

**“Does the doctor think I’m Crazy?”:  
Stories of low-income Cape Town  
women receiving a diagnosis of  
somatic symptom disorder and their  
subsequent referral to psychological  
services**

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## **Plagiarism Declaration**

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## ABSTRACT

Within the health system there is a group of patients who appear destined to remain at the borderline between medicine and mental health. They fail to fit into either discipline with any degree of comfort and so, to some extent, become marginalised by both. The presenting symptoms of these patients fall under the general rubric of “medically unexplained symptoms” (MUS), “medically unexplained physical symptoms” (MUPS), or “somatic symptoms disorder”. The physical manifestation of symptoms which have no known underlying organic cause creates confusion for the medical practitioner. Conversely, patients with apparent medical pathology superficially may appear to lie outside of the ambit and expertise of mental health.

The fear and uncertainty which is ubiquitously generated by illness and pain, appears to be complicated and exacerbated in patients with MUS. I attempted to explore the meaning and experience of these conditions “fraught with uncertainty” in the context of twenty female participants and their lives. As poor women of colour in South Africa, a country with a racialised and gender-weighted discriminatory history, these participants represent marginalisation on many fronts: socio-politically, economically, and medically – and who by their presence challenge the status quo of rendering them invisible.

This study explored and described the way in which this specific cohort of patients experienced and understood their medical management and subsequent referral to psychology. To this end, over a period of a year, I interviewed two groups of low-income women who presented to the state hospital system at two separate district level hospitals with unexplained physical symptoms. Ultimately, after varying periods of investigation these women were referred to psychological services in the respective hospitals.

I adopted a qualitative research approach, with an emphasis on foregrounding of the experiences of the women. I wished to obtain the rich and layered narratives of the women and their sense of identity within hospital and wider context. All the participants I interviewed had been referred to me as a psychologist by the medical

officers after no organic aetiology for their symptoms had been evidenced. While qualitative research frequently relies on the semi-structured interview, my research was particular in that it was conducted in circumstances which necessitated the accommodation of both clinical and research components. The aspect of maintaining the dual role became an important component of consideration and negotiation. This requirement impacted on the interview process. In this particular setting a formal clinical interview initiated the research process to accommodate the possibility of participants progressing to therapy.

**Conclusions:** Poor communication and misunderstanding of the role and function of psychology provide impediments to effective use of both medical and mental health services in low-income communities. Where knowledge is facilitated and patient participation encouraged the positive outcomes of referral to psychological services may possibly increase. Collaboration between mental and medical practitioners with patients with medically unexplained symptoms has the potential to alleviate distress and improve respectful and more effective management of these vulnerable and marginalised patients.

**Keywords:** Medically unexplained symptoms, somatic symptom disorder, medicine, mental health, women, low-income, poverty, marginalisation, South Africa, dual role, psychology, psychotherapy, gender

## OPSOMMING

In die gesondheidstelsel is daar 'n groep pasiënte wat hulleself op die grens tussen gesondheid en geestesgesondheid bevind. Hierdie pasiënte pas nie gemaklik in een van die bogenoemde velde nie en word dan, tot 'n mate, deur albei gemarginaliseer. Die simptome van die pasiënte val onder die breë sambreel van “medies onverklaarbare simptome” (MOS), “medies onverklaarbare fisiese simptome” (MOFS) of “somatiese simptome.” Die verskyning van fisiese simptome wat geen bekende, verklaarbare organiese oorsaak het nie, verwar die mediese praktisyn. Daarenteen mag pasiënte met oënskynlike mediese patologie weer voorkom asof hulle buite die kennissfeer van die geestesgesondheidswerker val.

In die geval van MOS-pasiënte blyk dit dat die vrees en onsekerheid, wat deur alle siekte en pyn veroorsaak word, erger en meer gekompliseerd is. Hierdie studie het probeer om die betekenis en ervaring van hierdie toestande "belaai met onsekerheid" in die konteks van twintig vroulike deelnemers se lewens te verken. As arm vroue van kleur in Suid-Afrika, 'n land met 'n rasgedrewe en gender-ongelyke diskriminerende geskiedenis, verteenwoordig hierdie deelnemers marginalisasie op verskeie vlakke: sosio-polities, ekonomies en medies. Boonop daag die teenwoordigheid van hierdie vroue ook die status quo uit wat hulle gereeld onsigbaar maak.

Hierdie studie ondersoek en beskryf die manier waarop hierdie spesifieke groep pasiënte die bestuur van hulle gesondheid en die daaropvolgende verwysing na sielkundiges ervaar en verstaan het. Oor 'n tydperk van 'n jaar is daar met twee groepe lae-inkomste vroue wat staats hospitale besoek het, onderhoude gevoer. Die deelnemers aan hierdie studie het twee verskillende distriksvlakhospitale met hul onverklaarbare fisiese simptome besoek. Mettertyd, na verskillende periodes van ondersoek, is hierdie vroue na sielkundige dienste in die onderskeie hospitale verwys.

Die navorsing is kwalitatief benader met die klem om die ervarings van die vroue op die voorgrond te plaas. Daar is gepoog om die ryk en gelaaide narratiewe van die vroue en hulle gevoel van identiteit te bekom. Al die deelnemers met wie daar onderhoude gevoer is, is na die navorser verwys vir sielkundige behandeling nadat

mediese personeel geen biologiese etiologie vir hulle simptome kon vind nie. Kwalitatiewe navorsing maak meestal van semi-gestruktureerde onderhoude gebruik, maar in die geval van hierdie navorsing was kliniese en navorsingskomponente van pas. Die handhawing van die dubbele rol as sielkundige en navorsers moes goed bestuur word en het die onderhoudvoering beïnvloed. Die navorsingsproses is geïnisieer deur 'n formele kliniese onderhoud om die moontlikheid te akkommodeer dat deelnemers aan die studie dalk later ook tot terapie kon oorgaan.

**Gevolgtrekking:** Swak kommunikasie en 'n misverstaan/wanbegrip van die rol en funksie van sielkunde verhinder die effektiewe gebruik van mediese-en geestesgesondheidsdienste in lae-inkomste gemeenskappe. Die positiewe uitkomstes wat voortvloei wanneer daar na sielkundige dienste verwys word, kan verhoog as kennis gedeel en pasiënte se deelname aangemoedig word.

Samewerking tussen geestesgesondheidswerkers en mediese praktisyns - wanneer daar met MOS-pasiënte gewerk word - het die potensiaal om angs van hierdie kwesbare en gemarginaliseerde pasiënte te verlig en respekvolle en effektiewe bestuur van hulle toestande te verbeter.

**Sleutelwoorde:** Medies onverklaarbare simptome, somatiese simptoombestuur, medies, geestesgesondheid, vroue, lae-inkomste, armoede, marginalisering, Suid-Afrika, dubbele rol, sielkunde, psigoterapie, geslag, gender

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## **DEDICATION**

To my mother, whose unconditional love and support enabled me to believe that I could do anything I set my mind to.

To my father, whose eccentricity taught me to tolerate difference and accept that there is no such thing as “normal”.

To my son and daughter, whose pride in me gave me the impetus to carry on so many times when I was disheartened, discouraged, or ready to give up.

## **CHAPTER ONE**

### **INTRODUCTION**

#### **1.1. INTRODUCTION**

Disease, disability and death are an unfortunate part of the human condition. There are few people who have been privileged enough to have completely escaped the experience of illness or pain. From minor and localized infections such as the common cold, to life threatening and disabling conditions including diabetes, HIV/AIDS, cancer or heart disease, most of us know the discomforting feeling of having our body fail us to a greater or lesser extent. In the majority of instances, medical expertise is sought in an attempt to establish cause and to alleviate the distress or suffering. Yet this process is not necessarily as unequivocal or clearly delineated as developing an illness, or physical symptom, receiving a diagnosis and obtaining definitive clinical management.

The research question guiding this study asks how a group of twenty low-income women experienced their process of being informed that their presenting symptoms of pain and illness had no underlying medical cause. Furthermore, the research question engages with the same women in attempting to elicit how they received, viewed and engaged with their referral to psychological services.

Inherent in the experience of illness is the identification and naming of the particular condition. There is the alleviation of incipient panic when an atypical symptom is investigated and diagnosed as something treatable. Many individuals have experienced frank terror, followed by comfort and relief when major diseases are identified, then referred to the appropriate discipline for medication or surgery to cure, or at very least to contain the progression. The anger and fear of knowing that a disease has grave implications, or even be terminal, may be ameliorated when there is a scientific label. Frequently, even when a particular disease is serious enough to threaten life, the validation of the symptoms through a medical diagnosis provides a palliative comfort. The philosopher Carel (2008), on receiving her diagnosis of the terminal and as yet untreatable lymphgioliomyomatosis (LAM,) gives voice to the bizarre comfort provided by finally being giving a reason for her puzzling and

disconcerting symptoms. “I remember feeling vindicated. Yes, I was sick. It was something serious and *it had a name*” (p. 5) (Italics added).

But what happens when there is no answer, no diagnosis and consequently no option of treatment? The failure of the healthcare system to identify a cause or category for a collection of symptoms may be very distressing for the patient. Jutel (2010) suggests that the function of a definitive diagnosis is to potentially explain, legitimize and normalize the disease entity or process. The patient feels validated and secure in the naming of their illness identity. Jutel (2010) quotes Balint (1964) in suggesting that diagnosis “provides a sense of order in the presence of disarray” (p.229). Similarly, Kornelsen, Atkins, Brownell, and Woollard (2015) suggest that in tolerating their medically unexplained symptoms, patients’ most acute need is to negotiate the existence and effect of the chronic uncertainty related to their lack of diagnosis. They highlight the therapeutic relationship as a primary factor in promoting tolerance of this uncertainty (Kornelsen et al., 2015).

The desire for the containment of confusion and uncertainty which a diagnosis provides is not confined entirely to the patient experience of medically unexplained symptoms. While from a medical perspective the “failure” to immediately diagnose should not necessarily be seen as entirely negative – it is a mark of good clinical practice not to label or diagnose too hastily and potentially inappropriately – it may ironically also be a source of discomfort and embarrassment for the doctor concerned (P. Smith, 2003; Stone, 2014).

The medical fraternity is trained in a clear trajectory of management: “assess, diagnose and treat”. The inability to fulfill this expectation creates a group of patients tainted with various, sometimes almost pejorative, labels: medically unexplained symptom (MUS), medically unexplained physical symptoms (MUPS), psychosomatic illness or somatoform disorders. Hurwitz (2004) provides a simple but adequate definition of somatization as the “psychological mechanism whereby psychological distress is expressed in the form of physical symptoms” (p. 172). Mobini (2015) quotes Olde Harman et al. (2013) in providing a definition of medically unexplained symptoms (MUS) or functional symptoms as “physical symptoms persisting for more than several weeks and for which adequate medical examination has not revealed a condition that adequately explains the symptoms” (p. 2).

For the patient, these “diagnoses by default” may carry with them connotations of disparagement, dismissal and even suggestions of psychological aberration. The patient is frequently left with the ongoing discomfort of the physical symptom, no validation in terms of diagnosis and consequently no hope of treatment; and, perhaps worst of all, the subliminal, sometimes overt, suggestion that their symptoms are figments of their imagination (Jutel, 2010; Nettleton, 2006; P. Smith, 2003; Stone, 2014). Stone (2014) provides an honest but sensitive description of the conundrum faced by doctors:

“Heartsink” patients present a moral dilemma. We recognise their suffering, but at the same time struggle with the feelings they trigger in us. Patients also experience negative feelings. Without a diagnosis they lack a narrative or vocabulary to make sense of their own suffering. (p. 191)

The focus of this study is primarily on understanding the subjective experience of patients who receive such a label. The data were collected within the circumscribed context of a very particular group of individuals within a specific socio-economic space. The participants interviewed for this study were economically poor women of colour, living in a country steeped in a history of racial, social and gendered discrimination and inequality. They presented to the public (State) healthcare system with various complaints and physical symptoms. These presenting complaints were investigated, found to be without known organic basis and referred to psychological services for follow-up.

## **1.2. BACKGROUND AND RATIONALE**

When Freud, Charcot and Breuer first coined the phrase “Hysteria” in the 1890’s (Webster, 1996), they might not have foreseen that over 100 years later, despite significant medical and psychiatric advances, patients would still be labelled with this non-specific and unsatisfactory diagnosis – albeit under numerous other taxonomies. In fact this perplexing condition has been around for much longer. Hysteria has been described as a “4,000 year old diagnosis that has been applied to no mean parade of witches, saints and, of course, Anna O” (Kinetz, 2006). Hustvedt (2012) explores the phenomenon in depth and her findings support Kinetz’s descriptions of it as a “murky” and somewhat misogynistic diagnosis where the incidence of diagnosis in

ratio of women to men is approximately 5:1 (Sadock & Sadock, 2007). The term “hysteria” is now largely obsolete, but the diagnosis remains and falls under the general rubric of medically unexplained symptoms (MUS) or medically unexplained physical symptoms (MUPS) or within the DSM categorization of somatization (DSM-IV) (APA, 2000) or somatic symptom disorder (DSM-V) (APA, 2013; Baller et al., 2015; Lipsitt, 2014; Rief, Mewes, Martin, Alaesmer, & Braehler, 2011).

I have spent several years working as a clinical psychologist in hospitals in low-income community settings in and around Cape Town. During this time I have been struck by the preponderance of female patients referred to me for management of what was previously termed somatoform disorder and now, with the recent publication of the fifth version of the DSM (Diagnostic and Statistical Manual) reclassified as “somatic symptom disorder” (2014). In this setting, the typical referral is of a woman who has undergone numerous investigations with no underlying medical cause found, followed by a referral for psychological assessment.

The areas in which I have worked, and in which these women live, are characterized by endemic unemployment, poverty and associated violence and crime. Understandably, many psychological studies concerned with violence and its sequelae focus on posttraumatic stress disorder (PTSD) (Guay, Billette, & Marchand, 2006; Kaminer & Eagle, 2010; Williams et al., 2007). There is sufficient evidence to support PTSD as a serious psychological response to either acute or chronic exposure to violence. However, there are also references in the literature to the comorbidity of physical or somatoform symptoms with PTSD (Kaminer & Eagle, 2010) which would indicate the possibility that violence and trauma can be associated with physical as well as psychological manifestations of distress (Romito, Molzan Turan, & De Marchi, 2005).

In my clinical practice in these poverty constrained and crime-ridden areas, I had few patients presenting with PTSD, but a steady stream of referrals for “somatoform” complaints. In a one-year period, when the total number of patients I saw (not including repeat visits) was 140, the proportion of patients referred for medically unexplained symptoms or somatoform complaints was approximately one third (i.e., 45 patients). Of these, 40 were women and five were men. Definitive statistics for female to male ratios in terms of mental illness are difficult to obtain – WHO (2002;

2006) suggests that figures are affected by such factors as under reporting, gendered willingness to acknowledge certain mental health problems, gendered bias in making diagnoses, etc. However, in my practice in the community setting, in keeping with other settings worldwide, the general ratio of female to male referrals for possible mental illness was approximately 3:1. The gender ratio for female patients presenting at the clinics with possible somatoform disorder, therefore, was substantially higher (at 8:1) and slightly higher for the general figures given for somatoform disorders of 5:1. (Kroenke & Spitzer, 1998; Sadock & Sadock, 2007). There have been other studies (Steinbrecher, Koerber, Frieser, & Hiller, 2011) which suggest that of the patients who present with medically unexplained symptoms, two-thirds are female. Howard (2013) suggests that while the reporting of somatoform disorders or medically unexplained symptoms may be as high as 30% in general practice, “higher prevalence occurs in cultures, families, and neurodevelopmental conditions in which the capacity to express emotion directly is attenuated” (p. 1). This consideration is perhaps cogent in the context of my study where this may be a possible contributing factor to the high number of women presented at the clinics I worked in.

Generally, few patients who were referred to psychology in the community health centre setting were enthusiastic about either the referral or the process in the initial stages. Many, in fact, never arrived for their first appointment. However, of those who did attend, I noticed a stronger sense of resentment and suspicion in the patients who had come to me after having asked for medical help for specific *physical* symptoms. They seemed distressed about the referral, and often confused, angry and resentful. I felt that finding a way to explore and document their experiences could be useful on several levels. The patients would be given the opportunity to voice their discomfort in a structured and focused way; I would have the opportunity to engage with them on a particular level which included both a clinical and research component; and the resultant data had the potential to facilitate providing information which could assist in formulating alternative approaches to managing future patients.

### **1.3. THE PROCESS: BOTH SIDES OF THE HEALTHCARE PARADIGM**

The process of accessing healthcare is ideally a clearly prescribed one, the specific interaction of which depends on the role of the participant, most notably whether they are patients or healthcare workers. Individuals enter healthcare institutions – doctors’



waiting rooms, infirmaries, clinics or hospitals – with emotions and expectations that relate to their particular identity, circumstance and purpose. Not all anticipated aspects are overt and acknowledged, many are unconscious or hidden as a consequence of misunderstanding, ignorance, medical illiteracy or the unequal power relationship. The patients' low socioeconomic status relative to that of the healthcare professionals may possibly have a direct impact on the way in which they are managed. In a study conducted by Olah, Giasano, and Hwang (2013), the socioeconomic status of patients impacted on the level of preferential management even when there was no direct impact on provider reimbursement.

In the South African situation, with the history of racial discrimination and evaluation, this relationship between service user and service provider may be further complicated. After the first democratic elections in 1994, it inherited, amongst other things, massive disparities in healthcare quality and provision, largely based on race (Myburgh, Solanki, Smith, & Lalloo, 2005). A survey conducted in 1998, four years after the first democratic election in 1994, found that, although race alone can no longer be the only criterion in determining satisfaction in healthcare delivery, and socio-economic considerations may play an equal part, the two are not unlinked. Myburgh et al. (2005) report on the findings of the study:

A 1998 countrywide survey of 3820 households assessed many aspects of health care delivery, including levels of satisfaction with health care providers among different segments of South African society. White and high SES respondents were about 1.5 times more likely to report excellent service compared with Black and low SES respondents, respectively. (p. 473)

Healthcare workers, whether doctors, nurses or paramedical staff, come to a place of employment where their function is prescribed within parameters relating to healing, curing or helping to alleviate suffering – especially physical suffering – in some tangible way. Professional competence and integrity is informed by the relative success in achieving these goals. Initiating this process, in the service of making the diagnoses, which in turn dictate appropriate treatment and care, examinations are done and tests of escalating sophistication and cost are conducted. The ultimate aim of this process, if not always to affect a cure, is to provide consolation to the patient in the form of a label, a medical term, a diagnosis which makes the pain and suffering

move from the unknown and intangible to the known, identified and acknowledged. There is a peculiar kind of comfort and feeling of competence for the medical practitioner being able to tell the patient: “*This* is what you have, *this* is what is wrong with you, *this* is causing the pain“. Even, at the very worst, if all that can be eventually offered is merely palliation, the legitimization of a diagnostic label is important (Jutel, 2010).

On the other hand, the recipients of care, the ill, infirm and injured, enter the same portals with different expectations. Most rudimentary is the optimistic hope of having their distress definitively diagnosed and effectively treated. The layperson, patient or client, to a greater or lesser extent, extends to the professionals in the healthcare environment, implicit trust regarding competence and expertise in successfully identifying and managing their presenting pathology. There is often the assumption and expectation of the near omnipotent capability of the medical personnel. The patients invariably arrive feeling physically discomforted in some way. They may also be experiencing an associated sense of emotional vulnerability as a consequence of “not knowing”. This comes with the insidious, often unspoken, fear associated with a body that suddenly appears to be inexplicably failing. But whatever the degree and component of distress, the patients generally come to the experts with the hope that the uncertainty will be resolved and a way forward prescribed.

When these respective expectations are not met, the relationship between the players may become fraught with feelings of anxiety, suspicion and even overt hostility. There are innumerable causations and contributory possibilities for the disconnect between expectation and experience. Frequently the facilities are inundated and overwhelmed by the numbers of patients presenting for treatment (Benatar, 2013; Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009; Lund, 2015). This difficulty in patient management and treatment may in various circumstances be the consequence of poor staff to patient ratio as well as inadequate, poorly maintained and functioning physical premises and equipment as a consequence of economic constraints. While the medical and paramedical staff may be performing to the highest standards in the context of suboptimal amenities, this may in the real situation translate into patients feeling ignored, neglected, marginalized and disrespected. At

the other end of the spectrum, the staff may feel overwhelmed, unappreciated and equally disrespected, with consequent defensive reactions.

While all these errors of communication and understanding may be enacted between staff and patients who present with obvious physical impairment, the potential for discord is exacerbated in a specific patient population. Those individuals who present with complaints that, despite the best medical investigation cannot be identified, represent a further complication of the tenuous patient-practitioner relationship. For these patients, who are told that there is no evident pathology, the system may appear to be failing them entirely. Although very real and appropriate medical exploration has been set in motion these patients are denied answers and solutions. For the attending medical practitioner these patients represent a challenge to the expected trajectory of medical care which anticipates diagnosis and treatment. Thus, the prospect for dissatisfaction and resentment is enormous for both parties.

Feeling ill or in pain, seeking help, or at very least explanation, and finding none is a distressing process. When the background of lived experience is one of material deprivation, social marginalization and gendered vulnerability it becomes a highly charged encounter with the potential for feelings of devaluation and humiliation (Olah et al., 2013). L. Smith (2010) discusses in eloquent detail the social isolation and exclusion experienced by poor people. When physical illness is factored into the equation, vulnerability and fear may increase. Within this context, to be told that the symptoms are inexplicable, or that the pain is phantom, has the potential to negate personal reality and identity in a particularly destructive and invidious way.

In terms of this study, the focus is on economically poor women who presented at a place of medical service complaining of some kind of physical impairment or pain, and who after investigation were told that there was no underlying medical cause. Some of the participants arrived at the respective hospitals at the end of a circuitous route, which may have involved private practice general practitioners (GPs), local clinics, and other hospitals. They had commonly held the perception that they had been pushed from pillar to post by a collection of puzzled, irritated and increasingly frustrated practitioners. While the perception of being the passive recipients of medical displacement occurs, the patients may also enact their own mechanism of dissatisfaction with the answers provided. A history of “doctor hopping” or “doctor

shopping” is not unusual for patients with medically unexplained symptoms (Aiarzaguena, Gaminde, Clemente, & Garrido, 2013; Baller et al., 2015; Servan-Schreiber, Randall Kolb, & Tabas, 2000; Servan-Schreiber, Tabas, & Randall Kolb, 2000; Stone, 2014). Where a diagnosis – or lack thereof – may be perceived to be incorrect or unsatisfying, the patient may choose the option of moving to another healthcare provider in the hope of receiving a more definitive or palatable outcome.

The individuals who participated in my study had been referred to psychological services at the end of a lengthy and inconclusive investigatory process. The patients in all but three instances did not understand these referrals. They had presented to the hospital with letters enumerating their specific physical complaints. They had invariably already been subjected to a barrage of investigations before coming to the hospital where many of these tests were repeated with the associated uncertainty, fear, discomfort and distress. At the end of this process not only were they not given a diagnosis, they received a referral to yet another healthcare worker whose expertise was purported to be in the realm of mental illness. The apparent relief of transferring responsibility on the part of the medical practitioner translated into feelings of confusion, resentment and hostility for the patient. These patients’ responses were not incomprehensible given the original expectation of coming to the hospital, and in addition were intensified by having no, or limited, understanding of the role of psychology in general, and in their situation in particular.

The history of my work in the community and in community health centres has provided me with experience of observing patients who find the psychology consulting room a strange and intimidating place, even in the context of acknowledged emotional distress. The concept and process of the discipline is generally poorly understood in the communities in which I both worked as a clinician as well as conducted my research. The limited knowledge that did exist situated psychological interventions as exclusively related to management of “crazy” people and carried with it consequent and not insignificant feelings of suspicion and prejudice. Of those patients referred, contacted and an appointment made, some never arrived. Those who did present at the first appointment were invariably anxious, defensive and/or uncooperative at the initial encounter. Colleagues in private practice (the predominant field of work for clinical psychologists in South Africa) may initiate

the first session with the assumption that the client understands, to a greater or lesser degree, the therapeutic process and the role of psychology. That luxury is seldom afforded to either the clinician or the patient in community work. In my experience, for the process to have any opportunity of succeeding, the initial hour is most often spent with an overview of the role of psychology, providing pragmatic examples of its *modus operandi* and the way in which it may benefit the particular individual and relate to their specific life circumstances. The initial time set aside to educate and elucidate invariably pays dividends in terms of ongoing attendance and engagement. There is often a shift in the patient role from passive recipient of information and instructions regarding personal healthcare, to one in which active participation and personal involvement are not only encouraged but also essential. Increasing engagement and active participation in the process generally follows initial hesitation and suspicion. For women who have been silent and silenced within their homes and communities, the opportunity to speak and give voice is often a unique and rewarding experience. I suspect that I am not alone in the feeling of professional validation I experience when a patient finds the therapeutic space an opportunity to voice previously unspoken thoughts or experiences and tell us, “I have *never* mentioned these things to anyone else” or “I have never told *anyone* what happened to me or how I feel.”

#### **1.4. PRECIPITATING EVENTS AND MAKING CONNECTIONS**

Individuals living in unstable and chaotic environments are particularly vulnerable to negative emotional and psychological responses (J. Smith, Swartz, Kilian, & Chiliza 2013; L. Smith, 2010). Where there are responses such as grief, depression and anxiety, there is some understanding and acceptance of the relationship between the two. The causal connection between a traumatic event and medically unexplained physical symptomology is not always so clear. Both generically and within the context of my research question, which concerns the experiences of low-income women in the context of medically unexplained symptoms, the association of traumatic event, bereavement or other loss with the onset of somatic symptoms is not always overt. But occasionally the realization that the physical pain, discomfort or symptom occurred concurrently with some life event, provides many patients with the opportunity to pause and reflect. In the context of clinical work this provides the

opportunity to mediate awareness of the process and assist in negotiating an exploration of the way forward.

In the setting in which I conducted research, where my data was collected from individuals who had the potential to be patients as well as research participants, this is more complicated. In research projects there is generally a clearly defined research population who provide data in the form of answers to questions, or questionnaires related specifically to the research question. In order for this mechanism to operate within a clinical situation there need to be separate researchers and clinicians each functioning within their own ambit. However, in neither hospital where I conducted my research was there another psychologist to whom I could refer patients who decided not to participate in the research process or participants who required ongoing therapy. However, I made the decision to continue under these circumstances. This resulted in me finding myself in the potentially awkward position of having to wear two hats: clinician and researcher. It was extremely difficult to negotiate a way to simultaneously collect relevant data and at the same time to encourage participation in a therapeutic process. The development of a therapeutic alliance was imperative in order to work ethically towards alleviating the emotional and somatic distress which were part of the presenting symptoms of the participants. This relationship is not necessarily part of the research process in other contexts. The challenge was to obtain objective and relevant data to illustrate the connection between stress and somatic symptoms while also providing the mechanism for the patient-participant to manage the process in a mentally and physically health-orientated way.

#### **1.4.1. Economic considerations**

Part of the *raison d'être* for initiating and conducting this research process was to highlight the place and management of somatoform presentations in the already overburdened healthcare environment. In South African state hospitals and clinics it is essential, for optimal functioning, to be able to move patients through the system rapidly and efficiently (Coovadia et al., 2009). Particular focus needs to be directed towards curtailing the so-called “revolving door” scenario which sees patients returning for repeat visits for the same or related complaints. Patients with MUS, whether their psychiatric diagnosis is somatoform, somatic symptom disorder or conversion disorder, represent a significant cohort of repetitive and chronic users of

medical services (Barsky, Ettner, Horsky, & Bates, 2001; Barsky, Orav, & Bates, 2005a, 2005b; Burton, McGorm, Richardson, Weller, & Sharpe, 2012; Merkler et al, 2015; Nimmo, 2015; Reid, Wessely, Crayford, & Hotopf, 2002). I did not explore this issue specifically in my research, but this group of patients highlighted the need to find more effective ways to investigate and identify these patients. Future research examining this specific consideration of medically unexplained symptoms could potentially lead to substantial savings in financial expenditure, personpower overloading as well as in reducing individual patient distress. For the patient this would translate into earlier rather than later symptom relief. For the institution, a reduction in the use of expensive and time-consuming procedures and investigations could provide much needed resource and financial relief.

#### **1.4.2. Diagnosis**

*Science must begin with myths and with the criticism of myths.*

**Karl Popper** (Overton, 2009, p. 147)

Early diagnosis has been argued to be a factor in managing patients with potential somatoform diagnoses or MUS. Howard (2013) writes eloquently about the dilemma facing doctors and their attempts to manage and diagnose patients with MUS and suspected somatoform disorders:

I over investigated, placing more diagnostic confidence in a negative test result than on my and the other consultants' clinical examinations. I remained concerned about misdiagnosing unexplained physical symptoms as psychiatric, colluding with the patients at times by imagining highly unlikely disease outcomes rather than treating what was most likely a psychiatric condition. (p 3)

There is some research and anecdotal clinical experience which both indicate that time lapse between the onset of medically unexplained symptoms and appropriate explanation, psychological support and intervention may mediate the effectiveness of the patient response either positively or negatively. Howard (2013) suggests that the medical management of somatoform disorders and other medically unexplained symptoms are “complex and challenging, and is often shrouded in a pall of pessimism and despair” due he suggests to the “frequent chronicity and tenacity” of the

symptoms. He does offer the hope that interventions, if offered before the symptoms become entrenched, may offer good, if not “dramatic” response. He suggests that the more chronic the physical complaints, the less amenable and more resistant these symptoms appear to be to psychological intervention (Howard, 2013). Howard (2013) suggests that the patients need to defend themselves against medical suspicions of malingering results in delays in the making of an appropriate diagnosis and thus entrenches negative functional outcomes. In my clinical work the patients who were referred to psychology soon after the onset or investigation of their medically unexplained symptoms, appeared to have a better outcome. As I will discuss in Chapter Four, the two patients with the most chronic presentation with medically unexplained symptoms appeared to have been the most resistant to the therapeutic process and whose symptoms remained entrenched. While not a component of the study, future investigation exploring early referral to psychological services with patients with MUS could provide helpful data.

While the physical diagnostic process is outside of the ambit of psychology, it directly and indirectly impacts on the process of therapy. As mentioned above, a long delay between initial presentations to medicine to referral to psychology appears to have a largely negative effect on therapeutic management. In addition, both the physical distress of ongoing invasive investigation and the attitude of medical practitioners to patients they suspect of having no underlying physical pathology, impacts on patients’ mental state and ultimate willingness to accept or engage positively with the referral. Doctors hostile to psychological issues in any patients, but particularly those with suspected psychosomatic symptoms, may translate their findings in a way that is unlikely to encourage optimal patient engagement. When the particular patient group has limited or no knowledge of psychology as a discipline, this relationship with the discipline is further invalidated.

#### **1.4.3. The hospital hierarchy and multidisciplinary relationships**

The focus of this research is neither to explore nor evaluate the healthcare system or institutions as such. However, some understanding of the internal working dynamics of the healthcare system is helpful in order to fully appreciate the particular difficulties experienced by the patients with MUS as they pass through the system and the associated ways in which they are viewed and treated. As a patient group, with



their apparently inexplicable symptoms, they create uncertainty and confusion. Furthermore, as has been documented in multiple other situations, response to “not knowing” is frequently acted out in aggressive and hostile ways by both patients and medical practitioners. I will explore and describe the participant responses in Chapter Four.

The process under consideration, i.e., patient referral from medicine to psychology, needs to incorporate reflection and examination of how the particular culture of professional hierarchy, function and focus has the potential to create additional complications. Relationships between provider and patient play out in subtle but far reaching and significant ways. Medical practitioners who are focused on physical symptoms and patients whose physical symptoms appear to have no valid cause, within the taken-for granted explicit and implicit parameters of the health system, do not make for a good fit in general. There are, moreover, doctors who find psychological concerns and the associated disciplines, particularly discomforting and difficult to engage with. There are categories of patients who could benefit from help with precisely these psychological issues, but who are themselves confused and ill-informed about the subject. The interface between these two groups creates the potential for significantly problematic relationships. The knock-on effect of mutual incomprehension does not necessarily end there. It may, and frequently does, extend beyond the physician-patient relationship to encompass and impact upon inter-disciplinary cooperation.

Cooperation and mutual respect between the various components and disciplines in the hospital system is essential for optimal patient management, as the literature on teamwork in healthcare clearly shows. Some researchers (Fernandes, Palombella, Salfi, & Wainman 2015) state unequivocally that a good team-based approach is essential for optimal healthcare delivery. But it is more complex than that. Weaver & Hall (2001) acknowledge that the complexities of disease, diagnosis and management faced by the modern physician require specialization as well as cooperation and collaboration across disciplines for optimal patient care. A great deal of research has been focused on ways in which to include aspects of teamwork and interdisciplinary cooperation within the healthcare industry (Baker, Day, & Salas, 2006; McKinlay, Gray, & Pullon, 2013; Reeves et al., 2008; Weaver, Dy, & Rosen, 2014). First class

delivery of healthcare services is promoted and upheld when there is recognition of the intrinsic value of each component in the system (Connell & Walton-Roberts, 2015; McKinlay, Gray, & Pullon, 2013). Respectful acknowledgment of each contributor, in conjunction with informed mutual understanding of the scope of practice of each discipline, has the potential to create a well-oiled, supportive structural machine whose most important function is the optimal management of patient health. (Connell & Walton-Roberts, 2015; St. George, 2013). Research is increasingly supportive of the value of teamwork within the healthcare system as a mechanism of promoting optimal patient care (McKinlay, Gray, & Pullon, 2013; Nancarrow et al., 2006).

A brief examination of the referral pathway can serve as a vivid and particular illustration for the real, but frequently unacknowledged, need for and value of interdependence amongst the healthcare disciplines within the system. Patients entering a hospital, in the context within which my study is situated, are either self-referred presenting at the emergency room, or if their symptoms are less acute or of a chronic nature they generally come via a private general practitioner or clinic. Once they enter the system, they are moved through the various processes and departments and are managed by and interact with nursing and medical staff with varying degrees of sympathy and consideration. The way in which all patients, but particularly those with MUPS, are treated may be influenced by the levels of work overload and job stress experienced by the health professionals at any given time. It has long been evident from research that exhaustion and chronic working conditions of chaos impact not only on clear thinking and patient safety but also on relational processes (Felton, 1998; Schull, Ferris, Tu, Hux, & Redelmeier, 2001; Welp, Meier, & Manser, 2015; Wisetborisut, Angkurawaranon, Jiraporncharoen, Uaphanthasath, & Wiwatanadate, 2014).

From the moment that they enter the portals of the institution the patients are passed from one professional to another, often in ways that make them feel powerless and unheard. There are good theoretical and practical reasons for patients being managed by different professionals in this way, but the experience may not be optimal for the patient. It is also well recognized that health professionals may refer patients to other professionals when they feel out of their depth or incompetent (this may in fact be one

of the explicit reasons for referral), and this sense of being unmanageable may be communicated, even if not deliberately, to patients. But where professionals have the power to refer on – to “get rid of patients” (GROP), as it has been called (Rhodes, 1995), impoverished patients in a public healthcare system do not have this power or choice. They may feel overwhelmed by the situation and by the perceived omnipotence of the professionals who are managing their health.

Inherent in the system is a subversive and often unacknowledged component which exacerbates this power differential – an internal hierarchy of value and prestige which places the various disciplines in comparative positions of importance and influence despite an overt ideology of equality across professions (Creed, Searle, & Rogers, 2010; Nembhard & Edmondson, 2006). When enacted, relative professional valuing and devaluing can be counterproductive to providing optimal patient care. When a particular specialty or discipline becomes prioritized at the expense of, and to the derogation of, others, there is a very real potential for breakdown in service delivery. Communication suffers, referral and treatment opportunities are ignored or invalidated and ultimately the concept of “best interests of the patient” becomes obscured or lost in the internecine squabbles between professionals.

Organograms, frequently used by institutions, can provide graphic illustrations of the relative importance of the various players. Within the state hospital structure in which I work, at the top of the clinical pyramid are invariably the doctors who, depending on their particular speciality, wield considerable influence and decision making power. Within the medical profession itself there are more subtle gradations of relative ranking. To a great extent this hypothetical status may be associated with the degree to which the speciality is seen to have immediate effect on and resolution of the presenting patient pathology. Surgeons, trauma specialists and certain physicians may carry particular prestige. This is conceivably linked to economic and pragmatic considerations. To ignore the business component of a healthcare system is naïve and unhelpful. In order for the institution to survive financially, patients need to pass through the system rapidly and efficiently. The way in which the particular discipline contributes effectively to this process is not without relevance, importance and consequent impact on status. Those specialties that are dedicated to critical

management (emergency room and surgery) often carry the greatest prestige in the hospital hierarchy.

For the so-called allied healthcare workers, physiotherapists, dieticians, social workers and particularly psychologists, whose roles frequently appear to be seen as largely supportive and supplementary, interaction with their medical colleagues plays out in accordance with this dynamic. Within these associated disciplines, the physical treatment component, the clear, speedy and effective contribution to acute resolutions of overt symptoms translates into associated levels of professional acknowledgment and gravitas. This effectively positions psychology in an extremely vulnerable place. The potentially open-ended, ongoing nature of therapy/treatment, together with the subtlety and non-physical nature of symptomatology, militate against the desired outcome of rapid treatment, symptom resolution and discharge from the institution. At its most extreme, medical personnel may see psychology as being superfluous to the real work of the hospital (Gallagher, Wallace, Nathan, & McGrath, 2015). Simultaneously, patient misunderstanding or ignorance regarding the nature of the work can negatively impact on attendance and willingness to engage with therapy. Collegial dismissal can further devalue the perceived relevance of the work. The way in which those considering – or not considering – a referral to psychology manage the process is extremely important in the facilitation of a successful transition for the patient.

How exactly does the interdisciplinary relationship affect the patients? How does the specific presentation of the particular patient influence or impact the process? Patients with what are understood as “physical” problems are dealt with in the context of medicine, surgery and pharmacology. Patients with clear and diagnosed mental pathology are passed on to the mental health team with varying degrees of alacrity and relief. For the patient described as “somatizing”, this process is hugely complicated and more problematic. Not only do they present initially exclusively to medicine but they utilize medical services beyond the expected trajectory and therefore are both financially and emotionally draining to the institution. The economic ramifications of patients who infiltrate the system on an ongoing and apparently ineffective basis represent very specific challenges. For many doctors, particularly those working under enormous pressure in high-turnover surgical and

emergency units, the scope of mental illness is intrusive, irrelevant and unwelcome. They find patients with atypical presentations frustrating and time-consuming in a setting where time and rapid triage, diagnosis and treatment are of prime and urgent consideration. This understanding filters down, sometimes overtly, occasionally with more subtlety, to a devaluing of the patient with a mental disorder. The “somatizing” patient, who in many ways is neither “fish nor fowl”, creates a particular kind of tension and response which may translate into less than optimal management and consequent patient satisfaction.

#### **1.4.4. Relative medical importance**

*Variability is the law of life, and as no two faces are the same, so no two bodies are alike, and no two individuals react alike and behave alike under the abnormal conditions which we know as disease. Medicine is a science of uncertainty and an art of probability.*

**William Osler, Canadian Physician** (Overton, 2009, pg. 8)

Ironically, the emergency room is frequently the first, repeated and ongoing medical port of call for a patient in distress about somatic symptoms. The so-called “thick folder” syndrome provides the staff with an immediate clue to a presenting patient’s history of visits and ongoing investigation. Patients will have many notes and records of investigations, but they may not have been optimally helped, nor will they have left the healthsystem – they remain part of the care burden. A potential lack of sympathetic response by the staff is both understandable and unfortunate in managing these patients. Feelings of irritation, resentment, dismissal and outright hostility have been expressed by doctors both in these circumstances and in general practice, using terms such as “black hole”, “heartsink” and even “hateful” (Jackson & Kay, 2013; Stone, 2014). The pressing need to attend to obvious trauma or medical emergencies may translate into annoyance and outright disparagement of the “somatizing” patient. Here they are, with symptoms which appear to have no cause, blocking up chairs, beds and trolleys in overcrowded emergency units with ambulances discharging wounded and ill patients in an ongoing and relentless stream. The need to clear the playing field is invariably urgent with treatment of “real” patients a priority.

So, what happens next to the patient with medically unexplained symptoms? There is generally one of two outcome possibilities: the patient is told – with varying degrees of frankness – that there is nothing wrong and they should simply go home. The other

is for a referral to be made to either psychiatry or psychology. While there are indubitably other contributory factors, it is my experience, both clinically and as a researcher, that a positive and empathic attitude on the part of the referring agent has the potential to significantly ameliorate patient anxiety, suspicion and understanding with regard to the referral to mental health services. This in turn would appear to potentially mediate positively in favour of patient willingness to engage with the therapeutic process. Making the referral, and the way in which it is done, is obviously only part of the process. An ongoing obstacle to managing these patients is the frequent failure of the referral to be acted upon. “No shows” for follow-up appointments with psychology in the outpatient setting is a frequent occurrence. What makes the difference in those patients who not only arrive, but who also indicate willingness to consider including the psychological management of their physical symptoms? In my clinical experience it appears to be a question answered, at least in part, by both previous medical management and the patient’s own pre-existing level of education and understanding.

In the general hospital environment, the focus is on visible damage or disease to the body. Many doctors do not engage enthusiastically with the psychological component of healthcare and in this they may reflect a bias in the training of medical personnel worldwide. Psychiatry has been viewed with suspicion by the medical fraternity almost from its inception (Gaebel, Zielasek, & Cleveland, 2010; Ironsides, 1975; Kleinman, 2007). This duality is occasionally played out by the psychiatrists themselves. I recently overheard a psychiatrist describe herself as feeling like a “real doctor” in the context of liaison psychiatry which involves an interface with medicine and collaboration on medical diagnoses. Recently there have been studies in an attempt to find a way to integrate the speciality into mainstream medicine (Yakeley, Hale, Johnston, Kirtchuk, & Shoenberg, 2014). The preparedness to engage with the non-physical components of illness and disease tends to encourage the doctors to refer and additionally, to present the referral in more positive ways. Blunt assertions, “there is nothing wrong with you” or “it is all in your head”, do not engender feelings of being heard, valued or understood. The time the doctor takes to explore with the patient the nature of what the doctor understands as psychosomatic illness and the way in which emotional experiences and trauma can translate into physical symptoms can make an enormous difference in patient acceptance of the diagnosis. This in turn

creates the potential for the referral to psychology to be seen by the patient as a positive step in the management of their symptoms and condition. However, the additional tragedy in managing these patients is that, even when there is medical willingness to sensitively and thoughtfully assist them with negotiating an understanding, time constraints in the system do not allow for it. Unfortunately this makes the weighting of effective treatment for this particular patient population less than optimal.

#### **1.4.5. Community understanding of and engagement with psychology**

In the community situation very few patients arrive at the door of psychology displaying attitudes of enthusiasm or the outward appearance of positive anticipation. Seldom does the patient reveal an understanding of the process they are about to engage with. In the years I have been working in community based hospitals and clinics, the patients coming to psychology for the first time can invariably be identified in the waiting room by their expressions of bemusement, irresolution, and occasionally downright fear. Even in circumstances when people have been referred as a consequence of being traumatized in some way, or who recognize that the turmoil of their emotional life or that their personal relationships are awry or destructive, these feelings of apprehension are evident. For the patient with somatization this is further complicated by confusion as to how a mental health practitioner can in any way contribute to the resolution of their physical symptoms. Even in the broader context outside of MUS, stigma and ignorance is seen as a limiting factor in individuals accessing mental health services in South Africa (Hugo, Boshoff, Traut, Zungu-Dirwayi, & Stein, 2003).

On the reverse side of the relationship, the patient with MUS in the community setting presents certain, very particular, challenges to the attending psychologist. Attempting to reconcile patient preoccupation with physical complaints and the expected role of providing emotional and psychological support, can tax the sense of professional focus and competence. With a background as a qualified and registered nursing sister with twenty years of clinical experience, my situation is somewhat different. I am fortunate in being able to understand much of the medical terminology and disease etiology which might obfuscate understanding for the non-medically trained psychologist or counsellor. This has provided me with the opportunity to engage in

dialogue and debate about symptoms in a more informed way. While increasingly the focus in psychology, particularly community psychology, is to diffuse the power differential between practitioner and patient, with regards to this particular patient group, the authority of “knowing” about physical pathology can be a positive attribute and help in the process of exploration and understanding. While being mindful of the potential to wield inappropriate authority from an expert stance, being able to talk the language of the medical practitioner can add weight to the process of cognitive restructuring, understanding and the challenging of dysfunctional thoughts in these particular patients.

For the professional, having an extended knowledge base may be a useful tool in maintaining credibility. Many patients, irrespective of their socio-economic status, are increasingly looking to technology to obtain information and to substantiate or explore diagnoses. No longer are they necessarily the passive recipients of information. Even amongst the women I have seen in my practice and during my research, who frequently had limited education and were unemployed or never employed, several had used the Internet and/or smart phones to access information to check their perceived conditions. A few used the digital photographic facility on their phones to take pictures of transient symptoms to show the doctors at their next visit in an attempt to validate their concerns. In my interaction with these patients, my ability to be able to talk the language of medicine helped them to negotiate the transition from one discipline to the other. It also gave me, perhaps a spurious, aura of authority which enabled them to accept my corroboration of the doctors’ diagnosis. Be that as it may, attempting to assist an individual to move from a conviction that their physical symptom augurs a serious disease or disability is not easy. It is one that needs to be executed with enormous sensitivity and an understanding of the real distress associated with the physical condition. This transition is not always possible to facilitate, which is upsetting for both patient and the practitioner.

However, depending on individual circumstances these patients can also respond very positively to therapy. Once the initial hurdles of trepidation and confusion have been overcome, frequently the response is one of enthusiastic engagement. Sigmund Freud’s term “The talking cure” is often aptly enacted. At times it has almost seemed magical to observe the palliation and resolution which follows disclosure of



previously unvoiced experiences. In the most graphic demonstration of the power and value of words, a patient who had been sent to me for idiopathic aphonia, told me (in strained whispers) that her husband continually told her to “hou jou bek” (“be quiet”). She had. Literally. As she attended the subsequent sessions, with increasing interest in the process and ability to describe her home dynamic, her voice returned. By the third session she was speaking completely normally. However, despite this dramatic improvement and her increasingly positive attitude towards therapy, this patient was obdurate in her refusal to accept an association between the physical loss of her voice with her husband’s aggression and his need to silence her. There was a profound need to attribute the loss of her voice to a physical event and causation. She had, a week prior to the development of her symptoms, become drenched in an unexpected downpour of rain while away from home. It certainly was not beyond the realms of possibility that this event was a precipitating factor. However, the reality that months later she had not regained the use of her voice – despite multiple medical interventions – and that it did return shortly after initiating a psychological therapeutic process did nothing to change her mind. Perhaps it is of no real importance in the bigger scheme of things. On presentation she was one of my most hostile and resentful patients. Two years later she continues to attend on a monthly basis – more frequent attendance is impossible because of her dire financial circumstances. She does so “just to talk”. Her home situation and economic status remains suboptimal to say the least, but her symptoms have never resurged. Despite her initial hostility she was able to express her experience of the therapeutic process positively, “I left this room the first time feeling like I was a bird that had been let out of a cage. Just because I could talk to someone.”

#### **1.4.6. Socio-economic environment**

However, sometimes the act of talking, and the disclosing of issues and experiences previously defended against and held secret, is helpful but not sufficient. Every one of the patients in my study and virtually all the patients I see in my clinical work live in circumstances which are significantly difficult, problematic, not to say completely untenable. The issues they are forced to live with include poor education, numerous and unplanned pregnancies, unemployment, abject poverty, ongoing exposure to substance and other abuse, violence and crime. These are so endemic and habitually

distressing that very real physiological manifestations of stress occur. The fragile stability of their lives can even be disrupted on a daily basis by seemingly insignificant events (L. Smith, 2010). Failure of a grant application, sudden minor illness or an accident requiring medical attention can precipitate a financial and personal crisis. Chronic headaches, high blood pressure that is unresponsive to medication, musculo-skeletal pains, gastro-intestinal discomfort and many other somatic symptoms may be traced to the stress of these difficult life circumstances. Without the appropriate service infrastructure these situations are not likely to change or improve and talking about them does little to alleviate either the distress or the effects. Sometimes very practical interventions aimed at managing the manifestations of stress are the most effective and visible solutions. Frequently introducing mechanisms such as progressive muscle relaxation<sup>1</sup> is helpful. Enabling patients to initiate activities or procedures to which they can see and to which they feel a response is enormously empowering. “Empowerment” both as a word and a concept has to some extent lost its meaning and impact because of over- and indiscriminate use. Yet to provide an individual with such mechanisms as a progressive muscle relaxation to self-manage, self-determine and self-soothe effectively is very satisfying. There are innumerable examples of other cognitive and behavioural interventions which can effect psychological change.

#### **1.4.7. Multiple roles and adaptability in service provision**

I have mentioned previously that I found myself in a conundrum in terms of my role and relationship with the individuals presenting, through referral from the doctors, to participate in my research. While patients had the potential to refuse to participate in the study, once they had accepted these individuals officially became “participants”. However, the absence of any other psychologist to whom I could refer necessitated that they also automatically assume the additional role of “patient”. This translated into an ethical duty for me to provide therapy and/or appropriate intervention to assist in the process of alleviating the suffering inherent in their referral. I had to find ways

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<sup>1</sup> A cognitive behavioural therapy process which involves instructing the patient to progressively tense and relax the various muscle groups in the body. Simultaneously the patient is asked to give considerations to feelings of calm and anxiety associated with the either the tension or relaxation. In terms of somatic symptoms, such mechanisms as checking blood pressure readings before and after the procedure will generally show a drop in the reading and provide the patient with evidence of the mind-body connection. Patients are generally encouraged to continue with the practice in their home environment and note changes in their feelings of calm and anxiety.

in which to obtain my data about their experiences, while simultaneously or subsequently initiating a mechanism for providing therapeutic assistance. Therapy in the community context frequently is very pragmatic and practically orientated. In this particular situation life circumstances were of particular cognizance.

Virtually every participant-patient in my study was able to identify “stress” as a major negative component in her life. As their presenting symptoms were specifically physical in nature they were particularly amenable to an intervention with a physiological component. The biofeedback basis of progressive muscle relaxation helped – with varying degrees and depth of explanation – both to render their symptoms explicable and to provide a way of targeting them in treatment. Half of the patients had hypertension (high blood pressure) either as a presenting symptom or as a corollary to the pre-existing one. In order to render the process visible, I formulated a protocol which involved having a member of the nursing staff check the blood pressure before and after a session of the progressive muscle relaxation. Whether or not this exercise impacted on the other somatic symptoms, the invariable drop in blood pressure subsequent to the exercise provided the participant with real and exciting evidence of the mutuality between the mind and the body. Either as an end in itself or as an initial part of the process, this intervention seemed to do more than anything else to help the patient with somatic symptoms release some of their disbelief regarding the diagnosis. They were able to observe and internalize the process of mental activity and thought processes on physiological functioning. This was helpful both in terms of illustrating the impact of stress in their bodies as well as validating the referral to psychology and the way in which the various healthcare disciplines have the potential to collaborate successfully in the process of patient wellness. Ethical management of hospital patients necessitates the promotion and respect each discipline accords the others. In the process of assisting the participants on my study to recognize the impact that emotional, psychological and life stressors had on the functioning of their physical bodies, not only was my own discipline validated, but indirectly the resentment and anger previously directed towards the referring doctors was dissipated to some extent.

#### **1.4.8. Referral pathways and pitfalls**

While it would be optimal, at present it would however be completely erroneous and misleading to suggest that seamless referral and management of the “somatoform” patient is the norm. There is a yet unmentioned and additional complication in managing these particular patients. Potential and very dangerous pitfalls exist in prematurely ascribing physical symptoms to exclusively psychological factors. It is the fear of failing to identify a real and serious causative factor that both disquiets and frightens the attending physicians. I do not think that a single doctor who I have spoken to, either clinically or in the context of the research, did not express the fear that they might “miss something”. This is not without possibility. Not only do these patients present a puzzle in terms of their inexplicable symptoms, they frequently have co-morbidity of other chronic and acute illnesses. This serves to confuse and blur the line between the organic and somatoform. Failure to identify the former can have disastrous consequences. A patient I saw a year before I started on my research process had been sent to me with “psychosomatic” pains in the legs. Apparently all tests had been done and there was the veiled suggestion that this particular patient was “work shy”. In my interaction with her I never received the impression that she was trying to malingering. In fact the very opposite. She was waiting to start an exciting and economically needed new job as soon as her symptoms had resolved. In my sessions with her, I developed a strong sense that her problem was not psychological in origin. I consequently consulted with and referred her to the hospital physiotherapist. Eventually with his input, more investigations were done and it was found that this patient had cancer of the spine. The tragedy of the situation was that an earlier diagnosis could have ensured the patient’s ongoing mobility. By the time the diagnosis was made the patient had become a wheelchair user. This kind of outcome cannot be avoided no matter how assiduous each participant in the process is. However, it certainly speaks, not only to the need to fully investigate the symptoms prior to referral to psychology, but also to the value of interdisciplinary cooperation. The doctors I had spoken to initially about my concerns were dismissive. However, the physiotherapist was appreciative of my input and referral and was available to carry the treatment and investigation beyond where I was able. Promotion of this kind of cooperation could potentially help to dissipate anxiety amongst individual

practitioners by promoting more holistic and proactive management of the patient with medically unexplained symptoms and possible somatic symptoms disorder.

## **1.5. STUDY CONTEXT**

The qualification process in South African requires certain healthcare disciplines to fulfil a year of so-called “community service” in order to practice. At the conclusion of academic training and internship requirements, doctors, dentists, nurses and various other paramedical specialties, including psychology, are allocated a placement at a healthcare institution somewhere in the country – frequently in under-resourced rural areas – to provide the relevant service to the community for the duration of a year.

As a newly trained psychologist, I was fortunate in being assigned a place at Hope Hospital in close proximity to where I lived. This meant that I was relieved of the inconvenience of relocating. However, the hospital was situated in a peri-urban area notorious for unemployment, poverty, gang-activity and crime. The population served by the hospital encompassed a large geographical area where the communities were living in conditions of great deprivation.

The four wards of the hospital were filled to overflowing with patients suffering from diseases which were exacerbated and complicated by poor diet, limited access to water and electricity and dwellings which lacked the basic necessities of safety and protection from the elements. In addition, there was a specialized HIV/AIDS unit, an attached rape crisis centre and a trauma unit which frequently had up to seven ambulances waiting to admit patients with injuries related to violence and aggression. A metal detector protected the entrance to the unit in an attempt to exclude gang members entering the hospital carrying weapons.

In such an environment of life-threatening physical illness and crime-related injuries, the place of psychology was a tenuous one. The over-extended medical staff had their resources strained beyond capacity in terms of managing acute medical and trauma situations. As a consequence, and quite understandably given the situation, the psychological concerns of patients were often either unacknowledged or relegated to the bottom of the list of management priorities. In addition, the population served by the hospital, despite the ongoing onslaught on their psychological as well as physical health, had little understanding of the place and value of the discipline.

I spent sixteen months at this hospital – the year of community service plus an additional four months, negotiated between myself and the hospital management, to remain there in the interval between the conclusion of my own contract and the commencement of the next community service placement. Part of my rationale for doing so was pragmatic: Hope Hospital had no fulltime psychologist post. Prior to my placement there had been a community psychologist working there and I had followed immediately afterwards in the same capacity. In the year I had worked I had managed to negotiate an office, which had not been available to psychology before, and the two successive years of psychological presence had raised the profile of the discipline. I was concerned that an interval without a psychologist would lose the ground we had gained. I also was grateful for the opportunity to work the additional months' employment at Hope Hospital for purely self-serving reasons. Professionally and personally the time spent at this hospital was one of the most significant of my life. The trepidation and downright fear I initially experienced was replaced, within a few weeks, by gratitude and awe for my good fortune in having been sent to work at this hospital. Thereafter I was fortunate enough to obtain a position at Waterstroom Hospital in a similar socio-economic environment, and I continue to be employed there at present.

In both these locations the presentation of patients with medically unexplained symptoms has presented a particular challenge. The doctors find the patients difficult to manage, and the patients are confused and unhappy. For both of them the option of referral to psychology has ambivalent value. The process of conducting this research was potentially helpful in the clarifying and understanding of the relevant positions within this particular context.

## **1.6. PROBLEM STATEMENT, GOALS AND RESEARCH QUESTION**

### **1.6.1. Problem statement and study rationale**

As I have described in the introduction, patients presenting at hospitals with physical symptoms which are found to have no organic basis, provide a particular kind of challenge to both medical and mental health practitioners, particularly in under-resourced settings.

From the doctors' perspective there is the real fear of missing a valid medical

diagnosis. On the other hand there is often a covert, even acknowledged, irritation with the “time-wasting” potential of these patients. Inherent in this needless waste of medical expertise is the potentially unnecessary and expensive utilization of diagnostic resources.

From the psychologists’ perspective, particularly working in a community setting, where lack of understanding of the discipline hampers interaction with patients, the individuals referred with MUS are particularly difficult to engage with. Predominant feelings of resentment and anger at having their physical symptoms negated colours their willingness to engage with psychology or psychiatry. This is problematic in providing appropriate mechanisms of psychological assistance to a population which has the potential to benefit from such interventions.

There are psychometric instruments to assess the possibility of malingering or purposeful presentation of fallacious or factitious symptoms (Larrabee, 2003; Lezak, Howieson, & Loring, 2004; Rogers 1997; Young, 2014). There are innumerable chemical, laboratory and imaging tests (X-rays, scans, ultrasound) to explore organic malfunction. However, for the patient who appears to have no conscious motivation of secondary gain, and who is both objectively and subjectively distressed by physical pain or discomfort, there is no clear pathway to connect symptom and pathogenesis.

From the patients’ perspective the entire process is problematic and fraught with opportunities for misunderstanding and alienation. The social exclusion experienced by individuals living in poverty is disabling, disempowering and humiliating and has a knock on effect both backwards and forwards in contributing to maintaining sub-optimal socio-economic circumstances (L. Smith, 2010). In a country such as South Africa, with its history of racial segregation and gender inequality the situation of healthcare management becomes more complex (Benatar, 2013; Lund, 2015). Black and Coloured women are statistically most likely to be poor, diseased, and suffering from such mental health conditions as depression and anxiety (Bean & Moller, 2002; Coovadia et al., 2009) and posttraumatic stress (Guay et al., 2006; Kaminer & Eagle, 2010; Williams et al., 2007). In my experience working in two separate poor communities, the presentation of female patients with psychosomatic symptoms or MUS is notable. However, very little has been written on this subject and virtually nothing from the perspective of the women themselves and how they understand or

experience the process.

Research to explore and capture the experience and emotional distress of low-income women who find their physical symptoms discounted, would appear to be of potential value to all three components of the conundrum: the patient, the medical practitioner and the mental health team.

### **1.6.2. Goals and research questions**

Taking into consideration the points made above, and in the context of the phenomenological underpinning of this research project, my preeminent purpose in conducting this research was to access data which made explicit the feelings and experiences of the female participants through their own words and voices (Carel 2011, 2012; Finlay, 2008; Husserl, 1962, 1970; Merleau-Ponty, 1962). Through these participants I hope to highlight not only their own experiences but also those of many patients within the same demographic who are faced with the diagnosis of MUS and who are then referred to mental health services after having had physical symptoms investigated and negated.

Inherent in the lived experiences of these women, is consideration of the extent to which their socio-economic context contributed or supported their particular presentation to the healthcare system. Contextual issues are increasingly taken into consideration when formulating mental health interventions (Sorsdahl, Stein, & Lund, 2012). This is of particular value in the context of my own research. Historically, psychology and psychological and psychiatric theory is grounded in a Western, first world milieu which may not translate well into understanding patients or populations in less advantaged communities and contexts. The experience of a poor, socially and racially disempowered woman with confusing physical symptoms, living in a third world context, has the potential to be different in many ways from that of a women with similarly puzzling symptoms but with greater choice, access to and understanding of the healthcare system.

In the service of achieving these goals my research question was potentially focused on one particular area:

- How the women, with similar socio-economic demographics, attending the



two geographically separate hospitals, experience the process of attempting to access medical help for physical symptoms but who were then referred to mental health services.

I obtained contextual data regarding the manner in which the medical staff, who encountered these patients, negotiated the investigation and referral, and how they felt about the presenting symptoms and their failure to be organically validated. While I had hoped to include this in my research, the interviews I conducted with the six doctors (four from Hope Hospital and two from Waterstroom Hospital) have not been included. The volume of data generated by my patient participants excluded this possibility. However my interviews with the doctors provided background to the patient interviews and the contextual relationship between the two. I intend reporting specifically on this data elsewhere.

In attempting to answer these questions and achieve the goals inherent in my research I utilized a qualitative research design, with a phenomenological emphasis. I collected data through the use of semi-structured interviews within a clinical setting. I examined the data through the lens of phenomenology. In this way I hoped to provide and describe data rich with the voices of the participants while containing and contextualizing their stories within a particular socio-economic milieu.

## **1.7. STRUCTURE OF THESIS**

This study was conducted at two hospitals in and near Cape Town as a consequence of my work in the community and my identification of a particular group of patients who were referred for psychological assistance. In this thesis I have attempted to present my findings in a way that gives prominence to the voices of those women who participated in the research project, and through them, to provide insight into the phenomenon of medically unexplained symptoms. In doing so I have organized the material into five chapters. A brief synopsis of the chapter outline follows:

### *Chapter One : Introduction*

In Chapter One, I give the background to the study as well as providing contextual information, the rationale and aims of the research.

### *Chapter Two : Literature Review*

In Chapter Two, I provide a review of the existing and current literature on the topic of medically unexplained symptoms which both informed and substantiated my research. While I have explored literature which examines the phenomenon of medically unexplained symptoms from the perspective of other sources, I have specifically attempted to source the literature available on low-income women and their experiences of having medically unexplained symptoms. Where possible I have attempted to establish relevant research and documentation available in the South African context.

### *Chapter Three : Methodology*

In Chapter Three, I reprise the aims of my research and enumerate the details of the methodology I used in achieving the objectives of the study. I provide information regarding methodological underpinning, the research design, sampling mechanism, data collection and subsequent analysis. In keeping with the phenomenological emphasis of this project, my data collection and analysis has focused as closely as possible on the experiences and narrative descriptions of the participants. I conclude this chapter with the important component of any research: transparency in terms of ethical best practice. This includes a clear description of adherence to the prescribed processes, as well as elucidation of ethical problems encountered during the particular project.

### *Chapter Four : Results*

In Chapter Four, I introduce the participants, and present and discuss the data which emerged from the interviews. The raw data will be explored in the context of the specific geographical and socio-economic environment in which the research was conducted and as well as in relation to both national and international literature. In keeping with the spirit of phenomenology, I will attempt to foreground the voices of the participants.

*Chapter Five : Conclusions and Recommendations*

In this final chapter I will provide a summary of the findings and engage briefly with both the limitations and challenges encountered. I will suggest possible ways in which future research and interventions may extend and provide resolution to these findings.

Finally in keeping with the underlying premises of qualitative research in general, and phenomenological research in particular, I will engage with aspects of reflexivity and personal experience during the process of conducting this research and interacting with my research participants.

## CHAPTER TWO

### LITERATURE REVIEW

#### 2.1. INTRODUCTION

My initial research topic/question was ostensibly clear and unambiguous: to explore the experience of low-income women as they moved from medicine to psychology as a consequence of having received a somatoform or somatic symptom diagnosis or were merely classified as having medically unexplained physical symptoms (MUPS). This anticipated simplicity was deceptive, and the reality was multifaceted, nuanced and enmeshed in ways that I did not anticipate. The juxtaposition of gender, poverty, health – both physical and mental – and systemic issues within the healthcare system resulted in a palimpsest of data which, while fascinating in its complexity, made exploration, understanding and integration somewhat challenging.

Both prior to data collection and as an ongoing process I looked to the existing literature for guidance and assistance. Silverman (2013) in particular provided clear and helpful guidelines to both negotiate an effective way through the qualitative research process and the ways in which to position it within, and in contrast to, the broader research output. In many instances previous research and literature has considered various aspects of my findings, but not necessarily all of it or in the particular configurations that emerged from my own research.

As a consequence of the unexpected complexity, I found myself becoming overwhelmed and confused in my attempts to find focus. I struggled to isolate the most important aspects of my data and to relate it to extant literature and research. The term “drowning in data” (McLean et al, 2010) seemed particularly pertinent and I developed an increasing concern with two possible contradictory outcomes: either diluting the richness of individual stories and issues, or the alternative potential of destroying the value of the data by presenting an unintelligible conglomeration of information. Ultimately in the service of clarity and coherence, I found it facilitated the process to make an initial division of the resultant data and the associated literature review into specific categories. The emerging trends and intersects would

then be related and cross-referenced in order to achieve a coherent and integrated presentation.

For clarity the initial consideration of the literature will be divided into the following categories:

- Psychosomatic illness: The body and the mind and the conjunction of the two in the context of dysfunction, pain and, illness;
- Poverty, gender and mental health;
- Psychiatry and psychology and their place in the biomedical model of healthcare;
- The organisation of healthcare within the South African context.

## **2.2. PSYCHOSOMATIC ILLNESS : THE MIND-BODY CONNECTION**

Inexplicable bodily pain, and the difficulty inherent in investigation, explanation and treatment, is not a new phenomenon. The literature dealing with the subject spans decades and reflects the way in which each epoch shapes the ways in which illness is viewed, categorised and managed (Epstein, 2014; Fabrega, 1990; Kradin, 2012; Shorter, 2008; P. Smith, 2003; Stainbrook, 1952; Webster, 1996). The connection between the mind and body is an area of mystique and intrigue evoking interest and scrutiny described in the earliest of annals of medical history (Kradin, 2012; Shorter, 2008; Webster 1996).

Psychosomatic conditions, and investigations into the intersect between the functioning of the mind and body, are not confined to a particular group – whether social, political, economic or educational (Fabrega, 1990; Kradin, 2012; Lee & Kleinman, 2007). Across these borders there is documented evidence of individuals presenting with physical symptoms which have perplexed and challenged the patient and practitioner alike and in certain instances not insignificant responses of controversy (P. Smith, 2003).

There is some indication that there is a gendered bias in patients reporting to hospitals with physical symptoms for which there is no apparent underlying organic cause. Statistics indicate both a higher incidence and prevalence in the female population (Brown, 2004; Kirmayer, Groleau, Looer & Dominice Deo, 2004; Kroenke &

Spitzer, 1998; Ussher, 2013). The validity of these figures is rendered tenuous by the possibility that under-reporting or diagnosing of the male population is at least in part the reason for this weighting (Sadock & Sadock, 2007). Yet in clinical practice the preponderance of female patients presenting with perplexing physical symptoms seems to exist. Investigation regarding the underlying foundation for this disproportionate weighting is an area for possible future investigation. Despite an existing and considerable body of research on this topic, there is no final consensus on the reason for the strong gender bias.

A full historical exploration of psychosomatic conditions is outside the remit of the present research exercise. However, a short consideration of the roots of the concept of psychosomatic illness may be helpful in placing the present data in context. Certainly the history of psychosomatic conditions is a “complex and tangled tale” (Shorter, 1997; Shorter, 2008) going back to the early days of medicine. The identification of psychosomatic illness begins with the Greeks (Cassell, 2012; Crivellato & Ribatti, 2007). Plato, Hippocrates and Aristotle all consider the conundrum of physical symptoms which appear to have a possible mental or psychological basis (Cassell, 2012; Crivellato & Ribatti, 2007). Psychological illness is constructed in Galen's system as “diseases of passion”, a concept which remained in use until the middle of the nineteenth century (Cassell, 2012; Kradin, 2012; Lopes de Mello, 2010). The notable French and German physicians of the nineteenth century were all conversant with psychosomatic diseases (Lipsitt, 2006; Stainbrook, 1952). During the twentieth century the field became the focus of attention, and to some extent the exclusive territory of Freud and the early psychoanalysts (Cassell, 2012; Overton, 2009; Webster, 1996). While they maintained the classification and defence of neurosis and neuroses – that is to say emotional diseases without apparent organic cause – there were other physicians who remained deeply suspicious (Overton, 2009; Slater, 1965; Webster, 1996). There was the inherent belief that neurotic disorders were better conceptualized “as the imaginary diseases of tiresome patients looking for attention.” (Greenberg & Fee, 2014). This uncomfortable status quo remains (Folks, Feldman, & Ford, 2000; Harsh, Hodgson, White, Lamson, & Irons, 2015; King, 1994; Mobini, 2015). Even in resource rich settings such as Norway, the study conducted by Grue, Johannessen, and Rasmussen (2015) indicated that healthcare providers view patients with unexplained physical symptoms, particularly when these are chronic,

more negatively than patients' whose diagnosis is unequivocal. The negotiation between medicine and psychiatry in managing somatoform disorders is to some extent a reflection of how patients with medically unexplained symptoms currently reside somewhat uneasily between medicine, on the one hand, and psychiatry and psychology on the other (Sharpe, 2013). The danger of dismissing patients with somatic symptom disorder is inherent in both disciplines.

Many contemporary medical practitioners, working with patients identified with somatoform conditions, find managing them particularly challenging. They express their difficulty and articulate their feelings of frustration with varying degrees of diplomacy, tact and compassion. As I have suggested in Chapter One, in a profession focusing on clear lines of assessment, diagnosis and treatment, the uncertainty and unclear trajectory of the patient diagnosed with a somatoform disorder creates feelings of discomfort, uncertainty and professional fear (Brown, 2004; Burton, 2003; Chaturvedi, Desai, & Shaligram, 2006; Howard, 2013; Mango & Mango, 1994; Mobini, 2015; Richter & Sansone, 1999; Walker, Unutzer, & Kanton, 1998).

There is a substantial body of literature in which the patient with inexplicable somatic symptoms is characterized as difficult and intractable (Gillette, 2000, 2003; Jackson & Kay, 2013; Mobini, 2015; Richter & Sansone, 1999; Webster, 1996). There is frequently the perception that the patient presenting with unsubstantiated physical symptoms may be malingering, grant-seeking or "work-shy" (Folks et al., 2000; King, 1994). Bass and Halligan (2014) discuss in some detail the difficulties encountered in clinical practice in differentiating between these categories of patients. Whether this is an accurate description of patient character or, in fact, a reflection of medical perplexity and consequence defence in the face of the apparently inexplicable, is an interesting area of consideration. In the study by Jackson and Kroenke (1999) describing patients presenting with physical symptoms, many of whom were labelled problematic ("heart sink", "black holes"), the issue of the dyadic relationship was considered, i.e., that both the patient and the practitioner contribute in specific ways to an encounter which may be perceived as unpleasant or difficult (Jackson & Kay, 2013; Mobini, 2015; Stone, 2014). They suggest that clinicians with poorly developed psychosocial skills may find the experience more difficult. This too is an area for potential future research but which remains outside the ambit of this study.

Some medical practitioners (Gillette, 2000; Evens, Vendetta, Krebs, & Herath, 2015; Howard, 2013; Kleinman, 1978; Mobini, 2015; Servan-Schreiber, Randall Kolb et al., 2000; Servan-Schreiber, Tabas et al., 2000; Stone, 2014) do appear to be able to write with great compassion about patients they describe variously as “emotionally needful” or “problem patients” or patients with “special needs.” While they may be sensitive to the underlying purpose served by the presenting symptoms, they acknowledge the irritation and vexation, with the accompanying pejorative terms (such as “difficult”, “hateful” and “thick chart”) utilized by many of their frustrated colleagues.

It would appear from the literature that the patients presenting with somatic symptoms which prove intractable to investigation are not viewed with any degree of enthusiasm by many clinicians. This has the potential of translating into less optimal management and reduced patient satisfaction (Evens et al., 2015; Jackson & Kroenke, 1999; LaFrance & McKenzie-Mohr, 2013). The situation of the patient between medicine and psychiatry is difficult for both practitioner and patient. The development of psychiatry liaison services has the potential to ameliorate this situation. This may prove useful in providing a way in which the system can facilitate improved communication between the specialties in the service of more effective patient management (Bromley & Turner, 2014; Röhrich & Elanjithara, 2014; Unigwe, Rowett, & Udo, 2014).

In addition to the establishment of liaison services, and despite the history of difficulty in dealing with these patients, there is an emerging interdisciplinary specialty of psychosomatic medicine in which the focus of attention is the exploration of the relationship between social, economic, environmental, psychological, and behavioural factors and the consequent effect of these on bodily processes and quality of life (Lipsitt, 2006, 2014). Certainly there appears to be increasing evidence that there is a causal connection between low-income and physical ill health (Pickett & Wilkinson, 2015). This discipline is engaging with all aspects of inexplicable somatic symptomology. At its most basic level it is finding ways to investigate and validate the subtle and overt connection between mental processes and physiological functioning which include methodologies such as eye movement and desensitisation (EMDR) (Grant, 2009; Lee & Cuijpers, 2015) and alternative ways of viewing



medically unexplained symptoms which draw on neuroimaging and neuropsychiatry in order to better explain the genesis of the physical signs (Kabat-Zinn, 2009; Sarno, 2006; Servan-Schreiber, 2004; Siegel, 2012a, 2012b). With the advantages that modern technology provides, particularly in the form of the sophisticated imaging techniques now available, there is increasing evidence of physiological processes which are initiated as a consequence of, or in response to, mental processes (Browning, Fletcher, & Sharpe, 2011; Siegel, 2012a, 2012b; Siegel & Solomon, 2003). This validation of the mind-body link has the potential for far-reaching and positive effects for the management of patients diagnosed with somatic symptom disorder.

The experience of frustration and helplessness, when no link is established between symptoms and etiology, is not confined to practitioners. The literature provides insight into the feelings of desperation experienced by those individuals who have the misfortune to experience physical symptoms for which medicine can provide no explanation or solution. There are elegant and insightful descriptions of inexplicable pain written by academics in a variety of disciplines. Some are personal reflections of great sensitivity (Carel, 2008; Hustvedt, 2010; Woolf, 2002) and professional understanding (Behar, 1996; Garisch, 2012) as well as medical, philosophical, political and literary explanations focusing on the universal vulnerability of the body (Scarry, 1987).

From these high profile and exquisitely articulated expressions of personal frustration and anguish, to academic research providing some insight into the experience of participants with a somatoform diagnosis (Aamland, Malterud, & Werner, 2014; Lidén, Björk-Brämberg, & Svensson, 2015; Nettleton, 2006; Nettleton, O'Malley, Watt, & Duffey, 2004; Nettleton, Watt, O'Malley, & Duffey, 2005; Tschudi-Madsen et al., 2014), there is evidence for serious feelings of incomprehension and escalating anxiety associated with a body and mind that appear to be out of synchronicity. While the studies cited were unanimous in their presentation of the confusion and anxiety experienced by this particular cohort of patient, perhaps Lidén, Björk-Brämberg and Svensson (2015) expressed it most succinctly when they said that for many women “the symptoms overwhelm life”.

However, within the existing literature, the voices of impoverished women living on the Cape Flats who present to hospitals with somatic symptoms not validated by the medical system have thus far been silent. There are few accounts of what it means to already disempowered individuals, specifically women, to have their pain discounted, or explorations of what the pain means to them in the context of their particular lives.

### **2.3. POVERTY, GENDER AND MENTAL HEALTH**

Poverty is a central concern in the African context (Acemoglu & Robinson, 2010; Hope, 2004; Mwabu & Thorbecke, 2004). It impacts on every aspect of life and creates disparities of access and entitlement between and within the members of the various populations (Lund et al., 2011; Woolard, 2002). Moving to the southernmost portion of the continent is South Africa, a country with enormous natural resources and the resultant and associated economic infrastructure and wealth (Woolard, 2002). The distribution of that wealth is not equal. In her paper providing an overview of poverty and inequality in South Africa, Woolard (2002) describes South Africa as country of “stark contrasts” where abject poverty exists cheek-by-jowl with enormous affluence. South Africa, while classified as a “middle income” country (United Nations Human Development Report, 2006) is in reality, one in which the disparities between wealth and poverty are vast and to a great extent remain racially demarcated (Mubangizi, 2008; L. Swartz, Gibson, & Gelman, 2002). The majority of the income is generated and enjoyed by a small percentage of the population (Gradin, 2013; Hoogeveen & Berk, 2005; Mubangizi, 2008). During the previous political regime this was held in the hands of a small minority group based on race. In the new dispensation the distribution of economic benefits remains limited to a small middle class, which although it now includes people of colour, continues to be situated within prescribed and exclusive boundaries (Hoogeveen & Berk, 2005; Klasen, 2000; May, 1998; May, Woolard, & Klasen, 2000, 2005; Woolard & Woolard, 2006).

As an area of research, South Africa offers great opportunities but also enormous challenges. It has a complex and painful past. The present socio-economic situation continues to evolve in idiosyncratic ways which challenge both the “previously disadvantaged” groups, who continue to battle against poverty, and its sequelae, as well as the healthcare professionals working in these communities who themselves have to negotiate a place situated between advocacy, professional service rendition

and personal and relational accountability (Appelt, 2006; Biggs et al., 2015; Carolissen, 2008; Carolissen & L. Swartz, 2009; de Villiers, 2011; Dukas, 2009, 2014; Mubangizi, 2008; Zulu, 1994.)

Research indicates that within particular socio-economic demographics the question of gender is an important additional factor for consideration across subjects and disciplines (Belle, 1990; Belle & Doucet, 2003; Bunting & McAuley, 2004; Woolard & Klasen, 2005; Woolard & Woolard, 2006). In South Africa the endemic absence of fathers or appropriate father figures places women in a financially vulnerable situation which has far reaching implications for both the women and their children (Barbarin, Richter, & De Wet, 2001; Bunting & McAuley, 2004; Madhavan, Townsend, & Garey, 2008; Padi, Nduna, Khunou, & Kholopane, 2014; Rabe, 2007; S. Swartz, Bhana, Richter, & Versveld, 2013). It is estimated that some nine million children are being raised without fathers (Meintjes & Hall 2013; Monama, 2011). In a large proportion of these instances the single, often unemployed, mothers are receiving little or no financial support from the biological fathers (Bunting & McAuley, 2004; Hall & Wright, 2010; Madhavan, Townsend, & Garey, 2008; Meintjes & Hall, 2013; Rabe, 2007). The stress of being unemployed, without social or financial support imposes considerable stress on the mental health of the general population but particularly women, which frequently translates into conditions of depression and anxiety (Belle, 1990; Belle & Doucet, 2003; Burns, 2015; Guay, Billette, & Marchand, 2006; LaFrance, 2009; Lund, 2015; Lund et al., 2010; Lund et al., 2011). This in turn provides yet another hurdle in being able to earn and care for the family.

Furthermore, women face many additional and specific societal and biological challenges which compromise their ability to escape the downward spiral of poverty. Teenage and unwanted pregnancies are rife, distressing and often denied (Jewkes, Morrell, & Christofides, 2009; Kaufman, de Wet, & Stadler, 2001; Kruger, 2005; Kruger & Van Der Spuy, 2007; Mushwana, Monareng, Richter, & Muller, 2015) which preclude any proactive management, thus adding to physical, economic and mental health vulnerability (Kruger, 2005; Mushwana et al., 2015). Residues of the apartheid regime in the South African context appear to have entrenched a culture in which women are generally devalued (Coovadia et al., 2009; Kaminer & Eagle, 2010). Education is not prioritized for women within certain communities and

invariably it is the girls who leave school early either to supplement family income or, more frequently, to take over family care duties. Although written twenty years ago, Fuller, Singer and Keiley (1995) describe the situation where both economic constraints and maternal influence affect the decision for girls to leave school – either to take up a caring role or to add to the family income. The culture of care within the communities is heavily weighted in favour of women providing care work. In post-apartheid South Africa issues such as early and unwanted pregnancies and the assumption of the caring role contribute to early school leaving and unemployment, and the women consequently remain compromised in their ability to transcend their circumstances of poverty and disempowerment (Bunting & McAuley, 2004). Addae-Korankye (2014) provides an excellent overview of the factors contributing to poverty in Africa. While he acknowledges the effects of the detritus of both current and inherited political and economic decision making, Addae-Korankye (2014) emphasises the tautological role of gender as a specific as well as the relationship between individual socio-economic status and gender.

The effects of poverty cannot be considered in isolation from the associated problems of crime and violence. The areas in which this research was conducted are characterized by endemic unemployment, poverty and associated violence and crime, much of it targeting women and children (S. Swartz, 2007). Rape and sexual abuse is widespread in South Africa, but particularly prevalent and unreported in the low-income Black and Coloured<sup>2</sup> areas (Harris & Vermaak, 2015; Jewkes, Levin, Mbananga, & Bradshaw, 2002; Jewkes, Penn-Kekana, Levin, Ratsaka, & Schreiber, 2001; Kaminer & Eagle, 2010; Williams et al., 2007; Zulu, 1994). The consequences are often associated with mental health issues which affect women in various and particular ways. Many psychological studies concerned with violence focus on posttraumatic stress disorder (PTSD). (Kaminer & Eagle, 2010; Williams et al., 2007). There is some indication of comorbidity of somatoform disorders with PTSD (Kaminer & Eagle, 2010), which would indicate the possibility that violence and

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<sup>2</sup> The use of racial categories in research and scholarship in general, and in South African research in particular, is controversial. However in the South African context with its recent, highly racialized history of apartheid, these categories continue to be weighted with meaning and inferences of relative power within social, economic and political life. Within my study the racial categories are particularly pertinent in that they speak to the voice and positioning of the participants within the broader South African context. In my use of the term “Black” I refer to people classified as African and the term “Coloured” refers to people of mixed race.

trauma can be associated with physical as well as psychological manifestations of distress (Romito et al., 2005). A recent Australian study (Meuleners & Fraser, 2015) examined the ways in which gender impacts on post-trauma recurring mental health problems in terms of manifestation and chronicity. While this is outside of the remit of this paper, it provides insight into the ways in which gender influences the way in which individuals may respond to violence and thereby provides potential to tailor interventions with more specificity.

### **2.3.1. The body as a mechanism of speaking under conditions of gendered oppression**

In certain circumstances and amongst certain communities, verbal communication may be eschewed in favour of physical expressions of emotions (Allaz & Cedraschi, 2015; Howard, 2013; Kirmayer & Young, 1998). This was an aspect of consideration in the community in which I conducted my research. While we need to examine the Western propensity to promote “increasing medicalization of misery” (Liebert, 2010; Ussher, 2013, p. 24), we must acknowledge that alternative possibilities of help-seeking are being enacted within the medical model. Included in this consideration is the possibility that in certain populations the mechanisms of help-seeking is expressed almost exclusively through the body (Cosgrove, 2003; Howard, 2013; Nettleton, 2006; Nettleton, Watt, O’Malley, & Duffey, 2005). In their chapter on women and their bodies, Chrisler, Rossini, and Newton (2015) explore the ways in which the use of the body has been a mechanism of help seeking and empowerment amongst women. Understanding physical modes of expressing distress may contribute to successful collaboration between the patient and the psychologist in the service of recovery (Brown, 2004; Kornelsen et al., 2015; Nettleton, 2006).

Outside of considerations of gender, it would appear self-evident that physical health and wellbeing is impacted negatively by poverty (Burns, 2015; Murray, 2006; L. Smith, 2010). However, in a more subtle way, the lack of such basic amenities as food, shelter, safety and education has the undeniable potential to create a climate which limits the possibility of mental equilibrium and mental health (Burns, 2015; Havenaar, Geerlings, Vivian, Collinson, & Robertson, 2008; Petersen, Bhana, & Swartz, 2015). If one looks at the basics of Maslow’s hierarchy of needs, however controversial, this becomes clear and unequivocal (Acton & Malathum, 2000;

Henwood, Derejko, Couture, & Padgett, 2014; Oleson, 2004; Richter, 2003). The literature abounds with findings relating to the existence of mental illness in sub-optimal socio-economic conditions. (Burns, 2015; De Silva, 2015; Patel & Kleinman, 2003). Ironically there is a tendency in resource poor countries to limit the budget for mental health services (Herrman & Swartz, 2007; Saxena, Thornicroft, Knapp, & Whiteford, 2007). In South Africa mental health facilities are severely under resourced as described by Lund, Kleintjies, Kakuma, and Flisher (2010). Reports have indicated that as many as one in three South Africans suffer from some kind of mental illness, yet the chances of receiving treatment are minimal (Tromp, Dolley, Laganparsad, & Goveneder, 2014). However, not only does poverty, and its sequelae, predispose individuals towards such psychopathology as depression and anxiety which are not unrelated to issues of exclusion and isolation (Baer, Kim, & Wilkenfeld, 2012; Belle, 1990; Belle & Doucet, 2003; L. Smith, 2010; L. Smith, Appio, & Cho, 2012; L. Smith & Chambers, 2014). In a tautological process, mental illness also increases the likelihood of socio-economic deterioration.

In the most basic and pragmatic terms: if you are poor you have an increased likelihood of developing a mental illness and, if you have a mental illness, your chances of being drawn into the downward spiral of economic vulnerability becomes exponentially more likely (Haushofer and Fehr, 2014; L. Smith, 2010). Haushofer and Fehr (2014), like L. Smith (2010), suggest that a negative feed-back loop occurs in situations of entrenched poverty. The negative socio-economic situation becomes a self-perpetuating system where goal-directed, problem-solving behaviour is replaced by less helpful risk-aversion attitudes and enactments. Basically poor people may lose the will or direction to make the kind of choices to help them escape the shackles of poverty. This intersect between mental and physical health is a consideration which Prince et al. (2007) suggest are linked with economy and not given sufficient attention.

While poverty as a socio-economic consideration has been shown to have a negative impact on both the physical and mental health of a population, literature indicates that it is in conditions of significant disparity that this impact is most severe and destructive (Kehler, 2001; Lund et al., 2010; Lund et al., 2011; May, 1998; May et al., 2000; Stavrou, 2000; L. Swartz & Bantjes, in press). Based on 2010 figures (Cobham

& Sumner, 2013) South Africa is found in the unenviable and shaming position as the country with the greatest disparity in wealth distribution. Within the focus of this study, unemployed and poor women, often living in informal developments on the Cape Flats, and within sight of Table Mountain and the affluent, mainly White suburbs, provide a graphic illustration of this disparity. To be poor and lack such basic necessities as adequate shelter, electricity, running water and sufficient food is challenging. To have in sight the unobtainable alternative must be difficult to endure. Lack alone is not necessarily responsible for psychosocial sequelae in the form of violence, crime and mental illness. The real insult comes in the constant exposure to wealth and privilege in immediate geographic proximity – physically close and visible but realistically unobtainable – which creates the potential for enormous emotional and psychological as well as physical difficulties. These challenges of poverty and disparity are possibly accommodated and expressed by the manifestation of both mental and physical symptoms in the particular conjunction found in somatic disorders.

Research shows a correlation between the physical impact of poor diet and lifestyle and mental health. In several studies (Patel & Kleinman, 2003; Lund, 2015; Tampubolon & Hanandita, 2014) results appear to indicate a clear connection between food insecurity, poor dietary and lifestyle choices and mental health problems. The negative effects include feelings of sadness, shame, impaired concentration and fatigue. L. Smith (2010) describes with great eloquence the negative tautological spiral which entrenches both poverty and mental illness.

#### **2.4. PSYCHOLOGY AND PSYCHIATRY WITHIN THE BIOMEDICAL SYSTEM**

While hypothetically they constitute allies in wellness management, medicine and mental health, the disciplines of psychiatry and psychology have a long and ongoing history of being uneasy bedfellows. Almost a century ago Owen (1936) described the relationship in the following way: “In general medicine and psychiatry we are dealing with a poorly functioning complex organization of integrated cell systems” (p. 557). In a strange way the patient diagnosed with psychosomatic symptoms provides a graphic illustration of this uncomfortable relationship. Sharpe (2013) makes an interesting point in terms of psychosomatic illness. He states, with some degree of

self-evidence, that the somatic symptoms may be classified as “medically explained” or “medically unexplained”. But as Sharpe (2013) suggests, what is interesting is that the apparently obvious distinction translates into the former being considered medical and the latter psychiatric. Between the two falls the patient with a somatoform diagnosis as a glaring illustration of the conundrum. In some ways the patient with a psychosomatic diagnosis becomes the “aberrant villager” described by Rhodes (1995). The aberrant villager who lives on the margins of society, reveals what is hidden and unacknowledged in the village situation to the larger society. In a similar way, the patient who has medically unexplained symptoms is relegated to the margins of both medicine and psychiatry, but through their existence and stubborn presence expose the underside of the medical world.

On a pragmatic level this difficulty in accommodating patients with unexplained symptoms is understandable, particularly within healthcare systems which focus on disease. However, Sharpe (2013) urges a more integrated approach in the service of more effective management. Medicine and medical management is firmly rooted in the biomedical model; mental health management, relatively, has a more ephemeral structure and location (Kleinman, 1978; Lloyd, 1996; Rhodes, 1995; Sharma & Kumar, 2015). While the relationship and cooperation between the two disciplines has the potential to fulfil the edicts of the WHO’s holistic definition of health, so often mutual incomprehension and suspicion erodes the process (Kleinman, 1978; Sharma & Kumar, 2015). Like Sharpe (2013), Lane (2014) advocates that “being mindful of our [biopsychosocial and biomedical] similarities and differences” has the potential to negotiate the divide and promote communication and collaboration across the medical disciplines.

Mental health in the State system exists, generally and somewhat tenuously, within structures dominated by medicine – clinics and hospitals (Allwood & Hart, 1991; Coovadia et al., 2009; Emsley, 2001; Kohn, Saxena, & Levav et al., 2004). Masilela (2000) describes mental health as having been the “pariah or stepchild” of health services in South Africa. It is frequently if not ubiquitously necessary for mental health practitioners to make accommodations to fit into the system (Emsley, 2001; Flisher, Fisher, & Subedar, 1999; Gibson, Kuluski, & Lyons, 2015). However this may be to the possible detriment not only of mental health as a discipline but also to



effective and respectful patient management (Freeman, 1991, 1995; Gibson et al., 2015; Uys, 1992). Certainly escalating expenses and resultant cost restraints have had a negative impact. Increasingly it is being advocated that mental health services would be best served by more inclusive policies with regard to their inclusion in the general healthcare system both in South Africa as well as in general health services worldwide (Gibson et al., 2015; Prince et al., 2007; Saxena et al., 2007; Sorsdahl et al., 2012). For as long as mental health is seen as separate and not equal, the focus of service provision will continue to be on the physical health services to the detriment of individuals with mental health disorders.

When suspicion and poor reciprocal interaction exists between the professionals, focus on the needs of mental health patients may become diluted and lost (Freeman, 1991; Gibson et al., 2015; Uys, 1992; Zolnierek, 2009). In the diagnostic processing of certain patients, the divide between the professional areas of expertise becomes blurred and potentially debilitating. Patients who are suspected of having a somatic disorder highlight and challenge the status quo in a particular way. They enter through the portals of medicine – frequently outpatients departments and trauma units – but after failed attempts at definitive physiological diagnosis, they are passed on to mental health specialists – either psychiatry or psychology, when such services are available. The patient may be puzzled and the various members of the health team may be equally confused and frequently resentful of the perceived wasted time and resources.

Within this conundrum, psychiatry itself holds a unique and tenuous position. It is rooted in the medical model but by the nature of its specialization sometimes creates the perception that it falls outside of the ambit of conventional or physical medicine and may even be stigmatised (Gibson et al., 2015; Goldacre, Fazel, Smith, & Lambert, 2013; Sartorius et al., 2010; Zolnierek, 2009). This professional identity confusion is not exclusively an external imposition but one that is frequently internalized by the psychiatric specialists themselves. They may collude with the perception that they have no right to inclusion in the general medical enclave.

The literature describes this insecure positioning of the mental health specialist which may be particularly difficult to negotiate within the State healthcare infrastructure as well as other medical environments (Gaebel & Zielasek, 2015; Goldacre et al., 2013; Rhodes, 1995; Sartorius et al., 2010). For systems overloaded with physical

complaints and demands for treatment – chronic diseases and injury as a direct consequence of poverty and violence – the inclusion of mental health services is often accommodated with difficulty, if not reluctance (Hensel & Flint, 2015). What does this mean for the mental health patient, and in particular those individuals whose presenting symptoms fall between mental health and physical medicine? The subtle but often unacknowledged subscript enacted in the narrative of medicine versus mental health has the potential to further exacerbate patient vulnerability and invisibility in this particular cohort.

It is not clear to what extent and under what conditions the patients with medically unexplained symptoms are able to identify this status quo – that is, of being diagnostically ambiguous. However, the overall societal climate creates a situation in which mental health is so generally misunderstood, ignored or stigmatized, that the result is ambiguity in both management and treatment (Jutel, 2010; Kornelsen et al., 2015; Nimmo, 2015). This translates into patients who may find themselves moving between the various members of the healthcare team as a consequence of their perplexing presenting symptoms. That is, symptoms related to or manifesting in the body which are essentially psychological in origin. Practitioners may be confused and resentful as a consequence of their own discomfort. The patient with a somatoform diagnosis can be seen to be in a precarious, if not untenable, position.

At this juncture, the question must be asked: are the issues of interdisciplinary misunderstanding on the one hand, and the stigmatization of mental illness on the other, in fact contributing to the incidence of patients presenting with psychosomatic illnesses? This may emanate from either professional or patient perspective. One way to facilitate the accommodation of both medicine and mental health is by creating a system whereby the body provides legitimization for help seeking. Entry into the hospital system is most effectively negotiated by presentation with physical complaints. A patient is more likely to be accommodated in a busy trauma unit if they describe some form of acute physical pain, than if they present with complaints of feeling anxious or depressed. In addition, the biomedical system demands that in the process of transferring a patient from trauma, or even outpatients, to psychiatry, all physical and medical eventualities have first been considered and eliminated. For example, a patient seeking help or being brought for help by family or relatives for

psychosis or anxiety may still be assessed extensively for underlying physical pathology. The extent to which this is done may confuse the patients to the point that they are unable to hold to their presenting complaint and will comply with the medical model in eventually ascribing their symptoms to what they think the doctors want to hear, i.e., exclusively physical symptoms (L. Swartz, 1992).

The balance between medical responsibility and competence in excluding empirical physical pathology, while simultaneously or subsequently identifying underlying emotional or psychological precipitating factors, is of necessity, a finely honed and intricate process (Govender, Oosthuizen, & Cloete, 2011; Hatcher & Arroll, 2008; Röhrich & Elanjithara, 2014). On the one hand the real concern and fear of missing a life-threatening or medically treatable condition has to be contained and managed. However, on the other is the necessity of avoiding unnecessary – expensive and time-consuming – investigations which often add to patient discomfort, distress and confusion while at the same time retarding appropriate psychiatric or psychological management (Govender et al., 2011; Hatcher & Arroll, 2008). While solutions to this conundrum are not offered by the present research this issue, particularly in resource scarce settings, needs to be held in mind and considered for future investigation.

## **2.5. THE HEALTHCARE SYSTEM**

The background of psychiatric and psychological services within the healthcare system have been considered above and in the context of extant literature and research. My own research attempted to include an exploration of the participants' perception of psychology as a discipline concurrently with its situation in the healthcare system. Referral within the hospital organization may contain the implicit assumption that the patient understands the relevant disciplines and the implications of referral. This is not the reality of referral to psychology in the communities under consideration. Frequently as a consequence of patient inexperience with the concepts associated with mental health, the need for psycho-education regarding the nature of psychology is imperative during the initial assessment in order to facilitate patient understanding and engagement. I have discussed this within the particular situation in which I work and conducted my research (1.3). Bruwer et al., (2011) suggest that the concurrent situation of low rate of treatment seeking accompanied by the high numbers of patient dropout for even common mental health disorders within the

South African context are of grave concern. They suggest that efforts within the public health sector to improve the management of mental health problems should take cognizance of the many influences impacting on both treatment initiation as well as discontinuation (Bruwer et al., 2011). This is supported by the exploration of the barriers to help-seeking behaviour described by Trump and Hugo (2006). While it is relevant to be aware of patient difficulty in engaging with psychology, extensive exploration of the macro system is outside of the remit of this dissertation.

However, one cannot ignore the milieu in which psychology and mental health patients are situated. The South African healthcare system exists within a broader socio-economic context. In this it is not unique. However, what is specific to this particular setting is the complexity of that socio-politico-economic history (Baldwin-Ragaven, London, & De Gruchy, 2000; Kohn et al., 2004; Mayosi et al., 2012; Motsoaledi, 2015). While the constitution of the “New South Africa” has been lauded both locally and internationally, remnants of the old regime remain and are enacted in both overt and subtle ways. The shame of the South African history of race-based service delivery has ostensibly been firmly obliterated but the effects linger on with varying degrees of malignancy (Baldwin-Ragaven et al., 2000; Mayosi et al., 2012; Motsoaledi, 2015). While legislation may have removed racial and other stigmatization from the constitution – and South Africa has a revised constitution that is exemplary in its inclusiveness – clearing the statute books of discrimination does not translate into obliteration of practices which have become part of the fabric of institutional functioning (Burns, 2010; Lund, Breen et. al. 2010; Lund, Kleintjies et al., 2010; Lund et al., 2011; Motsoaledi, 2015; Petersen & Lund, 2010).

Finally, within the present economic climate in South Africa, constraints regarding expenditure are of paramount importance. Pressure on the healthcare environment with the HIV/AIDS pandemic has brought into focus the need to factor concerns of costs – in terms of personnel, equipment and procedures – into strategic planning. In this regard patients with unexplained somatic symptoms pose a particular challenge. The literature abounds with accounts of the escalating costs associated with investigating patients with unexplained symptoms in healthcare systems worldwide (Hiller, Fichter, & Rief, 2003; Mobini, 2015; Nimmo, 2015). Reid et al. (2002) suggest that health service use by patients with medically unexplained symptoms is in

excess of that of other “frequent attenders”; the utilisation and expense of their medical investigations is notably greater. While it is outside of the ambit of this research to suggest solutions or advocate alternative management, it is of relevance to hold in mind the effect on the system of the patient who requires extensive investigation without apparent result. Studies examining the efficacy of particular interventions with patients with medically unexplained symptoms such as cognitive behavioural therapy (Hiller et al., 2003) and mindfulness (Fjorback et al., 2013) include in their studies the negative knock-on effect of work absenteeism with patients with medically unexplained symptoms. Once again, while outside the scope of this study, the impact is of particular importance in a country like South Africa where poor productivity in the work place is a problem of considerable proportions.

## **2.6. CONCLUSION: PULLING THE STRINGS TOGETHER**

From the exploration of the literature, it is clear that the topic under consideration is neither new nor without complexity. The literature provides facts and figures relating to mental health in South Africa and the way in which it is positioned in the larger frame. The economic implications of symptom investigation – both as a primary function of the medical system and as an adjunct to managing the somatising patient – has been explored and documented. There has been a great deal of research investigating the impact of mental health on poverty and vice versa. Increasingly there is both anecdotal and research interest in the reciprocal, functional relationship between the mind and the body. This we know. However, the experience and suffering of the individual can so easily be lost in the academic exploration of the system – political, economic, social or institutional. That is the very antithesis of what this particular research process is about. The intention was primarily to explore the experiences of a particular group of women who engaged with the healthcare system in a particular way. While their stories highlighted and engaged with aspects that have already been explored in the literature and previous research, it is the individual voice of women that is foregrounded here. The poignancy of a single heart-felt sentence uttered by a woman confused and humiliated by her circumstances should carry as much weight in contributing to our knowledge base and the consequent and compassionate management, as any statistical and empirical data. This literature

review has attempted to provide the latter; the exploration of the data which follows – in the form of women’s voices – aims to provide the former.

## **CHAPTER THREE**

### **METHOD AND METHODOLOGY**

#### **3.1. INTRODUCTION**

In Chapter Two, I described and reviewed selected literature, which relates to the topic under consideration. I paid particular attention to aspects of the socio-economic situation of participants which may have the potential to influence both the manifestation, as well as the subjective experience, of individuals who present with medically unexplained symptoms in the public health setting in Cape Town. In the current chapter, I will describe the processes and methodology I used to formulate, initiate and conduct my research project.

#### **3.2. BACKGROUND AND RATIONALE**

##### **3.2.1. Research in a clinical setting**

This research was conducted within a clinical setting. Specifically, interviews were conducted and data were collected by me, both as a clinician and researcher, in a hospital environment with research participants who had potential co-existing roles as patients and participants. While I am aware that the tradition of separating research from clinical work has been a common practice within both qualitative and quantitative research processes, there is also a movement towards the accommodation of clinical needs within a research activity (Borckhardt et al., 2008; Silverstein & Auerbach, 2009; Silverstein, Auerbach, & Levant, 2006).

This process, of concurrent clinical work and research activity, may be both particularly relevant and necessary in the context of resource-scarce environments. This was a predominant consideration in the two State hospitals at which I both worked as a clinician and operated as a researcher interviewing participants. As described in Chapter One, in both these settings I was faced with the knowledge that there was no alternative mental healthcare professional to whom I could refer the potential participants. If I did not see and treat the referred individuals clinically, either as an alternative to the research process should they decline to participate, or

subsequently, even concurrently, during the research process, they would have had no alternative access to mental health assistance.

In such situations, the challenge is to operate within appropriate ethical constraints as well as to offer a real and viable mental healthcare service. Smyth and Schorr (2009), in exploring effective ways in which to provide relevant amenities to “vulnerable and marginalized” populations, raise the challenge of mechanisms of operation in certain organisations and under certain conditions. While they acknowledge the necessity of evaluating efficacy both in terms of research process and subsequent clinical application, they suggest that strictly experimental designs are not necessarily best suited to either assessing the results or ensuring accountability (Smyth & Schorr, 2009). They suggest that responsible but innovative ways (which they term “what it takes”) may ensure that these populations have greater access to clinical services. They offer suggestions regarding the kind of programmes and interventions that will maximize and support enduring and pertinent change (Smyth & Schorr, 2009) rather than merely supply academic and scientifically grounded data. The need to be innovative in resource poor settings is an on-going challenge to both clinician and researcher in South Africa and has been the focus of research and exploration by local and international clinicians, researchers and academics (C. Smith, Lobban, & O’Loughlin, 2013; Smyth & Schorr, 2009).

### **3.2.2. Dual role**

In the specific context in which I conducted my research, the ethical dilemma of “dual role” was central (S. Swartz, 2015). It also required that the conundrum associated with the process and the quandary in which I felt myself to be should be clearly acknowledged and made visible. I have written at some length in Chapter One about the difficulty in moving between the two roles. It might have been more methodologically efficient to have been able to concentrate on the research question exclusively, without consideration of clinical responsibilities. However, in the spirit of “best interests of the patient”, I felt justified in conducting my research under these particular circumstances and in this specific manner. I received supervision, both clinical and academic, in negotiating my way through the process. Research highlights the value of supervisory structure and support particularly where the roles of clinical work and research may overlap (Giroto, 2010; McMaster, Jammali-Blasi,



Andersson-Noorgard, Cooper, & McInnes, 2013; Woodward, Webb, & Prowse, 2007). I will consider this more fully in the subsequent section on ethics (3.5.).

I am not alone in attempting to negotiate this process (Coy, 2006; S. Swartz, 2015; Woodward, Webb, & Prowse, 2007). The challenges in sustaining the dual role, the personal and professional conflicts and the need to manoeuvre the on-going and iterative transition between research and clinical service provision, have been well described by Coy (2006). Although the specific contexts differ, Coy (2006) clearly articulates the ethical dilemmas inherent in maintaining a balance between providing a mental healthcare service at one end of the spectrum, while eliciting sound and valid information for research at the other. Not least of this is, as Coy (2006) describes, the need to negotiate between the nuances of clinical constraints regarding patient confidentiality while structuring the inclusion of pertinent and valuable research data which has been elicited from the same individual.

Privileged insider knowledge obtained through the clinical relationship may add to the depth and understanding of data. However, there is also a continual and on-going necessity to evaluate issues of confidentiality and possible conflicts of interest. This needs to be foregrounded as a meticulous methodological requirement of the researcher. In addition, there may also be the need for particular sensitivity in managing potential feelings of confusion, even suspicion, experienced by the patient-participant. Within the hospital situation this confusion may relate to the participants' particular perception and understanding of the dynamic between patient and medical profession enacted in this unique and complex dyadic relationship. As Coy (2006) describes, the process of finding resolution to these issues became an integral part of my research journey, both personally and professionally, and will be examined in the final chapter. There is some acknowledgement that researchers and clinicians have the potential to deliver valuable insights to each other in the service of strengthening both understanding and client or patient service (Silverstein & Auerbach, 2009; Silverstein et al., 2006). Silverstein et al. (2006) advocate the use of qualitative research as a potential and valuable mechanism in strengthening clinical practice. When the two coexist within a single process, that is, research and clinical work being rendered by one individual, this mutual contribution becomes exponentially more visible and more complex. Certainly in the process of my own research, the heightened awareness

encouraged by the rigour of recorded and transcribed research interviews, provided me with valuable insights into my clinical functioning and expertise. Barrett (1988) describes with great clarity and insight the often unacknowledged interpretative transition which occurs during the transcribing of verbal clinical exchange into clinical notes. My own research process highlighted the way in which note taking and construction colours and transmutes the content of the clinical exchange. My experience was that in an almost symbiotic and iterative process my research refined and honed my clinical skills, and my clinical training possibly provided me with the expertise to conduct interviews more sensitively and effectively.

### **3.3. THE RESEARCH QUESTION OR STATEMENT**

The research question or statement is conceivably the most central and important component of a research project. Whether it is formulated as a declarative statement, a problem statement or as an inquiry, it constitutes the guiding principle of the entire process. At each stage, consideration of ways in which the question is to be answered will direct the decisions regarding theory, procedures, choice of participants, mechanisms of data collection and analysis (Silverman, 2013).

The following research statement guided my project: An exploration of the experiences of two groups of low-income women as they encounter the medical and mental healthcare systems in search of understanding their medically unexplained symptoms. Alternatively as the research question: How did two groups of low-income women experience the management of their medically unexplained symptoms within the State hospital system and the subsequent referral and experience of psychological services?

#### **3.3.1. The aims of the study**

In the service of answering the research question the aims of the study need to be clearly articulated and connected. The aim of my study was to explore, describe and attempt to understand the way in which the women attending the outpatients department of two hospitals, in similar socio-economic communities, gave voice to their experience. The particular experience concerned having their physical symptoms discounted from a medical or organic perspective and ascribed to psychological factors was also considered.

### 3.3.2. The research objectives

While in practice the research process is iterative rather than linear, theoretically objectives represent the processes and procedures undertaken in order to achieve the aim. In qualitative research the aim is achieved through rich and thick descriptions of the particular subject under consideration. Certainly much of the focus in social, specifically qualitative, research is on exploration, description and understanding (Babbie, 2014; Henning, Van Rensburg, & Smit, 2005; Silverman, 2013).

In qualitative research, the quantitative onus on discovering “new” factual information is more peripheral or possibly less emphasized. The evolution of unique perspectives or the exploration of previously under-researched areas of interest in qualitative research gains value from contextual issues. Silverman (2013) says that any “factual” evidence emerging from qualitative research endeavours, derive their real importance from the theoretical framework from which they originate and to which they have the potential to contribute.

While it is important that theory give structure, coherence and stability to the data, it should not however be foregrounded to the detriment of that data (Silverman, 2013). This should be particularly salient in the kind of research with advocates respect for the voice of the participant (Morrell-Bellai & Boydell, 2009; Nelson, Ochocka, Griffin, & Lord, 1998; Zimbardo, 1975).

My research, conducted within the context of the outpatient departments of two district level State hospitals, had the following objectives:

- To examine the experience of the socio-economic context in which the participants lived and interacted with the hospital situation;
- To consider the institutional process through which the patient-participants pass from the time of first presentation, either at the respective hospitals or at local clinics and private practitioners prior to this, until their referral to psychology at the respective hospitals;
- To collect information regarding patient perceptions of hospital management of their presenting physical symptoms and the consequent referral to psychology, i.e., to describe the subjective experiences of the participants as they passed through the system;

- To contribute to possible ways in which relationships between the patients and the system could be effected differently.

### **3.3.3. The study goal**

My primary goal in initiating and conducting this research was to explore women's understanding of receiving a referral to psychology when they had presented to the medical facility with specific somatic complaints. Implicit in this investigation was an exploration of the way in which this referral was both given to, and received by, the participant. This attempted to incorporate their feelings and understandings of psychology as a discipline.

As mentioned above (3.3.2.), in the service of obtaining rich and well-rounded data, I considered including the perceptions of the referral agents as well – the doctors in the outpatient and trauma units who had seen the patients and sent them to see me. To some extent my own perspectives and co-construction of the process mediated these perspectives – those of the patient or participant on the one hand, and the medical professional on the other. However, while I did interview six doctors, together with my supervisor, I decided that it would be difficult to include this data. The emphasis in this thesis is on the experience of the women and with the large number of participants and interviews I was left with a huge amount of data relating to their stories. Inclusion of the additional data would have made the resultant document cumbersome and beyond the constraints of the doctoral limitations.

## **3.4. THE RESEARCH DESIGN**

Constructing and implementing a research design involves important decisions regarding the procedures which will govern the research process. Silverman (2013) stresses the importance of choosing a research design and consequent methods based on a good match with what he describes as “the task at hand”.

### **3.4.1. Qualitative research**

I chose to do my research using a qualitative research design. Qualitative methods provide opportunities to more comprehensively understand complex social processes and relationships as well as to enable clarification and access rich description of lived

experiences from the perspective of participants (Bless, Higson-Smith, & Kagee, 2006; Denzin & Lincoln, 2005; Henning et al., 2005; Morrow, 2007; Silverman, 2013). The focus in my research, on the subjective lived experience of a particular group of patients in the hospital situation, made the choice of qualitative research a logical one. I wished to foreground the voice of the patient-participants, and to allow for collecting data, the form and content of which I could not anticipate.

Equally importantly, Morrow (2007) suggests that qualitative research provides an important vehicle by which investigation of poorly researched topics and experiences may be implemented. As a consequence, qualitative research has the potential to indicate directions in which to develop interventions which may result in social change and transformation (Morrow, 2007).

The choice of qualitative research methods may also present greater scope in terms of data gathering. Gergen (2008) asserts that in foregrounding participant voice and narrative, qualitative research provides opportunities of innovation. Gergen (2008) suggests that exploration of new ways of engaging with data collection may only be limited in scope by what she terms “outside gatekeepers” (p. 290). With the linguistic emphasis in qualitative research there is a reduced requirement to foreground one form of data collection over another. The emphasis on openness, Gergen (2008) suggests, has led to a great deal of creativity in obtaining and presenting data. While I considered some alternative data gathering techniques, unfortunately in the final analysis the “gatekeeper” of the hospital environment and the juxtaposition of clinical and research roles lead me to utilize the more traditional methods of semi-structured interviews, but which included the information from clinical notes from both intake sessions and ongoing attendance.

An important feature of qualitative research is the opportunity to investigate and understand social phenomena in situ. The opportunity exists to make visible interactions which are “taken for granted” and rendered invisible. Denzin and Lincoln (2005) provide a good general description: “A situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world” (p. 3). The possibility of contributing to a positive transformation is one that I have held in mind throughout

the research process. While the suggestions offered in my recommendations are tentative, they perhaps indicate areas in which further study may be directed.

### **3.4.2. Context**

Context is a central concern of qualitative research and the way in which it shapes and is shaped by interaction with the individual and between the participant and researcher (Baxter & Jack, 2008; Henning et al., 2005; Murray, 2015; Silverman, 2013). On the other hand there is also established and emerging research emphasising the need to contextualise and translate qualitative research into clinical practice (Forsythe et al., 2015; Frank, Basch, & Selby, 2014; Strauss & Sackett, 1998).

The context in which my study was conducted is crucial to both an understanding of the interpersonal dynamics, as well as to the way in which the data were collected and how the process was viewed and understood by the participants.

In addition, to a great extent, the context precipitated the research. The number of patients presenting with medically unexplained symptoms (MUS) in my clinical work and both Waterstroom and Hope Hospitals, generated questions that I felt compelled to investigate. These questions and my curiosity about the genesis of the symptoms as well as the patients' understanding of the process created the possibility of a specific research project. In essence, I worked in the environment which was generating the research question, and the patients with whom I worked were potential research participants.

As previously stated, the aim of the study was to attempt to explore and describe the way in which the participants – two groups of women in similar socio-economic circumstances and communities – experienced their transfer from medicine to psychology as a consequence of having had their physical symptoms negated from an organic perspective. As part of this process, I attempted to gain an understanding of the way in which the women viewed the nature, role and place of psychology within their particular socio-medical context. Psychosomatic symptoms and MUS have been extensively described in different contexts and from different perspectives in the literature for many decades (Govender et al., 2011; Kornelsen et al., 2015; Mobini, 2015; Servan-Schreiber, Randall Kolb et al., 2000; Servan-Schreiber, Tabas et al., 2000; Webster, 1996). Descriptions from the perspective of poor women of colour

living in socio-economically challenged areas in South Africa with its history of gendered and racial discrimination have been explored and described extensively (Sooryamoorthy, 2015; L. Swartz, 2004, 2012). However, my particular research context is concerned with a very specific geographic and socio-economic location and embedded in clinical work within a State hospital situation. These considerations have not, to my knowledge, been explored within these precise diameters.

### **3.4.2.1. The specific locations**

**3.4.2.1.1. Waterstroom Hospital** serves the surrounding areas of Eerste River, Kleinvlei, Mfuleni, Delft, Bluedowns, Blackheath and Kuilsrivier. The total population of these areas is estimated to be between 400 000 and 450 000. According to the hospital statistics<sup>3</sup> 1 900 patients pass through the emergency unit on a monthly basis, of which there are 1 300 admissions to the ward. Approximately 3 500 patients are seen in the outpatients department on a monthly basis. As well as attendance at the medical and surgical outpatient clinics these numbers include visits to the social worker, dietician, physiotherapist and psychologist.

**3.4.2.1.2. Hope Hospital** was established in 1976 and passed through many incarnations – as a convalescent home, post-acute hospital and trauma emergency unit. Table 3.1, accessed from a hospital information leaflet, provides an indication of the large catchment area served by Hope hospital. At the time of its closure in 2014, it provided a service to a potential population of over 1.5 million people on the Cape Flats. At this time it operated with a 24-hour emergency unit, 24-hour radiology unit, two operating theatres, four inpatient wards (two medical and two surgical including a high care unit) a specialised HIV/AIDS unit, Thuthuzela Rape Crisis Centre and an Outpatients Department. At the time of writing, the entire hospital had been closed with the exception of the emergency unit which will continue to operate until the hospital is demolished at a future date. The patients who utilised the services of Hope Hospital will now have to travel to the new Ubuntu Hospital, approximately 15 kilometres away, at their own expense until such time as the new Hope Hospital is built. There are suggestions that building will only commence in 2018.

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<sup>3</sup> Provided in personal communication from Dr. A. Medical Manager/CEO at Waterstroom Hospital.

Table 3.1

*Hope Hospital Catchment area*

Bayview	Lentegeur	San Remo
Beacon Valley	London Village	Sherwood Park
Bongweni	Lost City	Silver City
Brownsfarm	Mandalay	Strandfontein
Colorado Park	Manenberg	Strandfontein Village
Crossroads	Man-Man	Surrey Estate
Driftsand	Mitchells Heights	Tafelsig
Eastridge	Mitchells Plain	Tambo Square
Freedom Park	New & Old Cross Roads	Tembani Village
Gugulethu	New Rest	Town Two
Hazeldene	Nyanga	Vanguard Estate
Heideveld	Old Location	Wave Crest
Kanana	Philippi	Welcome Estate
Khayelitsha Site B, C	Phola Park	Westgate
KTC informal settlements	Portlands	Woodlands
Kwezi Park	Petunia Park	Woodridge
	Rocklands	Zweutsha

**3.4.3. Data generation****3.4.3.1. The hospital process**

I will deal with the particular process of research participant selection and inclusion more fully in the section on sampling (3.4.3.5.). However, the clinical context and State hospital healthcare system in which the study was conducted should be described and clarified at this point.

At the level of district hospitals, in which category both Waterstroom and Hope hospitals fall, apart from the emergency unit, no potential patient may access the hospital services directly and needs to come through a referral agent. Patients would be referred to either Waterstroom or Hope Hospitals via local clinics, day hospitals or occasionally private practitioners.

Given the socio-economic constraints of the majority of the population under consideration, the option or desire to use private facilities is generally rare. Private practitioners in the communities invariably require upfront cash payments and there is



not necessarily a sliding scale of fees. These private fees are not insubstantial, particularly given the limited income of many of the patients.

In the government healthcare system the majority of patients do not have access to commercial medical aids or insurance. The State has constructed a healthcare fee structure which provides a sliding scale for payment to accommodate patients across all economic spectra – from individuals who are employed with access to medical aid, to the indigent with no income other than, perhaps, State grants. Theoretically this ensures that every South African has the right of access to appropriate healthcare (Kleinert & Horton, 2009). However, as previously discussed in the introduction (in a country with its history of racialized care and its present status of economic disparity, the burden on State hospitals to provide free or limited-cost healthcare is enormous and facilities are generally over-burdened and understaffed and equipped (Coovadia et al., 2009; Gilson, 2005).

Patients with potentially life-threatening medical symptoms or injury such as severe cardiac pain, seizures, loss of consciousness, trauma, etc., will require no referral and may come directly to the emergency unit of the respective hospitals. Here they will be triaged by nursing staff, seen and assessed by a medical officer, stabilised and treated. Thereafter the patient will be admitted to one of the hospital wards, referred to a tertiary institution or followed up at one of the outpatient clinics.

As mentioned above, patients with non-emergency physical symptoms will be referred to the hospital through one of the various community healthcare facilities. This referral will generally be to the outpatient department of the district hospitals. Initially, the patient will be seen in the general outpatient clinic where a medical officer will assess them. He or she will either order further diagnostic tests, or if these have already been satisfactorily completed, initiate a treatment regimen or referral to a specialist clinic. These additional clinics may include paediatrics, orthopaedics, gynaecology, internal medicine, surgery and psychiatry and psychology.

On paper this process may appear seamless and efficient. However the large number of patients attempting to access the facilities, the limited staff to patient ratio, as well as often poorly maintained and inadequate buildings and obsolete equipment, makes it difficult for all concerned. If one factors in the additional challenge presented by the

patient with MUS (medically unexplained symptoms) the potential for resentment, dissatisfaction and overt hostility on all levels is increased.

The patients<sup>4</sup> or participants were referred to me at the end of this trajectory. Frequently, initial interaction with the individuals referred to me involves placation and explanation of psychology as a discipline before the actual interview – clinical or research – can be initiated.

### 3.4.3.2. Patient interviews and clinical notes

Data were generated for this study from the initial clinical intake interviews conducted with each participant, followed by semi-structured interviews at subsequent visits. Basic questions regarding patient demographic information were included (See Appendix A). The number of consultations varied depending on the follow-up visits which each participant attended. Three patients attended the intake interview but, although scheduled, did not arrive for subsequent appointments. Two participants had only one interview. These single interviews were constructed as retrospective considerations and explorations of their prior therapeutic process. Both had been referred to me at Hope Hospital for MUS and attended therapy for 10 months and a year respectively. Their therapy was terminated as a result of my leaving the hospital. They agreed to return for the one-off interview in order to participate and contribute to my research. Of the remaining sixteen all had at least a minimum of two interviews. At Waterstroom one patient continued to see me on a monthly basis until December 2014 and one patient has recently been re-referred to me for follow-up therapy (Table 3.2).

Table 3.2

#### *Participant Demographic Information*

<b>Pseudonym</b>	<b>Age</b>	<b>Ethnicity ***</b>	<b>Religion</b>	<b>Relational Status</b>	<b>No of Children (age in brackets)</b>	<b>Highest Level of Education</b>	<b>Employment Status ****</b>	<b>Source of income</b>
1.Raabia	37	C	Muslim	Married	2	Grade 10	U	Hus-

<sup>4</sup> Service users within the State hospital system continue to be generally referred to as “patients”. “Participants” is the term used to describe individuals who are the subject of research. Within my study the terms were used interchangeably.

								band
2. Davina	58	C	Convert to Islam	Divorced	1 (39)	Grade 7	U	Grant**
3. Gail	28	C	Christian	Unmarried	1 (4)	Matric	E	Work
4. Caroline	61	C	Christian	Divorced	3 (37, 30 & 29)	Matric	U	Grant
5. Angela	27	B	Christian	Single	1 (4)	Grade 11	U	Family
6. Shanaaz	20	C	Muslim	Single	2 (3 & 1)	Grade 11	U	Family
7. Allison	34	C	Convert to Islam	Single	3 (13, 9 & 3)	Grade 10	U	Family
8. Rivka	37	C	Muslim	Married	3 (15, 14 & 1)	Matric	E	Work/husband
9. Patricia	51	B	Christian	Married	4 (26 & 19 +2 deceased)	Grade 10	U	Husband
10. Nambitha*	19/21	B	Christian	Single	0	Matric	U	Family
11. Maryam	46	C	Christian	Divorced	0	Grade 11	U	Grant
12. Petunia	48	B	Christian + ancestors	Single	2 (25 & 12)	Matric	U	Family
13. Lianne	19	C	Christian	Single	0	Grade 11	E	Work
14. Mavis	48	C	Christian	Married	3 (20, 16 & 7)	Grade 7	U	Grant
15. Amelia	49	C	Christian	Married	2 (21 & 28)	Matric	U	Husband
16. Ingrid	44	C	Christian	Married	2+1 (23,16 & 4)	Grade 9	U	Family
17. Nomsa	31	B	Christian + ancestors	Single	1 (14)	Tertiary	E	Work
18. Elisha	23	C	Muslim	Single	1 (4)	Grade 10	U	Family
19. Kamila	47	C	Convert to Islam	Divorced	3 (27, 26 & 24)	Grade 7	P/T	Work
20. Joy *	37/39	B	Christian + ancestors	Divorced	2(16 &9)	Grade 11	U	Family

\* Patients interviewed retrospectively. Ages at original contact and subsequent interview.

Work status at time of original contact

\*\* Government grants either for personal disability or child support.

\*\*\*C=Coloured; B=Black

\*\*\*\* U=Unemployed; E=Employed; P/T=Part-time

As an adjunct to the taped and transcribed interviews, I also made extensive use of the clinical notes which I took at each interview or therapeutic session. The supplementary written commentary provided me with additional data to add to the transcribed interviews. From a personal perspective notes to complement the recorded and transcribed interviews were invaluable in adding depth to my understanding of the process, the relationship and questions of transference and countertransference, i.e., subjective and objective feelings elicited in either myself or the patients during

the particular encounter. Barrett (1988) substantiates the way in which juxtaposition of recorded and written documentation of patient-practitioner encounters or interviews may highlight discrepancies in meaning – which may be overt and intentional or subtle and unconscious – and which may significantly alter the final interpretation. While in the clinical context recording of the session may be neither desirable nor possible, in the qualitative research project in a clinical setting this additional mechanism has the potential to add to the richness and objective truth of the process.

#### **3.4.3.3. Research journal**

Throughout the research process, commencing at the time of my first interview in November 2012 at Hope Hospital, I kept a research diary. This journal included descriptions of the difficulties – both practical and ethical – that I encountered during the process. It described my subjective and internal ruminations regarding the individual participants – both patient and medical practitioner – as well as considerations of my own engagement with the data and procedures. It provided me with important supplementary data in terms of insights into my own processes which may have been lost without a written record. The journal informed and promoted the reflexivity which is acknowledged to be an important component of responsible qualitative research (Fitzpatrick & Olson, 2015). Reflexivity has increasingly been suggested as a valuable adjunct to the qualitative process and the previously held suggestions of “subjectivity with bias” are being challenged (Roulston & Shelton, 2015).

#### **3.4.3.4. Interviews with referring agents**

While my primary focus was on the lived experience of the female patient-participants, I felt that the perspectives of the medical professions, mainly doctors, who provided the referral, would enrich the data. I applied for, and was granted, ethical approval to interview doctors at both hospital sites. From the doctors who participated in the research project, data were collected in a single semi-structured interview each lasting approximately one hour. I made the decision to exclude this data for reasons of data overload. However, as I have mentioned too, this data will provide interesting insights. One of the ways in which this will be explored in

subsequent writings is the way in which the doctors' notes became an important consideration in the manner in which institutional information is transferred in the clinical setting as well as the way in which it impacts on patients' perceptions of both their symptomology and management (Barrett, 1988). The way in which doctors may describe the patients may be a formulaic way in which to both transfer information to a subsequent service provider as well as a self-protective device against future enquiry and investigation of patient management. These notes may signify an unacknowledged third party in the relationship between patients and practitioners.

### **3.4.3.5. Sampling**

The sampling process will be described initially, followed by a description of the interviewing protocol.

According to Silverman (2013), within qualitative sampling, procedures are implemented in order to access cases to study. He suggests that the function of sampling may be twofold:

- To find an appropriate and representative sources for data collection;
- To be sufficiently confident in that representation to be able to generate broader inferences.

This is generally problematic within the qualitative research process. The relatively small numbers of participants, the lack of empirical methodologies and the subjective nature of the data make generalizability difficult if not impossible. However, at all times, the depth and richness of the data remains the main focus of the qualitative research process (Denzin & Lincoln, 2005; Gergen, 2008; Gergen, Josselson, & Freeman, 2015; Henning et al., 2005; Silverman, 2013).

The issue of how a representative sample is obtained still requires consideration and justification. The average number of cases included for qualitative, phenomenological studies is generally limited to between eight and ten participants (Morse, 2000; Silverman, 2013; J. A. Smith, 2004). There are excellent single-study research projects where the depth of data is exponentially greater and which may serve the purpose of the study (Silverman, 2013). There are other instances where the numbers of participants may exceed the upper limit suggested by the literature in the service of

achieving saturation (Mason, 2010). In my own study the number of participants who were finally interviewed, for a minimum of the clinical intake interview, was twenty. Several other patients had been referred to me, but either by their failure to attend the first interview, or as a consequence of being outside the research criteria (gender and age), they were excluded.

Due to the specific circumstances, and ethical considerations regarding the lack of alternative treatment opportunities for the potential participants, I was unable to be selective in my sampling beyond the basic criteria of age (eighteen to sixty), gender (female) and socio-economic status (low-income). In obtaining my sample I considered each patient who was referred to me from the medical officers in the respective outpatient departments. If they met my research criteria and were willing to participate they were enrolled in the research process. None of the patients who arrived for the initial interview declined to participate. However, several patients agreed to attend and be included but did not, however, arrive for the first interview. This is a frequent occurrence within the community setting in terms of psychology attendance.

As such, my sample mechanism/technique would best be described as purposive (Palys, 2008; Silverman, 2013). Purposive sampling is one of a group of non-probability sampling techniques, also known variously as selective, subjective or judgemental. As such it relies on the judgement or discretion of the researcher in selecting the research units (Palys, 2008). A refinement of the purposive nature of the sampling in my particular study would be the component of homogeneity, i.e., the individuals chosen for my research share similar characteristics of gender, background and socio-economic status. As has been previously stated the purpose of this study was not to generate inferences which could be applied to the broader population but to obtain rich and complex data of a small and particular group. This remains in line with the emphasis and intent of research guided by qualitative designs (Palys, 2008).

#### **3.4.3.6. Interviewing**

The data were generated, in general, by an initial semi-structured intake interview followed by between one to five post-intake sessions. Two patients had completed a

therapeutic process with me at Hope Hospital and returned for a single interview to obtain a retrospective exploration of their experience with diagnosis and follow-up with psychology. Three patients did not return for follow-up interviews and one participant continued to see me as a patient for almost a year. In the initial and first subsequent interview, autobiographical information was obtained and specific questions and answers (relating to symptoms and feelings regarding the referral) were negotiated. Thereafter free association narrative was encouraged to enable the participants the opportunity of giving voice to their own experiences, unconstrained by specific questions.

Although I experienced both personal and professional anxiety about the interface between research and clinical work, I felt that this was generally undetected by the participants. Possibly this was due to the participants' lack of experience and consequent expectations of the therapeutic process. In addition, my work in the community over time has taught me the necessity of being adaptable in my application of the therapeutic process, and where "thinking on my feet" is part of the challenge of the work on a daily basis. While at times it was difficult to negotiate, largely due to lack of nursing staff support in order to conduct simple diagnostic tests (such as checking blood pressure and pulse rates) at no stage did I feel that the research was being contaminated by therapeutic processes, or vice versa.

#### ***3.4.3.6.1. Patient participants***

My clinical training and the need to hold the possibility that "participants" might evolve into "patients" created a more structured intake interview than might possibly be the norm within the research process. However, I felt it was imperative to obtain the necessary clinical background in order to facilitate the transition should this become necessary or desirable. In both settings there was no option of referring patients on for therapy. If the potential participant decided subsequently to withdraw from the research process, but still required therapeutic intervention, I needed to ensure that the necessary processes had been initiated.

While this might be viewed as an intrusion and entrenchment of a professional-patient power differential, I try to maintain a stance of respect and mutual exploration when working in the community, rather than of attempting to impose knowledge and or

direction. In my clinical training there was an emphasis that, no matter what the context, presenting complaint or treatment approach, the underlying principles of person-centred therapy, (empathy, unconditional positive regard and congruence) should prevail. I try at all time to foreground these values in my interaction with patients and/or research participants (Mearns & Thorne, 2007).

From my experience, in the community, of working with patients presenting with medically unexplained symptoms (MUS), I compiled a basic framework of questions (See Appendix B). In formulating this list I attempted to frame the questions to provide both leeway for participant contribution while simultaneously ensuring that they were specific enough to allow collection of the kind of data that would be relevant to my research question.

I conducted a total number of 43 interviews with 20 research participants. I have not included in this number the sessions for those participants who subsequently became patients on an ongoing basis. All interviews were recorded and I personally transcribed each one, despite being offered the possible assistance of a professional transcriber. I felt this to be necessary both as a way to stay close and involved with the data, as well as to maintain the confidentiality of the stories. I felt uncomfortable with the idea of anyone else listening to the participants' intensely private, often heart-breaking stories that were presented to me privately within the context of a conversation between two people in a room. While these are made public within the context of this research, some distance is created by the anonymity that is inevitable with the use of pseudonyms, the extraction of pieces of dialogue from the whole and the written word offered in place of the spoken.

While I am aware that in many qualitative studies a pilot study is performed initially in order to fine-tune the process and content of inquiry (Morse, Barrett, Mayan, Olson, & Spiers, 2008; Silverman, 2013), I did not feel this was necessary in my particular research situation. As previously mentioned, my prior work in the two hospitals concerned rendered this superfluous. I was familiar with both hospital environments and infrastructure, had significant clinical exposure in both settings to patients with the condition under enquiry, a pre-existing referral relationship with the medical officers and allied health workers, and had the full cooperation of the management at both Hope and Waterstroom Hospitals.



Listening to the interviews during the process of transcribing allowed me to refresh my memory of the content. While I had made supplementary clinical notes, I was surprised at how much of the subtlety I had missed while focusing on the exchanges in the room. Once all the interviews (forty three) had been transcribed, I did a close first reading of all these interviews and identified the sections which were related to physical symptoms, the patients understanding and experience of them, their interaction with the referral agent (apart from two exceptions they were all medical officers) and their feelings about being referred to psychology. Incorporated in the latter was an exploration of their understanding of psychology as a discipline. I grouped the initial headings into the following broad categories:

- Experience of symptoms;
- Experience of medical management;
- Understanding and feelings about referral to psychology;
- Their assessment of the outcome, i.e., how effective they felt the time with psychology had been.

During subsequent readings I further expanded these broad categories to include subheadings, providing more details and nuance in terms of their lived experience of the entire process.

I utilized a high quality digital recorder with excellent sound quality. I did not record the first session with **Angela**, as I hadn't anticipated the possibility of flat batteries. I was unable to record **Mavis's** first session due to her aphonia. However, in both instances I kept notes in the session and once it had been completed and the patient had left the room, added to them to supplement anything I had been unable to capture. I did not want the taking of copious notes to disturb or undermine the relationship.

As I mentioned in 3.4.3.3., throughout the year of data collection (and beyond) I kept a research diary in which I recorded my feelings – both positive and negative – about the process. My frustrations, observations, feelings of inadequacy, joy at pivotal moments, comments regarding transference and countertransference. Where appropriate these have been incorporated. I think that this journal, writing in it and

reading it periodically, was an extraordinarily helpful mechanism to allow me to reflect on what I was doing and where I was going. It gave me the opportunity to assess my own processes with regard to both roles – researcher and clinician. Through writing in this journal, sometimes on a daily basis, I learned to adjust and refine both my clinical skills and my research activity.

#### **3.4.4. Data management**

While the necessity of meticulous, verbatim transcriptions is a prerequisite in qualitative research, the delicate, underlying meaning and nuanced content are not necessarily reflected with mere technical expertise. Even with the intention of objective motivation and focus, transcribing incorporates elements of interpretation and subtle construction of meaning which are subjective. Perhaps this subjectivity is enhanced when the researcher is performing the transcription – clues in the re-listening creates a re-remembering of the actual interaction which will support decisions, about punctuation, pauses and tone for example, that can create a slightly altered meaning of the words.

However, on the other hand, the objective transcriber may miss elements of exchange that were non-verbal but which clarify or even alter the verbal exchange. Staying close to the data has the advantage of creating opportunities for the researcher to remain alert to potential areas of research omission or clinical errors in judgment. The very act of transcribing is intrinsic to the research activity that is supported and emphasized by the literature (Henning et al., 2005; Lapadat & Lindsay, 1999; McLellan, MacQueen, & Neidig, 2003). In my personal experience the process of doing the transcription myself, added not only to the research process, but provided me with an invaluable aid in refining my clinical work. I will reflect on this more fully in the final chapter.

Only one interview was conducted in Afrikaans; all the remaining participants were interviewed in English. With the exception of **Mavis**, all participants were completely fluent in this language and indicated that they were comfortable speaking English for the interviews. The subsequent transcriptions were done in the language used. During the final editing, the assistance of a professional was sought, who was conversant in both English and Afrikaans, to assist in the translation of the single interview

conducted in Afrikaans. This facilitated the inclusion of quotes from Afrikaans-speaking participants in such a way as to make them universally comprehensible and inclusive to non-Afrikaans speaking readers.

Immediately following each interview, the audio-recordings were downloaded onto my computer and deleted from the recording device. The computer is password protected to prevent the recordings being access by anyone other than myself.

I have mentioned at the beginning of this section that I did the transcriptions of all the interviews myself for the reasons already given. In addition, following the suggestions of Henning et al. (2005), I attempted to transcribe as soon after the interview as possible in order to enhance the memory of the nonverbal details contained in the interaction. In all cases I attempted to do the transcriptions within a 24-hour period.

There are numerous ways in which to transcribe the spoken data into the written format. The suggested notation symbols may vary. I chose to follow the recommendations outlined in Henning et al. (2005). The notations which are relevant to the material which is presented in this thesis mainly concerns pause and emphasis. I have utilised the notation (.1) to indicate elapsed time in silence with the number indicated the seconds passed. I chose not to capitalise emphasised speech but rather employed italics to indicate this change in volume and emphasis. I felt that it was less disruptive to the flow of reading, while retaining the indication of change.

### **3.4.5. Data analysis**

Henning et al. (2005) assert, “The analysis process is the ‘heartbeat’ of the research. Here the analyst’s quality of thinking will be evident” (p. 103).

In my study, my thinking in expanding the number of research participants beyond the number usually interviewed in qualitative studies, and my initial decision to incorporate the perspective of the referring agents, was motivated by a desire to obtain a research result that offered both depth and breadth. However, MacLean et al. (2010) suggest, “less is more” and warn against gratuitously collecting data and creating a situation where one feels “compelled to analyse because of feelings of responsibility for participants’ time and effort” (p. 288). I did reflect, both during the process of data collection and after its conclusion, whether or not I felt coerced into

seeing participants as the only option for clinical intervention. While this may partly have been true in some instances, each participant I saw and was included in my study made valuable contributions to my understanding of my research question in ways that were unique, rich and personal.

While gathering rich and thick data through interviewing the participants initiates the research process, the researcher needs to give intense consideration to exploring, understanding and interpreting the data (Henning et al., 2005). Data is just data without this process. However, the manner in which it is done is a tautological and iterative one in qualitative research. The stories provide the data, and the interpretation gives shape and substance and contextual richness to the data (de Villiers, 2011; Todres & Galvin, 2005).

#### **3.4.5.1. The sequence of analysis**

I employed the eight-step process suggested by Tesch, as cited in Creswell (2009, p. 186).

1. I read each transcript, in conjunction with my reflective notes, in order to obtain a perspective of the whole.
2. I then progressed through each transcript more thoroughly highlighting and making notes of the sections relevant to the research questions. During this process I made notes in the margins which I had allocated at both sides of the transcribed documents.
3. As I conducted this process both themes and subthemes were identified, listed and grouped.
4. I then examined the data once again within parameters of these groupings. Themes were abbreviated into codes at this stage.
5. I used key words to categorize the themes which were then grouped together to diminish the number of categories and make the data management less unwieldy.
6. After I had completed the abbreviations for the categories, I used colour coding to identify the specific codes.
7. I did an initial analysis after I had organised the information under each category.

8. I then perused the documentation and recoded.

While I considered several mechanisms of data analysis, including the use of grounded theory and interpretative phenomenological analysis in particular, in the final decision, I have used basic thematic analysis in order to keep most closely connected to the data which evolved from the women's stories.

I will briefly discuss the principles of reflexivity here but will deal with the specifics in more detail in the final chapter.

It is widely acknowledged (Guillemin & Gillam, 2004; Morrell, Epstein, & Moletsane, 2012; Pillow, 2003) that the need to include a consideration of reflexivity is an integral and essential part of qualitative research. While incorporation of the reflective process is in itself not an assurance of ethical practice, Pillow (2003) suggests that, on balance, it weighs in more effectively than adherence to ethical protocols in the process of having the research ethically approved.

The particular value of reflexivity in qualitative research is that it encourages introspection in the researcher who is engaging in relationships that depend on the development and maintenance of trust and respect over varying periods of time (Pillow, 2003; Ramcharan & Cutcliffe, 2001). The use of reflexivity as a tool encourages awareness of "microethics" in the form of "ethically important moments" as the research process unfolds (Guillemin & Gillam, 2004, p. 276).

Apart from the contribution reflexivity makes to the development of a sensitive and aware relationship between researcher and participant, Fine (1994) suggests that by revealing the process, as well as the outcome, we add to the knowledge base in more subtle but nonetheless invaluable ways.

### **3.5. ETHICAL MATTERS**

Maracek (2001) asserts that ethical constraints and considerations are fundamental to feminist research. With the feminist focus on power differentials and gender-based inequality she suggests that it is imperative to maintain stringent ethical standards. Morrell et al. (2012) concur and state explicitly that the necessity for developing for guidelines governing research ethics is based on the concern with preventing

exploitation of the individuals being researched and that the principle of “do no harm” should at all times be foregrounded. A spin-off from the HIV/AIDS pandemic and the upsurge in related research has resulted in the imposition of more stringent and increasingly carefully monitored controls, not only within the medical context such as my research, but with any research that involves human subjects (Angell, 1997; Boden, Epstein, & Latimer, 2009; Emanuel, Wendler, Killen, & Grady, 2004; Morrell et al., 2012).

When the power differential between the participant and the researcher is an overtly unequal one, adherence to the principles of both “procedural ethics” (which includes submission of a research proposal to the respective academic and medical committees) as well “ethics in practice” is essential (Guillemin and Gillam, 2004; Morrell et al., 2012).

### **3.5.1. Institutional approval**

In accordance with Stellenbosch University protocol and procedures, my proposal was submitted to the departmental and faculty doctoral research committee for review and consideration (Ethics approval reference number: S12/-8/218. Letters of approval see Appendix C). In accordance with regulations regarding medical research, and following acceptance and approval from the Stellenbosch University research committee, I submitted my proposal to the Health Research Ethics Committee (Tygerberg Campus) and the Western Cape Department of Health for ethical clearance. When my proposal was accepted with no recommendations for adjustments, alterations or additions, I was able to begin my data collection at the respective outpatient departments of Hope and Waterstroom Hospitals.

### **3.5.2. Consent**

While informed consent is a crucial ethical component of all research, Morrell et al. (2012) emphasize that this is just the first step in conducting ethical research. The considerations implicit in the consent should be held in mind throughout the research process.

The researcher is under strict ethical constraints to ensure that all information is understandable and accessible to the participants in words and concepts that are fully

comprehensible to them. This presupposes communication in the participants' mother tongue. In a multilingual society this becomes substantially more difficult and is not always feasible. Availability of an official interpreter is generally limited in the State healthcare system outside of tertiary institutions and was unavailable at either Hope or Waterstroom hospitals.

I formulated the original consent form in English and had it translated into Afrikaans by an Afrikaans-speaking professional. In the hospital situation, the majority of patients are able to speak either English or Afrikaans. However, the resultant Afrikaans translation was of a linguistic standard that was largely incomprehensible to my patients. I attempted to arrange a simplified Afrikaans version of the consent form, but before I could do so, my first interview was scheduled and with the time constraints imposed by the imminent closure of Hope Hospital I needed to find an immediate and negotiated solution. I therefore used the English consent form for all participants, but went through the document meticulously with each person, translating where there was any doubt and ensuring that the Afrikaans and isiXhosa speakers were comfortable with and fully understood the content.

As I have mentioned the ideal is for both the consent and interviews to be conducted in the patient's home language. In practice communication with isiXhosa speaking patients is in either English or Afrikaans, or the services of an informal interpreter (nursing staff, lay counsellors) is employed. Once again this situation creates practical difficulties in terms of issues related to both research (accuracy of the interpretation) and clinical work (dealing with confidential issues).

In the service of ensuring that Afrikaans and isiXhosa participants fully understood the content, and taking into consideration that all patients were fluent in English, I utilized the English consent form with their permission and acceptance. Each participant was given a copy of the signed consent form to take home and peruse at her leisure (See Appendix D). On the subsequent follow-up the participants were once again given the opportunity to ask any questions or raise concerns related to the consent process and form.

For each participant, I read through the form with them, stopping to explain concepts and encouraging questions and requests for further explanations. Two of the patients –

one English-speaking, the other isiXhosa speaking, came back in subsequent interviews to raise questions regarding issues of confidentiality and protection of their identity. We re-perused the consent form, with particular attention to their areas of concern. They were offered the opportunity to withdraw from the project, but both declined, saying that their concerns had been met and they were comfortable to continue.

### **3.5.3. Privacy and confidentiality**

Patient confidentiality is expressly addressed in the wording of the informed consent form. In reading through the document with each patient I focused on this issue in some detail. Except for two participants, the women appeared to be completely indifferent to the implications of having their identity protected. However, both **Rivka** and **Patricia** came back to me on subsequent interviews asking for clarification and reassurance about their anonymity. On each occasion, I suspended the research process and focused on answering their questions with as much depth and time as the participants required. I also offered them the choice of withdrawing from the research project. However, neither of them felt the need to do so and expressed satisfaction with the explanation I had given.

In the intake interview each participant was told about the use of pseudonyms in the writing up of the research. I offered then, and on each of the subsequent interviews, the suggestion that they be involved in the choice of name. I had anticipated that this would be an opportunity for the women to involve themselves in the process in a proactive and collaborative way. Feminism in all its forms, including ethical management of research, promotes the idea of a levelling of the power differential between researcher and participant (Bauman, 1993). However, to my surprise not one participant wanted to take advantage of this offer. Even my attempt to discuss it with them was met with shrugs and laughter. I felt that to insist would be counterproductive and in fact a subtle form of oppression. A negotiated alternative played out with my one retrospective participant. She is isiXhosa and, as is frequently practiced, used an English name as an alternative to her difficult-to-pronounce isiXhosa name. Her English name was too idiosyncratic, and in fact used by her own family and friends, to hold any promise of anonymity. However, I felt the need to capture the essence of her personality that had so contributed to the therapeutic



process and our very particular relationship. In writing to thank her for her participation I offered the name “Joy” as an option, which she embraced with the delight that characterized her way of being. For the remaining participants, I attempted to choose names that were not in any way allied to their own names, but still remained true to the nature of their background, i.e., English, isiXhosa, Afrikaans and Muslim names for those participants who came from those particular linguistic and cultural groups.

There is something of a contradiction in offering confidentiality with the simultaneous need to contextualize the research. While the name of the participant can be changed, the demographic details themselves can give significant clues to the participants’ identity. Yet, by altering these details the integrity of the findings becomes corrupted. The balance between the two creates a tension both personally and professionally (S. Swartz, 2015).

During my research proposal meeting, as part of the university’s project oversight and approval processes, one of the panel suggested broadening and deepening the scope of the research by extending it to conducting some interviews in peoples’ homes. He suggested it would provide additional contextual information that would add to the richness of the data. The tension between psychology and other disciplines, albeit related ones, was brought into focus and the psychologists on the panel felt that this would be a threat to the frame in which we work. While interviewing patients outside of the therapeutic space has been done successfully (de Villiers, 2011), it was agreed in subsequent discussions with my supervisor that to do so in my situation, in which therapy was potentially part of the process, would create more ethical problems than could be justified by adding to the richness of the data. Consequently all interviews were conducted at the respective hospitals in a room allocated for my use as a psychologist.

#### **3.5.4. Payment for participation**

The endemic dilemma regarding the payment of participants for research was exacerbated in my situation by consideration of the potential clinical role that I might need to engage with. I felt that payment had the potential to contaminate this possible future relationship. In fact, of the twenty participants, six continued to have on-going

therapeutic relationships with me. These participants had all been referred to me within the Waterstroom system. The participants at Hope Hospital were accommodated as far as possible within the constraints of the closure of the hospital. While I could not offer on-going therapy with the outpatients about to close, I continued to see the patients for at least an additional session in order to provide support to the point that I felt they were contained. I offered them all the possibility of exploring referral to Ubuntu Hospital once the psychology department had been opened. None of the participants felt this was necessary. In any event, it transpired that there was no post for psychology at Ubuntu Hospital. A year later this remains the situation.

However, having experienced the financial constraints to attend during my time at Hope Hospital, I felt it was unreasonable as well as unethical to expect patients to fund their transport to the hospital for the purpose of taking part in my research – whatever the eventual outcome. Transport was therefore paid for each visit. This was not intended to act as an inducement but rather as a respectful acknowledgement of their effort in coming to see me. Two of the participants returned to Hope Hospital to do retrospective interviews. Their therapy with me had been concluded 18 months prior to the commencement of my research. I felt that they deserved an extra acknowledgment of their participation in a situation that clearly had no benefit to them. Consequently they were each presented with a small gift as a token of my appreciation at the end of their single interview.

### **3.5.5. Roles and boundaries**

Other local researchers have described their difficulty with negotiating a comfortable place between the roles of researcher and clinician (Coy, 2006; Dukas, 2009; de Villiers, 2011). It is a complex relationship in any context, but within a setting where clinical work is needed, and there are no possible alternatives of referral, it becomes exponentially more difficult.

At Hope Hospital, I had originally anticipated having referral access to the community service psychologist who was working there. This avenue was blocked when she expressed herself unable to accept referrals and when the hospital did not take on a new community psychologist for the subsequent year. An added

complication arose from the fact that because I was known to the staff in the outpatients department, it was difficult to refuse to see patients who, as they were outside of my research focus, could have no place as a participant, but had no other option for therapeutic assistance.

At Waterstroom Hospital I am the clinical psychologist whose professional role is to see patients referred to me from within the hospital. The only other psychologist in the area is an intern working for three hours a week at the nearby clinic. There was, and is, no possibility of referral to this facility as it is already over-subscribed with mental health patients.

However, the lines between researcher and clinician were in fact not as difficult to negotiate as I had anticipated. The process was initiated when a referral was made, suitability for inclusion established and an appointment booked. Once the patient had indicated willingness to be included in the research project, I introduced and explained the use of the audio recorder, described the research process and discussed the informed consent. Initially the participants were intrigued by the recorder and even a little self-conscious. However, by placing the recorder in full view to avoid any covert implications, and while avoiding making an issue of its presence, I found that it became invisible and was in no way experienced as an intrusion. Thereafter, we simply proceeded, as I would normally do within a clinical situation. By making the clinical intake assessment part of the process I covered all the initial requirements should the process continue to clinical work. In the ensuing sessions(s) I tried to introduce the research questions early in the process so that they were answered fully as soon as possible. Thereafter, I allowed the subsequent sessions to progress as a usual therapeutic process.

In my experience of working in the communities in the Cape Flats, I have become inured to using a good part of the intake session to investigate the patients' perceptions of psychology. The research questions regarding subjective feelings of the referral were therefore almost implicit and dovetailed well with my way of working. Due to a high level of ignorance regarding the psychologists' function, as described elsewhere (de Villiers, 2011; S. Swart, 2007), this confusion occasionally led to expectations that I could not meet. The most common of these were requests to provide assistance in finding employment.

A somewhat unique dilemma which I found myself facing was attempting to hold not two but three professional hats. Working in a hospital environment, focusing on patients whose referral symptoms were physically engendered, created situations where I had to make judgment calls based on my nursing training and knowledge. Several times I had to negotiate interventions that directly related to physical symptoms and my concern for the patients physical welfare. While in my initial criteria I had hoped to exclude conditions such as hypertension, it proved extremely difficult. High blood pressure is so closely allied to stress and often is the presenting complaint that leads to referral to psychology, with or without underlying medical pathology. Several of my participants presented with headaches that, as I knew with my nursing background, were often linked to poorly controlled hypertension. The consequences of this are life threatening and could not be ignored. Where I could I called on assistance from nursing staff, but when they were unavailable, I was forced to do the necessary checks myself. With several patients this necessitated a return referral to medicine for adjustment of medication or an institution of a regimen to control the hypertension. In other cases cognitive behavioural therapy (CBT) interventions (specifically progressive muscle relaxation) resulted in a settling of the physical symptoms. While this is outside of the ambit of the research or therapeutic role, failure to address these situations would have constituted negligence in the context of prior medical knowledge. I took my dilemma with these situations to both my clinical and research supervisors who supported me in my decisions.

In making methodological decisions, consideration of ethics carries the same weight of importance as it does throughout the research process. In conducting research within clinical settings there are additional and complicating ethical imperatives (Bullen, Mahler, Rosenberg, & Smith, 2014). Bullen et al. (2014) argue both against compromising sound and valid research data, and in favour of the necessity of addressing clinical issues and of using findings to contribute to improved clinical work (Bullen et al., 2014). In attempting to juggle the demands of the two processes, collecting research data and providing clinical service, it may be necessary to leave the safety and constraints of rigid dogma and strict adherence to a pure theoretical paradigm. Such rigidity and uncompromising approaches have the potential to hamper effective dialogue, in the profession of psychology specifically, and research in general (Zerubavel & Adame, 2014). In his forward to L. Smith (2010), Prilleltensky

foregrounds the need to “free ideas from convention, psychologists from orthodoxy and poor people from injustice” (p. x). These ideas may be challenging, even frightening with the additional responsibility implied in exploring and forging new directions in the research process. However, there is also the possibility for working with innovation while maintaining ethical principles outside of the proverbial research box. My research provided an opportunity for exploring possible exciting and meaningful contributions to the knowledge base in the service of significant and relevant social change (L. Smith, 2010; Smyth & Schorr, 2009); or, as Prilleltensky says (in L. Smith, 2010), “We start where the clients are” (p. x). The imperative to start where the patient-participants found themselves was a significant deliberation in the choice of methodology and theoretical perspective in this research project. My research topic was to a large extent dictated by the circumstances in which I worked and the particular cohort of patients that I saw on virtually a daily basis in my clinical practice.

As an ethical consideration, within this specific clinical and research situation, I had to continually hold in mind the possibility of adding to or contributing in any way to the disrespect or exploitation of these women. I felt that it was untenable that my research was merely a vehicle for extracting information for research purposes. I believed the research to be ethically justifiable only if it offered some value to the experiences of the participants. From formulating my research question, to making decisions about methodology, to writing up the findings, respect for the wellbeing of the participants was the guiding principle. Through the particular qualitative research methodology of phenomenology the opportunity was created for these women to be exposed to the possibly unique experience of being heard, of having their words respected and taken cognizance of. This is the function of therapy. Albeit in a research context, therapy was an integral aspect of the interaction between the patient-participants and me. In the same way, the possibility of collaboration in exploring potential solutions and acknowledging their own subjective experiences was created in a way that was respectful, enlightening and useful in their daily lives – beyond the confines of the clinical or research space.

### 3.5.6. Research as a vehicle for social change

While my research does not fall into the category of “action research” per se, the consideration of facilitating social change through the accumulation of new knowledge, while certainly neither new nor unique, was of particular relevance and importance in the context in which my research project was conducted. My research focused on a population of economically poor people, specifically poor women, who have suffered both historically and contemporarily from poverty and deprivation, not only of material goods and possessions, but also of status, power and self-respect (L. Smith, 2010). These women, silent and silenced by their own particular and challenging circumstances, engendered feelings of vicarious anger, frustration and call for action in myself as a woman, mental health worker and South African. While my research and the methods I used may not immediately impact the way in which women presenting to local hospitals with MUS are viewed and treated, it is my hope that the information garnered in the process of this research will provide the potential for more respectful and effective management of this particular cohort of patient. Suggestions for potentially more effective ways to negotiate the transfer of information to patients are provided in the section on recommendations.

The exposure to both emotional and physical trauma in this kind of economically disadvantaged population, in South Africa and further afield, is well documented (Kaminer and Eagle, 2010; Martin, 2012; L. Smith, 2010). In line with previous findings, the impact of the economic deprivation, as well as exposure to both acute and chronic trauma, appeared to be either directly or indirectly involved in the genesis of physical symptoms and consequent presentation at the respective hospitals. In his paper on physical response to trauma, Martin (2012) explores the ways in which highly charged negative events, both physical and emotional, which are unexpressed through cognitive processes, may become articulated through bodily symptoms. Martin (2012) describes case histories, which closely duplicated the stories of my participants, in which failure to successfully integrate traumatic experiences into appropriate symbolic representation literally left a conceptual “black hole” in personal narratives. In ascribing meaning to both the experience and the physical symptom, individuals may find ways of symbolizing in unique ways, which in certain instances translate into physical symptomology. During the course of my interviews as well as

the subsequent therapeutic sessions, the opportunity was created to explore the possibilities for the underlying causes and manifestations of unexplained symptoms. My findings will be discussed in detail in Chapter Four.

### **3.6. CONCLUDING COMMENTS**

In this chapter I have discussed the procedural and theoretical perspective from which I worked and conducted my data collection. However, I have also tried to paint a picture of the specific challenges I faced working in a particular context, with a group of participants drawn from two different hospitals. This situational framework includes considerations of the socio-economic location as well as the specific political history of exclusion of the participants, the particular circumstances under which the data needed to be collected and my role as a concurrent researcher and clinician. The sum total of these considerations are important in establishing the choices made with regard to research design and the methodology used in order to collect, analyse and present the resultant data.

In the following chapter I will engage with the data that was generated by my research and attempt to provide an in-depth exploration and understanding of this data.

## CHAPTER FOUR

### RESULTS

#### 4.1. Introduction: Secrets and silences

*All research involves secrets and silences of various kinds, and these secrets and silences matter.*

(Ryan-Flood & Gill, 2010, pg. 1)

Hypothetically the research process is a clearly defined set of procedures governed by rules, regulations and tradition. Quantitative research to a large extent emblematises this procedure of clearly delineated processes resulting in empirical data in the form of numbers and statistics. Engaging in qualitative research, with its focus on eliciting rich, layered and nuanced data, complicates and blurs the clear trajectory of statistical data collection and information processing. Instead of, or in addition to, research instruments yielding numbers and percentages, the messiness of questions and answers is introduced. The inclusion of data input via participant narrative makes the process less linear. Data-collecting procedures such as focus groups, interviews, and open-ended questions may create richer and more fascinating information, but which, paradoxically, makes the process of analysis more difficult. Running numbers through a statistical programme which will generate numerical results at the other end, and which can be constructed into tables, graphs and pie charts provides potentially unequivocal and empirical information. This delivers a good fit with the scientific community's emphasis on evidence-based data. Questions and answers are messy. A likert scale will result in responses linked to a specific number, which has a clearly ascribed meaning. Asking someone a question about the same issue will result in words and sentences which, while providing a deeper and more idiosyncratic meaning, is more difficult to manage in terms of analysis and its resource intensive processes – transcribing, coding and analysing.

Certainly in my particular research, which was both qualitative and conducted within a clinical context, I encountered particular problems with data collection, management and analysis. MacLean et al. (2010) discuss the theoretical restraints to sample size and iterative approach to data collection as a practical check to obtaining



too much data. Morse (2000) clearly warns against the dangers of qualitative studies where a larger or unwieldy sample size does not necessarily translate into improved data or a superior study.

In many ways my study ran foul of both constraints. My sample size was too large and I collected too much data. However, during the process of my data collection and retrospectively after it had been completed, I remain convinced that I had no alternative. My population was a vulnerable one with limited access to mental healthcare services. My research project was situated in a location where I obtained data from a clinical setting, and as a consequence it created the dilemma of accepting participants beyond the number I needed for my study. Without inclusion in the study, the possibility of meeting the clinical needs of this population would not have been possible. I therefore chose to include individuals who fulfilled the criteria for my research beyond the normal sample size traditionally associated with a qualitative project of this kind. Without inclusion they would have received no mental health input or assistance. With the potential for therapeutic considerations, the need to include clinical intake questions also added to the bulk and magnitude of the totality of data, much of which was peripheral or irrelevant to my research question.

As a consequence of this particular conjunction of needs and decisions I was left with an enormous amount of data to both transcribe and analyse. Much of the information I obtained, as a consequence of the clinical component, was unrelated to my research question. However, these data provided me with insights into the lives of my participants which would have been lost otherwise. In the final process of analysis, the choice of inclusion and exclusion was extraordinarily difficult to negotiate. On the one hand keeping silent about supposedly non-salient issues felt like dishonouring the words, experiences and contributions of the participants. On the other, the amount of data was so unwieldy that inclusion of all elements and narratives – even those allied peripherally to the research question – was impossible.

In the quote that introduces this section (Ryan-Flood & Gill, 2010) there is an acknowledgment of the ubiquitous existence of withheld information in the research process and the concurrent recognition that what is kept private or secret has meaning. Even in the most carefully constructed interviews the participant has the potential and capacity to withhold information. In writing up the results, I was not alone as a

researcher in having to make decisions to include and exclude on the basis of practical considerations. Maclean et al. (2010), in advising constraint in the sample size, acknowledge the difficulty engendered by the sense of responsibility felt by qualitative researchers to include all data in the service of the time and effort expended by participants. Thus in the process of selecting pertinent data for inclusion, some mechanism needs to be held in place to maintain a respectful stance for participant contribution while foregrounding the meaning implicit in both the inclusion and exclusion.

All the literature on qualitative research advocates the foregrounding of the research question at all stages of the research process. There were times when I felt so overwhelmed by the data I had collected that I lost sight of this pivotal consideration. I seemed not to be dealing with a single research question but a myriad of enmeshed issues related to the central concern of patients with MUS. I required significant supervisory input to keep my focus on the experience of my participants confined only to their diagnosis. Even so, I had to refine and redefine my own understanding of the parameters of that experience. I frequently digressed and veered off on tangents related to other, not unconnected issues. However, ultimately, it was on the experience the patient-participants had of their process through the system and the sense of self which was entrenched, ameliorated or merely changed as a consequence. This, the experience of patients who by the nature of their symptoms find themselves on the perimeters of both the medical and mental healthcare discipline, will be the focus of the data analysis which follows. In the service of maintaining focus, much of the dialogue will be silenced and many secrets revealed will remain undisclosed.

There were twenty participants in my study. They each presented to the respective hospitals with unexplained physical symptoms and were referred to me for management. All these women were poor, they had suffered the hardships and sense of alienation associated with poverty, the legacy of racial discrimination and gendered bias. Each woman had her own story which included histories of particular loss, trauma of various degrees of intensity and duration and each exhibited courage or difficulty in coping with their life situation. Most of the participants had not told at least part of their stories to anyone else before they entrusted their secrets to me. I am aware that even in the confidential space of the consulting room patients do not tell it

all – either as self-protective device or as defence because the whole story may not have been in conscious awareness even for the participants in the narratives. While this is not an ethnographic study, information about the lives of the women and their particular biographies has been included in the appendices to place them each in the context of their own lives – to the extent that I was privileged to be told and they were willing to reveal (See Appendix E).

## **4.2. POVERTY**

### **4.2.1. The context of poverty**

*It is easy to romanticize poverty, to see poor people as inherently lacking agency and will. It is easy to strip them of human dignity, to reduce them to objects of pity. This has never been clearer than in the view of Africa from the American media, in which we are shown poverty and conflicts without any context.*

(Chimamandi Ngozi Adichie, 2009)

This is an African study, specifically a South African study, which situates it in a very specific context. My research and the data that emerged are embedded in the environment in which the participants lived and in which the study was conducted. Both hospitals attended by the two groups of participants are situated in areas of economic deprivation and the communities they serve are considered poor. In contrast, most members of the professional staff working in the hospitals do not reside in these areas and commute to the hospitals from middle class suburbs, frequently some distance away. Specific considerations of the relationship between class, privilege, poverty and each with race are outside of the remit of this study and have been dealt with elsewhere in the literature (L. Smith, 2010), and specifically within the South African context and the emerging Black middle class (Burger, Steenekamp, van der Berg & Zoch, 2015; Zoch, 2015). However, the particular racialized socio-economic location of the participants and their health services have, and are likely to continue to have, an impact on the ways in which the service is viewed and accessed and dictates to some extent the relationship between the patients and the providers (C. Smith et al., 2013; L. Smith, 2010; L. Swartz et al., 2002).

This challenging relationship between service user and service provider is particularly noteworthy in respect of mental health services. In the years I have worked in

hospitals on the Cape Flats<sup>5</sup> as a clinical psychologist, my patients have generally come to see me reluctantly and often failed to follow up. This is neither a new phenomenon nor one particular to my context. As far back as 1966 (Baum, Felzer, D’Zmura, & Shumaker, 1996) research indicated a correlation between failed attendance at psychotherapeutic interventions and socio-economic status. The fact that this paper (Baum et al., 1996) has been cited extensively over the years, up to and including L. Smith (2005, 2010) and Tyler, Brome, and William (2007), would appear to indicate that this is an ongoing and widespread phenomenon. I cannot think of more than a handful on individuals who were positive in their initial expectations. This applied to my research participants as well. Psychology is not well understood in low-income communities in South Africa. Some research may indicate alternative or contrasting viewpoints but to some, not insignificant extent, my own experience mirrors the perspective given by S. Swartz (2007) who states that even in situations where psychological services are available, the population does not necessarily access these facilities. One of my participants gave voice to this notion in a particularly poignant way, “The black community, those people they’ve got a *lot* of problems. Sometimes they *die*. Silent.” (**Nomsa**). A second participant had lost both her sons. Shortly afterwards she started visiting hospitals in search for resolution of her physical symptoms. This continued for many years, ultimately resulting in her referral to me. She refused absolutely to talk about their deaths or her feelings about them. “I’m not sure if I want or not, because eh, when I get a, uh that (.2) feeling and eh, it, it become [becoming tearful and distressed] It become a wound.” (**Patricia**). We never did discuss this. She, like many others, did not see the value of discussing painful feelings.

In my clinical work, I have become used to “no shows” as well as angry, suspicious and hostile first appointments. In my research if every person referred to me as a consequence of a somatoform diagnosis had attended, I would potentially have had double the number of participants. Of the twenty participants who did arrive for the first session, five did not return for follow-up as arranged. Whether this speaks to their response to psychology itself or the complication of participating in research is

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<sup>5</sup> The Cape Flats is a low-lying area to the south east of the central business area and affluent suburbs of Cape Town. Colloquially it is frequently referred to as “The Flats”. It is also seen as a remnant of the racialized population relocation or displacement which occurred during the previous regime and is sometimes referred to by the derogatory term “apartheid’s dumping ground”.

not possible to identify, but it follows a more general pattern I have observed in my clinical work. For patients referred for possible somatoform disorders in the clinical setting, as well as research participants who essentially followed the same trajectory, the process of exhaustive but inconclusive investigation they had endured, prior to arriving for their appointment with me, had further tainted their perceptions and expectations of psychology.

In finding a way to engage with and present my participants' narratives I decided to walk through the process with them, using their words whenever and wherever possible, from the very beginning when their symptoms first emerged, through their interaction with the medical world, and to the culminating referral to psychology. However, to initiate the process I have attempted to position their stories within the contexts in which they developed.

#### **4.2.1.1. Three wishes**

*Poverty is not just about material deprivation, but about relative deprivation as well. It is about shame and self-derogation and exclusion.*

(Prilleltensky. Introduction. In L. Smith, 2010).

*Endemic and widespread poverty continues to disfigure the face of our country. It will always be impossible for us to say that we have fully restored the dignity of all our people as long as this situation persists. For this reason the struggle to eradicate poverty has been and will continue to be a cornerstone of the national effort to build the new South Africa.*

(Mbeki, 2004)

While the issue of poverty may initially be seen to be peripheral to the participants' experiences of their process through the hospital system and their eventual diagnosis with a somatoform condition, it is in fact a central consideration. As I will attempt to illustrate, poverty and the sequelae were fundamental to the participants' self-perception, their interpersonal relationships, general levels of anxiety and the defences they used to manage these, both from a bodily and psychic perspective. The experiences of other women presenting with medically unexplained symptoms, in different socio-economic circumstances, may be different and future research would be helpful in this regard.

By whatever standards one measures economic poverty, all the participants on the study were poor<sup>6</sup>. Before they had even arrived at the portals of medicine, the participants' lives had all been marked, complicated and restricted by poverty. Codicils of poverty permeated the day-to-day experiences of the participants, coloured their social interactions, their interpersonal relationships, their choices of activity, including access to employment, impacted on their levels of anxiety and affected their help-seeking mechanisms.

Of the twenty participants only five were employed and all were living in circumstances constrained by food, shelter and clothing shortage as well as criminal and drug activity which are so closely allied with economic insecurity in this and many other contexts. Income sources varied and were uncertain and precarious. Casual work could be arbitrarily terminated, grants could be discontinued and earning partners or family members might die through illness or violence or leave and abandon the family in other ways. The opportunity to obtain employment outside of the home was constrained in some cases by limited education and training, and in others to the physical availability of suitable employment. To two of the participants, the hope of work and the possibility of my intervention is what brought them to the initial appointment.

Housing amongst the participants varied from brick RDP<sup>7</sup> houses, to so-called separate entrances to shacks made out of corrugated iron or wooden structures called Wendy Houses<sup>8</sup>; sometimes a single room housed an entire family. Often economic pressures or local crime and violence had forced the participants and their families to move frequently.

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<sup>6</sup> South Africa remains a country in transition and definitive methods of measuring and defining relative states of poverty are ongoing and challenging. The reader is referred to the article Magasela et al. (2007) *The Measurement of Poverty in South Africa Project: Key issues*, for a clear exploration of this process. For the purposes of this study poverty was taken to include the following core considerations: poor educational facilities, unemployment and food and housing scarcity.

<sup>7</sup> The Reconstruction and Development Programme (RDP) was a post-apartheid initiative the aim of which was to attempt to redress some of the socio-economic inequalities entrenched by the previous regime. In attempting to address the enormous shortfalls serious attempts have been made to provide low-cost housing to previously disadvantaged communities. The term RDP housing is ubiquitously used to describe these structures.

<sup>8</sup> In a largely illegal "entrepreneurial" activities, in the back yards of many residences, including the government-sponsored RDP houses, wooden or tin structures are erected and rented out to supplement family income.

I routinely ask my patients what three “wishes” they would hypothetically like to realise – what three things would they most like to see materialise, issues to perhaps change or improve in their lives. The answers invariably provide insight into both priority as well as possible areas of underlying anxiety, which may not be acknowledged or elicited by more direct questioning. I introduced the same question during my interviews with the participants. To give some indication of the centrality of physical security to the mental and physical wellbeing of the individual participants I provide their answers in Table 4.1:

TABLE 4.1

*The Three Wishes*

<b>Participant</b>	<b>1st Wish</b>	<b>2nd Wish</b>	<b>3rd Wish</b>
Raabia	To be a teacher, to have a job that I love.	To have a respectful husband.	To go for Haj.
Davina	To go on a holiday. To go away from here.	Peace and quiet in life. To live in a nice place.	My son [addicted to methamphetamines] to be sorted out. For him to be a nice grown-up.
Gail	To get married to Melvin [her long-term partner and father of her child].	To get a place [to live] of our own.	To get a better job. A <i>permanent</i> one.
Caroline	To get rid of the pain – to be myself again.	To have my sons <i>stop</i> whatever they are doing [both on drugs].	For my father to be alive. I miss him a lot.
Angela	To be able to provide for my daughter – food and education.	To get a job.	To move to a place of my own.
Shanaaz	To do my matric [school leaving certificate required for many employment opportunities].	To have a nice job to help provide for my parents.	To live in a better environment.
Allison	A house for me and my family.	A work.	Just to stay healthy.
Rivka	To get healthy – for the pain to go away.	For my husband to drink a bit less.	To be a stay-at-home mum.
Patricia	I couldn't get Patricia to answer this question. She initially said that she didn't understand the question but later denied that she had anything to		

	wish for. However, during the course of our interviews, the family's living conditions in a hostel built for single migrant labourers was something that she found distressing and she expressed the desire to have a home of her own.		
Nambitha	To get a tertiary education.	To get a job, a really good job.	To have a tombstone raised for my mother in the Eastern Cape.
Maryam	To be financially established.	To have a <i>good</i> husband.	Just for health and strength from God.
Petunia	To improve my education. I want to be a radiography[er].	To renovate my house.	To help children to further [tertiary] education.
Lianne	To accomplish my studies [complete matric].	To stay somewhere peaceful – I love the sea.	To forget about everything. The past.
Mavis	My husband to stop drinking.	To have a nice place to live, where my children will be happy and safe.	To finish my matric so that I can get training as a teacher or maybe a social worker.
Amelia	To have a “normal” life – that is happy and comfortable.	Stability – financial and personal.	Respect.
Ingrid	To make a success of my life. To accomplish my dreams and train as a nurse.	To be successful and have a happy marriage.	To be able to give my kids the things I wasn't able to have. To be able to pay for their further education.
Nomsa	To own my own business as a job consultant.	To take my son to university and to be with him as he is growing.	To have my own car and a big house in Cape Town.
Elisha	To know who my father is.	To have happiness – a happy family with more children and closeness.	To do my matric – to train as a psychologist or social worker.
Kamila	To own my house where I could invite friends and have social stuff and be safe.	My partner to love and care for me.	<i>Couldn't think of one.</i>



Joy	To have my own house.	To have a job.	To have a good partner.
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While I am not discounting the role of interpsychic mechanisms, when I looked at the collection of participant answers, the majority related around issues of physical survival.

11 wishes connected to the longing to have a home/living in peaceful surroundings
10 related to work and the desire to find employment and need for financial stability
10 concerned education – either self-education or to ensure children’s education
8 connected to relationships – family wellbeing, intimate partners, support, respect
3 only related to physical health (.2) or the specific wish to be pain-free (.1)
2 included spiritual connectedness as a priority in their lives
General wishes related to non-specific circumstances

As a consequence of this apparent emphasis on physical or environmental issues, in the section below I consider in detail the impact of the socio-economic circumstances on the lives and symptoms and healthcare management of the participants.

#### 4.2.1.2. Income and employment

*Employment precariousness is a social determinant that affects the health of workers, families, and communities.*

(Benach, Vives, Amable, Vanroelen, Tarafa, & Muntaner, 2014, p. 229)

The ability to earn a self-sustaining income appears to be implicated in both mental and physical health (Benach et al., 2014; Clark, Georgellis, & Sanfey, 2001; Paul & Moser, 2009; L. Smith, 2010).

Insufficient income was an issue which was foregrounded in my interactions with all my participants and which frequently impacted on their ability to attend follow-up appointments, or even delayed the initial assessment. While I had wondered if this was particular to my discipline and the nature of my participants’ referrals, studies show that financial constraints have a negative impact even when the hospital attendance is related to severe physical illnesses. In a recent study Ntamo et al. (2013)

suggest that the predominant (95%) reason for non-attendance at a stroke clinic was due to financial insecurity.

Of the five participants who were employed, one worked as a cleaner, one as a chef at a hotel, one as a cashier at a department store, one in the administration department of a NGO (non-governmental organisation) and one informally and part-time as a sports coach at a local school. The remaining participants relied on partners to provide income (four participants), family (eight participants), or government grants for childcare or disability (four), or a combination thereof.

Some participants expressed the feeling that their inability to earn or contribute financially marginalised them within their families and communities. This is not unique to this particular situation (Clark, 2010; L. Smith 2010). They felt that they were treated with disrespect or were the object of vilification or disparagement. There have been studies which indicate, not surprisingly, that unemployment and the feelings of inadequacy this engenders on multiple levels, has a negative effect on mental health (Clark et al., 2001; Paul & Moser, 2009). However, in one instance, although the altered financial contribution was not overt, the participant's feelings about worthy work made a difference to her self-perception:

When I first saw **Joy** in a clinical capacity in 2011, she expressed several times feelings of shame that she was unable to assist with the family income while living with her sister. She had taken on all the domestic chores – the cooking, cleaning, shopping – which enabled her sister, a traditional healer, to work unhindered. However, for **Joy** this wasn't enough. When I saw her for the retrospective interview two years later, she was working for her sister and helping in the practice as a traditional healer herself. Her sense of contribution and self-worth had changed, “It feels good. It feels good because I know I'm not *working* (.2) as going every day to the job. But, I know, this work I am doing is *very* important, because I am trying to help people (.1) to build their lives. Ja! So I am proud, very proud, even *though* I don't, uh, have a monthly, a monthly salary. But it feels *good!*”

In some cases the participants felt ashamed, guilty and isolated as a consequence of their failure to provide (Brand, in press). The tentative temporal link between financial crises and the manifestation of physical symptoms may possibly have

provided some of the participants with mechanisms by which they were able to justify and therefore self-soothe in respect of their inability to work. Some participants actively expressed feelings of shame and guilt particularly in relation to their children. There is research which confirms the negative impact parental unemployment has on the intergenerational relationship particularly in the context of "feminised" poverty (Odle-Dusseau, McFadden, & Britt, 2015).

**Mavis's** situation was particularly illustrative of this dynamic. Her children were angry and resentful because of the change in their living circumstances. Both parents had simultaneously lost their jobs – **Mavis** because of retrenchment, her husband because of his drinking. Prior to this, their lives had been hard but relatively stable with sufficient money for food, schooling equipment and transport. However, since the job losses, they had lost their home, were living in primitive circumstances (a single-roomed wooden structure on a pig farm with no electricity or water) and battling to keep food on the table. "Our children are angry with us (.3). They tell us that it is our job as parents to look after them (.2) . . . I feel sad and ashamed."

In many situations, the available but limited income had to be spread extensively and therefore thinly to cover the needs of extended families living together. In **Allison's** circumstances, which were not unusual, the childcare grants for the four children<sup>9</sup> in the extended family, together with her husband's salary as a casual labourer (minimum wage between R459 and R558 per week<sup>10</sup>), and her parents and grandparents' pensions, had to supply for the needs (housing, food, electricity, clothing, school requirements and transport) for the entire extended family. The extended family consisted of four family groups living in separate constructions on one property – ten adults and five children. Three of the adults, including the grandfather, were abusing methamphetamines. She described how the stress of coping with the physical needs of everyone impacted negatively on both her health and her mental state. In answer to my question about stress in her life she said, "Ah! (.1), Um I love my mom and dad (.1) very much. My, my family, like my sisters and brothers.

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<sup>9</sup> Child grants are awarded based on stringent criteria by the State agency SASSA (SA Government Social Security agency). The monthly amount at time of writing is R320 per child. The grant for a foster child is R830 per month. Pension and disability grants (which may not be awarded concurrently) were increased to R1 350 in the present financial year.

<sup>10</sup> At the time of writing the exchange rate between the South African rand (ZAR) and the American Dollar was 11.8:1.

But you see, I'm the middle one (.1) but everyone always come to me and I can never go to them. There's never enough." During times of particular financial stress her headaches would increase substantially.

All but one (**Davina**) of the unemployed participants wanted to work. Two of the participants asked me for help in obtaining employment or managing issues related to their social circumstances. My perceived failure in fulfilling this role was possibly responsible for both these participants failing to follow-up on their subsequent appointment. It also provided some indication of the participants' difficulty in understanding the role of psychology.

**Petunia** had recently lost her job and she described unemployment as the main stressor in her life, "Like I was stressing myself before when, like, I'm out of work." Despite having completed her schooling to matriculation level, **Petunia** had mainly worked in domestic service. She had wanted to train as a nurse but this was not financially possible, "After matric [sighs] I was nearly to try to school to train as an assist nurse, but I fail according to the money." She had registered with an agency that placed home care assistants. She enjoyed her job but despite promises of furthering education and not insubstantial monthly deduction from the salary to fund this, nothing ever materialised, "He [she]<sup>11</sup> said he's [she's] going to take us to school (.3) like take us back to train and (.2) finish our education. She just every month deduct our money (.3) about two hundred and fifty [rand] (.4) Never reach nothing!" The managing agent had reneged on the agreement leaving her no option other than to work as a cleaner in various homes. Her financial situation was precarious and her living circumstances chaotic. Her terminated unemployment was unexpected. She had been working as a domestic cleaner in an affluent suburb and her employer had left for overseas saying that she would contact **Petunia** on her return. This had never happened. "They phone me, Mrs W. phoned me, she say she's going away with her mother. So they will tell me when they are back. So ever since then, when it was December time they didn't phone me." I saw **Petunia** in the April of the following year which meant that she had been waiting to hear from her employer for approximately five months. Employment as a construct is not unambiguous within the

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<sup>11</sup> Because in isiXhosa there is no distinction made between "he" and she", isiXhosa management of pronouns, when speaking English, results often in using both feminine and masculine interchangeably.

communities my participants came from. **Petunia's** experience with the arbitrary and ill-defined termination of her cleaning job represents a common experience for low-income individuals. Many of the job opportunities – unskilled or semi-skilled work – for women may add to their sense of vulnerability and uncertainty. The precarious and poorly valued nature of work may add one more facet to the prevailing precariousness which permeates their lives.<sup>12</sup> Although no overt connection was ever made, **Petunia's** symptoms had begun shortly after this situation had arisen. At the time I spoke to her, **Petunia** received a State grant for her one child which was her only income. She lived in her deceased mother's brick RDP house together with her sister Rosaline, who worked as a housekeeper. Over the weekends, this sister would get drunk and abusive and make disparaging remarks about **Petunia's** failure to contribute financially. Occasionally her second sister and **Petunia's** son, both of whom were working, contributed money to assist them. **Petunia** felt like a burden at times, "Oh my sister, this one, Theresa, and my son, she help me sometimes, but I don't want to be on their shoulder every time, you know?"

While some participants had never had paid employment outside of the home, others who were now unemployed, had worked previously. Employment had been terminated for various reasons, such as retrenchment, workplace closure, pregnancies and occasionally because the salary was insufficient to warrant the expense and inconvenience of travelling to a job. L. Smith (2010) discusses the iniquitous situation where fulltime work fails to provide sufficient income to allow the individual to escape the downward spiral of poverty. One of the participants provided graphic illustration of this conundrum.

**Allison** had at one stage worked in a factory. She enjoyed her job, the companionship outside of the family and the self-respect that earning an income gave her. However, her salary hadn't covered the costs of traveling and care for her children while she was at work, "I was working a whole month for like one five, and I mean I've got three kids. So I thought to myself, no but I can't work for this money because I have

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<sup>12</sup> Originally published in 1983, but presented online as recently as 2007, the study by Gaitskell, Kimble, Maconachie, and Unterhalter examines the vulnerability and racialization of the domestic worker within the South African economic structure. The lack of agency and reliance of domestic staff on the whims of employers remains a problem in South Africa despite the improved legislation governing domestic employment (Department of Labour, South Africa, 2015).

to put my baby in the crèche, I must put my other two kids in aftercare (.2). What do I have left?”

**Allison** presented with “stress headaches” which were reportedly unrelated to her hypertension. She reported that the “stress” was generated by the constant anxiety of trying to balance funds and provide for the family. She also had to contend with the behaviour of the relatives on the property who were stealing to support their drug habit. She would come home from her job and find that her home had been broken into and items stolen, “That is one of the reasons why I did resign [from my job] . . . my pots was stealed, my children’s clothing was stealed.”

In her particular circumstances the benefits of working did not outweigh the stress and anxiety of coming home to a chaotic situation and the need to pay for her children to be safely looked after in her absence. Her description of her life while working was “Stress, stress, *stress!*”

However, when I asked, in response to her answers to my three wishes question, what kind of work she would do she answered, “Just to work around people, because I’m a people’s person, so, *anything* will do . . . I don’t mind even how much or how little.”

**Rivka** had finished school under difficult circumstances [it was a period characterised by widespread political uprisings in her community], but was unable to do any tertiary education due to financial constraints. She initially worked in a carpet factory, and then she started working at a city hotel, “I started in the rooms [cleaning]. (.1) And then worked myself up to be (.1) a chef!” My exclamations of admiration elicited the response, “Oooh I *love* it!” I’m, I’m the 1<sup>st</sup> October, I’ll be there for twenty years. I love my work.” Despite loving her job, **Rivka** found balancing work and home very stressful. This stress contributed to her physical symptoms. “When I am at work, I worry about them [her children] but when I am at home I worry about work!”

Some participants exemplified L. Smith’s (2010) criticism of a system where fulltime employment did not ensure against poverty. For example, **Gail** and her partner both worked fulltime but battled from one month-end to the next. **Rivka**, despite loving her job, spent most of her time worrying about her children in the crime-ridden area they lived in and wanted to be a stay-at-home mother. However, financially, despite her husband’s fulltime job, this was not a possibility. **Patricia**, felt that despite her

husband's fulltime employment, their situation was not going to improve, "Now, because of my (.2) husband, because my husband work, eh, *hard*, we [still] haven't got uh, a chance to buy a house!"

The effect of unemployment and the consequent stress it engendered appeared to be specifically linked to the development of somatic symptoms in two of the participants. Recent studies (Obimakinde, Ladipo, & Irabor, 2015) indicate that such socio-economic considerations as low social status and financial difficulties may be associated with the development of somatic symptom disorder.

**Lianne**, the youngest participant, was the only employed member of her extended family (six adults and two children). Together with her father's State pension, and a child grant for her younger sister, her salary as a cashier was the only income for the family. She was expected to hand over her entire salary to her mother at the end of the month and was given enough only for transport to and from her place of work. Her symptoms had begun several years earlier when her father was unemployed and the family had no income. There had been a recent resurgence of the symptoms and she felt that this was connected to her resentment about working, but also to having no independence or having no say in the way her money was spent or allocated. Her constrained independence was played out in the interaction with her mother in the only interview I had with **Lianne**. It took place on her 19th birthday, but despite her age and her status as family provider did not prevent her mother entering the room and initially answering all questions until I asked her to leave.

Initially **Lianne's** attitude appeared to be sullen and uncooperative, but once her mother had let the room she appeared to relax and volunteered, "Things are going a bit (.4) very, very rough at home because (.3) he [her father] is like, he's just the type of person, um, he's used to having money (.2) so even with the pension the last that he's got he will keep it. I bring home, uh, my mom gives me a two hundred rand of my pocket money. *For* my pocket money. Um, my mom will take the money for groceries and so on. So I basically don't get anything out of my own wage, you know."

**Shanaaz** had been referred with possible atypical posttraumatic stress symptoms, which included diarrhoea and abdominal pain. At the time I interviewed her she was

living in a family situation where the financial circumstances were precarious. She described previous incidents of gastrointestinal problems, “When I was younger [5 years old] I had um, (.3) I also had an abdominal problems.” I asked if she could remember what was happening at the time and she replied, “Just that my daddy didn't work at that time.” At her time of presentation to Hope Hospital and referral to psychology she has just given up her job to look after her children, but the financial impact on her family was weighing heavily on her.

In all three of my interviews with her, **Angela** focused on her lack of employment and the consequences it had for her quality of life. For **Angela**, both her depression and physical malaise were intimately related to her concerns about feeding herself and her child. In my first and second interviews with her, she described the ongoing situation, “There’s no food to be honest with you. There’s no food.”

While I am not making the simplistic assumption that financial concerns and the subsequent relief provided by employment were the only contributing factor in **Angela’s** symptom presentation and response, it is noteworthy that when she obtained employment, her mental state improved and her physical symptoms appeared to have gone into remission. Although it was not recorded, I made a note of **Angela’s** conversation and in it she said “I am okay now, I can feed my child.”

For **Raabia**, and other participants, **Caroline** in particular, work fulfilled a function outside of mere income. While increasing age and years obviously contributed, neither of them remembered suffering much from physical ailments at the time they were working. There are longitudinal studies which appear to confirm that positive work situations and mental and physical health are positively correlated (Hergenrather, Zeglin, McGuire-Kuletz, & Rhodes, 2015).

**Raabia** had left school as a consequence of failing her Grade 10 and had gone to work in a relative’s curtain-making factory. She looked back on her work with nostalgia, “Wow, I worked with amazing people. It was like a family . . . It was like you get out of bed, you woke up and you *wanted* to go to work.” She became sad when she described how the factory closed down and how she longed to return to that time of camaraderie, “And you know, I’m still in contact with my friends that I used



to work with. And then we would tell each other (.2) um, how come, why don't somebody open a company.”

**Raabia** also talked about the social aspects of working. Both she and **Allison** mentioned several times how much they'd enjoyed interacting with people outside of their homes. For both of them, their symptoms seemed to be related to the restrictions and complications of their home environments unrelieved by the opportunity to interact outside of domesticity. **Rivka** was still working with people she'd been at school with amongst whom were those who had supported her in her efforts to finish school.

Work was also important in expanding the experience of the women outside the domestic environment. **Caroline**, after many therapeutic sessions subsequent to the research interview, admitted that the constant visits to the hospitals, ostensibly in search of a diagnosis for her chronic pain, served the function previously achieved by her job – of getting her out of her home. Coming to the hospital gave a focus to her day and softened the isolation and loneliness that she had experienced after her retrenchment in middle age, “Yes, and I come here, and I see people, and I talk to people, even if they [the doctors] can't help me with my pain.”

**Davina** was quite frank about her inability to tolerate ongoing employment, “Ja, I did enjoy working! But I didn't enjoy working at the factory for long, I just worked there for a few months the, then I (.2) then I'm *tired* of working [laughs] . . . Ja, I was very naughty! Then I can stay out of work for, um (.3) for a month or two (.2). Cos that time it wasn't *hard* to find work.” Ironically she had been ambitious, “I really wanted to be a social worker (.3) that was always my *dream!*” I have mentioned the precarious nature of unskilled employment in relation to **Petunia's** experience. **Davina's** apparently cavalier attitude towards employment could have been a way of expressing some agency against the vagaries of a system which routinely offered employment only to arbitrarily remove it. South Africa has a long and disreputable history of racialized domestic service, etc. (Gaitskell et al., 1983) which the post-apartheid regime and economy does not seem to have adequately addressed (Barchies, 2011; Seekings & Natrass, 2002). Perhaps for individuals like **Davina** it proved easier to disengage than to risk disappointment. While for **Petunia** and many others like her, the confusion and vulnerability remains.

## CONCLUSION

Employment has the potential to provide individuals living in poverty with some security and the opportunity for upward structural social movement – better housing, access to safe transport, improved diet, etc. However, in many respects the negative spiral created by the correlation between poor education and the resultant low wage and stigmatised jobs is self-perpetuating. For many of the women who participated in my research the failure to complete schooling decreased their chances of obtaining well-paid or prestigious jobs. Inability to obtain cost-of-living related jobs condemned the women to remain in poverty. L. Smith (2010) discusses what she calls the double-bind facing many low-income individuals who are economically “damned if they do and damned if they don’t”. On the one hand, failure to find employment may carry connotations of laziness, lack of responsibility and commitment to self-determination. On the other hand the income from certain jobs is too low for an individual or family to survive on, yet the fact of employment excludes the possibility of accessing government support in the form of grants (L. Smith, 2010). Furthermore, low-income work is generally precarious, devalued and frequently stigmatised, which further isolates and renders vulnerable those who are unable to access stable, well-paid employment.

Apart from the financial benefits, the self-esteem and sense of autonomy and agency generated by even minimally paid employment should not be underrated. For several of the participants failure to contribute financially or to be seen to be working outside of the home was a source of shame. For others the opportunity to do so provided them with a sense of dignity and self-respect. There exists the possibility that the development of some of the participants’ medically unexplained symptoms might be related to their unemployment and poverty as has been examined in other studies (Obimakinde et al., 2015).

#### 4.2.1.3. Neighbourhoods and Housing

*Our neighbourhoods are poison.*

*Sondra*

(L. Smith, 2010, p. 68).

The quote above is cited in L. Smith (2010) from a study done in 2007 by Newman and Chen. It comes from a woman who was interviewed about the incursion of drug related activities and the associated crime and violence which had destroyed her neighbourhood and claimed the life of her son. The place she describes is an inner-city New York neighbourhood. These words could easily have been uttered by any one of my participants living on the Cape Flats outlying Cape Town. **Patricia** had lost a son to murder, **Kamila** watched as her son obtained tattoos which indicated his affiliation with a notorious gang, **Davina** lived in fear in her own home while her drug addicted son brought gangsters and drug dealers onto her property, and **Gail** and her family found themselves constantly moving to avoid the violence. At the time of writing there were calls in the media for the involvement of the South African army to curtail the escalating violence on the Cape Flats, particularly in Manenberg, where Hope Hospital was situated and where many of my participants live. Interviews on the radio with residents provide a picture of desperate mothers living in fear for their children's safety. Over the four months since the beginning of 2015 children, adolescents and housewives have died on the Cape Flats through some kind of violence – gunshot wounds, stabbings and murder.

Dozens of innocent people have been killed on the Cape Flats this year, many of them children playing in parks. Most died because they were in the wrong place at the wrong time, caught in the crossfire between warring gangsters. (Egginton, Collins, & Cornelius, 2015)

Research indicates that the environment – sense of community, feelings of security and aesthetic considerations – has an influence on mental health (Forrest & Kearns, 2001; Francis, Giles-Corti, Wood, & Knuiiman, 2014). The greening of urban areas has been well researched in many contexts in America (Bowler, Buyung-Ali, Knight, Pullin, 2010), Europe (Tzoulas et al., 2007) and Africa (Ward, Parker, & Shackleton, 2010). In a recent study (Shackleton, Chinyimba, Hebinck, Shackleton, & Kaoma, 2015) the specific benefits of trees in an urban landscape was investigated. While

results were not unequivocal, with some individuals in settlements expressing concerns about foliage supplying places of concealment for criminals, the overwhelming result was positive. Trees provide shade and soften the harshness of hot and dusty environments and their branches provide fuel for fires and fruits for sustenance. In the areas in which my participants lived, there are virtually no trees, few grassed areas and flowers in gardens are rare. Gascon et al. (2015) conducted a review of the literature on the mental health benefits of exposure to “blue and green” spaces and once again, while the results were not unequivocal, they suggest that the rapid and increasing urbanization linked to areas immediately outside large cities and the increase in mental health problems globally gives us cause to pause for thought.

While the impact of the greater macro system is important, the microsystem provided by individual homes is of equal significance in meeting those needs essential to survival illustrated by the patient responses to the three wishes in Table 4.1. Research seems to support this. Nelson et al. (2015) found a correlation with housing provision and an improvement in mental health status in a longitudinal study of a particular housing project initiation.

While an extensive exploration of the housing situation within South Africa or even on the Cape Flats is outside of the ambit of this research, it would nevertheless appear from the literature that the nature of the lived environment has an impact on the mental health of residents (Forrest & Kearns, 2001; Govender, Barnes, & Pieper, 2011; Schlesinger, Drescher, & Shackleton, 2015; Shackleton et al., 2015). The areas in which my participants live are not safe and they are not beautiful. Furthermore they look across the grim, dusty and treeless plain towards one of the most beautiful World Heritage Sites, Table Mountain. Once again it is not merely the lack of facilities implied by poverty, but the comparison with nearby safer, more beautiful and affluent areas which may constitute the greatest indignity and suffering.

## Informal settlements outside central Cape Town



Informal settlement outside Cape Town (Downloaded from Daily Maverick)



Informal settlement alongside the N2 motorway (Photo: Avril Cowlin)

Liba and Harding (2015) provide an interesting exploration of the aspect of right to adequate housing in the United States. In South Africa the problem of adequate and affordable housing is more complex and steeped in the history of apartheid and residential racial segregation. After the 1994 elections, an attempt was made to address the situation by present government through the development of the

reconstruction and development programme (RDP). While this process has enabled many individuals to nominally own their own houses, the implementation has not been unproblematic. Accusations of nepotism and corruption have tainted perceptions of fair allocation of houses. Many people have remained on the waiting list for several decades and the quality of buildings has come under a barrage of criticism (Manomano & Kang'ethe, 2015).

Of the 20 participants only six owned their own houses all of which had originally been RDP houses. One of this group was facing possible eviction due to inability to pay the mortgage. One family (three adults and two children) had lost their house due to defaulted mortgage payments when both parents had lost their jobs. They were now living rent-free in a wooden shed on a pig farm in return for feeding the animals. The remaining participants lived either with family (sharing rooms in the same house or in structures erected separately on the premises) or in informal settlements.

For single women, having a safe and secure home is frequently a luxury, particularly in low-income situations. **Raabia** at the time of the interview was living in the house that she and her husband had bought five months previously, when they had purchased it from her mother, in a process she called an “inheritance house”. This aspect of their divorce constituted an area of some anxiety for her. “What he [her husband] said, is, he said, he’s still going to provide for us, He’s going to pay the bond, um [deep breath] the house is for me and my kids. He’s going to give us his half to the kids.” The prospect of being without her own home had given her the uncharacteristic determination to fight, “I don’t really feel comfortable with, because that is, I don’t want him to think that I’m being *greedy* or something. But I think I have to take a stand there, because it’s for my kids.” Her prevailing feelings were of uncertainty as to whether he would honour this agreement but the need to have a home in which to raise her children and also to provide her with a sense of self-respect was the impetus which enabled her to show some determination.

For those participants who owned their homes, it was a source of pride and status. **Davina** and her first husband had been living in what she termed a “council house” or RDP house. Eventually after he died ownership of the house was transferred to her, “Then the council put the house on my name.” At the time of the interview, **Davina**, her long-term partner and her foster son of 10 were living alone in the house.

However, **Davina's** 34-year biological son and his girlfriend had been living in a "hokkie" (a ramshackle dwelling constructed with cast off building material) in the corner of the property. Both the son and the girlfriend were using "tik" (methamphetamines) and dealing drugs out of this area. Without ablution facilities they had been excreting into buckets. It was when a builder employed to enclose the property had discovered these containers that Davina's physical symptoms first started. She had at that stage evicted her son from the property, "That's why I put him out now . . . And it's *my* property, it's *my* place (.3) . . . Now what are they thinking! Because the way they are, are (.3) dirty! You don't do things like that! . . . It's terrible, it's not right! Because if I go to the Health Department I will get in trouble, not *him*, cos it's *my* property." The sense of violation permeated the entire first interview. Home ownership amongst the community is valued highly and to have it abused in this way was a significant event in Davina's life. Her symptoms of internal shaking started the weekend after the discovery and her decision to have her son, his girlfriend and by extension all the criminal activities, removed from her grounds.

### **Reconstruction and Development Programme (RDP) Housing**



RDP Houses (Downloaded from Times Live)



Newly built RDP houses (Photo: Avril Cowlin)



Close to Waterstroom hospital (Photo: Avril Cowlin)





“Wendy house” – wooden structure frequently erected in the back yard of brick houses to generate extra income for homeowner and provide rented accommodation for those unable to afford or qualify for RDP houses.  
(Photo: Avril Cowlin)

Poor housing and insecure living conditions contributed to the anxiety and stress of several of the participants. **Allison**, who had to contend with living in a wooden “Wendy” with four other families in various dwellings on her parents’ property, found the constant intrusion into her home most distressing, “The main thing now I just, (.2) I’m very unhappy where I live now (.2) That’s my problem.” Her anxiety about her living circumstances had manifested in tension headaches which had brought her to the hospital. Her understanding of the connection between the two was initially tenuous, but during the three sessions I spent with her, a relaxation intervention reduced both her blood pressure and her headache which allowed her to accept that her home circumstances were impacting on her health. However, the chaos of her family was weighed against the cost of finding their own accommodation, “We can’t just say we want to go, we can’t just cos we have to think about our kids, where do they go school . . . Its school, fees, the cost price there. It’s a *lot* of things It’s just like (.2) you can’t just say ‘I *want* to move’. My brother-in law, he’s like a drinker and (.3) I don’t want my kids to see that. Because, because we are living in an environment of *tik* [methamphetamine].”

Another participant felt that her adverse living circumstances had been directly responsible for her presenting symptoms. **Gail** and her partner were forced to move on innumerable occasions because of accommodation problems. **Gail** initially felt that her bodily symptoms of bodily swelling and pain were related to inadequate sleeping conditions. When she and her partner had been forced to escape the violence of their own neighbourhood to stay in the already overcrowded home of her sister, they had to sleep on mattresses on a cement floor. **Gail** described the situation, “I dunno if it was maybe the coldness of sleeping on the mattress that caused the swelling and the pain. Oh it was very sore!”

She continued to feel that this was the root cause of her continued sense of bodily swelling and intermittent pain – even though the sleeping arrangements had occurred several years previously and for a relatively short period and organic causes such as arthritic or rheumatoid changes had been excluded by investigation.

While at no time did **Patricia** accept that her body pain and symptoms were connected with her social and economic circumstances, she acknowledged that her hard life of domestic service and the difficult and overcrowded living circumstances impacted negatively on her emotional and physical wellbeing, “Where I, I, my dreams when I, I was before this [pains] (.3) started. My dreams I want to get my own house because I want my children to, to, study, to ah be *comfortable* . . . Now I’m staying here at this uh, this hostel. I, I’m *not* happy . . . because everybody here is making a *lot* of noise.” **Patricia** was a gentle quiet woman and the chaos of the hostel was very distressing to her. As I discussed above, despite her husband’s fulltime employment and the fact that he worked so hard, there was little hope for the couple to ever have their own house.

L. Smith (2010) discusses the precarious nature of life for poor people where situations, which would be managed effectively by more affluent individuals, can precipitate crisis for those living in poverty. For example job losses can translate immediately into home evictions and repossession. **Ingrid** and her husband had until fairly recently both been employed and lived in relatively comfortable circumstances, but without the safety net of savings. In a double financial disaster both were retrenched within a short period of time. This placed their home ownership in jeopardy and created the constant worry of having their house repossessed. **Ingrid** felt

that his had exacerbated her symptoms, “I am scared all the time we will lose our house and maybe that is making my blood pressure high.”

Similarly **Mavis** and her family had previously lived in their own brick house. However, as I have already mentioned, they lost their home when the bank reclaimed it due to defaulted payments. This not only impacted on their living circumstances, but had far reaching effects: the family were forced to move out of the area, the children had to change schools and were humiliated by the deterioration in their circumstances and blamed their parents. **Mavis** felt both personally ashamed and consequently isolated herself from her previous friends, her relationship with her children was impacted as she felt she had failed them and her husband’s drinking increased.

At the other end of the spectrum **Maryam**, after telling me how much she would like to be financially secure and to have a good husband, was able to express her feeling of gratitude for her living circumstances. She said that she felt she was incredibly lucky to have a house of her own, “Because I must say His [God’s] favour is really on me because I’m living *alone* in the house at the moment. Can you see the favour of the Lord? Three’s other people, children, husband that don’t even have a house so the favour of the Lord is there! So I must be thankful.”

I have touched briefly on the concept of relative poverty which may be exemplified in a comparison between houses and living environments. Two of the participants lived in particularly constrained financial circumstances, in overcrowded rented houses, with limited facilities and in areas of high density and crime. Both women worked in areas of affluence. **Lianne** when describing the stresses that were contributing to her ill health mentioned her job, “I’m a cashier . . . It’s a bit stressful because, um, we’re working with quite a few difficult, um, people. I work in Constantia [a very affluent suburb of Cape Town] so (.3) . . .” She left the sentence hanging in the air. We never unfortunately had the opportunity to explore her feelings about moving between her home circumstances of dire poverty and her workplace which involved accommodating the demands/requirements of an affluent and demanding customer base.

At the time I interviewed her, **Gail**, her partner and child were living in a single room attached to a house in a difficult area – unemployment, crime and drug abuse was prevalent. She had to travel on a daily basis to do cleaning work at a prestigious high-end guesthouse in an area which catered to wealthy foreign tourists. The guesthouse was situated in a particularly picturesque and affluent coastal area which may have been a daily reminder of the direct contrast of the flat, vegetation-free, sandy overcrowded area in which **Gail** lived.

Manchanda (2014) discusses the zip code (in South African terms the postal code) as an important marker of patients' socio-economic status and including access to “green spaces” (parks, trees, grass) and the health benefit associated with this privilege (Manchanda, 2014). None of the women who participated in my study were surrounded by natural beauty, but both **Lianne** and **Gail** had to work in environments and cater to the needs of people who may have taken a pleasant environment for granted.

**Petunia** lived in a brick RDP house that had belonged to her mother. She stayed together with her twelve year old daughter, her sister, her sister's twenty-one year old daughter and five-year-old child and a third sister's thirty-one year old son. By community standards it was a fairly substantial dwelling with a kitchen, dining room and two bedrooms but an outside bathroom. Yet it was a difficult place to live with the sister drinking heavily over the weekend, and the nephew abusing tik. The house was becoming dilapidated and **Petunia** wished she could renovate it out of respect and in memory of her mother. Given the substandard manner – both workmanship and materials – in which many RDP houses were constructed (Manomano & Kang'ethe, 2015) **Petunia's** concerns appeared to be justified, but left her feeling increasingly anxious without the means to resolve the problems.

As mentioned in the three wishes exercise, for many of the participants the hope of obtaining a containing and peaceful home environment was central. However, for some participants like **Kamila**, instead of being a safe haven, the home was a place to be escaped from. **Kamila** lived in the house belonging to her ex-husband with him and her three children, their partners and children. She and her ex-husband had been legally divorced for 13 years but financial constraints made it impossible for her to move out, “[sighs] (.2) My husband don't want to, my ex-husband didn't want to

move out. And we, didn't get divorced Islamically. Only got divorced, within the court." Despite being a Muslim convert and in the process of returning to her childhood religion of Christianity, **Kamila** felt that the process wasn't fully sanctioned. Her ex-husband owned the property and being tied by mutual debt together with her minimally paid salary, it was difficult for her to move out. The situation was difficult with the overcrowding generated by six adults and two children living in a two-bedroomed house with one attached back yard structure. The situation was acrimonious and punitive, "I just want my family to leave me alone...Um (.2) I just do my own thing. They didn't wanted to listen to me when I spoke to them. And (.2) they got no respect for me [very distressed]." **Kamila** would find ways to occupy herself during the day so that she didn't have to be there. During her time with me, she experienced the conflict of leaving the familiarity of her old home with prospects of moving somewhere else, unfamiliar but perhaps providing safety, security and privacy.

## CONCLUSION

Manchanda (2014) cites housing and the quality of accommodation as one of the primary contributions to relative states of health. Structurally adequate and environmentally safe accommodation can ameliorate physical health positively. He suggests that healthcare should look beyond exclusively medically exploration and explanations for physical symptomology to what lies "upstream". He postulates that questions regarding patients' living conditions have the potential to generate invaluable information about the genesis of symptoms. Poor sanitation and ventilation, pest infestation, neighbourhood violence may all be factors contributing to physical symptoms which appear to have no obvious medical etiology. With virtually every participant, some aspects of their housing situation– over-crowding and the sequelae (relational difficulties, inadequate facilities) as well as neighbourhood issues such as violence and crime – had impacted negatively on the quality of their lives. In many cases these issues had the potential to account, at least in part, for such physical symptoms as pain, headaches and anxiety expressed in hypertension or autoimmune illness.

#### 4.2.1.4. Education

*Education is the most powerful weapon you can use to change the world.*

(Nelson Mandela)

A factor which is sometimes overlooked is the impact that poor education has in maintaining the status quo and something that affects girls in a greater proportion to boys (Patel & Kleinman, 2003). Discussions regarding the impact of poverty on education and vice versa have been thoroughly explored in the literature but the conclusions reached are complex and nuanced. In his well-cited article, Connell (1994) suggests that while acknowledging that children who come from poor homes are generally at a disadvantage in the conventional educational system, he warns against the propensity to use education “in political rhetoric as a panacea for poverty” (p. 125). Patel and Kleinman (2003) take the stance that there is a correlation between poverty, vulnerability to mental illness and poor education. In a South African study, Stofile, Linden, and Maarman (2011) interviewed teachers who were firmly of the opinion that “poverty prevents learners and parents (or guardians) from full participation of the education provided by the schools” (p. 603). They also suggested the corollary that this in turn impacted and inhibited the ability of the teachers to perform effectively.

In this study only one participant had received tertiary education, seven had completed their schooling (one of whom was never able to access her final exam results which she had been told by the school principal had “been lost”). Three participants had failed to complete junior or elementary schooling and the remaining nine had left school at some stage during their high school years. The reasons given for failing to complete schooling were pregnancy, lack of interest, and the need to support their families financially.

There was some apparent link between employment and completed schooling. Only one participant who had completed schooling was unemployed and had been for a lengthy period (**Petunia**); two of the participants with matriculation were employed in jobs they enjoyed and where they had worked for several years (**Gail** and **Rivka**); one had been employed in a clerical capacity until near retirement (**Caroline**); one obtained employment subsequently in a call centre and began tertiary education (**Nambitha**); and the participant with tertiary education had a secure job with

prospects for advancement within the non-governmental organisation field. Of the remaining 12 participants, several had worked in factories early in their lives (**Raabia, Shanaaz, Maryam, Allison**), or in domestic service (**Patricia, Joy** and **Mavis**) two in offices doing clerical work (**Ingrid** and **Amelia**) and one as a cashier in a shop.

Failure to complete schooling was seen as a source of shame and regret to most of the women on the study who had left before writing final exams.

**Ingrid** said, “That [Grade 8] was the one and only year I [failed] (.1) and even when it happened, it (.2), I couldn’t understand it [sniffs] because I *studied so hard* . . . I used to get up at *five* and go and revise over my work and everything and (.2) the day I got my report and saw that I *failed*, I couldn’t believe it . . . It was a blow to me because I *always* wanted to matriculate.” She felt a deep sense of failure, “[Crying and talking through her tears] I’ve always wanted to make a success of my life. . . . And I feel [still crying] that I’ve failed *myself*.” She felt continually constrained in her search for better employment or training due to the fact that “I don’t have my matriculation.”

While several participants had articulated the hope or intention of going back and completing their schooling, only one participant had actually initiated the process. **Mavis**, during the period I saw her, made the decision to go back to school and attempt to complete her education. During the period I saw her clinically, subsequent to the research interview, against considerable financial and social difficulties, she had attended night school and written and passed three of the six required subjects for matriculation. When I last saw her she had registered for the remaining three and had started attending night classes again. Several of the others participants had said they would like to someday complete their schooling as, like **Ingrid**, they saw their lack of education as a limiting factor in their search for work.

**Joy’s** uncompleted schooling was a tragic consequence of indefensible bureaucratic failure. She had in fact completed her matric and written the final end-of-year exams under difficult circumstances in a rural area in the Eastern Cape. During her childhood she lived some distance from her school, her family were poor and did not always have the finances to pay for the transport to the school. However, she did well

academically, passing all grades until her matriculation year when she fell pregnant and left to get married. She later went back and did her final year through night school, but was unable to get her results from the institution due to some apparent clerical error. When I spoke to her many years later during our first interview in 2010 she was sad but philosophical about the principal's explanation that her results had been lost or mislaid. She never received them.

The youngest participant, **Lianne**, found it difficult to discuss the way in which she had found out that she would not be returning to complete her final year of schooling. For **Lianne**, her role as provider without any independence or authority was secondary to the event which appeared to have precipitated her symptom manifestation. Her father had, according to her, arbitrarily closed the informal family catering business and **Lianne** said, "I was under the impression okay fine, they got the backup plan for me because I *matric* [the final year in the South African school system] the following year, so I'm *excited* and so on . . . I went to fetch my results at college and I brought it home (.2) and I showed him [her father] I passed with flying colours . . . I was just like preparing myself now for the holidays and (.2) for going *back* to college and so. . . . Then the day before Christmas he told me 'I can't send you back because there isn't money' [told in a totally contained and unemotional way]. Then I started going backwards." I asked her if her problems started from then and she said, "What actually triggered it was the fact that I had goals set for myself and (.3) [takes a deep breath as she does frequently almost to control herself] and it was taken away."

Underlying the stories of these two women are issues about power and autonomy – or the lack thereof. The reactions of both **Joy** and **Lianne** to what were experienced as infringements on their basic rights, illustrate the tenuous place women have in the system. Neither of them felt powerful enough to challenge the status quo and demand not only the right to education but to redress for injustice in the way in which they were denied its completion.

Sometimes failure to complete schooling superficially appeared to be a personal choice. When I asked why **Davina** had left school early (she only had a Grade 7 education) she replied, "It was like (.1) too much [laughs]". She was only able to clarify this statement by saying, "I don't know (.3) it felt like too much work or



whatever.” Parental influence on school attendance and performance has been explored in the literature (Pomerantz & Monti, 2015) with some studies indicating a correlation between socio-economic status and school performance (Rindermann & Baurmeister, 2015). An early study indicated a correlation between single-parenthood and levels of encouragement for children to attend and perform at school (Astone & McLanahan, 1991). Single mothers in particular, who may not have completed their schooling themselves, may be too overwhelmed with financial and other stressors to provide adequate support for school performance and/or attendance. And while **Davina’s** answer may have seemed to indicate precocious autonomy, she was only 14 and without supervision had already started going to clubs, drinking and smoking, “Then I was very naughty [laughs] . . . I had all the wrong friends, doing the all wrong things (.2) . . . dancing, went clubbing . . . drinking, smoking and boyfriends.” When I asked where her parents were and how they felt, she just shrugged. However, during her second interview when I asked if she regretted giving up school so early, she said yes. However, when I enquired whether she had considered the possibility of returning and finishing her education she said, “Yes, I did think but (.2) um (.5) I prefer to be at home. Busy at home.”

The role of the woman in maintaining the domestic status quo was also illustrated in the narrative of **Kamila**. She described herself as having been “good at school”. She had, however, been forced to leave school at the end of her Grade 9 year to stay home to look after her father for the final two years of his life. He suffered from “heart disease”. Unlike other participants who regretted or resented the premature termination of their schooling, **Kamila** said, “I enjoyed, I enjoyed looking after my, I had the *privilege* to look after my father.”

**Rivka** was honest about the fact that she hadn’t enjoyed school. This was partly as a consequence of the political protests prevalent at the time, “There was (.1) at that time there was um (.1) they burned tires and stuff like was that time, so school wasn’t very good.” Despite her intellect she said she had struggled a bit because of home circumstances. Her mother and stepfather fought a lot and this impacted on **Rivka** and her siblings. “We received like lots of (.1) beatings and stuff and (.1) mental abuse as well.” She attributes the fact that she stayed on at school and eventually managed to matriculate due to the support of friends, “They motivated me because we, all my

friends were well, well they didn't have (.2) *home* problems so I'll go. Because you are there, I gonna go because you are there. So that's the reason why I finished school." She was unfortunately not able to study further, "I didn't uh there was no money for us to study further and stuff like that. So I *had* to leave and I worked at a (.1) carpet factory."

**Rivka's** experience of school provided a counterpoint to the descriptions another participant gave. **Caroline** also came from a poor, difficult background. She however, eventually chose to leave school rather than to contend with the perceived disparity in her situation compared to that of other children, "We were *poor* you know and there wasn't much. And you look at the other kids and they're all dressed up, in their smart uniforms and um, I didn't *have* that!"

**Petunia** had finished school and done well during her 12 years but there was no money for her to train as a nurse, which had always been a dream. She had been employed in domestic service but had however ensured that her son was able to go further than she had. **Petunia** was proud of her son who had completed his schooling, completed a diploma in management and was doing "retain [retail] management." Her daughter of 14 was also doing well, "She's very bright! Yes! So to even speak English, she speak fluent, as if she went to the White school, I don't believe it!"

## CONCLUSION

Despite Connell's (1994) injunction against seeing education as a "a panacea for poverty" (p. 125), education has been explored in sophisticated debates which in various ways suggest that a good or at least adequate education may be a primary mechanism to escape the downward spiral of poverty, particularly in postcolonial contexts (Dale, 2005; Tikly, 2001, 2004). Tragically it is the women, particularly single mothers, who are most vulnerable to economic insecurity and educational neglect (Haskins, 2014). Teenage pregnancies and women's role as primary caregivers all impact negatively on their being able to access adequate education even when it is available. Without basic education or training, job opportunities are limited in the context of strong competition in a country with a high unemployment rate. At the time of writing the most recent unemployment figures available for South Africa was 24.3 percent (Statistics South Africa, 2014). For the period between 2000 and

2014 the average unemployment rate was 25.25 percent (Statistics South Africa, 2014). Figures were not available for the first quarter of 2015. In my interactions with my participants and in the wider context of my clinical work this appears to be substantiated. Informal and anecdotal statistics garnered from local high schools in the area of Waterstroom and Hope Hospitals indicate numbers in the region of 1-2% drop-out rates for female students/learners, associated either with economic problems or pregnancies. On the national news service the countrywide figures reflected the same numbers. On Wednesday 15th March, 2015 (15:35) the following figures were given: “20 000 learners fell pregnant in 2014, of which 223 came from primary schools” (which cater for children up to approximately 12 to 13 years old). Financial difficulties were named as the primary source of stress, and “stress”, in turn, was the explanation most often given for their medically unexplained symptoms. The physical components of poverty – lack of education, unemployment and poor housing were cited most frequently as the aspects of the participants’ lives which had the greatest negative impact and which consequently positioned the individuals in situations of great vulnerability.

#### **4.2.2. RELATIONSHIPS**

##### **4.2.2.1. Community and family resources**

*Too much of the psychological literature treats the devastations that accompany a life lived in poverty as though they live in a socio-political vacuum.*

(L. Smith, 2010, p. 63).

Poverty is not an isolated economically exclusive construct. It encompasses more than the physical environment and practical limitations and deprivations related to physical needs. The impact of poverty may be exacerbated by other factors such as levels of equality within a community as well as exposure to other geographically close but economically different communities.

There has been a body of literature dealing with the impact of poverty (Patel & Kleinman, 2003; Lund et al., 2010). Despite the transition from apartheid to democracy South Africa has remained an economically unequal society (Nattrass & Seekings, 2001). According to the latest data collected (World Bank, 2011), of all the countries worldwide for which data was collected South Africa had the highest GINI

index.<sup>13</sup> This is a trend which is reflected as far back as 2009 and probably earlier. This situates South Africa as the top most “unequal” country in the world. I have mentioned earlier, in the section on employment, the situation experienced by two of the participants (**Lianne** and **Gail**) who had to contend with in moving between employment in affluent, middle class areas and returning home to situations of poverty, crime and deprivation.

However, this situation of relative economic inequality was not necessarily ubiquitous in the communities in which the research was conducted. Most of the participants were living amongst and mixing almost exclusively with people in similarly constrained economic and social circumstances. However, even under similar financial circumstances, poverty is a relational construct and may be influenced – positively or negatively – by the associations that operate within the constraints of lack. In the discussion of available resources the concept of sharing was prominent amongst the participants. Their descriptions included the camaraderie of shared resources but also the isolation engendered when the stigma of poverty was experienced or perceived to be experienced. While the family was often seen as a positive resource, sometimes the generosity and altruism came instead from the greater community. In contexts of the ongoing crisis management described by Smith (2010), the family in some instances represented an exacerbation of existing financial and other challenges and added to participants’ perceptions of stress and anxiety.

For several of the participants, their families represented the most stressful aspects of their lives. **Kamila** was faced daily with the hostility of her family. As described previously in the section on housing, **Kamila** and her family lived in overcrowded living conditions, which was made even more untenable by the hostility of her ex-husband and the antisocial behaviour of her two drug abusing sons. I asked how she felt when considering the possibility of living away from them on her own, “[Takes a deep breath and starts smiling] My feelings is totally different, I am more happy, I’m more relaxed, I can *do* what I want to, I don’t need to think about (.1) um, what is the children doing now, what (.1) *nonsense* they are doing. I just relax (.2), cut me off. I’m doing my *own* thing [leans back into the chair smiling] . . . I’m feeling lighter,

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<sup>13</sup> The GINI index, coefficient or ratio is, a measure of inequality of income or wealth. It is intended to represent the income distribution of any particular nation's residents. It is published by the World Bank and is considered to be the most, and is the most, generally referenced measure of inequality.

there's not that heavy feeling anymore (.1) I can control myself, I can *smile* more, I don't need to walk with a *sad* face!" I asked her what happened to her presenting symptoms of feeling that her heart was being stabbed and that she was being choked and she replied, "Um I don't feel it [smiles] the stabbing in my heart. There's only a small piece of it."

**Raabia**, the first participant in my study, in many ways emblematised the dichotomy of concealment versus exposure in close-knit families and communities where privacy is at a premium. While she acknowledged the need to talk about her situation – she was waiting for the outcome of a Muslim divorce process – she felt constrained about talking to anyone, in particular creating any sense of “talking bad” about her estranged husband. Her family, while close and supportive, did not interfere or become involved with her decisions and she felt that she had to manage on her own, “They will not tell me what to do, but I know they are there.” In the seventeen years of their marriage her husband had discouraged too much overt interaction with her family with whom she was close. Conversely, she had worked hard to create a good relationship with his family, and the loss of that contact was causing her some additional distress. She described how they “have cut me and my children out” with a very real sense of sadness. In the room, when describing their abandonment of her, she unconsciously put her hand on her heart – the seat of much of her physically described pain.

**Allison** described her family as disorganised and chaotic and this appeared to contribute to her high levels of stress and anxiety and which could possibly have been responsible for the development and maintenance of her presenting symptoms [headaches]. **Allison**, her partner and their children lived in a structure erected on the premises of property owned by her mother. By arrangement, no rent was paid but each family on the property contributed to the municipal amenities, mainly the electricity bill. This bill was meant to be equally divided between the various households on the property. However, when it needed to be paid, **Allison** and her partner were expected to make the major contribution even though their small family group used the least amount of electricity, living as they did in the outside wooden Wendy house. She had a pattern of “skelling”<sup>14</sup> to relieve her anger and when she

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<sup>14</sup> “Skelling” is an Afrikaans colloquial term for shouting and criticizing.

stopped this “I was skelling a lot! (.1) I, um, I just *stopped* skelling. I was just *stopped* just skelling at people and I just walk away.” She ceased venting her anger and frustration verbally at the request of her mother who said “**Allie**, stop (.1) stressing with the children. Stop shouting at them! Stop ah, um upsetting with everyone here in the yard. Just lay in the bed.” The decision to stop “skelling” and to let things go without argument had happened a month prior to the advent of her “tension headaches” and muscle spasms.

Her partner was a major financial contributor to the collective family income (he was the only member of the group who was employed). Yet in times of food shortage she was unable to rely on help from the family; she had to turn to access assistance from friends and neighbours, “Just everybody knows I’m very unhappy there, where I live now (.1) I told them now what’s happening now by the hospital. Like for instance (.1) for the few days, we have nothing to eat (.1) But I can’t ask my family on the yard, give my children a little food. No! Or give my children a piece. No! But one I step, once I put my foot outside that door (.2) everyone’s door open for me!” Despite this there was an undercurrent of resentment and feelings of isolation from her own family group.

The situation in which **Allison** lived was an illustration of how family and the demands placed on the individuals often contributed to the anxiety and stress of the participants, and by extension created the situations which could possibly be responsible for the development and maintenance of the presenting symptoms.

One of the participants I interviewed retrospectively was **Nambitha**, who was only nineteen years old when I first saw her and was coping almost single-handedly with the chaos of her extended family. She had lost her own mother when she was six, had no contact with her biological father and had come to live with her grandparents, aunts and uncles in Cape Town. There were six adults and two children living in a single house. During the time that I saw her, the number increased to seven adults when her uncle who had been imprisoned for possession of a firearm was released and returned home. The constant fighting and substance abuse were impacting negatively on both **Nambitha’s** mental and physical health. Yet she felt it was her duty as the granddaughter to stay and protect her grandmother who she described as “My favourite person in the world.” She was also able to relate the symptoms to the

family circumstances, “Yeh, okay, I’m stressing too much which (.2) causes this chest pains. And then you asked me, like what I’m stressing about. Like what problems am I having and then I told you my family, and myself, and my friends and everything. So that’s how it started.”

Even in almost optimal domestic situations, poverty had an impact on intimate relationships. **Rivka** described her marriage as a good one, and her husband as a loving father, but her symptoms were usually worse when she was forced to leave her children in his care. Her job as a chef in a city hotel required a great deal of weekend work and she felt she could not rely on him to be responsible in taking care of their children. She was concerned about working a particular weekend, “It’s the Two Oceans Marathon. It’s a *busy* weekend for us [at the hotel she was employed at]. Now I’m sitting there and I’m worrying is he [her husband] (.2) it’s not that he’s how can I say? (.1) Not (.2) um (.3) what’s the word now? I’m at work. He’s drinking, now he’s (.1) not worrying what (.1) I, I want him to clean the house or maybe make *food* or wash, do the washing or stuff like that but that doesn’t get done. He’s just on his own (.1) thingy.” For **Rivka**, it was a difficult situational paradox of living with a close family member who was both supportive (financially and emotionally) but stress engendering by his failure to be responsible for their children while she was working over weekends. At the time I interviewed her, **Rivka** expressed conflicting feelings about her situation. She was aware of her relative fortune in having a “good husband” and a job that she loved. However, financial constraints removed the possibility of giving up her work so that she could be there to look after her children. There was no option of employing an outsider to take on this responsibility and her family were not available to do so for various reasons.

Another participant developed symptoms which appeared to be chronologically related to a specific family interaction. **Gail’s** symptoms of pain started when she was living in difficult circumstances with her sister and her sister’s family, “We mos<sup>15</sup> moved from our house we rented and we went to live with my sister. And *there* things wasn’t so (.1) *nice*. We had to sleep on a mattress in the dining room (.2) . . . At first it was okay, but (.3) later on it was very difficult because of the way he [the brother-in-law] *is* man. Sometimes when we sleep on the floor, then he comes out of his

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<sup>15</sup> A colloquial Afrikaans saying approximating loosely to the English “just”.

bedroom, cos it's a one bedroom house, then he comes out of his bedroom, don't care if we sleep on the mattress, he just walk over us." However, **Gail's** MUPS became more complex, varied and inexplicable once she and her mother became estranged. Her mother had become religious and as a consequence wanted **Gail** to leave her partner, the father of their child, because he was divorced, "Because of this problem with my mom. And for me it's like I'm always thinking my mom don't want me to get married to Martin. In the meantime, I'm, I want to get married." To **Gail's** mother the prospect of marriage was out of the question as he already had a wife and consequently she considered him married. Her particular religious denomination did not recognise divorce. **Gail** related how her mother had said that, "I'm a whore and all that nasty stuff and I mean it really hurt. So she continuously saying over and over, *whenever* she sees me we have a fight." She felt however that there was no causative connection despite the fact that each time the relationship deteriorated further there was an exacerbation in her symptoms.

While lack of family support can be seen as an additional difficulty particularly within the context of poverty, some inter-family dysfunctions have the potential to be so toxic as to have far-reaching effects. One participant whose symptoms were longstanding (almost 30 years) had experienced a traumatic family tragedy shortly after which the symptoms began. **Caroline**, while in the process of divorcing her abusive husband, witnessed his murder of her sister. It was a tragedy with a twist as **Caroline** was the intended victim, "He tried to kill me, two shots and then she came into assist. And he turned on her and he shot her. And that is something I cannot overcome." Her physical pains had begun shortly after the incident and had continued unabated in various forms ever since.

Apart from the emotional and psychological impact of witnessing this violent incident, **Caroline** felt that there have been broader and more chronic consequences in terms of the family dynamics. Whether this was a reality or a projection of **Caroline's** feelings of guilt about her sister's death, the impact on **Caroline** was ongoing and she felt increasingly isolated by her family. She felt that her family – her mother and siblings – blamed her ongoing for the death of their daughter and sister and act this out in their treatment of her children, "It's like they're holding *my* children accountable for what their dad, what their dad did." She believed that her



father, with whom she was extremely close, was the only one who was able to love her children despite what their father had done. The memory of her father's difficult hospital death with end-stage emphysema in 2008 remained traumatic for her, both as an event in its own right as well as for the implications for her place in the family and the loss of her only emotional support.

Understanding of the nature and possible cause of the symptoms was also impacted – positively and negatively – by the input of family and friends. Concern regarding the underlying seriousness of the symptoms was in some occasions influenced by the comments of other people. **Davina** had tolerated her symptoms of internal “shaking” with a fair degree of equanimity, until an acquaintance suggested that they could be indicative of having a stroke when she became concerned and started consulting doctors. In her interaction with me, she constantly referred to the possibility, despite all the completed tests which discounted any organic possibility.

Occasionally family would dismiss the descriptions and concern about the symptoms and the participant would feel denigrated by punitive comments such as, “You’re just mad” which **Kamila’s** family regularly told her. **Gail** was able to laugh when she admitted that her mother would respond to her complaints with, “What is wrong with you *now!*” Perhaps in some ways the family were reflecting a more frank and overt expression of what many of the medical professionals felt when dealing with these individuals.

One of the participants, **Maryam** had been married to a man who had routinely been unfaithful, infecting her regularly with sexually transmitted diseases (STD's), and who drank heavily and abused her physically, “And I mean a lot of STDs for over the years that I was married to that man. And then I mean he *hits* me a lot and sometimes he don't want to work also. And uh, he had his good, good points also. He was sometimes a good [man]. But mostly if he *drink*, he, he was like he want to throw me with the stuff in the house, everything that's *heavy*. He hits me, he take my head and (.3) bump it through the pillars.” This memory of this prolonged and acrimonious relationship left **Maryam** wondering if they were the underlying precipitation of her present symptoms.

**Petunia**, who had recently and unexpectedly become unemployed, shortly after which her neurological symptoms manifested, was being assisted financially by her older sister and her own son. However, she felt the humiliation of not working and being a burden to them, “I don’t want to be on their shoulders every time, you know?” She was the youngest of four sisters and a brother. She had been close to her brother and missed his support, which had ended when he’d been killed in a stabbing six years previously. He was the only male sibling, as well the eldest and therefore his support would’ve been more acceptable to her. **Petunia** wouldn’t talk about her difficult home circumstances beyond becoming tearful and saying (of her older sister), “She drinks alcohol, and swears at me, because I am not working.”

One of the participants emblemized the way in which poverty and changes in economic circumstances impacted on familial and intimate relationships. **Angela** was battling to feed herself and her child. Her parents had been supportive, “My mother has always been there for my child. My parents have always been there for my child. I’ve always been there.” But since her mother stopped working, things had been difficult. **Angela** had broken off the relationship with her child’s father and as a consequence, “Since we, we’ve broken our relationship, he’s not the same with the child (.1). He’s not supportive the way he *was* supportive.” She had attempted to contact him with little result, “I can’t cope with what he’s doing, I can’t. I hate the fact that he has to be reminded.” Even, “When she [her daughter] cries and tells me that she is hungry I get *very frustrated*.” Despite the legislation entrenched in the constitution in South Africa, **Angela’s** experience with father’s defaulting on their responsibilities is ubiquitous in poor communities both on the Cape Flats and elsewhere in South Africa and impacts on the way in which the genders relate in the context of financial negotiation (Khunou, 2012). While redressed in some way by the system of child grants in South Africa’s constitutionally entrenched welfare system (Goldblatt, 2005), this process impacts negatively on both maternal and children’s health in other ways (Khunou, 2012).

During the times of **Angela’s** “acute” symptom presentation, “When I’m thinking (.2) this part, this side of my face. My left side gets (.1) shaky and I start getting sweaty and (.1) it normally happens during the night. During the day it happens for maybe an hour, not more than two hours.” Initially it would only affect her face but it got worse

and it would involve the entire left side of her body. When this happened at night it was her mother who helped, “And then (.1) my mother would give me uh, a wet cloth with vinegar (.1) to rub and um [clicks teeth] and ice block”. Their relationship was complicated moving from such supportive action to one when the mother or other members of the family would denigrate the symptoms. She had had an argument with one of her aunts who said, “Whoa, I don’t want to talk to, argue with you too much, because now, now again you, your whole side is going to be lame and the doctor will say that that maybe it’s my fault.”

## CONCLUSION

From the narratives of the various participants, the impact of personal relationships appeared to have either an ameliorating or exacerbating effect on their practical coping mechanisms – such as support in times of food or financial shortage – as well as a possible contribution to their presenting physical symptoms.

### 4.2.3. Prevailing uncertainty

*Current diagnostic models, in medical practice do not adequately account for patient symptoms that cannot be classified. When all known diagnostic possibilities have been excluded, physicians – and patients – confront uncertainty.*

(Kornelsen, Atkins, Brownell, & Woollard, 2015)

#### 4.2.3.1. Introduction

In lives already impacted by poverty and the way in which financial insecurity makes the entire process of survival precarious, the patients presenting with a possible somatoform diagnosis have, in addition, to endure a bodily process of symptoms and investigation which is fraught with confusion and uncertainty.

In the context of patients with medically unexplained physical symptoms (MUPS) Kornelsen, Atkins, Brownell, and Woollard (2015) describe and explore the effect of uncertainty, both prolonged and acute, inherent in this “diagnosis by default”. They highlight the need to somehow negotiate an acceptance, or at least tolerance, of that uncertainty in order to facilitate effective management with this particular cohort of patients. Amongst their findings was the suggestion that there is a relationship between levels of uncertainty and increased sensitivity to pain with the consequent emotional and psychological distress and reduction in quality of life. In my patient

interviews, the ambivalence of their medical status was foregrounded on many occasions as a source of particular distress and which appeared to impact negatively on their presenting physical symptoms.

I remember, in particular, the absolute desperation of **Maryam** in attempting to explain and receive validation for her symptoms, “Can you see there if I swallow? It’s like a bowl here [Shows me her neck, which looks completely normal to me]. And if I make like so [moves neck] it’s like a hole already in here.” I was caught in the dilemma experienced by so many practitioners with patients like **Maryam**: how to be honest without disrespecting their very real suffering. I will always remember the look of uncertainty and confusion when I said I could not identify anything and her plaintive, “Can’t you *see*?” I did not see this participant after the initial interview. I felt that I had failed her and that she would continue to move from one healthcare professional to another looking for an end to her uncertainty. Like the other participants **Maryam’s** domestic life was fraught with turmoil and uncertainty and the “not knowing” of her physical diagnosis appeared to be a disconcerting and frightening additional component of ambiguity and insecurity.

At the other end of the spectrum was a participant who found the drudgery of her existence unbearable. Despite her financial and social difficulties and the periodic disruption engendered by her drug addict son, **Davina** felt that she wanted an escape from the monotonous routine of her domestic life, the limitations imposed by financial scarcity and the ongoing demands of her family, “Then I haven’t got time for *myself!*” **Davina** felt constrained and restricted by the routine of washing, cleaning and cooking and just wanted the opportunity to indulge in her own activities and most importantly to be alone, “I am tired with all this people around me (.2). I want to sit (.2) and watch TV *alone* (.1) I want to read a book, I want to (.1) read my newspaper. Now I can’t, I can’t *really* do that at home.” **Davina** had minimal education but she was literate and she loved reading. It caused her considerable distress that she didn’t have the quiet and privacy to do so in her present domestic circumstances. She enjoyed coming to the hospital and sitting in the waiting room, generally positioning herself apart from other people where she could just observe or read. We did not discuss it at the time, and it is only retrospectively that I wondered if her medically unexplained symptoms possibly provided her with an escape from

home and introduced an element of uncertainty and frisson of excitement into the unchanging, humdrum nature of her domestic situation.

#### 4.2.3.2. Influence of substances: use and abuse

In terms of narratives of chaos and uncertainty the impact of substance abuse and the associated chaos was felt by nearly all of the participants. Thirteen of the participants identified substance abuse (either alcohol or drugs) as having a direct and negative influence on the quality and security of their lives. Substances use and abuse has an impact on economic stability (substance abusing behaviour causes job losses or decreases the opportunity for obtaining employment), interpersonal relationships (violence and aggressions as a consequence of substance intoxication disrupts family structures) and increases exposure to crime and criminal activities (either in pursuit of obtaining drugs for personal use or as part of the drug economy). None of the participants identified themselves as substance abusers. However, thirteen had partners, parents or siblings who were using substances (marijuana, methamphetamines or alcohol) which was causing emotional and/or financial distress.

Two of the participants had husbands whose heavy and regular drinking negatively impacted on the family functioning either in terms of relationships or family income and physical security.

**Mavis** had lost her home largely as a consequence of her husband's drinking. She also had to regularly intervene between her husband and her children when he became drunkenly abusive or they gave voice to their resentment about their deterioration in living conditions resulting from his alcohol abuse. While I was unable to record her first interview (her presenting symptom was one of aphonia<sup>16</sup>) I made notes of her response to my questions about her relationships with her husband. She said, "He used to be a good man, he provided for us, we had a good life, but now (.5) [didn't finish sentence]." His constant disparagement of her while drinking eventually caused her to stop engaging with him in anyway – she would invariably walk away when he became verbally aggressive. And at the time of her first interview with me, she literally had no voice.

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<sup>16</sup> Aphonia is the medical term for the loss of voice. Usually aphonia occurs as a consequence of an underlying organic condition such as inflammation or injury. No cause for **Mavis'** aphonia was ever established.

**Rivka's** husband, who in other ways she described as “supportive and loving”, drank heavily over weekends. She was finding it increasingly difficult to negotiate her roles of mother and employee because she could not rely on her husband as a responsible caregiver for their children because of his regular weekend binge drinking, “He is just a spoiled brat, he do (.2) he do whatever he want to do. That is how his mother brought him up (.4) and I am always worried about my children and are they fine when I am away at work.”

While the situation was not current, as she was separated and in the process of divorce, **Maryam** described the bouts of severe physical abuse when her husband had been drunk. She reported that when he had been sober he was a kind and loving man, but the alcohol changed his personality. “He was sometimes a good, but mostly if he *drink*, he, he was like he want throw me with the stuff in the house, everything that's *heavy*. He hits me, he take my head and (.4) bump it through the wall and (.3) . . .” She never knew what the day would bring and how his mood and condition would evolve. “I never knew (.2) [looks sad and confused] nothing was good enough for him. I think he will, he just *do* what he want to do (.3) and I never *know*.” She survived twenty years of unpredictable physical and emotional abuse before divorcing him. Retrospectively she still couldn't understand where she had done wrong, “But I was a *good* woman and that cook the food, clean and everything was on its place. But nothing was good enough for him.” Living on her own at the time of our interview she expressed ambivalent feelings – of relief but also of loneliness. While we did not talk about it, as she did not attend a follow-up interview, I did wonder afterwards whether her regular visits to the hospital outpatients department in an attempt to get an explanation for her symptoms, did no fulfil a dual, but unrelated, function for her: somewhere to go, a place to speak to people (other patients as well as the staff) and perhaps also a place of safety and predictability.

Sometimes participants described domestic situations where they were forced to defend one family member against the actions of intoxicated relatives. **Nambitha** was only 19 when I first saw her in a clinical capacity. Her life was being impacted on not only by her own unemployment and issues about her health but a very real concern for the safety of her grandmother. Two of the grandmother's children (**Nambitha's** aunt and uncle), a daughter abusing alcohol and a son who used tik on a daily basis,

either stole the grandmother's pension money or became violent towards her. "I need to look after my grandmother, she is like my mother, they abuse her." When **Nambitha** first saw me, despite no underlying organic etiology, her somatic symptoms appeared to closely mimic those of cardio-vascular disease associated with stress. Eventually in the period between the end of her therapy and the retrospective interview **Nambitha** negotiated alternative accommodation and found that her symptoms reoccurred only when she went home and was exposed once more to the chaos.

**Allison** was in a similar conundrum with her father and brother regularly becoming intoxicated with tik or alcohol and either stealing from her mother and herself or becoming violent when they were unable to do so. The widespread abuse of tik (methamphetamines) and dagga (marijuana) in the low-income areas on the Cape Flats is increasingly having a hugely destructive effect on family structures and relationships. Both drugs are widely available<sup>17</sup> and relatively inexpensive<sup>18</sup>. This affects many families directly. **Caroline** and **Kamila** both had sons who were using drugs so regularly that they had lost jobs but who had also become abusive and violent. **Kamila** felt particularly vulnerable after she realised her one son was part of a notorious gang, "When I saw that tattoo I felt *scared*, I didn't feel *safe* anymore . . . I felt *scared* in the way that he would *attack*." Both her sons had been physically violent, "Both my sons [attacked me]. I even went so far to make a court case against them (.3) and that. (.1) And he [the magistrate] just told me it was because of the drugs."

While initially **Caroline** had refused to acknowledge or discuss her sons' drug abuse, she eventually returned to see me therapeutically after an absence of several months during which she described her life of constant uncertainty, "I never know what I am going to come home to. I am so frightened. They fight, the one, the younger one has threatened to petrol bomb my house if I put him out." Descriptions of her symptoms

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<sup>17</sup> Figures supplied by South African Community Epidemiology Network on Drug Use (SACENDU) from: [www.sahealthinfo.org/admodule/sacendu.htm](http://www.sahealthinfo.org/admodule/sacendu.htm)

<sup>18</sup> Figures given for the street value of tik and dagga were obtained from the Addictions Division of Psychiatry and Mental Health as well as the Department of Criminology who indicated that there is 100% price disparity across the various areas, e.g., a gram of tik costs R150-R160 on the Cape Flats to R300 in an affluent area in central Cape Town. Most people buy less – amounts of .15gm to .25gm that may cost between R30 to R50. Marijuana (locally called "dagga") would cost on average R50 for a matchbox. Other common "hard" drugs (heroin and cocaine) cost R300 a gram.

which had receded to some extent became foregrounded as her domestic situation became more chaotic.

**Davina** reported she was afraid of her son. He had been abusing drugs for almost eighteen years. He was unemployed and periodically aggressive, “I’m always, I’m always scare that he can attack me.” “Because he threatened us, gonna (.2) burn us, gonna *kill* us, and all that”. Her symptoms had started when she had been forced to evict him from her premises after she found she could no longer tolerate his antisocial and unhygienic behaviour.

My participants’ descriptions of drug-fuelled violence are similar to those which I hear almost on a daily basis in my clinical work. I recall one particular encounter with a woman, a patient not a research participant, who had been forced to call the police when her son attacked her with a knife. He was consequently convicted and jailed in a notorious prison in Cape Town. What I remember so clearly was the poignancy of this mother describing, with tears rolling unchecked down her prematurely wrinkled cheeks (she was only fifty but looked at least two decades older), what a “good son” he was when he wasn’t on drugs. However, her feelings of guilt at having her son taken to prison were overwhelming. She and many other of my patients reflect the desperate parental dilemma which was acted out in the high profile case of Cape Flats woman, Ellen Pakkies, who murdered her son to protect herself and the rest of her family from his unremitting violence<sup>19</sup>.

Another participant, **Ingrid**, who experienced no substance abuse issues within her own biological family, was coping with the fallout of the drug use of a couple entirely unrelated to her. A child of this couple had been virtually abandoned by his drug-abusing parents when he was two months old. **Ingrid**, her husband and daughters had taken the baby in and were attempting to adopt him. This had been preceded by a period when they had merely fed him and provided his basic needs, but almost surreptitiously baby Brian had become an intrinsic part of their family, “His (.4) his *parents*, his biological parents are drug addicts . . . he was extremely, extremely ill as

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<sup>19</sup> The high profile court case which followed when Ellen Pakkies handed herself into the local police station after murdering her son, generated huge publicity including a highly acclaimed play and documentary. In a controversial ruling, she was sentenced to 3 years imprisonment which was suspended for three years and requirement of doing 280 hours community service.



a baby, due to his mother using drugs . . . No, it's [the biological mother and father] not family. And um, then his parents were put out [evicted] and they had nowhere to go . . . I used to send my daughter to fetch him everyday. So that I could bath him, feed him because she wasn't taking care of him. And when they had nowhere to go, they came to ask me if I could keep him there for the night until they had a place. (.2) And he's been in my home ever since [becomes tearful] . . . That is almost (.2) four years ago."

This informal "taking in" of children in need is not an unusual occurrence in the areas in which I worked. Most commonly it is a member of the extended family who will incorporate an abandoned or neglected child into the nuclear or extended family. Frequently there is no formal process of adoption. However, in the case of **Ingrid** and her family, the lack of blood connection made the "adoption" particularly tenuous and **Ingrid** lived in fear that the parents would return to claim him, "We went to see a social worker and we went to court and we got him, because we didn't want them just to come and take him away and put him back to that." However, at the time of the interview nothing had been achieved as the parents would not sign any papers despite having no contact with their child, "At the moment we are *stuck* because they have no communication with him, they are not interested in him, they walk past my house *every day!*" The accumulated uncertainty of the situation with the baby, together with the family's financial vulnerability as well as the fragility of her marriage, seemed to have reached a critical point six weeks prior to my interview, and simultaneous with the patient's attendance at the emergency room where a heart attack was disproved by the clinical examination and investigations. As a codicil, the biological mother with a subsequent premature baby were admitted to Waterstroom Hospital, to the Kangaroo Maternal Care unit, while I was still seeing **Ingrid** in a clinical capacity. Both the child's premature birth and the mother's subsequent abscondment from the ward and the consequent abandonment of the second baby, were drug related.

#### 4.2.3.3. Death, grief and bereavement

In consideration of social uncertainty, sudden death through illness or trauma needs to be a primary consideration. In poor communities where crime and violence result in many unnecessary deaths, this is pivotal and affected several of my research participants and many of my clinical patients. However, bereavement responses may

encompass other facets of sudden loss. George Engel (1961), responsible for the formulation of the biopsychosocial model of medicine<sup>20</sup>, provides a helpful and broadly encompassing definition of the extent of grief: “The characteristic response to the loss of a valued object, be it a loved person, a cherished possession, a job, status, home country, an ideal, a part of the body, etc.” (p. 18). The associated response may include “Sorrow, distress, affliction, bodily pain.” The development of posttraumatic stress disorder (PTSD) is associated both with exposure to violence and traumatic death, but as I have mentioned is also associated with somatic symptoms (Kaminer & Eagle, 2010).

If one moves beyond the limited perception of grief as an exclusive response to death and dying, poor people can be recognised as being particularly vulnerable to chronic bereavement and grief responses. L. Smith (2010) discusses the precarious nature of life for people existing in poverty, where there are few, if any, safety nets providing protection from sudden medical, financial or other catastrophes. For poor people, living in worlds where loss of any one of the components described by Engel is frequent and recurrent, the potential for developing chronic bereavement responses is heightened. L. Smith (2010) describes people living in what she calls a “crisis management way of life” (p. 71).

Some of the participants appeared to be actively mourning the loss of previous life circumstances, many of which had occurred suddenly: **Raabia** expressed feelings of anguish for the loss of her marriage and domestic role; **Gail**, despite attempting to minimise the effects, appeared to be grieving for the sudden termination of her previously close relationship with her mother; **Mavis** expressed sadness at the forfeiture of her home and deterioration in living conditions and the associated ending of valued friendships as a consequence of relocation to a new area; **Patricia** had lost two sons and while denying ongoing feelings of bereavement could not talk about them without crying; and **Kamila** actively grieved for the loss of her children’s affection. Underlying feelings of both guilt and resentment that she was indirectly

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<sup>20</sup> Traditional models of clinical medicine focused exclusively on the biological underpinnings of disease, or pathophysiology. With the development of the biopsychosocial model, Engel suggested inclusion of a broader frame with a concurrent acknowledgement of the complexities of human health and illness. In applying the biopsychosocial model the clinician includes consideration of not only biological but also psychological and social contributions (Engel, 1977, 1980).

culpable for the event complicated **Caroline's** grief for her sister's death. These participants were displaying somatic symptoms which, while they may not have been empirically connected to the events of loss and responses of grief, had clearly manifested after the events often in a close temporal relationship

In terms of uncertainty the sudden death of a family member, particularly through violence has the potential to impact on physical wellbeing for the survivors.

There are indications in the literature that grief and loss may contribute to the development of somatic symptoms. Gudmundsdottir (2009) conducted a study in which the embodied responses of fifteen members of seven families were described where there had been the loss of a child. In my study, **Patricia** had lost both of her sons suddenly and traumatically. One son had been murdered and the other died after having had a headache for only a week, possibly as the consequence of an intracranial haemorrhage. The understated simplicity of **Patricia's** description of her son's death added poignancy to the loss, "He was only got uh (.2) a headache (6). Was sick only for a week only. Started this Saturday, next Saturday he die." Both boys suffered from haemophilia and she had experienced many years of worry about their health and safety. **Patricia's** symptoms had developed shortly after the death of her first son in 2003 and had persisted over the intervening ten years (I saw her in April 2013). She never acknowledged any connection between their deaths and the advent of her symptoms. By the time I saw her, she was completely invested in the conviction that there was an underlying medical cause which the doctors had somehow failed to find.

For other participants, **Caroline**, **Kamila** and **Maryam**, although their children had not died physically, they seemed to be mourning the loss of their children in a different kind of way: as a consequence of their involvement in the endemic drug culture on the Cape Flats. For them it was a different kind of death, an ongoing and complicated one. A patient I saw in the community prior to my research had been sent to me for bereavement counselling. Her family was a close, supportive and religious one and only the youngest son had become involved in drugs. After many attempts at rehabilitation he came home and was clean for two weeks. At the end of this period, on New Year's Eve, he kissed his mother goodnight, told her how much he loved her and was grateful for her ongoing support. She could never articulate what made her suddenly feel concerned but she called her husband and they rushed to the son's

room. He was hanging from a rope and they were unable to resuscitate him. After many months of therapy, Mrs. M. was able to articulate a measure of relief at her son's death because she no longer lay awake at night fearful of the knock on the door to say he had died in the gutter or been arrested and thrown into jail. However, the relief was tempered by equal emotions of guilt that she should feel this way about the death of her child.

In consideration of grief and bereavement as a potential variable in the genesis of somatic symptoms, the study conducted by Mallouh, Abbey, and Gillies (1995) is of interest. Their work related to treating patients with persistent somatization appears to indicate that interventions for *recent* bereavements and loss have a better outcome than those with a history of much earlier adverse life events. For both **Patricia** and **Caroline** (who had lost her sister in a murder she had witnessed approximately twenty-eight years previously) the chronicity of their grief and associated symptoms appeared to have entrenched their somatisation as expressions of emotional pain and as mechanisms of help seeking. In contrast, while not a research participant, a patient who was referred to me recently had begun to display somatic symptoms after the suicide by gunshot of her husband. The somatic symptoms were rapidly replaced (by the second therapeutic session) by overt grieving processes (crying, expressing fear for her future, and verbally acknowledging loneliness and the absence of companionship) as she processed the loss (both financial and emotional) of a much loved husband. Fortunately she had been referred for therapy within a relatively short time after the traumatic incident.

If single traumatic loss has the potential to result in somatic response the literature indicates that serial loss and chronic and complex trauma have the potential to increase the likelihood of both physical and emotional responses (Kaminer & Eagle, 2010). In the study conducted by Holland, Graves, Klingspon, and Rozalski (in press) the results suggest that, after controlling for such variables as existing medical conditions and psychological status, individuals with prolonged, unrecognized and untreated grief symptoms were likely to be associated with an increase in healthcare utilisation. Multiple and chronic traumatization is recognized to be a feature of life in South Africa (Kaminer & Eagle, 2010). At both Hope and Waterstroom Hospitals, like other community-based healthcare workers, I have seen innumerable patients

who have survived multiple losses. In the week prior to writing this, I was called to see a young mother whose premature triplets had just died sequentially. She had already survived the sudden death of her mother and while she was in the maternity ward of the hospital her husband was murdered. A day later I was called to see a woman who had presented to the emergency room, as she was fearful of harming herself. In the interview it transpired that her husband had been killed in a car accident, her eldest son stabbed to death in a drug related altercation and a younger child had inexplicably died in her sleep, all in the period of the preceding year. In her desperation to access help for herself, this mother had abandoned her remaining five children, including a five month old baby, without making provision for their care. She was overwhelmed with grief and unable to function as she had prior to the recent losses. These are just two instances among the many in the health system. Neither of these women was able to follow up at the hospital and the concern for the future outcome for them and their surviving children is one which is endemic in the community situation in South Africa.

While death through trauma or violence is a predominant feature of South African life, death as a consequence of poor health and chronic disease is another. Physical health outcomes for poor people are generally not optimal (World Health Organization, 2015). Poor health consequences may result in both premature and unexpected deaths as well as physical disability. In low-income areas access to hospitals and basic healthcare amenities may be limited. Often there is suspicion about the quality of service provision. One of the participants was frankly terrified by the prospect of attending the outpatients department of Hope Hospital, “I was nervous, very nervous, because um (.1) friends of mine like (.1) mothers and dads and uncles and aunts that came here (.2) say two weeks they (.1) they just pass on.” She was concerned for her own survival because of her responsibilities, “What is going to happen if I’m going to die. That’s the worst fear I’ve got (.2), it’s *dying!* Because I’ve got (.1) three kids and they need me!” Such fear may lead to avoidance both of the institutions and to accessing appropriate health support and information resulting in avoidable loss and disability.

There are other poverty-related considerations which impact on individual ability to maintain physical health. Access to an adequate, well-balanced diet, exercise facilities

and acceptable sanitation all mediate physical health. Deficits in any of these areas impacts negatively on poor people's ability to sustain optimal health and results in both acute and chronic illnesses. In particular, inefficient management of chronic illness may result in physical incapacity and death. Poor diet and lack of exercise is evident in the escalating number of patients presenting with cardiovascular disease and diabetes. Figures provided by Statistics South Africa (Statistics South Africa, 2013) indicate that approximately 58 people die daily in South Africa as a consequence of diabetes, and place it as the primary cause of natural death in the Western Cape, where my study was conducted.

In respect of diabetes, one of the most notable physical manifestations of poor health management in the community setting is the number of amputations associated with inadequately managed diabetes. In the literature there are suggestions that limb loss or amputation evokes the same kind of bereavement process as the loss of a close relative or spouse (Horgan & MacLachlan, 2004; Parkes, 1972). In most clinics or district hospitals serving poor communities, the number of amputees who attend either emergency rooms or outpatient departments is alarming. Few of these surgeries are as a consequence of trauma. The vast majority result from elevated blood glucose levels associated with poor management of diabetes. This chronic condition, as well as the endemic cardiovascular disease, is both caused and exacerbated by poor diet and inadequate exercise. These uncontrolled chronic conditions affect not only the patient but also the extended family. The loss of the breadwinner through death or disability translates into an adverse life event for the entire family. A patient who attended therapy for several years was devastated by the premature death of her father, the family breadwinner, as a result of his diabetes. She had described to me how at times he was unable to take his diabetic medication because the household had no food. While not on my study, Elizabeth's grief at her father's death translated into an escalation of psychiatric symptoms and the development of such somatic symptoms as chronic headaches and body pain. I have also had other patients referred, at both Hope and Waterstroom Hospitals, with depression as well as somatic symptoms unrelated to their diabetes subsequent to an amputation. Some of the feelings expressed by these patients are not unlike the grieving experiences of individuals who have suffered the loss of a person (Horgan & MacLachlan, 2004; Parkes, 1972).

In his classic paper “Is grief a disease? A challenge for medical research”, Engel (1961) ostensibly explored the relationship between grief and a correlation between the development of both mental and physical symptoms. There has been a great deal of controversy regarding the meaning of this publication in the ensuing years. It is outside the ambit of this paper to explore the various interpretations. In the final analysis, Stroebe (in press) asserts, based on personal communication, that Engel’s purpose in writing the paper was to stimulate debate regarding the categorization of disease rather than attempting to define grief as a disease process. However, the controversy certainly stimulated consideration of grief as a process which has physical manifestations and “explored issues that lie at the very heart of psychosomatic medicine” (Oken, 1995, p. 1).

## **CONCLUSION**

Uncertainty permeated the lives of the participants. Their narratives reflected the broader socio-economic circumstances of the majority of the patients I see in clinical practice. Precariousness came in the guise of endemic uncertainty in employment and income, in volatile and vulnerable primary relationships, in disruption of the attachment process, in the endemic violence, crime and drug culture which permeates the areas in which the participants lived as well as considerations of disease, disability and ill health. The “normalisation” of this way of life in communities where many other women, experiencing the same or similar challenges, may have made acknowledging difficulties and seeking help difficult. It is possible that for the participants and other patients presenting to community health centres with somatic complaints it is easier to seek assistance for physical symptoms rather than to acknowledge underlying emotional and psychological difficulties.

## **4.3. THE MEDICALLY UNEXPLAINED SYMPTOMS**

### **4.3.1. Introduction**

In section 4.2.1. of this chapter I discussed in some detail the contribution of context. In this subsequent section the focus will be on the inter- and intrapersonal experiences and understanding of the women in this study and their medically unexplained physical symptoms. This arbitrary division should not, however, be taken as an indication that the two may be viewed as entirely separate considerations. The

meeting between the environment and the individual is key in understanding the particular manifestation of distress presented by the participants in the study. It may also be an important consideration in the medical and mental health management of many of the general population in the low-income communities which feed the respective hospitals. In addition, the gender of the participants is both an individual as well as contextual influence. The chapter “The feminization of poverty” (L. Smith et al., 2012), draws on extensive research indicating the particular dynamic experienced at the intersect of gender, poverty and experience of mental health services. In many ways, the women in this study with their somatic symptom presentation, represent a particular and vivid illustration of this interaction.

In the world of poverty which is permeated by uncertainty (L. Smith, 2010) the medically unexplained nature of the symptoms experienced by the participants had the potential to generate an additional anxiety characterised by yet further unknowing and ambiguity (Kornelsen et al., 2015). To this conjunction of dilemma and difficulty, Fels Smyth, Goodman, and Glen (2006) highlight the potential for further nuances of misunderstanding and distress for low-income women seeking assistance from the health services. They articulate a paradoxical, even contradictory, playing out of the interface where mental health (and other health workers) may inadvertently entrench and exacerbate the very distress they are contracted to alleviate. Within the specific mental health context they describe the misfit between conventional therapeutic interventions whose primary focus is on internal intrapsychic processes, while for most people living in poverty the impact on both their physical and emotional health derives from predominantly external and physical structures. In the context of my research the difficulty participants had in transitioning from the medical world of physical symptoms, to the one of mental health where the symptoms become peripheral to discussion of internal processes, illustrates this difficulty.

In diverse ways the relationship between the participants and the healthcare services was complex. On the one hand it was characterised by a desperate need for containment through clarity, identification and diagnosis. On the other the socio-economic interactions between service provider and service user created possibilities for the potentially damaging experiences described in the literature (Fels Smyth et al.,



2006; L. Smith et al., 2012). The presenting symptoms and the respective understanding of the underlying etiology provided the area of greatest challenge

### 4.3.2. Understanding the symptoms

#### 4.3.2.1. Participant explanation for symptoms

##### 4.3.2.1.1. *Concern about serious physical illness*

In low-income situations where physical health is vulnerable to chronic scarcities of resources, the predominant concern in individuals presenting with physical symptoms is focused on serious illness. In the absence of a definitive diagnosis, for some participants, anxiety and suspicion increased and they sought and tried to obtain support for their underlying apprehension that their symptoms indicated a serious medical condition. Several participants were concerned that their pain or discomfort was symptomatic of cancer.

Previous vicarious experience of illness frequently influenced patients' interpretation of their symptoms. In some instances the participants' symptoms were interpretively related to those symptoms and outcomes suffered by a friend or family member. **Raabia** had a very specific presenting symptom, a pain which she described as "Just the sudden (.2) stabbing pain on my back. It was on my spine, then all of a sudden it came to the front here on my chest, where my heart is. And I was very, very concerned because I thought it could be something else." When I asked her to tell me more about what this "something else" was she replied, "His [husband's] aunt died of cancer. And I thought it was *that*. Because she had the same symptoms and she complained of her neck pain and then she had, um, pain in her spine, and then they did an operation and not long and they found out she's got cancer and that she's got cancer in her brain and she passed." Comparing her own symptoms to that of this relative gave **Raabia** a perspective that she found paradoxically reassuring and frightening. Although cancer would be serious, at least it was a diagnosis and one which carried with it the weight and gravitas of serious medical intervention. Those participants who attempted self-diagnosis through comparison with the alleged symptoms of a friend or acquaintance generally attributed them to instances of serious illness.

Despite having no personal or familial exposure, another participant was also firmly invested in her self-diagnosis of cancer. **Joy** had multiple areas of pain, both in her breast and gastro-Intestinal tract, but was particularly concerned about the breast pain, “I had eh, I had pain in my breast, left breast, and under, under beneath here [points to left side beneath breast] sharp pain here. *Sharp* pains, yes . . . uh, (.1) okay, there’s another pain (.2) at the bottom of my stomach.” She had been absolutely convinced that these pains indicated a malignancy, “And I thought I had *cancer* in my breast. *Ja*.” Although both areas of discomfort had been extensively investigated at a large tertiary hospital and found to have no underlying organic cause she had remained unconvinced and was infuriated by the response of the doctor at Hope Hospital when she was referred there, “ Uh the doctor didn’t *examine* me, eh Avril! He just (.2) my notes, there were the letter that I brought from (.2) KTC day clinic. *Ja*. He (.2) read the notes and then asked me questions, regarding this, this, that letter . . . But he, he suspected that I’ve (.1) I’ve got uh (!) I’m over *stressed!*” **Joy** was particularly indignant by the doctor’s dismissal of her physical symptoms and pain to something as ephemeral and ubiquitous as “stress”. While **Joy** might have been the victim of the kind of inter-social microaggression described in the literature (L. Smith et al., 2012; Sue et al., 2007) my personal experience of the doctor concerned, weighed against this interpretation. He was a careful, impeccably polite and psychologized young medical officer who in all my dealings with him, impressed as sensitive and respectful in his dealings with his patients. Rather, in an enactment of the dynamic described by Fels Smyth et al. (2006), **Joy** and I had to mutually negotiate a path between acknowledging and accommodating the overt and external circumstances of her life with the intrapsychic processes which had the potential to be a contributing factor to her physical symptoms. When I saw her for the retrospective interview several years later she was able to acknowledge, with a fair degree of self-deprecating humour, the link between “stress” and recurrence of her symptoms. I asked her if the pains worried her and she replied, “No, funnily enough, it doesn’t worry me Avril. (.2) Because I tell myself, ‘Ag, if I am stressed I have the pain. If I am happy the pain will go away’ [Laughs] and [inaudible] I have to be stressed, *ja, sometimes*. So the pain will come if I’m stressed, and will go if I’m happy.”

All of the participants in the study endured lives impacted by considerable stress and anxiety. **Kamila** had symptoms which in some ways she could connect with the

chaotic nature of her particular situation, “I felt [the symptoms] when I worked me up, or when I *scold* with someone then it’s almost like it’s (.2) chocking me severely.” These symptoms would become acute and severe whenever she was exposed to conflicts with her family. However, when I asked her specifically what she thought the symptoms could indicate she said, “And that, and I thought something was *wrong*. I thought maybe I had *cancer* in my throat, or *something* was just wrong. And I wasn’t happy about it.” Unlike many of the participants or patients at the hospital, **Kamila**, who impressed as a perennially optimistic person, welcomed the results of the investigations which indicated that there was no underlying pathology or malignancy and she was willing to explore and embrace the possibility of relational influences.

For some of the participants their fears in respect of their symptoms were related to nonspecific possibilities of dying. **Rivka’s** particular presentation provided, in addition, an illustration of the palimpsest of potential physical and psychological diagnoses which is so perplexing to both practitioner and patient. **Rivka** had been told variously that her symptoms of “sudden episodes of headaches, dizziness, palpitation and sharp chest pains” were indications of panic disorder, gastro-oesophageal reflux, and stress. Immediately prior to her referral to psychology **Rivka** was given an additional diagnosis of depression and put onto an anti-depressant medication. While research indicates that poor women, who are constantly contending with acute and chronic stressors, are particularly vulnerable to depression (Kessler, Chiu, Demler, & Walters, 2005) as well as other psychological disorders such as posttraumatic stress syndrome (PTSD) and general anxiety disorder (GAD) **Rivka** did not appear to fulfil the diagnostic criteria. The literature also indicates a strong connection between stress of living in dangerous environments and mental illness in women (Mulia, Schmidt, Bond, Jacobs, & Korcha, 2008; L. Smith, 2010). Yet while **Rivka** acknowledged the ongoing concerns she had about safety for her children in the crime-ridden area in which they lived, neither they nor she had experienced any particularly traumatic or violent incident. **Rivka’s** symptoms were very specific and related to the birth of her youngest child who was almost a year old. She had been in protracted labour and had a difficult delivery but initially there were no symptoms, “Well (.2) everything was fine (.3) it’s just when (.1) after the birth of my baby. It’s almost a year. She’s almost a year (.3) Um then it started (.1) this headaches and heart palpitations.” With the

physical symptoms were the concerns “About, I’m just nervous I’m, I’m gonna die, I’m gonna *die*. Something is going to happen to me now! What am I going to do? What are *they* [her three children] going to do? That’s my *worst* fear!” She denied that her fear of dying was connected to her child’s birth but attributed them to her environment and domestic circumstances. As previously mentioned the family lived in a dangerous area and their financial situation was sufficiently precarious for her income to be essential for the family to survive.

For **Rivka** no single explanation for her symptoms appeared to fit. Eventually, after seeing four private doctors, she was referred to Hope Hospital. When I asked why she kept changing doctors she replied that nothing they did helped. During the time I saw **Rivka**, her headaches were alleviated to a great extent by implementing basic cognitive behavioural techniques (CBT) aimed at promoting relaxation, which seemed to support the contribution of stress as a major factor to her symptom presentation.

**Davina** was concerned that her symptoms indicated her vulnerability to suffering a stroke or cerebral haemorrhage. The symptoms began to manifest shortly after she had arranged for her drug-abusing son to be evicted from her property. She described the initial incident, “I was just still sitting on the bed (.3) and then I feel this like ‘shaking’ inside!” I asked what area of her body was involved and she said, “It was just my upper part, it was, it felt like hiccoughs, inside . . . Then it stops, then it starts again.” I asked how long the internal shaking had continued for and she replied that it had lasted almost 15 minutes during which time nobody else was able to see it. “But they [partner, his son and the son’s girlfriend] when *I* said I was shaking they didn’t believe me cos they can’t see it shaking. I didn’t shake like when someone gets *a fit* or so.” However **Davina** reported that once she had asked her partner to put his hand on her chest, he could feel it and immediately went to get help, “He could feel it and the moment he felt it he was so shocked. So he just went to the phone and called my daughter.” And from that time, the process of visiting one medical facility and practitioner after another began. Her vague concern was intensified when a friend of her partner’s visited while she was having an episode of the internal shaking. Despite not actually being able to see it, this man said “You must look out cos you can get a *stroke*”. From the medical records this possibility had been explored and discounted.

**Davina** remained unconvinced and remained seriously concerned about suffering from a serious and debilitating medical condition.

Other participants utilised points of diagnostic references for their symptoms by accessing information via the media and technology. **Gail**, for example, would routinely check her list of symptoms against medical sites on the web. On one occasion she told me, “I checked it [the symptoms] on my phone, on Google, and I said to the doctor I think I have kidney problems.” I recall a time when doctors found references to Reader Digest and other popular medical reference books onerous. The doctor-patient relationship is increasingly being impacted by the huge amount of information available via technology. Many doctors respond in the same way – with irritation, annoyance and dismissal. The doctor **Gail** saw told her, “Don’t tell me how to do my job. Put your phone away!” **Nomsa** also checked her symptoms by logging onto the Internet, but was more circumspect about suggesting her suspicions to the medical officers. “I look on the Internet to see what my symptoms mean (.2) But [laughs] I don’t tell the doctor that!” Occasionally, individuals still seek information via more traditional mechanisms. **Rivka’s** husband, who was unusual in that he accompanied his wife to her first interview, came into the room and told me that firmly, “I have read a lot and I think she has depression.” While libraries are available in the community, providing limited access to computers and internet, many poor people prioritise having cell phones, even smart phone which potentially provide them with access to healthcare information. While few of my patients have admitted to using them to access healthcare information, the potential to do so has been illustrated by these participants.

#### ***4.3.2.1.2. Psychological and emotional explanations***

As I have discussed previously, the research participants’ concept of psychology reflected the prevalent attitude amongst my patient population in general and those referred for somatic symptoms specifically: in a medical environment they found it challenging to negotiate effectively from their initial expectations of a physical diagnosis to one which incorporated explanations of psychological and emotional genesis. My participants’ were not unique in this. Research indicates that there is frequently a mismatch between expectations and outcome for low-income patients initially encountering psychological services both here in South Africa (S. Swartz,

2007, 2015) and internationally (Fels Smyth et al., 2006). Explanations for the difficulty appear to vary according to the particular situation. With my participants, the confusion was two-fold: firstly, most of my patients have had no prior exposure to psychology which created fear, suspicion and confusion. Secondly these difficulties of negotiation and understanding were further complicated by the physical nature of their presenting symptoms and the entrenched belief that they required medical management – in the form of medication or tangible procedures such as scans, X-rays, even operations.

However, some participants challenged the stereotype in a very positive way. **Rivka** had reacted with the same resentment as other participants about the suggestion that her pain was being discounted or that she was “crazy”. However, she was able to successfully negotiate to a position where she was able to consider and finally accept the possibility of an underlying psychological origin. She had no previous experience of psychology and her knowledge of the discipline was vague, but remarkably insightful. When I asked what she thought a psychologist could do to help her, she replied, “Maybe if I could *speak* to somebody, or may it, its (.1) how do they say? (.1) The ‘small brain’? Maybe there’s something wrong there?” I asked for her to elaborate on what she meant when she used the term “small brain” and she replied, “Almost like your (.1) um (.2) you’ve got your that, that, I’m telling you now there’s nothing wrong with me, but *deep down*, there, there *is* something that bothers me, but I just can’t put my finger on it.” I asked if she was referring to the subconscious, and she replied in the affirmative, “The subconscious, that’s it! Ja! The small one.”

**Rivka** was also the participant who provided an interesting distinction between “worry”, which she saw related to things that could be rectified or at least dealt with, “like problems at home, kids that’s worrying me, their school, work, um, baby,” and “stress” which was generated by issues that might be difficult or impossible to resolve, “Like my husband! (.2) Sometimes like I said, when I’m at work, but I’m not at work, I’m at home! When I’m home (.2) I’m at work . . . That’s what *I can’t fix* sometimes.” By making this connection, she reported that she felt less helpless in the face of her life circumstances. She would change what she could, and be tolerant of those issues which at present appeared insoluble. For **Rivka**, as well as several other participants who continued in therapy, the use of such cognitive behavioural therapy

(CBT) interventions as progressive muscle relaxation appeared to facilitate both the acknowledgement of stress as a contributing factor to their physical symptoms, as well as a way of managing problematic aspects of their lives more effectively. L. Smith et al. (2012) validate the usefulness of such concrete psychological interventions within low-income individuals.

As a corollary, outside of patients with medically unexplained symptoms, Fels Smyth et al. (2006) describe the psychological challenges faced by poor women encountering the mental health system and traditional psychological approaches. They discuss the shame and self-denigration that might be generated as a consequence of inappropriate interventions which appear to position the blame internally. While internal processes are of importance, many of the stress-generating factors associated with poverty are external and outside of the control of the women (L. Smith et al., 2012). For those of the participants who continued beyond the initial interview, the initial feelings of incomprehension, even resistance, became modified by explorations of externally generated stress as contributing factors to their physical symptoms, while at the same time the use of overt self-management techniques, such as those used with **Rivka**, which provided a sense of collaboration and autonomy in managing their life circumstances.

In several instances the participants symptoms were reported to have manifested in close proximity to a stressful or negative life event. This has been supported by some research (Kaminer & Eagle, 2010). **Raabia's** presenting symptoms had manifested shortly after her husband had told her he wanted to take a second wife. Throughout both interviews with **Raabia** she would describe the physical pain as a “stabbing in the back”. She felt betrayed by her husband and unconsciously appeared to recognise the symbolism of her description because almost immediately she would change the adjective to “pressing”. The prevailing uncertainty of her situation permeated both interviews. She was concerned about her marital status – would she end up divorced or not – as well as the financial and social implications. After she had described the process of marital uncertainty she acknowledged that perhaps it had made sense to be referred to psychology (although initially she had said that she had wondered if the referring doctor had thought she was “crazy”). She said she knew there was nothing wrong with her body, “I knew that” and that, “I *realised*, like I explained, um my

body couldn't handle the stress anymore." Acknowledgement of the stressful component of her life situation, while it did not ameliorate her physical symptoms, seemed to provide her with a degree of calm and acceptance. During her second interview we conducted a progressive relaxation intervention. Although **Raabia** was unable to return for a further follow-up, she reported telephonically that ongoing practice of the routine, helped her manage the ongoing stress of her marital relationship.

While not overtly discussed, the concept of reduced resilience emerged with one participant. This particular participant had lived a life defined by chronic stress and the impact of her social circumstances. When we discussed the possible reason for her emerging somatic symptoms she acknowledged that her middle age possibly made her less able to cope. As described in the section on physical explanations in section 4.3.2.1.1., **Davina** had originally been convinced that the explanation for her internal shaking was an imminent stroke. However, eventually during our second interview, she was beginning to entertain the possibility that the development and maintenance of her internal shaking was related to stress, specifically about her son. When I asked her about stressors in her life she said, "Oooh, I have such a lot of stress!" And she went on to describe the situation when she had to "put out" [evict] her thirty-nine year old son, "He's a big man, (.2) he's not working, he's doing drugs [tik and dagga] and (.4) I just put him out." She was able to say about the two separate incidents, "I think it, it's stress because the, the first time it [the internal shaking] happened (.2) I was also stressing with my son. *And* the second time!" The situation with her son had been going on for many years as he had started using drugs in his late teens. I asked why she thought it might have become untenable for her now after many years of enduring his behaviour, "I think that (.3) maybe um, that time I was still younger. You see? Now I'm older now and um (.4) being on my nerves all the time, maybe that affects me *now*." Unfortunately, due to her non-attendance at the third session and her failure to respond to messages asking to reschedule, I was never able to follow up on her ongoing understanding of the cause of her physical symptoms.

Another participant, **Maryam**, while invested in the physical nature of her symptoms, was also able to effect some relief through a basic CBT intervention aimed at reducing stress. She described symptoms which were predominantly concerned with



pain: up the side of her neck and the pulling of the muscles in that area, “The pain comes from here till in ears, and it like feel *tight* as I so move, man. Tight and *tight* my everything is like pulled together,” as well as the peculiar description of the “bowl” in her neck. She was also adamant that she had lost weight – specifically from her face. The pain and alleged weight loss had taken her on a circuitous route of investigation from the local Day Hospital where they did innumerable blood tests such as HIV, TB (tuberculosis) and thyroid function with no positive results. She went to a second clinic with the same result and then she demanded further investigation, “Then I told them, I want to see a doctor that can do a *scan* to see what is wrong because I can feel here is glands.” She was referred to Hope Hospital where both an X-ray and a CT scan were done and “They also find nothing [sounding disappointed] But the pain is there, the the, the *tightness* is there, the everything is there but (.3). She didn’t continue, looking sad and despondent. She offered no explanation for the symptoms but was prepared to consider the possibility that they were related to the stress of her unemployment. At the conclusion of her first interview I decided to do a progressive muscle relaxation exercise with her. She was almost childlike in her expectations of help and I felt that offering her a practical tool would perhaps provide her with the possibility of agency. She engaged with the procedure well, but failed to follow up with the subsequent appointment for us to explore the possible effect on her symptoms.

Another participant, who initially had also been preoccupied with the possibility of major illness, was able to move to a place of being able to link the advent of the symptoms to stress – specifically episodes of acrimony with her family. **Kamila** described the particular situation, “It’s almost like someone was choking me [actually puts her hands around her own throat] it’s almost like my family is *choking* me!” In fact, she was one of the few participants who could exactly identify the precipitating event, “I found out my son was tattooed out.” The significance of this was initially lost on me, but later she explained that the specific wording of the tattoo indicated membership of one of the Cape Flats most notorious gangs. Despite his history of drug abuse, she had felt that, “I thought there was something maybe I could do about it.” But the tattoo and associated gang membership was a final indication that he was lost to her. Her symptoms started immediately afterwards. The poignancy of her description of her symptoms, “Um, it’s almost like a stabbing pain, someone is

stabbing me with a knife continuously . . . in my heart,” together with the choking feelings seemed to be directly related to her sadness regarding the breakdown in her relationship with her children and husband. **Kamila** was one of the participants who continued in therapy, and with her both CBT interventions and explorations of interpsychic processes facilitated a shift in her perceptions and management of her physical symptoms.

The relationship between poverty and mental health has been well documented, particularly in the way it impacts most significantly on women (Belle & Doucet, 2003; Pearce, 1978; L. Smith et al., 2012). While much of the literature focuses on such psychological sequelae as depression (Belle & Doucet, 2003; Dukas, 2009; Kessler et al., 2005) there is some evidence for the development of somatic symptoms as a consequence of adverse economic conditions (Allaz & Cedraschi, 2015; Burns, 2015). One participant particularly illustrated this symptom configuration. **Angela** had a pre-existing diagnosis of depression and a history of suicide ideation and attempt. Her physical symptoms however had developed and intensified as her financial situation deteriorated. Her mother had been supportive, but then lost her job. **Angela** had ended her relationship with the father of her child and he had subsequently withdrawn financial support. At the stage at which I first saw her, **Angela** was struggling to feed herself and her child. Her symptoms had worsened from pain and shaking on the one side of her face to a general body palsy, which at one stage had resulted in hospitalisation at Hope Hospital and her mobility reduced to using a wheel chair, “It used to be my face only. But now, it was as my whole side, and then my leg. I would feel that this one is (.1) heavier than this one [pointing first to left, then right leg] . . . The second day it became the same, the *third* day, fourth day then I started even worse (.1). I started getting this needles. These needles and my face would be like a nervous, I’m a nervous person. Would shake, shake, *shake!*” I asked her what she thought the symptoms could indicate, “I *noticed* when it happens, it happens when I’m think or stressing or (.1) something bothered me.” At the end of her first interview **Angela** was able to walk back unaided to her ward. During the second interview I asked her how she understood it, “I think that (.) I have to put my body in a position whereby I (.1) relax my body, I relax my mind [sounding dreamy]. You know?” She went on to describe incidents where her she had shown a capacity to

manage problematic situations and relationships more calmly with a consequent reduction in her symptoms.

**Angela** was unfortunately unable to attend a third session due to the positive event of obtaining employment, so we were unable to explore this connection more fully. However, our telephonic conversation after she had begun working was characterised by a voice that sounded clear, concise and without the slow and monotonous tone that had prevailed in her sessions. She also described a reduction in her somatic symptoms. The opportunity to have explored this with **Angela** would have been an interesting addendum to my research, but was unfortunately not possible.

One of the benefits of having interviewed two participants, who had previously been patients with somatic symptom disorder, was the opportunity to obtain a longitudinal impression of the evolution of somatic symptomology and understanding following intervention. For **Nambitha**, whom I had last seen approximately two years before, continued to have the occasional symptoms (chest pain) but she reported that the process of identifying the underlying stress had enabled her to manage, “Like I know now, that when I’m hurting, *why* am I hurting and how does it feel to hurt. Let it make me to, it make me to identify [the underlying cause or stress] . . . But what *it is* that is stressing me is my family.” **Joy**, who provided the second of my retrospective interviews, was one of the participants who had initially been concerned about cancer underlying her symptoms of pain. However in hindsight she reported that she could now entertain the possibility that her inability to express feelings had been a contributory factor, “I think that the problem that uh, I’m *not* open with my feelings, ja. (.2) Even if I’m angry with something, I (.2) keep it inside, ja.”

#### ***4.3.2.1.3. Cultural and religious explanations***

While other causative considerations were held as possibilities, two isiXhosa-speaking patients considered an underlying etiology which related specifically to their cultural background. Both these patients displayed an ability to tolerate ambivalence comfortably. **Joy** and **Nomsa** described themselves as able to embrace Christianity

alongside their traditional beliefs which required reverence for the role of ancestors and certain rituals not accommodated by Christianity.<sup>21</sup>

**Joy**, who had moved from suspecting cancer to engaging with entertaining the possibility of psychological contributions to her somatic symptoms, provided an additional dimension to the interpretation of her symptoms genesis. “I *knew* I had dreams leading me to the calling. But the, this pains, they are the ones that *pushed* me to (.2) to make the decision that I must take the calling *now*. I thought that maybe I have this bad lucks, including these pains from the accident because I am running (.1) to, to take the calling”. **Joy’s** family had a strong history of the women being called to be traditional healers – the sister with whom she was living was practising as a traditional healer, her mother, grandmother and aunt had all received callings. Dreams are an important component of the work of traditional healers. During the dream state it is believed that the spirit of the individual leaves the body and makes contact with the spirit world, specifically the ancestors. As a consequence any information or messages obtained in the dream state are considered to be of greater import than similar messages received during full consciousness (Elion & Strieman, 2004). As an interesting codicil, a dream had apparently been responsible for positively mediating **Joy’s** continuing attendance at therapy [See Appendix E].

Together with **Joy**, **Nomsa** had considered the possibility that there was a connection between her symptoms and her failing to take her calling to be a traditional healer. We had discussed her understanding of her symptoms in her first interview in the context of her cultural background, “When I grew up, you know, when you believe in traditional things, then at home (.2) it, like *my* ancestors, meaning that they *need* me, they need me to be a sangoma<sup>22</sup> one day”. She said that she had managed to negotiate a delay “it’s on hold for now. I’ve done something [a ritual which she didn’t elaborate on] but (.2) just to *calm* them [her ancestors]. So uh, at least for now it’s on *hold*, I, I’m considering it.”

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<sup>21</sup> South Africa is society of diverse religions and cultures. Amongst the Xhosa and Zulu populations the choice of embracing particular religious denominations or combinations thereof is largely dependent on the particular family history and on such personal circumstances as living in rural versus urban areas (Elion & Strieman, 2005).

<sup>22</sup> There is frequently a misattribution of the name “sangoma” as being synonymous with “witch doctor”. The Xhosa and Zulu people consult Sangomas to facilitate communication with spirits or deceased ancestors (Elion & Strieman, 2005).

During the first interview we did not explore this issue but in the second I asked what she thought would happen if she did not answer her calling. “Uh! You know the headache is going to go away. But something else is going to (.2) come again!” She described how her symptoms had worsened at the time of her graduation and she had sought traditional help, “Because when I went to some (.2) spiritual healers they told me that they [her ancestors] were so (.1) furious because she saw that no (.1) I was taking like, uh, education *more* than (.1) them.” I asked her to clarify whether this meant that if her ancestors became angry this anger could be expressed through physical complaints and her answer was an emphatic, “Correct. Ja!”

**Nomsa** however was able to negotiate a sequential or alternative understanding of the evolution of her symptoms. I asked her about her reason for coming to see a western health practitioner when she already had a cultural explanation for her symptoms based on her traditional beliefs, “It’s because uh, (.1) maybe you *do* understand different things, as I’ve mentioned to you now, it’s because of this spirituality. But because you’re a professional it might happen that whatever (.2) currently is happening to me, it is not *really* because of what I think . . . This headache, it wasn’t because of that [failure to take the calling]. It might happen because I was under a *lot* of stress.” Approximately a year after I last saw her for the research interviews, **Nomsa** contacted me in some distress wanting to schedule an appointment. At this time, although she generally felt physically well, she was feeling distressed about a situation which related to her traditional beliefs. An uncle had died and according to the traditional belief system he now entered the realms of her cohort of ancestors. This necessitated that she display appropriate reverence and respect. What was causing her enormous distress was the need to reconcile his earthly existence as a dubious character and suspected paedophile with his posthumously elevated status. Once again we explored her willingness to incorporate input from both Western and traditional perspectives and the way in which this impacted on her self-image and health. Her somatic symptoms had briefly resurfaced, but she reported that she was able to manage them without undue anxiety.

Another participant, **Gail**, was a committed Christian, and also offered an explanation related to spiritual or supernatural intervention. She suggested that either the women with whom she worked (both Xhosa) or alternatively her husband’s ex-wife used

“witchcraft” or “dirt” to create her symptoms as a form of retribution or vindictiveness, “There *must* be something wrong, which they [the doctors] don’t see or (.2). . . And the other one also, on the other side I was also thinking, it could also maybe (.2) “dirt”. People using, people that’s maybe jealous of me (.2) using muti or something because (.1) that what happens in reality. People *do* used bad stuff like witchcraft. If I maybe don’t like you, I maybe use witchcraft or, I dunno how they do it but they do it.” I asked her what had given rise to this possible explanation for her symptoms and she replied, “Um (.4) I do work with two um (.2) African (.1) girls. And they also talk a lot about muti and (.2) in their culture. (.2) So I thought maybe (.1) and I used to fight a lot with them at work, cos they very bossy . . . So I thought maybe *they* could’ve maybe put in something in my drink or my food which I didn’t know about, so.” But **Gail** didn’t confine her suspicions to her colleagues whose culture may include aspects of witchcraft but also attributed the possible use of malicious spiritual means, “And then another one it could also be Martin’s [partner] ex-wife maybe, that’s jealous about me because in the past I used to stop Martin from (.1) doing favours for *her*. (.1) I stop her every time that’s why maybe she could also use dirt against me.” **Gail’s** attitude towards her symptoms provided an interesting vignette of the coexisting cultural (witchcraft) and technological (Googling symptoms on her smart phone) explanations for her unexplained somatic symptoms.

Not all spiritual explanations concerned retribution or punishment. One of the Muslim participants expressed a more positive spiritual explanation for her symptoms. **Raabia**, although she had initially expressed confusion about the genesis of her symptoms, by the end of my second interview she offered an explanation related to some kind of divine message. She felt that her body was sending her signals, “That was also God’s way of *talking* to me (.2). ‘Take note!’ ‘Open your eyes’. He maybe gave me signals inside, but I couldn’t, I couldn’t open my eyes”. Her place as a devout Muslim was a central to the sense of stability in her life and this explanation possibly made her symptoms more palatable and less frightening to her.

#### 4.3.2. Conclusion

The participants’ search for explanations for their physical symptoms broadly included concerns about serious physical illness, mainly cancer, as well as considerations of the impact of stress and the challenging life circumstances. In

addition, four participants offered cultural and religious explanations as a possible alternative. However, underlying all the tentative suggestions was the insecurity and very real fear which the lack of definitive and medical diagnosis generated. The participants – like all patients presenting to healthcare services – were looking for a clear and unambiguous medical explanation for which there would be a solution in the form of medication, surgery or other appropriate and visible treatment.

#### **4.4. RELATIONSHIPS WITH PROFESSIONALS**

*When illness is fraught with uncertainty, the therapeutic relationship becomes paramount.*

(Kornelsen, Atkins Brownell, & Woollard, 2015)

##### **4.4.1 Introduction**

In attempting to suggest mechanisms to promote positive outcomes, Kornelsen et al. (2015) describe the importance of the clinical relationship. Psychological investigations and research have also foregrounded the patient-practitioner relationship as the pivotal positive factor in the therapeutic space (Lambert & Barley, 2001; Martin, Garske, & Davis, 2000). I would suggest that this therapeutic relationship is pivotal in engaging patients with somatoform diagnoses. A good patient practitioner relationship is more likely to generate a positive outcome in the form of self-awareness, self-regulation, developing autonomy with improved help-seeking mechanisms and potential for symptom alleviation. On a cautionary note, Fels Smyth et al. (2006) warn against professional collusion with the “external brutalities of poverty” by entrenching blame and shame in interactions with women living in poverty.

In the stories that follow, I hope to illustrate that relationships – with individuals at both sides of the professional continuum – had an impact on understanding, acceptance and physical and emotional regeneration for the research participants. The experiences of the patients and participants within the hospital environment are shaped and influenced by their interaction with doctors, nurses and other healthcare staff. Equally, the impact of their personal relationships cannot be discounted and were equally important and in many, if not all cases, had both positive and negative influences on both symptoms and response.

Within the hospital environment, complexities permeate all interactions with patients with MUPS. Both within and without the research situation, “professional relationships” with patients with somatoform disorders must of necessity encompass engagement with both the medical personnel as well as with mental health in the form of psychology and in some cases psychiatry.

In the search for clarity regarding their physical symptoms, the participants’ first encounter was with the doctors who ultimately referred the patients to psychology. At a recent psychology workshop, a colleague described the process of “surveillance until invisibility [is reached]”, which seemed to serve as an appropriate description of the experience of patients diagnosed with somatoform disorders. They enter the system, they are investigated exhaustively, and once those methods of surveillance reveal no underlying cause, they become metaphorically invisible to the medical fraternity. At this stage their invisibility is mobilised and they are passed onto mental health services. This is both an unexpected and frequently humiliating and denigrating process for the patients.

Subsequently entering a space – that of psychology – that was essentially alien, confusing and discomfoting, elicited different responses from the various participants. The women were largely ignorant not only of the function of a psychologist, but also of the dual process of referral that was being enacted. Advocacy as an integral part of psychological services has been acknowledged and promoted (Ali & Lees, 2013). The kernel of health advocacy involves the promotion of collaboration through understanding rather than the imposition of treatment options. I have mentioned earlier that in my clinical practice I invariably spend part of the first appointment providing some explanation to facilitate understanding of the methods and purpose underlying psychology. In my experience this time pays dividends in terms of subsequent understanding, cooperation and outcome. In promoting understanding there is the concurrent development and strengthening of the relational capital so essential for therapeutic work.

As I have mentioned in the previous section the mechanism of introducing into the research process this “educational” component was not without difficulty. To attempt to negotiate education of the participants in terms of the specific discipline of psychology and, simultaneously, to inform them about components of research



working alongside a therapeutic intervention, became something of a conundrum. Negotiation between clinical and research foci are not unproblematic. Kvale (1999), not unreasonably, likens the process to navigating between the twin monsters of Scylla and Charybdis.

#### 4.4.2. Presentation to medical services

For both the patients and participants the first encounter in their search for explanation for their physical symptoms was with the doctors.

Many patients arrived at the respective hospitals via a circuitous route. This often started, when there was money available, with a private general practitioner (GP), described colloquially as “the house doctor.” When the GP’s were unable to find the root cause of the presenting problem, the patient might be referred to the nearest clinic or directly to the district hospitals. The experiences the individual participants had impacted both on the way they viewed their symptoms and their response to the referral to psychology. For the participants the moving from one service provider to the next had been lengthy and unhelpful and provided no solution to finding an explanation for their symptoms.

**Allison’s** journey to Hope Hospital was typical of the experiences of many of the participants and involved moving from one institution or practitioner to the next, “I went to a, the XXX hospital. (.2) So they refer me to the Day hospital. So I went to the Day Hospital (.1) in Heideveld. And immediately the doctor, um, saw me and just sent me straight away to Hope.” At Hope hospital she saw the neurologist in the outpatient department who ordered X-rays, CAT scan and examined **Allison** “from top to bottom” and eventually told her that, “Nothing seems wrong, I need to speak to some[body] to *you* today.”

Not all participants were negative about the prolonged medical investigative experience. I first saw **Joy** (one of the patients with whom I did a retrospective interview) in December 2010 but her process had begun many years earlier, “This thing started 2003! I’ve been going up and down – KTC, Hope, Groote Schuur, KTC” [Laughs]. She was able to hold confidence in the system and engage with it until she found resolution, “I knew I would get help. I just had to be patient, ja.” Her sister supported **Joy** in this process. It was in fact this sister who had originally insisted that

**Joy** seek medical assistance for her somatic symptoms. This sister was a traditional healer who worked in close conjunction with a nearby municipal clinic, and who encouraged **Joy** to continue seeking help from the formal healthcare system. In the interval between seeing me initially as a patient and being interviewed for the research project, **Joy** had begun working as a traditional healer herself. In the end **Joy** was able to integrate her symptoms, their management, both medical and psychological, to incorporate aspects into her own work as a traditional healer. She expressed respect for the Western medical model and the attempts to assist her with her physical problems. In our discussions of her experience with the doctors, **Joy** was positive in her evaluation of the role of both her own and other traditional healers and that of the hospital: “For me, Avril, ah (.3) I take them as one thing. Because (.2) they are doing the same thing, but differently. Ja. (.2) When (.1) how (.3) I’m a traditional healer, I help people. And there’s the doctors [and psychologists]. (.1) And they help people.”

**Kamila** had also had many visits and exploratory tests at her local day hospital before being referred to Hope Hospital, “I went to the Day Hospital *five* times. I was three times at trauma and I was twice at the doctor. And then I came at Hope.” She had been under the impression that she was coming to the thyroid clinic but was confused, “Because the doctor didn’t explain to me . . . And if I ask him, it’s almost like they irritable cos I’m asking questions which I feel I have the *right!*” The doctor at Hope requested an ultra sound which excluded the thyroid as a contributing factor and **Kamila’s** response was “And, I thought at least I don’t have cancer if it’s not the thyroid and there’s nothing wrong.” I asked how she felt – whether it was a relief or whether she was puzzled. She replied, “I was a bit puzzled at the time because I dunno what was going on.” **Kamila** was expressing the feelings experienced universally – by practitioners and patients suffering from somatic symptom disorder. With the referral to psychology **Kamila** responded with the kind of pragmatism which appeared to be her general coping mechanism, “Maybe you will tell me I’m just over reacting, (.2) to the way my health is concerned.”

For some participants, once they had arrived at the hospital, there was a sense of escalation in seriousness. One patient, **Gail**, was incensed that her symptoms were not given sufficient emergency attention: “For me it’s like, for *me* I felt like an emergency

case because, um even if the doctors look at me they can see I am swollen, if they touch me, I couldn't walk properly. Why didn't they take me so seriously?" Outrage at not being "taken seriously" permeated the narratives of many patients with medically unexplained symptoms.

Nowhere in the medical notes was there any validation of **Gail's** bodily swelling and at no time in the three sessions I spent with her was I able to truthfully confirm that I could identify these symptoms. The dilemma of acknowledging patient suffering while simultaneously engaging with them with honesty and transparency regarding their symptoms is a difficulty experienced by both medical and mental healthcare practitioners who encounter patients with medically unexplained symptoms. In their search for validation patients may inadvertently antagonise the medical professionals and entrench their own feelings of being disparaged or negated. As I mentioned previously, **Gail** was one of the patients who accessed the Internet in an attempt to self-diagnose. She regularly Googled her symptoms and then at the next visit would suggest possible underlying reasons for their development to the attending doctor. Their failure to agree with her self-diagnosis was something she found difficult to accept, "I Googled it on the phone, and the symptoms was the same as kidney disease . . . And he didn't listen."

For all the participants the fact that they could not be given a label was almost the most distressing component of their experience. Many felt that a diagnostic marker would vindicate their physical suffering – both for themselves and for their families. The uncertainty they were holding would be ameliorated by a scientifically verified underlying cause.

**Ingrid** was certain she was having a heart attack, "It feels like somebody is either *pushing* down on my chest or *sitting* on my chest. And my *heart* would beat *so* fast and it (.2) would, it would beat so fast and this (.2) pressure feeling it would actually *hurt*. You know?" And when the doctor said she was referring the participant to psychology to "find a way to *cope*" she felt disbelieved about the reality of her physical symptoms. **Ingrid** had pre-existing hypertension which added to her conviction that there was something organically wrong. This also contributed consequently to her feelings of humiliation when the doctor referred her to psychology which she felt was suggestive of him not believing her.

For some patients, particularly the two older patients whose somatic symptoms spanned several decades, the relationship with the medical fraternity was not viewed positively.

**Caroline** had run the gamut of medical investigations for close to 20 years with no resultant diagnosis. She did not engage well with me and was dismissive of the process which had brought her to psychology: **Caroline** was frankly disparaging during her intake interview. She had been sent to see me by the Waterstroom physiotherapist who had been trying to treat her nonspecific muscular pain unsuccessfully for several months. When I asked **Caroline** to describe her understanding of the referral she replied, “I was referred because for the pain that I endure that doctors, or whoever, cannot make what is wrong with me.” And later, “I’ve been for physio until *she* eventually decided that there was nothing she could do for me to relieve me of the pain and that’s the reason why she referred me to you people!” Later in a subsequent interview, she described trying to get hold of a doctor in the busy State system and who had failed to get back to her or respond to messages, “To go through that type of pain, and, and that feeling and you trying to get hold of the doctor to, to *help* you. She, she’s not really *interested* in you, you know.” Her response to my question about her feelings was a furious, “Anger (.2) Anger (.2), anger, anger, anger [said rapidly and vehemently]. And it will go further because now I’m going into a depression.” I spoke to the doctors who had attempted to find an underlying cause for her symptoms. Some of them were perplexed and curious but those doctors she had seen on several occasions spanning innumerable visits to the outpatient and other departments found the interactions difficult and frustrating. Her situation and relationship with the healthcare system in many ways emblematised the place of the patient with medically unexplained symptoms within any given healthcare facility.

Another chronic healthcare user, **Patricia**, was the second oldest participant (fifty-one years old) and together with Caroline had the longest standing somatic symptoms. Although the exact date was difficult to establish, she had been seeking medical help for various somatic symptoms from approximately 2003. She felt that the system had completely failed her and that she had been mismanaged by the doctors and given the incorrect medication, “I take a lot of time, using medicines, pills and all that. Eh (.2)

*but* in my, in my heart (.2) I'm not really sure. I'm thinking about. This cause in my mind, this cause is, is that I use uh, the wrong medicine for a *long* time. I dunno is that a problem but I think so! Because I use wrong medicine for years and *years!*" I asked her why she thought this was so and she described coming to Hope Hospital and seeing the doctor in outpatients after having been referred from a large tertiary institution, "And he ask what treatment they give to me and I see doctor and say [to] doctor 'Here is my treatment.' And say the doctor, they mustn't give me this medicine like this." **Patricia**, of all the patients, was meticulous about keeping records of her medication and the various treatments she had undergone. She kept a homemade notebook – made of cut pages stapled together – which she consulted whenever I asked specific questions about her medical treatment. She felt that she had done everything asked of her, but the continuation of her symptoms was an indication of the failure of the system, rather than as an indication of an alternative explanation.

The way in which determination to find an explanation sometimes impacted negatively on the doctor-patient relationship was illustrated by the story of **Davina**. She had come to the hospital via both State clinics and private doctors. She was seen and assessed by the medical officer in the outpatients' department of Hope Hospital. Dr. M. was in fact a neurologist and able to conduct an intricate and specialised assessment of the patient. When she found that there was no underlying organic disorder she referred the patient, with some relief, to me. In the interim between **Davina's** two interviews with me, she was taken to see a private neurologist by one of her relatives. The doctor at Hope Hospital appeared incensed. She denied feelings of anger that the patient was doubting her abilities, but felt that this example of "doctor shopping" was a particularly unhelpful process for an unemployed patient who would have had to pay a considerable amount for an appointment with a private practitioner – to repeat all the same investigative procedures which had already been done at Hope Hospital.

Participant experience of the investigation of their symptoms ranged from rage and frustration, to resigned acceptance. Those participants whose symptoms were of recent manifestation, appeared to be less angry and more available to engage with alternative explanations and management. Within the context of this research the alternative was in fact referral to mental health in the guise of psychological services.

#### 4.4.3. Referral to the psychological services

All the participants were, at a particular point – generally when the attending doctor had run out of options or patience – referred to psychology. The responses varied and were only loosely correlated to the way in which they had been told about the referral.

Most participants, when asked about the role of psychology, would attempt some explanation. **Davina** however, said frankly, “To tell you the honest truth, I don’t know.” She clarified this by saying, “Because I’m not so (.2) educated.” When I attempted to obtain some understanding beyond the basic information about her level of education (Standard 6 or Grade 8) she avoided answering by becoming preoccupied with some somatic symptoms, “I don’t know what’s wrong with my eyes [removes glasses and wipes beneath both eyes]. (.3) Sometimes it’s (.2) water and sometimes it’s not watery.” She later admitted that she’d initially come to see me out of curiosity, “I think that um, (.4) why then am I seeing a psychologist cos there’s nothing with my mind or so. (.3) Cos I know everything that’s going on around me (.3). The doctors can find nothing wrong with me, so (.2) why must I see a psychologist? But just of curiosity that I come to see the psychologist”. At end of initial session she cried. She couldn’t tell me why, she just said, “I don’t know why I feel like this [softly] . . . I don’t know when I last cried (.2) because I always have to be strong at home.” Patients like **Davina**, poor, uneducated and vulnerable, illustrate the importance of sensitive and empathic management across all disciplines in order to avoid the possibility of entrenching shame and self-blame as described by Fels Smyth et al. (2006). Sadly it is the patient with medically unexplained symptoms, variously called “heart sink”, “exhausting” and “frustrating” that most challenge this capacity in the healthcare professionals.

**Raabia** initially tentatively suggested that attending psychology sessions could provide her with the opportunity to talk, “to help me with my [problems] (.1) to make me feel better? [Laughs uncertainly]”. She seemed shy, quiet and private, and in fact described herself as an “introvert.” Her sense of privacy and family loyalty made it difficult to seek out confidants amongst her friends or family. There was some initial confusion for her because when the original referral was suggested, she thought maybe it was an indication that “maybe it’s something *worse!*” I asked her to explain to me what she meant by this. She did so with difficulty, “(.2) Um (.2) how can I say

now? Explain it? Because the doctor say it [her physical symptoms] can, it can affect my mental problems.” Despite the hope that the opportunity to talk to somebody neutral would assist in helping her to negotiate a difficult process, **Raabia** remained cautious and her main concern appeared to be related to issues of confidentiality. She opened her second appointment with “Okay, you said no names is going to be mentioned.” She was referring to the recording and writing up of her sessions which we had discussed in detail during her initial interview prior to her signing the consent form. Her main concern was that she didn’t want “trouble.” Even after I reassured her once again about the process of confidentiality and anonymity she went on to say, “I don’t [inaudible] I don’t want anybody to come ask me is, if I’m responsible for what’s written in there or (.1) what’s been said in there. You know what I’m saying? I don’t want, cos I’m not that kind of person that wants trouble.” Her ambivalence to engagement with psychology, perhaps a playing out of her way of interacting with the world in general, was enacted in her failure to attend several subsequent appointments and then later to contact me over two years later “asking for advice”. Despite my attempts to accommodate her at this later date, she once again failed to maintain contact and I never managed to speak to her or arrange an appointment.

For the majority of the participants they, like many of the patients in clinical practice, associated psychology with management of insanity or “madness”. Sometimes this attitude was precipitated or reinforced by the referring agent.

**Gail** had been told frankly by the last doctor she had seen, “You’ve seen, uh, very *good* doctors at our hospital (.2) and they found *nothing* wrong with you. (.2) So, there might be something wrong with (.2) you, upstairs.” While she was a bit affronted, saying, “To me it was strange because I don’t react like some that’s “cuckoo”, you know? **Gail** wasn’t particularly insulted by the referral to psychology. While she had no previous history with psychology she gave a fairly pragmatic explanation, “The help you get your mind clear, um (.1) sort out yourself.”

Another patient became tearful when I asked about her feelings when she was referred to me. **Ingrid**, “[sighs loudly] (.3) To tell you the honest truth (.2) “That is what we are everything looking for.”] (.4) I didn’t understand *why* they would send me to one [a psychologist] . . . I felt, I felt it was (.3) I felt that (.4) they thought that (.2) what I was telling them was not the *truth* [becomes tearful].” This sense of being disbelieved

was reflected by several of the other participants. Reassurance didn't come necessarily from my explanations or those of the referring doctors. Several sessions later **Ingrid** described how she had felt vindicated when an acquaintance had disclosed that she too had received therapeutic help. She said, "I didn't feel ashamed [when I told her] I think, why, I also never felt ashamed was because (.2) I told her that [she had been to see a psychologist] after she told *me* that (.2) when *she* found out the first time about *her* husband [having an affair], she ended up in a clinic!" The relief of hearing about someone else going through the trauma of a partner's extra-marital affair and her relatively more dramatic mental health deterioration, seemed to vindicate **Ingrid's** sense of shame at having been referred to psychology herself. She also mentioned that part of her reluctance to attend psychology was the expectation that she would be forced to face emotional issues from her past, "I think (.2) what, what really made me (.2) I would have to *face* (.2) *everything* [becomes tearful] even the things that I'm trying not to think about anymore [crying]."

Sometimes participants didn't recollect their initial hostility. **Nambitha**, one of two participants I had seen previously in a clinical capacity and then interviewed for my research retrospectively, could not remember having been negative or unenthusiastic about her original referral. However, she did say that she had been puzzled, "[Laughs] No! But I didn't think like that but I also wondered, like okay *why* did she [the referring doctor] send me here?" This was an interesting contradiction because earlier in the same retrospective interview she acknowledged that the word "psychologist" had negative connotations in her community, "When even you hear the *word* [psychology], its about madness . . . I was thinking maybe Dr. W. thinks I'm mad or something. But what does madness have to do with my heart?" This reflected her initial response. During her very first clinical assessment interview, almost exactly two years prior to the research interview she had been angry and resentful about her referral to me and could not understand why her physical heart pain was potentially going to be managed by a psychologist.

Another participant, **Maryam**, also felt that her sanity was being impugned by the referral, "I thought maybe she [the referring doctor] think I'm mad! Nuh! I thought so maybe she think I'm now *mad* that because I know the pain, the tightness, I can feel the glands but the, the *tests* show that there's *nothing* wrong [sounding very puzzled] .



. . there's the file [pointing to her hospital file on the desk] there's nothing, nothing wrong!" The disconnect between her subjective experience and the objective results was largely incomprehensible to **Maryam**. She displayed an almost childlike naiveté in her engagement with the process. This carried through to her understanding about the role of a psychologist. She wasn't at all sure what the work of psychology involved and had difficulty relating it to her particular referral, "(.4) Um, to, to, to do mentally, to (2) how can I said? To, um, to be positive. To, to get a person positive and mentally to um, like some people, um, mentally disturbed they (.2) *do* things (.1) abnormal and then a psychologist try to get them on a, on a positive level!"

In many ways **Maryam** represented a cohort of patients seen in the community. These patients experience real physical distress, they look to the system to resolve the problem but exhibit the tendency to move from one service to another and to find it difficult to sustain a treatment path for any extended period. **Maryam's** failure to follow up deprived both of us of the opportunity to engage with her situation in a potentially positive way. I suspect that she may have attempted to access help at another facility in the mechanism of doctor hopping or doctor shopping so ubiquitous amongst patients with medically unexplained symptoms.

Sometimes the punitive ascription by other people regarding psychological services caused the participants additional distress. While **Kamila's** attitude to the referral was fairly benign, saying that she thought "A psychologist is uh, help a person, maybe if they are um [sighs] *disturbed* or [sighs] if someone can't cope with whatever is going on in their life." Yet she suffered negative repercussions when she disclosed to her family that she had been to see a psychologist. Her son jeered, "Yes, for mal mense! [mad people]." And later she related the conversation when she told her husband that she had come to the end of her tether and wanted to move out, "I told him that I feel I want to move out . . . because I can't cope and (.1) I'm not prepared to go on with my life like that anymore. On Tuesday morning I got up, I just felt I needed to come away from that house and that is the time he tell me. He told me I'm mad! He told me I'm *mad!* I can't handle when someone accuse me of a thing that I didn't do." So in addition to worrying about physical symptoms she had to contend with disparagement as a consequence of her attempts to find a solution.

Other participants were blatantly angry, resentful and insulted because of the connotations associated with mental health problems and services.

**Joy** remembered very clearly how she had felt, “I had, had mixed reactions, Avril. I, I was *angry!*” I asked her why and she replied “Eh, just to hear that name psychiatrist [psychologist]. Uh, I just became *angry*, I don’t know.” I continued to probe in an attempt to find out just why she had been so angry and what she thought the referral meant. “In my knowledge I thought ‘Ah, maybe this doctor thinks that I, I’m *crazy!*’” She admitted that she had been reluctant, “I didn’t want to come. *Really!* But then my sister forced me.” I asked her how and why and she replied “Mmmm. She (.1) she forced me in a way that she (.2) she *begged* me in fact to do it for *her*, if not for me.” By her own admission she had become difficult to live with. She was lonely, moody and negative. After being less than impressed by her initial session I asked why she had come back, “Eh (.4) Ag man [sighs] I thought I must go back maybe it will be better (.2) than the first time. I was *curious!* . . . Then I told myself “Ag, Avril will not help me, but I must go (.2) I must go and, and *do this.*”

In the section on cultural understanding of symptoms (4.3.2.1.3) I discussed the cultural significance of dreams to the Xhosa participants. **Joy** later referred to a dream which had positively impacted on her ongoing attendance at therapy. She said, “Mmmm. I remember, the thing that (.2) the *real* reason that made me kept on coming here was a dream. You remember? I had a dream . . . That dream, that uh, I was in a *dark* room . . . I was in a dark room with no windows or doors. And I was afraid, how would I get out of that room. (.2) Then, Uh, I am going to summarize it, I can’t remember it correctly but then I (.2) I saw *you* coming *through* the wall. Then the wall (.3) parted? Yes, parted, and then the light came through. And then I go out . . . Avril, this dream made me, *need* to have this need to come *here*. And (.2) every time you made an appointment. That’s what kept me coming.” In my years of clinical work, **Joy** provided me with the most unique explanation for therapeutic adherence!

Occasionally both participants and patients alter their perceptions of therapy and psychological intervention – either overtly by expressing their feelings verbally when they feel safe enough to do so or by enacting displeasure or disappointment through failure to follow up. One participant, **Petunia**, was initially quite positive about the referral, her response to my question elicited, “Yes, it’s a great thing!” When I asked

for her to expand on this she said, “Because not, its, it’s a time now I’m going to (.3) maybe there is a thing that is hurting me every time. So I haven’t got support who can share.” And that her understanding of psychology as a discipline “Is to help people if those people, if a person doesn’t have somebody who can share something.” When I asked why she specifically had been referred to psychology she replied with some hesitation, “(.5) I think it’s what they [the medical doctors] don’t see. They put me this morning in a scan and the results was everything was fine (.3) so maybe there is something that (.3) is inside to me and I want to share. Maybe I don’t share it enough because I’m an *open* person. If I’ve got something that is hurt me I open my mouth.” Interestingly, **Petunia** did attend her follow appointment, but only in a nominal way. She arrived several hours early but when I explained that I had prior commitments and would only be able to see her at the appointed time, she did not look happy at all, but failed to say anything to me. However, when I returned to see her at the correct time, she had disappeared from the outpatient department and my attempts, then and later, to contact her telephonically were unsuccessful. She seemed to have enacted her displeasure rather than to choose to “open her mouth” and discuss the situation with me.

Endemic stress experienced by the communities in which the participants lived, and the impact it potentially had on their mental wellbeing, often provided explanations which made the referral more palatable for the patients. Specifically this might be worded as “panic attacks”. For example, **Lianne**, when I asked her why she thought she’d been referred to psychology said, “Because (.2) she [the attending medical officer] found that they did a lot of tests already, and they found nothing *wrong*. Like I went for my CT scan, EEG, MRI, bloods, lumbar puncture so there’s (.1) nothing (.2) wrong there so she, I think that she felt that there is *something* that is cause this panic attacks.” Frequently both patients and doctors (despite the fact that the symptoms did not fulfil the DSM criteria) would ascribe the symptoms to panic disorder. When I asked how **Lianne** felt about the referral she said, “I feel (.2) I feel comfortable. I feel like (.2) you might be able to help me. That’s how I feel because (.2) speaking to my mom (.1) she can’t help me with the problems I’m dealing with. You know?” However, she had some ambivalence, which was felt by many patients/participants – the simultaneous need to receive assistance with the coexisting feelings of resentment about the intrusion into their private space. “I wasn’t too sure

at first when Dr. M. tell it to me that I should come and see you. Because to me, I, I've, I'm working at WW and um, they send a social worker because (.2) um, I had a (.2) little quarrel with my father and um, she started digging into what happened and so I (.1) but she also couldn't give me much advice because to me it's just she can't do anything about the situation."

In general referral to psychology was not viewed positively by the participants. Only two, **Elisha** and **Nomsa** had previous exposure to the discipline, and both were more curious and open to the referral as a consequence.

#### **4.4.3.1. Feelings after having seen a psychologist**

Although it was not always possible due to failure to follow up, I tried in each case to ascertain whether participants' perceptions of psychology had altered as a consequence of their interview.

##### ***4.4.3.1.1. Fear of disclosure or repercussions***

Those patients I was able to ask, and who were willing to answer the question regarding their experience of the psychological intervention, were generally positive. For the majority, their response was related to the relief of having had a safe space in which to talk. In many instances pre-existing constraints about sharing their problems – either with friends or family – were connected to concerns about having private matters move into the public domain and the vulnerability to criticism and judgement which this might incur. Many of the participants had even hidden the fact that they had been referred to psychology due to stigmatisation which is connected to any mental health issues. **Kamila**, for example, greatly regretted telling her family about her appointments with me as from that time forward she was regularly taunted with imputations about her sanity, "He [her ex-husband] told me I'm mad! He told me I'm *mad!* I can't handle when someone accuse me of a thing that I didn't do."

**Caroline** too had been subject to victimisation as a consequence of disclosing her visits to psychology. She had, fairly early in the process, told her two sons that she was seeing a psychologist as a consequence of their violent and anti-social behaviour. This appeared to have backfired on her as they subsequently accused her of being crazy and needing to see her "mad doctor".

#### 4.4.3.1.2. *Shame related to substance use*

The widely prevalent culture of substance abuse within the communities on the Cape Flats directly affected 11 of the participants. Despite the prevalence, it remained a subject of shame to be hidden if possible from friends, family and neighbours. In this context the space provided by a psychological intervention enabled talking about what was hidden outside of the room.

Even **Davina**, who had not impressed as a particularly private or secretive person, felt the humiliation of her son's drug habit and anti-social behaviour. She had not discussed the situation with anyone beyond her partner and subsequently to disclosing to me said, "I feel much better because the thing is this, I don't have friends you can *talk* with them, but you can't talk your heart out with your friends. Cos you, you know today (.2) people is like this, if you talk your heart out then they just turn around and talk with the next person." She was referring specifically to her shame at her son's drug use and the necessity of having had him evicted from her home. **Davina** remained circumspect about the content of her time with me. When her partner and a friend asked about her sessions, she told them firmly that what was said in the room was confidential but was prepared to tell them that, "We had a nice talk and I feel much (.2) better talking someone. Talking your heart out".

While our interviews in no way ameliorated her symptoms, she felt that she was better able to manage them, "Ek vole meer betere, ja. Al ooit van my hand wat moet regkom." [I feel more better, yes. Even despite my hand which must still come right." Referring to a physical symptom with an established underlying cause.]

At the end of her final session with me, **Davina** sat quietly with tears rolling down her cheeks. She was unable to say why she was crying – she seemed almost unconscious of the process – but perhaps the feelings evoked were "too much" for her, in a similar dynamic to her history with schooling and employment, and she did not return for her follow-up appointment. Her disconnect with the bodily expression, in the context of her MUPS, were also of note and which unfortunately I did not have the opportunity of exploring with her.

**Caroline**, who I saw on and off for almost three years initially as part of the research process and then in a clinical capacity, took almost that amount of time before she

could overtly acknowledge that her two sons were using drugs. She would refer obliquely to “the stuff they are busy doing.” And when she returned for therapy after a period of absence, initiated the first session with a firm, “I don’t want to talk about my sons.” Apart from their humiliating response to her disclosure of her attendance at therapy, they made her life untenable – stealing, threatening and coercing. Yet she found it difficult to acknowledge the underlying problem. Despite our tentative examination of the dynamics of her son’s reaction and the possibility that it emanated from perceptions altered and skewed by chronic drug use, **Caroline** felt humiliated and protected herself from further denigration by never telling anyone else about her sessions. Even in the room with me **Caroline** also consistently refused to refer to her sessions as therapy, counselling, or psychological services. She would invariably talk about the “pain clinic” and would end the therapeutic sessions with “thank you for the chat.” Our sessions remained characterised for almost the entire period with a focus on **Caroline’s** physical pain and ongoing medical investigations. We had a potential breakthrough in the process when she suddenly acknowledged her son’s substance abuse and the way it was having a deleterious effect on her life. She however, found this difficult to sustain, and retreated into preoccupation with her somatic symptoms.

#### *4.4.3.1.3. Feelings of relief*

From **Raabia**, the first participant on the study, who had been so suspicious of the process, I obtained a muted but positive response, “Actually I feel a bit relieved speaking about it.” She had initially hidden the fact that she was seeing a psychologist, but a friend had inadvertently mentioned that she had gone for therapy during her own divorce. This allowed for a mutual exchange of confidences, not only about their personal processes but the relief of talking to an objective outsider. **Raabia** had said that initially she had been “scared” to tell anybody she was seeing a psychologist and when she did tell a friend she said, “Maybe you’ll think I’m crazy!” The friend’s reassurance “No!” and admission that she too had seen a psychologist normalised the process for her, because she could then acknowledge the difficulty/feelings of isolation and vulnerability in disclosing to people in her social and family group. But that talking to a psychologist “talking about your feelings and (.2) life and what you’re going through . . . It will relieve the things that you are going through, it will relieve your stress. That will ease it more.”

**Mavis** had been sent to me as a consequence of her idiopathic aphonia (which lasted for a year prior to her referral). Throughout the two years I saw her subsequently she was adamant that this was due to physical causes, but did admit that she felt some sense of relief after the initial contact told me that, “After the first time I saw you, I felt that I was, I was like a bird in a cage and that the door had been opened.” Despite her initial reluctance **Mavis** continued to see me regularly – usually on a monthly basis because of the difficulty in transport – for almost 18 months. The challenges in establishing effective communicating with her husband continued unabated, but she felt the time spent in the room at the hospital provided her with the opportunity “to talk about things with freedom.” She couldn’t talk to her husband, she couldn’t talk about her problems to her children, and she was isolated physically and socially living on the farm. However she had been able to maximise on her monthly therapy sessions to express feelings and concerns in an articulate and thoughtful way. Her presenting symptom – loss of voice – was resolved by the third time she attended the hospital for appointments with me and never reoccurred. **Mavis** did not however capitulate on her initial assertion that the symptoms did not have an underlying psychological component and were of a physical origin. We had an unvoiced understanding that we would “agree to differ.”

#### ***4.4.3.1.4. Opening up alternative avenues of assistance***

For one particular participant, **Nomsa**, although she had some pre-existing knowledge about the profession, personal exposure to psychology had created the possibility of people in her community accessing help where they might not have been aware of it before. She gave a poignant summary of her understanding, “It [psychology] does make sense, it does make sense. It *does!* More especially for the Black community (.2) those people they’ve got a *lot* of problems sometimes they *die*. Silent. (.2) And, only because they didn’t know where to go . . . Then coming into my culture, there is this thing I hate, a man, if you are a man you cannot *cry*. But inside you are hurting.” When we talked about her experience she was clear that she would talk about her positive experience and how close she came to walking away, “I *will* [tell people about mental health services] because now I *know* and I’m just happy to myself that when Dr. S. talked about that [referral to psychology] then I didn’t like whew! Uh, uh

[shakes her head and points to the door to indicate walking off]. I was just ‘oh okay, I will do it!’”

**Ingrid** who had felt so insulted at the initial referral, continued to see me in a therapeutic capacity for several months. She said fairly early on in the process that attending psychology had enabled her to consider things, “I haven’t thought of in a *long* time. And (.7) I feel I can (.6) *talk* to somebody now, about (.2) things that (.2) I tend to keep to myself, and that I, I *don’t* uh, speak to anybody else about.” She discontinued therapy when she renewed acquaintance with somebody who had experienced similar marital betrayal and deterioration in economic and social status through loss of employment. This friend had also received psychological intervention and through her, **Ingrid’s** process with me was sequentially validated and then rendered obsolete.

I asked **Gail** what it had been like coming to see me (she attended the initial intake interview and then three subsequent sessions). Despite her ongoing belief that the symptoms were unrelated to her particular social or economic circumstances, specifically the deterioration in her relationship with her mother with whom she had previously had a close relationship, she was able to say, “I was excited because I thought, ‘What’s next?’ So, you trying to help me, getting maybe rid of the pains and (.2) just to maybe get my (.1) mind relaxed and just talk and stuff.”

In psychology there are stringent professional constraints against forming personal relationships with patients. However, no professional injunction can protect against a subtle and sneaking admiration and unvoiced affection for particular patients. **Rivka** was one such individual. Like virtually all of the participants on the study she had not had an easy life. But what made her stand out as a participant, patient and person was her lack of self-pity and her willingness to engage with enthusiasm with whatever life offered. I have described her concerns about being labelled “mad”, yet she persevered, engaged with the relaxation interventions and told me that she would advocate psychology as a mechanism to manage stress to her family and friends. She was one of the participants who was most able to make the connection between her physical symptoms and the underlying psychological contribution.



**Kamila** was another participant who felt the therapeutic component to have been helpful and stimulating. She had originally been apprehensive, but by her second session she said that she had looked forward to the session, “I was *excited!* I couldn’t wait for the session [laughing].” She also felt reassured about the issue of confidentiality within the professional parameters, “Um (.2) at least I *know* there’s confidentiality, um (.1) I don’t need to be *scared*. Um (.2) at least I know whatever is going to transpire about being at the psychologist it’s about honesty. And (.2) I want to be honest with myself.” And in her final interview she said, “At least I could talk to someone that would give me a hearing. At least um, I could *express* myself in my own way, even (.4) in my *own way*. Never mind if I *cried* or whether I laughed.” This provided her with an alternative experience to that of her family where she was continuously derided and dismissed.

#### **4.4.3.1.5. Negative response to the referral process**

Of all the participants **Patricia** was the one participant who was entirely and vocally unimpressed about the encounter with psychology. When we concluded our third and final session and I asked if she wanted to return for a follow-up appointment, her reply was emphatic, “No! Because this process is the same, it is not changing. It is the same process.” However, she did acknowledge that there had been some improvement in her physical symptoms. I asked about the pain and she said, “I think they are getting better now because it was painful all from *here* [indicates down neck and arms] and round my shoulder. Now, it is, is this [shows just shoulder area] better.” However, she did not attribute her improvement to psychological intervention. I had shown her some progressive relaxation exercises but she maintained that the easing of her pain was due entirely to the help she received from her husband, “.4) I think it’s changed because uh, day and night I feel this and I wake up. Say to my husband, ‘Make so and so’ [indicates rubbing her neck and shoulders]”. She had not been using the exercises I showed her.

I was unable to ask questions of evaluation from **Maryam**, **Lianne**, **Shanaaz**, **Petunia**, **Angela**, or **Amelia** due to failure to attend follow-up appointments.

#### 4.4.3.1.6. *Retrospective insights*

I will conclude this section by referring in some details to my interviews with **Joy** and **Nambitha**, the two participants with whom I had a prior therapeutic relationship and who were interviewed retrospectively. They were able to provide more nuanced and detailed descriptions of their process through the system and in particular the shift in their understanding and engagement with psychology. They were also, several years later, able to consider changes in both their symptomology and interaction with their bodies in this specific context.

Both **Joy** and **Nambitha** acknowledged that although their symptoms still occasionally resurfaced, they were able to manage and accept them with relative equanimity, as they understood the underlying genesis. **Nambitha** said, “Like I know now, that when I’m hurting [chest pains] why am I hurting, *why* am I hurting and how does it feel to hurt.”

**Joy** had moved to a place where she could begin to integrate aspects of the mental with the physical. She said in response to my question as to how she managed differently now, “Uh, uh, I, for starters I can *feel* the *pain* now!” I was a bit confused about what pain she was talking about and she replied firmly, “No not the uh, *body* pains, the (.2) I can feel that I’m *hurt*! *Ja*! I’m not afraid to voice out my feelings to the person who maybe hurt me.”

We discussed her final therapeutic session with me eighteen months previously when there had been similar confusion. She had said, “The pain has gone!” and I had asked whether she was talking about the breast pain which had brought her to the hospital. She had looked at me in outright amazement and said, “No, no, no, *no*! I’m not talking about the *breast* pain, I’m talking about the pain inside that I didn’t know I had.”

However, **Joy** had continued to experience the breast pain periodically in the year and a half since I had last seen her, and I asked how she felt when this happened, “(.3)[Clicks tongue] Uh, funnily enough (.2) I don’t (.1) I don’t care anymore! [Claps hands]. I just tell myself, this gonna pass because its normal . . . Ah, it will *pass*, it’s just the same like having headache, or toothache! *Ja*” and she later clarified saying,

“And these breast, breast pains, (.1) *come* when I have something that stresses me! (.2) For instance they started coming by the time my father was sick.”

**Joy** was not completely resolved in her understanding of the connection, “I don’t know Avril. I’ve been asking myself this question, ‘Why (.3) I don’t know why these two are (.2) if I got pain, if I got stress (.2) this pain starts, if I am happy there is no pain!’ (2) So I don’t know.” However, she was able to hold the ambivalence.

However, in **Joy’s** story and in the history of our interaction, for me the most noteworthy and poignant aspect was her transition from initial hostility, which bordered on disparagement, to one in which she described and compared our respective roles – as clinical psychologist and traditional healer. I have mentioned this before, but I believe it is worth repeating. **Joy** saw them as complementary and collaborative, “For me, Avril, ah (.3) I take them as one thing. Because (.2) they are doing the same thing, but differently. Ja. (.2) When (.1) how (.3) I’m a traditional healer, I help people. And there’s the doctors [including psychologists]. (.1) And they help people.”

She went on further to describe the way in which she borrowed and adapted ideas and interventions from her sessions with me in her own work, “Some of the things (.2) you, you *do*, for example in my case, with *you*. Some of the things you, we talked about and you helped me with are, are the same with the things I tell my people, my clients, yes! I would, let me put it (.1) I would “steal” some of the ideas from our sessions [bursts out laughing]. I mix with these ideas I had from you. Yes. *So* I think it’s the same thing but we differ (.2) in the way of putting it, ja.” She was also cognisant of where her boundaries ended and those of my profession began. She went on to describe a client she had seen, but felt unable to help her and had suggested that she go to the local clinic and ask for a referral to psychology!

I will conclude with **Nambitha**. She, who had initially been so resentful and sceptical about the referral to psychology, said in response to my question regarding her initial feelings and any changes in perception that might have occurred, “Yow, First of all it made me realise that there are things that I, I am *not* even *aware* of that are bothering me.” She was able to define the process of therapy by saying, “So you helped me to be specific about what I’m stressing about so that I can be able to (.2) attack it. Then I

learned how to be [clicks fingers and smiles] “proactive”! Without the intervention from psychological services she said, “I’d just be eating those Isordils [medication to treat angina], not even knowing what they help me with.”

I asked her if she thought that maybe the talking had helped with clarifying her thoughts and she said, “Yes! And actually like I put them down here [makes a gestures as if placing something on the desk]. And also it, like, relieves the heaviness in your heart.”

Because we had a pre-existing relationship we were able to talk in detail about how she had moved from where she had been, incapacitated by stress, to one in which she felt able to manage the difficulties which inevitably arose. In my final question, I asked what she now thought of psychology and she replied, “For me, psychology is something of everyday. Everything of it.”

In **Nambitha’s** final words the prospect and value of an integrated health service was articulated in a way which mirrored to some extent **Joy’s** remarks. I asked her if she had admitted to anyone that she had seen a psychologist. She replied firmly, “I’d recommend them to, to meet a psychologist and I’ll tell them why . . . And there’s *Doctor Avril*, and *Doctor W.* [the medical officer who had made the original referral] . . . So I have *two* doctors [laughs]. It’s crazy but it makes me feel (.2) good. I don’t know, in a way. Like I’m taken care of by my *doctors*, you know?”

#### **4.4.4. Conclusion**

In this chapter, I have attempted to describe the subjective experiences of the research participants, two groups of low-income women diagnosed with somatoform disorders, as they moved through the healthcare system in a search for satisfactory explanations for their medically unexplained symptoms. In keeping with the phenomenological emphasis of this research project, their words have been used wherever possible in an attempt to provide rich and personal expressions of the data.

The data were collated over a period of a year from multiple semi-structured and clinical interviews within the physical structure of two district level State hospitals. Accommodating, transcribing and analysing, the large volume of resultant transcribed interviews, while simultaneously remaining within the structural constraints of the

thesis, was not easy. I was constantly challenged to find ways in which to present individual participants' stories in the depth and richness that they deserved while being mindful of the structural academic limitations regarding word and page count. I have attempted to ensure that each voice has been heard, while facilitating the interweaving of the general thread of experience and the individual stories to create a cohesive and respectful account. Yet I am aware of the necessity of accommodating "secrets and silences" (Ryan Flood & Gill, 2010) and the associated need to both reveal and conceal (Finlay, 2008), which have been maintained through the practical necessity of inclusion and exclusion of data. This is a complex topic, and one, which would benefit from further research. I have positioned the participants within their particular lived environment and, as I have attempted to illustrate, their contribution needs to be viewed within that context. However, they should also be situated within a broader socio-political and healthcare environment.

In the subsequent and concluding chapter, I will attempt to present a comprehensive summary of the findings as well as to provide insight into the process from a reflective perspective.

## CHAPTER FIVE

### CONCLUSIONS

#### 5.1. INITIAL REFLECTIONS

This research journey has been a great deal more than merely an academic endeavour, but an enormously challenging and enriching experience on many other levels.

Increasingly in qualitative research there is an emphasis on reflectivity as an integral part of the process. I refer to Silverman (2013) who urges a careful negotiation between what he calls “the balance between confessing to your errors and proclaiming your achievements” (p. 374) or, more colloquially, what he terms “confessions and trumpets” (p. 376). While initially this felt like a precarious pathway to navigate, his additional suggestion that this final chapter should operate as a mechanism to “stimulate your readers by demonstrating how your research has stimulated you” (p. 376) was particularly helpful to me. There were times during which I wished fervently never to have started the doctoral process. There were moments of utter confusion and overwhelming feelings of incompetence, but the process has stimulated me in ways in which I would never have imagined when I first began formulating my research proposal. In this concluding chapter I hope to provide a retrospective glimpse into the personal and professional insight and reflective understanding I have gained through the process as well as potential and objective areas of clinical and research contribution.

The question of distance and objectivity is one that seems to be wrestled with by most (qualitative) researchers. There is also a subliminal expectation that the scientific collection of data should be predictable, sequential and ordered. And that the final interpretation should provide some clear resolution to previously unanswered questions. Certainly in my own case, I set out with my research question clearly in my mind, the process hypothetically outlined and chronological. However, the social sciences deal with people, and people are confusing, contradictory and complex. That conundrum comes into play as soon as the interview process begins and participants bring their bodies, personalities and stories to hijack the neat and linear frame.

I embarked on this project operating through the paradoxical lenses of chronological age and professional youth, which has led to an experience which has been exciting, frightening, enlightening and confusing. I often felt inept and fraudulent regarding involving myself in a process that was so complex and layered, without, I felt, the necessary equipment to engage effectively and appropriately. However, at the end I am immensely grateful for having been given this opportunity for exploration and for the generosity of the participants in providing me with their rich and layered narratives. Most importantly I am cognisant that I was enabled by the personal and professional support provided by both clinical and academic supervision. Where I was inadequate, ignorant or inexperienced, I was able to access the guidance, proficiency and wisdom of individuals within my profession, through personal interaction as well as their research and writing.

On a personal level, the relevance of research to real life, the need to make it pertinent and to contribute is one that I hope I have achieved and experienced in an unexpected way. What ostensibly was an academic exercise has for me also been a deeply personal journey of exploration. I have had to re-evaluate myself on multiple levels – as a woman, as a person of privilege, as a clinician and as a novice academic.

During my first exposure to academia as a student in my late teens, much of what I studied could be compartmentalized into something outside of me: intellectual gymnastics and explorations that appeared to have little to do with either “real” life or myself. The surprise and delight I felt, when I started studying psychology in my early fifties, was connected with the exciting way in which it was so entwined with personal relationships, experience and ways of viewing and interacting with the world.

This research process brought me in contact with that world in ways that were not necessarily pleasant. There were times, as I sat at my laptop in the safety of my own home and secure, picturesque suburb, away from the noise, physical ugliness and limitations of my interview locale, that I cried with overwhelming anguish and experienced heart pain as somatic equivalence with my participants. The process of listening and transcribing interviews that I would ordinarily have left at work brought the stories into the sanctity of my home. I transcribed the words of devastated women who were ravaged by memories of abuse, violence and fear. I listened and typed as

mothers' disembodied voices described the aggression and disrespect of their children, particularly their sons. I shuddered as I listened to their halting words, and tear-imbued voices describing having to witness their families being decimated by the drug and gangster culture, while they were forced to stand at the side-lines feeling helpless. I tried to compare my own mothering experiences with that of these women attempting to be both mother and father to children growing up in a society where there is so often an absence of a supportive or functional father-figure.

However, in the final analysis, research is about adding to the knowledge base and finding new ways in which to engage with existing social dilemmas. I hope that I have achieved this to some degree. The final pages of my thesis will be devoted to suggestions and insights that have emerged out of the narratives I have been privileged to hear from my twenty participants and the contributing medical personnel.

## **5.2. SUMMARY OF FINDINGS, STUDY LIMITATIONS AND RECOMMENDATIONS**

In the first chapter of this thesis I introduced the ubiquitous presence of illness, physical pain and disability as an intrinsic part of the human condition. However, within this caveat, exists the subset of illness without apparent physical or organic cause. This particular category of bodily suffering has attached to it very different mechanisms of emotional experience and practical management. During the course of my research, through the eyes of a particular group of women, I considered how their specific experience of this process was viewed and articulated. While ostensibly exploring the physical and mental process of diagnosis, in fact on many levels, this research project engaged intimately with issues of isolation, marginalisation and exclusion.

Outside of the specific research considerations of diagnosis and lived experience, I have attempted to explore and discuss the enmeshment of various components: of the juxtaposition of research, clinical and therapeutic considerations; of poverty and deprivation existing cheek by jowl with privilege and wealth in a particular geographical, social and political amalgamation; of relationships and the way in which they modify responses and outcomes; and finally how personal experience



interacted with professional understanding. In short, as I said in the opening paragraph, this was not a simple academic research project in which data were collected, analysed and reported upon. It was simultaneously an intellectual examination of potential clinical importance as well as a deeply personal exploration of clinical, social and interpersonal issues which engaged with the data on multiple levels and in complex ways.

In this final chapter I will attempt to follow the advice of Silverman (2013) who cautions against using the conclusion as an opportunity to simply summarize the findings of the data analysis chapter. He suggests that a need to merely recapitulate the data in an abridged form is indicative of a failure of confidence in the structure and content of the previous chapter (Silverman, 2013). He offers the following suggestions in terms of formulating the final chapter in the service of connecting the specificities of the individual PhD process to broader research and academic considerations:

- To create a conceptual bridge between existing data on the subject and any new observations which have been obtained;
- To answer the question whether you, as the researcher, were offered the opportunity to begin again what, if anything, would you do differently and if so why;
- To suggest ways in which your research might have immediate or subsequent future implications for either policy or practice;
- Any possible implications for future research endeavours in the field.

I hope to use this final chapter to cover these considerations both clearly and succinctly in the format suggested by Silverman (2013).

### **5.2.1. The bridge between existing information and new observations**

*There is nothing new under the sun.*

#### **Ecclesiastes 1:4-11**

I began my first chapter with the reminder that medically unexplained symptoms – under whatever terminology they are categorized or described – have been with us since time immemorial. There is a great deal of extant literature and research written

and published about this subject. Consequently, there were periods where I doubted whether my research had the potential to add in any way to the reservoir of knowledge which had already been accumulated on the subject.

However, while there may putatively be nothing “new” under the sun or in the arena of academic exploration, each particular configuration of events, interactions and relationship has the potential to provide unique perspectives. While international literature has described the experiences and interactions of patients presenting with medically unexplained symptoms or somatic symptom disorder, the participants in my study were distinctive in the context of place, race, economics and gender. The patient population from whom I drew my participants are historically notable for being marginalised and rendered invisible on multiple levels. South Africa is a country with a shameful history of racial discrimination. It is also a nation steeped in patriarchy and patriarchal practices. Attached to these two larger issues are the broader but equally pervasive influences of education, economics and the associated delegation of power. My participants embodied vulnerability on every one of these levels.

On average, the participants’ level of education (with 25% or five of the twenty participants having completed schooling) was slightly lower than the South African national average of just under 28.4% (UNISA, 2011). Fifteen out of the twenty participants were unemployed (75%) and fifteen out of the twenty participants (75%) were legally single (two had a partner with whom they lived), divorced or in the process of divorcing. All the participants in the study were women of colour, identified within the South African system of racial categorisation as Coloured or Black. International figures indicate that single, poorly educated and unemployed women are particularly at risk for both physical and mental health pathologies (Fels Smyth et al., 2006; L. Smith, 2010; Ussher, 2013). While the broader international literature may give consideration to the additional challenge presented when race is factored into any equation, South Africa has the dubious privilege of being at the forefront of entrenched racial discrimination which crosses all aspects of society. This too has been described particularly in the context of mental health provision, but is of particular importance in the African context and related to mental health provision (C. Smith et al., 2013; L. Swartz et al., 2002). The participants and their narratives also presented lived evidence of the national economic disparity which places South

Africa at the forefront of global inequality (World Bank, 2011). Poverty is not new, neither is gendered violence and inequality, or social isolation. However, the narratives presented by the participants are rendered unique by the particular configuration of vulnerability and marginalisation. The participants, and the patient population they represent, are largely invisible. Situated geographically on the outskirts of a large city, they emblematised the aesthetic “picturesque” described so eloquently by Baderon (2014) in her analysis of artistic representation of life in the Cape where poor people of colour are both physically and symbolically moved to the margins of society in this country. She describes the paintings and etchings which depict the early European settlement in the Cape Colony. While the input of the slave population was pivotal in the running of the colony – both in the domestic as well as farming capacities – in all pictorial representations this section of the population is placed in colourful traditional and picturesque clothing on the extreme outskirts of the paintings and by default of the central focus of the painting.

If I were to summarise the way in which my research has added to existing data I would frame it as possibly highlighting existing literature in a way that emphasizes the unique situation which operates in South Africa and foregrounds the similarities and discrepancies which exist for the patient with medically unexplained symptoms in this particular configuration of economic, social and political issues:

- Poverty has been extensively described in international literature and has been investigated within the South African research community, but not in the particular population group which provided my participants;
- Responses to trauma and violence have been examined. However, most investigation and results focus on post-traumatic stress disorder (PTSD) and not on somatic responses;
- Medically unexplained symptoms have been explored and examined in the literature for decades, but not from the perspectives of a group of poor, South African women;
- Grief and bereavement as a reactive emotional processes have been both normalized and pathologised but relatively little focus has been placed on the possibility of somatic responses;
- The disenfranchisement of and social violence and vindictiveness towards

women in general, and poor women in particular, have been the subject of a great deal of investigation and subsequent literature. However, no particular concern is connected to women attempting to access the healthcare system with medically unexplained symptoms;

- The participants in my study may have the potential to be representative of a group of individuals in society who symbolically enact the function of the “aberrant villager” described by Rhodes (1995). Through their determined presentation in hospital situation, these patients challenge professional and organizational “taken for granted” stances on what constitutes illness, both mental and physical, and good healthcare provision.

While the suspicion that the “nothing new” concept may encompass failure to provide definitive or novel academic data, this research may have generated helpful insights in terms of professional functioning. In the context of my own attempt to conduct research in a clinical setting, I was given new insights into my own performance on multiple levels. Very little has been written about the dual roles of providing therapeutic services alongside research, and particularly the challenges presented with psychology and the emphasis on the sanctity of therapeutic space. My own experience of honing my clinical skills through juxtaposing collecting data and rendering therapy has the potential to add to the existing database in terms of my own profession. In the words of S. Swartz (2007):

Traditionally, clinicians complain that clinical research does not speak to the complexity of their environments; and clinical researchers feel that clinicians are sluggishly responsive to research findings. A . . . research agenda might tease out the complexity of this relationship, particularly its gender ramifications. (p. 180)

I will discuss the potential for taking my research beyond the confines of my own research question in the final section

### **5.2.2. If I could begin again**

There have been innumerable occasions when I have wished I could start this research process all over again. Frequently I regretted that I had ever embarked on the doctoral research journey at all. At each stage I realised how limited my knowledge was, how

much I had to learn and how helpful that knowledge would have been at the beginning of the process.

Throughout the respective stages I have periodically reflected on ways in which I could have done things differently: more effectively, more dexterously, and more professionally. At the end of the day I realised, through the wise input of my supervisor, that the very process of doing a doctoral degree is both iterative and didactic. Initially my knowledge of the research process was limited to the projects associated with my Honours and Masters degrees. I therefore had no background in research beyond the rudimentary. I was not sufficiently experienced to anticipate the development of unplanned situations or responses. I had limited hands-on knowledge or experience of the mechanics of collecting and transcribing data or mechanisms to approach analysis beyond a purely theoretical understanding. However, through access to support and, most importantly, by making mistakes and taking wrong turns, I developed the ability to reassess and adapt as a professional tool – in both clinical and research work.

Possibly the issue which concerned me most was the practical and ethical dexterity with which I needed to balance clinical and research work. I have discussed at the end of section 5.2.1. the potential for valuable information that this process initiated. However, it was extraordinarily difficult to manage. If I had to begin again, given that there was the option of separating the research process from the clinical component, I am not sure whether I would repeat this complex and combined process. It generated an enormous amount of data which made the analysis difficult and unwieldy. It created confusion in my mind, and perhaps in the participants' perceptions, about my role. It also translated into difficulties in separating data into appropriate research categories. Yet given the same set of circumstances, I do not believe that I would choose to sacrifice providing clinical services to ease the research burden. The reality of this particular project, as I have discussed in the introduction, is that with the limited resources available, and the absence of a colleague to whom I could refer participants, exclusion of the clinical component would have had a negative impact on the opportunity of the individuals to access psychological care. And, ironically, in the final analysis, this factor that troubled me most potentially resulted in data that was richer, rounder and provided greater perspective than if I had been able to be

“research exclusive”.

I did consider the possibility of triangulating data collection through the introduction of such quantitative methodologies as questionnaires. However, while pragmatically this may have provided more easily accessible data, the essentially phenomenological emphasis of my study generated the kind of data which is so intrinsic to my discipline. The discipline underwriting my research is psychology. Clinical psychological practice encompasses the assessment, diagnosis and treatment of serious mental conditions. Such a basic definition fails to capture the richness, complexity and humanity of the work. A psychologist whose professional expertise I admire recently replied to a question about what she did for a living, “I am privileged to listen to the stories of peoples’ lives, the hidden and concealed narratives which, until they are revealed to me, may never have seen the light, and provide relief and healing.” Hearing this reminded me of the words of a song:

Ring the bells that still can ring  
Forget your perfect offering  
There is a crack in everything  
That's how the light gets in.

**Leonard Cohen: “Anthem”**

Although I contemplated alternatives, the very imperfection of the process, of attempting to combine clinical work within the research process, enabled a mechanism whereby I was able to conduct and view my project through two lenses and thereby to facilitate the access to light on different levels. In the final analysis, this decision enriched my data and allowed me to hold to the ethical tenants of my profession and provide a service. I must conclude therefore, that retrospectively, I would not have changed anything in respect of the dual interaction and data collection with regard to my patient participants.

I do, however, regret that I was unable to incorporate the data I collected from the medical officers. The huge amount of patient-related data made this impossible but I plan to utilize the contributions made by the doctors in a subsequent paper.

### 5.2.3. Practical and theoretical future implications

In the final analysis research is about adding to the knowledge base and, in research connected to the social sciences, finding new ways in which to engage with existing societal dilemmas. In this regard, I would like to briefly innumerate aspects of my research which illuminated possible areas of future enquiry. The final pages of my thesis will be devoted to suggestions and insights that have emerged out of the narratives I have been privileged to hear from my twenty participants as well as the contributing medical personnel.

#### 5.2.3.1. Community education

A central consideration, and an ongoing aspect of clinical work, was foregrounded by the research. This was a growing realization that as psychologists we need to find ways to educate our communities about the function, role and value of our profession. With the very rare exception, both during my research as well as in my clinical work in the hospitals in the communities, a good proportion of the first intake session is taken up with trying to explain to sometimes bemused, often angry, hostile and resentful patients, just exactly what we as psychologists do and how it has the potential to help ameliorate their distress. And that is with the patients who arrive. Many refuse outright to attend, in an admirable but, in my view, misplaced demonstration of autonomy and independence. Others play into the passive patient role, ostensibly accepting the referral from the omnipotent doctor but obdurately avoiding coming to that essential first therapeutic session.

The consequence of this ignorance and avoidance can have devastating results. One of the most poignant comments was made by one of the research participants, **Nomsa**, who recognized that the need to talk about and engage with interpsychic issues was foreign to her community. A community ravaged by violence, poverty and endemic HIV/AIDS she said, “My people are dying. Silent”. This is a personal reflection echoing the professional words of S. Swartz (2011) who, in exploring the impact that our racialized past and intercultural incomprehension has on our professional interaction, suggests:

Often there is no encounter: the majority of South Africans do not, would not, seek psychotherapy, even if it were available. (p. 179)

I would however, challenge this with the suggestion that the “availability” of psychology is not entirely the issue for consideration. It is also the understanding, or lack thereof, of what psychology is and purports to do which is a greater or at least an equivalent stumbling block to access and utilisation. There is a practical difference between the hypothetical availability of psychology and an understanding of the way in which the discipline operates, and its potential to be inclusive across racial, cultural and socio-economic divides in the “deeply African hybridization” that S. Swartz (2011) mentions. Further research in this regard would be helpful in finding ways in which to make access both possible and desired in the communities in South Africa who would benefit from psychological interventions.

In considering potential ways to implement greater patient understanding and therefore engagement with the therapeutic process, I have considered the possibility of formulating an information leaflet outlining the aims, process and advantages of psychological intervention which doctors could hand to patients at the time of referral. It may also be a consideration to provide information regarding the way in which stress may be reflected in the body which would assist patients in negotiating an acceptance of their somatic symptoms diagnosis.

#### **5.2.3.2. Potential for cooperation and integration**

Considerations of race have been alluded to. With its lengthy racialized history, very little activity in South Africa is undertaken without some kind of overt or covert racial implication or influence. Adding to the complexity of race are considerations of cultural difference and alternative practice. While outside the ambit of this research, considerations of inclusion and exclusion extend to ways in which traditional healthcare practices may be accommodated within the Western model and vice versa.

Psychology is essentially a discipline which has its roots in Europe and North America. Following on from 5.2.3.1., I would emphasise that misunderstanding had the effect of diminishing utilisation and efficacy. The participants in my research, as well as the patients in the community, who had been exposed to psychology, either through education or personal experience, were the ones most willing to take the leap of faith and come to the first session with an open mind and a sense of possibility. Those patients who arrive and are willing to suspend suspicion and hostility are often



the ones who are most able to utilise the opportunity, even when their cultural background may superficially appear different. The possibility to explore ways in which to accommodate professional practices in the best interests of the patients was articulated by one of my participants.

**Joy**, the patient-participant interviewed retrospectively, described how she had attempted to integrate elements of her own psychotherapy into her management of her clients in her traditional practice:

“Some of the things (.2) you, you *do*, for example in my case, with *you*. Some of the things you, we talked about and you helped me with, are, are the same with the things I tell my people, my clients, yes. [Okay] . . . Yes! And then I tried, if I tried to explain some condition with my client, I *mix* with these ideas I had from you [Okay] Yes. So I think it's the same thing but we differ (.2) in the ways of putting it, ja.”

She also illustrated how good healthcare provides opportunities to share knowledge and expertise within our multi-cultural society. In dealing with a client with HIV/AIDS who presented at the traditional practice, her sister, the senior healer, identified that he was too ill to be managed in their practice and immediately took him to the local hospital:

“*Yes!* [Laughs] We took him *there!* [Names a local hospital] Ow, the staff, the staff was (.2) they were mixed Coloureds, Whites and (1) isiXhosa. But then again the doctors and nurses were friendly. Ja (.2) And even the doctor who was treating him, phoned my sister, to come and my sister told me that they share some notes on what my sister was doing to the patients. . . . And, and that doctor (.2) I think he liked my sister because she, when he told her about this patient's condition, HIV, my sister was (.3) she, she told the doctor, she understands this doctor. She explained to him every step of it and then she end up telling him she *knows* about this thing because we had someone in the family who had HIV. So we know how to treat people with it. So the doctor says, “Ag [clicks tongue] you are a *doctor* [Laughs]”.

While it would be naïve to ignore the well-publicized incidents of harm done in the name of alternative medicines, the kind of relationships described here are far more

likely to engender an inclusive, beneficial and cohesive healthcare system for the population of this country. Further research into the existence of, or potential for, respectful and empirical ways of fostering this relationship could be of great value. Exploration of the way in which the “talking cure” could be accommodated in other cultural contexts where the verbal sharing of problems is not foregrounded could provide an exciting opportunity for investigation.

### **5.2.3.3. Fostering inter-disciplinary relationships**

As mentioned in Chapter Four, the healthcare system in South Africa is one which is stratified largely by discipline and a hierarchy of perceived importance. While not the focus of my research, the benefits of interdisciplinary respect and understanding emerged strongly.

Psychologists need to become more proactive in advocating for their profession within the pyramid of health provision. In my interviews with the medical doctors, it was with those with whom a good personal and professional relationship had been established that I got my most thoughtful and sympathetic response and interesting data.

At Hope Hospital I worked in the outpatients department for 18 months. During that period three of the four permanent medical officers remained unchanged. This facilitated good communication on all levels. Because the association was a stable and ongoing one, the relationship promoted ongoing discussion and reflection in the process of patient referral. The doctors discussed potential referrals with me; I gave them feedback about my intervention with the patients. This reciprocal communication carried through into the research process.

All of the doctors interviewed at Hope Hospital indicated that they appreciated feedback during the clinical process and all signified that they would be interested in hearing about the final outcome of the research. Several mentioned that this was more on the basis of our personal and professional relationship than out of any particular interest in the topic I was researching.

At Waterstroom Hospital, only one of the two doctors I interviewed was interested in feedback. We had worked together at Hope Hospital and again his response was

largely based on our personal relationship. The second doctor interviewed was not particularly enthusiastic about feedback although this may have been a function of the type of patient I was researching. She acknowledged that she found somatoform patients difficult and irritating, as reflected in the literature on medical attitudes towards patients with medically unexplained symptoms.

Thus in both research locales, personal relationship or interdisciplinary cooperation was influential in management of patients and in willingness to participate in the research project. Further examination of this relational aspect of interdisciplinary cooperation might have the potential to promote improved patient management.

#### **5.2.3.4. Professional flexibility and consideration of alternatives**

Perhaps as health professionals' psychologists need to negotiate a less rigid approach in the service of the "best interests of the patient". Our total potential patient population here at the tip of Africa encompasses a spectrum as broad as there are categories of people and nuances of humanity. However, statistically, within so-called community healthcare work, the majority of patients are psychology naïve and vulnerable. To rigidly adhere to systems developed within a different socio-political context, so outside of the ambit of many of South African people, is helpful to neither the professional nor the patient. It creates the potential for significant misunderstanding and anxiety.

We also need to move out of the artificial and unhelpful restraints of assumption. I attended a colloquium on community psychology at the Stellenbosch Psychology Department during the course of last year (2014). At the end of the presentation, the visiting foreign clinicians disclosed a developing trend in their country for psychologists to visit patients and conduct sessions in their homes. There was a collective gasp of horror and professional disapproval of this threat to "the frame". One might be forgiven for jumping to the conclusion that these foreigners were from further north in Africa or another Third World country where such professional deviation might be more comprehensible and forgivable. However, the contingent was visiting from one of the most efficient and sophisticated First World countries in the world: Norway. I left the presentation asking myself how much we could learn from our visiting guests within the context of our own divided society. How much

could it add to our understanding of our patients if we were to view them in the social space that informs their physical and mental health? S. Swartz (2011) highlights that the majority of qualified clinicians cannot conceptualize a life lived without basic services such as electricity and running water. I am cognisant of the fact that, despite exposure to domestic living conditions in poor areas from my previous work as a nurse in the community, I retain an unfortunate tendency to make assumptions based on my own life situation. With the best intentions in the world, this ignorance can promote the kind of microaggression described in the literature (L. Smith, 2005, 2009; L. Smith et al., 2012; L. Smith, Mao, & Deshpande, in press). Perhaps the opportunity to remind myself, or for other professionals to be exposed and sensitised to the lived experience of our patients, would be infinitely helpful to the therapeutic process. The possibility of exploring more context-sensitive services opens up the potential for exciting future research.

In “re-newing” old information, this research has the potential to facilitate re-examination of untenable but unseen circumstances. The communities in which these women live are characterised by violence, crime and scarcity. Privacy and opportunities to disclose personal exchanges are limited. Like many psychologists doing community work I have needed to function professionally in suboptimal conditions and around physical limitations in the context of our places of employment. I have sat in storage cupboards doing assessments for suicidality; I have conducted therapy in rooms providing a spurious sense of privacy with curtains functioning as doors. I have wrestled with consuming my lunch or drinking coffee between sessions knowing that the next patient may not have eaten that day.

Many of my colleagues wrestle with the same challenges in performing their functions within the ethical and disciplinary boundaries of their professions. Many of us, in the words of Theodore Roosevelt, “Do what you can, with what you have, where you are.” Further exploration of alternative ways of engaging with implementing service could assist us and our patients in forging more effective collaborations in the service of health provision.

### **5.3. CONCLUSION: THE GOLDEN THREAD**

Much is made of the concept of the “Golden Thread”, the central theme that must

traverse the length of the research from inception to conclusion. I confess that in conducting and writing up my research I was frequently drawn by fascinating asides and tempted into abandoning, or at least losing sight of, the golden thread. I have found it difficult to adhere to that injunction as my data periodically took me off in directions only peripherally related to my research question. However, while I was guided back to the research question through supervision, I continued to believe that, as appealing as it may be to hold onto the security of this fundamental ingredient, the willingness to engage with the unexpected and idiosyncratic can add to the richness in the same way that colour complements and enriches a tapestry. Within qualitative research the unexpected which might emerge within participant narratives can add immeasurably to the depth and breadth of the data. Henning et al. (2005) emphasize the fine balance between planning research with a clearly delineated focus while simultaneously being available to make adaptations or adjustments to the original plan.

In my research, while I felt it was important to acknowledge and incorporate the richness of unexpected insights and information provided by the data, I have attempted to maintain my focus on the golden thread: the patient-participant narratives and experiences as they were exposed to the process of moving through the hospital system until they ultimately were referred to, and engaged with, psychology.

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## APPENDIX A

### Participant Demographic Questions

#### Socio-demographic Questions:

1. Age: \_\_\_\_\_
2. First Language: \_\_\_\_\_
3. Marital/relationship Status:
  - Married \_\_\_\_\_
  - Live-in partner \_\_\_\_\_
  - Separated \_\_\_\_\_
  - Divorced \_\_\_\_\_
  - Widowed \_\_\_\_\_
4. Education:
  - Primary School – highest grade passed: \_\_\_\_\_
  - Senior School – highest grade passed: \_\_\_\_\_
  - Tertiary Education: \_\_\_\_\_
5. Does participant work for an income:  
No   
If yes:   
What kind of work: \_\_\_\_\_  
Within the home or outside: \_\_\_\_\_
6. Monthly household Income: \_\_\_\_\_
7. Number of children: \_\_\_\_\_  
Ages: 0-5: \_\_\_\_\_  
6-12: \_\_\_\_\_  
12-18: \_\_\_\_\_  
Older: \_\_\_\_\_
8. Number of children living at home: \_\_\_\_\_
9. Ages: 0-5: \_\_\_\_\_
10. 6-12: \_\_\_\_\_
11. 12-18: \_\_\_\_\_
12. Older: \_\_\_\_\_
13. Housing:  
House: \_\_\_\_\_  
Flat: \_\_\_\_\_  
Rented: \_\_\_\_\_  
Owned: \_\_\_\_\_

## APPENDIX B

### Participant Questions

#### **Clinical Interview Questions Focusing on the Experience of Receiving a Somatoform Diagnosis**

*While the proposed questions will provide some structure, it is anticipated that in line with the guidelines for open-ending interviews (Bless, Higson-Smith, & Kagee, 2006; Henning, 2005; Smit, 2008) the interviewer will intrude as little as possible, allowing the participants to articulate their experiences freely. The researcher will attempt to fully cover the topics below, but the order of questions may differ and not all of the stated questions may require overt asking.*

#### **1. Current signs and symptoms:**

Good morning Ms. X. In our first meeting I explained why I will be talking to you today. You were referred to me by Dr. X. You originally came to the hospital for help.

- May I ask you to describe the symptoms that brought you to see the doctor?
  
- May I ask how you are experiencing these symptoms today? *(It will be important not to indicate any opinion on the validity of these physical symptoms of pain and discomfort, but to provide an empathetic listening space where the patient can clearly state their experience of their physical condition. While questions to clarify symptoms or reactions to them may be asked, no leading questions should direct the process of the patient's narrative.)*
  
- Do these physical feelings impact on your daily activities and relationship?  
*(If no):*
  - How do you cope when you are experiencing pain or feeling unwell?
  - When was the pain/discomfort really bad?
  - Do you talk about these problems with other people – your family or friends?*(If yes):*
  - How long have you had this pain/discomfort?
  - When did you decide to come to the doctor for help?
  - In what way has the pain/discomfort impacted on your activities and/or relationship?
  
- Are you receiving any medication for these physical symptoms? Do you feel that they are helping you?

**2. First contact with medical profession in respect of presenting problem:**

I'd like you to try and remember when you first went to a doctor to tell him/her about this pain/discomfort

- Can you remember what tests he/she did?
- How long did this take (weeks, months)?
- How did you experience going for all these tests?
- What did the doctor tell you when he/she had all the results?
- What further action did he take (further tests, referral to other medical practitioners)?
- How did you feel when the doctor told you that he/she could find nothing wrong?
- When did this happen?

**3. First referral to psychology:**

I want you to try and think back to the first time it was suggested that you come and see a psychologist.

- Who made the suggestion?
- When was this?
- How did you feel about this?
- Did the doctor/medical person explain why he/she was making this referral?
- What did you understand by this referral?
- How did you feel about coming to see a psychologist?
- How do you understand the kind of work a psychologist does?
- How do you feel about it now?

**4. Prior to the first experience of the particular symptoms of pain/discomfort:**

I'd like you to think back to the first time you had this (use patients words from question 1):

- Can you describe what was happening in your life at that time?
- Can you remember any changes that might have been happening then?
- What emotions do you remember feeling at the time?
- What were your thoughts about this pain/discomfort?
- Before you came to the hospital, did you speak to anyone about this pain/discomfort? (*Avoiding leading questions, an attempt will be made to establish the patients' mechanism of help-seeking behaviour. What interpersonal resources they utilise in times of physical and psychological distress.*)

*Without an attempt to lead the patient, the researcher will endeavor to ascertain whether the participant is able to theorize in any way in respect of linking the emotional, psychological environment with precipitation of physical symptoms.*

**5. Reasons for the medically unexplained symptoms:**

I'd like you to think about each time you get this pain/discomfort (using patients own descriptions from question 1) and try and think of anything that might be happening in your life at those times. Can you think of times when the pain/discomfort is worse? When it is better? (*With empathy and respect and the utilization of appropriate, non-leading prompts, attempt to elicit the patient's own explanation for the symptoms*).

**6. Personal and community reactions/resources:**

When you are suffering from the pain, who were the people around you who you were able to turn to? What do they think that the doctors can find no reason for your pain/discomfort? What did they say when you told them you were being sent to see a psychologist? (*An attempt will be made to establish the wider context and narrative in which this referral is viewed and the way in which it might have impact on the patients feelings, responses and expectations*).

**7. Impact on life:**

What effect does your pain/discomfort have on your life?

- Ability to work;
- You relationship with family and friends;
- The way you feel about yourself.

How do you think that coming to see a psychologist might help change this?

**8. Closure:**

Thank you so much for spending this time talking to me about your experiences of your pain/discomfort and what happened when you came to the hospital for help. It might have been difficult for you. How do you feel about it now? Are you feeling calm enough to continue with your day or would you like to spend a few more minutes talking about how you feel?

*(Depending on the patient's mental state, the patient/participant will continue with therapy on an ongoing basis. They will be given a follow-up appointment as well as hospital contact details should they become distressed on leaving the session. For those participants who feel they have no need of immediate follow-up, the contact details will also be supplied to facilitate help-seeking from psychological services should this become necessary at a later stage.)*

## APPENDIX C

### Ethical Approval

#### Appendix C: Ethical Clearance



UNIVERSITEIT-STELLENBOSCH-UNIVERSITY  
UNIVERSITY OF STellenbosch

#### Approval Notice New Application

02-Oct-2012  
Cowlin, Avril AM

Ethics Reference #: S12/08/218

\* Title: A feminist social constructionist study of low income South African womens experience of receiving a Somatoform diagnosis

Dear Mrs. Avril Cowlin,

The New Application received on 17-Aug-2012, was reviewed by members of Health Research Ethics Committee 1 via Expedited review procedures on 28-Sep-2012 and was approved.

Please note the following information about your approved research protocol:

Protocol Approval Period: 28-Sep-2012 -28-Sep-2013

Please remember to use your **protocol number** (S12/08/218) on any documents or correspondence with the HREC concerning your research protocol.

Please note that the HREC has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

#### After Ethical Review:

Please note a template of the progress report is obtainable on [www.sun.ac.za/rds](http://www.sun.ac.za/rds) and should be submitted to the Committee before the year has expired.

The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly for an external audit.

Translation of the consent document to the language applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372

Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

#### **Provincial and City of Cape Town Approval**

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health ([healthres@pgwc.gov.za](mailto:healthres@pgwc.gov.za) Tel: +27 21 483 9907) and Dr Helene Visser at City Health ([Helene.Visser@capetown.gov.za](mailto:Helene.Visser@capetown.gov.za) Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

We wish you the best as you conduct your research.

For standard HREC forms and documents please visit: [www.sun.ac.za/rds](http://www.sun.ac.za/rds)

If you have any questions or need further help, please contact the HREC office at 0219389657.

#### **Included Documents:**

Synopsis  
Checklist  
Consent Form  
Investigators declaration  
Protocol  
Application Form

Sincerely,

Franklin Weber  
HREC Coordinator

**NOTE:** During the formulation of the initial research proposal the working title presented on the Ethics Clearance Notice was used as a possible format in which to frame the process. However, as the research interviews progressed and the study developed, together with input from my supervisor, I felt that the narrative quality of the study seemed to be foregrounded as the central focus and consequently changed the title and emphasis to the one under which the thesis is now presented.

## Appendix D

### Informed Consent Form

#### PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

##### TITLE OF THE RESEARCH PROJECT:

*“Does the doctor think I’m Crazy?”: Stories of low-income Cape Town women receiving a diagnosis of somatic symptom disorder and their subsequent referral to psychological services.*

**REFERENCE NUMBER: S12/08/218**

**PRINCIPAL INVESTIGATOR:** Avril Cowlin

**ADDRESS:** 2 The Hague, Tamboerskloof Road, Tamboerskloof, Cape Town, 8001.

**CONTACT NUMBER:** 082 8073449

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask Avril Cowlin any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are free to withdraw from the study at any point, even if you originally do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

##### **What is this research study all about?**

- The study will be conducted in the psychology offices at Eerste River Hospital, Eerste River and G.F. Jooste Hospital in Manenberg, Cape Town.
- It is expected that approximately 20 participants will be recruited for this study.
- The project aims to record the thoughts and feelings of women like you, who have been diagnosed with a somatoform disorder (physical pain or discomfort for which the doctors can find no underlying cause).
- I would like to understand how it feels to be referred to psychology when the original reason for seeking help was for a physical complaint. I would like to obtain this information specifically from you as a woman.
- The “study” will consist of normal therapeutic interview/discussions between you and me. We will focus specifically on your experience of being sent to see a psychologist by the doctor to whom you went for help with physical complaints. Our discussions will be recorded on a digital voice-recorder.

- I will then listen to and transcribe (write down in words what was said during) the sessions.
- Finally, I will compare all of the discussions I have had with each participant. I will look for contrasting and recurring themes in how women who find that there is no medical cause for their physical complaints understand and make sense of their experiences. I will document my findings in the form of academic research.

At all times the identity of each participant will be kept anonymous, as I will use pseudo names. You may choose a fake or false name by which you will be known in my research.

No randomization process will be used in this study.

Medication will not be used or prescribed as part of this study, but participants may be referred to an outside person for medication.

**Women who are eligible to take part in this study must:**

- Be at least 18 years of age
- Be able to understand and speak English and/or Afrikaans
- Have physical symptoms of pain and/or discomfort for which they have sought medical assistance and for which no underlying cause has been found
- Have low/no-income
- Be willing to participate in this study by agreeing to have their therapy sessions recorded and used for academic purposes

**Why have you been invited to participate?**

You have been invited to participate in this study because:

- You are 18 years of age or older
- You can speak English and/or Afrikaans
- You are a woman who has experienced physical symptoms of pain and/or discomfort for which there is no apparent medical cause
- You have referred for therapy with a psychologist by a medical doctor
- You fit the income bracket for this study (you have low/no financial income)

**What will your responsibilities be?**

It is your responsibility to answer the questions about your experience of finding that there is no medical cause for your physical problems with honesty and as much detail as possible. However, you are also free to *not* answer any question that makes you feel uncomfortable.

Although I will do my best to ensure you understand the details or questions contained in this study, it is also your responsibility to ask for clarification if you do not understand something.

You may ask me to stop recording our discussion at any time. If you choose to withdraw from the study and have your records destroyed, you may still continue with therapy.

**Will you benefit from taking part in this research?**

There will be no financial benefits to taking part in this research.

Many women feel better once they have spoken about their feelings after they find out there is no medical reason for their physical pain and/or discomfort.



By allowing me to publish the information from our discussion about your experiences, other people might gain a better understanding of what it is like for women in your position. This may lead to better management of the referral to psychology by the medical profession in the future.

**Are there risks involved in your taking part in this research?**

Talking about your experiences of being told that your pain has no physical cause might be emotionally difficult for you, as an unexpected referral to psychology may be a confusing and distressing experience. You might start to cry or feel vulnerable when talking about your feelings.

If you feel that you need extra emotional support after our discussion hour, I will schedule a follow-up session or refer you for extra care.

**If you do not agree to take part, what alternatives do you have?**

You may choose any one of the following options:

- 1) You can choose not to enter therapy with me.
- 2) You can choose to enter therapy with me, and our sessions will not be recorded or used for research.
- 3) You can choose to enter therapy with me, and our sessions will be recorded and used for research.

**Who will have access to your medical records?**

Only I and the psychologist at G.F. Jooste will have access to your medical records. The information collected during our sessions will be treated as confidential and protected under password on my private computer.

When I publish the results of this study (my thesis, articles, book or presentation at a conference), all names will be changed so that your identity will remain anonymous (your real name will not be used).

My supervisor and all interested parties will be able to read the finished article/thesis.

**What will happen in the unlikely event of some form of injury occurring as a direct result of your taking part in this research study?**

In the extremely unlikely event that you are injured as a direct result of taking part in this research, you will be referred back to the medical staff at the hospital (Eerste River or G.F. Jooste) for emergency medical attention. (Standard government clinic emergency protocol will be followed.)

**Will you be paid to take part in this study and are there any costs involved?**

You will not be paid to take part in the study.

If you do take part in the study, there will be no costs involved for you. I will therefore pay your transport costs to and from the hospital for our session(s).

**Is there anything else that you should know or do?**

It is very important that you understand that you have the right to decide whether or not you will participate in this study.

You do not have to have your discussion with me (Avril Cowlin) recorded if you do not want to.

You may change your mind and cancel the recording of the session at any time, with no repercussions.

Whether you participate in this study or not will not affect any of your future treatment or access to services.

You can contact the Health Research Ethics Committee at 021-9389207 if you have any concerns or complaints that have not been adequately addressed here. You may also call the study Supervisor, Professor Swartz at: 021 8083461

You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ..... agree to take part in a research study entitled

*“Does the doctor think I’m Crazy?”: Stories of low-income Cape Town women receiving a diagnosis of somatic symptom disorder and their subsequent referral to psychological services.*

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is voluntary and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ..... on (*date*) .....  
2011.

.....  
Signature of participant

.....  
Signature of witness

**Declaration by investigator**

I (*name*) ..... declare that:

- I explained the information in this document to .....
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.

Signed at (*place*) ..... on (*date*) .....  
2011.

.....  
Signature of investigator

.....  
Signature of witness

## APPENDIX E

### Patient Participant Biographical Notes

In the service of providing the reader with an appreciation and sense of the participants in my study I have provided short biographical notes in the following section. I have presented them in the order in which I interviewed the participants from the period beginning November 2013 until the final research interview.

However, with the variability of interaction – from a single intake interview to therapeutic sessions for periods of more than a year – I was left with greater knowledge and insight into the narratives of some of the participants.

Once again the duality of my role impinged, but not necessarily in a negative way. I learned a great deal about the lives of those of my participants who continued to see me beyond the initial research orientated appointment – infinitely more than would be expected in a formal, prescribed single semi-structured research interview. The constraints imposed by an interview with a single purpose – to elicit data on a specific subject – are removed in the therapeutic relationship. When the participants were the focus of interest, in and of themselves, rather than as a source of information, a subtle shift occurred in the dyadic relationship and interaction. Information was volunteered, and which while not superficially related to the question in hand, i.e., their experience of receiving a diagnosis of MUS, added depth and nuances to my understanding of the world in which they lived and the way in which this might have contributed to their symptoms and their management of them.

While this created a large and unwieldy burden of data to be considered and analysed, it certainly provided me with a depth and richness that I could not have otherwise obtained. The following vignettes only skim the surface of the respective narratives but their function is to situate the participants within the place, family and society in which their stories are embedded. Some of the biographical notes are longer than others. This is a result of the different number of interviews the participants' each had, largely dependent on whether or not they progressed to a therapeutic relationship.

## **1. Raabia (37)**

Raabia was the first participant enrolled on my study. She came to see me as a consequence of a referral from the outpatients department at Hope Hospital. I am not sure which of us was more apprehensive. She was overtly nervous on entering the room. She had no previous experience of psychology and freely admitted that she was slightly confused by the referral. In addition, of all the participants, she was the one who was most uneasy about the issue of confidentiality, requiring a second explanation of the process at her subsequent visit and repeating on several different occasions during my two interviews, “I don’t want trouble.”

Raabia was 37 years old but her age would have been difficult to determine, as she was clothed in hijab [traditional Muslim headscarf and dress], with only her face and hands showing. I particularly noticed her hands as she spent most of each interview moving, twisting and clenching them in ways that indicated her anxiety. She was, as her clothing indicated, a devout Muslim whose life revolved almost entirely around her family, domestic activities such as cooking and cleaning, and religious observance. She was the mother of two children, a son of sixteen and a daughter of twelve. She lived in close proximity to her family of origin who she saw on a daily basis.

Although she had done well at school, passing every grade, she left at the end of Grade 10 in order to go to work and supplement her family income. She had worked in several factories in the clothing industry and talked fondly of her colleagues and the experience of working. At the time I saw her she was unemployed and had been at home since the birth of her first child. She married at 20, to her first boyfriend. She had no prior dating or sexual experience. She had been married for seventeen years but her marital status was in jeopardy at the time of her first interview. She was in the process of receiving “Taraq” [a formalized period of separation] from her husband as a consequence of her refusal to accept his decision to marry a second wife. The inevitable outcome at the time I saw Raabia appeared to be divorce. Her husband was determined on his course of action and Raabia was adamant that their marriage would have to be terminated first. In her implacable decision an interesting paradox played out in the form of balancing acquiescence to the tenets of her faith but simultaneously drawing on an internal locus of strength to maintain a personal principle.

A not inconsiderable part of the time spent with Raabia involved discussion of her religion, its meaning to her and her explanations to me as a non-Muslim. At the time she was living in the family home with her children, and according to Islamic law, while under Taraq was not permitted to socialize or have any contact across the gender bar. Her visits to me for our two interviews constituted virtually the only contact outside her home or immediate family that she had. As mentioned in my introductory paragraph, the transition from a relationship based on exclusively research orientated interviews, to one in which there was space for the participant to speak without constraints, added dimension to my understanding. For Raabia, her religion was a pivotal and grounding feature of her life. Her relationship with me was mediated positively by the opportunity to “educate” me about something so important to her and about which I was prepared to acknowledge my own ignorance. It provided a mechanism whereby the potential power disparity was to some degree moderated and equalised and thereby added to the possibility of genuine interpersonal engagement.

The only medical condition from which Raabia suffered was psoriasis [a chronic but fluctuating immune-mediated skin condition characterised by red, scaly and itchy skin], which she had developed seventeen years previously, at almost the same time as she got married. In a throwaway remark I almost missed, Raabia acknowledged her husband’s serial infidelity from almost the first year of their marriage. We never discussed or explored the virtually simultaneous eruption of her skin condition with the advent of her married life.

A few months prior to her referral to me, Raabia had presented to Hope Hospital with thoracic back pain which had initially been investigated in the orthopaedic clinic and then referred to outpatients when there was no diagnostic support for her symptoms. The investigations by the attending medical officer in outpatients included a battery of blood tests and an ECG [electrocardiogram] all of which proved to be inconclusive.

Raabia was in fact distraught about the situation with her husband. Her identity as a wife was pivotal to her place in her society. During both interviews, her descriptions of feeling lost and abandoned induced such anguish that she was unable to talk for short periods. During our interviews she frequently described the pain in her back as “stabbing” but virtually immediately would correct herself to say “pressing” in an

almost instinctive or subliminal denial of the symbolism in matching her physical symptoms to her emotional experience.

I saw Raabia twice and after the second interview she indicated that she would prefer not to continue. About four months after we concluded, I received a call from her saying that she needed to see me again as the situation with her husband had deteriorated. I made an appointment for her but she never arrived. I attempted to contact her telephonically on several subsequent occasions but shortly after this the hospital outpatient department was closed down as a precursor to its demolition. I regretted enormously not being able to see Raabia again. Feelings of loneliness permeated the interactions I had with her. Despite the support she had from her family, the potential loss of her role as a wife and mother had caused a seismic shift in her sense of identity and place in her community.

## **2. Davina (58)**

Davina, a fifty-eight-year-old Coloured woman, had a convoluted history. She had been born Christian, converted to Islam when she married her husband and since his sudden death from asthma in 1997 had been ambivalent about her religious status. This was reflected by the two names she used selectively, Davina and Diana.

She had not married again subsequently but had been in a stable relationship for the past 20 years. She had one biological child, a son who was now thirty-nine years old, by a relationship before she was married. Her son was unemployed, living on the streets and addicted to “tik” [methamphetamine] and dagga [marijuana]. At her first interview she brought with her a ten year old boy, who was her deceased brother’s child and whom she was raising as her own. She also referred to her “daughter”, with whom she had a close relationship, but who was in fact the grandchild of her husband by a previous marriage. Both of her parents were still alive and in their eighties, and because they were never married and lived separately she had to make time to visit them both. This proved difficult as the areas in which they lived were frequently the site of gang shootouts. Davina found it extremely amusing that I struggled to follow the intricacies of her family dynamics.

Davina had had a rudimentary education, leaving school when she was fourteen, as by her own admission, she had lost interest and was “naughty”. At that age she was

sexually active, went out clubbing, drinking and smoking. She remained a heavy smoker – smoking up to a packet of 20 cigarettes a day but denied ongoing alcohol use apart from the occasional beer when her son upset her. She was a sociable individual, with an affectionate relationship with her partner and good friends who she saw regularly and who were supportive of her difficulties.

After leaving school she worked intermittently in factories doing unskilled jobs, but again by her own admission she would often just not go to work. At the time I saw her she had been unemployed for many years and lived on a government grant.

In our first interview when I attempted to elicit from her an understanding of both her referral and of psychology, she brushed my questions aside saying that she was not “so educated”. She had a pragmatic outlook on most of the vicissitudes of her life. Her main complaint was with the unremitting boredom and routine of her day. However, the one issue which caused her to react with distress was the anti-social behaviour of her son. He had lived in a temporary structure in her back yard, and engaged with drug dealing and various other criminal activities. From being fairly calm and phlegmatic in the room she became visibly distressed in discussing the process of having her son evicted from her property. When his behaviour reached the point where she could no longer tolerate the situation, she instigated his removal from her property by the local police force. The somatic symptoms – both pain in her arm and an “internal shaking” appeared to have developed at approximately the same time. Despite the fact that neither I, nor the attending doctors, had been able to objectively see this shaking, she remained convinced of some underlying pathology. I saw Davina twice, and during that time, her subjective experience of her symptoms remained unabated.

### **3. Gail (28)**

Gail, a twenty-eight year old unmarried mother of a six-year old daughter, lived with the father of her child in what appeared to be a healthy and supportive relationship. Unlike the majority of my participants she and her partner were both working and were reasonably stable financially. Gail was employed as a domestic worker at a guesthouse in an affluent coastal suburb in Cape Town.

However, due to a backlog of debt, they were unable to buy their own home and were finding it difficult to obtain suitable rented accommodation. This necessitated frequent moving, which they both found disruptive. Several times they were forced to relocate because of violence in the kind of neighbourhood they were able to afford renting in.

Melvin, her partner, was an excellent father to their child and supported Gail both financially and emotionally. However, his status as a divorced man was causing significant discord between Gail and her mother – with whom she had previously been very close. Gail was an exuberant and happy-go-lucky young woman who invariably spent a great deal of the three sessions during which I saw and interviewed her, laughing self-deprecatingly about the family conundrum. Yet, underlying the superficial equanimity was a real sense of pain about the refusal of her mother to accept her partner or give her blessing to their proposed marriage.

When the situation came to a head, several months prior to her presentation at the hospital, all ties between Gail and her mother had been severed. While there was no overt synchronicity between the onset of the presenting symptoms (pain, swelling and discomfort in the limbs and gastro-intestinal tract) and the escalation in the discord between Gail and her mother, there definitely appeared to be some correlation in their intensity.

#### **4. Caroline (61)**

Caroline in many ways personified the patient with long-standing MUS and diagnosis of somatoform disorder. She had been utilising the services of both the private sector (until funding became problematic) and the State health services for more than two decades. Despite innumerable investigations, including several gastroscopies, MRI and CAT scans, x-rays, barium enemas and meals and a battery of blood tests, no explanation could be established for her severe and chronic pain. She elicited strong negative feelings in the clinicians she had been treated by and was finally referred to psychology by the Waterstroom physiotherapist who said frankly, “She is driving me crazy!” Caroline was a sixty-one year old divorced woman who lived in her own house with her two sons of thirty and twenty-nine years old respectively. She suspected that they were both using illegal substances. Neither son was employed.



She had a married daughter of thirty-seven years old who lived nearby with her husband and two children. Caroline was unemployed having been retrenched from her clerical job in the insurance industry four years previously. She received a fairly substantial retrenchment package from her employers, but the bulk of this money had been spent on various medical consultations and investigations. Initially these were done in private practice, but when funds ran out, she resorted to the State health system. At the time of our contact she existed precariously on the meager funds provided by a government disability grant.

On her first visit to me Caroline, short, immaculately dressed and groomed, and significantly overweight, came into my office leaning on a stick and moving slowly and painfully to seat herself with considerable difficulty in the chair. She presented as a woman twenty years older than her chronological age. She gratefully accepted a cushion behind her back to “ease the pain.” It took quite some time for her to settle before we could start the initial interview.

Caroline seemed amenable to participating in the research and went through the consent form with me slowly and meticulously and interrupted several times to ask for clarification. On completion of the signing and witnessing she immediately asked for a copy to take home with her. At the time I felt that this was an attempt by Caroline to assert control in the room. It was in fact unusual as most of the participants were happy to wait until the end of the session or the next one, depending on the availability of photostatting facilities.

Despite my clear explanation and her careful perusal of the consent form, Caroline seemed uncomfortable with the research focus, the topic of MUS and my role as a psychologist. Throughout our interaction she referred to her meetings with me as “attendance at the pain clinic.”

From early on in the first interview there appeared to be underlying feelings of anger and resentment towards the medical profession and themes of blame permeated her narrative. She blamed medical negligence for the death of her father ten years previously, she blamed the doctors for failing to find a diagnosis for her pain, “I was referred [to you] because of the pain that I endure, which doctors can’t find anything wrong” and at the end of our interaction I suspect she blamed me as the manager of

“the pain clinic” for failing to help her in any way. This, I felt, was enacted by her decision not to see me therapeutically on an ongoing basis.

When she did not arrive for her third appointment, I called her and she told me, in a fairly peremptory manner, that she was far too ill to come to the hospital for her appointment. In fact she was speaking to me from the radiology department of the nearby tertiary hospital where she was about to have yet one more scan. I attempted to schedule a follow-up appointment, but in the face of her apparent reluctance I suggested that she contact me should she wish to resume attendance in a therapeutic capacity. I have had no word from Caroline. However, at the time of writing I had just received another referral letter from a medical officer in the outpatients department at Waterstroom Hospital – some twenty months and several investigations since our last contact.

What made Caroline a particularly valuable participant and potential patient was her history of traumatic loss. In her early thirties, while in the process of obtaining a divorce from her physically abusive husband, she witnessed his shooting and murder of her sister. The irony and tragedy of the event was that the bullet had been meant for Caroline. While she never articulated feelings of personal guilt she suspected that her family had blamed her for her sister’s inadvertent death. From that time forward Caroline felt like a pariah within her family circle, with the exception of her father with whom she had a close relationship. When he died, in her presence, of respiratory complications she felt as if she had lost all support.

Caroline denied any childhood or young adulthood history of illness, but from the time of her sister’s death the experience of pain gained momentum to the point where she felt completely incapacitated and frequently spent days lying in bed. The conflicting feelings which patients with MUS elicit in their clinicians were well illustrated by interactions Caroline had with both physicians and myself. Her history was one of deprivation and loss. She was not unintelligent but grew up in an impoverished family which had a negative impact on her ability to access a good education, she had endured a violent and abusive marriage and witnessed the death of her sister, and finally watched as her father died in a particularly unpleasant way in her arms. This history called for sympathy, compassion and patience in interactions with her. Yet, her mechanism of help seeking was so layered with feelings of anger,

entitlement and blame that the end result was alienation of the very people best placed to help her.

After several decades of using somatic symptoms as a mechanism of asking for assistance, Caroline appeared to have lost the capacity to make adjustments or consider alternatives. I found it difficult to like Caroline. Despite injunctions against allowing the intrusion of personal feelings in the therapeutic space, I commonly develop feelings of respect, admiration and/or affection for my patients. I do not apologize for this. However, on the other hand, my inability to surmount my negative countertransference towards this particular participant left me with residual feelings of guilt, of having failed her. Perhaps, as the literature indicates, this is frequently the plight of patients with MUS.

### **5. Angela (27)**

Angela was a twenty-seven year old, single isiXhosa speaking mother of a four year old daughter. She lived in a predominantly female household consisting of her mother, two aunts, their daughters and their children. None of the adults worked and relied on the government child grants to support the entire family. They were considered fortunate in that they lived in a brick RDP (Reconstruction and Development Programme<sup>23</sup>) house and not in an informal (shack) dwelling.

Angela, unlike the majority of my participants, had a history of accessing mental health services. She had previously been diagnosed with major depressive disorder, had seen the community service psychologist<sup>24</sup> for several sessions at Hope Hospital the year before I arrived, had had a single admission to a State psychiatric facility and had attempted suicide the year before.

At the time of her first interview Angela was an inpatient in the medical ward at Hope Hospital. She had developed an apparent left-sided paralysis which necessitated her being brought to the outpatients department in a wheelchair. She reported difficulty

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<sup>23</sup> A South African socio-economic policy programme implemented in the early years of the African National Congress government, the focus of which was to address shortfalls in social services amongst the poor and previously disadvantaged, and with an emphasis on providing adequate housing to replace the informal settlements which had arisen on the periphery of the big cities.

<sup>24</sup> As part of completing training, medical and paramedical students are required to complete a year of work at an allocated placement which may have, either historically or concurrently, had inadequate service provision.

with walking from a motor and muscular perspective as well as problems with maintaining her balance. During the first session, she sat heavily in the chair, leaning slumped to one side, with her arm on the desk and her hand supporting her head throughout the hour-long interview.

Apart from her physical symptoms, her depression was palpable in the room. She spoke in a monotone, had poor eye contact and initially did not engage well. But she was not intimidated by the referral to psychology and showed a good understanding of the process. She was an attractive young woman and on the very few occasions she smiled during the interviews one could see the potential for good rapport and interaction.

Angela had become pregnant in Grade 11 but had returned to school afterward the birth of her child and completed her matriculation. She received little financial or other support from her child's father. She had worked briefly as a home-based carer, but the agency had closed down and she hadn't found other work. She impressed as intelligent with great potential. However, at the time of both of the interviews she was unemployed and displayed no optimism that the situation would change in the foreseeable future.

Her focus seemed to be entirely on the poverty and the dire circumstances in which she and her daughter were living. She talked frequently about the anguish she felt at being unable to provide for her child. She described them being hungry and her attempts to source food and money from neighbours. The conflicts between researcher and clinician were exacerbated in these interviews by my feelings of personal inadequacy and guilt about her status quo. Working in communities where poverty is rampant and basic needs such as food and shelter are not being met, creates ongoing conflicts about roles and social responsibility which need to be continually negotiated by the clinician.

What made Angela such an idiosyncratic participant were two separate but memorable incidents. The first occurred at the end of our first interview. I felt that it hadn't gone well. My recorder had unexpectedly failed to work and as a consequence I had been forced to frantically try and record the details of our interaction and her responses to my questions on the notepad in front of me. Psychologists, like all

professionals, work in particular ways. I find note taking, beyond the rudimentary, has the effect of creating a barrier between myself and my patient, or the unwanted intrusion of a “third voice”.<sup>25</sup> However, at the end of the session Angela told me firmly that talking had been helpful and that she would walk back to the ward. The sight of her stalking out of my room and dismissing the use of wheelchair did an enormous amount to improve the status of psychology in the outpatients’ department of Hope Hospital!

The second noteworthy event related to this patient, and which foregrounded aspects beyond the scope of pure research, occurred in a subsequent telephone conversation. Angela had been unable to commit to a time or date for a follow-up appointment and asked me to phone a week later in order to do so. I didn’t recognise the voice that answered the phone, and was completely taken aback when the person I was talking to laughed uproariously and said, “Its Angela!” She went on to tell me with evident delight that she would be unable to attend follow-up appointments as she now had a job. The change in her voice tone and intonation, the improvement in articulation was remarkable. The fact that she now had the potential to provide for herself and her child provided the palliation for her feelings of despondency. While this is helpful in illustrating that social circumstances have a significant effect on mental state, it is no way an attempt to imply that psychopathology is exclusively the consequence of adverse circumstances. This patient merely provided an important codicil to emphasize the contribution of poverty to wellbeing, or lack thereof, in this country.

## **6. Shanaaz (20)**

Shanaaz was a beautiful but delicate looking twenty year old Muslim woman, with two small children of three and one year old. She was no longer in a relationship with the father of her children, who did not support them financially in anyway. She lived with her parents and three of her five siblings. Her three sisters were all working either fulltime or part time and contributed to the family finances, which together with the government child grants, constituted the family income. Shanaaz had recently resigned from a job as a shelf packer in a factory as the hours were difficult, necessitating her getting back home in the early hours of the morning. While she

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<sup>25</sup> Swartz, S. (2006). The third voice: Writing case notes. *Feminism & Psychology*, 16(4), 427-444.

wanted to find more work, she felt that her previous job had impacted negatively on her ability to look after her two young sons.

Shanaaz was sent to see me with a complex referral diagnosis of possible anxiety attacks, PTSD (posttraumatic stress disorder) and somatic symptoms of chest pain and intermittent GIT (gastro-intestinal tract) pain and diarrhoea. She volunteered the information that she had “read that anxiety can cause this.” I ascertained that while her health was generally good she had had a similar instance of abdominal pain as a young child of five. When I asked her about the family situation at that time, she initially denied any problems, but later was able to recall that there was a great deal of tension in the home as her father had been unemployed at the time and consequently there was no family income.

The referring doctor had suggested that Shanaaz was suffering from either panic attacks or PTSD as a consequence of an incident of car hijacking which had happened the year before. However, her symptoms of anxiety seemed to be related to her abdominal pain and the fear that it could indicate a serious medical condition. Like many of the participants the unspoken fear was of cancer. While Shanaaz had some of the symptoms (nightmares and avoidance) she did not fulfil the criteria for PTSD. She did, however, appear to be depressed with a strong neurovegetative shift [aspects of sleeping, appetite and energy which were either elevated or depressed].

Shanaaz, despite her youth, showed maturity and good insight into her symptoms. Sitting in the room with me she exuded a feeling of serenity, despite her concerns and symptoms, which was remarkable. Her family, although impoverished, were close and religious and appeared to interact with mutual calmness and respect and without the intrusion of substances or aggression. Although she had had no prior exposure, she engaged with me, and the concept of psychology, with quiet and thoughtful consideration. She definitely appreciated the tautological connection between her GIT symptoms and her anxiety. I did suspect that Shanaaz was depressed and discussed the possibility of going onto an anti-depressant with her. I suggested that I consult with the attending medical officer regarding the prescription of the medication. She was dubious about this, but was prepared to give it some consideration. Shanaaz said that she had found the hour with me helpful but due to the

cost and difficulty of getting to Hope Hospital, which were not insignificant, she felt that she didn't feel able to reschedule another appointment.

Shanaaz did have a follow-up appointment booked with the referring doctor who was still waiting the results of some of the blood tests. I discussed the situation with Dr. D. who agreed with the possibility of prescribing an anti-depressant. I didn't see Shanaaz again, but I heard from the doctor that her blood results had come back indicating that she was suffering from hyperthyroidism which would account for certain of her symptoms, including the anxiety. The appropriate medication was prescribed and when I was last in contact with the doctor she reported that Shanaaz was doing well.

Shanaaz, both as a patient and a participant, provided illustration of how difficult it may be to disentangle the comorbid symptoms of physical and mental health diagnoses. In addition the management of her presenting complaints foregrounded the advantages of interdisciplinary cooperation in the service of the best interests of the patient. Finally, her situation and presentation most clearly indicate the way in which the orchestration of appropriate clinical management could be simultaneously conducted with obtaining pertinent data in the service of my research.

## **7. Allison (34)**

Allison, a thirty-four year old woman who had converted to Islam, had a fairly straightforward referral complaint: tension headaches and muscle spasms. The referring doctor was a neurologist who had excluded all underlying neurological or organic pathology. However, what was not indicated in the referral letter was that Allison was on antihypertensive medication. This immediately raised a red flag for me. With my background in nursing I was aware that inexplicable headaches are often indicative of raised blood pressure – particularly when the individual has already been diagnosed with hypertension. Thus, with an acknowledgement of the mind-body connection, specifically the effect of stress on blood pressure, I held in mind the possibility of such a connection.

In psychology we frequently allude to the concept of countertransference. This in its simplest form is the feeling elicited by the patient in the clinician. Allison was a tiny, tense little woman whose hair was covered in a headscarf leaving her mobile and expressive face clear of any obstruction offered by hair. She talked rapidly in a

staccato way, in a voice made harsh and grating by many years of heavy smoking and laughed like a machine gun firing shots. Her energy was palpable, intrusive and exhausting. Within minutes of her entering the room on both the occasions I saw her, I felt myself experiencing countertransference of defensiveness – of needing to protect myself from the onslaught of her powerful personality.

Her personal history and life were chaotic. She had been born Christian, had an eighteen year relationship with a Muslim man by whom she had three daughters of thirteen, nine and three. She had only converted to Islam two years prior to seeing me as she felt at that stage that she wanted to practice the same religion as her children. In her family history there were innumerable instances of inter-faith conversion. Although her Muslim name was Nula, she had continued to use her birth name of Allison.

Allison, her partner – they never married - and their three daughters lived on the property of her parents in what is known as a “separate entrance” (a dwelling generally attached to the main abode but with its own entrance). Her mother and father (both pensioners) and her two brothers lived in a second separate entrance in a condition of constant acrimony. Her father had taken to using “tik” [methamphetamine] and her brother was in and out of the nearby State psychiatric Institution. I suspected that he had either a diagnosis of schizophrenia or substance induced psychosis as Allison maintained he too used “tik” and was frequently “psycho”. Finally, Allison’s maternal grandparents, aunt and the aunt’s “tik” abusing son lived in the main house. This nephew was causing tension between the various households due to his habit of stealing appliances, clothing and other items to support his drug habit.

Factored into this chaos was the constant battle to find funds to pay for essentials such as food and electricity. Allison’s partner had a stable job, the only person on the property to be employed. Her ambivalence between loyalty to her mother and the need to support her, and resentment about indirectly funding the drug habits of the various users, translated into a barely controlled fury. She admitted to “skelling” (shouting and swearing) during nearly all engagements with her family.



While her irritability was possibly masking depression Allison was resistant to any discussion of this diagnosis. Like many of my patients in my clinical work and the participants of my research, she wanted an explanation and clear diagnosis for her physical pain. She was one of the patients who created a dilemma in terms of my functioning and role. I was justifiably concerned about her blood pressure, but on both occasions when I wanted to have it measured, there was no nursing staff available. I was forced to perform the function myself and found, as expected, that Allison's blood pressure was significantly raised. I referred her back to the medical outpatient for reassessment of her medication. As an acute measure, I conducted a session of progressive muscle relaxation. I then followed up with a second blood pressure assessment which indicated a drop in both her systolic and diastolic readings. This provided her with real evidence of the impact of her stress and anxiety-generated emotions on the functioning of her body. She maintained during her follow-up interview that she had made serious attempts to relax and curtail her angry outbursts.

Allison saw me only one more time, during which we repeated the blood pressure assessment process. However, she failed to return for the third appointment and I was unable to ascertain whether she had attended her medical follow-up. I tried to contact her telephonically without success. The chronic disorder of Allison's life and the potential violence continually hovering on the fringe are endemic in the areas in which I conducted my research. In my clinical work the emotional impact is frequently mirrored by physiological symptoms. I do not always, however, have such clear illustration of the mutually dependent effects.

### **8. Rivka (37)**

Rivka was a confident, engaging thirty-seven year old Muslim woman, in a stable marriage with a Christian man, with whom she had three children – a son of fifteen and two daughters of fifteen and one respectively. The children were being brought up Christian and there seemed to be an atmosphere of mutual tolerance and acceptance in terms of religious practice.

In many ways Rivka and her family were unique in my clinical and research settings. Firstly, not only did she and her husband both have stable jobs but, in addition, she was employed doing work she frankly "loved". She had started off as a cleaner in a

hotel and at the time of our interview she was employed as a chef. She described her rise in the ranks and the responsibility and creativity of her present tasks with evident pride. However, the difficult hours she was required to work were definitely contributing to what she called “stress” in her domestic situation.

Unlike any of the other patients at Hope Hospital, Rivka had brought her husband with her as “backup.” He too was overtly anxious about her physical welfare and confused by the involvement of psychology, especially when I asked him to wait outside while I started the interview. Their relationship appeared to be an essentially healthy and supportive one, although she overtly took over the responsible role in terms of managing most family issues including finances. However, this appeared to be well balanced by his concern and involvement in her wellbeing and that of the children. She reported that he was an excellent father, providing financially and engaged with the children’s day-to-day upbringing. Her one concern was that on a Friday night, when she was frequently at work, he would invite friends over and they would drink excessively. This constituted another component of what Rivka terms “stress”.

Like virtually all my participants, Rivka was reluctant to see a psychologist. When I asked how she felt about the referral she replied that she couldn’t understand why the doctors couldn’t help her with her pain. Her referral was for atypical headaches (which moved location during any one episode from the front of her head, to the sides and back). She asked quite frankly whether the doctors thought she was “mad”. However, with the humour and tenacity that characterized her way of being, she was prepared to engage with this new discipline as a possibility of resolving her concerns about her physical symptoms.

What I found fascinating in our interaction was that that Rivka, although having absolutely no previous experience of psychology or real understanding of the discipline, grasped the concept of unacknowledged psychological issues having the capacity to influence her feelings and mood and indirectly her body. She described the unconscious as “the little brain” and was able to engage with the possibility that her fears and anxieties were in some way impacting on her physical functioning.

As with Allison, I was challenged to find ways of incorporating data collection with rendering clinical service. However, such was Rivka's openness and curiosity that I managed somehow to negotiate through this dilemma to obtain wonderful data with regard to her understanding of the process, while simultaneously implementing clinical interventions which resolved to some extent the impact of her somatic symptoms.

### **9. Patricia (51)**

Patricia was an immensely dignified, quietly spoken and private amaXhosa woman who looked perhaps a decade older than her fifty-one years. She had had a hard life and it showed. Her face was lined beyond her years, and she sat solidly in the chair with an air of utter exhaustion. Her head was covered by the "doek" (scarf) with which much older amaXhosa women traditionally cover their heads.

Perhaps her history had made her wary of exposing her private life, but apart from Raabia, she was the only participant with active concerns about confidentiality and the purpose to which our interviews would be put. She queried the presence of the recorder in the room on several occasions. I offered her the options of either withdrawing from the study or for me to remove the recorder and merely make handwritten notations of our interviews. Perhaps it was my willingness to accommodate her questions and concerns but she eventually indicated that she was prepared to continue as we were.

In many ways Patricia and I represented the two sides of the great cultural and racial divide which is so emblematic of South Africa – both historically, and contemporarily. We were women of a similar age, but our histories and experiences were as different as the colour of our skins. Which in South Africa, for women of our generation, meant all the difference in the world.

The interviews were conducted in English as I don't speak isiXhosa and there was no interpreter available. Although Patricia was proficient in English I noticed that she stammered frequently. This became more pronounced when she was feeling anxious or distressed, and less so when she was relaxed. I had hoped to engage the services of an interpreter even for part of a session, to establish whether the speech impediment was related to speaking another language, but this was not possible.

Patricia was born in a rural area in what was then known as the Transkei and is currently part of the Eastern Cape Province of South Africa. It fell into the geographical areas allocated by the Nationalist government for the amaXhosa people to live and work in and was isolated in terms of facilities and employment opportunities. Like many women of colour of her generation, she was forced to leave school before completion to help assist with the family's financial income. Unusually in rural families, Patricia was an only child and therefore felt a particular responsibility for helping and supporting her parents.

Eventually, after her marriage in 1980, and with the slackening of the Group Areas Act (which restricted movement of Black people in the country) she and her husband relocated to the sprawling townships outside of Cape Town. Despite her obvious intelligence Patricia had been employed exclusively as a domestic worker until 2006 when her husband insisted that she stop work.

Patricia was the mother of four children, only two of whom survived. She lived with her husband, one daughter and grandchild in a hostel in Township X<sup>26</sup>. She had a second, married daughter who lived nearby with her husband. Both daughters had finished school and started tertiary education but had dropped out due to pregnancies.

Patricia and her husband had lost both their sons in tragic circumstances. From what I was able to ascertain, both boys suffered from haemophilia but only one death was possibly related to the condition. Her first son was twenty when he was attacked and killed in 2003. Her second son had died after a short unnamed illness, possibly a brain hemorrhage, in the year before I saw her. Although she related the incidents with apparent calm, at the end of her description tears were running unchecked down her cheeks and we needed to take a break for her to regain her composure. I had the sense that she was not comfortable with me seeing her distress.

Patricia had been extensively investigated both at Hope Hospital and the large nearby tertiary hospital. She had even accessed private care in her search for some definitive diagnosis. No underlying organic cause was ever established for her multiple

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<sup>26</sup> Under the apartheid government, migrant workers – mainly men – were brought into work in the large cities from the outlying rural areas. They were housed in single-sex hostel accommodation during the period they were employed. After the transition to the new dispensation, these hostels were converted into low-income housing for families.

presenting symptoms which included chronic headaches, neck, thoracic and general body pain, and cramping in her hands and legs. The pain was unresponsive to analgesia. She had been diagnosed with depression many years previously and had been on a low dose of medication ever since.

When I asked Patricia what had brought her to the hospital originally, she said that it was a headache. She brought out from her bag a small homemade notebook (cut up pages stapled together) that she consulted whenever she needed specific information regarding her medical history. She was meticulous and unusual in her maintenance of detailed records of her symptoms and medical treatment. However, despite the potential for psychological contributions for her symptom, Patricia insisted that there had to be some kind of medical explanation. She strenuously denied any emotional impact from the death of her sons, and appeared to me to be held together precariously by gossamer threads of self-control and repression.

However, Patricia's apparent fragility hid a steely determination not to condone the failure of the health system to diagnose the cause of her pain. At the end of her second and final interview, she told me firmly that the doctors had let her down and that coming to see me was "a waste of time." Despite my failure to help her in a visible or even tangential manner, I was left with the feeling that in some way Patricia and I had made a connection that transcended either clinical or research considerations. Perhaps from her perspective, it provided a small but meaningful opportunity to redress the power imbalance through her courage in articulating disagreement with the symbols of power

#### **10. Nambitha (19-21)**

A distinctly grumpy and hostile young face surrounded by long dreadlocks met me as I opened the door to admit my patient at Hope Hospital in December 2011. Nambitha, like Patricia, was amaXhosa but there in many respects the similarity ended. Nambitha was young, single, a deeply religious Christian, had completed her schooling, and was an only child of a teenage mother and an absent father. At that first appointment she was furious and resentful of her transfer from medicine to psychology. I saw her the first time exactly four months before her nineteen birthday.

The referral letter described her as having “great potential”. The opportunity to see this realised in the clinical situation is not always possible. However, my research provided me with the opportunity for follow-up which might not have materialised otherwise. Nambitha and our interaction in 2011 were pivotal in my decision regarding a research topic. So when I was interviewing participants I consulted with my supervisor about the possibility of doing a retrospective interview with her to obtain her input regarding her own process. When I saw Nambitha for this retrospective interview, as part of my research two years later in 2013, the potential had been largely realised.

Nambitha was initially referred because of idiopathic chest pains, tachycardia (rapid heart-beat) and arrhythmia (irregular heart-beat). At the time she had completed her schooling, but was unemployed and living with her maternal grandmother and extended family in fairly disruptive circumstances. She was closely attached to her grandmother, but the members of her extended family appeared to be abusing substances with consequent and associated violence and aggression. Nambitha was still mourning the loss of her mother who had died suddenly twelve years previously of HIV/AIDS complications and distressed at her ongoing failure to establish contact with her biological father. He had abandoned her teenage mother when she fell pregnant.

During my initial intake interview in 2011, I asked Nambitha what she dreamed of achieving. She said that apart from the desire to “get well” she wanted to be able to pay for the erection of a tombstone on her mother’s grave, to get a tertiary education and to develop her musical talent. However, she was, at that time, experiencing daily chest pains and palpitations and feeling frustrated and sad.

Two years later, when I interviewed her retrospectively as part of my research project in April 2013, she was in her second year of tertiary education, for which she had been awarded a full scholarship based on her academic performance, financially self-sufficient through part-time employment as a telesales person, living in the college residence, functioning well and without any somatic symptoms. Shortly after this interview she contacted me to say that she had been talent-spotted and sponsored for a music-related tour of Sweden.

Nambitha's inherent exuberance and willingness to engage with psychology, despite her initial reaction of overt scepticism, seemed to be what translated into effective change. One of her greatest assets, both in the therapeutic space as well as in her life outside, was her wonderful sense of humour. So when she recalled her feelings on seeing me for the first time, and the suspicion that she was not being taken seriously, she laughed uproariously. Nevertheless underlying it was a real sense of remembered confusion. That initial referral to psychology had puzzled, insulted and angered her.

When I asked Nambitha at the conclusion of the research interview how, or if, she now saw her life differently, she told me that she was happier than she'd ever been, feeling increasingly like she was moving forward and fulfilling her dreams. She acknowledged the need to manage problems proactively and was proud of her developing ability to do so. I asked about the role psychology had played and she said that she had moved from her initial position of seeing it as: "When even you hear the word [psychology], it's about madness!" To a position where: "For me, psychology is something of everyday. Everything of it."

Nambitha's commitment to her personal growth and understanding her somatic symptoms translated into attendance at Hope Hospital as frequently as she could afford over the year following her initial referral. I saw her regularly until I completed my rotation at the hospital in December 2011. When I contacted her in March 2013 and asked if she would be prepared to be interviewed for my research I got an enthusiastic, "Yes. Now I can give back to psychology." Her response provided me not only with validation of psychology in treating patients with MUS, but also held out the possibility of combining the insights from clinical work and research procedures in the service of understanding and managing the condition with more insight.

### **11. Maryam (46)**

Maryam was a forty-six year old Coloured Christian woman who was in the process of getting a divorce. She lived alone in the house that belonged to her mother since her husband had left several months beforehand. She described her marriage as having had "broken service": five years after she and her husband were first married they separated for a period, they then got together for the next fourteen years until she

finally instituted divorce proceedings. Her husband had been a heavy drinker and serial womaniser who had given her STDs (sexually transmitted diseases) periodically, culminating in syphilis two years previously. She had been tested for HIV but was at that stage still negative.

Maryam had never had children due to an early ectopic pregnancy and other gynaecological problems, possibly due to her recurrent infections. She spoke about this with a kind of detached longing but without any sense of self-pity or anger.

There was an appealing childlike quality to Maryam despite her weathered appearance and incongruously lurid makeup. She seemed innocently pleased to have been referred to psychology but clearly had absolutely no concept of what the referral entailed. She variously asked for my help in negotiating her way through the legal system in terms of her divorce and then later requested my assistance in finding a job, going so far as to offer to work for me in a domestic capacity. She cheerfully accepted my explanation that both these issues were outside the realms of either my expertise or professional boundaries.

Maryam's presenting symptoms were interesting. Initially she described her problem as non-specific chest pain, which had taken her to her local day hospital a year prior to our appointment. They had been unable to find the underlying problem, the pain had escalated over time and she was eventually referred to Hope Hospital. By this time her subjective description of her symptoms had intensified and now included a bilateral "moving" pain which radiated up the sides of her neck to her ears which resulted in the "pulling tight" of all those muscles and the formation of a "bowl" or "hole" at the base of her throat at the sternoclavicular joint. Responding to her desperate appeal that I acknowledge the existence of this apparent anomaly on her very normal looking neck was difficult to negotiate. However, when I had to say, as had the medical offer before me, that I could not see the anatomical aberration, she was quite philosophical about accepting this.

We discussed and explored the advent and evolution of these symptoms together, but there appeared to have been no particular precipitating event. However, she was a known hypertension patient who was non-adherent to her medication and was experiencing significant stress about her unemployed status. She felt enormous guilt



that she often had to ask for money from her widowed pensioner mother and rely on hand-outs from her siblings. She had a touching dignity which made her situation so difficult to listen to and hold in check the desire to “fix it” for her. Fortunately she had a deep and sincere religious belief system which enabled her to be optimistic despite her difficult circumstances. Equally fortunately Hope Hospital had an excellent social worker to whom I could refer Maryam. However, I did not see her for a follow up appointment myself. She expressed no desire to see me again and I suspect that despite our discussion, my failure to either provide practical help or acknowledge the existence of her symptoms rendered this totally unnecessary and superfluous to her and her life circumstances.

## **12. Petunia (48)**

Petunia was a forty-eight year old, single amaXhosa woman with two children, a son of twenty-five and a daughter of twelve. The children had different fathers. She no longer had contact with her son’s father but was still in a relationship with her daughter’s father. They did not live together, but saw each other regularly and he provided financial support for their daughter.

Petunia belonged to a Charismatic Christian denomination while simultaneously maintaining traditional beliefs in ancestors. She reported no difficulty in balancing the two belief systems, both of which provided her with comfort and direction in negotiating her way in a difficult life.

Her reaction to the referral was unique. When I asked her about it, while having had no previous exposure to or experience of psychology she maintained with some degree of confidence that it was “a great thing”. When I asked why, she replied that this was an opportunity to share some of the burden she’d been carrying. She described psychology as being something to help people, especially if “a person doesn’t have somebody who can share something.”

Petunia’s history and living circumstances were extremely challenging. She had done well at school and had hopes of becoming a nurse. She had managed to matriculate successfully but due to financial problems there was no possibility of tertiary education. She had briefly trained and worked as a nurse aid in an old age home, but reported that the management had “crooked” the staff and they had all lost their jobs.

Since then she had been employed as a domestic worker but this had been suddenly terminated without explanation five months previously. She was still unemployed and was despairing of finding another job. She was the youngest in a family of five siblings and was particularly close to both her mother and father who had died suddenly (heart attack and asthma respectively) and fairly young. Her brother had been murdered four years before our interview.

At the time we spoke she, her two sisters and their five children lived in a two bedroomed house. While it was a brick construction there was a single toilet situated outside of the main house in the back yard. Only the one sister was employed. She drank heavily and would become abusive towards Petunia when she was drunk. The one nephew of thirty-one was using drugs and possessions had to be guarded against his theft. The third sister also drank heavily but only at weekends and was generally unaggressive while drunk. Petunia denied any substance use herself apart from the occasional cigarette.

Petunia gave me a description of her presenting symptoms that differed significantly from those given to me by the referring doctor. We unfortunately never got to the point of exploring this disparity. The referral note indicated neurological problems – right-sided paralysis and loss of sensation – all of which had been investigated, including a brain scan, with no satisfactory results. However, when I asked Petunia to describe what had brought her to the hospital she said only that she had experienced a sudden and severe pain in her back that started in the middle of the night approximately four to five months previously. Once again, I missed the opportunity to explore her particular circumstances at the time of this interview, but retrospectively I calculated that the pain seemed to have started about the time her employment was terminated. Certainly when I asked Petunia about stress, she minimised the domestic chaos and maintained that her concerns were all related to being unemployed.

Unfortunately Petunia's contribution to my research question was limited, as I didn't see her for a second interview. I had scheduled a follow-up appointment which she arrived for an hour early. I was unable to see her immediately due to a prior commitment and explained that I would probably only be able to conduct our interview at the scheduled time. However, I assured her that would make every effort to get back to her as soon as possible. A few minutes later I noticed that she had left,

but assumed that she would return at the correct time. This didn't happen and she failed to answer my subsequent telephone calls. In clinical work, failure of patients to return for follow-up appointments is a frequent occurrence. During our training we are taught to contain our frustration and curiosity about the outcome. However, in the community, even though I am aware of the restrictions placed by economic constraints, I am still frequently plagued by the sense of "wanting to know". Particularly in instances where one has spent sufficient time engaging with an individual patient the loss of follow-up can be difficult to contain. In the research situation, this is highlighted and complicated by the self-interested need for data. I regretted Petunia's decision to leave as I had felt that she had not only a valuable contribution to make but that she might have benefited from the "someone to talk to" that she had seemed so willing to engage with.

### **13. Lianne (19)**

Lianne came to see me on her nineteen birthday. She was a quiet, pretty, gentle-looking young woman who didn't make good eye contact and who seemed to shrink in size in the presence of her mother. Despite her age and the fact that she was the only employed adult in her household she was accompanied by her mother to the appointment. Not only this, but her mother walked into the room ahead of Lianne, seated herself perfunctorily in the only chair apart from my own, leaving her daughter standing awkwardly, and proceeded to launch into a lengthy explanation for the reasons for the appointment. Although a parent's input is useful in establishing early childhood history, I had enormous difficulty in dissuading Mrs M. from answering the questions I directed specifically at Lianne. I eventually had to ask her to wait outside of the room, which she did with evident reluctance. As psychologists we value family contributions and involvement as it provides important information and valuable insights into family dynamics. This was certainly the case with Lianne and her mother and no less so in the context of my research.

Lianne's family was complicated. Her parents both had children from previous relationships, Lianne and her younger sister from their marriage, and a son from an extra-marital relationship of her father's. This resulted in a conglomeration of relationships, which I wasn't entirely able to disentangle. It also created potential for

considerable conflict as several of the half siblings and their offspring lived in the house with Lianne, her sister and their parents.

While Lianne and her mother clearly had an enmeshed relationship, within minutes I'd heard from Mrs M. that the father was "the problem" and that he wasn't to be involved in the process at all. I explained that at this stage it was merely a research interview and that if it progressed to a therapeutic intervention Lianne would be my potential patient and that the decision would be hers to make. Mrs M. appeared somewhat taken aback at this information.

As the interview progressed (with Mrs M. out of the room) it became evident that the relationship between the parents was acrimonious. Mr M. also appeared to be a controlling and abusive father. I heard from Lianne that her father had drunk heavily when she was a small child and used to come home violent and destructive. She recalled one specific occasion when she woke one night, when she was about six years old, to witness her father holding a gun to her mother's head. He only removed it when he heard Lianne screaming. There were numerous other instances of physical and emotional aggression. From what I heard in that single interview, Lianne felt continuously as if she was the buffer between her parents and felt overwhelmed by the responsibility. She felt continually on edge, "preparing" herself for what could happen.

The responsibility extended to a financial one. The family had run a successful food takeaway service from a container outside the hospital. However, Mr M. for no reason either Lianne or her mother could discern, decided to close it down. As a consequence the family had been living in precarious financial circumstances ever since, with a devastating impact on Lianne's schooling. She had done well and anticipated completing her matriculation. The day before she was due to start her final year, her father informed her that there was no money to fund her schooling and that she would need to go to work. She was justifiably devastated and said, "I had goals set for myself and it was taken away, just like that." She never became emotional at all during the interview, but would take deep controlling breaths when her memories made her feel vulnerable.

Since then Lianne had been working as a cashier in a high-end department store in a very exclusive and wealthy suburb. She made the daily transition from the bleak poverty stricken neighbourhood she and her family lived in to her place of work in beautiful surroundings with its cohort of demanding wealthy customers. She was required to bring her salary home and give it directly to her mother. She was allowed only a small amount of pocket money. Her anger and resentment was barely concealed, but she tried very hard not to allow it to become overt.

Lianne had been referred to me as a consequence of atypical seizures which extensive investigation had shown to have no organic origin. In our discussion, Lianne disclosed that these pseudo seizures had occurred previously during her childhood at times of particular stress. She also referred to “panic attacks”, the symptoms of which were also atypical and were characterised by fatigue and sleepiness rather than anxiety.

Although I had managed to elicit the data I required in terms of my research question, I felt challenged by Lianne’s situation and eager to follow up with a clinical appointment. Lianne, like Nambitha, impressed me as a young woman of great potential. She too seemed enthusiastic about a subsequent appointment and we scheduled one to accommodate her work roster. When she didn’t arrive, I called her and was told that her schedule had been altered and she was working. While I was more than willing to reschedule another appointment, her evident disinterest and obstructive responses to my attempts to find a subsequent date left me with no option but to abandon my attempt.

One of the most difficult aspects of clinical work is the thwarted attempt to follow up with patients we believe would benefit from a therapeutic intervention. Knowing that the research goal had been achieved did not lessen my disappointment about unanswered clinical questions.

#### **14. Mavis (48)**

Mavis was a tiny, feisty, forty-eight year old Coloured woman who gleamed with cleanliness and careful grooming despite living in a semi-derelict dwelling, without running water or electricity on a nearby farm. She, her husband and their three

teenage children lived there in a kind of grace-and-favour arrangement with the farmer in return for feeding and caring for the pigs on the farm.

Mavis came to me in an unusual way – referred simultaneously by the social worker and physiotherapist at Waterstroom Hospital. Both allied health professionals were bemused by the referral they had in turn received from the speech therapist at the large tertiary institution associated with Waterstroom. Mavis presented with chronic dysphonia [loss of voice] that had not responded to the throat and laryngeal exercises given by the speech therapist. She had been fully investigated by the ENT (ears, nose and throat) department for any physical pathology but none was found. Quite frankly, nobody knew what to do with her.

Mavis arrived in my room looking both resentful and sceptical. She had absolutely no idea why she had been referred to me and was clearly doubtful of my ability to help her in any way. She was tired of being pushed from pillar to post – despite the patently good intentions of all those medical professionals involved. When I tried to elicit her understanding for her referral she simply glowered at me. I then asked Mavis what had brought her to the hospital and I got the terse reply in a barely audible whisper, “Ek kan nie praat nie” [I can’t talk]. I asked how it had happened and received an equally curt, “My bors het toegetrek” [My chest got tight].

Eventually, Mavis provided me with some details of the onset of her strange symptoms – all conducted on her side in a hoarse whisper. I had to write everything down, under her disparaging gaze, as I could obviously not use the recorder. She had reportedly got wet in a downpour of rain early one morning during the previous winter. She suffered from asthma and felt that the two were connected. She denied any particular stressful event at the time. She did acknowledge that it was an unusual situation and that she admitted that she couldn’t understand why she still had no voice one year after the incident.

Our conversation, audible on only one side, continued and I learned that she was in a very unhappy marriage. It had started well and for many years she and her husband had coped adequately. Then circumstances changed. Her husband had begun drinking, she lost her job in domestic service, had been unemployed for 16 years and her husband only worked intermittently as a labourer. Their house had been repossessed

two years previously due to debt accrued as a result of their limited income. When I asked her to list her stresses she included the fact that her husband drank heavily, her children fought between themselves and blamed their parents for the loss of their home and the way they had to live. She also mentioned the fact that her mother had died on her birthday 11 years previously and said that she still missed her mother and the support that she had provided.

One of the most telling things that Mavis divulged during that first interview was that her husband was continually telling her to “Hou jou bek” (a colloquial expression literally translated as “hold your mouth<sup>27</sup>” and meaning “Be quiet”). She had gradually stopped talking to him anyway, as any attempt to defend herself or reason with him merely prolonged and exacerbated the argument. When I tentatively suggested that there might be a psychological connection with this and her physical loss of voice, she looked at me with frank incredulity and did not reply to what she evidently thought was a ludicrous idea.

When Mavis left my office that first day I had no expectation of seeing her again. However, the following week she was waiting outside the door. By that second interview Mavis was able to talk with some difficulty. Her voice steadily improved and was back to normal by the fifth session. It has not deteriorated since. My first interview with Mavis was on the 22nd April 2013 and I was still seeing her on a monthly basis in October 2014. It has remained an unsaid agreement that we “agree to differ” on the subject of what caused her voice to disappear.

On several occasions we have talked – and laughed - about how she felt when she had first arrived. About halfway through the year we began talking English as she was preparing to enroll for night school and wanted to practice. I asked what it had been like for her to come to see a psychologist and she replied, “After the first time I came, I felt like I was a bird that had been let out of a cage.” I asked her to explain and she said that the relief of having been able to talk about issues was enormous. She had not felt able to do this since her mother had died 11 years previously.

My research project was responsible for the questions in our first interview and the

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<sup>27</sup> In Afrikaans, the word for “mouth” of a person is “mond”, and the word “bek” is used exclusively to refer to the mouth of an animal, except as part of an insult, as in “hou jou bek”.

particular interest I had in her somatic symptoms. However, my clinical role enabled me to continue seeing Mavis for the following 20 months and facilitate the privilege of being with her as she negotiated her return to school in an attempt to obtain her matric, to console her when she failed and to encourage her to try again. We have shared her concerns for her son's rebellion, her daughter's difficulty in organising her matric ball dress and her youngest child's confirmation. Despite the inauspicious beginning Mavis and I have experienced an enriching interaction, which has developed my understanding of my profession, my role as a researcher, and hopefully for Mavis an appreciation of her own life processes.

### **15. Amelia (49)**

Amelia was an attractive, well-dressed and well-groomed forty-nine year old married woman. She had two grown up sons of twenty-eight and twenty-one. She had been married for twenty-eight years in what appeared to be a mutually supportive, respectful and affectionate marriage. Her husband accompanied her to her interview, clearly concerned about her wellbeing. He initially walked into the room with her, but was happy to leave when I asked him to wait outside. However, Amelia asked that he be allowed to stay for the duration. I explained that this would interfere both with the research process and any therapeutic interventions and she reluctantly agreed to continue on her own.

Although initially Amelia had been confused about the referral, she had no real objection to being seen by psychologist, as she had previously had therapy for depression and possibly anxiety. She was unable to be specific about her psychiatric history. Her presenting symptoms – irritable bowel syndrome and tachycardia (rapid heartbeat) – at the time of her referral to me all appeared to be anxiety related.

Amelia reported that she was unhappy at work, feeling victimized by her immediate boss. She had also experience significant personal loss in the preceding decade: both her parents had died, her father suddenly as a result of a stroke and her mother, with whom she had been particularly close, after a long and painful struggle with lung cancer. Her eldest sister and only brother had also died with cancer related illnesses. Her previous boss, with whom she had worked for many years, had died shortly after her mother, also of cancer. She was clearly anxious about the possibility of an



underlying malignancy.

I had the one session with her when her focus was entirely on her medical history – an ectopic pregnancy, some gynaecological problems and a possible heart attack (although I could find no reference to this in her folder). The predominant feeling was one of chronic anxiety. I felt that the most important, certainly clinically responsible, consideration was to provide Amelia with tools for dealing with her anxiety rather than to focus on questions regarding her present somatic symptoms. To this end I called her husband into the room, as his involvement seemed to be pivotal to her wellbeing. I then put them both through a session of progressive muscle relaxation. They both responded well and I thought it provided for a good basis for further interaction. However, Athena cancelled two subsequent appointments due to work commitments. While this may have resulted in a failure to get more substantial data, once again clinical considerations needed to be taken into account from an ethically responsible perspective. I may not have obtained the maximum data in terms of her somatic presentation and understanding thereof, but I judged it more essential to be proactive about containing the anxiety which was probably responsible for the physical manifestations. I never saw Athena again, and I have not seen her name on the outpatients or emergency room lists either.

#### **16. Ingrid (44)**

Ingrid was a well-dressed, beautifully groomed forty-four year old Coloured woman, married with two biological daughters of twenty-three and sixteen from the marriage and a son of four who she was in the process of adopting. The adoption process was tenuous as the initial contact had been informal. The parents of the child, both drug addicts, had virtually abandoned him in the street outside Ingrid's house. Ingrid and her husband were in the process of attempting to navigate the legal system in order to ensure that the parents could not reclaim the little boy.

This process constituted a major stressor in Ingrid's life. She had taken on the care of the little boy from when he was a two-month old baby and not only she, but also the entire family, had bonded strongly with the child. Ingrid lived with a constant fear that he would be taken away from her. While informal child-rearing arrangements are common in the communities I work in, they generally involve extended family

members. The parents of the little boy were in no way related to Ingrid and her family which created legitimate concerns that the parents could, and would, one day arrive to reclaim him.

Ingrid was articulate in describing her life circumstances and difficulties, but was tearful throughout her first two interviews with me. While she foregrounded the situation with baby Thomas as the predominant stressor, the family were also experiencing considerable financial difficulties. Both she and her husband had been made redundant virtually simultaneously. Both had been employed in good and previously stable jobs. She had worked as a doctor's receptionist and he as a mechanic in a large motor company. At the time I first interviewed Ingrid, they were desperately trying to avert the repossession or sale of their house. During the time that I saw Ingrid, the situation stabilised somewhat as her older daughter found employment and her husband started doing private mechanical work from their back yard. However her daughter's job in itself created difficulties for Ingrid, as she felt guilty that the young woman had given up her plans to study in order to support the family financially. Her role as a good mother who could provide for her children was important to Ingrid, as she had undergone infertility treatment to conceive both her daughters.

Ingrid also revealed in a subsequent interview that she had strong suspicions that her husband was having an affair. She admitted that he had a history of infidelity from the early days of their twenty year marriage, but somehow they had managed to surmount these incidents. Basically she felt that they had a good marriage. He was generally loving and affectionate, had always supported them financially, he didn't drink and was in no way abusive. However, at this stage of her life, she wasn't sure that she could cope with yet one more assault to her self-esteem.

Despite the plethora of stress-inducing circumstances, Ingrid found it difficult to understand why she had been referred to me. She broke down and cried piteously saying, "I felt that they thought what I was telling them wasn't the *truth!*" Her symptoms, while they clearly mimicked possible cardiac problems – chest pain and tachycardia (rapid heartbeat) – had been exhaustively investigated and excluded by innumerable tests including several ECGs (electrocardiograms) and a plethora of blood tests.

I saw Ingrid for a total of five sessions. While concerns about her somatic symptoms remained, and did not entirely resolve through therapeutic work, she was able to make strides towards understanding the impact the various stressors had on her physical health. She was able to express an appreciation of the role of psychology and that she would recommend therapy to other people. Which, given her initial distress, was a valuable development in itself. We terminated our contact by mutual agreement when she developed a friendship with a woman who was going through similar marital and financial difficulties. While acknowledging the ongoing contribution of therapy, she felt that the personal connection was a sufficient alternative and one that did not involve the costs associated with travelling to the hospital.

### **17. Nomsa (31)**

Nomsa was a thirty-one year old, single isiXhosa woman who had been referred to me by the neurological consultant for severe but idiopathic headaches. All investigations had failed to show any organic cause or neurological deficits. The doctor reported that there had been some improvement when the patient was put on a low dose antidepressant. Ironically, Nomsa did not impress as either depressed (she was sleeping and eating well and had good levels of energy) or anxious, in spite of some work related and other stressors. In fact she brought with her an aura of pervading serenity which facilitated a peaceful interlude for both of us amidst the chaos of the outpatients setting.

Nomsa had been born and raised in the Eastern Cape. She came from a close family with parents who were married and still together. She had four siblings, all of whom remained in the Eastern Cape, but with whom she had regular contact. Nomsa had only relocated to Cape Town in order to improve her employment opportunities. She had done well throughout her schooling but had fallen pregnant during her matriculation year. She wrote her final exams while in the last stages of her pregnancy, but felt her results were below what she would normally have achieved. She had a fourteen year old son who lived with the extended family in the Eastern Cape. Nomsa described their relationship as good, but more like siblings than mother and son.

Nomsa was unusual in the community setting in which both my clinical and research work were situated in that she had finished her matric exams despite adverse circumstances and then continued on to obtain a tertiary education. At the time I saw her she was studying for an additional qualification through a technical college. She was employed in the HR (human resources) department of a nearby old age home run by an NGO (non-government organisation). She was ambitious and wanted to extend both her qualifications and work experience. Her job constituted a major stress factor as the internal politics were making it difficult for the institution to be run effectively. Nomsa felt distressed at the impact this was having on the elderly residents of the home.

When I asked Nomsa about her religious affiliations she corrected me by saying she was not “religious” per se but would prefer to describe herself as a “spiritual” person. She ascribed to tribal ancestor beliefs but also incorporated an acceptance in the God of Christianity. This was specifically in a congregation allied to the isiXhosa, called Zion, in which tolerance of traditional beliefs was assimilated. The aspect of spiritual commitment was an important component of Nomsa’s understanding of her symptoms. Three generations of women had been called to traditional healing, specifically to become izangoma (customary spiritual mediums who mediate communication between the living and the spirits of deceased family members or ancestors). Acceptance of this calling is considered obligatory and negotiating a way of either delaying or ameliorating its impact was part of the dilemma facing Nomsa.

During the two sessions I interviewed Nomsa, a great deal of the conversation revolved around her medical history (previous headaches and a torsion of her one fallopian tube) and the synchronicity with dreams she had in which she was invoked to accept her calling. At the end of the second interview, which had incorporated aspects of therapeutic work, Nomsa indicated that it would be difficult to return from a financial perspective. She felt that in our two sessions she had been able to work through some of her confusion and furthermore would be travelling to the Eastern Cape later in the year to consult with her mother and aunts about the way forward in respect of her calling.

**18. Elisha (23)**

I was on the point of completing my data collection when I received a call from the head of the trauma unit asking me if I would consider seeing a young female patient. She fulfilled the criteria for my research but he felt that she also needed to see a psychologist in a clinical capacity. There was nobody else he could refer her to.

I did not receive a written referral but the doctor provided the necessary information telephonically. Elisha had presented to casualty on numerous occasions with somatic complaints for which they could find no underlying organic cause. The trauma centre at Hope Hospital was unrelentingly busy and chaotic. Victims of gang and domestic violence, drug abuse and motor vehicle accidents crowded the available beds to the point that many patients spent days sitting in chairs waiting for medical management to be initiated and completed. An ostensibly healthy young woman presenting in this environment was almost an anomaly and it speaks to the dedication of the medical staff that a referral was considered and made to psychology.

Elisha, a twenty-three year old single mother, arrived for her first appointment early and came into the consulting room looking uneasy and without making eye contact. She was in traditional Muslim clothing and seemed to be shy and overtly apprehensive.

However, Elisha was able to clearly explain her physical symptoms (recurrent abdominal pain and headaches) and the history of medical intervention that brought her to the hospital. Like many patients, she had even visited a private doctor in her search for a diagnosis before being referred to the hospital system. She gave a history of two months of non-specific abdominal pain saying that differential diagnoses had included appendicitis and an ovarian cyst. These diagnoses were not supported by the investigations.

While I probed for her understanding of the situation, she suddenly became distressed and spontaneously raised two issues that became the prevalent themes throughout our sessions together. Her father was unknown to her – her mother had categorically refused to tell her who her father was, “I grew up without a father, I don't know *who* he is!” The second critical event was falling pregnant at nineteen while in a short-lived and abusive relationship. As a consequence, she went through the pregnancy

and delivery of her son without the support of a partner, which served to exacerbate her distress about her own fatherless state. Her vulnerability and feelings of abandonment prevailed throughout this and the subsequent session.

Almost without exception the participants in my research had previously failed to talk to either friends or family about their concerns and Elisha was no different. During our second interview I asked how she felt about talking to anyone and she responded by saying that she hid her feelings behind a façade of happiness, “but under that pretend smile it's a whole lot of sadness.”

In the subsequent interview she was able to express feelings of relief as a consequence of having talked about her situation with me and that people had seen a difference in her – that she felt that she had become more social and was smiling with genuine contentment more frequently.

Leading up to her referral Elisha had met and become engaged to a devout young Muslim man and was preparing to get married. The frenetic activities around the wedding preparation curtailed Elisha's ongoing attendance with me. While we successfully explored many of the questions related to my research topic, there were unresolved issues which could have benefited from ongoing therapy. The role of this supportive and loving man in her life had obviously evoked feelings which she had difficulty in identifying and which may have contributed to the escalation of her somatic symptoms. I phoned her the day before her wedding when she seemed distracted but happy and excited. Any possibility of following up in the future became unfeasible with the closing of the outpatients department at Hope Hospital.

### **19. Kamila (47)**

The number of participants in my study far exceeded the number I had anticipated including, however I found it personally and ethically impossible to refuse to see individuals who not only fitted my research criteria but who, through the imminent closure of the Hope Hospital facility, would have had no access to clinical interventions should I not see them while there was still the opportunity.

Kamila was referred to me in the final month of my data collection and very near to the time that the Hope Hospital outpatients closed its doors. She was a forty-seven

year old Coloured women at a pivotal stage of her life and suffering from somatic symptoms which were causing her enormous distress. For about eight months she had been experiencing what she described as a “choking” feeling in her throat. Although she was aware that these feeling usually occurred at times of stress, particularly when she was angry, she had lived with the fear that it indicated some kind of cancer. Eventually she sought medical help and was very specific about the details, “I went to the Day Hospital *five* times. I was three times at trauma and was twice at the doctor [private practitioner]. And then I came to Hope Hospital.” The lengthy and unsuccessful attempt to find an explanation for her symptoms reflected the experience of many of the patients on my study as well as in my clinical work.

Kamila was one of my last research participants, and I had become more adept at integrating my usual intake interview and the relevant research questions. At an early stage I asked about the time the symptoms started (January that year) and whether any particular incident was associated with their onset. Unlike the majority of participants Kamila knew exactly what had happened. In trying to tell me she became so distressed and tearful that she ended up speaking through gasping breathes as she described how she had discovered that her son had become “tattooed out” with the words, “In God we trust, and die we must.”

Throughout my clinical and research work juxtapositions of difference and similarity occur with regularity in my exchanges with my patients. This was a pivotal moment in my interaction with Kamila because it highlighted the unspoken socio-cultural differences between two women of roughly the same age. While I could understand her distress about the background to the event (the son had a long history of drug abuse) the significance of the tattoo and the words was completely lost on me. Later on I came to understand that these words were related to membership of one of the most notorious and violent gangs on the Cape Flats. For her as a mother, it appeared to be the point at which she felt she had lost hope for her son. With the generosity of spirit and tolerance that characterized the responses of so many of my patients, Kamila did not hold my ignorance and insensitivity against me. Instead her explanations and my sincere reaction of horror as a mother forged a link between us that certainly enhanced the therapeutic relationship. From that time on, she became more confident in disclosing details of her complicated life.

At this point the fairly unusual domestic arrangement of Kamila and her family emerged. She had been divorced from her husband for 13 years previously, was in another stable and supportive relationship, but remained living in the house with her ex-husband and their three adult children. She was no longer close to her children and reported that they were disrespectful and abusive. When I asked about the reason for them continuing to live together, she explained that although she had been brought up Christian, she had converted to Islam when she got married. She and her husband had been legally divorced but not by Islamic law. This was partly the reason for her reluctance to move out, along with the fact that she had originally stayed to care for her children. At the time I saw her she was regretting the decision to stay, because under their father's influence all three children (two sons and a daughter) were estranged from her. Her ex-husband was derogatory and verbally abusive towards her on an ongoing basis. Kamila came to connect the development of her somatic symptoms with an escalation in his abusive behaviour.

I saw Kamila two more times. During this time we explored options and ways in which she could support herself. The outpatients department was preparing to close so it was difficult to continue. However, her physical symptoms had abated and she was feeling better able to deal with the domestic problems. She was making plans to move out and was actively looking for better paying, more fulltime employment than her part time sport coaching provided. She was also returning to the religion of her childhood. I asked her how she was feeling. Her answer epitomized her innate courage and willingness to engage with life and any opportunity offered her, "I'm *nervous*, because I, I have to get used to it. Um (.1) I have to learn, again, but it doesn't matter by me, I'm always willing to *learn*. Um, I'm always prepared to take the extra step. (.2) And nothing is going to stop me!"

## **20. Joy**

I shamelessly orchestrated scheduling Joy's interview to be my last. Despite the *tabula rasa*, or blank slate, advocated as professionally appropriate by psychology, and injunctions against emotional involvement in the clinical setting, I have a sneaking suspicion that I am not alone in feeling particular connections with certain patients. Joy must rank as a favourite amongst all those patients I have seen during my years working in the Cape Flats community. Our initial meeting was not



auspicious, yet our relationship developed in a way that my respect for her humour, courage and insight is unparalleled by any other of the many patients or participants I have seen either inside or outside this research process.

This affection and respect transcends the apparent diversity of place, race and status in our particular and peculiar society. South Africa is a country beleaguered by narratives of division, difference and inequality which many feel to be inviolate. Sitting in the room together at the beginning of our first appointment in December 2010, Joy and I might have been seen to emblemise this. What possible interface could there exist between the professional, middle-aged White woman of privilege and the Black woman, some two decades younger, living in poverty and steeped in the role of traditional healer? Yet one of the last comments Joy made to me at the conclusion of her initial therapy was both a confirmation that the feeling was mutual but also a bizarre kind of reflected inversion of the words that initiated and supported the apartheid regime, “We are the same, but different.” She was referring to the way in which both worked for people’s health and wellbeing, but that we did so in different, but not mutually exclusive ways.

I have become inured to the initial hostility of the large majority of my patients and many of the participants in my research. I have learned to see it as a challenge to my therapeutic skills and feel disproportionately elated when I manage to successfully breach the defences. Even so, the baleful and apparently malevolent stare directed towards me by Joy during our first encounter gave me pause for consideration that maybe on this occasion I had more than met my match.

When she first saw me Joy was a thirty-nine year old, isiXhosa woman, living in one of the sprawling informal developments which surrounded Hope Hospital. She was divorced, living with her older sister, unemployed and existing on a government disability grant.

Joy had been born and educated in the Eastern Cape. She had done well at school until her matric year when she fell pregnant and got married. She had relocated to Cape Town in 2006 to stay with her older sister. While living in the Eastern Cape she had worked as her father’s assistant in his estate agency, but had not worked since coming to Cape Town.

Her physical symptoms of pain, abdominal, thoracic and breast, were of long-standing duration. These symptoms had apparently started some 10 years previously following a car accident. While she was hospitalized for a short time as a consequence of a brief loss of consciousness there were no other reported physical injuries.

Recollections of that period of her life were pervaded by the memories of an unwanted divorce. Her husband had initiated it unexpectedly to her bemusement and great distress. Despite parental and family emotional support she still grieved the ending of her marriage. At the time I saw her she was neither objectively nor subjectively depressed, but she did report pervading feelings of anxiety. Her anxiety related largely to the lack of employment. While she did all the domestic work in the home she shared with her sister, she had an urgent need to make a greater contribution. Her sister worked as a traditional healer from her house. During my time with her, it transpired that Joy had also received the calling, but had hesitated to accept it.

In my notes of that first visit I had commented, “Patient seems reluctant to engage with therapy. I doubt she will return for her follow-up appointment.” When I finished my rotation at Hope Hospital a year later, Joy had been coming to see me as regularly as her finances allowed and she was the last patient I saw there. We used the final session to reminisce about our contact over the past twelve months. She talked about the path which led to her feeling confident enough to work in her calling and how she continued to negotiate having to deal with traditional and western health management.

She reminded me how important dreams were to her work and then said, “I remember, the thing that (.2) the *real* reason that made me kept on coming here, was a dream. You remember? I had a dream.” I didn’t remember and she had to remind me:

“That I was in a dark room, with no windows or doors. And I was afraid, how would I get out of that room. (.2) Then, uh, I am going to summarize it, I can't remember it correctly but then I (.2) I saw *you* coming *through* the wall. Then the wall (.3) parted. Yes, parted, and then the light came through. And then I go out (.3). That's where, I came and told you that “Avril, this dream made me, *need*, have this need to come *here*. And (.2) every time you made an appointment. That's what kept me coming’.”

In my years of practice as a psychologist, these words provide the greatest vindication of the value of the work, and the importance of the value of respectful and honest relationship with our patients. The gift given to me by Joy has, on many occasions, provided me with the impetus to carry on working in the community at times when I have felt unequal to the task. The trust that patients, and research participants place in our hands is enormous and we owe them a debt of gratitude.

### **In Conclusion**

As in all the other processes of this research project, clear delineation between data collection and clinical work was not possible in compiling these biographical notes. Here, as elsewhere, something more crept in, something infinitely personal and precious. As I consulted my notes and read the transcription of successive participants, each woman seemed to slip into the room and keep company with me as I wrote. I was ephemerally held responsible to handle the secrets and disclosures with respect and honesty. The depth and detail of these life stories have only been touched on here. It was difficult to decide what to include and what to leave out. As difficult as it was, practical constraints dictated that this process of selection be implemented but I hope I have been true to the spirit of each woman's life. However, I am left with a sense of many other stories which remain untold and invisible.

In my interactions with each patient or participant I have invariably been left with a sense of having taken so much more away from the room than I have been able to give. Research carries with it connotations of taking. However, in some way the added clinical component possibly provided an opportunity to redress the expediency and self-serving potential of the research process.