

**Accommodating illness:  
the experience of suffering in a physically unwell  
homeless population**

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*To the man upstairs always lends an ear,*

*To the man downstairs even though he doesn't care,*

*The man up the spiral staircase, love the sympathy,*

*With the man downstairs and the same old face (John Martyn, 1977)*

## **Abstract**

The knowledge relating to objective health outcomes in the homeless population is extensive, but our understanding of illness experience and subjective health indicators is based on limited evidence. This study examines suffering, the experience of distress in circumstances which threaten sense of self, in a sample of 48 homeless persons hospitalised with physical illness. It addresses the questions: are illness related suffering (SIS) and suffering related to housing difficulties (SHS) associated? Does SIS or SHS predict quality of life, distress and well-being?

A significant small positive correlation between SIS and SHS was observed, supporting the hypothesis. Multiple regression analyses found SIS independently accounted for the variance in distress and quality of life, but not well-being. SHS did not predict quality of life, distress or well-being. Many participants placed illness and housing related suffering inside-self.

The findings suggest that physically unwell homeless persons experience suffering related to illness, as distinct to suffering related to housing difficulties. The predictive value of SIS is discussed with respect to the unique experience of hospitalisation for this population. The quantitative and qualitative data build on prior literature by highlighting novel threats to homeless persons' autonomy, dignity and integrity. The findings generate important questions regarding the conceptualisation of suffering for this population and this may be a promising avenue for developing collaborative health practices with unwell homeless persons. The cross-sectional design and heterogeneous sample limit the generalisability of findings. This thesis concludes with a recognition of the study strengths in engaging with a clinical sample, advancing the psychological understanding of homeless health, and the involvement of experts with experience.

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## **Chapter one: Introduction**

### **Overview**

In the UK, use of health services by homeless people is between four to eight times higher than the general population (Department of Health, DoH, 2010). A recent health audit in England found 78% of hostel dwelling homeless persons (n=2,452) report a physical health problem (Homeless Link, 2014). They present with more acute and chronic difficulties and are at up to five times higher risk of mortality (Hwang, Aubry, Palepu et al, 2011). Physical illness and disability are known risk factors for becoming and remaining homeless (Wong and Piliavin, 2001; Busch-Geertsema, O'Sullivan and Pleace, 2010). Homelessness is estimated to have increased by 40% over the past four years (Inclusion Health Audit 2015-16); the implications for health and social care are critical.

The following chapter firstly reviews the relationship between homelessness and health. An outline of the effects of both homelessness and physical illness on subjective health points to the importance of enhancing our knowledge of illness experience of this population. It argues for the development of health psychological understanding of homeless health, and a move to examining the subjective experience of distress related to illness. There is an emerging evidence base, but the relationship between physical illness and subjective health of this population is based on limited evidence (Hubley, Russell, Palepu et al, 2014).

This review will argue that Cassell's (1982) framework of suffering - the subjective experience of distress in circumstances which threaten sense of self - provides an important avenue of investigation for homeless experience of physical illness and subjective health outcomes. Homelessness, like illness, threatens sense of self; unwell homeless persons face unique and multiple threats (Boydell, Goering and Morrell-Bellai, 2000). This chapter will conclude with an outline of the rationale, aims and research questions of the current study.



## **Defining ‘homeless’**

To be homeless is to have “a lack of a safe, stable, and appropriate place to live” (Bray, Milburn, Cowan, 2010, p. 9). People without shelter and *with shelter* can be homeless. The legal definition accounts for the multitude of ways in which an individual can be homeless for example unable to stay in the home due to violence or threat of violence, unable to live together with family, or it is not reasonable to stay in the current conditions for example due to overcrowding or unaffordable costs (Homelessness Act, 2002). The definition of homeless has direct implications for care provision, for example the UK Parliament recently recognised the barriers to support for individuals in temporary accommodation or at imminent threat of homelessness, an increasing portion of the homeless population (Crisis, 2017). Homeless people themselves reject the term commonly used in the literature, ‘no fixed abode’ which does not capture the multiplicity of living patterns and lifestyles that exist (Law and John, 2012). Heterogeneity in the homeless population is also a significant challenge facing research designs. Homelessness is episodic and transient, therefore measures of homelessness have had difficulties capturing the nature of an individuals’ housing experiences (Hwang, 2002). Given these issues, the current review will aim to describe the specific research samples where possible.

## **Homeless health outcomes**

The Department of Health (DoH) indicate five domains for health outcomes: premature death; quality of life (QoL) in long-term conditions; recovery from episodes of ill health; experience of care; safe environment and protection from avoidable harm (DoH, 2016-17). As a social group, homeless persons suffer amongst the worst health outcomes (DoH, 2010).

Homeless persons are at increased risk of death, in the UK the average age of death for a homeless man is 47, and 43 for a woman, compared with the national average of 77 (Crisis,

2011). With regards to morbidity, in a hostel dwelling sample 85% have been found to experience at least one chronic health problem (Hwang et al, 2011). Rates of infectious diseases such as HIV, hepatitis C, and tuberculosis are extremely high (McCormick and White, 2016). Homelessness has been identified as an independent risk factor for heart failure readmission, controlling for treatment adherence (Shalen, Patts, Weinberg and Philippides, 2016). The homeless population are aging significantly, even taking into account the aging of general population (Culhane, Metraux, Byrne, Steno and Bainbridge, 2013). This phenomenon may be due to a cohort effect, with economic recessions in the 1970s and 1980s causing depressed wages for unskilled workers, higher housing costs and instability, paired with increased drug influx and rise of addictions at this time. Therefore, a substantially increased risk for young adults in this period, represented in current older homeless cohort (Culhane, et al, 2013). Older age also magnifies health risks, individuals over the age of 50 are 3.6 times more likely than younger homeless persons to suffer a chronic medical condition such as hypertension, lung disease, diabetes or arthritis; the older subgroup face increased morbidity, disability and need for medical care (see Grenier, Barken and Sussman et al, 2016 for review).

Health related QoL (HRQoL) in the homeless population is considerably worse than the general population (Sun, Irestig and Burstom et al, 2012). Homeless persons experience lower QoL and higher distress than the general population (Gadermann, Hubley, Russel and Palepu, 2014; Stein, Anderson and Gelberg, 2007). Life satisfaction has been found to be considerably lower than in the general population, and compared with people with severe and persistent mental health problems (Wolf, Burnam, and Sullivan, 2001).

With regards to recovery, homeless persons are more likely to be hospitalised, readmitted and have longer hospital stays (Kushel, 2016). Over a period of 6 months, a quarter of homeless hostel population are admitted to hospital and a third will visit accident and emergency in England (Homeless Link, 2014). A cohort study found homeless persons to be nearly four

times more likely to be readmitted within 30 days compared with low income matched controls (Saab, Nisenbaum, Dhalla and Hwang, 2016). Admissions in the UK are most commonly for physical trauma, respiratory illness, inflammatory conditions, infections, drug/alcohol related difficulties, and a range of mental health problems (McCormick and White, 2016).

Research investigating homeless persons' experience of health care consistently identify barriers at an individual and systemic level: lack of trust; information or knowledge about obtaining care; waiting times; lack of fixed address; immigration status; substance misuse and co-morbidities prohibiting provision (Canavan, Barry, Matanov et al, 2012). A systematic review of the qualitative literature identified numerous key challenges to provision and access to palliative health care for homeless persons: chaotic lifestyles, stigma, burden on hostel staff, and lack of expertise or flexibility in mainstream health setting (Hudson, Flemming, Shulman and Candy, 2016). A health audit of homeless persons in England found that while 85% reported being registered with a GP, close to 10% said they had been refused access for 'unsuitable behaviour', lack of ID, or proof of address (Homeless Link, 2014).

There is no specific NICE guidance for homelessness. However, homelessness is highlighted as an important consideration in NICE guidelines for numerous conditions: tuberculosis (NG33); HIV (LGB21); Oral Health (clinical pathway); Hepatitis B and C testing (PH43); alcohol use disorders (CG100); borderline personality disorder (CG78); coexisting mental illness and substance misuse (CG120) (Public Health England, PHE, 2016).

Finally, in terms of safety in the environment and protection from avoidable harm, homeless persons are frequently victims of abuse and assault (St Mungo's, 2016). In the UK, they are twice as likely to die of infections (Homeless Link, 2014). Homeless persons have a markedly higher in-hospital mortality than the general population, 37% higher for those aged 45-64, and up over 200% higher for those aged 25-34 (McCormick and White, 2016).

In light of the above severe health outcomes, it has been argued that homelessness must be addressed as a health issue (Cornes, Mathie and Whiteford et al, 2015; Fazel, Geddes and Kushel, 2014). Research has tried to determine the complex relationship between homelessness and health problems.

Physical illness and disability are risk factors for becoming homeless (Busch-Geertsema et al, 2010). A study of the causes of homelessness in newly homeless persons found that 77% identified physical health problems (Crane, Byrne, and Fu et al, 2005). In the English subsample, 10% reported health problems as the principal cause of homelessness, for example problems accessing or maintaining housing, or coping at home when their health deteriorated. Furthermore, physical illness was identified as a predisposing or contributing factor for 28%, for example stopping work due to ill health, leading to financial problems or family and marital breakdown (Crane et al, 2005). Ill health is also an important predictor in chronicity of homelessness (Wong and Piliavin, 2001). Older age is a known risk factor for long-term homelessness amongst those with first-time homelessness (Caton, Dominguez, Schanzer et al, 2005); a possibly causal pathway for this association is greater physical health difficulties in this subpopulation; the average age of single adults experiencing homelessness has increased, approximately 50% are aged over 50 (Brown, Goodman, and Guzel et al, 2016).

From an empirical perspective, there are obstacles to defining the nature of the relationship: measuring exposure to homelessness; major confounds (e.g. drugs, alcohol use); the transient nature of homelessness; and the challenge of longitudinal assessment in this population (Hwang, 2002). Although there are numerous challenges to defining the nature of the relationship (measuring exposure to homelessness; major confounds such as drugs, alcohol use; the transient nature of homelessness; and the obstacles to longitudinal assessment in this population, Hwang, 2002), the body of evidence so far indicates that physical health problems are both a cause and consequence of homelessness.

## **Relevant UK policy**

### **Towards an inclusion health agenda**

Tackling the inequalities which lead to poor health and result from poor health has become a fundamental government priority (NHS England, 2014). Parliament have pledged commitment to homelessness, recognising it as a symptom of health inequalities and placing new duties on public health providers to offer care (PHE, 2016; Crisis, 2016-17). Recent guidance '*Improving Health Through the Home*' (PHE, 2016) recognises the costs of poor housing. Poor housing is believed to cost the NHS at least £1.4bn in the first year, in terms of treatment costs (Nicol, Roys and Garret, 2011). It is no surprise this is on the government's agenda, reports of public spending on health services are estimated to cost more than £85 million per year (Buck, Simpson and Ross, The King's Fund, 2016). Additional costs of the NHS use for one single homeless person is estimate to rise to approximately £25,000 for 12 months (Crisis, 2015). In 2011, The Faculty for Homeless Health published the first set of standards for health services for homeless health in England with guidelines for improving hospital admission and discharge (Albanese, Hurcombe, and Mathie, 2016). The London Homeless Health Programme worked towards improving policy and provision via service user involvement and improved commissioner awareness, however momentum has been severely affected by welfare reform and financial austerity (Whiteford and Simpson, 2016).

### **Integrating health and social care**

Statutory and NHS frameworks, as well as community care law have adapted accordingly over the past decade to match the need. An emphasis has been on the reform of health and social care, towards integration. The Care Act (2014) removed conditions of eligibility which previously would lead to the exclusion of homeless persons from health and housing support, falling between the gaps of services (Cornes et al, 2015). Local Authorities have a responsibility to support integration of services with the NHS, and address the wider

determinants of health, such as housing (Health and Social Care Act, 2012; The Care Act, 2014). Partnership between health, social care and housing is a legal recognition of homelessness as a public health issue, with direct consequences for legislation. Developments in homeless health practice in hospitals match this move towards integration (Dorney-Smith, Hewett, Khan, Smith, 2016).

### **Clinical health psychological perspective**

According to the World Health Organization (1948) definition, health is “a complete state of physical, mental, and social wellbeing and not merely the absence of disease or infirmity”. The past four decades has seen a shift beyond medical outcomes, towards examining the social and psychological processes in health (Suls and Rothman, 2004; Taylor, 2015). Health research has been mandated to achieve parity of esteem between physical health and psychological health (Royal College of Psychiatrists, 2013). Prevalence of mental illness in homeless persons is well documented. Meta-analytic data estimate rates of drug and alcohol dependence to be at 38%, personality disorders at 24% and close to 13% psychotic illness (Fazel, Khosla, Doll et al, 2008). In the UK, homeless persons attending primary care were found to receive the diagnosis of depression (29.7%), or alcohol dependence (29%) more than any other physical or mental health diagnosis; the study found 8.3% had attempted suicide or self-harm (Hewett, Hiley and Gray, 2011).

The discipline of health psychology has significantly contributed to advances in medical practice and theory. “Health psychology aims to understand psychological influences on how people stay healthy, why they become ill, and how they respond when they do get ill.” (Taylor, 2015, p. 3). A biopsychosocial approach is its core “*conceptual base*” (Suls and Rothman, 2004); that is, a recognition that health outcomes are the consequence of the complex interplay between biological disposition, an individual’s cognitions, emotions and behaviours, as well as their social context (Kaplan, 2009). The discipline has been instrumental in key health

developments over the past four decades notably, in the treatment and prevention in the HIV/Aids epidemic, smoking cessation, and reducing disability in long-term conditions such as diabetes, heart disease and cancer (for review see Michie, West and Spring, 2013; Freeland, 2017). The following section will describe the shift in the wider medical, and health psychological literature towards examining subjective health outcomes. It will then outline the several key constructs in this movement, QoL, distress and well-being. This will provide a framework for reviewing the current knowledge in subjective health outcomes for homeless persons, and examining the implications for homeless health research.

### **Questioning the dominance of objective health outcomes**

Research introduced above demonstrates the stark reality of physical and mental illness in this population. These findings are mostly drawn from allied disciplines such as medicine, public health, epidemiology, psychiatry and behavioural medicine. These fields dominate the wider health literature. Primacy is given to *objective* physical and mental illness symptomatology, evaluating outcomes in terms of the absence, or presence of pathology (Cassell, 2016a). A historical review of health psychological research in the UK highlights that journal articles since the 1990s have primarily applied behavioural and biological models, relying on objective markers of disease such as mental illness (Murray, in preparation, 2017).

This focus on disease variables provides a restricted picture of *health*. In the context of physical health for example, examining psychiatric symptomatology has the underlying assumption that poor adjustment may reflect mental illness (Moss-Morris, 2013). Furthermore, objective indicators of illness have a weak predictive value in terms of understanding subjective self-reported health. In the general population, objective disease variables (e.g. severity, nature) are not robust predictors of QoL, depression or anxiety (Sensky, 1990; Eack and Newhill, 2007). Health psychology has underlined the importance of two related but distinct constructs, illness experience, and subjective health which will be defined in the following sections. This

mirrors a wider movement in health evaluation, capturing outcomes which are meaningful to service users (Kaplan, 2009; Ogden, 2012; Taylor, 2015). While health psychological research has primarily examined objective markers of disease, a branch of the field has also helped extend how health outcomes are evaluated, beyond objective illness markers. The following section will present QoL, distress and wellbeing, key factors in the measurement of subjective health.

## **A move towards subjective health outcomes**

### **Quality of life**

The World Health Organisation (WHO) defines QoL as, “an individual’s perception of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (WHO-QoL, 1997, p. 1). It is influenced by multiple domains: physical and mental health, social functioning, pain, role limitations, environmental factors and personal beliefs. Health is an instrumental component of QoL and wellbeing, yet it is a separate concept (Bickenbach, 2017). Crucially, subjective self-report of QoL departs from objective indicators (e.g. Income, employment or social interaction) which attempt to quantify the frequency or nature of for example social interactions, rather than measure subjective rating of the quality of social interactions (Ogden, 2012). An adaptive outcome in the context of rheumatoid arthritis for example, may be maintaining self-reported QoL in face of pain and progressive loss of function (Moss-Morris, 2013). While a metric of QoL and wellbeing can be objectively assessed, it is (arguably) dependent on subjective self-report (Schramme, 2017). There has been increased emphasis on subjective ratings of QoL and psychological wellbeing in chronic health conditions (Taylor, 2015); this follows findings of a ‘disability paradox’, individuals with serious medical conditions and high disability may continue to report good QoL (Albrecht and Devlieger, 1999).



## **Distress**

Psychological distress has been a term used in the research literature to reflect physiological hyperarousal, and low positive affect, and negative affectivity (Hamer, Chida and Molly, 2009). These dimensions of overall distress can be represented by depression, anxiety and stress (Henry and Crawford, 2005). These terms are widely used in everyday reference to psychological health. Phenomenologically, it has been difficult for research to disentangle depression, stress and anxiety (Henry and Crawford, 2005; Miloyan, Bulley, Bandeen-Roche et al, 2016). Overall distress, as well as each subdomain, is associated with increased risk of health conditions (e.g. cardiovascular, metabolic) and individuals with poor health status have report higher anxiety, depression and stress (Miloyan, et al, 2016; Ogden, 2012; Robinson, McBeth and MacFarlane, 2004). Anxiety and depression are the most common forms of mental health conditions, and leading causes of disability (Baxter, Scott, vos and Whiteford, 2013). Multiple meta-analyses have identified distress, depression and stress each as an independent risk factors of mortality across health conditions (Gathright, Goldstein, Josephson and Hughes, 2017).

## **Wellbeing**

Wellbeing has also emerged as an important measure in the UK government's agenda, it is now monitored as a key national indicator for 42 countries (Diener and Tay, 2016). It has been argued that wellbeing should also be a standard measure in routine health evaluation (Ryff and Boylan, 2016). QoL and wellbeing are terms which have been interchangeably in the literature (Schramme, 2017). Definitions vary across disciplines and operationalised for sociological or economic instruments for example (see Veenhoven, 2017 for review). In the clinical psychology literature, wellbeing has been defined as having two aspects, hedonic (i.e. Subjective experience of happiness and life satisfaction) and eudaimonic (i.e. Psychological

functioning such as autonomy, sense of mastery, personal growth) (Tennant, Hiller, Fishwick et al, 2007).

Interest in wellbeing developed out of findings that reducing negative states, which preoccupied the field of psychology, did not equate with increase in positive states (Diener, Lucas, and Oishi, 2009). Findings have since pointed to an important role of wellbeing in health. In the general population, self-report hedonic wellbeing is independently associated with fewer visits to the doctor (Kim, Park, Sun and Smith, 2014). In samples with chronic health conditions such as rheumatoid arthritis and fibromyalgia, high hedonic wellbeing was found to be prospectively linked with lower pain (Ryff and Boylan, 2016). Several reviews have identified a role of hedonic wellbeing in objective health outcomes for example in reducing cardiovascular risk and even mortality for renal failure and HIV (Chida and Steptoe, 2008; Boehm and Kubzansky, 2012). In English older adults, wellbeing was found to be a key protective factor, reducing the risk of co-morbid physical illness and promoting longevity (Steptoe, Deaton and Stone, 2015). Numerous physiological mechanisms have been hypothesised, including improvements in neuroendocrine, metabolic and immune systems (Ryff and Boylan, 2016).

The following section will firstly review the relationship between objective health status and the subjective health outcomes. It will then examine the knowledge regarding the relationship between housing status and subjective health outcomes, QoL, wellbeing and distress.

### **Physical illness and subjective health outcomes in homeless persons**

The following section reviews the current knowledge which derives predominantly from research investigating perceptions of health in the hostel homeless population, and secondly from qualitative investigation of physically unwell homeless persons. Early research from Gelberg and Linn (1989) found 62% of shelter dwelling individuals observed to have high

blood pressure were unaware of their condition. Daiski (2007) interviewed 21 Canadian homeless adults recruited from the street, and a drop-in centre, about their perceptions of health. Participants had multiple health conditions including respiratory, infectious and cardiovascular diseases, described their physical illnesses, injuries and disabilities as caused or worsened by homelessness. The homeless sample were found to perceive their health as secondary to security and safety (Daiski, 2007). Homeless persons possibly minimise health concerns due to complexity in their lives. The analysis identified constant fear of violence, lack of security in homeless shelters, and a sense of being dehumanised by the fear. Emotional distress was associated with mental health problems, addiction and crime, the participants reported feeling guilt and shame related to their drug and alcohol use. Exclusion and being invisible to the world was an important cause of suffering. Flick and Röhsch (2007) qualitative study of 24 German adolescents recruited at a social care support service, found participants defined good health as simply being able to function. Many denied health problems or saw their own health as not highly relevant, and mentioned deliberate neglect, substance misuse and the consequences of health as of low importance.

Gelberg, Anderson and Leake's (2000) seminal findings challenged the above conclusions that homeless persons were unaware of their conditions. They examined the hypothesis that homeless persons would only seek care for more immediate and obvious health problems (e.g. Skin, or foot problems, vision impairment) and not for health conditions which were asymptomatic but with long term consequences (e.g. High blood pressure, TB). Brief structured interviews and physical health checks were conducted with 363 persons temporarily accommodated, and shelter dwelling homeless populations in Los Angeles USA. The sample were screened for four physical health conditions (skin/ leg/ foot problems, blood pressure, vision problems, or tuberculosis). They were followed up at two time points, four months apart. One third were covered by health insurance. They hypothesised that care would be

sought for conditions which were symptomatic and have more immediate impact on their ability to function, that is, skin/leg/foot problems and vision impairment. In fact, they found the reverse, four-fifths of the sample with high blood pressure and tuberculosis obtained care. Less than half of participants with vision or skin/leg/foot problems sought medical care. Therefore, homeless persons were more likely to seek care for conditions with less immediate, but longer-term effect. The authors argued that knowledge and concern of homeless persons may have been underestimated (Gelberg et al, 2000).

Rae and Rees (2015) qualitatively analysed (using an interpretative phenomenological method) semi structured interviews with 14 participants from a UK homeless hostel regarding their health needs. Homeless persons did recognise their health needs but prioritised shelter, food and stability. Participants had found previous health care experiences to be negative, feeling unwelcome, treated badly or uncared for. The authors also argued that alcoholism and drug use were ways of avoiding distress related to illness and homelessness. O'Brien, Schuttke and Alhakeem et al (2015) found homeless drug users were four times more likely to report poorer QoL compared with homeless persons who did not take illicit drugs.

Recent findings stimulate further questions regarding homeless persons' perceptions of health and HR-QoL. Gadermann et al (2014) observed self-reported health-related QoL in a vulnerably housed sample in Canada. Using The Quality of Life for Homeless and Hard-to-House Individuals Inventory (QOLHHI; Hubley, Russell, Gadermann and Palepu, 2009). They found that despite 87.9% of participants reporting at least one physical condition, overall individuals were neither satisfied nor dissatisfied in their health-related QoL (HR-QoL). Homeless persons saw their health as average, and only slightly worse than they wanted or considered ideal. Close to one third reported their health was "the same or better than I want". Participants described their health as "fair". The authors argued that the unexpected self-report

HR-QoL may be due to skewed social comparisons, 42% of participants compared themselves to family or friend who were also faced significant social deprivation. Alternatively, it was proposed that homeless persons make positive adjustments to their context and expectations (Gadermann et al, 2014). Several studies have begun to translate our knowledge of health beliefs, attitudes and behaviours to understand the experience of illness.

The above studies, Gelberg et al (2000), Rae and Rees (2015), and Gadermann et al (2014) each examined perceptions and attitudes towards personal health and seeking care, rather than illness experience. The findings highlight that there is a discord between homeless person's objective poor health and the subjective report of average health. The more plausible explanations for this are that individuals prioritise more imminent threats to safety, and/or due to skewed social comparisons. Furthermore, while homeless persons, many of whom are physically unwell, report poor QoL and high distress, there is lack of clarity regarding whether this is directly related to their experience of illness. The above studies provide some insight into homeless health experiences, yet in each case the illness experience was not examined, and its relationship to QoL, wellbeing or distress was not of primary interest.

An important longitudinal study suggested health may be a stronger factor than housing in homeless persons' QoL. Wolf et al (2001) examined QoL (Lehman Quality of Life Interview, 1991) scores for three homeless groups in Los Angeles USA, 1. Did not exit homelessness 2. Allocated dependent housing 3. Allocated independent housing. The study captured data at multiple time points over a 16-month period, a rare achievement for the homelessness research literature. They found 'exit from homelessness' did not have a significant effect on overall life satisfaction. The authors reported that mental health and functioning, as well as life satisfaction were better predicted by ill health or self-care, rather than housing satisfaction or being housed. In this sample of 485 participants, change in self-assessed general health was a significant

predictor of change in QoL. A limitation of the findings was the use of crude idiographic measures of mental health, rather than using standardised distress or wellbeing questionnaires.

Two recent reviews conclude that few studies have specifically examined the experiences of homeless persons who are actively unwell, that is, in need of immediate medical treatment through hospitalisation (Chant, Wang and Burns et al, 2014; Hubley et al, 2014). Chant et al, (2014) found of 2,563 citations, just five papers examining critical illness with homeless participants. Hubley et al (2014) review of the literature into subjective QoL in homeless persons, concluded, the subjective health experiences of homeless persons remains understudied, notably those actively unwell.

One qualitative study provides useful insight into the unique experiences of homeless persons facing current physical illness difficulties. Håkanson and Öhlén (2016) examined the illness narratives of nine rough sleepers with multiple chronic conditions, receiving physical and social care. Individuals described falling ill as feeling “without a parachute”, lacking social support or professional care. Prior research found physical illness to trigger a sense of isolation for homeless persons (Song, Ratner and Bartels et al, 2007). Song et al (2007) interviewed 53 adults using social services for homeless persons, using qualitative thematic analysis. They found nearly all participants had personal experiences of death and loss from a young age, as well as serious illness and injury. The authors suggested that this had led to a sense of fatalism as well as fear relating to death. Individuals also felt isolated in relation to institutions and friends; they highlight feeling rejected and stigmatised by services and that friends showed little care for them.

Håkanson and Öhlén (2016) found illness was associated with a loss of the freedom they felt on the streets, to a feeling of becoming dependent and being institutionalised. Illness triggered feelings of hopelessness regarding the future,

“It doesn’t end just because you end up in health care. It never ends you see, nothing ever ends. And the disease only gets worse. The cancer in my liver will remain, and all the cysts in my arms will remain.” (p. 8)

The authors draw on Frank’s (1995) theory of illness narratives, which points out that illness creates a disruption to temporality in one’s life and yet typically individuals are able to observe the future by maintaining a desire for health. Håkanson and Öhlén (2016) contrast this with the illness experience of homeless persons. They found that for unwell homeless persons, self-care, hope and recovery were beyond imagination. They argued that homeless experience of chronic and/or multiple conditions should be conceptualised as akin to a palliative health model of care, with focus on wellbeing, QoL and meaning in the context of illness (Håkanson and Öhlén, 2016).

## **Homelessness and subjective health outcomes**

The literature also finds unexpectedly that housing status or satisfaction with housing does not reliably predict subjective QoL, wellbeing and distress in this population. Numerous authors have drawn on Maslow's (1954) classic hierarchical theory to understand the effects of housing on subjective or psychological health. Maslow's (1954) early work viewed behaviour as goal oriented, organised in terms of necessity, and hierarchical; fundamental or 'deficiency needs' such as food, water, safety, security, excretion, and sleep are given primacy. Humans prioritise deficiency in basic, or 'being needs' over belongingness, love, self-esteem, therefore an individuals' psychological health is not realised.

His theory has provided a useful framework for understanding the experiences of individuals facing *significant deprivation*, including addiction (Best, Day and McCarthy et al, 2008) serious mental illness (Roychowdhury, 2011) homelessness (Hamlet and Hetherington, 2011). Maslow's (1954) final stage of self-actualisation overlaps with current understanding of mental health recovery and wellbeing (Henwood, Derejko, Couture and Padgett, 2014). The homeless intervention literature provides an important insight into the burden of housing on subjective health. The following section will present four seminal studies which address a renown polemic in the literature and in homeless policy, Housing First (HF) versus Treatment First (TF). These intervention approaches simply differ in the order in which homeless care needs are met. HF approaches align themselves with Maslow's hierarchy i.e. Housing is a precondition for physical and subjective health. TF approaches argue that biopsychosocial interventions are required for individuals to access or benefit from independent or other housing.

Patterson, Moniruzzaman, Palepu et al, (2013) conducted a randomised controlled trial (RCT) with two groups, high needs or moderate needs (according to mental health diagnoses and service use over five years) who were either assigned no additional housing or support services



(TAU), or two types of supported housing. In a Canadian sample of 497 homeless adults with mental illness, the authors found that provision of housing and support services significantly improved overall QoL (Quality of Life Interview-20, QoLI-20, Uttaro and Lehman, 1999) after six and twelve months compared with the no housing or social support. This significant difference was observed independent of type of housing and support received, or level of need. Unsurprisingly the most notable impact of housing provision were QoL domains of safety and living situation (Patterson et al, 2013). Individuals with higher needs reported the greatest improvement in feelings of safety and satisfaction with living arrangements compared with the TAU group.

Receipt of housing may not reduce suffering as this group continue to face isolation and material deprivation (Hopper, 2012). Bild and Gerner (2006) found that a supportive housing intervention for individuals with drug and alcohol difficulties, improved overall QoL but had no impact on increasing social contacts, meaningful daily activities or substance misuse. Patterson et al (2013) conclude that while studies find the effects of housing on fundamental needs such as security, as they term “housing-related QoL”, there is limited insight into the other domains of QoL for homeless persons, notably health related aspects of QoL. In Patterson et al (2013)’s total sample, 82% had more than two chronic physical health conditions, and yet health related-QoL (HR-QoL) was not captured in their study. This is a common feature of the literature (Hublely et al, 2014).

A longitudinal comparison of the effectiveness of HF and TF randomised 63 homeless adults enrolled in a North American treatment programme for serious mental illness into either one housing first one of three treatment first programmes. Using Maslow’s hierarchical needs framework, the authors found that participants randomised into HF expressed fewer ‘deficiency needs’ (such as need for housing and employment), and could name more self-actualisation goals (Henwood et al, 2014). The TF group continued to be preoccupied by housing needs,

and were also more likely to disengage from services. However, Henwood et al's (2014) study uncovered a more complicated picture. Firstly, identification of recovery-oriented goals was associated with *not* having basic needs met rather than fulfilment of basic needs (Henwood et al, 2014). For example, those with housing security continued to feel unsafe; they expressed needs relating to material deprivation, relationships and employment. Furthermore, there were no differences in subjective health needs expressed between the two groups after one year. The authors concluded that housing security could not predict firstly the pursuit of or achievement of recovery oriented goals in this population. The study highlighted the limited conceptual value of Maslow's hierarchical theory in understanding the subjective health, QoL, distress or wellbeing of homeless persons.

Prior studies have also identified a complex relationship between homelessness and subjective health. Wong and Piliavin (2001) investigated stressors, resources and distress in a sample of over 430 adults in homeless shelters in North California. This longitudinal design used structured interviews relating to physical status, service use, as well as a measure of stress (Centre for Epidemiological Studies Depression Scale, CES-D) at two time points, follow-up conducted between three months and one year after baseline. The authors found high levels of psychological distress. They reported that the greatest predictor of psychological distress at the follow up, was greater duration of homelessness, which unexpectedly predicted lower distress. There had been no effect of homeless chronicity on distress at baseline. The authors propose that their measure of homelessness did not capture the episodic character of homelessness and experiences of housing which were unstable and insecure, may have been greater distress in those who were less chronically homeless. Alternatively, this may be due to acculturation, homeless persons assimilate their lifestyle and identity. A recent review also found age may be a factor in this process, being older is associated with better subjective QoL in homeless samples (Hubley et al, 2014).

More recently, in North America Tsai, Mares and Rosenheck (2012) investigated the effect a housing intervention for 756 chronically homeless individuals with disabling health conditions. The study assessed subjective QoL using a single item rating on seven-point scale, functional outcomes using a 16-item scale (Katz, 1963), medical outcomes using the Medical Outcomes Study Short Form-12 (SF-12, Ware, Kosinski, and Keller, 1998), social support, life satisfaction, and housing satisfaction across two years. Despite successful provision of housing, housing satisfaction was found to not be predictive of QoL, life satisfaction, distress, functional outcomes or physical health in this population (Tsai et al, 2012). The authors did however find significant difference when comparing housing satisfaction between two sites, with site significantly accounting for the variance in QoL. Satisfaction with housing environment did also predict higher QoL, and satisfaction with landlord interactions predicted greater social support. The authors conclude that housing satisfaction is therefore multi-faceted, with numerous domains. They argued that change to housing situation or satisfaction should not be used as an indicator of global indicator of outcomes.

These findings reviewed in these four, large-scaled North American studies indicate that subjective health outcomes, QoL or distress are not reliably predicted by housing status or housing satisfaction. The experimental findings suggest the relationship is more complex. There are parallels with the ‘disability paradox’ outlined above in the health psychological literature.

Research into psychological wellbeing also shed light on the factors implicated in homelessness. Subjective wellbeing has increasingly been recognised as an important outcome (Diener, Tay and Oishi, 2016), however few studies have examined positive psychological constructs in the homeless population. A cross cultural study comparing wellbeing and life satisfaction in Indian and North American homeless persons found Indian sample were in the positive range, significantly higher than US counterparts (Biswas-Diener, 2006). The authors

argued that social relationships mediated the relationship between material deprivation and wellbeing. They suggest that the Indian sample benefited from a collectivist society, which allowed greater opportunity for social connections amongst the homeless community. Kidd and Davidson (2007) found an association between resilience and independence, or what they termed a disconnection from others. These adaptive processes in the face of adversity highlights the unique cultural and social lives of homeless persons as well as the importance of context on mental health in this group.

### **Critical appraisal of the current knowledge**

The above findings demonstrate the complexity in homeless experience of housing and health, and how these factors relate to subjective health outcomes such as QoL, wellbeing and distress.

#### **Limited psychologically informed homelessness research**

Integrating housing and health has become a key priority in policy and intervention (Health and Social Care Act, 2012; St Mungo's, 2015), as has a psychological perspective in health (DoH, 'No Health Without Mental Health', 2011); however, the empirical literature has not mirrored this shift. Two reviews of psychological research in homeless populations both conclude that homeless health and housing has seldom been the focus of empirical investigation (Hubble et al. 2014; Philippot, LeCocq, Sempoux et al, 2007). Medical, epidemiological or public health research dominate the field. Consequently, examination of psychological and social wellbeing is secondary in research aims. This has also contributed to the use of brief measures for example of QoL, creating methodological limitations (Hubble et al, 2014). Health psychological theory has been primarily concerned with behavioural change (Murray, 2014).

Davis, Campbell, Hildon, Hobbs and Michie's (2015) scoping review identified 82 theories of health behaviour change, just four dominant theories<sup>1</sup> accounted for 63% of papers.

Psychological research has continued to use psychiatric symptoms or substance use as distinguishing sample features (Matejkowski, Lee and Henwood et al, 2013; Patterson et al, 2013). The limited predictive value of diagnostic symptoms has been outlined. A longitudinal investigation of risk factors for homeless chronicity emphasises this (Caton et al, 2005). Caton et al (2005) found that coping skills and functioning were better indicators of one's ability to exit homelessness than psychopathology, diagnosed mental illness, or substance use disorder. The wider health psychological literature has moved towards subjective experience, as findings demonstrate the limited value of objective measures of disease in understanding individuals' unique experience.

### **Generalisability of the research**

The majority of research is in Canadian and US samples, where health and social care systems are highly distinct (Schüz, 2017). The role of social and cultural context on homeless health experience is critical. A significant number of the above studies were based North America and Canada. The Canadian 'Health and Housing Transition' study for example has been instrumental in providing longitudinal data on homeless health, housing and QoL in the past decade (Hwang, Aubry, Palepu et al, 2011). Schüz (2017) Identified 82 theories of health behaviour change, 63% of articles used just four of these theories, over 60% of articles were in North America, and 60% were intervention studies. Applying findings to homeless experience in the UK is problematic as Hsieh (2016) qualitative study of homeless health concerns and strategies in the USA highlights. Hsieh (2016) found that, while illness did pose a threat to their identity, their primary concerns were a lack of resources, which inhibited their chance of

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<sup>1</sup> The Transtheoretical Model of Change, The Theory of Planned Behaviour; Social Cognitive Theory and The Information-Motivation-Behavioural Skills Model (Davis et al, 2015)

treatment. Participants from USA and Canada face a distinct medical system, this has a direct impact on illness experience. Of the studies cited in the section above, just two were European, and one in the UK.

A further sampling bias is the lack of representation of physically unwell homeless persons in the literature (Toro, 2007). There remains relatively little understanding of the subjective health and wellbeing of homeless persons in the context of physical illness. A systematic review of psychological research in European homeless literature found the overwhelming majority of research to have recruited ‘hostel dwelling’ homeless persons, with findings subsequently generalized (Philippot et al, 2007). Homeless persons can be conceived of as a cultural group (Law and John, 2012).

#### **Lack of consideration of SES in psychological theories relating to health**

Finally, given the equivocal nature of so much of the research findings it is crucial that a comprehensive theoretical understanding is developed. Health psychological theory has facilitated understanding, dissemination and the advance of clinical health research across chronic health conditions (Taylor, 2015). The British Psychological Society Code of Human Research Ethics (BPS, 2010) places *social responsibility* and *societal contribution* as core values of research. Clinical health psychology has become a key component in understanding and managing long term health conditions (DoH, ‘No Health Without Mental Health’, 2011). Schüz’s (2017) critique of mainstream health psychological theories highlights a failure to account for factors of socio economic status and health inequality, either ignoring it as a factor, or controlling for it, that is “treating it as a nuisance variable” (p. 3). Yet in homeless health literature there is a dearth of health psychological input; it is a perspective which could be critical in confronting the challenge of perpetuating homeless cycles (Maguire and Ritchie,

2015). The *duty* to reduce health inequalities not only lies with commissioning groups, policy and practice, it also rests with clinical research and theory (Homeless Link, 2014).

I have argued that homelessness should be conceptualised as a health issue, however clinical health psychological theory has rarely examined homelessness under this assertion. This is a wider problem with regards to theory-driven research, just one third of health psychology studies are guided by theory (Painter, Borba, Hynes et al, 2008). A review of psychological research on homelessness in Europe also stated that a major weakness is the atheoretical nature of literature (Philippot et al 2007). In the intersection of clinical health psychology and homelessness, theoretically driven research is even more sparse. As a crude yet significant indicator, literature searches of “homeless” in the title or abstracts of the leading clinical and health psychological journals rendered extremely few results (Appendix 1). Theorists and researchers have demanded that health psychological models be tested and developed in vulnerable populations, for validation, specific cultural understanding and as an ethical requirement (Leventhal, Weinman, Leventhal and Phillips, 2008; Taylor, 2015; Sensky and Büchi, 2016). The following section will argue that Cassell’s (1982) conception of suffering will be important framework for developing our theoretical understanding of homeless health and illness experience.

### **Illness experience: Suffering**

Suffering is the subjective experience of distress in circumstances which threaten sense of self; it is unique to the values, history and context of the individual (Cassell, 1982, 2004, 2010, 2014). Hoffman (2017) provides the distinction between illness, disease and sickness. Disease is the objective, the biological, sickness refers to the social role and disability, illness refers to the person’s experience of disease; the fundamental component of illness is suffering. Aspects of disease, such as pain, can be a source of an individual’s suffering, but not necessarily their priority. Relief of pain for example may not relieve suffering.

Illness can impact on any aspect of a person, their physical state, thoughts, feelings, or social functioning. “The first lesson of suffering is that bodies do not suffer, persons suffer” (Cassell, 2014, p. 2). The cognitive, physical or emotional meanings for an individual influences their illness experience, and consequently, suffering. Suffering is also shaped by the social, spiritual or political context of the person (Cassell, 2010). Therefore, Cassell emphasises, it is the meaning for the person which leads to suffering. The example of childbirth is used to explain the importance of context and meaning in his model, in labour severe pain may be matched with an uplifting experience (Cassell, 2004). In contrast, little but unexplained pain can cause high level of suffering to the person, similarly, the reduction in pain may not prevent suffering from continuing.

“Meaning is the medium, the intervening agency, which unites all aspects of sickness and its impairments with the person” (Cassell, 2010, p. 52).

Suffering is entirely personal, relating to loss of purpose and dignity. Dignity is a human right for self-worth and respect.

Cassell (2014) contends that the dominant model in medicine, disease theory (the primacy of a physical cause and cure for sickness), fails to account for the *person* in illness manifestation and treatment. Language is crucial to understanding the varying goals of medicine, disease is a cluster of symptoms, in contrast, illness encapsulates the social definition, perceived by the individual and others. The physical manifestations of disease are neither predictive, nor representative of illness experience (Cassell, 2010). He argues that medicine continues to give primacy to objectivity, attending to measurable evidence of sickness in patients. This reductionism, focus on sickness symptomatology neglects the person in the patient (Cassell, 2014). Yet, in face of illness, prioritising the disease may not reflect the person’s experience, their illness suffering may have its source elsewhere, which should thus be the focus of medical



attention (Cassell, 2010). Knowledge of the person should be equal to that of the illness. Equal weight accorded to objective and subjective knowledge (Cassell, 2004). A persons' subjective experience, their *suffering*, is key to the understanding of illness and provision of compassionate care. There is evidence that Cassell's notion of suffering is an important predictor of subjective health outcomes across health conditions.

### **The relationship between illness suffering and subjective health outcomes**

Individuals' unique perspective on how their illness affects their lives is an important predictor of distress or disability (Rapoff, 2009). Cassell's construct of suffering has been examined using a psychometrically robust measure, The Pictorial Representation of Illness and Self Measure (PRISM; Sensky and Büchi, 2016). PRISM is a visual tool which asks individuals to place a disk representing their illness on a board in proximity to another disk representing their 'self', with the instruction 'where would you put your illness in your life at the moment?' Less separation between self and illness indicates higher suffering and is associated with greater distress (Büchi, Buddeberg, Klaghofer and Sensky et al, 2002). Suffering is also related to less controllability of illness and symptoms, as well as greater intrusion on one's life and self. Suffering is determined not by intensity, severity of symptoms or the illness itself but by its meaning to the individual (Wouters, Reimus, Nunen, et al, 2008).

A recent qualitative synthesis of over fifty publications across a range of illnesses such as cancer, PTSD or chronic pain, reported consistent significant correlations between suffering and depression, pain and QoL measures (Senski and Büchi, 2016). Several studies have reported discrepancies in findings using PRISM. Denton, Sharpe and Schrieber (2004) did not find a correlation between illness suffering and depression in a sample with a chronic disease, symptom lupus erythematosus (SLE) which can cause symptoms such as skin and joint pain. Denton et al (2004) argued that PRISM measured enmeshment of illness with self rather than suffering. Streffer, Büchi and Morgel et al (2009) also failed to find a relationship between SIS

and depression in a sample experiencing orofacial pain. Streffer et al (2009) attribute the latter findings to a floor effect in the depression scores. Sensky and Büchi (2016) highlight that Denton et al's (2004) findings may reflect variation in patient populations, as would be expected of a measure of suffering.

PRISM has been adapted to examine the position of work, or family, which are also placed in context of their life, self and illness (Sensky and Büchi, 2016). Kok, Hein and Sensky et al (2017) used PRISM to quantify and compare suffering from two distinct illnesses, trauma, and addiction. The authors found that the correlation between the two self-illness scores were significant but low, suggesting that individuals did distinguish between suffering related to each stressor. Individuals reported greater suffering related to trauma, despite their presence in a substance use disorder treatment programme.

### **How is suffering linked to homeless health?**

Cassell's (1982) model enables comparison of the burden of numerous threats to self and observe which are salient for that person (Senski and Büchi, 2016). There is a conceptual overlap of illness suffering and suffering related to homelessness. Homelessness, like illness, threatens sense of self through loss, stigma, isolation, disconnection from social or former identities (Boydell et al, 2000). Cassell's (1982) model points towards health outcomes which are important to that person, in contrast with behavioural health outcomes which may be more salient to professionals (Steward, Holt, Pollio et al, 2016).

No prior study has examined suffering in a homeless population using Cassell's (1982) definition. Homeless health outcomes are objectively poor, this is matched by poor overall subjective quality of life, and well-being and high distress. It would be logical to assume homeless persons experience extremely high suffering. However, findings in physical health populations have shown objective poor health is not a robust predictor of suffering.

Furthermore, the subjective experience of illness and of homelessness for this population has had little investigation, and numerous studies have found unexpected results. Suffering is inherently linked to the personal meanings associated with a threat to self, the current knowledge does not provide this depth of understanding; limitations have been outlined above. Suffering may therefore be an important avenue for understanding the experience of two significant threats to self, illness and homelessness. A discussion of how Cassell's (1982) model may be applied to understanding the effects of housing first approaches for example helps to make sense of paradoxical findings in the literature.

As described, prior studies have found housing provision and housing satisfaction do not systematically predict QoL, distress or wellbeing (Hubley et al, 2014). Cassell's (1982) conception of suffering helps understand these findings. Hopper (2012) contends that receipt of housing does not reduce wider causes of suffering such as ongoing isolation, and material deprivation. There is evidence to support this (Tsai et al, 2012; Patterson et al, 2013). For example, Henwood et al (2014) longitudinal study found homeless individuals who obtained housing security continued to feel unsafe, restricted relationships, as well as significant welfare and employment needs. Hopper claimed that change in housing would therefore not directly reduce suffering due to the broad range of suffering associated with homelessness. This hypothesis has similarities with Cassell's (2014) understanding of illness suffering. Cassell (1982) draws parallels, referring to homelessness as an injury to the integrity of the person in his seminal paper,

“We all recognise certain injuries that cause suffering: the death or distress of a loved one, powerlessness, helplessness, hopelessness, torture, isolation, homelessness, memory failure and fear. Each is both universal and individual. Each touches features common to all of us” (p. 643 – 644)

Cassell (2014) argues that when suffering starts, it is no longer the disease that is the primary cause of distress, it is the suffering itself. That is, the individual's experience of intrusion on their self, their person, their life. For example, pain may cause suffering for an unwell individual, yet when pain is relieved the suffering may continue due to changes in pleasure from food, or their intimate relationship. Therefore, in applying Cassell's framework, the receipt of housing does necessarily reduce isolation or deprivation, and if these factors are the primary causes of distress, then suffering will continue. As Cassell notes,

“injuries to the integrity of the person may be expressed by sadness, anger, loneliness, unhappiness, melancholy, rage, withdrawal, or yearning. We acknowledge the person's right to have and express such feelings. But we often forget that the affect is merely the outward expression of the injury, not the injury itself.” (Cassell, 1982, p. 643)

Cassell's (1982) model gives primacy to the individual's experience. He places illness, meaning and suffering all within the frame of life context as illness is conceived to threaten all aspects of personhood, the psychological, social, political spiritual and functional aspects of self. This model therefore provides the possibility for an integrated formulation, of health and housing, within medical, social and political systems. Cassell's model posits that suffering will be associated with biopsychosocial outcomes.

This section has examined the relevance of Cassell's (1982) model of suffering for understanding homeless health. It was argued that it is an important psychological model of illness and self which can advance our understanding of homeless illness experience by examining two significant threats to self. Cassell's (1982) conception of suffering provides a important framework for making sense of paradoxical findings from the housing first literature. It was argued that objective outcomes may not reflect the complex subjective experiences of unwell homeless persons. Given the knowledge relating to homeless persons' objective health

outcomes, health behaviours and experiences of care, Cassell's model of suffering may provide a critical insight into the unique subjective experiences of illness and housing difficulties in this population.

## **Conclusion**

This review has highlighted that as a cultural group, homeless persons amongst the worst health outcomes. The argument has been made for conceiving of homelessness as a health issue. The ethical rationale for examining physically unwell homeless persons was stressed, homeless persons face major health inequalities which is a key issue in government health agenda. Yet, homeless persons presenting for health care are under-represented in the literature. A psychological perspective is deemed central to health provision across medical conditions in the general population, however, this review has revealed that the psychological perspective which remains largely absent in the homeless health literature. Interventions and policy such as the housing first and treatment first approaches have moved towards a more holistic, biopsychosocial view of homeless needs; for ethical and empirical reasons, the research science must match this.

Evidence in the homeless population suggests that neither objective illness, nor changes to housing status and satisfaction, are reliable predictors subjective health outcomes. An investigation of Cassell's (1982) model of suffering could advance our theoretical and clinical understanding of illness experience. Suffering occurs when the integrity of the person is threatened, including all aspects of that person (e.g. social, physical, spiritual) (Cassel, 1982). Illness suffering has been demonstrated to be important construct for understanding illness experience and its relationship to subjective health outcomes (Sensky and Büchi, 2016). Cassell's (1982) model emphasises meaning for an individual in face of threats to self. It was argued that homelessness, like illness, threatens the self.

The current study will investigate the relationship between illness suffering and suffering related to housing in a physically unwell homeless population. It is hypothesised that there will be a significant, moderate positive correlation between suffering related to illness and housing difficulties. It will also examine to what extent illness suffering and suffering related to housing difficulties predict QoL, distress and wellbeing.

### **Clinical implications**

To develop an understanding of homeless subjective illness experience can have important implications for clinical practice. Suffering is unique to specific persons, but also to a specific time (Cassell, 1982), the current study will provide an investigation of suffering related to illness and housing difficulties at a critical moment, that is during hospitalisation. This review has highlighted the poor health care experiences reported by homeless persons, who face stigma, and feel unwelcome and uncared for (Rae and Rees, 2015). This investigation will advance understanding of experience of immediate physical health needs, help seeking and hospitalisation. A psychological understanding of illness and homelessness experience in this setting can contribute to enhancing compassion in current health care practices.

The primary goal of health care is the relief of suffering (Cassell, 1982). A clinicians' capacity for compassion in medicine relies on understanding of suffering,

“In the absence of an understanding of subjectivity and the knowledge of persons for which it is essential, neither human dignity nor suffering can be fully comprehended as concepts and in their actual presence in sick persons. Objectivity in the absence of subjectivity renders persons one-dimensional and robs medicine of the compassion and human relationships that define it in history and in the care of an individual sick person.” (Cassell, 2014, p. 22)

## **Research questions**

The current study will address the following research questions:

1. Is illness suffering associated with suffering related to housing difficulties in physically unwell homeless persons?
2. Does illness suffering or suffering related to housing difficulties have a greater independent effect on QoL, distress and wellbeing?

## **Chapter Two: Method**

### **Design**

A single group cross sectional design was used to investigate associations between illness related suffering (self-illness separation; SIS) and housing related suffering (self-housing separation; SHS) and quality of life (QoL), wellbeing and distress, in a sample of homeless persons with physical health problems.

### **Participants**

#### **Sampling**

A total sample of 48 participants were recruited (between 4<sup>th</sup> November 2016, and 3<sup>rd</sup> March 2017) from two London hospitals, 38 from the first site and 10 from the second, both have GP-led homeless healthcare teams (Hewett, Halligan and Boyce, 2012). The sample (N= 48) were predominantly male, age ranged from 20-77, mean age was 47.1 (SD = 12.7). Demographics and clinical characteristics of the sample will be outlined in the following chapter. One participant asked to withdraw during the interview, with difficulties understanding English, and pain relating to illness given. Data were not kept on participants not meeting inclusion criteria, however demographics (described in the results section) are consistent with a recent large study in this population (Hewett, Buchman and Musariri et al, 2016).

#### **Inclusion criteria**

- Referred to homeless team
- Adults (18+)
- Capacity to consent
- English speaking
- Physical illness

#### **Exclusion criteria**

- Patients solely seen in Accident and Emergency Department.
- Patients with traumatic injuries (e.g. Stab wounds, road accidents), without physical illness



Participants were identified with support of the homeless health team. Ward staff were informed of the study and service users were subsequently approached for participation while bedside. Three participants declined to participate in the study, one cited imminent discharge, another due to pain, and one provided no reason.

### **Prospective power analysis**

A prospective power calculation was conducted for a multiple linear regression with six predictor variables. The multiple regression has two independent variables (IVs), SIS and SHS, and three dependent variables (DVs), QoL, distress and wellbeing. Four factors are controlled for: housing situation, age, drug and alcohol use. For the calculation, alpha = .05, power = .80 and an estimated medium effect size of .30 selected according to Cohen's  $f^2$  (1992). This effect size is in line with the magnitude of effects reported in studies using designs with related variables, in comparable populations including a homeless hostel population (Gadermann et al, 2014) and patients in hospital experiencing pain (Kassardjian, Gardner-Nix and Dupak, 2008). The prospective power analysis indicated a total sample size of 48 (Clark-Carter, 1997).

### **Measures**

#### **Demographics**

A socio demographic questionnaire was created (Appendix 2), which asked participants about their age, gender, ethnicity, physical illness, length of current stay in hospital, living situation, length of homelessness, alcohol and drug use, access and receipt of benefits.

## **Pictorial Representation of Illness and Self Measure (PRISM) Büchi, Sensky, Sharpe et al (1998)**

PRISM is a brief (5-10 minutes) visual tool to measure suffering according to Cassell's (1982) conceptualisation. In the standard PRISM task, an individual is asked to place a disk (5 cm in diameter) representing their illness on a board in proximity to another disk (7cm in diameter) representing their 'self' (see Appendix 3) with the instruction 'where would you put your illness in your life at the moment?' (Büchi and Sensky, 1999). The distance between the two disks provides the quantitative measure, 'Self-Illness Separation' (SIS) with a range of 0-27cm. Wider separation between self and illness, indicates less suffering. Higher suffering is associated with greater distress and intrusiveness and less controllability of the illness or symptoms (Büchi, Buddeberg, Kalaghofer et al, 2002). The authors define this as the 'burden of suffering', smaller distance indicating increased burden (Büchi, Sensky, Sharpe et al, 1998).

A recent synthesis of the evidence summarised the significant correlations of SIS with other measures of illness experience, "the strength of these correlations has varied according to diagnosis and between samples with the same diagnosis... this is exactly what would be expected of a measure of suffering as defined by Cassell" (Sensky and Buchj, 2016, p. 9). Büchi et al (2002) found good convergent validity in seven different physical health samples, between SIS and a measure of health-related QoL (SF-36; Ware and Sherbourne, 1992), a coping resilience scale (Sense of Coherence, SOC; Antonovsky, 1993) and The Hospital Anxiety and Depression Scale, (HADS). In the overall sample (n=568), they found moderate to large, significant positive correlations ( $r = 0.204 - 0.392$ ,  $p < .0001$ ) between SIS and all SF-36 subscales (e.g. Vitality, general health and pain) as well as a significant large negative correlation with HADS ( $r = -0.312$ ,  $p < .0001$ ), and a significant moderate positive correlation with SOC ( $r = 0.233$ ,  $p < .001$ ). The authors also reported good test-retest reliability ( $r = 0.95$ ;  $p > .001$ ) and interrater reliability ( $r = 0.79$ ;  $p > .001$ ) (Büchi et al, 2002).

Peter, Kleinjung, Horat et al (2016) found SIS to be significantly inversely correlated with high tinnitus severity ( $r=-.568$ ,  $p<.001$ ), as well as the WHO measure of quality of life global ( $r=.371$ ,  $p<.001$ ) and psychological domains ( $r=.421$ ,  $p<.001$ ) (WHOQOL Group, 1998), and inversely correlated with the Becks Depression Inventory (Beck and Steer, 1993) the Tinnitus Handicap Inventory (Newman, Jacobson and Spitzer, 1996) ( $r=-.389$ ,  $p<.001$ ).

PRISM has been implemented in 53 published studies in relevant samples, individuals with alcohol dependence, substance abuse, with post-traumatic stress disorder, chronic pain and samples in psychiatric and palliative care (Sensky and Büchi, 2016; Kok et al, 2017). A review of assessments of suffering identified PRISM as superior to other measures due to “strongest psychometric properties”, and most conceptually coherent instrument” (Krikorian, Limonero, and Corey, 2013, p. 8). Alongside psychometric strengths the authors also report PRISM to score best in terms of acceptance with participants, and ease of use. PRISM can be used with patients with verbal or written communication difficulties, an important strength for the current sample.

### **Modification to PRISM (PRISM+)**

Numerous studies have modified the PRISM task. Büchi and Sensky (1999) proposed the use of multiple disks to represent family, work, pain, as well as illness. They argued that the ‘PRISM+’ would allow the illness to be mapped in its biopsychosocial context, and facilitate observations between illness and other aspects of the patient’s life. This initial modification was for clinical use but the authors concluded that it would have important applications as a research tool, which has since been developed. Reinhardt, Bischof and Grothues et al (2006) used the moveable disk to represent ‘my drinking’ in a population with alcohol dependence and abuse. Kassardjian et al (2008) adapted the PRISM task to include illness (pain) and non-illness disks, representing partner, family, recreation and work. They observed test re-test reliability  $r>.95$  ( $p<.001$ ) for the partner, family and work disks, and good content validity.

### **PRISM adaptation for the current study**

The current study adapted PRISM to include two disks (5 cm in diameter), representing illness and housing difficulties. Consultation with an Experts by Experience (EbE) group was important to assess the face validity and acceptability of PRISM. The EbE group found PRISM to be clear and easy to use. Several members queried whether the board could be circular rather than rectangular. Previous studies have implemented a PRISM+ disc using a circular version (Rumpf, 2004); however psychometric validation of PRISM is overwhelmingly using the traditional design, and a recent systematic review highlights it is more effective in allowing greater movement of the illness disk (Sensky and Büchi, 2016). An important consideration for additional disks is that the relationship between the subject and the object must be univalent, either positive or negative, i.e. Like illness, closeness to self needs to be intuitively understood as negative (Sensky and Büchi, 2016). Therefore, the additional disk was labelled 'housing difficulties' as consulted by Professor Sensky, a creator of PRISM, it is simple and univalent (personal correspondence, 2016). The EbEs had also indicated that some individuals may not identify with being homeless, however would describe themselves as having housing difficulties.

The EbEs suggested changing the additional instructions for individuals who did not intuitively understand the task. Standard instructions for PRISM use the example of a disc representing 'work' (Büchi and Sensky, 1999), but the group thought that an explanation using the example of 'partner' (e.g. Wife) would be more accessible for service users. The EbEs were clear that one disk representing illness would be preferable to multiple illness disks despite high comorbidity. As indicated in the standard instructions, after placing each disk participants were asked to explain why they put illness, or housing difficulties in the positions they had and a note of these comments was made. This yields valuable qualitative data.

### **Depression, Anxiety and Stress Scale (DASS-21 Henry and Crawford 2005, Appendix 4)**

The DASS-21 is a brief 21 item self-report scale on relating. Each item is rated on a four point scale ranging from ‘*Did not apply to me at all*’, to ‘*Applied to me very much, or most of the time*’. In addition to a total score, it also reliably assesses and discriminates three subdomains, depression (e.g. Loss of self-esteem and depressed mood) ( $\alpha=.90$ ), anxiety (e.g. Fear and anticipation of negative event) ( $\alpha=.90$ ) as well as overall stress (persistent state of over arousal and low frustration tolerance ( $\alpha=.88$ )) (Henry and Crawford, 2005; Oei, Tian and Sawang, et al, 2013). Distinguishing three related but distinct symptom domains is a strength for use in heterogeneous populations (Weiss, Aderka, and Lee et al, 2015).

The DASS-21 has been implemented across the age span, with a range of populations, including a sample of over 1,400 psychiatric patients aged between 14 – 83 (Page, Hooke, and Morrison, 2007). It has been validated across cultural groups (Oei, Tian and Sukanlaya et al, 2013) and in medical populations, including pain patients (Wood, Nicholas and Blyth et al, 2010). In a physical health inpatient setting DASS-21 was found to demonstrate excellent internal consistency with high Cronbach’s alpha values (0.92-0.95) for each subscale, as well as concurrent validity with the Hospital Anxiety and Depression Scale for stress, anxiety and depression (0.67-0.91,  $p<0.001$ ), yet superior internal consistency (Sukantarat, Williamson, and Brett, 2007). The DASS-21 has been used successfully in an Australian older adult homeless sample (Rogoz and Burke, 2016). For the subscale scores, standard DASS-21, cut off scores were used to identify ‘mild’, ‘moderate’, ‘severe’ and ‘extremely severe’ symptoms (Lovibond and Lovibond, 1995). Moderate scores for depression were above 14, above 10 for anxiety and above 19 for stress (Lovibond and Lovibond, 1995).

## **World Health Organisation Quality of Life: Brief Version (WHOQOL-BREF)**

### **(WHOQOL Group, 1998, Appendix 5)**

The WHOQOL-BREF is a 26-item instrument for assessment of subjective QoL, with four domains, physical, psychological, social relationships and environment (WHOQOL Group, 1998). Each item has a five-point scale relating to their experiences in the past four weeks, questions are either from 'Very Poor' to 'Very Good' (e.g. how satisfied are you with your health) or relating to how much one has experienced things 'Not at all' to 'An extreme amount' (e.g. to what extent do you feel your life to be meaningful?). In the well and unwell general population across 23 countries, it demonstrated good internal consistency on total score ( $>.7$ ), and for each domain physical health .80, psychological .81, environment .80, and social relationships .68 (Skevington, Lotfy, and O'Connell, 2004). A global QoL estimate is calculated by combining the first two items, how would you rate your QoL? And how satisfied are you with your health? The authors report significant discriminant validity results in each domain for well, and unwell samples (Skevington et al, 2004). It has high acceptability, low responder burden and is robust across 27 health conditions including drug use, depression and chronic pain (Skevington and McCrate, 2012).

Garcia-Rea and LePage (2010) assessed the psychometric properties of the WHOQOL-BREF in a North American homeless veteran sample, finding good internal reliability and test-retest coefficients for each domain ( $>.7$ ). They report moderate to high covariation with the WHOQOL-100 (WHO-QOL Group, 1995), the extended version of the measure which had previously been validated with homeless veterans with substance dependence (Garcia-Rea and LePage, 2008). The WHOQOL-BREF has since been used in a Dutch homeless population. Van der Plas, Hoek and van Hoeken (2011) used the WHOQoL-BREF in a homeless population with serious mental illness. It has specific advantages for use in this population, due to its brevity and broad domains.

## **Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS, Tennant, Fishwick and Platt, 2006; Appendix 6)**

The WEMWBS is a brief 14 Likert-style self-report scale of mental wellbeing. It requires participants to rate items on four points according to how often a statement relating to feelings and thoughts relates to their experiences (from 'None of the time' to 'Often'). Mental wellbeing pertains to an individual's psychological functioning (sense of autonomy, self-acceptance, personal growth), life satisfaction and ability to maintain positive relationships (Stewart-Brown and Janmohamed, 2008). Items are positively worded which is believed to increase acceptability amongst participants. In a population sample it has shown good internal consistency (Cronbach's alpha, 0.91), did not suffer floor or ceiling effects, and strong criterion and discriminant validity (Tennant, Hiller, Fishwick et al, 2007). It was recently demonstrated to be a valid and reliable measure in a secondary care population (Bass, Dawkin, Muncer et al, 2016). The authors report high internal consistency (Cronbach's alphas, 0.95), and confirmatory factor analysis found it to measure a single construct of wellbeing in this population. It is also robust across cultures (Taggart, Friede and Weich et al, 2013).

An earlier review of scales of positive mental health, recommended the WEMWBS as an overall measure of positive mental health, giving it the highest scores on overall rating, due to good responsiveness, structure, content and construct validity as well as brief completion time (Speight, McMillan, Barrington and Victor, 2007). WEMWBS has no clinical cut off, scores range from 14-70 and can be compared with population norms (mean= 52, SD = 8.7) and clinical samples.

### **Experts by Experience**

Eight experts by experience (EbEs) from the Pathway Homeless Health EbE team (Pathway, 2017) provided consultation specifically regarding the measures used in the study, recruitment

and procedure. Ages of the group ranged from twenty years old to 50 year olds, six were white British men, one white British female and one black British male. They all had experiences of homelessness, with many experiencing addictions and mental health problems, as well as physical illness. They could represent not just personal experiences but those of their peers (Brett, Staniszewska, Mockford et al, 2012). This EbE group were also unique in that they were employed as care navigators, providing peer support on the hospital ward and for a period after discharge (for further information regarding the model of care see Buchman and Hewett, 2011). Therefore, their professional experiences were also highly relevant. The EbEs were consulted regarding recruitment issues and the measures used in the study (21<sup>st</sup> September 2016) and then with regards to understanding the findings (19<sup>th</sup> May 2017).

The group encouraged the project to use incentives as part of recruitment. While one individual believed that value £4 would be inadequate, the rest of the group suggested that the incentive would act as a gesture of appreciation which participants could turn down if they wanted. The suggestion to offer television credits in one hospital, as well as the offer of food, drinks, or socks, was suggested by the EbEs and the Pathway team who had recognised that service users request these items. The EbEs were clear that they believed homeless persons would be keen to participate in the study, and would appreciate the chance to talk while admitted to hospital.

The two measures, PRISM and WEMWBS, which had not previously been used with a homeless population were presented and feedback discussed. WEMWBS was deemed to be clear, they liked the fact that it was positively phrased in contrast to the WHOQoL-BREF and DASS-21. All the items were deemed to be relevant. The contributions of the EbE group to the adaptation of PRISM has been described. They found the measure to be visually appealing and deemed the instructions to be simple. The EbEs believed that all measures should be presented verbally to service users, due to high levels of illiteracy, to assist comprehension.



The consultation group expressed that the research questions, and issue of suffering related to illness and housing difficulties were salient issues.

## **Procedure**

Individuals who had been admitted to hospital and referred to the Pathway homeless health team were screened. This was with support from the Pathway team who had previously assessed the service users as part of routine practice and therefore could help screen according to the inclusion and exclusion criteria. Subsequently, participants gave consent to clinical team member to be approached and consider participation. The principal investigator approached the nurse manager and senior ward sister on the wards for consent to talk to service users. Participants were subsequently approached on the hospital wards by the principal investigator, and provided with information sheets (Appendix 7). Information sheets were then presented orally for individuals, with issues arising discussed. Consent forms were also read aloud and completed by participants (8). A participant payment consent form was also completed prior to conducting the interview, and they had the choice of receiving incentives either before or after the interview. If consented to, the battery of measures lasted approximately forty minutes. Short breaks were offered to participants, particularly if there was evidence of fatigue or pain for example.

## **Ethical approval**

The study was granted Health Research Authority approval from Westminster NHS Research Ethics Committee on 7<sup>th</sup> September 2016 (ref. 16/LO/1346; Appendix 9). East London NHS Foundation Trust Research and Development Department provided confirmation of capacity on capability on the 28<sup>th</sup> October 2016 (ref. 199528). Barts Health NHS Trust provided confirmation of capacity and capability on the 15<sup>th</sup> September 2016 (ref. 011539). The study was self certified with Royal Holloway University of London Ethics Committee on 1<sup>st</sup>

September 2016. University College London Hospitals provided study approval and letter of access on the 4<sup>th</sup> January 2017. Copies of the favourable letters are included in Appendix 10. Guidelines and recommendations regarding completing best practice research within vulnerable populations were adhered to (BPS, Code of Human Research Ethics, 2010). Local trust risk protocol and guidelines were adhered to (Policy Guidance for Trust Staff, 2016).

### **Ethical considerations**

Participants were required to be able to give informed consent to participate in the study and accessible information sheets and consent forms were developed to support this. Special considerations include easy to read participant information stating clearly the aim and nature of the study, there was consideration of appropriate study design procedures (i.e. Brief measures, cross sectional). Capacity was initially screened in discussion with the clinical team, it was then further assessed the point of gaining informed consent, with the understanding that individuals who did not have that capacity would not be interviewed. Good practice guidelines for completing research with vulnerable adults were consulted (BPS, 2010; HRA, 2016). No current or historical medical records were accessed during the research process.

There was small risk that individuals could find participation distressing due to the nature of the measures and the context. However, these measures are routinely administered in medical and psychiatric inpatient clinical settings. The DASS-21 and WHOQoL-BREF had also been used and validated in a homeless population (Garcia-Rea and LePage, 2010; Rogoz and Burke, 2016; Van der Plas et al, 2011). PRISM had been used and validated extensively in inpatient settings with numerous physical health populations (Sensky and Büchi, 2016). It had also been used with individuals with mental health diagnoses (e.g. PTSD), alcohol and substance misuse and patients consistently report it as being easy to use and acceptable (Sensky and Büchi, 2016). The wellbeing measure is positively worded questions; it had been used routinely in mental health clinics and was therefore unlikely to raise distressing emotions for participants over and

above the other selected questionnaires. The clinical team and EbEs were consulted regarding the acceptability of the measures. The researcher was experienced in working clinically with vulnerable populations who are distressed so this was managed in the interview and support from the routine clinical team, or signposting was provided if required. Furthermore, the clinical team were used to conducting research in this setting, they were supportive of this project aware of possible risks. Flexibility was offered regarding the location of the research to minimise burden involved in participation. Signposting was provided if required.

**Anonymity and confidentiality:** All data were stored anonymously. Each participant was assigned an identification key on participation in the study and only the researcher will know each participant's identity. Thus, no participant was identifiable. All data collected were kept confidential via restricted access; only the two members of the research team had access to the data, which were stored in password protected university computers. No third party had access data gathered in the study, except for the overall published results. Confidentiality was maintained unless there were significant concerns about the safety of the participant or another individual, at which point BPS procedures followed (BPS, 2010). Concerns were discussed with research supervisor, clinical team, and relevant guidelines consulted (BPS, 2010). As in clinical practice, the ward setting is limited in ensuring privacy for participants. Efforts were made to increase the privacy of participants on the busy hospital ward setting which included closing curtains, maintaining proximity to participants so voices did not have to be raised, and checking whether participants were willing to participate in a discussion of personal information in this setting.

**Benefit for participants:** Participants were provided with an incentive to the value of £4, from the choice of a meal deal (e.g. £4 Tesco), coffee (e.g. £2-£4 Costa), socks (e.g. £2 Sports Direct), or television credit (four £1 television credits provided 24 hours of viewing bedside). This reward for consenting in the research was deemed to be a proportionate for the time

provided by participants. It was a reasonable recompense given the nature of the study, and not large enough to be coercive or affecting the autonomy of decisions to participate in any way (BPS, 2010). The EbE group and Pathway team believed this value was appropriate. There was no further benefit to individuals participating in the study. However, it was hoped that the research would be beneficial for homeless adults in the future as findings would inform the education of health care professionals and enhance provision.

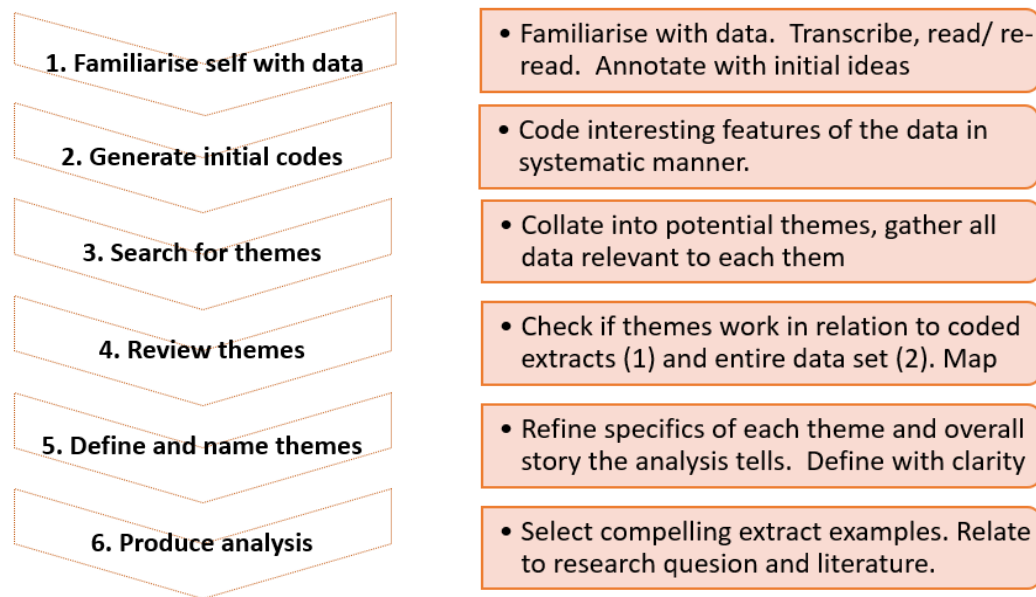
### **Analyses**

All data were analysed using SPSS 21 (IBM Corp, 2013). A Pearson's correlation was used to examine the relationship between two continuous variables, illness related suffering (self-illness separation; SIS) and housing related suffering (self-housing separation; SHS). Three multiple linear regression analyses were used to examine continuous IVs, SIS and SHS, and three dependent variables DVs, QoL, distress and wellbeing. Four factors were controlled for: housing situation, age, drug and alcohol use. Further exploratory analyses were conducted. Ten two-way ANOVAs observed the difference between SIS and SHS inside-self compared with outside-self. The IVs, SIS and SHS, were each transformed to dichotomous variables, below or above the median of 6cm. There were ten DVs: total QoL, QoL subdomains environment, social, psychological and physical QoL; distress; distress subdomains depression, anxiety and stress; and wellbeing.

Qualitative data rendered by PRISM were analysed using Braun and Clarke's (2006) thematic analysis six stage guidelines (see Figure 1). Thematic analysis has numerous strengths, including the capacity to summarise and present data, a flexible epistemological position,

“acknowledge the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings, while retaining focus on the material” (Braun and Clarke, 2006, p. 81).

Figure 1. Phases of TA (adapted from Braun and Clarke, 2006)



## Chapter Three: Results

### Overview

The results chapter outlines firstly the demographic data from the sample, before situating the sample in terms of descriptive findings. The statistical methods are introduced with parametric assumptions described. The main statistical analyses are then presented. Finally, the qualitative findings are reported.

### Sample demographics

Table 1. provides demographic and clinical characteristics of the sample. Twenty (41.7%) individuals presented with infections (e.g. Cellulitis, pneumonia, septisemia, tuberculosis, other), ten (20.8%) had alcohol related concerns (e.g kidney, pancreatic, liver problems), six (12.5%) presented with deep vein thrombosis, four (8.3%) had respiratory conditions (e.g. COPD, asthma, enphesema), four (8.3%) had diabetes, three (6.3%) had Hepetitis C and two (4.2%) had sickle cell anaemia. Other conditions reported by individuals included a stroke, leg ucler, a metabolic condition, ecsema, gout and cancer. Twenty-nine (60.4%) of the sample reported multiple, comorbid health problems. Twelve (25%) individuals reported consuming

four or more alcoholic per day. The most frequently used drugs were heroin (20, 41.7%) and crack (19, 41.7%), with considerable overlap in use, 17 (35.4%) used both.

Twenty-six (54.2%) individuals were receiving benefits (e.g. Employment and Support Allowance, Personal Independence Payments). Of the 22 (45.8%) individuals not receiving benefits, 14 (29.2%) reported that they were eligible for benefits yet were not currently in receipt. Reasons given by participants included the following: *“no birth certificate or passport and it costs money to get these”*, *“medical letters not processed and ESA refused”*; *“I need an address and I’m not registered with GP”*; *“I came out of prison and I was refused benefits because I had no identification”*. Seven (14.6%) of the sample had no recourse to public funds, due to immigration status.

Table 1 Participant demographics

	Category	<i>N</i>	<i>Frequency (%)</i>
<b>Gender</b>	Male	43	(89.6%)
	Female	5	(10.4%)
<b>Age in years</b>	20 – 25	2	(4.2)
	26 – 35	8	(16.7)
	36 – 49	17	(35.4)
	50 – 60	14	(29.1)
	60 +	6	(12.5)
<b>Ethnicity</b>	British	34	(70.8)
	White British	24	(50)
	Black British	7	(14.6)
	Mixed race British	1	(2.1)
	Asian British	2	(4.2)
	White European	5	(10.4)
	Black African	4	(8.3)
	Middle Eastern	1	(2.1)
<b>Current housing situation</b>	Street homeless	21	(43.8)
	Hostel	10	(20.8)
	Temporary accommodation	9	(18.8)
	With family and friends	5	(10.4)
	Hotel / other	2	(4.2)
<b>Length of current episode of homelessness</b>	<1 month	1	(2.1)
	1-12 months	17	(35.4)
	1-5 years	22	(45.8)
	>5 years	6	(12.5)
	Not given	2	(4.2)

(*M* = 29.97, *S.D* = 35.99; *N*=46, missing 2)

<b>Length of current episode of hospitalisation</b>  (M= 16.83, SD = 29.51; N = 47, missing one)	< 4 days	17 (36.2)
	5-10 days	11 (23.4)
	11-15 days	6 (12.7)
	16 – 30 days	8 (17.1)
	1 – 2 months	4 (8.5)
	3 months +	2 (4.25)
<b>Number of visits to hospital in past 12 months</b> (Mean 3.89, SD=4.34; N=45, three outliers excluded on dialysis)	Once	16 (33.3)
	2 – 4 occasions	17 (35.5)
	5 – 10 occasions	7 (14.5)
	11 – 20 occasions	5 (10.5)
<b>Alcohol use</b>	Does not drink alcohol	30 (62.5)
	Drinks alcohol	18 (37)
<b>Drug use</b>	Do not use drugs	25 (52.1)
	Use drugs	23 (47.9)



## Parametric assumptions

No missing data were identified in quality screening. The data were analysed to examine whether parametric assumptions of normality were met. The shape of the distribution for each variable was examined with frequency histograms, and skewness and kurtosis z scores using the following formulae:

$$\text{Skewness} \\ Z = \frac{S}{\text{s.e. Skew}}$$

$$\text{Kurtosis} \\ Z = \frac{\sqrt{K}}{\text{s.e. Kurtosis}}$$

Skewness and kurtosis were considered normal where  $z < 2.58$  ( $p > .01$ ) (Field, 2013). The total and subscales scores for Quality of Life (QoL), wellbeing, distress were all found to be normally distributed. Self-illness suffering (SIS) was positively skewed ( $z=3.17$ ,  $p < .01$ ). Self-housing suffering (SHS) was also positively skewed ( $z=3.451$ ,  $p < .01$ ). Outliers were examined using boxplot graphs, extreme cases more than three standard deviations from the mean were defined as outliers (Tabachnick and Fidell, 2013). No outliers were identified for SHS. One outlier was identified for SIS; however, following transformation this score did not impact on normality of the distribution. It was therefore considered part of the target population and retained to prevent loss of power (Tabachnick and Fidell, 2013).

Square root transformations were performed on both SHS and SIS to bring both variables into compliance with parametric analysis (Field, 2013). Consequently, SIS met acceptable range of normality for skewness ( $z=0.752$ ,  $p > .01$ ); and kurtosis ( $z=-1.468$ ,  $p > .01$ ). Following transformation, SHS also met normality assumptions for skewness ( $z=0.381$ ,  $p > .01$ ) and kurtosis ( $z=-1.385$ ,  $p > .01$ ). A Kolmogorov-Smirnov (K-S) test found SIS,  $D(48) = .30$ ,  $p < .01$ , and SHS,  $D(48)$ ,  $.26$ ,  $p < .01$ , deviated significantly from a normal distribution despite square root transformations. However, the K-S test was deemed too conservative (Tabachnick

and Fidell, 2013). Linearity and homoscedasticity of the variables was observed using scatterplots and partial plots (P-P) indicating that all variables were within acceptable ranges of normality (Tabachnick and Fidell, 2013). Parametric tests for correlational and linear regression analyses were run with square root transformed SIS and SHS.

Further assumptions for Standard Linear Regression were examined using the following methods.

- a) A Durbin-Watson test showed independence of errors; values below one or over three were deemed to violate the assumption (Field, 2013). Normality of residuals were further assessed visually with scatterplots, histograms and P-P plots demonstrated linearity and homogeneity of variance (Cohen, Cohen, West and Aiken, 2003).
- b) Multicollinearity, the intercorrelations amongst the IVs, was screened via a Pearson's  $r$  correlation matrix of predictor variables, indicating no high correlations ( $R > .8$ ) (Field, 2013). Examination of the variance inflation factor (VIF) and the respective tolerance statistic provided further assessment of multicollinearity (Myers, 1990).
- c) Finally, Cook's Distance assessed the influence of outliers in the regression model, no values were above one and therefore no further investigation required (Cook and Weisber, 1982; Field, 2013).

## Descriptive Statistics

Table 2 presents descriptive statistics for SIS, SIS, QoL, wellbeing and distress.

*Table 2 Descriptive statistics*

	Mean	Median	Interquartile range (25%-75%)	SD	Range
SIS (cm)	5.43	6	0 – 6.8	6.46	0 – 23
SHS (cm)	6.89	6	0 – 11	7.74	0 – 27
Wellbeing	33.08	30	23.5 – 41.75	11.83	14 – 56
QoL	4.10	4	3 – 5.75	1.87	2-9
Distress	37.50	40	49 – 104.5	15.74	3 – 60

*NB: SIS and SHS means are reported in non-transformed state but analyses are based on transformed data.*

## **Situating the sample**

### **PRISM**

Studies using an equivalent PRISM format (e.g. Size, shape, disks) provide comparative data for SIS (low scores reflect higher suffering). All but one study reported lower suffering. In a sample of service users with COPD, osteoarthritis or systemic lupus erythematosus (SLE) Büchi et al (2002) reported mean=12.2cm, SD 6.96 (n=714). Denton et al (2008) found mean=7.5, SD=7.1 in participants with SLE (n=43) and more recently, Peter et al (2016) report mean 9.3, SD=7.7, for participants with Tinnitus. One study reported higher suffering in a sample with chronic urticaria (hives, persistent rash) (n=57), mean=4.1, SD=3.2 (Töndury, Muehleisen, Ballmer-Weber et al, 2011).

### **WEMWBS**

The current sample wellbeing mean score (33.08) on the WEMWBS is low compared with the general population 50.7 (Tennant et al, 2007). Just four participants (8.3%) scored equal or above the national standardised average. Scores in the current sample are in line with findings in a sample of adults using secondary mental health care (community mental health care and acute adult inpatients) who reported a mean of 34.9 (n=1180) (Bass, Dawkin, Muncer et al, 2016).

### **WHOQoL-BREF**

WHOQoL-BREF subdomain scores were poorer (lower scores indicate poorer QoL) than population norms (Hawthorne, Herrman and Murphy, 2006). Scores are consistent with findings in a sample of homeless adults with serious mental illness (van de Plas, Hoek and van Hoeken (2012).

Table 3 WHOQOL-BREF Mean Comparisons

	<b>Current sample</b>	<b>Hawthorne et al (2006) General adults (n=535)</b>	<b>Van der Plas et al (2012) Homeless population (n=114)</b>
<b>Physical</b>	10.08	73.5	15.0
<b>Psychological</b>	10.43	70.6	13.7
<b>Social</b>	9.71	71.5	11.7
<b>Environment</b>	8.67	75.1	13.9

NB: Hawthorne et al (2006) do not report global QoL mean, van de Plas et al (2012) use incomparable score for global QoL, therefore subdomain scores provide comparison

## DASS-21

The current sample scored markedly higher (high scores indicate high distress) than the general population on the DASS-21 and higher compared with samples from adult psychiatric inpatient and with chronic pain (see Table 4). Forty (83.3%) participants in the current sample scored in the moderate to extremely severe range for depression, 39 (81.3%) for anxiety, and 44 (91.7%) for stress. The current sample scored notably higher than the only prior identified study using DASS-21 in a cognitively impaired older homeless population (n=134) recruited from hostels (53.2%), shelters (32.8%) and hospital (10%) (Rogoz and Burke, 2016). In a sample with mean age of 55.04, 56.3% of participants reported moderate to extremely severe depression, 46.9% anxiety, and 33.6% stress (Rogoz and Burke, 2016<sup>2</sup>).

<sup>2</sup> Mean scores for DASS-21 not reported by Rogoz and Burke (2016)

*Table 4 DASS-21 Comparisons*

	<b>Current sample*</b>	<b>Henry and Crawford (2005) General adults* (n=1794)</b>	<b>Page et al, (2007) Adults in mental health inpatient care (n=124)</b>
<b>Distress</b>	75.50*	18.86*	Not reported
<b>Depression</b>	27.58*	5.66*	24.15
<b>Anxiety</b>	20.96*	3.76*	17.85
<b>Stress</b>	26.96*	9.46*	23.07

*\*Scores doubled for comparison with DASS full scale (Lovibond and Lovibond, 1995)*

## Main findings

### Research question one: are SIS and SHS correlated?

#### Correlational analysis

A Pearson's  $r$  correlation identified a significant weak positive correlation between SIS and SHS, that is, higher levels of illness related suffering were related to higher housing related suffering ( $r_{(46)} = .268, p < .05$ ). Bootstrapped confidence intervals (95% CI) were computed. Bootstrapping is a resampling method which provides confidence intervals to enable more accurate inferences, the current data were resampled 1,000 times (Efron and Tibshirani, 1993). To maintain inferences regarding the significance test, confidence intervals must not cross zero. Bca (95% CI) indicate that the hypothesis that SIS and SHS would be correlated is supported.

Table 5 Pearson's  $r$  correlation (one-tailed)

	Self-Housing Separation	Bca 95% CI	
		Lower	Upper
Self- Illness Separation	.268*	.005	.532
	P=.033		

Note: bca = Bias corrected bootstrapping  
\* $p < 0.05$

**Research question two: does illness suffering or housing suffering have a greater independent effect on QoL, distress and wellbeing?**

**Regression analyses**

Three regression analyses were run with the respective dependent variables (DVs): wellbeing, QoL and distress. The regression model had six independent variables (IVs): SIS, SHS, age, housing situation (split), drug use and alcohol use. Alcohol and drug were both dichotomous variables, yes or no. Housing Situation was coded to also become binary, street homeless or vulnerably housed (including hostel, family and friends, hotel, other). These were exploratory investigations. In view of the exploratory nature of the analysis, Bonferroni corrections to alpha values were not implemented; this procedure was considered too conservative and deemed to reduce power, increasing chance of type II error.

**Wellbeing (WEMWBS)**

The multiple regression model did not account for a significant amount of the variance in wellbeing ( $R^2 = .23$ , adjusted  $R^2 = .12$ ;  $F_{(6,41)} = 2.06$ ,  $p = .08$ ). The partial regression coefficients showed that SIS did not provide a significant contribution to wellbeing, after controlling for SHS, age, housing situation and substance use, it was however approaching significance ( $B = 0.61$ ,  $\beta = 0.27$ ,  $t_{(41)} = 1.84$ ,  $p = .07$ ). SHS did not provide a unique contribution to the variance of wellbeing ( $B = .26$ ,  $\beta = -.13$ ,  $t_{(41)} = .10$ ,  $p = .33$ ). Age ( $B = 0.26$ ,  $\beta = .27$ ,  $t_{(41)} = 1.79$ ,  $p = .08$ ), housing situation ( $B = -2.62$ ,  $\beta = -.11$ ,  $t_{(41)} = -0.67$ ,  $p = .50$ ), drug use ( $B = -1.47$ ;  $\beta = -.06$ ,  $t_{(41)} = -0.40$ ,  $p = .69$ ) and alcohol use ( $B = 3.36$ ;  $\beta = .14$ ,  $t_{(41)} = 0.96$ ,  $p = .34$ ) were not independently associated with wellbeing. Therefore, the model did not demonstrate a significant relationship with wellbeing. Furthermore, neither SIS nor SHS predicted wellbeing however SIS did approach significance.



### **Quality of Life**

The multiple regression model accounted for a significant amount of the variance in QoL ( $R^2 = .31$ , adjusted  $R^2 = .21$ ;  $F_{(6,41)} = 1.66$ ,  $p=.01$ ). The model accounted for 21% of the variance in QoL. The partial regression coefficients showed that SIS provided a significant unique contribution to the variance in QoL ( $B = 0.12$ ,  $\beta = .34$ ,  $t_{(41)} = 2.43$ ,  $p=.019$ ). Lower SIS (indicating high suffering) predicted poorer QoL. SHS was not independently associated with QoL ( $B = 0.09$ ,  $\beta = .25$ ,  $t_{(41)} = 1.67$ ,  $p=.10$ ). Age ( $B = 0.02$ ,  $\beta = .19$ ,  $t_{(41)} = 0.81$ ,  $p=.42$ ), housing situation ( $B = 0.24$ ,  $\beta = .06$ ,  $t_{(41)} = 0.41$ ,  $p=.67$ ) and drug use ( $B = 0.40$ ,  $\beta = .11$ ,  $t_{(41)} = 0.73$ ,  $p=.47$ ) were not independently associated with QoL. Alcohol use did independently predict QoL ( $B = 1.41$ ,  $\beta = .37$ ,  $t_{(41)} = 2.70$ ,  $p=.01$ ). Therefore, the model did have a significant relationship with QoL which was explained predominantly by SIS and alcohol use. SIS did independently account for the variance in QoL, however SHS did not predict QoL.

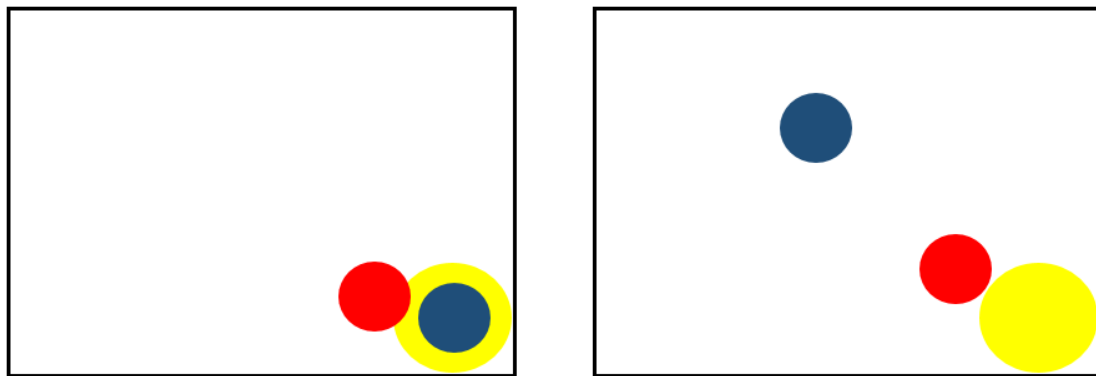
### **Distress**

The multiple regression model significantly accounted for the variance in distress ( $R^2 = .28$ , adjusted  $R^2 = .17$ ;  $F_{(6,41)} = 2.65$ ,  $p=.029$ ). The model accounted for 17% of the variance in distress. The partial regression coefficients showed that SIS provided a significant unique contribution to the variance in distress ( $B = -2.57$ ,  $\beta = -.43$ ,  $t_{(41)} = -3.04$ ,  $p=.004$ ). A negative Beta value indicates lower SIS (i.e. High suffering) predicted high distress. SHS was not independently associated with distress ( $B = -1.08$ ,  $\beta = -.19$ ,  $t_{(41)} = -1.23$ ,  $p=.22$ ). Age ( $B = -0.44$ ,  $\beta = -.18$ ,  $t_{(41)} = -1.19$ ,  $p=.24$ ), housing situation ( $B = -4.11$ ,  $\beta = -.07$ ,  $t_{(41)} = -0.41$ ,  $p=.68$ ) drug use ( $B = -2.62$ ,  $\beta = -.04$ ,  $t_{(41)} = -0.28$ ,  $p=.79$ ), and alcohol use ( $B = -10.30$ ,  $\beta = -.16$ ,  $t_{(41)} = -1.14$ ,  $p=.26$ ) were not independently associated with QoL. Therefore, the model did have a significant relationship with distress and this was predominantly explained by SIS which independently accounted for the variance in distress. In contrast, SHS did not predict distress.

### Inside-self and outside-self: an exploratory analysis

Twenty-three (47.9%) participants placed SIS inside-self, 25 (52.1%) placed illness disk outside-self. Nineteen (39.6%) placed SHS inside-self, 29 placed it outside-self (60.4%). Prior studies have split PRISM scores to compare individuals placing SIS inside-self with participants placing the illness disk outside-self (Streffer et al, 2009; Peter et al, 2016). Median split of the sample provided group comparisons; values below the SIS and SHS median represented inside-self (<6cm) and those equal or above the median were outside-self ( $\geq 6\text{cm}$ ).

Figure 2. Left - SHS and SIS Inside-Self (<6cm); Right - SHS and SIS Outside-Self ( $\geq 6\text{cm}$ )



Inspection of the descriptive statistics suggest differences on scores of distress, depression, anxiety and stress scales. Global QoL and wellbeing scores appeared to differ for both SIS and SHS inside-self and outside-self. No visible differences were apparent in the WHOQoL-BREF subdomains scores. Ten two-way ANOVAs were performed with each binary IV (SIS and SHS), and ten DVs: WHOQoL-BREF Global score, physical, psychological, social and environment subdomains, wellbeing, and DASS-21 distress, stress, depression and anxiety subdomains. The ANOVAs found individuals placing SIS inside-self reported significantly poorer global QoL, distress, anxiety and depression compared with SIS outside-self. No significant differences were found for SIS in WHOQoL-BREF subdomains, wellbeing, or stress subdomain. SHS inside-self and SHS outside-self did not significantly differ on any measure.

Table 6 Two-way ANOVA: SHS Inside/Outside-Self; SIS Inside/Outside-Self

Variable	PRISM Group	Mean (SD) Inside/ Outside	F (df)	P
<b>Global QoL</b>				
	SIS Inside/ Outside-Self	3.34 / 4.72 (1.38) / (2.07)	F (1, 44) = 4.48	P = .04
	SHS Inside/ Outside-Self	3.63 / 4.41 (1.67) / (1.96)	F (1, 44) = .813	P = .37
<b>Physical QoL</b>				
	SIS Inside/ Outside-Self	9.83 / 10.32 (1.87) / (2.12)	F (1, 44) = 0.07	P = .78
	SHS Inside/ Outside-Self	9.63 / 10.38 (1.89) / (2.04)	F (1, 44) = 1.06	P = .31
<b>Psychological QoL</b>				
	SIS Inside/ Outside-Self	9.78 / 11.04 (2.41) / (2.52)	F (1, 44) = 2.31	P = .14
	SHS Inside/ Outside-Self	9.79 / 10.86 (2.15) / (2.70)	F (1, 44) = 0.38	P = .54
<b>Social QoL</b>				
	SIS Inside/ Outside-Self	9.70 / 9.72 (3.98) / (4.37)	F (1, 44) = .004	P = .95
	SHS Inside/ Outside-Self	9.21 / 10.03 (3.77) / (4.41)	F (1, 44) = 0.26	P = .61
<b>Environment QoL</b>				
	SIS Inside/ Outside-Self	8.96 / 8.40 (2.75) / (3.21)	F (1, 44) = 0.72	P = .40
	SHS Inside/ Outside-Self	8.11 / 9.03 (8.11) / (9.03)	F (1, 44) = 1.59	P = .21

<b>Wellbeing</b>			
SIS Inside/ Outside-Self	30.39 / 35.56 (10.37) / (12.73)	F (1, 44) = .137	P=.25
SHS Inside/ Outside-Self	29.74 / 35.28 (11.29) / (11.83)	F (1, 44) = .813	P=.37
<b>Distress</b>			
SIS Inside/ Outside-Self	87.48 / 64.48 (24.06) / (33.84)	F (1, 44) = 6.04	P = .018
SHS Inside/ Outside-Self	84.63 / 69.52 (25.23) / (34.06)	F (1, 44) = 1.92	P = .17
<b>Depression</b>			
SIS Inside/ Outside-Self	33.22 / 22.40 (8.28) / (13.14)	F (1, 44) = 8.58	P = .005
SHS Inside/ Outside-Self	32.11 / 24.62 (10.45) / (12.61)	F (1, 44) = 1.71	P = .45
<b>Anxiety</b>			
SIS Inside/ Outside-Self	24.17 / 18.00 (11.72) / (11.20)	F (1, 44) = 4.48	P = .04
SHS Inside/ Outside-Self	22.32 / 20.07 (11.30) / (12.15)	F (1, 44) = 0.14	P = .71
<b>Stress</b>			
SIS Inside/ Outside-Self	30.09 / 24.08 (8.19) / (12.77)	F (1, 44) = 2.71	P = .15
SHS Inside/ Outside-Self	30.21 / 24.83 (7.24) / (12.74)	F (1, 44) = 0.71	P = .41

## Thematic analysis

### Inside-self

Fourteen (29.2%) individuals placed both illness and housing on top of their self, while 28 (58.3%) placed either illness or housing on top of their self.

#### *“They’re on top of me”*

Participants conveyed a sense that illness and housing suffering came hand in hand, a vicious cycle. Suffering was described as a feeling of being engulfed.

SIS: *“It should be on top, the longer I stay homeless, the weaker and sicker I feel, the more negative”* (p.36; SIS=0, SHS=0)

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SHS: *“That’s on top of my illness. When I had my flat I wasn’t so miserable, I had my son around me. I always had a front door and when they took that away from me I can’t cope. The longer it’s going on the harder it’s getting. Everything is intertwined, with no flat you get worse”* (P. 16; SIS=0, SHS =0)

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SHS: *“My housing and my body, without housing how will I pass my life. One is depending on the other”* (p.10; SIS=0, SHS = 0)

Participants emphasised that their lives were intertwined with suffering related to illness and housing difficulties. Weakness and deterioration seemed to be caused by the combination of SIS and SHS. Participants expressed by a sense of being paralysed, literally immobilised by illness, but also unable to manage the world around them.

SIS: *“I’m sick so it’s on top. I can’t move. I don’t know, I’m in here, half paralysed, can’t move, nowhere to go, nowhere to live.”* (P.48; SIS = 0, SHS = 0)

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SIS: *“I’ve no freedom to do anything and I’m too tired to do anything.”* (P.19; SIS = 0, SHS = 60)

Illness and housing both contributed to their sense of self as immobile.

### ***“Powerlessness”***

Having access to health or a home was portrayed as critical, yet out of reach.

SHS *“It’s important to me but I can’t get to it.”* (P. 46) SIS = 60, SHS = 60

Many expressed this inability to proceed with their own lives. This was reflected in their lack of control due to suffering related to illness and housing difficulties. Like the paralysis described above, trapped by a vicious cycle.

SIS: *“I also have diabetes so how do I control diabetes, so how do I deal with that, just come home to eat what I can.”* (P. 5; SIS = 60, SHS = 0)

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SIS: *“I’m in pain, even food I can’t enjoy. The last thing I had to enjoy, food, is not there anymore. I’ve no freedom to do anything”* (P. 19; SIS = 0, SHS = 60)

The combination of housing and illness suffering evoked a sense of having “no safety net” (P. 21). Participants expressed not being cared for as an important sense of security which they did not have, *“nowhere to go no one to count on”* (P.25). This was mirrored by their difficulties looking after themselves.

SIS: *“Being homeless it’s hard for me to keep control of my health ...it’s no way to start the day, how do I stay healthy, how do I work, how do I look after myself?”* (P.5; SIS = 6cm, SHS = 0)

## “They are me”

Participants described SIS and SHS as a part of their self.

SHS: *“Being homeless and sick, they’re my two main problems, they’re the same, they are inside of me, they are attached to me”* (p. 28; SIS = 6cm, SHS = 6)

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SIS *“that dictates everything I do, I can’t do anything, I can’t even walk my own dogs. It’s suffocating me, there’s nothing I can do without thinking of that first.”* (P. 11; SIS = 6, SHS = 0)

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SIS: *“All I seem to be is ill”* (p. 17; SIS = 3.5cm, SHS = 0)

Having SIS and SHS so near their self in life was dangerous. Participants expressed desire to protect their selves from illness and housing difficulties.

SIS: *“I want my life to be better, I want it (SIS) to be there I put it near me, I know it’s dangerous, it’s danger, I want it to go away from me. I know it’s red, I know it’s danger.”* (P. 6; SIS = 9.3cm, SHS = 6cm)

One man describes having to protect his sense of who he is from homelessness,

SHS: *“Being homeless does affect your day to day life but does not stop you from being who you are, but it does stop you showing other people who you are.”* (P. 36; SIS = 0, SHS = 0)

They expressed a sense that suffering related to illness and housing difficulties had consumed their lives, and their self.

SIS: *“Me, then housing, then illness. In order... I was like, ok I’ve got sickle cell anaemia, but it’s not gonna have a total effect on me, like it does other people, it’s not just all me. Having all this, I felt I was running out of time”* (P. 37; SIS = 0, SHS = 26cm)

**“It’s not life”**

Participants identified the importance of illness suffering in not being able to perform everyday tasks. This reflected a feeling that not only was there little quality of life, but that they had no life.

SIS: *“Cause my illness won’t go away... I can’t function like everyone else, not being able to go toilet, having to be in a wheelchair.”* (P. 4; SIS =12cm, SHS = 89cm)

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SIS: *“I just feel I’ve got no life at the moment because of my illness, things I can do and can’t do. There’s so much I can’t do, washing and dressing myself, I feel useless, this has affected me in a big part of my life, my daily life, everyday”* (P.1; SIS = 0, SHS = 0)

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Illness and housing suffering were both related to an inability to participate in the world.

SIS: *“I can’t do anything, I feel so bad about my life because of my health... This is very very important, very close to my life. If I’m not strong I can’t do anything, do my duties even if I’m old, I can’t participant with my friends, my life.”* (P.38; SIS = 6cm, SHS = 11cm)

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SHS: *“if I have no house I’m going to work I’m earning money until tea break I then I’m not thinking about work, I’m thinking about where I’m going to sleep tonight”*  
(P.8; SIS = 15.5cm, SHS = 15.5cm)

Participants described an inability to live their lives. Suffering related to illness and housing both represented a constant concern about their safety,

SHS: *“Everything would be all together, worry about it all the time. Just having roof over head means security, decent, future, not feeling out in the open. Being able to better myself, not having to worry about health... Confidence to live again.”* (P. 15; SIS = 0, SHS = 0)

SHS: *“I don’t exist, cause without these things they want, birth certificate, passport, I can’t afford that, day to day life is very hard. Housing is more dangerous than the illness, I’m out in danger zone, don’t know what can come”* (P. 13; SIS = 20.5cm, SHS = 0)

Participant 9 extends this to imminent danger. For him, suffering related to housing was associated with a sense that he did not exist, the implications for this were dangerous.

### **Danger and dying**

The analysis revealed a sense of significant danger. Disconnection from a world in which there is care, safety and stability meant participants felt exposed.

SHS: *“Stability isn’t it, real world. It’s a dangerous situation, in hostels. Get back to reality otherwise it makes me ill.”* (P. 13; SIS = 20.5cm, SHS = 0)

Suffering related to illness and housing created distress associated with death. For SIS there was an awareness of imminent risk of dying.

SHS: *“Staying outside with this is not easy. See the toe, the cold is too much and I have pressure. The diabetes is dangerous, if you don’t have any help you just die that’s why I go hospital, my situation is more dangerous.”* (P. 14; SIS = 0, SHS = 0)

Aged 39, one participant expressed “feeling like an old man of sixty or seventy” (P. 9). Similarly, another young man aged 29 stated *“having all this, I felt I was running out of time”* (P. 47). Numerous participants identified a fear of not knowing their futures, associated with SHS and SIS

SIS: *“(It’s) scaring me. I don’t know what the future holds”.* (P. 15; SIS = 0, SHS = 0)

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SHS: *“Housing is more dangerous than the illness, I’m out in danger zone, don’t know what can come.”* (P. 14; SIS = 0, SHS = 0)

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SHS: *“Just having roof over head means security, decent, future, not feeling out in the open.”* (P. 15; SIS = 0, SHS = 0)

### **Responsibility and shame**

Participants seemed to reflect a feeling of shame related to their SIS. Illness related suffering seemed to be affected by sense that the external world would place blame on them.

SIS: *“Depression causes fatigue and fatigue causes things not to get done, soon as you know you can’t get things done. People say lazy but it’s not, just can’t get stuff done. I want to get sorted but can’t.”* (P. 48; SIS = 0, SHS = 0)

SIS: “*I’ve damaged myself, I’ve knackered myself up*” (P. 42; SIS =0, SHS=27cm)

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SIS: “*It’s on top of me, I will get back into detox centre and do it properly this time, not just fall off the wagon*” (P. 46; SIS = 6cm, SHS = 6cm)

This was in contrast with housing related suffering which appeared to be identified as a basic need, a human right therefore not associated with feelings of shame relating to SIS.

SHS: “*Everyone needs somewhere to live; I can’t live in hospital forever*” (P. 46; SIS = 6cm, SHS = 6cm)

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SHS: “*Because everybody needs place to lie down, to live at the moment I need place to sleep*” (P. 20; SIS = 23cm, SHS = 6cm)

This was a notable difference. While the basic need of housing created distress and impacted their lives, the responsibility and shame associated with their illness was distinct.

## Chapter Four: Discussion

### Overview

The first aim of this study was to examine whether self-illness suffering (SIS) and self-housing suffering (SHS) were associated. A Pearson's  $r$  correlation revealed that there was a significant small positive correlation between SIS and SHS, which supported the hypothesis. A thematic analysis provided further investigation of this association. Participants described feeling overwhelmed by SHS and SIS, they were unable to engage with tasks of everyday life. Illness and housing difficulties interacted, inhibiting participants' ability to function in their lives, participate in the world or have any sense of control. Participants perceived illness and housing difficulties as intrinsically related to who they are, and this was associated with a sense of danger, overwhelming their lives, and their self. There were differences in terms of responsibility as individuals expressed a sense of stigma, and blame related to their illness suffering and the external world was perceived as "*looking down*" on their inability to improve their health. In contrast, SHS was perceived as a fundamental need, a human right, with responsibility externalised.

Multiple regression analyses then examined whether SIS or SHS had a greater independent effect on QoL, distress and wellbeing. The analyses found that SIS significantly accounted for the variance in distress and QoL, independent of SHS, age, housing situation, and drug use. SIS did not predict wellbeing. However, SHS did not independently account for the variance in distress, QoL or wellbeing. A thematic analysis revealed that participants described SIS as inhibiting their ability to perform everyday tasks. Suffering related to illness and housing difficulties both intruded on their capacity to live a life. Safety and death were prominent themes in the analysis. Participants described SHS and SIS as directly implicated in fears about survival and imminent risk, they felt exposed and fragile.

Exploratory analyses were conducted following findings that a high portion of participants placed SIS and SHS inside-self. Individuals placing illness inside-self, reported significantly poorer QoL, distress, depression and anxiety compared with those placing illness outside of their self. In contrast, SHS inside-self compared with SHS outside-self did not score on any measure.

This chapter will summarise and discuss the main findings in relation to the literature. A study summary was designed to help communicate findings to the Expert by Experience (EbE) group, the health care teams at recruitment sites, and for future dissemination (Appendix 11). The EbEs provided consultation to understand the findings, and their perspective is presented throughout this chapter. This chapter will explore the implications for theoretical understanding of suffering in physically unwell homeless persons; findings are discussed with respect to the study strengths and limitations. A discussion of the findings will provide insight into future directions for research, policy and practice.

### **Does illness suffering or housing suffering have a greater independent effect on QoL, distress and wellbeing?**

The objective was to examine whether SHS or SIS had a greater independent effect on QoL, distress and wellbeing in a physically unwell homeless population. The literature reviewed highlighted several key issues with regards to subjective health in homeless persons. Homeless persons' QoL, distress and wellbeing is considerably worse than the general population (Biswas-Diener and Diener, 2006; Sun et al, 2012; Hubley et al, 2014). Yet, the relative impact of housing difficulties or illness on subjective QoL, distress and wellbeing is not clear. Contrary to the objective evidence regarding homeless health, research has identified counterintuitive reports of how homelessness and illness are related to QoL, wellbeing and distress. For example, greater duration of homelessness has been found to account for lower distress (Wong and Piliavin, 2001). Furthermore, housing provision does not systematically

affect the domains of QoL (Patterson et al, 2013), and housing satisfaction may not predict QoL, life satisfaction or distress (Tsai et al, 2012).

With regards to the relative impact of illness, research into the subjective experience of this population also does not seem to match homeless persons' poor objective health status. For example, Ko et al (2015) found in a sample of older homeless persons with a multiple chronic health conditions, that 57% described their health as good or very good; just 19% stated their health was poor. Similarly, Gadermann et al (2014) found homeless participants rated their health as only slightly worse than they wanted or considered ideal, which they argued was due to skewed social comparisons. It has also been suggested that this reflects an adaptive process, whereby homeless persons prioritise everyday dangers and daily life experiences over health, or alternatively that they lack understanding, or this is part of a denial or avoidance (Flick and Röhnsch, 2007; Rae and Rees, 2015).

Therefore, the current study aimed to address the lack of consensus regarding experience of illness and homelessness in a physically unwell population. Analyses investigated the unique contribution of SIS and SHS to subjective QoL, distress and wellbeing. Age, housing situation, drug use and alcohol use were controlled for. The total model significantly predicted QoL, accounting for 21% of the variance and 17% of the variance in distress. Neither the total model, nor any independent factor, explained the variance in wellbeing. Alcohol use independently predicted QoL but no other control variable independently predicted change in QoL, distress or wellbeing. With regards to the research question, suffering related to housing did not predict the variance in QoL, distress or wellbeing. In contrast, high illness suffering did predict poor global QoL, and high distress. Illness suffering demonstrated a trend towards predicting wellbeing, however this was non-significant.

This is the first study to examine Cassell's (1982) concept of suffering in a homeless population. Prior uses of PRISM have most consistently reported significant negative correlations of SIS with depression, anxiety, and QoL (Sensky and Büchi, 2016). Several prior studies have reported mixed findings. For example, in a sample of adults experiencing psoriasis, Reimus, Vingerhoets, Soons and Korstanje (2007), found SIS did not correlate with any measure of subjective health. They implemented The Health Monitor Questionnaire, which has subscales relating to wellbeing, as well as items relating to DASS and WHOQoL (Reimus and Vingerhoets, 2006). Streffer et al (2009) also did not find the expected relationship between SIS and depression, possibly due to a floor effect in the depression scale (HADs). Finally, Denton et al (2004) failed to find relationships between SIS and health-related QoL using (SF-36). However, the current finding is consistent with most studies which have observed a negative relationship between high suffering and poor QoL, and a positive relationship high distress (Sensky and Büchi, 2016).

The current findings extend our understanding of homeless illness experience. They support Gelberg et al's (2000) view that we underestimate the concern homeless persons have for their health conditions; a contention which remains pertinent. The current findings are consistent with qualitative studies in samples of homeless persons in which there is immediacy to illness, where illness may pose a distinct threat to identity (Hsieh, 2016; Håkanson and Öhlén, 2016). In the context of hospitalisation, self-illness suffering, and not suffering related to housing, is key to QoL and distress. The following section will frame these results in context of the wider literature. It will consider the immediacy of illness and the role of hospitalisation on illness suffering, before discussing the findings related to self-housing suffering.

### **Immediacy of illness**

The current study is one of few studies to investigate the experiences of the *actively* unwell homeless population, that is, in need of immediate medical input. Chant et al (2014) systematic

review screened 2,563 relevant studies, finding none that focused specifically on *critically ill* homeless individuals. The current study has no objective measure of disease state; therefore, it is not possible to determine the severity of illness. While many participants were not critically ill, a large portion of the current sample were experiencing serious physical illness; this can be inferred by the fact that they were hospitalised, as well as the range of conditions reported, and how many participants had been hospitalised for more than two weeks (29.1%). The finding that self-illness suffering predicts QoL and distress may therefore reflect the immediacy of physical illness needs. Several prior authors have noted the importance of timing. John and Law (2011) comment that homeless persons' recognition of health problems depends on their immediate situation and severity of their health needs, thus explaining poor help-seeking behaviours. Rae and Rees (2015) argued that homeless persons do recognise their needs, yet seeking medical attention may continue to be side-lined. These arguments fit with Cassell's (2010) understanding of illness experience, individuals will not prioritise disease if the source of suffering is elsewhere. The current findings extend the knowledge by examining a unique time point, in which illness is immediate, and help has been sought.

The predictive role of illness suffering may reflect participants' awareness of danger. Fear is an inherent experience related to disease (Hoffmann, 2017). The qualitative analysis found suffering was related to their fragility, fear for the future and feeling exposed. Hudson et al (2016) conducted a systematic review of the qualitative research on critical illness in homeless persons found just four studies directly examining perceptions of death. The studies, each in hostel dwelling samples with palliative care needs, found individuals felt in constant danger, feeling exposed to the cold, drugs and violence; this mirrors qualitative themes elicited in the current sample. While the current sample were not in palliative care, the immediacy of illness and need for medical treatment appears to have stimulated an awareness and distress relating to their own vulnerability. In the current sample, 70.4% of individuals reported their health



was either poor or very poor, compared with 14.6% stating their health was neither good nor poor, and a further 14.6% stating their health was good. This departs from previous studies in which over a third of homeless persons reported their health to be ‘close to ideal’ (Gadermann et al, 2014) or close to two thirds stating that their health was “good” or “very good” (Ko et al, 2015). The following section will examine the role of hospitalisation in homeless persons’ illness experience.

### **Hospitalisation and suffering**

The experience of being hospitalised may be key to illness suffering in this population and its association with QoL and distress. In examining the findings from the current study, the EbE group highlighted that in hospital, a homeless person’s difficulties become translated into the language of health. The EbEs believed that professionals treat the health concerns as the primary issue, therefore influencing participants’ experience of their current illness and housing difficulties. Additionally, the EbE group suggested that prior to hospitalisation, an individual may not have identified that the lifestyle associated with being homelessness can contribute to health problems, but in hospital this becomes clear. In understanding the findings, the EbE group pointed to hospitalisation as marking a moment of reflection on one’s unhealthy habits, as well as often the enforcement of a lifestyle change. Following hospital care for example, an individual may have to cope with changes in physical ability, or the EbE group gave the example of subsequently requiring regular healthcare appointments, enforcing the homeless person to remain within the borough. The following section will discuss the experience of self-illness suffering in the current sample with regards to dignity and losses; the literature extends these ideas presented by the EbE group.

### **Dignity**

The admission as inpatients creates novel threats to dignity for homeless persons, this attack on self is a core feature in Cassell’s (1982) conceptualisation of illness suffering. The current

findings may highlight the social experience related to hospitalisation, and the role of shame as an additional threat to dignity.

The impact of illness on sense of dignity in the current sample will differ compared with the general population. This is in part due to distinct experiences of hospitalisation. Cassell (2014) describes loss of dignity as the disruption of a person's intactness and integrity, central to illness suffering. It is connected to the human right of self-worth, and respect (Cassell, 2014). For the general population, there is a social impact of illness due to visible signs of illness which may trigger disgust or pity in others, and thus a threat to one's integrity (Carel, 2017). A consequence of illness may also be a sense of vulnerability related to disruption of activities that are meaningful to the person. In contrast, for the current population, homelessness is likely to have already threatened and violated an individuals' integrity, dignity or sense of meaningful activities (Boydell et al, 2000). Therefore, illness experience without admission may not cause suffering due to these threats to self.

The social impact of illness which Cassell (2014) describes may therefore vary according time and place for this population. Suffering is shaped by surroundings, and cultural context; for homeless persons, admission to hospital entails a sharp move to a distinct world (Priya, 2012); in this case that is the exposure to a hospital, which contrasts with the demands of the street or hostel environment. The association between SIS and QoL and distress may reflect self-illness suffering due to feelings of disempowerment, stigma or disability in this setting. The qualitative analysis indicated themes of stigma related to illness and feeling disempowered through hospitalisation. While the current sample are likely to have more advanced and acute health needs, partly explaining increased report of dissatisfaction with health, these experiences through admission may also create novel attacks to their integrity and dignity.

Prior research has hypothesised that homeless persons' report of subjective good health may be due to positive adjustments to their harsh living environments (Gadermann et al, 2014). An alternative explanation may be that in this environment, illness is not experienced as an additional threat to integrity or dignity. Carel (2017) argues that illness suffering increases in a medical setting because the individual's experience of their own illness moves from being subjective, to an objectified disease. Consequently, hospitalisation is connected to a series of losses, "loss of wholeness, loss of certainty, loss of control" (Carel, 2017, p. 94). As an inpatient, homeless persons are required to place their trust in a professional system, systems which may have historically been perceived as causing loss and distress (Hudson et al, 2016); homeless persons also experience significant stigma and discrimination in healthcare settings (Rae and Rees, 2015).

### **Freedom to act and loss of a familiar world**

Carel (2017) describes two further losses which individuals face in being hospitalised, "loss of freedom to act and loss of the familiar world" (Carel, 2017, p. 94). Self-illness suffering is associated with loss of autonomy and inability to perform personal functions (Büchi et al, 2002). The current finding that SIS predicts poor QoL and high distress may also be due to threats to personal autonomy and loss of freedoms in this setting. Homeless persons may experience significant threats to autonomy and freedom in their everyday lives, however previous research has found the effect of hospitalisation may activate a loss of independence. Håkanson and Öhlén (2016) found homeless persons in residential care compared the experience of the institution with the freedom felt on the streets. Individuals expressed a loss of freedom in this context, losing the independence which they had on the street. Individuals found the institution triggered feelings of hopelessness, with illness forcing individuals to reflect on their lives in this setting, yet the future and recovery were deemed unimaginable.

Hudson et al (2016) review also found loss of independence was an important factor in increased distress for physically unwell homeless persons.

Carel (2017) describes suffering in a medical context as being related to the medicalisation of self. She describes a common transition from subjectivity, the persons' illness experience, towards objectivity through examination and medicalisation of the disease (Carel, 2017). Loss of control, lack of safety net, and disconnection with the world were features of the current sample's qualitative experience. This may reflect unique self-illness suffering in this setting: loss of independence, reflections on danger and death, hopelessness, loss of control over illness and housing. Cassell (2014) highlights the impact of losing one's autonomy,

“all suffering involves loss of, or profound change in purpose. Purpose pervades every moment and every part of being leading to central purpose - the being of oneself” (p. 2)

The high proportion of individuals placing illness and housing inside-self may also reflect the above themes, as well as loss of meaning and purpose. Illness in the general population can limit participation in social occasions or inhibit freedom to engage with the world (Carel, 2017). For homeless persons, such losses of social freedoms may not be experienced simply through illness, but it is expressed in the current sample by the combination of illness and hospitalisation.

This section has highlighted the unique experience of hospitalisation for this population, and its role in illness suffering for this sample. It highlighted firstly the novel threats to dignity and integrity, before discussing the violation of autonomy and freedoms. This may in part explain the predictive value of SIS for this population. The following section will discuss the finding that housing related suffering did not predict QoL, distress or wellbeing.

### **Suffering related to housing difficulties**

It was surprising that suffering related to housing difficulties (SHS) did not predict QoL, distress or wellbeing. There are several possible explanations for the finding. It could reflect the unique time point of the study, heterogeneity in the sample, lack of power to detect an effect, or measurement error in the use of an adapted PRISM.

In contrast with a street homeless population, this sample were sheltered in the hospital, many were to continue inpatient stays in a setting in which their basic needs are arguably provided for in terms of safety, warmth, health care and temporary shelter. Homelessness is a present concern in their current lives, yet their immediate situation may temporarily reduce its salience in contrast with illness. One could therefore conclude that suffering related to housing is side-lined, denied or neglected by this sample. This hypothesis mirrors the research into health experiences of hostel homeless, whereby health concerns are side-lined (Gadermann et al, 2014).

It is unclear whether the hospital environment could reduce SHS. For example, the safety of hospital environments for service users can be questioned. Safety derives from not just a reduction of physical risk, but a feeling of psychological safety, a sense of security in one's future along with clarity, consistency, and built relationships (Cockersell, 2015). Rae and Rees (2015) found a UK hostel sample reported negative experiences of medical care, being treated badly, feeling unwelcome and uncared for. Participants in the current study did however receive enhanced hospital care, in which a specialist multi-disciplinary team addressed housing and health care needs (Hewett et al, 2016). Service users have reported feeling supported by this service, having a newfound trust and hope with regards to moving into more secure housing situation (Hewett et al, 2012); furthermore, an RCT found enhanced hospital healthcare improved QoL compared with standard hospital care (Hewett et al, 2016).

In consultation regarding the findings, the EbE group suggested that housing difficulties may not have predicted QoL, distress or well-being in part due to participants receiving enhanced care. The EbE group indicated that homeless persons receiving enhanced health care can view hospitalisation as a chance to address longstanding housing difficulties. Therefore, it is plausible that in the unique context of being hospitalised, SHS was influenced by the additional care, with participants feeling the team could improve the housing situation. Alternatively, one EbE suggested homeless persons attending hospital can feel hopeless with regards to addressing their housing situation. He believed that an apathy towards housing difficulties may explain the lack of explanatory value of SHS in QoL, distress or wellbeing. However, there are several points which counter this hypothesis. Firstly, the qualitative data demonstrated housing difficulties remained a primary preoccupation for service users; SHS was linked with feeling in danger, limiting their capacity to live life and affecting individual's sense of who they are. Furthermore, the median score of SIS and SHS were equal, indicating a high overall level of housing related suffering in the sample. Finally, a high proportion of the sample placed housing difficulties inside-self, a finding which will be discussed.

### **Illness and housing difficulties inside-self**

Exploratory analyses were conducted to investigate the high number of participants placing SIS and/ or SHS inside-self. Close to half, 47.9%, of participants placed SIS inside-self and 39.6% placed SHS inside-self. Of these, 29.2% participants placed both SIS and SHS inside-self. A two-way ANOVA compared inside-self and outside-self, finding significant differences in SIS on QoL, as well as distress, depression and anxiety. SHS inside-self did not differ from SHS outside-self on any measure.

Büchi et al (2002) early use of PRISM identified a normal distribution, however the authors suggested future research could interpret SIS in terms of categorical ranges, and degree of overlap with self, as a meaningful use of the measure. Numerous studies have since reported

high numbers of participants placing SIS inside-self. Streffer et al (2009) found 25.7% of participants with orofacial pain, placed a cross, representing illness, inside-self (n=102). Peter et al (2016) found 51.6% of participants with Tinnitus (n= 180), using a computerised version of PRISM, placed illness disk inside or overlapping with self. Each of these studies used adapted versions of the traditional PRISM task. Peter et al (2016) compared illness inside-self groups with illness outside-self group, also finding significant differences in WHOQoL-BREF global scores, but also on the psychological domain. Weidt et al (2014) reported that a quarter of participants placed illness (dizziness) inside-self. The authors compared participants placing dizziness inside- and outside-self, finding significant differences in severity of dizziness, and distress on the Hospital Anxiety and Depression Scale (HADS, Zigmond and Snaith, 1983). In contrast, Streffer et al (2009) found no significant differences between inside-self and outside-self groups on the anxiety and depression using HADS. In comparison with these studies therefore, the current sample demonstrated particularly high levels of illness inside-self, matched by Peter et al (2016) findings.

Denton et al (2004) argued PRISM captured enmeshment with illness rather than just suffering. They pointed to Pincus and Morley's (2001) model of chronic illness in which patients view the self as disease and disease as the self. Enmeshment, they suggest, occurs where illness threatens the self and causes loss of meaning, autonomy and purpose, and so enmeshment of illness with self determines suffering (Denton et al, 2004). In reviewing the findings, the EbE group also believed that the overlap of the illness disk with self might represent a sense of self as the problem. However, the EbE group suggested that service users may be referring to their mental illness or addictions. Following personal experience and work with homeless persons, they suggested that homeless persons with drug and alcohol difficulties can feel this becomes their whole identity, losing a sense of who they are or had been. However, the EbE group did not deem this process of enmeshment to occur in physical illness. Sensky and Büchi (2016)

query this conceptualisation of enmeshment, pointing to recent studies which have failed to find a correlation between enmeshment and depression or anxiety. There is a conceptual overlap, intrusiveness and controllability are key themes of illness suffering (Sensky and Büchi, 2016). The current study finds illness and housing suffering to be overlapping with self for many. This fits with the qualitative data indicating a loss of control, lack of access, and intrusion on capacity to live life. The analysis found participants reported both SHS and SIS to be intrinsically linked to their sense of self.

These findings also reinforce the reality that there will be individual variation in terms of where homeless persons identify their primary cause of suffering. The sample were almost evenly split in the order of suffering experienced, 35.4% of individuals reported higher SIS than SHS, 25% of participants placed SHS higher than SIS and 39.6% reported SHS and SIS as equal. This highlights the need for communication, collaboration and shared formulation between services, and with service users.

### **Did PRISM perform in this population?**

The performance of the adapted PRISM task may explain the lack of effect of SHS in the regression analyses. The current study adapted PRISM to include SHS, with participants asked where they would place housing difficulties in their life at the moment. Prior studies have extended the task to include disks representing family, work, fatigue and pain. Additional disks must be univalent (i.e. Positive or negative), as with illness in the original measure, its presence one's life close to self is universally recognised as negative (Sensky and Büchi, 2016). For example, Kassardjian et al, (2008) used a disk to represent 'partner' which was not univalent and thus closeness to self represented a range meaning including feeling controlled by partners (i.e. Negative), or emotional closeness (positive), and participants also reported high suffering related to partners when they did not have a partner. In these instances, the measure no longer assesses burden of suffering according to the Cassell's (1982) definition.



In contrast, conceptually the literature has understood homelessness, like illness, is a severe threat to an individuals' personhood, their sense of self in their life (Boydell, 2000; Håkanson and Öhlén, 2016). Cassell (1982) provides the example of homelessness as a threat to the integrity of the person in his seminal paper introducing a definition of illness suffering. In discussing the adapted measure to the EbE group, the concept was described as easy to understand, and the idea of comparing housing difficulties and illness in this way deemed to be interesting and important. Individuals intuitively interpreted the closeness of the disks as reflecting 'importance in one's life', as described in the development of the measure (Büchi et al 2002). This consultation was important in assessing face and content validity, as well as clarifying instructions. The term 'housing difficulties' was used, this emphasised the univalent nature of the disk in relation to self in one's life. However, there was no further piloting of the measure.

Many participants intuitively understood the task in placing SIS and SHS on the board in relation to their self. Consistency in interpretation was reflected in the thematic analysis, with disks on top of themselves representing negative feelings, inability to function in everyday life, feeling paralysed, out of control and intruding on sense of self. These match themes cited in prior studies: unpleasant emotions, inability to realise life plans, worries about the future, loss of autonomy or roles, not feeling oneself, lack of control and intrusiveness are familiar themes in qualitative analyses of PRISM (Büchi et al, 2002; Wittman et al, 2009; Sensky and Büchi, 2016). Furthermore, while differences between SHS inside-self, outside-self were non-significant, they were in the expected direction.

Four participants demonstrated alternate interpretations of the task with regards to SHS. SHS seemed to cause significant burden of suffering for participant four. It had importance in his life and affected his ability to meet needs, but it was placed at a distance from his self in his

life. The interpretation seems to be inability to access housing, therefore far away from him at 8.9cm from self,

*“Far away at the moment, I can only live in certain places that will meet my needs, my mum’s is not wheelchair accessible... It’s on my mind. It’s on my mind more, constantly thinking about it.” (P. 4)*

In contrast, inability to access housing, was also interpreted as close to self,

*“Because everybody needs place to lie down, to live at the moment I need place to sleep. So this is close to my heart” (p. 20, SHS=6cm)*

Participant 47 described his life as empty, again SHS seemed to be interpreted as inaccessible, playing it at 24cm from self, *“until I can get house and have stability”*.

Some variation was reflected in the qualitative responses regarding SIS also, reflecting possible language or cultural barriers. For example, participants 8 and 47 placed illness in the middle of the board representing different meanings,

*“It’s in the middle because it’s affecting everything, my work it’s affecting everything if I’m not going to work” (P. 8, SIS= 15.5cm)*

*“In the middle, try to stay trim. Depression causes fatigue and fatigue causes things not to get done, soon as you know you can’t get things done. People say lazy but it’s not, just can’t get stuff done. I want to get sorted but can’t” (P. 47, SIS=14cm)*

Participant 47 was Portuguese, and participant eight was Polish, therefore English was not their first language and there may have been misunderstanding in the instructions. PRISM has mainly been used in English or German speaking European and North American samples, but it has been applied cross-culturally with success in Gambian, Nepalese, Kurdish and Colombian samples (Sensky and Büchi, 2016). However, Sensky and Büchi (2016) question

whether there may be cross-cultural differences in conceptualisation of the 'self' disk, therefore affecting the interpretation and performance. The current study used service user consultation to pre-empt challenges relating to understanding or interpretation, however a more robust approach would have been to pilot the adapted version of PRISM in this population. Above are examples of a minority of participants whose interpretations seem incongruous with the original conceptualisation of the PRISM task (Büchi et al, 2002). Most participants, as indicated by the thematic analysis, understood the task and described themes coherent and novel, to describe their burden of suffering. The task was kept simple by having just two movable disks, presented successively, and placed in relation to self rather than in relation to one another as has created challenges (Sensky and Büchi, 2016).

Retrospective analyses of the qualitative findings are limited in assessing to what extent PRISM performed as a measure of SIS in this sample, or with the inclusion of a new disk SHS. A pilot could have systematically asked participants, following placement of each disk, to comment on why they had placed it at that distance, and then subsequently asked what it would mean if the disk were far away, or close to self. Additionally, it may be important to examine how participants interpreted the relationship between the two movable disks, which the task does not intend to assess. Piloting of this adapted PRISM in this population would have enabled a more rigorous assessment of the tool, and increase confidence that results did not reflect measurement error.

### **Strengths**

The current study is unique in examining the psychological experience of illness in a hospitalised homeless sample. Homeless persons in inpatient care are a significant minority, a quarter of the homeless hostel population are admitted to hospital over a six-month period (Homeless Link, 2014). A further strength of the current study has been its ability to draw the knowledge provided by experts by experience.

An important component in the design and interpretation of the current study has been the consultation of individuals with lived experience of ill health and homelessness. Service user consultation is central to the NHS vision for developing services (DoH, '*Five Year Forward View*', 2016). However, a systematic review of user involvement in health and social care research found the perspectives of individuals with severe and enduring mental and physical health, minority ethnic groups, older people and people with disabilities are rarely represented in user consultation (Brett et al, 2012). Reasons cited for lack of representation may be ill health, time, cost, lack of expertise or not prioritised (Kylberg, Haak, Iwarsson, 2017). EbE's unique experience and perspective was invaluable in this project. The current study could draw on a group who had been trained in consultation work, who provide collaboration at key stages of the research (Pathway, '*Experts by Experience Handbook*', 2017). Their positive influence can be noted on the study recruitment.

Through service user consultation, adaptations were made to the recruitment methodology and procedure: the provision of incentives, engagement approach, and implementation of measures. The project title, as stated on research documents, was also amended due to a prior version being perceived to be harsh. A recent review highlighted the difficulties research has in recruiting homeless participants for research (Hudson et al, 2016); a possible explanation for few clinical health psychological studies examining physically unwell homeless population. In large part, due to service user consultation, the current recruitment strategy was an overwhelming success. On average 3.69 participants were recruited per week over thirteen weeks. Only three participants refused to participate (3, 5.77%), and one withdrew. The sample appears to be representative of the population. Demographics from the current sample matched the characteristics reported in a recent RCT of in-hospital management of homeless persons in London (Hewett et al, 2016). Hewett et al (2016) report a mean sample age 42.5, with 81.5% male and 70.5% UK nationals, 17.6% from the European Union as well as 47.1%

street homeless. English hospital statistics for homeless persons also show a match with the current sample in terms of age, gender, race and illness presentations (McCormick and White, 2016).

There were numerous barriers to recruitment: substance misuse; pain, fatigue, nausea, infection; busy hospital environments; routine care including operations, ward rounds, restricted hours of ward access and pressures for discharge. The experts by experience group provided valuable knowledge about managing these barriers to recruitment. Crucially, the experts by experience expressed that homeless persons will have a desire to talk and participate in the study. This was an enthusiasm for participation in research amongst this population which contradicted the literature; the consultation provided both direction and confidence to achieve this sample.

The active involvement of this group significantly enhances the ecological, or ‘real world’ validity of the current project (Faulkner, 2012). Their voice in this consultation role has been described throughout this section in interpreting results, limitations, implementation and proposing future directions. The following section will discuss the limitations of the study.

## **Limitations**

### **Sampling**

There are several limitations with respect to sampling. Firstly, the sample size of 48 may have contributed to a type II error, that is, failing to detect an effect in the population due to a lack of statistical power. The a priori power analyses were based on an estimate of a moderate effect using Clark-Carter (1997) criterion for power. Given SHS and SIS required square root transformation to align the independent variables (IVs) with normality assumptions, more conservative power calculations and a larger sample size would have provided greater confidence in central limit theorem for parametric analyses (Wilcox, 2010).

The heterogeneity of the sample has implications for interpretation of the findings. In consultation for the design of the current study, service users queried the variance relating to the timing of illness and hospitalisation. The EbE group argued that the nature of the illness, in terms of chronicity, and also the length of time in hospital would influence homeless persons' SIS. The current sample varied according to length of hospitalisation, with the largest group staying under four days (36.2%), almost two thirds staying under ten days (59.6%); six participants had been hospitalised for over one month (12.5%). This was not controlled for in the analysis. The current study could have measured number of nights sleeping rough in the past 40 days to capture exposure to street homelessness as used by prior research (Hewett et al, 2016).

There was also high heterogeneity in terms of disease variables (e.g. Illness type, stage, severity); significant health co-morbidity in the current sample is in line with prior research (Hewett et al, 2016). Prior studies using PRISM have predominantly focused on patient groups with a common diagnosis (Sensky and Büchi, 2016), therefore reducing variation in the sample. Heterogeneity and lack of measure of objective disease is a limitation of the current project, there was no control for the effect of disease type or severity.

### **Cross sectional design**

The cross-sectional design inhibits inferences regarding causality and bias. As discussed above, the unique time point of hospitalisation may have been central to the current findings, the setting of interviews may also have been important. Interviews were conducted orally, bedside, on busy hospital wards, which could have influenced participants' willingness or nature of what personal information individuals were willing to disclose. For example the qualitative findings highlighted that individuals felt some shame related to their illness, the open ward setting therefore could have biased self-report.

While identifying significant associations, it will not be possible for the study to rule out numerous possible causal effects. As recommended in service user consultation, having multiple time points, or a comparison group would have enabled inferences regarding causation. Unfortunately, there are significant obstacles to experimentally determining the complex relationships between variables in this population (Hwang, 2002), which was beyond the scope of the current study. However, a longitudinal project would provide an important examination of these factors.

Interviewing service users exclusively while in inpatient hospital care was raised as a limitation by EbEs in consultation. The EbE group suggested future work could compare homeless persons prior to attending hospital, with individuals during admission and post discharge. Service users argued that illness-related suffering would vary according to this timeline. They believed that an inpatient period was unique for people with housing difficulties in terms of recognising illness severity. They believed that illness experience for homeless persons may not be represented by capturing this time point; most physically unwell homeless persons are not in hospital care. Recruiting this population over numerous time points, or identifying a matched comparison group is a significant challenge (Hwang, 2002) but it would also be a useful direction for future research.

The lack of experimental design means that one cannot rule out confounding factors, that is the effects of unmeasured variables on DVs, IVs, and their hypothesised relationship. A large portion of the variance in the DVs was unexplained. One possible explanatory factor is social support, as indicated in the literature. Theoretical and research findings have highlighted the role of social support in QoL (Leventhal et al, 2008), it is also implicated in homeless distress (Irwin, LaGory, Ritchey et al, 2008) and has been recently found to affect subjective wellbeing in a Japanese homeless population (Ito, Morikawa, Okamura et al 2014). Relationship status was not recorded in the current study, nor information regarding perceived social support but

the current thematic analysis did highlight the feeling of not having a “safety net”, and thus a possible link between social support and suffering. Perceived social support may play an important moderating role in the relationship between SIS and quality of life, distress and wellbeing.

### **Validity of self-report measures**

The validity of the three self-report measures WHOQoL-BREF, WEMWBS and DASS-21 in this population should be critically analysed. As outlined, all three measures were selected based on robust psychometric evidence, use in physical and mental health settings and across cultural groups. WHOQoL-BREF had been validated and used in a homeless sample (Garcia-Rae and LePage, 2010; van der Plas, Hoek and van Hoeken, 2011). The DASS-21 had also performed well in a homeless population (Rogoz and Burke, 2016). Each tool was presented and discussed with the EbEs. The group were specifically asked to examine the WEMWBS due to no prior use in this population and they described the tool as simple, relevant and clear. Service user consultation did indicate that all measures be read aloud and completed with support.

The DASS-21 asks service users to respond to what extent statements applied to them over the past week. Participants highlighted numerous conceptual issues in responding to DASS-21. Firstly, most participants had been inpatients for under four days (36.2%), consequently numerous participants reported finding it difficult to amalgamate two distinct periods into one week. Several items on the DASS-21 appeared to lack face validity for service users. For the first item the phrase ‘wind down’ was unfamiliar and often had to be elaborated. Numerous items could be explained due to substance use or medical problems, including ‘dryness of mouth’ (item two), ‘breathing difficulties’ (four), and ‘trembling’ (seven). Two items drew on the premise that participants had things they were attempting or expecting to do, ‘I find it difficult to work up the initiative to do things’ (five), and ‘I was intolerant of anything that kept



me from getting on with what I was doing'. A number of participants commented that this concept did not fit with their current lives, as inpatients (some long term), and as homeless persons. Finally, item 20 'I felt scared without any good reason' was incongruous for many participants who explained they had good reason to be scared given their life experiences.

On the WEMWBS, the following items were incongruous with participants' current state: 'I've had energy to spare', 'I've been interested in new things or other people', 'I've been feeling usefulness'/ 'relaxed'/ 'cheerful', 'I've been dealing with problems well'. Given their health and hospitalisation, participants felt these items lacked meaning. Participant 42 commented with regards to 'I've been thinking clearly', "*what do I think of, drugs, my next hit?*". Ryff and Boylan (2016) comment that a major limitation of the literature into wellbeing in the physically unwell, is the overlap of subjective health and indicators of wellbeing. WEMWBS was the only measure to not have been previously used in a homeless population. Floor effects or measurement error may account for wellbeing as the only variable not significantly predicted by SIS.

Ogden and Lo (2012) examined the meaningfulness of using Likert scales to measure QoL in a homeless population. They compared responses of homeless persons with a student, and general population. Participants completed several idiographic items drawn from typical QoL measures, with items about mood, health status and satisfaction, they then also answered two open ended questions regarding their thoughts and feelings relating to these items. The authors found 'striking contradictions' between the structured and unstructured accounts, with distinct interpretations of homeless persons to the questions. For example, according to the Likert scales homeless persons reported feeling less tired and more healthy compared with a student group and general population. However, qualitative data found significant sleep and physical health problems. Similarly, with regards to food, they reported feeling fine, well or ok, yet qualitatively they added that they do not eat much or had not eaten for several days. The

authors argued this reflected measurement error and psychometric limitations of the scales in capturing QoL for the homeless population (Ogden and Lo, 2012).

There are further complications relating to use of self-report measures in this population. In conjunction with significant substance misuse, physical and mental illness, homeless persons have markedly high rates of traumatic brain injury, learning disability, autism spectrum disorder (Topolovec-Vranic, Ennis, Colantonio, Cusimano, 2012). A recent study in a UK city found 48% had a history of traumatic brain injury (Oddy, Moir, Fortescue and Chadwick, 2014). These additional neurological needs often go unrecognised, and may be higher in a sample requiring hospitalisation (Song, Nikoo, Choi et al, 2017).

While there is a proliferation of studies examining the validity of WHOQoL-BREF, including in individuals with traumatic brain injury (Smith, Raskin and de Joya, 2015), the distinct circumstances of this sample may not be accounted for in these measures. Rae and LePage (2010) tested the psychometric properties of WHOQoL-BREF in a homeless sample, however this was in a sample of North American veterans, living in residential rehabilitation, undergoing a treatment programme, without specific physical health needs. The issue of heterogeneity in this population is significant, these samples are distinct. It has been argued that homeless persons can be conceptualised as a cultural group, and transcultural lenses are required in care and understanding (Law and John, 2012). The cultural context of London is also critical, for example a significant minority of the homeless population are vulnerable migrants (Hewett et al, 2016) and they face socio-political challenges. There is evidence that hospital use by homeless migrants and refugees is greater than nationals (Silvestrini, Federico, Damiani et al, 2017). This group may be underrepresented in the current sample due to exclusion criteria of non-English speaking, 14.6% of the sample had no recourse to public funds, lacking eligibility for UK health and social care due to immigration status.

A critical analysis of DASS-21, WEMWBS and WHOQoL-BREF encourages caution with regards to structured questionnaires in this population; it highlights the role of culture in participant responses, demonstrating the unique context and experiences of homeless persons with physical illness in the UK. Yet these scales used were selected due to robust psychometric performance, across cultures and in relevant samples. A balanced approach to interpretation is needed; psychometric validity may be limited when making inferences across social, linguistic, cultural and political contexts (Suarez-Orozco, 2012). There are implications for future research into suffering in this population.

### **Implications for future research**

Replication will be an important next step in understanding burden of suffering in physically unwell homeless population. A future study could aim for greater homogeneity in the sample. While housing situation, age and drug use were found to not have independent effects on QoL, wellbeing and distress, a follow up may aim to reduce variation by controlling for these factors in sampling methodology. As discussed, measuring exposure to street homelessness may best capture differences in participants' exposure to extreme homeless conditions. With regards to age, a specific examination of the younger population under 25 (4.2% of current sample), may be warranted as this group have distinct social, psychological and health needs (Krabbenborg, Boersma, and Vollebergh et al, 2017). Equally, older physically unwell homeless adults over 40 (72.9% of the current sample) would provide useful insight into suffering in a population who are at higher risk of morbidity, disability and death (Grenier et al, 2016). The following section will propose further advances using alternative research designs.

### **Suffering at multiple time points**

The EbE group proposed that future research investigate SIS and SHS prior to admission and post discharge. Several of the EbE consultants are also employed as 'care navigators', former homeless persons who provide peer support as part of the multi-disciplinary team (Hewett et

al, 2012). They support after-care, a period that they highlight is critical to the health and housing of service users, and a key time for intervention, as multi-agency care plans are formed (Hewett et al, 2016).

The EbEs pointed to a critical issue in the examination of homeless health. The current study reinforces the reality that health needs can be acute, chronic and co-morbid, but it has also provided new evidence that this time point may be unique for illness experience in this population; SIS is extremely high during hospitalisation, and a greater predictor of QoL, distress and wellbeing than SHS. Prior research has found homeless persons minimise health concerns, citing neglect, denial or lack of understanding (Gadermann et al, 2014). This study therefore suggests that hospitalisation may be unique in service users' awareness and recognition, and thus a crucial time point in terms of intervention and accessing motivation to change.

Helgeson and Zajdel (2017) point to time course as a crucial variable in the empirical investigation of chronic illness, "it may be that predictor variables are more or less potent at different stages of illness" (P. 564). Ogden (2012) describes a surprising process of change which occurs in self-reported QoL in physically unwell participants which was previously interpreted as measurement error. Individuals who report poor QoL soon after serious health problems, several months later can report high QoL despite no change in objective health. This has been attributed to changes in frame of reference, standards or strategies (Ogden, 2012). For example, homeless persons may judge their current experiences in relation to a previous period when they were worse off. Dempster, Carney and McClements (2010) found post diagnosis cardiac patients self report QoL is poor, yet several months later, despite minimal physical improvements, participants reported significant improvement in subjective QoL, this is possibly due to changes in internal standards, and coping strategies. Furthermore, social comparisons may play a significant role in homeless minimisation of health concerns

(Gadermann et al, 2014). The process of hospitalisation and discharge would be expected to affect how an individual appraises what is important in their life and therefore their personhood. Comparing SIS during hospitalisation, with groups pre-or post-hospitalisation for example would be an important next step.

The current study provides preliminary evidence for use of PRISM as a research tool in this population. SIS appears to be a valid and valuable construct in predicting QoL and distress. Service user feedback indicated that it was interesting, clear and important. PRISM has been found to be sensitive to change at three month follow up post rehabilitation in a sample with respiratory conditions (Büchi et al, 2002). Use of PRISM as a tool to measure change has been replicated with strengths highlighted in its ease of use, low responder burden and sensitivity to change (Gielissen et al, 2013). Kok et al (2017) and Töndury et al (2013) report that PRISM complements disease specific or QoL questionnaires as it provides personally salient information relating to an individuals' current experience.

The wider body of health psychological research examining cultural and socioeconomic factors implicated in disease have contended with difficulties demonstrating causal pathways, (Leventhal et al, 2008). Longitudinal research or larger cross-sectional sample would enable a robust examination of possible confounds such as social support. However, recruitment at multiple time points in this population is extremely difficult. Hewett et al (2016) RCT found just one quarter of physically unwell homeless participants could be contacted within six weeks of discharge.

The consultation group believed that PRISM could be used to assess interventions and motivation in this population. Reinhardt et al (2006) used PRISM to assess readiness change in alcohol addictions, finding SIS to be a significant independent predictor. The current population have sought help, a design with follow up could provide important information

regarding experience of care, help-seeking behaviour and suffering related to illness and housing.

### **Qualitative investigation**

An important direction for future research would be to extend the current findings with in depth qualitative investigation of homeless suffering. PRISM may be the best measure of suffering, yet there remains no gold standard tool (Krikorian et al, 2013). Limitations relating to use of PRISM in this population have been discussed, particularly in capturing SHS. While PRISM yields an invaluable quantitative assessment of suffering, the qualitative data rendered by PRISM is restrictive. Cassell's definition of suffering emphasises personal meaning in understanding impact of illness on self: unique to the individuals' psychological, personal, political and spiritual aspects of the person (Cassell, 2014).

Priya (2012) states that socioeconomically deprived individuals with chronic illness may refuse to voice their stories due to potential costs of being exposed, causing pain to others, feeling others cannot understand or that others would not want to hear their stories. The success of PRISM in rendering responses may be due to the visual and succinct nature of the task (Sensky and Büchi, 2016). For example, asking a physically unwell homeless person "what causes you to suffer?" Could feel overwhelming for a participant and may elicit an unfocused response. Sensky and Büchi (2016) comment that such an open question would require an individual to define their life at the moment, what they value, and how illness fits. However, it may enable participants to provide their own definition on the term suffering and understanding of how they experience illness in their life. One EbE found the term 'suffering' harsh and believed participants would not refer to their current experiences using this word.

The current study has applied Cassell's (1982) conceptualisation of suffering to homelessness. SHS was found to not predict QoL, distress and wellbeing, this may be due to theoretical

problems in use of PRISM to capture suffering related to housing difficulties. The current study has argued that there are conceptual similarities between illness and homelessness, yet this may require further investigation. Parallels with Cassell's (2014) understanding of suffering related to illness include the broad consequences of homelessness such as loss of meaning, purpose, relationships, as well as threats to dignity, and intactness of person. A qualitative examination of homeless suffering using Cassell's (1982) framework would be invaluable to enhance our knowledge of the meaning of homeless suffering in individuals' lives.

### **Implications for service provision and clinical practice**

#### **PRISM as a clinical tool**

Professionals and services find it challenging to engage homeless persons in care (Rae and Rees, 2015). In hospital settings, discussions regarding key aspects of their health care can be neglected. This may be due to multiple and chronic, health and social care needs, challenging behaviour, risk, lack of experience and difficulties professionals have in framing discussions with homeless persons (Hudson et al, 2016). Use of PRISM in this study provides preliminary encouragement for its use as a clinical tool in this population.

Previous studies have explored the use of PRISM as a clinical tool. Evidence suggests PRISM may be a useful accompaniment in a motivational interviewing approach to change (Reinhardt et al, 2006). Qualitative findings in the current study found parallel themes regarding control of illness and accessibility to housing. This is congruous with Cassell's definition of illness suffering, helpless and loss of control as central features of the lived experience (Cassell, 2016a). Themes of accessibility in understanding of illness or housing suffering may reflect participants' inability to affect change. Reinhardt et al (2006) found associations between SIS and stages of change contemplation, in alcohol use. Due to this significant correlation, closeness to self, was therefore interpreted as motivation to recognise or manage alcohol use,

taking ownership (Reinhardt et al, 2006). While the current study cannot make inferences regarding readiness to change, qualitative findings suggest participants associated SIS and SHS with ability to change. Participant 6 placed SIS close to self, indicating an awareness and a desire for change.

*“I think I want my life to be better, I want it to be there I put it near me”* (P. 6; SIS=9.3cm)

Participants 4 and 20 presented the opposing position, placing illness far from their self, indicating desire to avoid, possibly reflecting difficulties contemplating change.

*“When you are sick you don’t want to know, you don’t. You have to have a gap between you and it. No one wants sickness to get close to you.”* (P. 20, SIS= 23cm)

*“Because my illness won’t go away, it has left me with deep scars I can’t accept, looks deformed and I can’t accept that.”* (P. 4, SIS 12cm)

Additional disks have been used to represent key relationships, work (Kassardjian et al, 2008), suicidality (Ring, Harbauer and Haas et al, 2014), or to represent resources (Büchi, Straub and Schwager, 2010). Schmid-Büchi, Halfens and Dassen (2011) asked individuals to complete the task from the perspective of someone who cares for them. Drawing on any individual or systemic resources available to service users will be essential for change in this service user group.

Büchi et al (2010) trialled the use of PRISM to facilitate shared decision making in clinical practice in the context of psychiatry inpatient care. They found PRISM enabled collaborative conversations and the development and measurement of shared treatment goals. Case reports have replicated this, using PRISM for shared treatment understanding and communication (Töndury et al, 2013). This is particularly relevant for unwell homeless persons given the multiple competing stressors in their lives.



As a visual metaphor, PRISM facilitates personal interpretation and creativity in responding (Sensky and Büchi, 2016). The limitations of self-report measures in this population have been discussed, in clinical use, PRISM allows for greater flexibility and investigation of meanings for service users, central to understanding their suffering (Cassell, 2016b). Given the high rates of illiteracy and disempowerment experienced by this population, “a diagram is worth ten thousand words” (Sensky and Büchi, 2016, p. 12).

Used clinically, it would also be possible to locate and compare suffering related to multiple illnesses. Reimus et al (2007) for example asked service users to choose what the illness disk represented for them. Kok et al (2017) compared self-trauma separation, with self-addiction separation in inpatient treatment in patients with substance use disorder. PRISM performed well psychometrically, it was praised for its ease of use, providing a direct comparison of key illnesses, and discriminating effects in face of comorbidity. The authors conclude,

“Suffering, as measured by the PRISM, gives a measure of the person’s appraisal of the intrusiveness and lack of controllability of the condition(s) being assessed. This is probably more relevant to the person’s perceived need for intervention or support than the number of symptoms experienced, or their duration.” (Kok et al, 2017, P. 16)

This study found homeless persons to consider PRISM to be simple, clear and that it raises challenging yet meaningful subjects. It’s flexibility and the range of adaptations and uses provide a promising avenue for implementation in practice, use in motivation for change, assessing resources, and enhancing shared decision making, however further research is warranted first. As discussed, PRISM has the unique capability to assess disparate stressors impinging on an individual’s life, essential for this population. PRISM may be a valuable tool for developing shared health care decisions in this population.

## **Housing First vs. Treatment First**

A key polemic in the literature is comparative effectiveness of the housing first vs. treatment first intervention approaches. In recognition of the limitations of the current study, no general inferences can be made regarding treatment priorities of physical unwell homeless persons. The current study does indicate the high level of variation in terms of individuals reporting higher suffering related to illness or housing. This highlights how important collaborative conversations and person centred care will be in intervention decisions. Therefore it is in the interest of the housing first vs. treatment first approaches to work towards enhancing change oriented clinical practice, and shared decision making.

Staff and homeless service users struggle to discuss their care collaboratively (Shulman and Hudson, 2016). Recent research by Steward et al (2016) found divergences in the views of patients and providers in primary care for homeless persons. They compared priorities of homeless patients and professionals in health care and found that providers/experts assigned high priority to giving service users control in their health care (4<sup>th</sup> of 16), but patients saw this as far lower priority (10<sup>th</sup>) (Steward et al, 2016). Homeless persons and professionals both ranked ‘accessibility of care’ as the most important component of their health care for homeless service users and ‘shared knowledge of information’ at 4<sup>th</sup>, compared with professionals who placed this as 14<sup>th</sup> (Steward et al, 2016). While ‘control’ was not ranked as important, transparent conversations were highly valued by this population. This is consistent with research findings that service users with serious mental illness and physical health comorbidity want transparency and involvement in key decisions (Small, Brooks, Grundy et al, 2017). In the unwell homeless population, this could facilitate treatment plans which are adapted to an individuals’ needs as well as their priorities and motivation for change.

## **The role of clinical psychology**

A psychological perspective is increasingly valued across hostel and health services. Psychological frameworks are influencing staff environments (Cockersell, 2015), identifying hidden psychological needs (Song et al, 2017), guiding service development and enhancing engagement of service users (Maguire and Ritchie, 2015). Yet, the clinical psychology perspective remains underrepresented in the field of homelessness, a sparse resource compared to social care, medical and allied health professionals (Maguire and Ritchie, 2015). Brown (2015) calls for a BPS strategy for working in this field and clinical guidelines for direct and indirect work. The American Psychological Association has developed a taskforce, to “identify and address psychosocial factors, and define the role of psychologists in ending homelessness” (Bray et al, 2010, p. 1).

A key strength of the current study has been to offer this psychological perspective in an interdisciplinary context, relying on the engagement of ward staff, nurses, doctors and social workers as well as research evidence and theory from across allied health and social care. Indirect involvement of professionals surrounding the current sample has created a project relevant and meaningful to their direct work. As a fundamental feature of homeless care, this project highlights that a multidisciplinary approach will also be central to the development of psychological theory and research in this field. This will be critical to dissemination, bridging gaps between research and practice, but also between clinical health psychology and allied disciplines.

Specialist psychologically informed environments have been developed across homeless hostels, social care, and mental health services (Cockersell, 2017). Maguire and Ritchie (2015) argue the clinical psychology skillset matches the need ideally, across intervention, research and commissioning. This study has demonstrated the severe distress, complex biopsychosocial processes experienced by this population. Clinical health psychology should be offering the

individual and the system with specialist formulation to enhance compassionate care. As Cassell (2014) states,

*“Objectivity in the absence of subjectivity renders persons one-dimensional and robs medicine of the compassion”* (p. 22)

The current project therefore recommends the integration of psychologically informed practice on hospital wards to enhance formulation and compassionate care. Finally, the engagement of participants in this study suggests a desire in this population for psychological input. Numerous participants explained that the issues addressed in the current study were central to their experience but had not previously been discussed as part of their care. The EbEs and participants explicitly fed back in the current study that there is a need for psychological involvement and perspective.

## **Conclusion**

The current study aimed to advance our understanding of the experience of suffering related to illness (SIS) and housing difficulties (SHS) in a physically unwell homeless population. Whilst acknowledging the study limitations, several conclusions can be drawn from the findings. Given previous findings indicate a strong objective relationship between homelessness and illness, the small size of the association between SIS and SHS was surprising. This suggests that SIS and SHS are distinct causes of suffering. The predictive value of SIS in subjective QoL and distress demonstrates that the immediacy of illness and experience of hospitalisation are important factors in homeless persons' experience of illness. Homeless persons may face novel threats to their dignity and integrity at this unique time point when they have sought help, have current physical health needs, and are hospitalised. Stigma, losses of freedom to act, control and a familiar world are threats to the dignity and integrity of homeless persons in this context.

SHS does not predict QoL, distress or wellbeing in this context. Homeless persons may be adjusting to illness as a new threat to self, while hospitalisation is a chance for housing difficulties to be addressed with the support of professionals. Hospital admission provides shelter, food and safety therefore the immediacy of the threats related to homelessness may be reduced. However, many participants placed housing difficulties and/ or illness inside their self. Homeless persons experience high suffering but also a sense of enmeshment of their illness and housing difficulties with their self, a finding supported by the qualitative data. The strengths of the current study are that it has presented the real-world experiences of homeless persons. It has provided a psychological perspective in an interdisciplinary field, and collaborated with experts by experience (EbE). The findings contribute novel insights into experience of homelessness and illness for physically unwell homeless persons. It has generated new questions relating to SIS and SHS during hospitalisation.

There are real world applications, findings suggest hospitalisation can be important time-point for health and housing intervention and PRISM may be a useful tool for collaborative conversations relating to suffering, care plans and change. The study findings will be disseminated to the Homeless Health and Inclusion conference, and published in a peer reviewed journal. Continued consultation with EbEs will help translate findings to practice (Michie et al, 2013). The research *process* has highlighted a great level of homeless service users with a psychological perspective. This study can act as stark reminder that the psychological profession must match this engagement by participating in the critical issues homeless persons face in the UK today.

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## Appendices

### Appendix 1: Literature review strategy

A literature review was conducted between September 2015 and February 2017 using Science Direct, PubMed, Psych Info, and Google Scholar. The following keywords were used to search the databases, present in the title or abstract: homeless\*homelessness, illness\*health\*physical, model, mental health, distress, PRISM\*suffering, quality of life\*life satisfaction, well-being. Article titles and abstracts produced from these searches were excluded if not published in peer-reviewed journals, English, or relevant third sector organisations. Studies conducted in highly specific and non-relevant samples were excluded. Further searches examined specific peer review clinical and health psychology journals for 'homeless', rendering limited results (see table below).

#### Example Pub Med and Psych Info:

Suffering AND Homeless (Title/Abstract): 63 results.

((homeless [Title]) AND health [Title]) AND model [Title/Abstract]: 0 results

Journal	Number of results with 'homeless' in the article title Since year 2000
British Journal of Clinical Psychology	<b>2</b> Rajan, Macleod and Spence et al (2011) Neurobehavioural and cognitive function is linked to childhood trauma in homeless adults Hodgson, Shelton, and van den Bree (2015) Psychopathology among young homeless people
Journal of Clinical Psychology	<b>3</b> Resnik et al (2016) Which Homeless Veterans Benefit from a Peer Mentor and How? Held and Owens (2015) Effects of self-compassion Workbook training on Trauma related guilt in homeless veterans Herdina, Munguia et al 2006 Relationship among respondent ethnicity, ethnic identity, acculturation, and homeless status on a homeless population's functional status
Journal of Clinical Psychology in Medical Settings	<b>0</b>

In British Journal of Health Psychology	<b>0</b>
British Journal of Psychology	<b>0</b>
Health Psychology Journal	<p><b>13 Including the following</b></p> <p>Stein et al (2007) Applying the Gelberg-Andersen Behavioral model to health services utilisation in homeless women</p> <p>Kelly and Caputo (2007) Health and stress/homeless youth</p> <p>Fitzpatrick, Irwin and LaGory et al (2007) Just thinking about it: social capital and suicide ideation among homeless persons</p> <p>Flick and Rohnsch (2007) Idealization and neglect health concepts of homeless adolescents</p> <p>Dashora et al (2011) Better to bend than to break: coping strategies by substance abusing homeless youth.</p> <p>Rew et al (2007) Outcomes of brief sexual health intervention for homeless youth</p> <p>Schumann et al (2007) HIV risk reduction in a nurse case managed TB and HIV intervention among homeless adults</p> <p>Stolte and Hodgetts (2013) Being healthy in unhealthy places: Health tactics in a homeless lifeworld</p>
Health Psychology Review	<b>0</b>
International Journal of Clinical and Health Psychology	<b>0</b>
Psychology and Health	<p><b>1</b></p> <p>Nyamatnathi, Stein and Bayley (2000) Predictors of mental distress and poor physical health among homeless women</p>
Psychology Health and Medicine	<p><b>2</b></p> <p>Rosenthal, Mallett, Gurrin et al (2007) Changes over time among homeless young people in drug dependency, mental illness and their co-morbidity</p> <p>Martin, Bonner, Brook et al (2006) Factor structure and use of the Hospital Anxiety and Depression Scale in the homeless and socially marginalised.</p>
Health Psychology and Behavioural Medicine	<b>0</b>
Annual Review of Clinical Psychology	<b>0</b>

## Appendix 2: Participant Demographics Questionnaire



10.11.16 IRAS Project ID: 199528  
Participant demographic sheet  
Version 2

Barts Health   
NHS Trust

East London   
NHS Foundation Trust

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### **Accommodating illness: The experience of suffering in a physically unwell homeless population**

**Age:**

**Gender: Male – Female (Please circle)**

**Ethnicity: White British / White other (please specify):**

**Asian British/ Asian other (please specify):**

**Black British/ Caribbean/ African (please specify):**

**Other (please specify):**

**How many times have you visited a hospital in the past 12 months?**

**Length of current stay in hospital:**

**Illness/ diagnosis:**

**Living situation: Hostel**

**Temporary accommodation**

**With friends/family**

**Living on the street**

**Other (please specify):**



10.11.16 IRAS Project ID: 199528  
Participant demographic sheet  
Version 2



**Alcohol per week:** None

One/ several drinks a week (1-5 units = A pint; or single spirit; small glass of wine)

A drink every day or equivalent (6-10 units per week)

Several drinks a day or equivalent (10-21 units)

4 drinks per day or more

Other:

Do you use any drugs/substances? Yes No

If yes, please circle: Cannabis

Solvents

Heroin

Crack

Other simulants (ecstasy, amphetamine, cocaine)

Benzodiazepines (e.g. Valium, tempazepam, Rohypnol)

Hallucinogens (LSD, magic mushrooms, ketamine, PCP)

Are you getting any benefits? Yes No

Are you able to access benefits? Yes No

If no, please specify:

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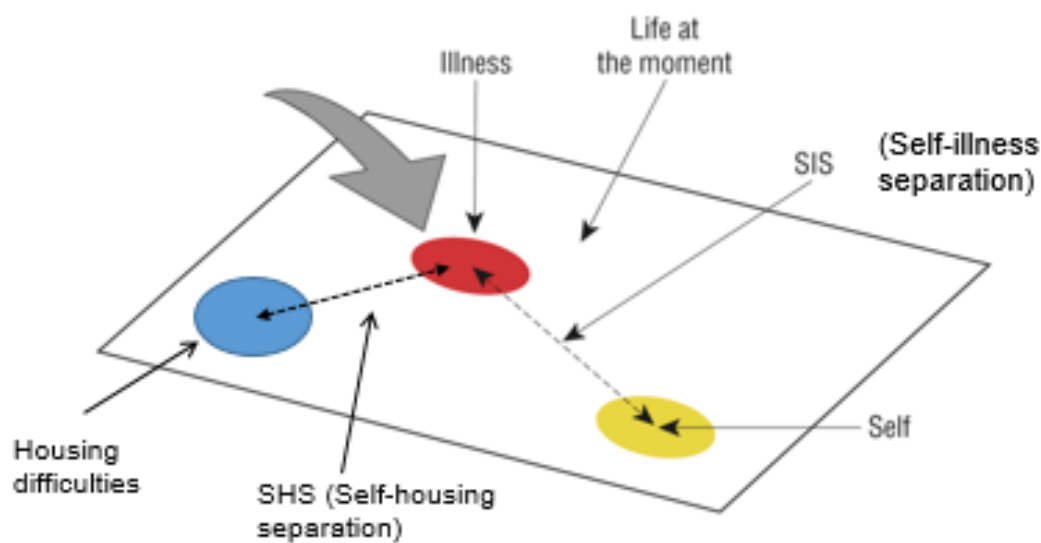
### Appendix 3: Pictorial Representation of Illness and Self Measure (PRISM) and Standard Instructions



27.09.16 IRAS Project ID: 199528 PRI  
 PRISM  
 Version 1



#### Pictorial Representation of Illness and Self Measure (PRISM) and standard instructions



Above: Adapted from Mnlaisen, Buchi, Schmidhauser et al, (2009)

TABLE 1. Standard instructions for PRISM
We would like to understand better how your illness [mention the illness] affects your life at the moment.
I'd like you to imagine that this white board represents your life as it is now.
The yellow disk in the bottom right corner represents your "self," and this red disk represents your illness.
Where would you put your illness—the red disk—in your life at the moment? [Hand red disk to patient]
<i>Most people have an intuitive idea of where to place the illness disk, but if someone does not appear to understand the above instructions, go to those below:</i>
As this may be a rather unusual way of showing the place of your illness in your life, let me give you another example.
The blue disk represents your work or your job. For some people, work is an essential part of their lives and makes all the difference in how they see themselves. Such a person would put the "Work" disk on top of the "Self" disk [demonstrate this]. For other people, work is not that important. For example, they may work just to earn money. Such a person would place the "Work" disk quite far from the "Self" disk [demonstrate].
Where would you put your illness—the red disk—in your life at the moment? [Hand red disk to patient]
Measure the distance between the centers of the two disks—the Self-Illness Separation (SIS).

Side: Büchi and Sensky, (1999).

## Appendix 4: The Depression Anxiety and Stress Scale (DASS-21; Henry and Crawford,



27.09.16 IRAS Project ID: 199528 PRI  
DASS-21 Version 2 25.07.16



### Depression, Anxiety and Stress Scales (DASS-21: Henry and Crawford, 2005)

DASS21	Name:	Date:
<p>Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you <i>over the past week</i>. There are no right or wrong answers. Do not spend too much time on any statement.</p> <p><i>The rating scale is as follows:</i></p> <p>0 Did not apply to me at all            1 Applied to me to some degree, or some of the time            2 Applied to me to a considerable degree, or a good part of time            3 Applied to me very much, or most of the time</p>		
1	I found it hard to wind down	0 1 2 3
2	I was aware of dryness of my mouth	0 1 2 3
3	I couldn't seem to experience any positive feeling at all	0 1 2 3
4	I experienced breathing difficulty (e.g., excessively rapid breathing, breathlessness in the absence of physical exertion)	0 1 2 3
5	I found it difficult to work up the initiative to do things	0 1 2 3
6	I tended to over-react to situations	0 1 2 3
7	I experienced trembling (eg, in the hands)	0 1 2 3
8	I felt that I was using a lot of nervous energy	0 1 2 3
9	I was worried about situations in which I might panic and make a fool of myself	0 1 2 3
10	I felt that I had nothing to look forward to	0 1 2 3
11	I found myself getting agitated	0 1 2 3
12	I found it difficult to relax	0 1 2 3
13	I felt down-hearted and blue	0 1 2 3
14	I was intolerant of anything that kept me from getting on with what I was doing	0 1 2 3

2005)



27.09.16 IRAS Project ID: 199528 PRI  
DASS-21 Version 2 25.07.16



15	I felt I was close to panic	0 1 2 3
16	I was unable to become enthusiastic about anything	0 1 2 3
17	I felt I wasn't worth much as a person	0 1 2 3
18	I felt that I was rather touchy	0 1 2 3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0 1 2 3
20	I felt scared without any good reason	0 1 2 3
21	I felt that life was meaningless	0 1 2 3

## Appendix 5: The World Health Organisation Quality of Life Questionnaire - BREF (WHOQoL-BREF)



10.11.16 IRAS Project ID: 199528  
WHOQoL Bref



### World Health Organisation Quality of Life Questionnaire (WHOQOL-BREF)

The following questions ask you how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	<b>How would you rate your quality of life?</b>	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
2.	<b>How satisfied are you with your health?</b>	1	2	3	4	5

The following questions are about how much you have experienced certain things in the last 4 weeks

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	<b>To what extent do you feel that physical pain prevents you from doing what you need to do?</b>	5	4	3	2	1
4.	<b>How much do you need any medical treatment to function in your daily life?</b>	5	4	3	2	1
5.	<b>How much do you enjoy life?</b>	1	2	3	4	5
6.	<b>To what extent do you feel your life to be meaningful?</b>	1	2	3	4	5



		Not at all	A little	A moderate amount	Very much	An extreme amount
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks?

		Not at all	A little	A moderate amount	Very much	An extreme amount
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5



		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity to work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health care?	1	2	3	4	5
25.	How satisfied are you your transport?	1	2	3	4	5

This question refers to how often you have felt or experienced certain things in the last 4 weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

## Appendix 6: The Warwick Edinburgh Mental WellBeing Scale (WEMWBS)



27.09.16 IRAS Project ID: 199528 PRI  
WEMWBS Version 2 25.07.16

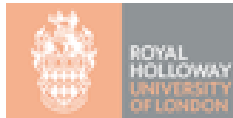


### The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts  
Please tick the box that best describes your experience of each over the last  
2 weeks.

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

## Appendix 7: Participant Information Sheet



27.09.16 IRAS Project ID: 199528  
Participant Consent Form  
Version 5



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### PARTICIPANT INFORMATION SHEET

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#### **Accommodating Illness: The experience of suffering in a physically unwell homeless population**

##### **What is the purpose of the study?**

To explore how people with no safe place to live or temporary accommodation understand their health and housing difficulties, and whether these two factors are related. We are also looking at whether the way people experience their illness and housing difficulties influences their well-being, quality of life and distress. We are hoping to speak to 48 patients.

##### **Why have you been invited?**

We are inviting all patients, over the age of 18, who come into Pathway care at this hospital to take part in the research. Declining to take part in this study, or deciding to withdraw will have no effect on the standard of your current or future care.

##### **Who is carrying out the study?**

This is a project carried out by Jacob Clark who is a doctoral student at Royal Holloway University of London.

##### **What will happen to me if I take part?**

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form which will be stored safely.

You will have one meeting in which you will be asked to complete several brief questionnaires about your current health, well-being and housing, and this should take around 40 minutes.

If you participate you will be thanked by **choosing £4 worth** of the following:

- \*TV credit at hospital: £1 per day
- \*Tesco's meal deal (sandwich, crisps, drink): £3
- \*Costa coffee: range from £2 - £4
- \*Sports Direct 3 pack socks: £2



If you decide to take part, you are still free to withdraw at any time and without giving a reason. This will not affect the care you receive.

### **Confidentiality**

All data will be confidential. All information that you give will be held anonymously on computers which are encrypted and password protected. They will be accessible only by those involved directly with the study. We will *not use your name* in storing the data. The consent form that you sign will be held separately from the answers that you give the researcher. However, in certain circumstances it may be necessary to share information without your consent e.g. to protect you, or someone else from harm.

### **Who has reviewed the study?**

The study has been reviewed and approved by the Royal Holloway University of London ethics committee as well as Barts Health NHS Trust, East London Foundation Trust and NHS ethics.

### **Results of the study**

At the end of the study the information collected will be analysed and published in recognised medical journals. You will be able to request a copy of these publications through the nurse or doctor involved in your care. Professionals in the Pathway team will be informed of the overall results from the study. The identity of the patients who took part in the study will remain confidential.

### **Time to consider**

You can take at least 24 hours to decide if you wish to take part.

### **Who should you contact with questions?**

You will be given a copy of this information sheet and the signed consent form to keep. If you have any problems or questions about this study or your rights as a patient in clinical research you should contact:

Researcher: Jacob Clark  
Tel No: 01784414012  
Email:  
Jacob.Clark.2014@live.rhul.ac.uk

Barts Health or ELFT PALS (Patient Advisory Liaison service)  
Tel No: 020 3594 2040 or  
Freephone 0800 783 4839  
Email: [pals@bartshealth.nhs.uk](mailto:pals@bartshealth.nhs.uk) or  
[PAL.SandComplaints@elft.nhs.uk](mailto:PAL.SandComplaints@elft.nhs.uk)

**Thank you!**

## Appendix 8: Participant Consent Form



27.09.16 IRAS Project ID: 199528  
Participant Consent Form  
Version 4

Barts Health   
NHS Trust

East London   
NHS Foundation Trust

### PARTICIPANT CONSENT FORM

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#### The impact of suffering in a physically unwell homeless population

Participant ID:

Please initial each box

1. I confirm that I have read and understand the information sheet version 1 titled 'Suffering in a physically unwell homeless population' and have had the opportunity to consider the information and ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw from this study at any time, without having to give a reason and without my medical or legal rights being affected.
3. I understand that the information collected will remain confidential and will only be used by individuals involved in this study. However, in certain circumstances it may be necessary to share information without my consent e.g. to protect me, or someone else from harm.
4. I understand that data may be used anonymously in future reports presenting research outcomes
5. I agree to take part in the above study.

\_\_\_\_\_  
Name of participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of person taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

## Appendix 9: Health Research Authority Letter of Ethical Approval



Health Research Authority

Mr Jacob Clark  
Trainee Clinical Psychologist  
Royal Holloway University  
Royal Holloway University of London  
Egham  
TW20 0EX

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

07 September 2016

Dear Mr Clark

### Letter of HRA Approval

<b>Study title:</b>	<b>Suffering related to health and housing difficulties: Are these factors associated, and do they predict quality of life, well-being, and distress?</b>
<b>IRAS project ID:</b>	<b>199528</b>
<b>REC reference:</b>	<b>16/LO/1346</b>
<b>Sponsor</b>	<b>Royal Holloway University University of London</b>

I am pleased to confirm that HRA Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

# Appendix 10: Letters of Research Approvals



1<sup>st</sup> Floor, Bloomsbury Building  
31 Pancras Hospital  
451 Pancras Way  
London, NW1 0PE  
Tel: 020 3317 3045  
Fax: 020 7685 5830  
Email: contact.noclor@nhs.net  
www.noclor.nhs.uk  
28 October 2016

Mr Jacob Clark  
Trainee Clinical Psychologist  
Royal Holloway University  
University London  
Egham, TW20 0EX

Dear Mr Jacob Clark,

**Employer:** Camden and Islington NHS Foundation Trust  
**Accountable to:** Mrs Angela Williams

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in this organisation. This confirms your right of access to conduct research through the trust(s) identified in the box below, for the purpose and under the terms and conditions set out in page 2 & page 3.

<b>Study Title: Suffering in a physically unwell homeless population</b>		
<b>R&amp;D reference: 199528</b>		
<b>REC reference: 16/LO1346</b>		
<b>Letter of access duration:</b>	<b>Start date: 28/10/2016</b>	<b>End date: 01/06/2017</b>
<b>East London NHS Foundation Trust</b>		
<i>If any information on this document is altered after the date of issue, this document will be deemed INVALID</i>		

Yours sincerely,

Pushpsen Joshi  
Research Operations Manager

Page 1 of 3

NCLF0107 - 3.0.0 - 23/07/15 - Letter of access for NHS employee  
It is the researcher's responsibility to provide their substantive employer with a copy of this document



**Dr. Sally Burtles**  
**Joint Research Management Office**  
Queen Mary Innovation Centre  
5 Walden Street  
London  
E1 2EF

15 September 2016

Jacob Clark  
Royal Holloway University  
Work Address Royal Holloway University of London

Tel: 020 7882 7250  
Email: Sponsorsrep@bartshealth.nhs.uk

Dear J Clark

## Barts Health NHS Trust Confirmation of Capacity and Capability

**Project Title:** Suffering in a physically unwell homeless population  
**IRAS Project ID:** 199528  
**HRA approval date:** 07 Sep 2016  
**BH REDA Reference:** 011539

All internal approvals and all regulatory approvals are now in place.

Barts Health NHS Trust can confirm that it has the capability and capacity to deliver the study.

Kind regards

Dr Sally Burtles  
Director of Research Services and Business Development

SOP13b AD 1 BH Confirmation of Capacity and Capability V1.0 08/09/2016



Joint Research Office  
(Part of Research Support Centre)  
1<sup>st</sup> Floor Maple House, Suite B  
149 Tottenham Court Road  
London  
W1T 7DN

Direct line: 020 34475557

Postal address: Joint Research Office, UCL, Gower Street, London, WC1E 6BT

Date: 04 January 2017

Dear Jacob Clark

### Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through **University College London NHS Foundation Trust** for the purpose and on the terms and conditions set out below. This right of access commences on **04 January 2017** or only once **R&A approval has been issued** and ends on **21 September 2017** unless terminated earlier in accordance with the clauses below.

**Title:** Suffering related to health and housing difficulties: Are these factors associated, and do they predict quality of life, well-being, and distress)

**R&D number:** 16/0794  
**REC number:** 16/LO1346

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to **University College London NHS Foundation Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **University College London NHS Foundation Trust**, you will remain accountable to your employer **Camden & Islington NHS Trust** but you are required to follow the reasonable instructions of your nominated manager **Lorna Farquharson** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.



### Ethics Review Details

<b>You have chosen to self certify your project.</b>	
Name:	Clark, Jacob (2014)
Email:	PBVAD02@live.rhul.ac.uk
Title of research project or grant:	Suffering in a physically unwell homeless population
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Dr Lorna Farquharson
Email address of Academic Supervisor:	Lorna.Farquharson@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	25/08/2016
End date:	17/09/2017

### Research question summary:

Homeless people experience significant physical health burdens. Ill health is a predictor of chronic homelessness, distress and life satisfaction. Conversely, changes in housing or satisfaction with housing, do not predict positive changes in physical or mental health. In the general population we know that subjective experience of illness plays a significant role in quality of life, distress and well-being; however, our understanding of the psychological experience of illness in this population is under examined. Consequently, the relationship between these factors for homeless persons remains unclear, and there are critical implications.

The proposed research project proposes to investigate firstly, is illness suffering associated with housing suffering in physically unwell homeless persons? And, a regression analysis will explore to what extent does suffering (housing and illness) have direct, independent effects on the levels of quality of life, well-being and distress? Forty homeless inpatients in hospital care will complete the PRISM task, World Health Organisation Quality of Life Scale: Brief Version, The Warwick-Edinburgh Mental Well-being Scale and The Depression, Anxiety and Stress Scale. This study will provide critical insight into the key psychological factors involved in illness experience for a population which has been largely neglected in the psychological literature.

### Research method summary:

The study will require a total sample size of 48. The intended multiple regression has two predictors, self-illness suffering (SIS) and self-housing suffering (SHS), and three dependent variables, quality of life, distress and well-being. Four factors will be controlled for: nature of homelessness; health diagnoses; substance and alcohol use. A power calculation for a multiple linear regression with six predictor variables was conducted using alpha = .05, power = .80 and an estimated medium effect size of .30 selected according to Cohen's f<sup>2</sup> (1988). This effect size is in line with the magnitude of effects reported in the associated studies using related designs (Wong and Pillavin, 2001; Kaszardjan et al, 2008; Gademmann et al, 2014); however these designs had key differences therefore Cohen's benchmark was used.

### Analysis

1. A correlation will examine the relationship between two continuous variables, illness related suffering (SIS) and housing related suffering (self-housing separation; SHS).
2. A multiple regression analysis examine to what extent dependent variables - quality of life, distress and well-being - can be explained by the following independent variables: SIS and SHS.



## Appendix 11: Study summary for Expert by Experience consultation and dissemination

### Accommodating illness: Experience of suffering in a physically unwell homeless population

#### Intro

#### Why this study?

Homeless persons suffer amongst the worst health outcomes (DoH, 'Inclusion Health', 2010). Homelessness is a health issue (Fazel et al, 2014; Cornes et al, 2015)

#### Health outcomes

- 85% of hostel sample have at least one chronic health problem (Hwang et al, 2011)
- Over period of 6 months, 25% of the homeless hostel population are admitted to hospital and a third will visit A&E in England (Homeless Link, 2014)
- Recovery: homeless persons are more likely to be hospitalised, readmitted and have longer hospital stays (Kushnir, 2016)

#### Psychological perspective

We know plenty about illness outcomes, but little about the illness experience. What we do know suggests it is not clear how homeless persons experience their physical illness.

Findings that homeless persons perceive health as secondary to safety (Daiki, 2007); deny health needs, and do not necessarily report poor health, despite seemingly poor health (Gaderman et al, 2013).

Housing provision and housing satisfaction do not necessarily improve QoL (Patterson et al, 2013; Tsai et al, 2012)

#### Limitations of previous research

- Overwhelmingly in USA or Canada
- Lack of psychologically informed homelessness research
- Few studies have looked at homeless illness experience
- Homeless persons presenting at hospital are underrepresented

#### What is suffering?

It is distress in circumstances which threaten sense of self (e.g. illness, or homelessness)

Suffering is also related to less controllability of illness and symptoms, as well as greater intrusion on one's life and self. Suffering is determined not by intensity, severity of symptoms or the illness itself but by its meaning to the individual

*"The first lesson of suffering is that bodies do not suffer, persons suffer"*

#### Two research questions

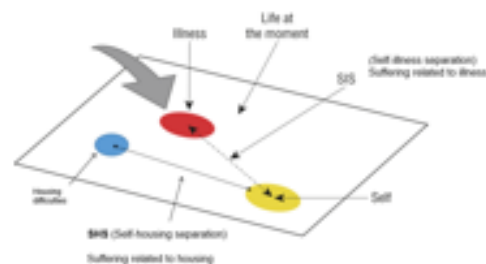
1. Are illness suffering and suffering related to housing associated?
2. Does illness suffering or housing suffering have a greater independent effect on QoL, distress and well-being?



## So, what did we do?

Interviewed 48 homeless persons in hospital using a measure of suffering related illness, and related to homelessness. As well as measures of quality of life, distress and well-being.

We used this visual measure of suffering, called PRISM



## Findings

### Sample demographics

43 males (89.6%), 5 females (10.4%). Average age was 47. 50% were white British, 17% were black or mixed race British, 10% were European, 8% black African. Most participants were street homeless (44%), others were in homeless hostels (21%). Many had been in hospital under 4 days (36.2%), some for 5-10 days (23.4%), or between 11-30 days (29.8%). The largest presenting conditions were infections 41.7% (e.g. cellulitis, pneumonia, septicaemia, tuberculosis, other); alcohol related concerns (e.g. kidney, pancreatic, liver problems) (20.8%), deep vein thrombosis (12.5%) and diabetes (8.3%). Just over 60% reported multiple comorbid conditions.

### Research question 1.

There was a significant positive correlation between illness related suffering, and suffering related to housing difficulties. Higher levels of illness related suffering were related to higher housing related suffering. However this correlation was surprisingly small ( $r_{(46)} = .268, p < .05$ ).

### Research question 2.

**Illness suffering significantly predicted distress and quality of life, and almost (but not quite) well-being**

This effect was independent of the effects of suffering related to housing, age, housing situation, alcohol use and drug use.

Suffering related to housing difficulties surprisingly **did not** predict quality of life, distress or well-being.

Also, many participants placed illness suffering and housing suffering **inside their self**.

Qualitative: There were themes of illness and housing difficulties being inseparable from their self, feeling powerlessness and responsibility and shame related to illness but not housing difficulties

## Understanding these findings

1: This was an unexpectedly weak correlation between suffering related to housing and suffering related to illness. This differs to the objective evidence that illness and housing difficulties are strongly linked. Maybe this suggests they are two distinct or unique causes of suffering.

2. Illness suffering predicted quality of life, well-being and distress. The immediacy of the illness is likely to be an important factor in this finding. Being hospitalised may be a specific cause of suffering for homeless persons as they suffer further losses of control, freedom, dignity and threats to self.

3. Housing related suffering did not predict quality of life, well-being or distress. Possibly due to the unique time point of being hospitalised, maybe because the measure was not capturing what we hoped it would, and maybe because of the range of types of homelessness in the sample?

Possibly this measure was capturing illness enmeshment rather than suffering?

**Study strengths:** the sample, psych\* perspective. **Study limitations:** one time-point, sample variation