been one of them at any stage" (P26). Participants maintained that health professionals would also become aware of their lack of understanding of participants' experiences, of their own misconceptions and of their abuse of power.

The last way of changing people's minds was through education. Participants emphasised that the public, including health professionals, have to be educated how to interact with consumers. For example, children in schools should be taught "compassion, fair play and correct treatment of others [and] that it is important to be considerate of other people's feelings" (P22). Participants explained that education on signs and symptoms and how to deal with them is only useful for potential consumers and their families so that they can recognise

them and seek treatment. However, it does not change the minds of the general population.

Participants pointed out that in order to educate the general population it is important to engage them on an emotional level by emphasising the "human perspective" (P30). They explained that emphasising the human perspective involves both describing consumers' experiences and what they are going through. Giving hypothetical examples of how the public's own family members could be affected if they had a mental illness is also useful: "That's how I do it to them.... I say, 'So, tell me, if this is your wife [with a mental disorder] and you had children [with a mental disorder], would you be saying that?'" (P30). Furthermore, participants in this study identified how charismatic leaders had changed the minds of large numbers of people through education by reaching for people's hearts: "Human nature is the first consideration in bringing about change, and wisdom and patience are required in persuading people" (P22).

Participants hoped that when the general population became aware and was educated about consumers' experiences and what they have gone through, including the experience of being on Community Treatment Orders and residing in locked wards of mental hospitals, it would be possible to reduce the violation of human rights occurring under these circumstances. They further hoped that the public might then even protest for human rights to be upheld.

6.3: Providing effective help

The second condition required to bring about a *transformation of society* is to identify what type of help is effective and how it can be provided. As will be seen, providing effective help principally addressed *the disempowering conditions* from chapter three of *having a mental disorder, society did not want to believe what consumers said, society devalued and dehumanised them, society was not willing to help and society mistreated them. Providing effective help* would also prevent further instances of abuse in childhood and/or adolescence in other generations.

Participants emphasised that finding a medical cure for mental disorders was the most important way of helping them because they knew this was the only way of combating *having a mental disorder*: "If there was a cure tomorrow, I'll be lining up for it" (P17). By medically curing mental disorders, life would not

be turned into a struggle and they would not have to *transform themselves*. *The transformation of society* would also not be necessary. Repper and Perkins (2003) have also come across consumers who think the same way: "The continued search for a cure has been a motivating force in the lives of many people [with a mental disorder]" (p. 96). However, in the absence of a medical cure, participants realised that a "cure is only found in society" (P7). The ways of finding a cure in society is doing one's duty, standing by consumers and showing compassion.

Doing one's duty is seen as something that ought to be done. Participants explained that they regarded it as a duty to treat every person who needs help equally. If treated equally participants would be valued the same as other people who receive ready help when required. *Society's unwillingness to help* would thereby be counteracted. Part of doing one's duty, according to participants, lies with governments: "[The] government has a duty to... improve people's lives" (P22). They reasoned that governments have a duty to improve people's lives, in this case through *providing effective help*, because they regarded this as a hallmark of a civilised society. Participants insisted that, although everyone has to help themselves as much as possible, as they had done in the basic social psychological process of *transforming themselves*, anyone who requires help should receive it for the sole reason that they are members of this society. Van der Kolk, McFarlane and Weisaeth (1996) agreed: "People have the right to expect support when their own resources are inadequate" (p. xi).

Participants explained that governments could do their duty by providing effective health services. They called for a transformation of the present health system to one that is "sane, decent, compassionate, consumer friendly system [and] in line with... [21st] century thinking" (P22). The consumer-writer Deegan (2005a) also affirms the same call: "We say no to second-class health care" (p. 67). Participants realised that bringing about this improved health service would then tackle the *disempowering conditions* related to health care, as covered in chapter three.

Participants outlined what they regarded as the provision of effective health services. Firstly, it requires making adequate funding available. This is also the view of the Mental Health Economics European Network who insisted that adequate funding is at the root of a good mental health system (Knapp et al,

2007). Participants in this study called for extra funding for mental health services so that they would get the same attention as other health services: "I mean mental illness is a growth industry... it is just increasing and increasing and increasing... but it's just not prioritised" (P12). They said that prioritising mental health services and thereby providing a percentage of funding equal to that of general medical services would allow the tearing down of the dehumanising and prison-like mental hospitals. Participants recommended building units of the type now found in modern retirement villages instead. They suggested that these units should be centrally located with easy access to "transport... shopping centers... [and] natural vegetation" (P22) and include libraries and other educational facilities with computers. They should also include amenities for socialisation, opportunities for craftwork and other activities such as holiday camps for younger consumers. Participants also thought of locating "Centres of Excellence" (P30) there to run intensive programmes with a focus on preparing resident consumers for living independently in the community. To this end, staff of these Centres of Excellence should consist of a team of dedicated specialists: "No one should be considered too insane or impossible to help" (P22). A study interviewing consumers on what they need in crisis added that they wanted mental hospitals to have "homelike surroundings, [be] comfortable... warm and friendly" (Agar-Jacomb & Read, 2009, p. 107). Participants in Borge and Fagermoen's (2008) study on their experiences of hospital treatment expressed their desire for the hospital to be "open and free" (p. 197).

Furthermore, targeting funding to what participants in this study said they required would shift financial and human resources away from the current narrowly based medical services to broad-based services in the community. Many of these services in the community are now provided by non-governmental organisations (NGOs) as laid out in the *Western Australia's Mental Health Strategy 2004-2007* (Office of Mental Health, 2004). In Western Australia, 23% of consumers in contact with mental health services reported having used specialist NGOs (Department of Health, 2010). However, the funding source of NGOs is only guaranteed for the length of the contract with governments and their services can be discontinued for a variety of reasons without a replacement being made available, as participants had come across.

Participants pointed to the importance of providing accommodation in the community. They explained that having somewhere to stay is particularly important for people like them, even if it meant that the equality principle was violated: "Everyone knows how important it is to have a house, but to a mentally ill person it is even more important. It is vital" (P22). Accommodation had to be tailored to their needs. For example, some participants were very happy with hostel accommodation because staff "actually look after you" (P3). Others wanted housing where they would live alone so that they could recover from the turmoil of the basic social psychological process of *life being a struggle*. They said that, above all, they wanted accommodation that was affordable and had security of tenure.

The provision of suitable accommodation was also important to other consumers. A report on housing needs of people affected by mental health problems in Perth, Western Australia, called for accommodation to be "secure and safe" (Kadmos & Pendergast, 2001, p. 7). A study on the nature of recovery as lived in everyday experience quoted participants as wanting accommodation where they could "relax and find peace" (Borg & Davidson, 2008, p. 136). Living alone was also mentioned as being important in a study on housing following discharge from hospital (Browne et al., 2008).

Participants in this study further outlined that broad-based services in the community should include the provision of sufficient numbers of case managers. They said that case managers could help them with *getting better as a person* by taking up a role similar to that of a life coach: "[This] is what... would... help me the most" (P20). The roles of case managers were listed as watching over them, ensuring their safety and acting as intermediaries with the health system. Additionally, case managers should be backed up by home help services that would assist with everyday tasks such as collecting medications from the chemist, shopping and cleaning.

Broad-based community services were also seen as important for providing help for families. For example, those participants who had been abused in childhood and/or adolescence emphasised the importance of preventing similar abuse from occurring by providing help to those at-risk.

Other consumers also had in mind similar roles for case managers, such as being "a guide or facilitator" (Shattell et al., 2007, p. 281) and a "coach" (Hardy,

2008, p. 39). A call to "invest in families... at risk" (Bloom, 1997, p. 229) was also made. Furthermore, with regards to health services, a need to enquire routinely and systematically into a history of childhood abuse has been identified in many studies (Ford & Fournier, 2007; Goodman et al., 2001; Humphreys & Thiara, 2003; Jacobson & Richardson, 1987; Janssen et al., 2004; Krabbendam et al., 2004; Marley & Buila, 2001; Nilsson et al., 2005). Education for health professionals (Agar & Read, 2002; Bengtsson-Tops & Tops, 2007) with "clear information on their role in extricating... [affected patients] from violent circumstances" (Rice, 2009, p. 847) has been seen as important as a basis for pursuing legal action (Goodman et al., 2001) and providing trauma-based treatment (Harper et al., 2008).

Participants in this study believed that their suggestions for broad-based community services would be much more cost effective than the current medical services: "It will cost less, especially in the long term, than the present system" (P22). They asserted that, by using broad-based community services, the severity of their mental disorder would be reduced and they would be less likely to commit suicide. Therefore, they argued, expensive medical services would have to be used less and access to mental health specialists would be freed up. Adequate communication channels within and between services could also be more easily established, as was brought up in *the disempowering conditions* in chapter three. Participants thought that these services would then also be reasonably priced: "I need help that I can afford" (P33).

Participants stated that another way of doing one's duty towards them lies with individuals in society. For example, participants wanted to be treated with politeness and courteousness just like any other person. In addition, they stressed the importance of following three principles, aimed at counteracting some of the *disempowering conditions* from chapter three, in particular *society did not want to believe what consumers said* and *society devaluing and dehumanising them*. These principles were being listened to, being believed and to be told the truth.

Participants explained that other people, but especially health professionals, have to listen and "to look where we've come from" (P30). To look where participants had come from would be revealed by asking what had happened to them: "Wouldn't it be nice to say, 'What happened to you?... What went wrong?'" (P30). Participants stated that finding out what had happened to

them and what had gone wrong would then unlock the many events recounted in the *disempowering conditions*, especially their background of abuse: "I tell you what happened to me. Somebody fucked my life up" (P30). By omitting to ask what had happened to them and what had gone wrong was "derogatory... [and makes] you feel so to blame" (P30). Furthermore, in order not to feel blamed participants wanted an explanation as to what physical changes had occurred in their brain and they wanted an assurance that these changes were part of a recognised disorder. They said getting a psychiatric diagnosis told them that they were not "mad" (P10) after all: "[Getting a diagnosis] was a HUGE relief... Finally I felt there was a reason for what had been going on" (P7). They explained that not feeling blamed would be deeply "consoling" (P10) and would contribute to the realisation that they did not need to commit suicide after all: "Then why do you need to die?" (P10).

Participants stated that looking where they had come from would also lead to an increase in other people's understanding. For example, if health professionals were looking where participants had come from they would get an understanding of how manifestations of healthy feelings and behaviour differed from those pertaining to a mental disorder.

The second principle participants highlighted as important in doing one's duty towards them was the principle of believing what they said. This would counter *society not wanting to believe what consumers said*, also explored in chapter four:

The... most... important thing to do [is]... to BELIEVE them [consumers]. The mentally ill tend to be more truthful than other people, not less, and yet almost everything they say is doubted.... Remember, stranger things tend to happen to the mentally ill than [to] others. Of course they CAN lie like everybody else, but it should not be assumed that just because something sounds weird, it didn't happen. (P22)

Participants in this study pointed out that believing what they said has the consequence of turning the spotlight on the *disempowering conditions* and the need for addressing these. For example, they explained that if they were believed, health professionals would realise that many mental health signs and symptoms present as superficial manifestations of deeper-seated horrors: "If they [health professionals had] discovered what was going on internally [mentally] in you, you might not continue to have these outside symptoms" (P30).

Furthermore, abusive events would be investigated: "Check out what the people [consumers] are saying.... We are not all paranoid" (P5). Then action could be taken, such as providing help with taking abusers to court or, at least, with issuing moving-on orders.

Telling the truth was the third principle participants listed in doing one's duty towards them. For example, they wanted to know the truth about the current limited state of psychiatry as a science, about the uncertainty of identifying causes of mental disorders and the inadequacy of many treatment methods. Participants pointed out that being told the truth is so important because it acknowledged them as someone who was able to think rationally. Moreover, they insisted they had a right to know the truth about what was happening and what was being done to them:

If there is a reason for all the damaging substances [medications] he [the doctor] is making me put into my blood, don't I have a right to know what it is? Shouldn't he discuss it with me? If they know something I don't, why don't they share it with me? I have to suffer the consequences. (P22)

Lastly, participants wanted to be told the truth because it constituted the first plank in finding solutions to their problems. Participants knew that doing one's duty towards them by listening to them, believing what they said and telling the truth would transform many clinical practices into "top quality" (P22) care.

Other consumers also stressed the importance of similar practices. For example, participants in a Norwegian national survey on psychiatric outpatients' experiences with specialised health care delivery asked to be treated with politeness (Oltedal, Farratt & Johannessen, 2008). Furthermore, other consumer-writers mentioned the same three principles as participants in this study. They wanted to be listened to (Norwood, 2007; Short, 2007). Participants in a study on consumers' experience of the therapeutic relationship wanted to be asked about what had happened to them (Shattell et al., 2007). Likewise, getting a diagnosis had provided "tremendous relief" because "finally [I] had an explanation for my unrelenting... misery" was mentioned by a consumer-writer (Rowe & Rowe, 2005, p. 75). Consumers in other studies also said they want to be believed (Happell, 2008; Humphreys & Thiara, 2003) and to be told the truth (Hardcastle, Kennard, Grandison & Fagin, 2007; Shattell et al., 2007).

A second way to finding a cure in society is to stand by consumers. Repper and Perkins (2003) agreed: "The common denominator of recovery is the presence of someone who 'stands by' you" (p. 54). Participants explained that supporting them, giving them solace, genuinely caring and showing love were ways to stand by them. These were actual examples participants had encountered. Participants asserted that in standing by them they were seen as being worth something in the eyes of others. That empowered them.

Participants revealed that support did not entail complex acts of practical help or the solving of their life problems. Instead, merely "be[ing] there for me" (P28) was at its core. Being there showed a readiness to help in simple ways, such as making an effort to understand participants, being concerned about their wellbeing by ringing them up to see how they were going and by being interested when they wanted to talk about mental health issues. Visiting them in hospital and accompanying them to meetings with health professionals was another way of being there: "Just giving... that little bit of leg up. Not much at all.... It doesn't take much" (P30).

The need for support (Browne et al., 2008) and in particular being there was also mentioned as important by other consumers in other studies (Agar-Jacomb & Read, 2009; Harper et al., 2008). Being there was described by a consumer-writer as simple acts of "sit[ting] quietly and... be[ing] with a person who is suffering" (Deegan, 1997, p. 17). Making a phone call (Happell, 2008), sending a letter (Joiner, 2005) or a get-well card (Hughes et al., 2009) were specific acts of support identified. A review of studies on how people live with or get over being suicidal (Lakeman & FitzGerald, 2008) and a substantive theory on this subject (Joiner, 2005) found that even suicidality was reduced with simple support like this.

Some participants in this study indicated that fellow consumers were also supporting them in this way and that it was important to pay them a wage so that they could provide these services on an ongoing basis. Participants felt that in having the opportunity to listen to their fellow consumers' life experiences made them realise that they were not the only ones whose *life was a struggle* and that they could, indeed, survive it: "[If] they [other consumers were]... able to make it, then maybe I can, too" (P7). Furthermore, they found that fellow consumers, occupying a unique position, could assist them in getting through the basic social

psychological process of *transforming oneself* because they had already gone through the same process themselves: "[They are] giving [you]... all these tools and tips... championing you, pulling you through" (P30).

The importance of peer support was also emphasised in the literature. For example, an Australian study on mental health peer support for hospital avoidance and early discharge (Lawn, Smith & Hunter, 2008) and statements by consumer-writers who run peer-support groups (Mead, Hilton & Curtis, 2001) highlighted its importance. Employing consumers (Hutchinson et al., 2006) with appropriate remuneration (Townend, Tew, Grant & Repper, 2008) to provide peer support was also called for elsewhere (Happell, 2008; Malins et al., 2006).

Another way of standing by consumers was to give solace. Some participants in this study found this in religion. They said that they received solace when explanations were forthcoming in religious writings that helped them understand what they were going through: "It doesn't matter what you go through there is... something there [in the writings] that'll talk to you" (P9). Some participants, especially those who had been abused as children and/or adolescents, found solace through the protective mantle religion provided. They pointed out that religion had protected them by defending them when they had been helpless and that many further abusive instances had thus been avoided. They explained that praying had stopped the memories of the abuse from haunting them. They also knew that they had been looked after by religion even in the bad years by, for example, being rescued from becoming as evil as their abusers: "I think it is a spiritual thing when you get abused.... Their [the abusers'] evilness or their bad spirit comes into you and... goes into your mind.... I am so glad that * [divine entity] rescued me from that" (P13). Participants also remembered when they had been saved in the act of committing suicide. They said that "some sort of divine intervention or providence" (P7) had guided other people to discover them before they had died.

As a result of the solace forthcoming from religion, participants said that they were also able to get through the basic social psychological process of *transforming oneself* better. They recounted that religion had taught them to be patient when they were suffering and to accept whatever had happened in their life. Religion also kept up their hope even though hope had often been sorely tested in the many despairing years. Religion strongly advised against

committing suicide, which further supported them in deciding not to go through with it.

Other consumers had also found "solace in religion" (Repper & Perkins, 2003, p. 99). Two studies in particular examined the role of religion. Awara and Fasey (2008) asked whether spirituality was worth exploring in psychiatric out-patient clinics and found that religion "provided comfort and hope, [had a] positive impact in improving their [consumers'] coping strategies with life vicissitudes [and] gave them a new meaning to life" (p. 189). Bhui, King, Dein and O'Connor (2008) looked at religious coping with mental distress and identified that consumers found "strength, knowledge, wisdom and guidance" in religion and that it had "helped... in a difficult situation" (p. 146). Furthermore, religion also assisted with understanding that "you are not responsible for everything" in a study on consumers' views of self-help strategies (Lucock et al., 2007, p. 799).

The further way of standing by consumers was to genuinely care. Participants in this study recalled how they had encountered people, for example members of community groups, who showed them how highly valued they were by "genuinely caring" (P9). Participants explained that genuinely caring involved connecting to other people on an emotional level, making them feel welcome and acknowledging how they felt. Being non-judgmental, tolerant, a "good sounding board" (P34) and giving participants roles of responsibility also contributed.

Some health professionals also genuinely cared. These health professionals went "beyond the job kind of thing" (P34) and were "dedicated and interested and enthusiastic" (P32). Participants remembered how they were treated like special people: "When I go into hospital, they actually love having me.... They do everything to make me want to get better" (P2). Furthermore, these health professionals were thorough in their assessment, went out of their way to find the right treatment and explained everything they did. They even drew out their hidden abilities: "[The health professional] nurtured the qualities that I had and encouraged me into reaching my potential" (P12). Some health professionals put the needs of participants above their own. They were "not in it just for the cash" (P26) and responded even out of office hours because that was what participants required at the time: "He'd come in especially to give [me help]; he'd know what... state... I was in" (P9).

As a consequence of health professionals genuinely caring, participants found that an environment of mutual trust came to the fore. They said that this mutual trust was created when health professionals consulted them about symptoms and about the type of treatment they thought most suitable, including medications: "It becomes... a discussion... [between] both sides of what I need" (P4). Participants pointed out that in such an environment they felt at ease to talk openly about what concerned them without fear of being condemned.

Other consumer-writers had also found health professionals who genuinely cared (Norwood, 2007; Steele & Berman, 2001). In a study on consumer experiences of hospital treatment these health professionals were characterised as possessing "both heart and head" (Borge & Fagermoen, 2008, p. 197). Connor and Wilson (2006) quoted consumers who implicitly trusted these health professionals.

The last way of standing by consumers was for family members to show their love. The family member in this study who was also a participant illustrated the large amount of love she had for her son who had a mental disorder: "We've got a bond and that bond has never ever been broken" (FM). Other family members had shown participants their love by giving generously of their time and finances: "They [have]... given me their clothes off their own back" (P6). They also went out of their way to help participants with managing the difficult times: "[They] bend over backwards... to help me cope in life" (P29). Help ranged from doing the laundry, assisting with choosing a new car or buying a house for them. Others took over roles that participants had previously performed: "My wife said, 'Ok, well, I'll work. You stay at home'" (P29).

During episodes of illness, these family members showed participants their love by offering to monitor signs and symptoms in case participants did not notice their recurrence and helped them with adhering to medication regimes. They also went to extraordinary lengths to get them out of locked wards of mental hospitals. Furthermore, they acted as an interface between participants and the devaluing and dehumanising society. For example, they were willing to persist, often at substantial personal costs, to obtain suitable help from social and medical services:

I will have to lobby and lobby and lobby because he's [son is] not high on anyone's priority.... As far as * [son] goes, he'll get as good as I can help him with. So if there is nothing offered... I will become very vocal. (FM)

Those participants who had been abused in their childhood and/or adolescence said a consequence of having been shown love by a spouse and children in later life had furthered the healing that took place as part of resolving *the struggle with the impact of having been abused*.

The third way of finding a cure in society, according to participants in this study, is to show "compassion" (P22). They defined compassion as "REALLY wanting to help, REALLY caring, and showing respect and generosity to a person to whom these things have been missing from their life" (P22). The importance of compassion was identified as an essential element for *providing effective help*: "This is the key to improvement in the lives of consumers" (P22). Participants explained that compassion had to be displayed throughout society, including in health organisations. They pointed out that compassion would become widespread in health organisations if it were made a mandatory theme for all concerned, from Ministers of Health to receptionists. For this reason, participants suggested that during the initial education health professionals are taught how to show compassion and for this to be reinforced throughout their working life. Moreover, they advised that it should be made a prerequisite for employment by devising a pre-recruitment test to that end: "They should employ people who have to prove... when they apply for [a job]... that they have compassion" (P22). Participants recommended that those health professionals who have already been employed and show a lack of compassion should be removed from their positions: "They should be sacked and sacked right now. They shouldn't be allowed another minute near sick people" (P22).

A call to show compassion in the health services was also made by other consumers (Deegan, 2005b) and was present in other studies, for example in Borge and Fagermoen's (2008) study on consumers' experiences of hospital treatment. A participant in Connor and Wilson's (2006) study said that being shown compassion "lifted me out of the hell" (p. 468).

6.4: The creation of a more equitable society

Participants in this study reasoned that the *transformation of society* through *treating consumers with justice* and *providing effective help*, if achieved, would culminate in the creation of a more equitable society. This would mean that people with a mental illness could assume their place as full citizens. They would be seen as "human beings" (P30) who merely had some problems: "Just because we have problems, [nobody should] call us crazy.... Even schizophrenics or bipolar people, they are still not crazy; they are just like another person" (P2). Moreover, in a transformed society the public would be willing to "show kindness, respect and generosity" (P22) towards consumers and would regard them as the compassionate, trustworthy and honest people that they were. The media would also portray them in a positive light, reducing the fear and stigma in the general population. Their reputation would no longer be defamed: "We [would]... not [be seen as]... violent, dangerous people that need to be locked up... [with] no credential[s]... no trade or skill or anything" (P3).

Participants said that in a more equitable society they would also be appreciated as employees who are able to make important contributions. This would give them a chance of reaching their "level of vocational potential" (P22) and allow them to gain their "proper social status" (P22) through work. Participants explained that they would be included in decision-making and their suggestions would be taken into account: "The true stuff, not this shit token stuff [happening at present]" (P30).

Participants pointed out that in an equitable society there would be little discrimination in regard to housing. Neighbourhoods would be open-minded about consumers living in their midst, which would allow participants to reside in close proximity to each other if that is what they wanted. Participants explained the advantages of living near each other in that it would allow for easy socialisation and engender a feeling of belonging to the same community: "It's not two or three or so people against the world. It is all of us, all of us. Here, this is our place. This is our home. This is our community" (P22). Participants said that they would also have the opportunity to devise a common strategy if problems surface. Instead of being seen as bad neighbours and "no-hopers" (P22) they would be regarded as competent and confident people, which would bring

about respect and even admiration from the public and further enhance their standing in the community.

Creating a more equitable society would largely mitigate the *disempowering conditions* related to their social sphere, explored in chapter three, and therefore life would not be a struggle to the same degree. Participants explained that *the struggle with having a mental disorder* in particular would be reduced because society would not reject them any longer but would value them instead. Being isolated, ostracised and abandoned could thus be avoided. Furthermore, by being listened to, any frustration at how they were treated by health professionals with accompanying reprisals would also be prevented: "[Health professionals should] sit them [consumers] down, talk to them, instead of just jumping and throwing them on the ground... [and] giving [them] an injection and then putting us in a room somewhere for a few hours" (P3).

Participants also pointed to the benefits *the creation of a more equitable society* would bring to the general population in that the "social capital" (P30) of all its members would be utilised. Participants said that their children would benefit: "Your children need you. You can do things that your partner cannot and vice versa" (P26). Workplaces would benefit from their work skills and governments would not have to give as much financial support. Lastly, participants explained that health professionals would achieve the highest goal, namely the relief of the suffering of others: "Alleviating suffering is the highest and noblest act" (P22).

The benefit to the general population of *the creation of a more equitable society* was also noted by others, for example by Koenig (2007), the recipient of the 2003 UN Human Rights Award: "Living in a world of human dignity, freedom, and social and economic justice ... [will] empower us all" (p. 74).

6.4: Summary

In this chapter, participants in this study outlined their vision of how a *transformation of society* would give them sufficient power and equal value and standing to everyone else. They identified two requirements that were necessary to achieve this transformation: *treating consumers with justice* and *providing effective help*. *Treating consumers with justice* means that they would be treated the same as anyone else in the courts and with regards to new laws.

Discrimination at the workplace and with regards to housing would also be mitigated. Participants explained that *to treat consumers with justice* would be brought about most importantly by finding the cause of mental disorders and by changing the attitude of society to consumers.

In *providing effective help*, participants stated that a cure for mental disorders would be the most significant. However, in the absence of a cure, governments and individuals could *provide effective help* if they did their duty towards participants, stood by them and showed compassion.

According to participants, implementing *the transformation of society* would culminate in the creation of a more equitable society where consumers could sit at the same table as everyone else and take part in all facets of life. Society as a whole would also benefit.

CHAPTER 7: DISCUSSION

7.1: Introduction

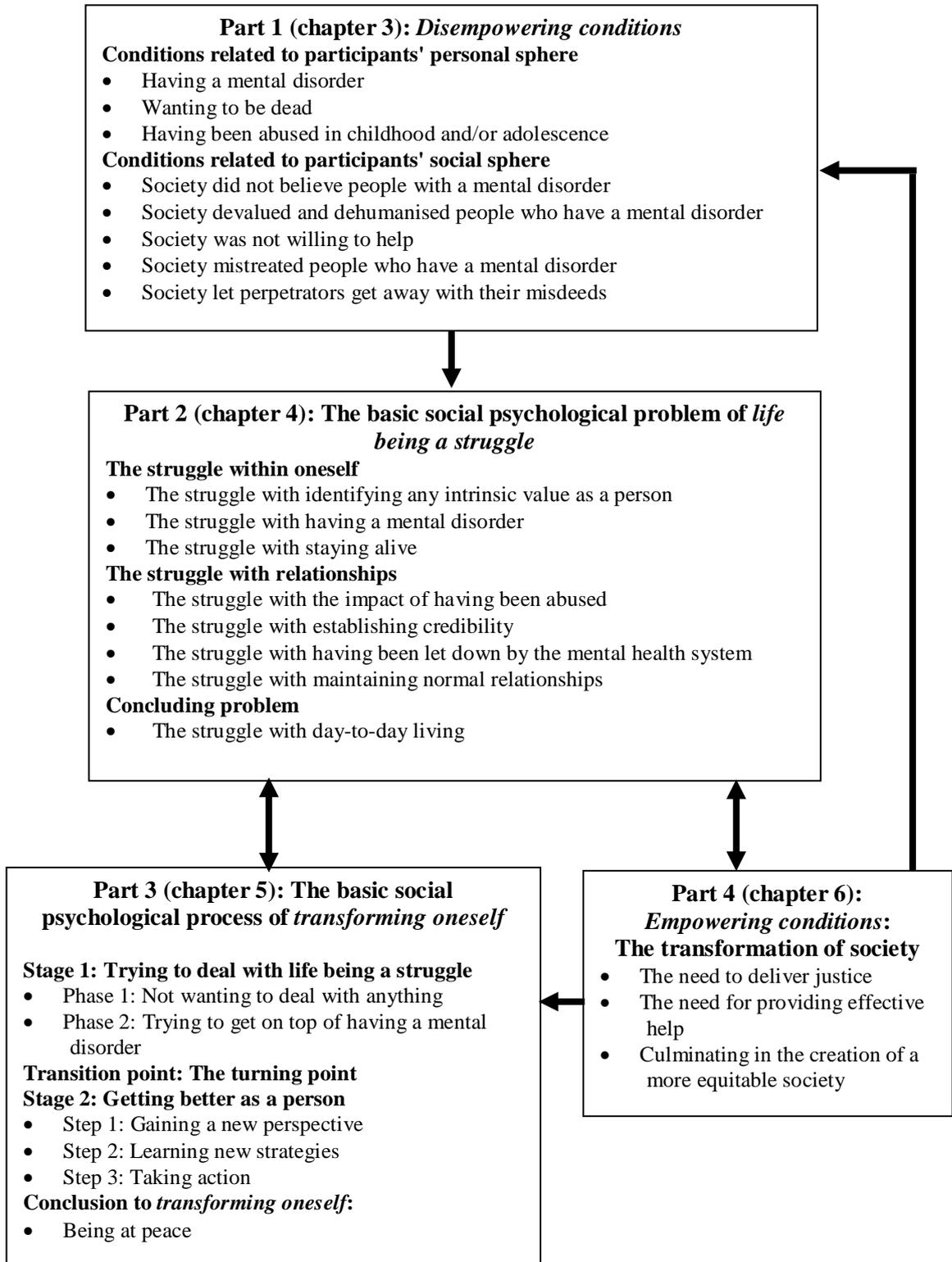
This chapter commences with a brief overview of the substantive theory of *transforming oneself and society to resolve life being a struggle* and then goes on to compare it with relevant literature. Although literature has already been included in the body of the substantive theory as additional data, further literature is selected to broaden the theoretical context of this study. The disease model, psychological models and theories, the disability model, and socio-political models and theories were chosen because they are relevant to the experience of consumers residing in the Western Australian community. The selected models and theories address topics ranging from those at the beginning of the thesis, that is, *the disempowering condition of having a mental disorder*, explored in chapter three, to those at its end, which detail *the empowering conditions* and *the transformation of society* in chapter six, or from a relatively narrow perspective to those with wider and wider spheres of influence. The discussion chapter will conclude by comparing the substantive theory of this study with the study of psychological trauma. Although the theories and models discussed in this chapter are important, it is felt that the substantive theory developed in this study is able to explain the experience of consumers to a fuller extent and therefore explores their journey better.

7.2: The substantive theory of transforming oneself and society to resolve life being a struggle

Grounded theory methodology mandates the identification of the core category and the conditions influencing these. This core category consists of how participants resolve their main concern. In this study, the main concern was the basic social psychological problem of *life being a struggle* and the resolving as a basic social psychological process of *transforming oneself*. Conditions bringing on the basic social psychological problem of *life being a struggle* were found to be *disempowering conditions*. Other possible conditions, named *empowering conditions*, facilitated the gaining of power of participants and amounted to a *transformation of society*, which has the potential to counteract or prevent many

of the *disempowering conditions* that brought on the basic social psychological problem of *life being a struggle* (see figure).

Figure: The substantive theory of transforming oneself and society to resolve life being a struggle (Arrows indicate the direction of influence)



The substantive theory of *transforming oneself and society to resolve life being a struggle* was divided into four parts. Part one, explored in chapter three, contained the *disempowering conditions*. The *disempowering conditions* disempowered participants in both their personal and social spheres because they were beyond participants' power to control. These were placed ahead of the basic social psychological problem of *life being a struggle* because they explained why *life being a struggle* occurred. They were the foundation for the rest of the thesis and this was the most important insight of this study.

Part two of the substantive theory of *transforming oneself and society to resolve life being a struggle*, laid out in chapter four, explained the basic social psychological problem, or participants' main concern, which was how life was a struggle for them. Participants described its aspects as *the struggle within themselves* and *the struggle with relationships*, which culminated in the *struggle with getting through daily life*.

Part three of the of the substantive theory of *transforming oneself and society to resolve life being a struggle*, related in chapter five, explored how participants were faced with what to do about the basic social psychological problem of *life being a struggle*. They went through a basic social psychological process, entitled *transforming oneself*. This involved two stages, separated by a *turning point*. The fulfilment of the basic social psychological process of *transforming oneself* was reached when participants were *at peace*.

Part four of the substantive theory of *transforming oneself and society to resolve life being a struggle*, covered in chapter six, contained *the empowering conditions*. The enactment of *the empowering conditions* would give participants sufficient power, or influence and authority, to become equal in value and standing to other people. This amounted to a *transformation of society*. As *the empowering conditions* in the form of a *transformation of society* was able to directly influence many of the factors of the *disempowering conditions* that brought on the basic social psychological problem of *life being a struggle*, it is seen as the way forward for mental health.

In summary, the substantive theory of *transforming oneself and society to resolve life being a struggle* saw participants move from being disempowered by conditions beyond their control to people who were largely in charge of how they saw themselves and how they ran their lives. A *transformation of society* into one

where the *disempowering conditions* are prevented or alleviated sufficiently from bringing on the basic social psychological process of *life being a struggle* is fundamental to the person's process of transformation. This substantive theory will now be compared with other relevant models and theories to further illustrate how this theory has relevancy and value for consumers.

7.3: A comparison of the substantive theory of transforming oneself and society to resolve life being a struggle with the disease model

Taber, Quay, Mark and Nealey (1969) explain that the disease model, also referred to as the medical model (Edwards, 1988), is "a belief system basic to the practice of medicine" (p. 350). They ascribe to it four main features: nosology, pathology, aetiology and therapy. Under nosology, they identify the belief that diseased and non-diseased states are qualitatively different and can be identified through "a unique set of observable signs and 'symptoms'" (p. 351). The second feature, pathology, consists of the belief that an abnormality of a physical organ exists, which is "inimical to normal functions" (p. 351). The third feature, aetiology, refers to the belief in a specific "pernicious" (p. 352) cause. The fourth feature, therapy, according to Taber et al. (1969), is "the belief that how the patient is treated makes a difference" (p. 352).

The advantage of a belief in the disease model is that it is able to explain and treat many diseases successfully. In these cases, a belief in the disease model can pinpoint the cause of the pathology, assign a diagnosis according to a unique set of observable signs and symptoms, and prescribe effective treatment. However, with many diseases there are grey areas. Medical discoveries are ongoing and not all causes of diseases, their diagnoses and treatments have been confirmed (Mechanic, 1999). In addition, not all diseased and non-diseased states are qualitatively different. For example, the debate on the cut-off point between normal blood pressure and hypertension is continuing (Mechanic, 1999). In another example, type II diabetes, the causes and the exact pathophysiological abnormalities are still being discovered and further differentiation into more refined disease categories is being developed (John Hopkins Medical Institutions, 2010).

The differentiation between physical diseases and psychiatric disorders is also in flux in some instances. For example, some diseases are classed as

psychiatric when it is difficult to group signs and symptoms, a cause has not been found and no effective treatment is available. Once these requirements have been established, the disease is then reclassified away from the field of psychiatry. This occurred with syphilis (Szasz, 2007) and Gulf War Syndrome (Research Advisory Committee on Gulf War Veterans' Illnesses, 2008). In addition, the demarcation between, for example, normal grieving and minor depression (Aldhous, 2009), and minor depression and major depression is also not entirely clear (American Psychiatric Association, 2000).

Despite the grey areas in a belief in the disease model, contemporary mental health care is largely defined by it (Thompson, 2007). Participants in this study also wanted it to be successful. They hoped that applying the disease model to mental disorders would lead to an explanation of their signs and symptoms and that it could, with further scientific research, elucidate a cause and identify a cure.

In line with the first feature of a belief in the disease model, nosology or the belief that diseased and non-diseased states are qualitatively different and can be identified through a unique set of observable signs and symptoms, psychiatry has defined signs and symptoms and grouped them into categories (American Psychiatric Association, 2000). These categories aim to describe the difference between how healthy people think, feel and behave and how consumers think, feel and behave. However, instead of these signs and symptoms being clearly demarcated between diseased and non-diseased states, as a belief in the disease model indicates, threshold problems have surfaced (Bebbington, Fowler, Garety, Freeman & Kuipers, 2008). These authors explain that the threshold between the signs and symptoms belonging to a mental disorder and healthy thoughts, feelings and behaviours is difficult to locate. For example, Verdoux and van Os (2002), in referring to studies from Europe and the USA, found that 5 to 28.5% of non-clinical populations report phenomena that cannot be distinguished from delusions and hallucinations.

Another difficulty with a belief in the disease model as applied to mental disorders is the boundary problem. Bebbington et al. (2008) explain that the boundary problem refers to the hard to define line between different diagnostic categories, such as between bipolar disorder and schizophrenia. Participants in this study also alluded to the boundary problem when they voiced their fears

about their mental disorder's capacity to progress to other, to them, even more serious disorders in *the struggle with having a mental disorder* in chapter four: "Some of the fears for me are things like... [my] bipolar [disorder] going on to schizophrenia" (P28).

There are also difficulties with applying the second and third features of a belief in the disease model, pathology and aetiology, to mental disorders. Over the last 100 years (Bebbington et al., 2008) studies on family histories, including twin studies and adoption studies, have given strong indications of a physical pathology existing in many mental disorders due to their heritability (Joiner, 2005). However, despite a huge investment of intellectual energy and monetary resources (Bebbington et al., 2008), the discovery of specific aetiologies of mental disorders based on a specific pathology or pathologies has been elusive (Leff, 2008; Singh & Rose, 2009; Shi et al., 2009).

Due to the difficulty in applying the first three features of a belief in the disease model to mental disorders, psychiatric practice has been presented with problems. Assessment has been left with depending on identifying signs and symptoms that are solely based on personal accounts of patients and on visual observation (Faulkner & Thomas, 2002). No laboratory tests or scans are available (Mechanic, 1999). Therefore, instead of diagnostic categories of mental disorders depending on discovering (Szasz, 2007) naturally occurring (Edwards, 1988) diseases, they reflect concepts of illness formulated by committees using broad professional consensus (Mechanic, 1999). This weakness is illustrated by the fact that, although the existence of naturally occurring mental disorders has been recognised in many diverse cultures (Mechanic, 1999) over many centuries (Szasz, 2007), the number of psychiatric diagnoses formulated by committees has varied greatly. The *Statistical Manual for the Use of Institutions for the Insane* from 1917 lists only 22 diagnostic categories (Committee on Statistics, 1918), whereas the *Diagnostic and Statistical Manual-IV-R* from 2000 contains 408 (American Psychiatric Association, 2000). In Australia, the *2007 National Survey of Mental Health and Wellbeing* (Slade et al., 2009) found that the lifetime prevalence of mental disorders, such as affective disorders, anxiety disorders and substance use disorders, excluding schizophrenia, now covers 45.5% of the general population.

Therapy, or the belief that how the patient is treated makes a difference, also has been found to be problematic in applying a belief in the disease model to mental disorders. Mechanic (1999) points out problems with pathology and aetiology are not so important if the therapy at least makes a difference. In psychiatry, therapies try to make a difference mainly through the use of biological agents such as medications (Vassilev & Pilgrim, 2007) and electro-convulsive therapy (Rose, Fleischmann, Wykes, Leese & Bindman, 2003). According to Repper and Perkins (2003), the initial intent of curing mental disorders with medications has not been achieved and the aim of therapy has been scaled back to alleviating signs and symptoms. Although some success in alleviating signs and symptoms by using the right medication was reported by some participants in this study as well as by other consumer-writers, for example Steele (Steele & Berman, 2001), participants in this study also said in the *disempowering conditions* in chapter three that many medications and ECT resulted in damaging them. Morgan, McKenzie and Fearon (2008a) note that "responsiveness to... medications is not uniform, and there is a sizeable minority of subjects [patients] who remain resistant to most common forms of treatment" (p. 2). Rose et al. (2003) add in their systematic review of 16 studies that consumers' satisfaction with electro-convulsive treatment is variable and depends on the type of research method used to elucidate the consumer response.

Despite these drawbacks, applying the disease model to mental disorders can have some socially advantageous implications and participants in this study wanted very much to benefit from these. These socially advantageous implications come about because a belief in the disease model rests on a claim that it can provide an "objective understanding of a universal reality" and is "rational and measurable" (Faulkner & Thomas, 2002, pp. 1-2). Therefore any moral judgment of the sick person is out of place because no personal motive can be attributed to the occurrence of the pathology (Szasz, 2007). The lack of a personal motive then precludes responsibility, blame (Thorncroft & Kassam, 2008) and moral condemnation (Aldridge, 1998). Participants of this study hoped, in the *empowering conditions* in chapter six, that if their mental disorder was acknowledged scientifically as a disease by the identification of a physical cause, thereby moving their mental disorder firmly into the orbit of the disease

model, that their condition would become viewed as value-free and they would no longer be blamed and condemned.

However, researchers from Australia, New Zealand and the United Kingdom, disappointed this hope (Read, Haslam, Sayce & Davies, 2006). They looked at the 'mental illness is an illness like any other' use in countering prejudice with regards to schizophrenia in 58 studies from 17 countries spanning over 50 years. They found that using this catchphrase, contrary to received wisdom, increases negative stereotypes, produces harsh and punitive behaviour and worsens prejudice and discrimination in the public as consumers remain viewed as incapable of judgment, reason and autonomy, all of which negate their personhood.

Lauber, Nordt, Falcato and Rossler (2004) back this up in their vignette-based opinion survey of a representative population sample of 594 people in Switzerland. They found that a disease orientated understanding of mental disorders such as schizophrenia may indeed increase stigma. They, along with Repper and Perkins (2003), conclude that this may have important implications for anti-stigma campaigns based on linking mental disorders to a belief in the disease model. They are convinced that such campaigns may be ineffective or even damaging to the reputation of consumers.

A further disadvantage of a belief in the disease model is its focus on biological origins of diseases and the subsequent de-emphasis of psychological and socio-political factors. This is termed decontextualising (Van der Kolk & McFarlane, 1996). Participants in this study reported that the *disempowering conditions* from chapter three, with the exception of *having a mental disorder*, were excised from psychiatric knowledge. Salter and Byrne (2000) add that not even stigma is mentioned in any main psychiatric text. Participants in this study therefore reported on *the struggle with having been let down by the mental health system* in chapter four.

Another consequence of decontextualising the psychological and socio-political factors in this study led to mental health care concentrating on the *disempowering condition* of *having a mental disorder* from chapter three and not taking into account the basic social psychological problem of *life being a struggle*. This is a mistake which participants in this study eventually discovered in stage two of the basic social psychological process of *transforming oneself*, in

chapter five. In addition, the necessity of a *transformation of society*, as outlined by participants in chapter six, is not recognised.

In conclusion, the comparison of the substantive theory of *transforming oneself and society to resolve life being a struggle* with the disease model shows that the disease model with regards to mental disorders has not been successful despite its usefulness in explaining and treating many general medical conditions. The discussion elucidated some reasons for this failure. This failure leaves the question open whether mental disorders can be attributed to the disease model. Therefore, their hope that the disease model would grant them a better life, and mental health services operating within this model would help them, were not fulfilled. An exception is the beneficial effects of some medications. Instead they found that a belief in the disease model fostered disempowerment.

7.4: A comparison of the substantive theory of transforming oneself and society to resolve life being a struggle with psychological models and theories

Psychology is the "scientific study of the behaviour of individuals and their mental processes" (American Psychological Association, 2009, no pagination). Psychological models and theories seek to explain both abnormal and normal behaviours and their associated mental processes.

7.4.1: Concerning abnormal behaviour and abnormal mental processes

Psychological models and theories concerned with explaining abnormal behaviour and abnormal mental processes concentrate on how behaviour has become abnormal, also called psychopathology, and how this abnormal behaviour can be corrected through intervention (Peterson, 1999). The four models chosen for discussion are the psychoanalytical model, the cognitive-behavioural model, the phenomenological-existential-humanistic model and the model employed by the Network of Voice Hearers.

7.4.1.1: The psychoanalytical model

This model has been selected for inclusion in the discussion because it was the first modern psychological model developed. Created by Freud in the early part

of the 20th century, it sees the nature of behaviour as being determined by a conflict between drives, such as sexuality and aggression (Sharpe & Faulkner, 2008), and defenses, which try to keep these drives in check (Peterson, 1999). For example, one central defense is repression and another denial (Milton, Polmear & Fabricius, 2004). The development of multiple personalities is also described as a defense against intolerable abuse (Peterson, 1999). The psychoanalytical model states that drives and defenses, and the conflict between them, often occur in an unconscious part of the mind (Milton et al., 2004). A balance in the conflict between drives and defenses is achieved by applying the right amount of psychological energy on each. Psychological energy originates with innate drives (Peterson, 1999).

Psychopathology is produced according to the psychoanalytical model if too much psychological energy is expended either on drives or on defenses (Peterson, 1999). It is corrected by revealing to the patient why the imbalance between the drives and defenses has occurred. Teaching the patient to apply the right amount of psychological energy to each restores the balance. Intervention depends on gaining insight, which is obtained through free association (Sharpe & Faulkner, 2008) and dream interpretations (Freud, 1931/1994). These help with bringing the presence of the drives and defenses into the conscious realm. Intervention also aims to recreate the patient's past relational difficulties by enacting these between the patient and the emotionally neutral therapist (Milton et al., 2004). It is hoped that reenactment will help the patient learn how to cope with any further problems in the future.

With regards to the substantive theory of this study, there are similarities between the psychoanalytical model and participants' description of how they denied that they had a mental disorder in stage one of the basic social psychological process of *transforming oneself*, in chapter five. Participants' withdrawal behind a façade and a mental brick wall can be construed to be equivalent to the repression of unconscious material in the psychoanalytical model. How participants in this study felt split between an outer persona and an inner true self is similar to the development of multiple personalities as a defense against intolerable abuse in the psychoanalytical model.

There are also similarities between the psychoanalytical model and stage two of the basic social psychological process of *transforming oneself* in this

study. Participants consciously remodeled their view of themselves and their place in society by *gaining a new perspective*. In *learning new strategies* they started to redirect their feelings, thoughts and behaviour, analogous to learning how to cope with future problems in the psychoanalytical model. They also spoke of the role of mental energy. This can be equated with psychological energy in the psychoanalytical model.

7.4.1.2: The cognitive-behavioural model

The second psychological model seeking to explain abnormal behaviour and abnormal mental processes was selected for inclusion in the discussion because it is regarded as first line treatment in psychology. Heavy emphasis is placed on the cognitive-behavioural model's validity and effectiveness in contemporary psychology, including as an intervention for depression (Moore & Garland, 2003) and schizophrenia (Kuipers et al., 2006). Originally developed by Beck and colleagues (Moore & Garland, 2003) in the 1970s (Free, 2007), this model's focus is on learning through cognitive, or thinking, processes (Peterson, 1999). It states that people learn, for example, by associating emotional reactions with stimuli, also called classical conditioning. They learn by responding to the consequences of their actions, as in operant conditioning. They also learn by observing and imitating the behaviour of others, as in modeling. The cognitive-behavioural model further teaches that the correct thinking produces the correct behaviour (Peterson, 1999).

In the cognitive-behavioural model, a psychopathology occurs when people learn the wrong thing, either by being placed in the wrong learning environment or by being "ignorant, confused or mistaken" (Peterson, 1999, p. 112). Free (2007) explains that affected people develop "cognitive distortions" (p. 14), also referred to as logical errors, which are "errors in the processes of reasoning, such that a distorted conclusion or inference is drawn from the facts" (p. 14). These are then reflected in more permanent ways of how the person sees the world and organises their behaviour (Free, 2007).

Intervention, called cognitive-behavioural therapy, then concentrates on correcting the faulty learning by providing education that instructs patients to "relearn" what they think (Peterson, 1999, p. 112). Peterson (1999) explained that the aim of relearning is to see the world more "accurately" (p. 112) and to

reevaluate one's "'reality' of... beliefs" (p. 113). According to cognitive-behavioural therapy, this relearning will result in producing the correct behaviour. Which worldview is accurate, what reality of beliefs should be adopted and what is the correct behaviour is not elaborated on. How the wrong learning environment consisting of other people's actions can be altered is also not mentioned.

Intervention in the cognitive-behavioural model consists of challenging the patient's views so that they are changed to "thoughts that are more consistent with objective reality" (p. 15) and in line with "appropriate logic" (Free, 2007, p. 17). However, if the objective reality of the patient is negative, cognitive-behavioural therapy may be futile.

Many participants in this study also talked about negative thoughts that had become quite permanent and in some instances overwhelming. They reported seeing themselves, the world and the future as negative, as elaborated in *the struggle to identify any intrinsic value as a person* and subsequent aspects of the basic social psychological problem of *life being a struggle* in chapter four. They also affirmed that thoughts influenced behaviour in *developing new skills* in stage two of the basic social psychological process of *transforming oneself* in chapter five.

However, with the exception of linking *having been abused* to the occurrence of their mental disorder in chapter three, participants in this study gave no indication that their thoughts and behaviour, as explored in *having a mental disorder*, had been learnt through either classical conditioning, operant conditioning or modeling. They were also aware that their worldview and how they saw reality differed markedly from those of other people, including health professionals. They said that the reasons lay in the *disempowering conditions* as explored in chapter three, in particular with *society not wanting to believe what consumers say* and *society devaluing and dehumanising them*. Instead of being accurate and logical, participants considered other people's views concerning participants as distorted. Participants in this study also gave detailed explanations as to why their thoughts and views were negative in the basic social psychological problem of *life being a struggle* in chapter four that justified their perspective. Participants also stressed that merely changing negative thoughts to positive ones would not help because negative thoughts were not at the root of

their disorders but emotions, as they explained in *the struggle with establishing credibility*. Emotions are not dealt with in the cognitive-behavioural model.

7.4.1.3: The phenomenological-existential-humanistic model

The third psychological model explaining abnormal behaviour and abnormal mental processes chosen for discussion is regarded as just outside of current mainstream psychology and is seen as an "alternative" or "third force" (Misiak & Staudt Sexton, 1973, p. ix). It views behaviour as freely chosen and not as subject to unconscious drives or cause and effect as in the psychoanalytical and the cognitive-behavioral models (Misiak & Staudt Sexton, 1973).

The phenomenological aspect in the phenomenological-existential-humanistic model, originating with Husserl in the early part of the 20th century, delves into understanding the subjective meaning of the patient's experiences, or the "essences of things" (Misiak & Staudt Sexton, 1973, p. 7). The existential aspect, developed by Kierkegaard, Heidegger and Sartre in the first half of the 20th century, emphasises the need to understand the person's "individual existence" (Misiak & Staudt Sexton, 1973, p. 84). The humanistic aspect, espoused by Maslow amongst others from the 1950s onwards, stresses the importance to human beings of needs and values and sees people as rational beings who want to do their best in life (Peterson, 1999). According to Misiak and Staudt Sexton (1973), the humanistic aspect contrasts with some other psychological models, which portray people as "mechanistic... reductionistic" (p. 110) or as "dehumanised" (p. 109).

Psychopathology in the phenomenological-existential-humanistic model comes about when personal choices or circumstances do not allow the individual to achieve their potential. Problems are seen as "derailments along the way to self-actualisations" (Peterson, 1999, p. 116) where the patient has "lost, erred [in]... or twisted [his/her] mode of existence" (Misiak & Staudt Sexton, 1973, p. 86, citing Binswanger, 1968). The aim of therapy is to help the patient achieve his/her "authentic self... [and] a degree of self-realisation" (Misiak & Staudt Sexton, 1973, p. 86).

One type of intervention in the phenomenological-existential-humanistic model follows Rogers' client-centered approach, where the therapist, through warmth, concern, genuineness, empathy and a non-judgmental attitude, tries to

help the individual find their own solutions to the problems they face (Peterson, 1999). However, if the patient does not acknowledge that his 'problematic' behaviour is linked to his free choice then he is seen as either deceiving him/herself or as acting in "bad faith" (Sartre, 1956/1992, p. 86). It is then up to the therapist to reveal to the patient "what his choice had been and also the fact of his being in 'bad faith'" (Misiak & Staudt Sexton, 1973, p. 77).

The phenomenological-existential-humanistic model resonates with much of the basic social psychological problem of *life being a struggle*, from chapter four in this study, where participants struggled with existential problems such as who they were as a person and what their standing was in society. Participants also described elements akin to Rogers' client centered approach as beneficial in *the empowering conditions* in chapter six. They said how much they valued being supported and genuinely cared for. Moreover, they expressed the wish that their life experiences be taken into account and they be shown compassion.

The disadvantage of the phenomenological-existential-humanistic model is the belief that behaviour is freely chosen. Participants in this study emphasised that they had not chosen to have a mental disorder and that any behaviour derived from it was not under their control in *the struggle with having a mental disorder* in chapter four. How social circumstances can be changed to reduce problems from arising or how they could be changed from causing further problems is also not covered in the phenomenological-existential-humanistic model.

As part of the phenomenological-existential-humanistic model a prominent nurse theorist also noted the importance of interpersonal relationships. Peplau (1997) based her theory of interpersonal relationships on the interpersonal relationships theory used in psychology. She stated that relationships constitute the "social fabric of life" (p. 166) and to establish positive relationships between the nurse and the patient aids the nurse in helping the patient to make sense of his illness. She encouraged nurses to develop "*empathic linkages*" (p. 163, italics in the original text) with the patient, which Peplau (1997) explains as "the ability to feel in oneself the emotions experienced by another person in the same situation" (p. 163). Respect and regard for personal dignity, and being interested in and hearing the health concerns of patients are also included. Peplau (1997) stated that these kinds of relationships between nurses and patients would result in

increased self-worth and self-esteem in the patient. Participants in this study highly valued health professionals who displayed these kinds of qualities in their relationships with them in *the empowering conditions* in chapter 6. Although Peplau (1997) wanted her theory to be practiced widely in both the generalist and the mental health field her theory was directed solely at the "dyad" (p. 162) between nurses and patients.

7.4.1.4: The Network of Voice Hearers

The fourth and last psychological model explaining abnormal behaviour and abnormal mental processes chosen for discussion is also not part of mainstream psychology and addresses only a small part of the experience of some of the participants in this study but its popularity is growing. The Network of Voice Hearers is now established in over 10 countries (Romme & Escher, 2004) and includes a branch in Perth, Western Australia (Richmond Fellowship, 2009). It illustrates how the seemingly intractable hearing of voices can be managed and is therefore useful to those participants in this study who were subject to this experience.

The model used by the Network of Voice Hearers provides a new approach to the phenomenon of hearing voices, identified as hallucinations in psychiatry and attributed to the disease category of schizophrenia. The Dutch psychiatrist Romme (Romme & Escher, 2004) describes how he and Escher gained a different insight into the phenomenon of hearing voices in the late 1980s, based on interviews with large numbers of voice-hearers.

Romme and Escher (2004) establish that hearing voices is not mental disorder specific. They conclude that it is not a symptom but a reaction to highly disruptive and often traumatic life experiences, which the voice hearer is powerless to deal with. They postulate that hearing voices is part of a survival strategy, which ensures that memories of the highly disruptive and often traumatic life experiences are kept hidden: "The voices emerge instead of the memories" (Romme & Escher, 2004, p. 15). Romme and Escher (2004) go further and take the phenomenon of hearing voices out of the realm of pathology and place it into the context of the voice hearer's life-problems, how they interpret these problems and how they deal with them.

Romme and Escher (2004) further researched what type of intervention is useful. Based on interviews with voice hearers, including those not diagnosed with a mental disorder, they formulated some general guidelines about how voice hearers cope with their voices. They found that the voices have to be accepted as real experiences and understood as being linked to the voice hearer's life history. The content of what the voices say and how they say it must be listened to because each can reveal why the voices first appear and what their function is. As Coleman (Coleman & Smith, 2007) explains: "These are the building blocks of recovery (or healing) - it is a power taking process" (p. 6).

This interpretation then leads to exploring strategies. One strategy, according to Romme and Escher (2004), is to increase the control the voice hearer has over their voices. Medication also has a role to play in reducing anxiety associated with hearing voices. Another strategy deals with making sense of the meaning and function of voices as being an understandable reaction to specific life experiences. A third strategy is to "restore... [the voice hearer's] honour by acknowledging their real pain and trauma" and to work with them through "relinquishing the events of the past" (Romme & Escher, 2004, pp. 96-97, referring to Herman, 1992). They maintain that the voice hearer will then be able to make choices for their future life within society.

Participants in this study also finally recognised the connection between the abuse and their mental health symptoms, which contributed to the healing that took place as part of resolving *the struggle with the impact of having been abused* in chapter five.

The model of the Network of Voice Hearers has advantages in that it formally recognises the causative link between often highly disruptive and often traumatic life experiences and hearing voices. However, it does not mention that society also needs to be changed and how this can be achieved in order to prevent any further highly disruptive and often traumatic life experiences from taking place.

7.4.2: Concerning normal behaviour and normal mental processes

Two psychological models, being attribution theory and positive psychology, have been chosen to further clarify the reasons for some of the behaviour and mental processes recorded in this study.

7.4.2.1: Attribution theory

This theory is a core theory in psychology. It seeks to understand some of the mental processes that organise behaviour (Ross, 1977). Attribution theory is particularly helpful in further explaining some of the attitudes and behaviours displayed by members of the general population towards participants in this study, as recorded in *the disempowering conditions* in chapter three.

Attribution theory postulates that people attribute a cause for the occurrence of the behaviour of others. This cause can be ascribed to either a personal disposition or to situational circumstances (Landman, 2001). Ross (1977) gives examples of personal dispositions, such as abilities, traits, feelings or motives. Examples of situational circumstances are social pressures, forces or constraints, such as incentives, peer pressure, financial need, alcohol consumption, or a spouse's threat of abandonment. Attributing the cause to either category allows people to then infer the future behaviour of others. As Ross (1977) points out the advantage of attributing either a personal disposition or situational circumstances as causing behaviour is that it becomes possible to predict how 'people in general' respond in relationships. Social chaos is thus avoided in the interaction with others.

However, errors in attribution occur, called fundamental attribution errors. According to Ross (1977), fundamental attribution errors overestimate personal dispositions as causative factors of behaviour and underestimate situational circumstances. One reason for these errors is that attributing the cause of behaviour to personal dispositions is much easier than to analyse complex situational circumstances.

Ross (1977) further explains that this fundamental attribution error leads to other errors. For example, one's own attributes are often believed to be more valid than those of others, especially those that are different from one's own. Furthermore, ignoring or overlooking situational circumstances leads to reaching hasty conclusions. Both of these errors underlie biased and erroneous judgments of the behaviour of others and result in the misinterpretation of why other people do what they do.

Ross (1977) points out that these fundamental attribution errors form deep convictions in people and are therefore difficult to invalidate or reverse even in

the face of contrary evidence. As a consequence, a change in social attitudes and behaviour is very hard to achieve. Attribution theory also explains why the distortion of judgment and the resulting misinterpretation of the behaviour of others can lead to "personally maladaptive, socially pernicious, and often puzzling" behaviour in the holder of these fundamental attribution errors (Ross, 1977, p. 181).

Attribution theory is highly relevant to the substantive theory of *transforming oneself and society to resolve life being a struggle*. It explains many of the beliefs, values and actions of members of society that were puzzling to participants, as detailed in the *disempowering conditions* in chapter three. For example, attribution theory can explain why participants were not believed as participants' accounts were outside the experience of the general population and therefore regarded as unbelievable. Furthermore, attribution theory can highlight why participants were devalued and dehumanised. Other people felt superior to participants and used this as justification for mistreating and not helping them. Attribution theory also explains why the views, values and actions of society including those of health professionals would be very hard to change, as envisaged by participants in this study in *the empowering conditions* in chapter six. However, attribution theory does not suggest how this can be remedied.

7.4.2.2: The study of positive psychology

A second psychological model explaining normal behaviour and mental processes belongs to the study of positive psychology. Seligman (2002) explains there are three pillars of positive psychology. The first pillar deals with positive emotions such as confidence, hope and trust. The second pillar consists of positive traits such as strengths, integrity, loyalty, future-mindedness, leadership, kindness, originality and wisdom. The third pillar describes positive institutions, which, in turn, support the first two pillars. Examples of positive institutions are democracy, strong families and free inquiry or a free press.

Keyes and Haidt (2002) further describe individuals who possess positive emotions and positive traits as "flourishing" (p. 6). Flourishing individuals are healthy, productive and happy. They know what makes life worth living, are filled with emotional vitality, function positively in their private and public lives and are said to be "truly living rather than merely existing" (Keyes & Haidt,

2002, p. 6). Furthermore, they reach out to others and engage positively with their social environment. Most of all, flourishing individuals are free from mental illness.

The purpose of studying positive psychology, according to Seligman (2002), is to prepare oneself for troubled and difficult times. By possessing positive emotions, nurturing positive traits and shoring up positive institutions, strengths and virtues that would "effectively staunch wounds" (Seligman, 2002, p. xii) are built up. How individuals have gained these positive emotions and traits and how they can use them in hard times is not discussed. Furthermore, how the third pillar, positive institutions, helps is not mentioned.

The positive emotions and positive traits described in positive psychology are similar to the emotions and traits exhibited by those participants who had reached the fulfilment of the basic social psychological process of *transforming oneself*, explored in chapter five, and identified as *being at peace*. They described how they had become content, how they had gained strengths and capabilities, especially with regard to their helping ability. They said they had gained a positive identity with good self-esteem and had found meaning in life. It is interesting to note that participants in this study had succeeded in reaching these positive emotions and positive traits despite the continuing presence of their mental disorder, albeit after overcoming enormous hardships in enduring and then resolving the basic social psychological problem of *life being a struggle*.

7.4.3: Conclusion to the comparison of psychological models and theories

Advantages of psychological models and theories, both those explaining abnormal behaviour and abnormal mental processes and normal behaviour and normal mental processes, lie in their ability to further illuminate many parts of the substantive theory of *transforming oneself and society to resolve life being a struggle*. They also outline interventions, some of which would be useful to participants in this study.

However, none of the psychological models discussed here encompass participants' entire experience. A major disadvantage was either a complete absence or a non-recognition of the role of power in initiating and resolving the basic social psychological problem of *life being a struggle*. In this study, the role

power played and the recognition of who held this power at different stages was crucial.

Another disadvantage of the psychological models presented for discussion is that many do not acknowledge the impact of social influences. None show how to address these. Yet social influences, as explored in *the disempowering conditions* related to participants' social sphere in chapter three, were of primary importance in bringing about the basis social psychological problem of *life being a struggle*. As Aldridge (1998), a psychologist, points out, "individuals are treated [by psychology] to promote their accommodation within society" (p. 265). He states that this stance absolves society from taking any responsibility for the causation, correction and prevention of patients' problems. He concludes that psychological intervention, by regarding the social context as not being in its remit and concentrating on the "individualistic perspective" (p. 158) only, may thus become part of the problem and contribute to further damaging the patient.

Furthermore, Aldridge (1998) found in his substantive theory on suicide that the psychoanalytical and the cognitive-behavioural models in particular largely lack any explanatory power and intervention methods with regard to suffering and distress. Thus Aldridge's (1998) substantive theory on suicide, as well as this study, clarifies why patients consider many psychological models of limited help.

In conclusion, the psychological models and theories discussed here reflect many parts of the substantive theory of *transforming oneself and society to resolve life being a struggle*. However, the disadvantage of psychological models and theories in not taking into account the importance of social determinants and a need for social change remains. In light of the strong emphasis placed on the need for social change by participants in this study, this disadvantage may offset the advantages.

7.5: A comparison of the substantive theory of transforming oneself and society to resolve life being a struggle with the disability model

In contrast to the disease model and psychological models and theories, the disability model is not concerned with the past but with the future. It does not look at where the disability has come from (Read et al., 2006) or even what indicators of disability there are (Coleman, 2004). Identifying and categorising

signs and symptoms, locating a particular cause, whether biological or psychological, or finding a 'cure' are considered unimportant (Repper & Perkins, 2003). The disability model instead looks to the future, to how the affected person can go about "getting on with your life" (Coleman, 2004, p. 84). Its goals are to "see people beyond their problems - their abilities, possibilities, interests and dreams - and recovering the social roles and relationships that give life value and meaning" (Repper & Perkins, 2003, p. ix).

Inherent in the disability model are two interconnected aims: devising personal ways of improving one's life despite an ongoing disability, and changing society so that people with disabilities regain their rights and are not discriminated against (Repper & Perkins, 2003). Within mental health, the disability model has been translated into the recovery paradigm (Repper & Perkins, 2003).

The recovery paradigm sees the subjective experience of people with a psychiatric disability as central. It argues that this experience is different from the knowledge and experience of other people, including health professionals (Rose, 2008). As Deegan (2005), a consumer-writer, explains, the recovery paradigm is "an attitude, a stance, and a way of approaching the day's challenges" (p. 67). A central element of the recovery paradigm is gaining personal power (Deegan, 1997; Jacobson & Greenley, 2001; Spaniol et al., 2005; Torgalsbøen, 2005). Gaining personal power means to take an "active stance" (Deegan, 2005a, p. 66), to be "in the driver's seat of my life" (Deegan, 1997, p. 21) and "taking back control over one's life" (Repper & Perkins, 2003, p. 48). It means making one's own decisions (Repper & Perkins, 2003) and creating the life of one's own choice (Mead & Copeland, 2005). It also means insisting on being seen as a human being who has the right to be heard and to be regarded as an expert on one's own life (Deegan, 2005a). Gaining power in the recovery paradigm also means to be actively involved in all facets of treatment (Coleman & Smith, 2007) including the freedom to choose not to have any (Anthony, 1993, cited by Repper & Perkins, 2003). Medications are used as tools, as a consumer, quoted by Romme and Escher (2004), explains: "It is of critical importance that we don't allow drugs [medications] to oppress us. We use drugs; we won't be used by them" (p. 63).

The recovery paradigm contains many elements also present in the substantive theory of *transforming oneself and society to resolve life being a struggle*. The role of power is central to both. It also closely resembles many parts of the social psychological process of *transforming oneself*, explicated in chapter five, especially stage two.

The greatest advantage of the recovery paradigm is that it leaves behind the passive stance expected of patients in the disease model and in some psychological models and theories. People with psychiatric disabilities are accepted as they are and are not expected to change what they cannot change. They are also not required to comply with treatment or interventions that are damaging. The literature in this area does not identify that they are ever blamed nor are they urged to "fit in" with the rest of society (Repper & Perkins, 2003, p. 27).

The greatest disadvantage of the recovery paradigm is the invisibility of what is stage one of the basic social psychological process of *transforming oneself* in chapter five. People who are in the equivalent of this stage could therefore get the impression that they have been rejected and feel excluded, although this seems far from the intention of the recovery paradigm. They get no guidance as to how to proceed through *the turning point* into stage two, detailed in this study. *Turning points* are also either mentioned only incidentally in the recovery paradigm literature (Deegan, 1997) or not at all (Repper & Perkins, 2003).

Another disadvantage with the recovery paradigm is the near non-existence of ways to change society. Although this is a prominent feature of the disability model and the most important part of the substantive theory of this study, it is either not mentioned at all in the reviewed recovery literature, or relegated to an add-on position (Repper & Perkins, 2003).

In conclusion, the disability model as applied to mental health is very useful to those consumers who are in the equivalent of stage two of the basic social psychological process of *transforming oneself* in this study. However, the recovery paradigm leaves the many people who are in the equivalent of stage one out in limbo without recognition and guidance. It also does not adequately address *the empowering conditions*, which this study found are necessary to gain empowerment and allows for lasting gains to be made in the recovery process.

7.6: A comparison of the substantive theory of transforming oneself and society to resolve life being a struggle with socio-political models and theories

Socio-political models and theories try to explain the behaviour of groups of people (Smelser, 1973). According to Giddens (1984), behaving as a group means being able to act in such a way that that action is able "to make a difference to a pre-existing state of affairs or course of events" (cited by Oliga, 1996, pp. 81-82). Therefore it involves the use of power. Issues of power and control are political issues (Romme & Escher, 2004, referring to an article written by members of the support group Power to Our Journeys, 1996). Power, the lack of it and how to gain it, was a central topic in this current study and therefore examining socio-political models and theories is important.

Oliga (1996) refers to power as not being inherently "noxious, oppressive, and exploitative" (p. 84) and says that how it is exercised determines whether it has a positive or negative influence.

7.6.1: The negative impact of power

The negative influence of power manifests itself through the exercise of social domination by one group over another (Edwards, 1988). This domination is achieved through ideology and social control (Oliga, 1996). Ideology is defined by Edwards (1988) as "meaning a biased and often false representation of social reality but one consistent with the selective interests of a particular, and typically dominant, section of society" (p. 160). Ideology is usually concealed and most groups in society, even the dominant group, are often not aware that the representation of social reality is biased and false (Oliga, 1996).

Ideology, through its biased and false representation of social reality, is inculcated through education (Durkheim, 1895/1938) to such an extent that it becomes part of a highly pervasive and internalised "social consciousness" (Durkheim, 1887/1952, p. 315). As Oliga (1996) explains, powerless groups, by having internalised the highly pervasive social consciousness, may acquiesce in the power structure that disadvantages them. They may think of it as inevitable or fear it. This fear may be in response to physical force and violence or it may

consist of a moral fear of being ostracised. A social fear of losing one's job or social position may also be present (Olga, 1996).

Participants in this study reported that they experienced some of these influences of ideology. They said they were ostracised and some experienced physical force and violence. Others reported that they had lost their jobs and social positions.

The negative influence of power is then enacted through social control (Edwards, 1988). Social control is the "regulation of... behaviour in accordance with some dominant interests" (Olga, 1996, p. 40). It has been argued that social control is essential to maintaining social order: "It... [is] impossible to contemplate social life without social control" (Roach Anleu, 2006, p. 76). Furthermore, it has been maintained that social control is beneficial for society and this has been used to justify its continuation (Szasz, 2007). However, social control is not always beneficial because the dominant group doing the social controlling does not necessarily act in the best interests of the common good but seeks to only bolster its own position (Roach Anleu, 2006).

In the health field, the enactment of social control also has two sides. It is deemed beneficial if it protects the public and seen as harmful, and therefore not justifiable, if it interferes with private matters and violates human rights (Szasz, 2007). In mental health, discussions are ongoing about where the line falls between the need to protect the public through the social control of consumers and the need to respect their private interests and human rights (Thorncroft & Kassam, 2008). Olga (1996) maintains that when social control crosses the line between being beneficial and being harmful it becomes exploitative and should be seen as "sociopathology" (p. ix). Similarly, participants in this study also referred to the world being crazy in *the struggle with establishing credibility* in chapter four because other people mistreated them and in so doing violated ethical standards and criminal laws and got away with it.

Social control is achieved, according to Edwards (1988), by deciding which values, norms and beliefs are right and should be adopted society-wide, and which are wrong. Making these decisions is referred to as rule making and is carried out by the dominant group (Marshall, Douglas & McDonnell, 2007). Rule making is not arbitrary because the rules decided on "defend and reinforce

entrenched power positions and interests... [and thereby] help to maintain... [the] social order" (Edwards, 1988, p. 67).

Rules are then enforced by designated control agents (Edwards, 1988). Control agents are individuals (Roach Anleu, 2006), such as neighbours and employers (Repper & Perkins, 2003), and social institutions, such as families and schools (Durkheim, 1895/1932). The state as a control agent uses its medical, welfare and justice systems to enforce rules (Edwards, 1988).

Rules shape "moral and social judgements about human beings and their behaviour, and how to deal with them" (Edwards, 1988, p. 162). In order to make these judgements, control agents need to be able to distinguish between themselves, that is, the dominant group in society who sets the rules, and those whom they are tasked to control. This distinction again is defined by the dominant group in that they have the power to determine who is "them and [who is] us" (Repper & Perkins, 2003, p. 49). They do this by deciding that the 'them', that is, the powerless, display "undesirable and problematic" behaviour (Edwards, 1988, p. 13). This undesirable and problematic behaviour is referred to in sociology as deviancy, or as rule breaking (Marshall et al., 2007). As the rules and therefore deviancy are defined by the dominant group, "deviance is determined not by the nature of the deviant acts, but by societal responses to those acts" (Morgan, 2008, p. 28).

Participants in this study recalled how they were battling in *the struggle with having a mental disorder*, in chapter four. They were highly dismayed that they felt powerless to control it and prevail over its impact. In sociological parlance they acted with deviancy, as they were unable to stick to certain socially agreed on rules due to *having a mental disorder*. This is backed up by Scheff (1966, cited by Morgan, 2008) who extended the general sociological research on deviancy to consumers. He reframed mental health symptoms as "rule... violations" (Morgan, 2008, p. 28). Mental health symptoms are viewed as rule violations because consumers are seen as not wanting to conform to how society expects one should behave (Thoits, 1999).

The literature on social control elaborates how people who display so-called deviant behaviour can be identified. They are identified by "naming" them as deviant (Marshall et al., 2007, p. 42). Naming is done through labelling.

Again, these labels are applied by the dominant group to the powerless. Therefore labelling is a political act (Marshall et al., 2007).

In this study, participants told in the *disempowering conditions*, in chapter three, how they were labelled by society as irrational cases beyond comprehension and as having a condition that was demonised. Through these labels they said that they were marked permanently as non-persons who were not part of the human family.

Once so-called deviant people are labelled, social control springs into action to eradicate, correct or contain the behaviour deemed deviant (Roach Anleu, 2006). Again, this is carried out by the dominant group against the powerless. Social control is therefore also a political act (Aldridge, 1998). It is achieved through regulatory interventions that seek compliance and conformity with the rules (Roach Anleu, 2006). Regulatory interventions are called sanctions (Roach Anleu, 2006). Sanctions can be restricted to the ethical realm with measures that put pressure on the so-called deviant person. Some of these measures include blaming the individual and not the context of their lives (Aldridge, 1998), restricting choices (Laverack, 2005) including political decision making, and monopolising resources, together with knowledge (Olga, 1996).

The participants in this study reported that they were exposed to all these measures, as explored in the *disempowering conditions* in chapter three. Speed (2007) adds that even the term consumer is a misnomer as there is little choice for consumers in a psychiatry-dominated health system.

Social control is then enacted as sanctions in the form of discrimination. Discrimination consists of the unfair treatment of the stigmatised (Sayce, 2000) and is practiced by creating a social distance between society and the stigmatised person (Lauber et al., 2004; Link, Phelan, Bresnahan, Stueve & Pescosoli, 1999). Discrimination in the mental health field occurs particularly as a consequence of the fear of dangerousness, as Corrigan et al. (2002) concluded in attitude questionnaires of 213 people from the public and based on research over four decades. For example, consumers are denied work opportunities because they are seen to be potentially dangerous at work, or they are refused housing because they are assumed to damage the rental property (Corrigan, 2005). Participants in

this study also reported how people cut off contact with them and wanted nothing to do with them, in *the disempowering conditions* in chapter three.

Social control is also carried out by the judicial system. Here the so-called deviant behaviour becomes punishable by criminal law. That many consumers have become embroiled in the judicial system is reflected in the number incarcerated in prison (Corrigan & Kleinlein, 2005). For example, Butler and Allnutt (2003) found that in New South Wales, Australia, 74% of prisoners had a mental disorder compared with 22% of the general population in a 12-month timeframe. In this study, participants' fear of becoming entangled with the justice system was therefore justified.

Lastly, social control also answers the question why *society let perpetrators get away with their misdeeds*, as described by participants in chapter three. According to Roach Anleu (2006), perpetrators are allowed to get away with their misdeeds because they do not offend the collective consciousness. They do not disturb social cohesion, which can be maintained or even enhanced by their actions against the devalued and dehumanised sections of the population.

In conclusion, well-established socio-political explanations of the negative impact of power put the experience of participants in this study into a broader social context by explaining how the negative impact of power is exercised in general. The disadvantage of the socio-political models and theories on the negative impact of power is that they do not a remedy.

7.6.2: The positive impact of power

One socio-political theory explaining what to do about the negative impact of power and how to turn it into a positive impact is the social movement theory (Adam, Duyvendak & Krouwel, 1999). Social movement theory describes how the actions of individuals and small groups can be transformed into a widespread collective social and political movement (Woolcock & Altman, 1999). The central goal of these social movements is to achieve broad social change through reforming society (Goodman & Epstein, 2008). Adherents seek to change a system that deprives them of power to one in which they gain sufficient power to be accepted as equal citizens, or, as Adam et al. (1999) put it, where they go from "repression to liberation" (p. 346). Having sufficient power to free oneself from being repressed, or from being disempowered as it is referred to in this study,

means to seek equal amounts of power to that of other groups and not be dominated.

According to the social movement theory, powerless social groups gain power by "challenging the structural arrangement of society and the prevailing ideologies, social expectations and moral codes which they see as resulting in their own marginalisation and devaluation" (Edwards, 1988, pp. 71-72). Social movement theory thereby takes on what the recovery paradigm in the disability model and socio-political models and theories on the negative impact of power leave unfulfilled and what participants in this study were seeking, in chapter six, when they called for *the transforming of society*. Social movement theory therefore confirms participants' aspirations for a transformed society as a legitimate goal. Examples of other groups of people who have achieved some measure of power show that participants' wish for a transformed society is achievable. In addition, social movement theory gives participants in this study guidance as to how to go about attaining *the transformation of society*. Therefore it is important to include an analysis of the social movement theory in the discussion.

Social movement theory marks out four areas for change. The first area of change, occurring earliest (Kaufman, 1999), concerns the change occurring in powerless individuals. Individuals are changed by becoming aware of "previously unrecognised societal forces that shape their roles and limit their opportunities" (Goodman & Epstein, 2008, p. 31). By sharing and analysing their life experiences within a group of similarly affected people they come to recognise that there are commonalities between them (Adam, 1995). These commonalities tell them that it is external, societal factors that predominantly contribute to their predicament (Kaufman, 1999) and that they, as individuals, are not at fault for what has happened to them. This realisation leads to a reinterpretation of what needs to be changed and points to society and not to the affected individual (Goodman & Epstein, 2008).

Coleman (2004) refers to this realisation and reinterpretation as "the politicisation of the self within wider society" (p. 49). According to Adam (1995), this realisation leads initially to "immense anger" (p. 83). However, the subsequent reinterpretation about the causes of what has happened then turns into "joy, pride and a boiling over of new ideas" (Adam, 1995, p. 83). It also results in

"an enormous sense of relief, connection and healing" (Goodman & Epstein, 2008, p. 31). Stroman (2003) states that this realisation and reinterpretation resulting in a "dramatically new and positive valuation of [oneself]" amounts to "a personal transformation" (p. 70). Increasing self-confidence and self-esteem (Laverack, 2005) and a sense that one can determine what one wants to do (Stroman, 2003) become evident.

The second area of change advocated by the social movement theory concerns the judicial system. Affected people demand "basic [legal] rights and [legal] equality as citizens" (Kameny, 1969, cited by Adam et al., 1999, p. 77). Responding to international human rights, many governments formulated anti-discrimination laws. For example, in Australia about 100 laws were amended to ensure legal equality between the general population and gays and lesbians (Berman, 2008, p. 241). Anti-discrimination legislation is further strengthened by "constraining derogatory representations in television series and inflammatory media coverage" (Repper & Perkins, 2003, p. 217).

These laws then enabled affected individuals and groups to fight discrimination (Adam et al., 1999). This fight entails challenging interpersonal discrimination, institutional discrimination, employment discrimination and housing discrimination (Stroman, 2003) in areas ranging from sports (Barkham, 2010) to the armed forces (Adam et al., 1999) and marriage (Kirby, 2010). Joining up with other "sibling" movements also engaged in the fight against discrimination (Adam et al., 1999, p. 358) can lead to further creating an atmosphere where discrimination becomes politically unacceptable. In coupling with mass demonstrations and the lobbying of politicians, even becoming politicians themselves, a degree of political legitimacy, now backed by the media, is attained (Adam et al., 1999). In this way the social movement concerned has moved from being a stigmatised, pathologised and even criminalised group residing in seclusion (Adam et al., 1999) to becoming a legitimised group getting diversity acknowledged as a source of strength (Berman, 2008). It has moved towards becoming accepted as part of the mainstream (Robinson, 2008) in being a "recognisable political and societal actor" (Adam et al., 1999, p. 346).

Participants in this study also called for being treated with justice in *the empowering conditions* in chapter six. They wanted to have equal rights and

wished not to be discriminated against. They advocated for anti-defamation laws with regards to consumers. In order to assert human rights and strengthen the fight against discrimination even further, Thornicroft and Kassam (2008) have urged mental health anti-stigma campaigns to focus on discrimination, on who is involved and how it is carried out. This contrasts with anti-stigma campaigns based on a belief in the disease model, which, according to Thornicroft and Kassam (2008), do not decrease stigma but merely perpetuate stigmatising labels.

The third area of change in the social movement theory concerns the change in public attitude towards the affected group (Robinson, 2008), as participants in this study also emphasised. The social marketing approach has been found to be effective in changing public attitudes (Corrigan & Gelb, 2006; Kirkwood & Stamm, 2006). The aim of the social marketing approach is in line with the social movement theory as it seeks to empower those groups of people it serves (Kirkwood & Stamm, 2006). Each particular campaign is therefore designed "by the people it is about" together with experts in this approach (Kirkwood & Stamm, 2006, p. 472).

Three ways are used in the social marketing approach: protest, education and interpersonal contact. As Corrigan and Gelb (2006) explain, protest seeks to portray the attitude of the public as a moral injustice and advises them not to act in "this socially inappropriate way" (p. 393). It has been used to call for boycotts of businesses and in convincing the media not to present stigmatising images. Protest can also achieve a level of public attention that the other two tactics do not attain (Stroman, 2003). The second tactic, education, challenges inaccurate stereotypes and seeks to replace them with factual information (Corrigan & Gelb, 2006). The third tactic, interpersonal contact between affected people and the public, has been found to make the greatest difference to a change in attitude (Corrigan et al., 2002), especially if the affected person is perceived to be of equal status (Corrigan & Penn, 1999; Corrigan & Wassel, 2008). However, a disadvantage of interpersonal contact is that a much smaller audience is reached (Corrigan & Gelb, 2006).

The fourth and last area of change addressed by the social movement theory concerns a change in health care. With some social movements this involves demedicalising their 'condition' (Stroman, 2003). Some proponents of the Disability Rights Movement do not see themselves as sick and in need of

treatment, such as the deaf (De Clerck, 2006). However, those in the Disability Rights Movement who are in need of medical treatment demand a transfer of power and authority for decision-making from health professionals to themselves (Stroman, 2003). They want to determine the planning, budgeting, selection and evaluation of services (Stroman, 2003).

In order to affect change in the four areas of a social movement, that is, change of the affected individual, the justice system, public attitudes and the health system, support from like-minded advocates is also required (Stroman, 2003). This support comes from forming alliances with lay, academic and/or professional groups (Goodman & Epstein, 2008).

However, within mental health, a consumer rights movement remains embryonic and isolated (Repper & Perkins, 2003). Protests by consumers started to be made in the 19th century (Deegan, 2004) and some campaign groups were founded in the 1970s such as the British Networks for Alternatives to Psychiatry and the Campaign Against Psychiatric Oppression (Repper & Perkins, 2003). In the USA the impact of the consumer movement on health care has been described as "policy innovation on the edge of desperation" with the existence of "some thoughtful and creative experiments... that deserve wider notice within the health care field" (Tomey, 2006, p. 727). Although identified as isolated experiments they seem to have "nonetheless succeeded in turning mental health care in more patient-centred directions" (Tomey, 2006, p. 727). However, how health services can incorporate consumer-centred practices remains under discussion (Institute of Psychiatry, 2010).

In Australia, the National Mental Health Strategy (Australian Health Ministers, 1992c) took up the call of consumer involvement early by emphasising the principles of human rights and a focus on consumers, as described in chapter one. However, these principles have not suffused to all grassroots health services, as attested to by the Not for Service (Mental Health Council, 2005). This report identified that consumer participation had, in fact, diminished or even been abandoned in many parts of the country. It furthermore stated that in the parts of Australia where consumer participation was still operating, there was often a lack of meaningful consultation with a tokenistic approach and consumer input often being ignored. However, the newly established Mental Health Commission (2010) in Western Australia is moving

towards establishing a non-governmental body for promoting the interests mental health consumers.

In conclusion, the social movement theory backs up the calls made by participants in this study in the empowering conditions in chapter six. It gives credibility to participants' aspirations. It also shows them that that these aspirations can be realised and their vision of such a society is the way forward to permanently improve their situation.

7.7: A comparison of the substantive theory of transforming oneself and society to resolve life being a struggle with the study of psychological trauma

The study of psychological trauma has pulled together most of the theories and models discussed in this chapter and has shown how they can work together in order to improve the lives of traumatised people. In addition, *having been abused* and its sequelae played a central part for many participants in this study. Therefore it is important to discuss the study of psychological trauma and how it has helped other people. The study of psychological trauma has arisen out of years of research with a wide-range of traumatised people, including children, women, soldiers and holocaust survivors, following their experiences of child abuse, domestic violence, rape, captivity, natural disasters, accidents or wars (Herman, 1992). It defines trauma as following an "inescapable stressful event that overwhelms people's [everyday] coping mechanism" (Van der Kolk & Fislser, 1995, p. 505).

The study of psychological trauma has recognised the need to develop a substantive theory that encapsulates "a new way of thinking about human experience, human tragedy, and the universal human response to that tragic experience" (Bloom, 1997, p. 113). The theory seeks to include a "comprehensive, cohesive, and compassionate cognitive framework that provides us with a direction and process for strategising about meaningful and effective social change" (Bloom, 1997, p. 220). The psychiatrist Judith Herman (1992) formulated such a theory in her book *Trauma and Recovery*. This seminal work was the basis for other prominent research conducted by, for example, the psychiatrists Bloom (1997) and Van der Kolk and colleagues (1995, 1996, 2005).

Psychiatry has made valuable contributions. It has recognised the role of psychological trauma in the development of mental health disorders, albeit

belatedly after a delay of nearly 100 years (Hammersley, Read, Woodall & Dillon, 2008; Herman, 1992; Van der Kolk, Weisaet & Van der Hart, 1996). The creation of a new disease category in its classification system, named post-traumatic stress disorder, has given legitimacy to the suffering of trauma victims and allowed resources to be assigned to its management (DeVries, 1996). Pioneering research was conducted in the 1990 (Hammersley et al., 2008), some of it cited in this section, to substantiate this new disease category. Research funding has also been forthcoming for extensive quantitative studies, some of which are cited in the *disempowering conditions* from chapter three herein.

Experiences described in the study of psychological trauma closely mirror most of the experiences of *having been abused* described by participants in this study. As participants also claimed, the study of psychological trauma links trauma with the development of a variety of mental disorders including all those that participants were diagnosed with, namely major depression, bipolar disorder and schizophrenia (Janssen et al., 2004; Herman, 1992). The study of psychological trauma also concurs with participants in this study in asserting that "symptoms may reflect permanent damage and change... in the brain structure" (Shalev, 1996, p. 95) thereby incorporating the disease model.

Most importantly, and in line with socio-political models and theories and agreeing with this theory, the study of psychological trauma acknowledges the centrality of power:

The methods of establishing control over another person are based upon the systematic, repetitive techniques of psychological trauma. They are the organised techniques of disempowerment and disconnection. Methods of psychological control are designed to instill terror and helplessness and to destroy the victim's sense of self in relation to others. (Herman, 1992, p. 77)

The study of psychological trauma regards the use of power in traumatising others as not being accidental or incidental but as "a central organising principle in the formation, development, and maintenance of human society as a whole" (Bloom, 1997, p. 212). It further documents how trauma victims are seen society-wide as "mendacious, greedy and vengeful" (McFarlane & Van der Kolk, 1996, p. 573) and in need of social control. For example, reports by trauma victims are discredited and not believed (Erdmans & Black, 2008), as also happened to participants in this study: "Despite the vast literature documenting the

phenomena of psychological trauma, debate still centers on the basic question of whether these phenomena are credible and real" (Herman, 1992, p. 8).

The study of psychological trauma also examines the response of the health system to the trauma victim. It finds that the health system denies or even furthers the abuse (Bloom, 1997; Herman, 1992). The decontextualisation occurring as part of the disease model regards the "idea [of abuse as]... simply unacceptable" (Herman, 1992, p. 18). In addition, many psychological models and theories, also in thrall to decontextualisation, ignore the source of the abuse: "The exploitative social context in which... [abusive] relations actually occur... [become] utterly invisible. [For example,] psychoanalysis became a study of the internal vicissitudes of fantasy and desire, dissociated from the reality of experience" (Herman, 1992, p. 18). For these reasons, and as has happened to participants in this study, a history of abuse is not linked up to the signs and symptoms of a disorder and misdiagnoses occur (Herman, 1992).

The resulting lack of progress in the patients' conditions due to not addressing the underlying issues of trauma (Herman, 1992) then causes health professionals to exhibit "coercive behaviour" (Bloom, 1997, p. 146). Health professionals' abuse of power therefore takes the place of the abuse previously encountered elsewhere (Herman, 1992). These responses of health professionals were all experienced by participants in this study.

Furthermore, participants in this study reported how society was not willing to help them and thereby *let perpetrators get away with it*. They particularly singled out the mental health system as standing by and not being responsive when criminal acts were committed against them. This is interpreted by the study on psychological trauma as exhibiting the behaviour of a bystander. Herman (1992) explains what this involves:

When traumatic events are of human design, those who bear witness are caught in the conflict between victim and perpetrator. It is morally impossible to remain neutral in this conflict. The bystander is forced to take sides. It is very tempting to take the sides of the perpetrator. All the perpetrator asks is that the bystander do nothing. He appeals to the universal desire to see, hear, and speak no evil. The victim, on the contrary, asks the bystander to share the burden of pain. The victim demands action, engagement, and remembering. (Herman, 1992, pp. 7-8)

The response of the justice system is then to often further traumatise the victims due to its hostile environment that an adversarial legal system produces a for them (Herman, 1992).

The study of psychological trauma also confirms what abused participants went through in other aspects of the basic social psychological problem of *life being a struggle*, as explored in chapter four. *The struggle to identify any intrinsic value as a person* is documented, complete with feelings of having no self-worth, no self-esteem and of being completely inadequate (Bloom, 1997; Herman, 1992). Likewise, *the struggle with responding to the impact of having been abused* is present, including living in fear and self-blame (Bloom, 1997; Herman, 1992). Stockholm Syndrome is renamed "traumatic bonding" (Herman, 1992, p. 92). As participants in this study reported, traumatised people get to the point of being suicidal. The study of psychological trauma explains that being suicidal is due to feeling "utterly abandoned, utterly alone, cast out" (Herman, 1992, p. 52) and "outside the bounds of the normal human community" (Bloom, 1997, p. 70).

With regards to the basic social psychological process of *transforming oneself*, as explained in chapter five, the study of psychological trauma also describes what trauma victims do. For example, withdrawal is acknowledged as a common reaction (Herman, 1992). Dissociation is identified as a "hallmark of trauma" (Bloom, 1997, p. 249) and seen as an "ordinary response to... *unspeakable... atrocities*" (Herman, 1992, p. 1, italics in the original text). However, a *turning point* is only mentioned incidentally (Bloom, 1997; Herman, 1992) whereas in this study *the turning point* was pivotal.

Herman (1992), in her substantive theory on trauma survivors, conceptualises stages in the process, in which trauma victims engage. As with this study, Herman (1992) presents empowerment as an overarching fundamental component. In common with the recovery process discussed under the recovery paradigm in the disability model, Herman's (1992) process of recovery starts with the equivalent of stage two of the basic social psychological process of *transforming oneself*, as explored in chapter five. Many of the same elements were present as in this study.

In the study of psychological trauma, the importance of other people providing support by counteracting disempowerment is also mentioned (Herman,

1992). Herman describes how this type of support facilitates healing. She writes that healing is achieved by being a witness and ally, by "detoxifying... [the] sense of shame, stigma, and defilement" and by employing fairness and showing compassion (1992, pp. 67-68). The health professional becomes an assistant, a trainer and coach who gives expertise and moral support in what Herman (1992) calls a "cooperative therapeutic alliance" (p. 127). The role of support groups has also been highlighted in providing an environment for a "widespread, if not universal, mode of healing" (DeVries, 1996, p. 409).

The study of psychological trauma also calls for a *transformation of society* with regards to how to treat trauma victims. Bloom (1997) points out that, as psychological trauma is a "social disease" (p. 75), the "mechanism for healing is [also]... social" (p. 59). She proclaims that "it is not the traumatised person who is... sick. It is those people who fail to understand [him/her]" (p. 59).

Herman (1992) sees society as being transformed when its members take responsibility. This responsibility lies in two areas: recognition and restitution. Recognition means to fully reveal the extent and complicity of society in perpetrating violence. This revealing involves "public truth-telling" (Herman, 1992, p. 208). Public truth telling then becomes the factor that allows for social action (Herman, 1992). This action involves repairing the harm done through society's second responsibility, restitution. The justice system is the arena for this (Herman, 1992).

According to McFarlane and Van der Kolk (1996a), the media, in being "prime purveyors of traumatic news" (p. 42), can also play an important role in assuring that trauma victims are treated with compassion and understanding.

In the twentieth century, despite extensive research laying the cause of mental disorders in the realm of trauma, biological causative theories of mental disorders treatable mainly by medications remain dominant (Ross, 2008). Even many adherents of the study of psychological trauma believe that individual based psychotherapy can be sufficient in helping patients (Ross, 2008). Exhortations to "hear, listen and help" (Karon, 2008, p. 143) are still being made and calls for justice and social change remain peripheral (Hammersley et al., 2008).

In conclusion, the study of psychological trauma rests on the study of many diverse groups of trauma victims. It confirms the reports of those participants in this study who had been abused. The study of psychological trauma also illustrates how aspects of the disease model, psychological models and theories, the disability model, and socio-political models and theories including psychiatry can work together to help trauma victims.

7.8: Summary of the discussion

The models and theories selected for comparison with the substantive theory of *transforming oneself and society to resolve life being a struggle* brought with them further illuminations of the experiences reported by participants in this study. The one theory giving practical guidance as to how to accomplish a permanent change in the lives of participants in this study, as they outlined in *the empowering conditions* in chapter six, is the social movement theory. This underscores this substantive theory's assertion that a *transformation of society* is the way forward in mental health.

CHAPTER 8: RECOMMENDATIONS, LIMITATIONS AND CONCLUDING STATEMENT

8.1: Introduction

Participants in this study laid out their main concern in the basic social psychological problem of *life being a struggle*. They determined that *life being a struggle* was brought on by *disempowering conditions*. They recounted how they resolved the basic social psychological problem of *life being a struggle* through the basic social psychological process of *transforming oneself*. They also identified *empowering conditions* that helped them in this process. Moreover, they outlined how they wanted society to be transformed so that the *disempowering conditions* that brought on *life being a struggle* in the first place would be ameliorated or even prevented from occurring. The resulting substantive theory is called *transforming oneself and society to resolve life being a struggle*. The discussion chapter, chapter seven, then expanded further this substantive theory by providing additional corroboration and offering further guidance to participants in this study by a comparison with other models and theories.

In this last chapter of the thesis, recommendations are made, based on the substantive theory of this study and its discussion. These recommendations are for consumers, health professionals, governments and health services, and members of the general public. This section concludes with an example of a successful application of the recommendations in a health service. The chapter ends with an outline of the limitations of the study, including suggestions for future research, and a concluding statement.

8.2: Recommendations for other consumers

Based on the substantive theory of *transforming oneself and society to resolve life being a struggle*, which rests on the grounded theory analysis of interviews with 35 people diagnosed with major depression, bipolar disorder and schizophrenia, and relevant literature, other consumers may want to consider tracing the footsteps of participants in this study. The decision of those consumers who choose to shut themselves off from society as a wise measure after long and careful deliberation, as some participants in this study did, has to be fully respected. Other consumers may decide to come together, share their

experiences, validate each other and provide support to each other for their long and arduous journey towards fully resolving the basic social psychological problem of *life being a struggle*. With this theory now to hand both groups would now realise that they were not at fault and not to blame. They would also realise that they have to make their own decisions and take ownership over their life in spite of any ongoing *disempowering conditions*. This would give them sufficient power and strength to gain a new perspective, learn new strategies and take action so that they can *transform themselves* and attain *being at peace*, as identified in chapter six. They would also now realise that the dehumanisation occurring through being disempowered, as Freire (1993/1996) put it, "although a concrete historical fact, is *not* a given destiny but the result of an unjust order" (p. 26, italics in the original text) and that being disempowered should not be seen as a "closed world from which there is no exit, but as a limiting situation, which... can [be] transform[ed]" (p. 31).

Yet other consumers may want to join those participants in this study who wanted to take political action but did not know how to at the time of the interviews. These consumers may choose to engage in a different struggle, a struggle that tackles consumer disempowerment politically. Oliga (1996) urges these consumers on in this "long term, arduously uphill struggle" by issuing a "battle cry... against entrenched and often unwitting forces of social domination, oppression and exploitation" (p. x).

This different struggle then involves changing the disempowering aspects of society according to participants' vision in the *transformation of society*, as presented in chapter six, and as elaborated on in the social movement theory in chapter seven. The consumer-writer Deegan (1992) proclaims that in order to move towards this vision it is necessary "to organise our movement, raise our consciousness, develop our own lived philosophy, and discover and develop services that we need in order to live independently" (p. 18).

8.3: Recommendations for health professionals

Health professionals are invited to support consumers to gain power. These tasks should be carried out on a personal, professional and societal front. As called for by participants on a personal front, a major cultural change is required for health professionals: "There needs to be a change of ethos overall" (Connor & Wilson,

2006, p. 467). This involves altering the balance of power between consumers and health professionals (Repper & Perkins, 2003). Coleman (2004) calls for a "deconstruction of the power of the psychiatric system and [a] reconstruction [of] power as a personal commodity [belonging to consumers]" (p. 45). The psychiatrist Bloom (1997) adds that this requires health professionals to "lay aside the brute power of our authority and to try other methods instead" (p. 152). These other methods, according to Høyer (2008) "would 'coerce' psychiatrists and other mental health professionals to develop non coercive alternatives" (p. 288). To help with the implementation of empowerment a consumer-participant, in Brody's (2008) study suggests that "rather than measure individual 'outcomes', why don't we measure consumers' empowerment as a whole?" (p. 35).

Guidelines for measuring, or better recognising, consumers' empowerment can be obtained from this study. Empowerment on the individual level would be present when consumers make the decisions, as participants did during *the turning point* and in stage two of the basic social psychological process of *transforming oneself* in chapter five. On the social level, consumer empowerment is evident when their decisions are respected by others, even if they do not coincide with other people's viewpoints. For example, respecting the decision not to use abusive health services and damaging treatments, as some participants in this study decided to do when they *took action* to protect themselves, also in stage two of the basic social psychological process of *transforming oneself*, would indicate empowerment.

On the professional front, the health professionals' task involves resolving the contradictions inherent in the dual roles of psychiatry as a 'curing' agency and as a control agency. Many mainstream authors assert that they cannot exist together (Anthony, 2006; Bloom, 1997; Iversen, 2009; Jacobson & Greenley, 2001; Vassilev & Pilgrim, 2007). Moreover, all that participants in this study want from mental health care is help. They found that neither role fulfills this request. Jacobson and Greenley (2001) emphasise that coercion in particular has no place in mental health care and consent has to be "the bedrock of daily practice" (p. 484). However, psychiatry can help consumers by transforming itself into a healing agency. Healing does not promise an elusive cure at some time in the future but is achievable at the present time. This healing, as found both in this study and in the literature presented in the discussion, has to occur

with awareness of the wounds that opened up in *having a mental disorder* and with respect of *having been abused*, both explored in the *disempowering conditions* in chapter three.

Healing with regards to *having a mental disorder* can be achieved by focusing on *getting better as a person*. In stage two of the basic social psychological process of *transforming oneself* in chapter five, participants demoted *having a mental disorder* to a less important position. They also destigmatised it. Healing with regards to *having been abused* occurs by uniting the split between an outer persona and an inner tormented self and getting a congruence in the feeling that one is one person, not two, as participants in this study had done in creating a new perspective, also as part of stage two of the basic social psychological process of *transforming oneself* in chapter five. Other people can help in this process by empowering consumers through recognising them as humans with equal power. The question of whether mental disorders are diseases has now become redundant:

What exists, in the truly existential sense, is not an illness or disease. What exists is a human being and wisdom demands that we see and reverence this human being before all else. Wisdom demands that we wholeheartedly enter into a relationship with human beings in order to understand them and their experience. Only then are we able to help in a way that is experienced as helpful. (Deegan, 2005a, p. 58)

On the societal front, the health professionals' task has to be directed towards the cure through relationships. Engagement in social and political reform is one way. Healing the wounds created by *the disempowering conditions* related to participants' social sphere will result. Bloom (1997) asks: "Should we be helping them [consumers] 'adjust' to a sick society, or should we be doing something to make society less sick?" (p. 97). Some health professionals have already taken on this task and see their role as "radical social activists, proselytising for changes in our society to make it more supportive, less dehumanised" (Bloom, 1997, p. 97). They have come to realise that many consumer concerns are "resolved not by therapeutic strategies but by political moves and revolutionary changes. The therapist or practitioner must become, in this view, revolutionary" (Aldridge, 1998, p. 267). The psychiatrists Salter and Byrne (2000) urge health professionals to "stand up and be counted" (p. 283).

Health professionals are tasked with learning that empowerment is essential to the therapeutic approach and that they can help consumers to bring about their vision of a transformed society by lobbying for justice and *providing effective help*, as outlined by participants in this study in chapter six. These recommendations also need to be included in health professionals' education programmes.

8.4: Recommendations for governments and health services

Providing a healing environment is also a task for governments. They can heal the wounds that have been inflicted on consumers, as detailed in the *disempowering conditions* in chapter three, and by providing justice, as outlined in *the empowering conditions* in chapter six: "Justice heals wounds" (Abu Ahmed, n.d., cited by Algazy & Vidal, 2009, p. 1).

Participants in this study called for justice by being treated equally in law. They wanted governments to reform laws to ensure they had equal status with the rest of society. Court judgements should be impartial and fair so that perpetrators do not get away with their abuse and other misdeeds but are brought to task. Human rights violations have to be abolished. Moreover, anti-discrimination should also be enforced and anti-defamation laws created with regards to consumers.

Furthermore, participants in this study insisted that all those individuals who are a danger to others should be dealt with under the justice system irrespective of whether they have a mental disorder. This study therefore calls on governments to re-examine the line between protecting the public, including consumers, and human rights laws that recognise all people, including those with a mental disorder, as being capable of knowing the difference between right and wrong. As Szasz (2007) puts it: "The [mental] illness limits their [consumers'] freedom of action but not their status as moral agents" (p. 14). Participants in this study provided ample proof that they were capable of being moral agents, for example in the basic social psychological process of *transforming oneself* in chapter five. However, governments sanction compulsory treatment of consumers before any crime has been committed which, according to participants, violates their human rights. Participants called for governments to transform health services. The old style mental health hospital should be

redesigned into modern village type units with suitable amenities and Centers of Excellence to run intensive programmes. Affordable accommodation with security of tenure should be made available in the community. Broad-based community services should be provided with a sufficient number of caseworkers and home help workers. This would then free up access to specialised mental health services and allow for adequate communication channels between and within services.

Health services should be trained to listen to consumers, believe what they say, and tell them the truth. They should also ask what had happened to consumers so that the *disempowering conditions* are uncovered and addressed. Being there for them, genuinely caring and showing compassion should be routinely practiced. The search for the right medication must be persisted with if necessary. Enquiring about abuse in childhood and /or adolescents should be routinely carried out with the permission of the consumer and with sufficient specialised help available. Ongoing support for consumer movements needs to be provided.

Support for families-at-risk would prevent or at least reduce further abuse from occurring, whether in childhood and/or adolescence or in domestic violent situations. Anti-stigma campaigns have to be directed towards changing the attitude of the general population using the principles of social marketing, as explained in the positive impact of power in chapter seven. All these ways of *providing effective help* should be enshrined in education programmes, including in policy documents.

Governments also have to allocate adequate and appropriate financial resources so that health services can implement these recommendations.

8.5: Recommendations for the general population

The task of healing the wounds perpetrated on consumers has to continue into the general population. As this study showed and is also documented by other consumers in the literature (Connor & Wilson, 2006; Hughes et al., 2009), the healing of wounds in this context comes about through positive relationships. How positive relationships can be occur has been set out by participants in this study, at the heart of which is empowering them by valuing them as equal human

beings. Martens (2005) asserts that "stigma will only cease to exist when people are valued for who they are" (p. 3).

In order for positive relationships to occur and the prevention of wounds being inflicted by the views, values and actions of society, as covered in *the disempowering conditions* in chapter three, participants in this study explained that a change of mind has to occur in the general population. In *the empowering conditions*, as laid out in chapter six, participants suggested using persuasion, education and a personal approach involving other people emotionally. The social marketing approach, described as part of the social movement theory from chapter seven, adds that protest is also useful when the public are urged to practice moral justice and act accordingly.

A second way to empower consumers is to stop pointing the finger at them, blaming them for *having a mental disorder* and ignoring or dismissing *the disempowering conditions*, elaborated on in chapter three. As other authors point out, the general population should reflect "upon the society that we have produced" (Aldridge, 1998, p. 271). When reflecting upon what society has been produced, according to Van der Kolk and McFarlane (1996), the public will "inevitably [be] confronted with issues of man's inhumanity to man, with carelessness and callousness... with manipulation and with failures to protect" (p. 6). This also points to the necessity for societal change.

In order to change society, Marshall et al. (2007) emphasise that the focus has to shift from labelling the powerless, in this case consumers, as so-called deviants, towards challenging the rules, particularly the rules underlying the discriminatory behaviour of the dominant group: "This means sharpening our sights on human rights, on injustice and on discrimination as actually experienced by people with mental illness" (Thornicroft & Kassam, 2008, p. 192).

As part of challenging the rules, the "shuffling out of our own responsibilities" (Aldridge, 1998, p. 7) for creating them has to be addressed. These responsibilities come in five forms. In the first, members of the public are called upon to take responsibility for their own views, values and behaviours towards consumers:

Taking responsibility means to uncover what society has done to "cause the person to be mad". When someone goes mad in our culture it is off to the

hospital with him or her. It is not a gathering of the local community that gets together to decide what is wrong with the community. (Coleman, 2004, p. 14)

As a result of such a change in focus, people with mental disorders would not be seen as the perpetrators of violence but as the victims (Rice, 2009).

In the second form, in Bloom's (1997) words, responsibility lies in caring for others. She states that this responsibility is "fundamental... [and] not just an abstract concept" (p. 243). She explains that taking responsibility to care for others involves "making peace and eschewing violence, to create an atmosphere of kindness, respect, mutual regards, and tolerance rather than one of hostility, fear, disrespect, shame, or intolerance" (p. 120).

In the third form, responsibility entails deciding what to do when one is confronted with situations where injustice and the mistreatment of others is played out: "Every day, in virtually every situation in which there is a power imbalance, an injustice, a hurt person or hurt feeling, we are offered the opportunity to play one of three parts: the victim, the perpetrator, or the bystander" (Bloom, 1997, p. 243). Bloom (1997) urges people to decide to take the side of the victim because this can make a crucial difference: "All it takes is for one bystander in a group to take some sort of positive action against perpetration and others will follow" (pp. 244-245). She refers to widespread research, which shows that "the behaviour of the bystander determined how far the perpetrators went in carrying out their behavior" (p. 243).

In the fourth form, taking responsibility refers to speaking out about the actions of perpetrators and making it known that they are not acceptable. This gives legitimacy to the disempowered by "counteracting the ordinary social processes of silencing and denial" (Herman, 1992, p. 9). Speaking out then leads to the containment of mistreatment: "This containment can happen... only if bystanders choose to become witnesses and rescuers, instead of silently colluding with the perpetrators" (Bloom, 1997, p. 245). According to Bloom (1997), the actions of bystanders can then create physically and ethically safe environments, or what she calls a "sane society" (p. 1).

In the fifth and last form, responsibility is "confronting and addressing explicitly... the existing social order" (Olga, 1996, p. 169) that enshrines unequal power relationships. Olga (1996) calls for a "radical transformation of

that social order" (p. 169). The necessity for this radical transformation is demonstrated throughout this study.

8.6: An example of a successful implementation of the recommendations in a health service

The mental health services in Trieste, Italy, are an example of how the struggle against disempowerment and for the humanisation of the treatment of consumers through empowerment can be implemented. At the centre of the mental health services in Trieste is the assertion of the humanity of the patient (Kendall, 1996). Its theoretical underpinnings were formulated by the Italian psychiatrist Basaglia in the 1960s (Kendall, 1996). Kendall (1996) summarised Basaglia's ideological stance:

The psychiatric patients' real problem was not their mental illness but rather the way we treated them and how we viewed them; in particular our substitution of the illness for the patient and the subsequent incarceration of the patient in the mental hospital, excluded from the rest of society. (p. 4)

Along with this study, Basaglia (1987a) recognised the central importance of power in the relationship between society and consumers. He stated that mental health care must not be used as social control measure. He set about to "dismantle what has been done" (p. 81) and advocated to "confront the world of terror, the world of violence, the world of exclusion" for consumers (p. 81). He realised that in order to effect this change and translate the humanisation of the treatment of consumers into practice, health professionals themselves had to become politicised. He pursued this politicisation, along with colleagues and a substantial part of the Italian society that had joined a popular struggle as part of an anti-institutional movement in the late 1960s (Scheper-Hughes & Lovell, 1987), by creating a "radical movement for the liberation of psychiatry" (Kendall, 1996, p. 1). Basaglia (1964) explained that the liberation of psychiatry depended on health professionals freeing themselves from seeing patients as objects, which he described as an "alienated relationship of *slave* towards *lord*" (p. 3, italics in the original text). Instead Basaglia (1987a) emphasised that health professionals should establish "a real relationship" (p. 80) based on a subjective understanding of "anguish and suffering" (1987b, p. 304) that went beyond the "cultural schemes that imprison us" (1987b, p. 303). He wrote that health

professionals "must grasp the world of needs from which suffering emerges, restoring it to the history from which it was banished in the very moment it was defined as an illness" (1987b, p. 303).

Basaglia's movement succeeded in enacting a law in 1978, called Law 180, that outlawed the construction of new mental hospitals and facilitated the gradual closure of existing ones (Basaglia, 1987b). It also addressed issues of dangerousness so important for participants in this study. Law 180 also outlawed the use of the judicial concept of dangerousness so that psychiatry had to "confront those who suffer from psychic disturbances without protecting itself behind the screen of dangerousness and custody" (Basaglia, 1987b, p. 300). If hospitalisation was required, it was due to a lack of capacity in the community to respond to the "needs and rights of the citizen, in sickness and in health" (Basaglia, 1987b, p. 300). The onus was therefore put on the community to set this right. This was similar to the call of participants in this study for a *transformation of society*. Another facet of Law 180 was to prevent the ideology practiced in mental hospitals with its "persistence of social marginalisation [of consumers], justified by the alibi of illness and treatment" (Basaglia, 1987b, p. 301) to be carried over into services provided in the community, as suggested in the recommendations for health services in this chapter.

As with this study, a respect for patients' decision-making power was at the heart of the humanisation of the treatment in Trieste (Mezzina et al., 1992). Health worker-patient co-operatives were established (Kendall, 1996) where consumers were not only directly involved in creating their own personalised treatment programmes but also in strategies aimed at restoring their rights and integrating them back into society. Mezzina et al. (1992) argued that this overcame the "separation between 'the illness' and the clients' comprehensive existence in society" (p. 69). Consumers discussing and analysing their relationships with the community, "in particular the process of exclusion/marginalisation" (Mezzina et al., 1992, p. 71), was the aim of restoring the "opportunity to have access to these rights" (p. 72). This mirrored parts of the social movement theory.

By 2006, a report on the mental health services in Trieste by Australian Senator Lyn Allison, then chair of the Senate Select Committee on Mental Health, found that no electro-convulsive treatment was used, no homelessness

had occurred, only one consumer was in a forensic ward, suicide rates had dropped by 30%, and many patients, even those with psychosis, were employed in competitive industries on award wages (Allison, 2006). However, the humanisation of the treatment of consumers through empowerment as practiced in Trieste has not been implemented in many other places. Basaglia (1964) gave as one reason for this "the fear of the mad overcoming every logical and humanitarian comprehension" (p. 2). This still seems to be the case today as documented by participants in this study.

The success in Trieste shows that the recommendations from this chapter are not fanciful but can be translated into reality. Consumers in Trieste welcomed the effort undertaken by Basaglia and his colleagues as illustrated by a graffiti painted in large letters on the wall of a closed mental hospital: "Liberty is Therapy" (Kendall, 1996, p. 8). Participants in this study would also surely welcome such a health service.

8.7: Limitations of the study and future research

The objectives of this study were to explore and explain the experience of consumers living in the Western Australian community; to identify conditions, or factors, that influence this experience; and to develop a substantive theory that explains consumers' common shared experience. The developed substantive theory of this study, entitled *transforming oneself and society to resolve life being a struggle*, was formulated using the grounded theory method based on qualitative data elicited through open-ended interviews with 35 people who identified themselves as having been diagnosed with major depression, bipolar disorder and schizophrenia about their experience as consumers living in the Western Australian community. Participants were over 18 years old, spoke English as their first language, largely belonged to the Anglo-Saxon culture and lived in the Perth metropolitan area in Western Australia.

Two areas of limitations can be noted here. The first concerns the selection of participants. A relatively small number of people were selected to be interviewed. However, the grounded theory method uses diverse concepts and their relationships with each other as the building blocks for a substantive theory and not the number of experiences or the number of people relating an experience. The latter two are unimportant. Data collection is sufficient and

interviewing is stopped when no new concepts can be added and the same concepts indicating a recurrent pattern in behaviour are found. This is termed saturation. Saturation was reached at 35 interviews in this study. In the literature review, concepts pertaining to the experience of other consumers then substantiated the concepts identified in the original 35 interviews. Representativeness is not required for a grounded theory study.

Another limitation of the selection of participants was the restriction of data collection to those people who identified themselves as having been diagnosed with major depression, bipolar disorder and schizophrenia. These three mental disorders were chosen because they represent the greatest burden of disease, or years of life lost due to disability, in terms of personal, social, financial and economic costs attributed to mental disorders (Robinson & Pennebaker, 2002). Some data from people without a mental disorder were also included in the literature review and in the discussion in order to include negative cases and to broaden the scope. Further research is recommended in conjunction with people affected by other mental disorders. However, a note of caution has to be given with regards to including the experiences of the general population and other people, such as health professionals (for example, Jung & Newton, 2009) and family members (Wynaden, 2002), as their perspectives have been found to be very different to the experiences of participants in this study. The one health professional and the one family member included as participants in this study only contributed a few concepts to the substantive theory despite giving frank and detailed interviews about their relationship with consumers.

Moreover, the mental health diagnoses were not confirmed by doctor's reports but were based on what participants identified they had been diagnosed with. However, it was evident in the interviews that all participants had experience of the phenomenon under study, namely what it was like to be a consumer with such a diagnosis living in the Western Australian community. This was the critical criterion for inclusion in the study.

Another limitation concerning selection was that participants were self-selected. All participants, with the exception of two, responded to advertisements placed in community newspapers, through invitations at support groups and a drop in centre as well as through announcements about the study on a community radio station. However, self-selection ensured that the participants who came

forward were eager to share their experiences because they saw this study as a way to help other consumers.

The self-selection of participants also produced a relatively high proportion of those with university degrees and consumer activists. This may be regarded as a limitation because it may not be seen as typical of the general consumer population. However, their comments were in line with those of the other participants and only extended them in the section on *facing other people head on* the basic social psychological process of *transforming oneself*.

The selected participants were also over 18 years old. This age restriction occurred for consent reasons. Therefore further research is needed to take into account the experience of consumers under the age of 18.

Another limitation concerning the selection of participants was that participants spoke English as their first language and largely belonged to only one cultural group. The literature review in the body of the thesis and the literature used for discussion was also restricted to English language publications and to the same cultural group. Therefore, the many other people who do not speak English as their first language and/or belong to other cultural groups were excluded. However, it was found that including other cultural groups in this study was beyond its scope. In fact, Read et al. (2006) warn not to export a substantive theory to the experiences of people belonging to other cultures without a great deal of thought. Therefore, substantive theories on the experiences of consumers using other languages and belonging to other cultural groups need to be written.

A last limitation of this study is that participants lived in the Perth metropolitan area, a relatively small geographical region, and interviews were conducted only over a period of three months. However, studies conducted in other parts of Australia and in other countries such as those in North America and Europe ranging over many years were included in the literature review and in the discussion.

A second area of limitation pertains to the grounded theory method. This method only concentrates on one core category, that is, how participants resolve their main concern, and the conditions influencing it. However, concentrating on this one core category "focuses on the interests of the participants in favour of that of [others]" (Glaser, 1998, p. 45). It also does not allow for sidetracking into

irrelevant and/or unimportant matters. Reproducibility (Glaser, 2001) and objectivity (Glaser, 2003) are unimportant in a grounded theory study.

In conclusion, despite the limitations listed here the objectives of this study have been achieved. The substantive theory of *transforming oneself and society to resolve life being a struggle* fits, works, is relevant, modifiable and is "applicable in daily life" (Glaser & Strauss, 1967, p. 237), as was also testified to by the 16 participants who gave feedback. It has logical consistency, clarity, parsimony, density, scope and integration. However, the limitations indicate that the developed substantive theory of this study does not speak for all consumers. It is important that further research expands on the substantive theory so that a sound theoretical base is developed to explain what happens to all consumers and what they suggest they and others can do to prevent the *disempowering conditions* from occurring and subsequently life becoming a struggle, and to achieve a permanent *transformation of themselves and society*.

8.8: Concluding statement

This study put forward a theory that explored and explained the experience of consumers living in the Western Australian community. It is hoped that it will contribute to the increasing literature emanating from the consumer community so that their power is strengthened through research that will highlight their concerns and their solutions so that they no longer must struggle.

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APPENDIX A: Diagnostic and Statistical Manual of the American Psychiatric Association classification of disorders (DSM-IV-TR)

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Mood disorders

The DSM-IV-TR diagnostic criteria for Major Depressive Disorder

- A. Five (or more) of the following symptoms have been present during the same 2 week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.
1. Depressed mood for most of the day, nearly every day, as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful)
Note: In children and adolescents, can be irritable mood
 2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated by either subjective account or observation made by others)
 3. Significant weight loss when not dieting or weight gain (e.g., a change of more than 5% of body weight in a month), or decrease or increase in appetite nearly every day
Note: In children, consider failure to make expected weight gains.
 4. Insomnia or hypersomnia nearly every day
 5. Psychomotor agitation or retardation nearly every day (observable by others, not merely subjective feelings of restlessness or being slowed down)
 6. Fatigue or loss of energy nearly every day
 7. Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self-reproach or guilt about being sick)
 8. Diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)
 9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide
- B. The symptoms do not meet criteria for a Mixed Episode.
- C. The symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The symptoms are not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

- E. The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one, the symptoms persist for longer than two months or are characterised by marked functional impairment, morbid preoccupation with worthlessness, suicidal ideation, psychotic symptoms, or psychomotor retardation. (p. 356)

DSM-IV-TR Diagnostic Criteria for Manic Episodes

Manic episode

- A. A distinct period of abnormally and persistently elevated, expansive, or irritable mood, lasting at least one week (or any duration if hospitalisation is necessary).
- B. During the period of mood disturbance, three (or more) of the following symptoms have persisted (four if the mood is only irritable) and have been present to a significant degree:
1. Inflated self-esteem or grandiosity
 2. Decreased need for sleep (e.g., feels rested after only 3 hours of sleep)
 3. More talkative than usual or pressure to keep talking
 4. Flight of ideas or subjective experience that thoughts are racing
 5. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli)
 6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation
 7. Excessive involvement in pleasurable activities that have a high potential for painful consequences (e.g., engaging in unrestrained buying sprees, sexual indiscretions, or foolish business investments)
- C. The symptoms do not meet criteria for Mixed Episode.
- D. The mood disturbance is sufficiently severe to cause marked impairment in occupational functioning or in usual social activities or relationships with others, or to necessitate hospitalisation to prevent harm to self or others, or there are psychotic features.
- E. The symptoms are not due to the direct physiological effects of a substance (e.g. a drug of abuse, a medication) or a general medical condition (e.g., hypothyroidism).

Note: Manic- like episodes that are clearly caused by somatic antidepressant treatment (e.g. medications, electroconvulsive therapy, light therapy) should not count toward a diagnosis of Bipolar I Disorder. (p. 362)

DSM-IV-TR Diagnostic Criteria for Bipolar I Disorder Variants

Bipolar I disorder, single manic episode

- A. Presence of only one Manic Episode and no past Major Depressive Episodes

Note: Recurrence is defined as either a change in polarity from depression or an interval of at least two months without manic symptoms.

- B. The Manic Episode is not better accounted for by Schizoaffective Disorder and is not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

Bipolar I episode, most recent episode hypomanic

- A. Currently (or most recently) in a Hypomanic Episode.
- B. There has previously been at least one Manic Episode or Mixed Episode.
- C. The mood symptoms cause clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- D. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

Bipolar I episode, most recent episode manic

- A. Currently (or most recently) in a Manic Episode.
- B. There has previously been at least one Major Depressive Episode, Manic Episode, or Mixed Episode.
- C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

Bipolar I episode, most recent episode mixed

- A. Currently (or most recently) in a Mixed Episode.
- B. There has previously been at least one Major Depressive Episode, Manic Episode or Mixed Episode.
- C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified.

Bipolar I episode, most recent episode depressed

- A. Currently (or most recently) in a Major Depressive Episode.
- B. There has previously been at least one Manic Episode or Mixed Episode.
- C. The mood episodes in Criteria A and B are not better accounted for by Schizoaffective Disorder and are not superimposed on Schizophrenia, Schizophreniform Disorder, Delusional Disorder, or Psychotic Disorder Not Otherwise Specified. (pp. 388-391)

*Schizophrenia**DSM-IV-TR diagnostic criteria for schizophrenia*

- A. Characteristic symptoms: Two (or more) of the following, each present for a significant portion of the time during a 1-month period (or less if successfully treated):
 - 1. Delusions
 - 2. Hallucinations
 - 3. Disorganised speech (e.g. frequent derailment or incoherence)
 - 4. Grossly disorganised or catatonic behaviour
 - 5. Negative symptoms, i.e., affective flattening, alogia, or avolition.

Note: Only one Criterion A symptom is required if delusions are bizarre or hallucinations consist of a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other.

- B. *Social/occupational dysfunction:* For a significant portion of the time since the onset of the disturbance, one or more major areas of functioning, such as work, interpersonal relations, or self care are markedly below the level achieved prior to the onset (or when the onset is in childhood or adolescence, failure to achieve expected level of interpersonal, academic, or occupational achievement).
- C. *Duration:* Continuous signs of the disturbance persist for at least 6 months. This 6-month period must include at least 1 month of symptoms (or less if successfully treated) that meet Criterion A (i.e., active-phase symptoms) and may include periods of prodromal or residual symptoms. During these prodromal or residual periods, the signs of the disturbance may be manifested by only negative symptoms or two or more symptoms listed in Criterion A present in an attenuated form (e.g., odd beliefs, unusual perceptual experiences).
- D. *Schizoaffective and Mood disorder exclusion:* Schizoaffective Disorder and Mood Disorder With Psychotic Features have been ruled out because either (1) no Major Depressive, Manic, or Mixed Episodes have occurred concurrently with the active-phase symptoms; or (2) if mood episodes have

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occurred during active-phase symptoms their total duration has been brief relative to the duration of the active and residual periods.

- E. *Substance/general medical condition exclusion*: The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition.
- F. *Relationship to a Pervasive Development Disorder*: If there is a history of Autistic Disorder or another Pervasive Development Disorder, the additional diagnosis of Schizophrenia is only made if prominent delusions or hallucinations are also present for at least a month (or less if successfully treated). (p. 312)

Schizophreniform Disorder

Criteria A, D and E of Schizophrenia are met.

An episode of the disorder (including prodromal, active, and residual phases) lasts at least 1 month but less than 6 months. (When the diagnosis must be made without waiting for recovery, it should be qualified as “Provisional”.) (p. 319)

Schizoaffective Disorder

- A. An uninterrupted period of illness during which, at some time, there is either a Major Depressive Episode, a Manic Episode, or a Mixed Episode concurrent with symptoms that meet Criterion A for Schizophrenia.

Note: The Major Depressive Episode must include Criterion A1: depressed mood.

- B. During the same period of illness, there have been delusions or hallucinations for at least 2 weeks in the absence of prominent mood symptoms.
- C. Symptoms that meet criteria for a mood episode are present for a substantial portion of the total duration of the active and residual periods of the illness.
- D. The disturbance is not due to the direct physiological effects of a substance (e.g., a drug of abuse, a medication) or a general medical condition. (p. 323)

Re: Copyright permission

Dear Sir/Madam,

My name is Karola Mostafanejad and I am a PhD student at Curtin University of Technology in Perth Western Australia. I am completing my thesis on "Mental Health: The way forward. A Grounded Theory on the experience of mental health consumers living in the Western Australian community".

In writing my methodology chapter I must include the criteria for the types of mental disorders in my study. The participants have major depression, bipolar disorder and schizophrenia. I need to include a description of each of these disorders as an Appendix in my thesis. I would like to use the DSM-IV-TR diagnostic criteria and therefore, I am writing to seek permission to include these criteria as an appendix in my thesis. My estimated date of submission is April 2010.

Yours Sincerely

Karola Mostafanejad
19th January 2010

Dear Ms. Mostafanejad,

Your request to reproduce the DSM IV TR Diagnostic Criteria for Major Depressive Episode, Bipolar Disorder and Schizophrenia is granted for use in your thesis only.

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Sincerely,

Cecilia Stoute

(CStoute@psych.org, received 31st March, 2010)

APPENDIX B: INFORMATION SHEET

**Curtin University of Technology
School of Nursing and Midwifery
Department of Postgraduate Studies**

Title of study: Mental Health: The way forward. A Grounded Theory on the experience of mental health consumers living in the Western Australian community

My name is Karola Mostafanejad, and I am Doctor of Philosophy student at the School of Nursing and Midwifery, Curtin University of Technology. The purpose of my study is to describe the experience of mental health consumers in the context of the Western Australian community. I hope that the information obtained during this study will contribute to the understanding of this experience from the consumers' point of view.

I wish to invite consumers to participate in this study. Information about your experience as a consumer will be obtained through an interview lasting approximately 60 minutes. The interview will be audiotape-recorded, transcribed and analysed. When this process is completed I may need to make a further appointment with you to discuss or clarify issues. Your participation in this study is voluntary and you can withdraw at any time. If you sign the consent form you are consenting to:

1. Be interviewed at a mutually agreed place regarding your experience as a consumer.
2. Have the interview audiotape-recorded.
3. Be re-interviewed to clarify any issues arising from the first interview.
4. The findings of this study being published in the scientific literature.

During the interview you may decline to answer any question and you may ask to cease the interview or turn off the audiotape-recorder at any time. At no time will you be able to be identified by the information you have given me. Any reports or articles written about the data generated by this study will protect your confidentiality and will be presented as group data only. Code numbers will be given to each interview and I will be the only person involved in the study who knows your name.

The information obtained during the interview (including the tapes) will be stored in a locked cupboard during the study period. At the completion of the study the tapes will be erased. All transcribed interviews will be stored in the locked cupboard for five years after completion of the study and then destroyed. No other person will have access to this data.

If you would like to participate or have any questions or require any further information concerning the study please contact me on 0427 289 927 or e-mail karola.mostafanejad@modnet.com.au. Alternatively you may wish to speak to my supervisors Dr Dianne Wynaden on 92662203 or Associate Professor Dr Barbara Horner on 92667993. Ethics approval for this study has been obtained from Curtin University of Technology Reference Number: HR116/2006.

Thank you for taking the time to read this information sheet.
Karola Mostafanejad

APPENDIX C: INFORMED CONSENT FORM**Mental Health: The way forward. A Grounded Theory on the experience of mental health consumers living in the Western Australian community**

I..... have read the information sheet accompanying this informed consent form relating to the study on the experience of mental health consumers. I understand by signing this consent form I am agreeing to be interviewed by Karola Mostafanejad, to have that interview audiotape-recorded and to be reinterviewed if necessary. I understand that I may cease the interview and withdraw from the study at any time. I have been given a copy of this consent form. I understand that if I have any questions or concerns I can contact Karola Mostafanejad on 0427 289 927 or by e-mail karola.mostafanejad@modnet.com.au. Alternatively I may wish to speak to the supervisors Dr Dianne Wynaden on 92662203 or Associate Professor Dr Barbara Horner on 92667993. If I have any concerns or complaints about the way in which the study is being conducted, I may contact the secretary of the Curtin University of Technology's Human Research Ethics Committee Sinead Darley on 92662784. Ethics approval number Curtin University of Technology: HR116/2006.

Signed.....Participant

SignedResearcher

Date:

APPENDIX D: ETHICS APPROVAL

memorandum

To	Dr Dianne Wynaden Nursing and Midwifery
From	Dr Stephan Millett, Executive Officer, Human Research Ethics Committee
Subject	Protocol Approval HR 116/2006
Date	14 November 2006
Copy	Karola Mostafanejad (PO Box 118 Geraldton WA 6531), A/Prof Barbara Horner Graduate Studies Officer, Division of Health Sciences

Curtin 
University of Technology

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784

FACSIMILE 9266 3793

EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "*The experience of mental health consumers in the context of the Western Australian Community. A grounded theory study*". Your application has been reviewed by the HREC and is **approved**.

- You are authorised to commence your research as stated in your proposal
- The approval number for your project is **HR 116/2006**. Please quote this number in any future correspondence
- Approval of this project is for a period of twelve months **14-11-2006 to 14-11-2007**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **14-11-2007**
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Divisional Graduate Studies Committee.

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should to be completed and returned to the Secretary, HREC, C/- Office of Research & Development.

When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,



pp Dr Stephan Millett
Executive Officer
Human Research Ethics Committee

Please Note: The following standard statement must be included in the information sheet to participants:
This study has been approved by the Curtin University Human Research Ethics Committee. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au

APPENDIX E: INTERVIEW GUIDE**Thesis Title: Mental Health: The way forward. A Grounded Theory on the experience of mental health consumers living in the Western Australian community**

An open-ended interview format will be used in this study. Prior to the interview the researcher will establish rapport with the participant and explain the purpose of the study. Participants will be invited to talk with the following statement: Tell me about yourself.

The future direction of the interview will centre on the responses obtained from the participant's account. However, the following prompts will be reflected in questions used in the interview to ensure that the objectives of the study are met. Statistical information was also collected from the interviews to allow for a description of participants.

Tell me more.

How did that come about?

What did that entail?

What led to that?

How does the illness manifest itself?

How did that affect you?

What made you seek help?

How do you handle it?

How did you get to this point?

What do you think might have changed your outlook?

Why did you decide not to try dying again?

What do you see for your future?

What did health professionals do?

How did you find your stay in hospital?

What about community services?

What about your family?

At no time were participants asked about abuse occurring in childhood or adolescence or asked to elaborate on this abuse when it was volunteered by them.