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**Yates, A.**

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**“Considering there’s supposedly nothing wrong with me, it’s  
not a life”: Women’s Narratives of Distress, Visiting  
Herbalists, and Being Well in the 21<sup>st</sup> Century.**

**A.J. Yates**

**A thesis submitted in partial fulfilment of the requirements of  
The University of Westminster for the degree of Doctor of Philosophy**

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'John Case became concerned about his wife. She had always been a good housekeeper; now, they began to run out of things. When one evening there was nothing but cold meat and cheese for supper he protested. She said she had not been able to shop because it had rained all day; on rainy days the dog was always outside, waiting for her.'

PENELOPE LIVELY *BLACK DOG*

'I don't know what's right and what's real anymore  
And I don't know how I'm meant to feel anymore'

LILY ALLEN *THE FEAR*

## ABSTRACT

Distress can have a profoundly negative impact on the well-being of women (who are the main receivers of treatment for distress). Distress also poses a huge financial problem for the United Kingdom, the cost of which is predicted to reach over £26bn by 2026. A growing body of research has shown that various medicinal plants have potential to treat different aspects of distress. However, there is little research investigating the patient experience of western herbal practice (WHP), and none investigating women's experiences of WHP for distress. In response, this longitudinal study utilised interviews with twenty-six women who were visiting herbalists for distress across the south-east of The United Kingdom to elicit their stories of distress, as well as their experiences of WHP. The narratives were analysed from a constructionist standpoint, using inductive thematic analysis.

The participants' narratives highlighted the profound impact of everyday distress, whilst feelings associated with distress (anxiety, low mood, isolation, shame and guilt) were frequently communicated via the use of metaphors. These negative feelings, often combined with unsuccessful biomedical encounters, frequently led to the women feeling desperate when first visiting a herbalist. The participants' experiences of WHP showed that an accessible practitioner and good therapeutic relationship combined with flexible herbal treatment, allowed women with diverse stories of distress to overcome feelings of desperation. Ongoing support allowed the women to feel like they had a safety net as they journeyed from a place of distress, back into the wider world. These findings were supported by more unusual negative accounts, which showed how the herbal therapeutic process could be unsuccessful if elements were missing.

This research is of significance as it helps to deepen our understanding of women's experiences of distress – particularly perceptions of stigma which surround feelings of shame (linked to an inability to cope) and guilt (linked to the perceived impact of distress on others). The research also has relevance for WHP, as it highlights which positive aspects of WHP are of particular importance to women patients who are living with distress.

**Key words:** women, distress, narratives, thematic analysis, metaphors, isolation, shame, guilt, western herbal practice, accessibility, support.

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## DISSEMINATION OF FINDINGS

### Poster Presentations:

Yates, A., Whitehouse, J., Ridge, D., Green, J., (2012). How women experience distress, and western herbal practice for the treatment of distress: implications for health care and self-management approaches. *National Institute of Medical Herbalists' Annual Conference*. Crewe Hall. 20 Oct 2012.

Yates, A., Whitehouse, J., Ridge, D., Green, J., (2013). How women experience distress, and western herbal practice for the treatment of distress: implications for health care and self-management approaches. *University of Westminster Post-Graduate Fair*. University of Westminster. 25 Apr 2013.

Yates, A., Whitehouse, J., Ridge, D., Green, J., (2013). How women experience distress, and western herbal practice for the treatment of distress: implications for health care and self-management approaches. *UCL School of Pharmacy Conference. Spices and Medicine: From Historical Obsession to Research of the Future*. University College London. 24 May 2013.

Yates, A., Whitehouse, J., Ridge, D., Green, J., (2013). How women experience distress, and western herbal practice for the treatment of distress: implications for health care and self-management approaches. *CAMSTRAND 2013*. University of Westminster. 2 July 2013. *European Journal of Integrative Medicine*. 5, (6), 579-580.

Yates, A., Whitehouse, J., Ridge, D., Green, J., (2013). How women experience distress, and western herbal practice for the treatment of distress: implications for health care and self-management approaches. *University of Westminster 175<sup>th</sup> Anniversary Event*. University of Westminster. 23 Oct 2013.

Yates, A., Whitehouse, J., Ridge, D., Green, J., (2014). "I just went with hope, because I thought I'm doing something": women's experiences of western herbal practice for distress. *College of Medicine Summer School*. King's College School of Nursing and Midwifery, London. 5 Sep 2014.

### Oral Presentations:

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Yates, A., Whitehouse, J., Ridge, D., Green, J., (2014). "It felt like someone holding you up and lifting the pain away": women's experiences of western herbal practice for the treatment of distress. *CAMSTRAND 2014*. The Christie NHS Foundation Trust, Manchester. 18 Jun 2014. *European Journal of Integrative Medicine*. 6, (5), 612-612.

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Reflecting back, this PhD process has been very much like driving a Formula 1<sup>®</sup> car. Apart from the obvious analogies of highs (reaching the chequered flag) and lows (the wheels falling off), Formula 1<sup>®</sup> always appears to be a very individual sport in which one person is showered in glory, when the reality is that it is very much a team sport – you just don't generally see the large numbers of people in the background that make it all possible for one person to shine.

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to bear witness to their stories was a privilege – I hope that I have done them justice.

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## **AUTHOR'S DECLARATION**

I declare that all the information contained in this thesis is my own work.

Signed:

A.J. Yates

Date:

## **CHAPTER 1: INTRODUCTION**

### **1.1 Background and Rationale**

#### **1.1.1 Research Question**

How do women describe and understand their experiences of distress, and how does use of western herbal practice (WHP) play a role, if any, for women who are living with distress?

This study collected and analysed patient narratives at two different points in time to investigate women's experiences of distress, and their experiences of visiting a herbalist for their distress. In addition, it investigated how women perceived seeing a herbalist for dealing with distress, and what aspects of the encounter they felt were effective or ineffective.

#### **1.1.2 Distress**

All stories start with a beginning. For the research participants, their beginning could vary, but this research concentrated on their story of distress, so this is the first area of focus that helps to explain why this study had relevance for the participants.

Distress is a complex concept with an intangible nature (Nosek et al., 2010). Indeed, "distress" is frequently used in healthcare literature, in spite of the fact that the term is often ill-defined (Lomas et al., 2012; Newton et al., 2012; Khatib et al., 2013). This situation results in distress being used differently to describe a number of conditions/situations/feelings within a range of contexts. A review of the research literature highlighted that distress is frequently spoken of as a type of pathology, with anxiety and depression commonly cited when talking of distress. These labels are often utilised as clinical diagnoses, and are made by using an individual's story as a way of identifying associated symptoms (Holm & Severinsson,

2014). McPherson & Armstrong (2006) argue that there is a tendency within medicine to attach a label to an illness in spite of individual differences between patients with regards to presentation. This process of labelling illnesses helps to explain the way that distress is often characterised as depression or anxiety (European Union Health & Consumer Protection Directorate-General 2004). However, this view has come under some criticism (Busfield, 2012).

Cromby et al. (2013, p.6) use the term distress to refer to “*all* (authors’ emphasis) of the different kinds of difficult or unusual experiences associated with the hundreds of psychiatric diagnoses currently employed”. Other critics go further, and argue that the publication of systems such as The Diagnostic and Statistical Manual of Mental Disorders (DSM) was driven by the need for psychiatry to establish a specific area of expertise in the medical marketplace which, in part, led to a strengthening alliance with the rest of medicine through a medicalisation of mental illnesses such as anxiety and depression (McPherson & Armstrong, 2006). This has resulted in the suggestion that normal sadness is increasingly being pathologised (Henderson, 2012), that it is normal to feel dissatisfied, disillusioned or depressed at times (Williams, 2000b), and that depressive symptom screening tools fail to take into account the context of a person’s distress (Horwitz & Wakefield, 2007, p.223). This situation was typified by the latest version of DSM (DSM-5), which categorised feelings of sadness associated with the loss of a loved one as “a mental disorder” (Bondolfi et al., 2015).

The tendency for medical research to define distress in pathological terms is problematic as it limits the scope of what distress is. For example, distress can be caused by other conditions such as chronic illness or pain (Edwards et al., 2006; Keles et al., 2007; da Rocha et al., 2014; Buchmann et al., 2015). Distress can also be associated with events occurring in an individual’s life that do not normally carry a clinical definition, such as dealing with bereavement (Thomas et al., 2014) or caring for loved ones who are ill (Haun et al., 2014). Individuals can also experience somatisation of their distress, which is the cultural patterning of psychological and social distress into mainly physical signs and symptoms (Helman, 2007, p.260). These varied experiences of distress can occur along a continuum in terms of how

bad an individual can feel. However, despite the apparent dominance of biomedical thinking across the research literature, there has been an increasing acknowledgement amongst some disciplines in recent years that distress is more than just a type of pathology.

In 2009, the United Kingdom (UK) Department of Health acknowledged that an individual could live with distress but have no clinically identifiable mental health problem (Department of Health, 2009), whilst Green et al. (2010) recognised that distress is often used to denote negative subjective experiences that fall short of clinical diagnoses for mental disorders. These follow on from the suggestion by Heller et al., (1997, p.9) that the term distress should draw attention to “an experience rather than the symptoms or problems which may be presented”. However, this focus on the individual presents a problem as it means that distress covers a huge range of human experience in its depth and duration, the feelings and perceptions of the people experiencing it, and the way it is presented to the world (Read & Reynolds, 1996, p.1). One useful definition – adopted in the current research – that appeared to encompass the range of experiences of distress was that made in 2008 by The National Comprehensive Cancer Network (cited in Bultz et al., 2009):

*“Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioural, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively... Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis”.*

As there was no consensus within the literature on what constituted distress, it was necessary to be clear about how distress would be recognised for the purposes of this research. A review of the literature had necessarily looked at papers concerning various aspects of distress, but rather than looking at distress from a pathological point of view, this research has focused on the participants’ experience of distress. In one way, distress was defined by the participants, as they self-selected to take part in the study. However, the researcher was initially influenced

by Heller et al., (1997, p.9) who had highlighted the need to examine the experience of those that live with distress, and subsequently The National Comprehensive Cancer Network (2008, cited in Bultz et al., 2009), which specified the range of experiences that could constitute distress. The participants' distress was therefore recognised as they could include a range of negative emotions such as such as those outlined by Ridge et al. (2011) (stress, anxiety, anger and low mood), a range of features such as anorexia, fatigue and insomnia (Butt et al., 2008; Herlofson et al., 2012; Suh et al., 2012; Haun et al., 2014), all of which may have been present in the absence of normal stressors or may have been present with conditions that have a known co-morbidity of distress, such as chronic illness or pain (Edwards et al., 2006; Keles et al., 2007; da Rocha et al., 2014; Okoro et al., 2014). The distress did not necessarily have a clinical diagnosis: it may have been associated with feelings of "normal sadness" (Henderson, 2012), or associated with stressful events such as bereavement (Thomas et al., 2014), isolation (Burton et al., 2011), or caring for loved ones who are ill (Haun et al., 2014). However, the distress may have been accompanied with a clinical diagnosis (such as depression, or generalised anxiety disorder) as these diagnoses are considered separate from distress within biomedicine and may only respond to pharmaceutical intervention: depression is considered distinct from distress when there is a markedly low mood over an extended period of time, with the presence of "anhedonia and depressive thoughts" (Terluin et al., 2006); whilst anxiety is considered distinct from distress when there is the presence of "irrational fears, anticipation anxiety and avoidance behaviour" (Terluin et al., 2006). Ultimately, for the purposes of this research, the heterogeneous features that can be experienced were labelled "distress" due to the perceived negative impact that they had on the individual's well-being, and their ability to function (Aina & Susman, 2006; Emmanuel & St John, 2010; Panayiotou & Karekla, 2013). This negative impact is best illustrated by a quote made by one of the participants who was living with irritable bowel syndrome – a condition which she felt was not considered serious from a biomedical point of view:

*When I saw the gastroenterologist at the hospital, I literally felt like it was a quick case of sort of weigh her, "Oh yes, she's not at death's door yet – fine. Talk to her, poke her belly – oh yeah, she's*

*not at death's door. Yeah, off she goes – see her in three months”. And I felt like I didn't have a chance to say anything, and I felt like I didn't have a chance to say to him “No offence, but I realise I'm not dying, but this is affecting every single aspect of my life – I can't stay like this for another three months. I can't”. (Beth)*

Beth's (all names have been changed to help ensure anonymity) feelings of desperation had resonance with research which has shown that conditions which may be considered to be mild from a medical perspective (such as alopecia in women) can be viewed as serious and disturbing by the individual, and so lead to distress (Cartwright et al., 2009). Whilst Beth reported feelings of desperation on a personal level, the impact of distress can extend beyond that of the individual. Distress can affect an individual's ability to function (Emmanuel & St John, 2010): Tulman & Fawcett (2003) described normal functioning as the ability to maintain usual activities, which could include personal care but also the ability to care for others (cited by Emmanuel & St John, 2010). This could potentially impact on women's self-perception as they often see themselves as central to the health and well-being of the family unit (Lewis & Ridge, 2005). Others have highlighted how distress can affect an individual's ability to carry out everyday tasks (Fullagar, 2008; Rhodes & Smith, 2010), whilst Edhborg et al. (2005) described how feelings of an inability to cope with everyday life could leave women who lived with distress after giving birth feeling like they were “struggling with life”. An inability to cope due to distress (Ridner, 2004) can also “impact on behavioural choices in a negative way” (McKenzie & Harris, 2013) related to a lack of self-care confidence and a perceived loss of control (Heo et al., 2008). These, in turn, can prevent lifestyle changes which would normally be deemed beneficial: Xiang (2015) gave an example of “self-neglect” whereby women with distress were less likely to take part in routine breast and cervical cancer screening compared to those without distress.

There is also a strong association between distress and the ability to hold down a job (Aina & Susman, 2006; Guidi et al., 2012). However, the wider impact that distress can have from an economic perspective may be masked as the term is often placed within phrases such as “common mental disorders” (National Health Service Information Centre, 2007). In spite of this, it is clear that feelings associated with

distress do have a major impact on the economy. Statistics suggest that in the UK, mental health problems are the largest single source of disability (British Medical Association Board of Science, 2014), with at least one in four people affected at some time in their life (Her Majesty's Government, 2011), costing the UK economy £70-£100 billion per year; 4.5% of Gross Domestic Product or GDP (Davies, 2013). In 2011, distress (along with other common mental disorders) was thought to account for one in five of all work days lost and cost UK employers £25bn each year (National Institute for Health and Care Excellence, 2011), whilst the gap in unemployment rates between individuals with and without mental health problems has significantly widened in recent years (Evans-Lacko et al., 2013). Part of the cost of distress is due to pharmaceutical treatments: in 2013, antidepressants were among the top five pharmaceuticals dispensed in the UK by net ingredient cost with over 50 million prescriptions (Scholes et al., 2013). However, the total cost to the UK economy for conditions such as depression and anxiety alone is predicted to be over £26bn by 2026 (McCrone et al., 2008). As well as the financial costs associated with distress, the major impact that it can have on the well-being of women and those around them make it a relevant social issue and thus an important area to explore empirically (Chonody & Siebert, 2008).

### **1.1.3 Women and Distress**

The study of gender grew during the 1970s and 1980s as second wave feminism gained momentum (Annandale & Clark, 1996). Whilst "sex" refers to biological factors that distinguish "male" and "female", "gender" denotes the sexual distinction society makes between male and female that is an amalgamation of biological, cultural, historical, psychological and social factors (Branney & White, 2008). Cosgrove (2000) argued for a constructionist approach (constructionism is discussed further in section 3.1.3) that maintains gender is not a natural category of being: rather, gender is produced and reproduced inter-subjectively in social life. Sex and gender are increasingly seen as "malleable concepts" that can be invested with a variety of meanings (Annandale & Hammarström, 2010). Gender

performativity theory proposes that individuals utilise a series of acts to produce the apparent truth of self (and gender) as a performative accomplishment (Schlichter, 2011), reminiscent of the work by Goffman who used the metaphor of theatrical performance to consider how individuals might “perform” different “roles” during various interactions with others (Goffman, 1956, p.8). Thus, “gender is better understood in terms of how it is performed, rather than by ascribing essentialized characteristics on the basis of body sex alone” (Gringeri et al., 2010). In spite of this, epidemiological studies still tend to use “gender” to refer to biological factors that distinguish “male” and “female”.

Mindful of the fact that all the participants who took part in this research described themselves as “female” upon inclusion to the study, it is important to consider what has previously been reported about women’s experiences of distress. In line with the literature of distress in general, much of the literature with regards to women’s experiences of distress places less emphasis on their experience and approaches the subject from a biomedical viewpoint: that is to say that as noted in section 1.1.2 their distress is frequently described in terms of various pathologies, and in comparison to the experiences of men. In 2007, the UK National Health Service (NHS) described distress as a “common mental disorder” that women were more likely to suffer from than men: 19.7% incidence as opposed to 12.5% (National Health Service Information Centre, 2007). The European Union Health & Consumer Protection Directorate-General (2004) have also approached distress from a biomedical standpoint, and reported that women’s distress was likely to manifest itself as depression and anxiety – what they described as “internalising disorders”. These internalising disorders are frequently considered to be distinct from the externalising disorders that men are thought more prone to experience, such as alcohol misuse and anti-social behaviours (MacKenzie & Fowler, 2013). What is clear is that in the UK antidepressant use by women is twice that of men, with usage most pronounced in women from low income backgrounds (Scholes et al., 2013). However, whilst anxiety and depression may form part of a woman’s distress, the reliance on biomedical thinking and/or gendered assumptions can detract from the wider picture: women’s experiences of distress are diverse (Emslie

et al., 2007; Danielsson et al., 2011), and the feelings and emotions that they have to deal with may not necessarily lead to a clinical diagnosis (Department of Health, 2009).

Distress may be perceived by individual women as being part of their everyday life: an example of this was reported by Newton et al. (2012), where women who had scleroderma rejected labels of depression, but were more likely to describe themselves as “demoralised” as they felt that their feelings of low mood were a reasonable reaction to their circumstances. Similarly, many patients diagnosed with depression have understood their issues in social terms, e.g. by interpreting their depression as a reaction to events such as the breakdown of a relationship (Granek, 2006). In doing so, their interpretation has then “normalised their experience and so effectively removed it from the scope of medical intervention” (Burton et al., 2011). Lovell et al. (2015) have also shown how mothers of young children often exhibit poor well-being, but not at clinical levels. Despite this, some research suggests that women are still likely to receive a biomedical diagnosis for distress as they are likely to talk about their experiences of distress to others (Breslin & McCay, 2012; Kinglerlee, 2012; MacKenzie & Fowler, 2013). This is seen to be in contrast to men who are reported as being likely to try to “mask” their distress in public (Rabinowitz & Cochran, 2008), and whilst others suggest that in reality (as with women) there is substantial variability between each man’s individual experience (Addis, 2008) women are more likely than men to seek professional help for problems such as distress (Buffel et al., 2014). Ussher (2010) has argued that the psychiatric diagnosis is a gendered practice that pathologises femininity, as she posits that practitioners are still likely to invest patient symptoms with “gendered assumptions” so that women’s emotions are deemed a sign of pathology, whereas men’s are “understandable” (Ussher, 2013). Even when feminine traits are argued to be a positive thing, this “benevolent sexism” (Travis et al., 2012) can lead to the neglect of symptoms that do not match what is expected from the patient (Annandale & Hammarström, 2010), and so result in the fact that doctors are more likely to diagnose depression amongst women compared to men, even when they

present with identical symptoms (Afifi, 2007), which may help to explain the gendered differences in the prescribing of antidepressants (Scholes et al., 2013).

The findings in the literature pose potential problems with regards to women and distress. The epidemiological figures suggest that women are likely to seek help for defined clinical diagnoses, but this runs the risk of overlooking a range of negative emotions associated with distress that fall outside these parameters. In addition, those that do not seek help run the risk of struggling to cope as their distress may remain invisible. Annandale & Clark (1996) have argued that the view of women suffering with “internalising disorders” has negative consequences – particularly the universalisation and pathologisation of women’s health, which has been criticised over a number of years for suggesting that the female role as it is socially constructed is conducive to mental illness (Doyal & Pennell, 1979, p.227). This research wanted to go beyond biomedical definitions of distress, to focus on how distress felt for the women interviewed, and the how it could affect their everyday lives. For this reason, narratives were collected to analyse the women’s stories of distress. These narratives were then compared to other research which has looked at women’s experiences of distress – a more thorough review of the literature on women’s personal experiences appears in section 2.2.

#### **1.1.4 Well-Being**

One aspect of distress which is often referred to within research is the potential for distress to have a negative impact on an individual’s well-being. Like distress, defining the term well-being can be problematic as “well-being” is sometimes associated with “mental health”. This is partly because mental health is seen as having two dimensions: the negative aspect of mental health includes distress, whilst the positive aspect is often spoken of in terms of well-being (Schütte et al., 2014). Well-being is also often used by healthcare organisations when trying to define what mental health is. For example, The World Health Organisation (2010) described mental health as “a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively

and is able to make a contribution to his or her community". Similarly, in the UK, The Department of Health has described mental health as "the foundation for well-being and effective functioning" (Department of Health, 2009). However, whilst the term well-being is often used to help describe mental health, there is no agreed definition of what the term well-being means (Anderson et al., 2011; Bowling, 2011) other than the assumption that it is "a good thing" (Bowling, 2011). Ganesh & McAllum (2010) have argued that as well-being is ill defined, it can function as a "red herring". However, others have suggested that because well-being is positively related to health (Mullan & Xavier, 2013), defining the term is the first challenge for anyone wanting to try and improve well-being (MacLeod, 2012).

Historically, two main research perspectives have been influential when considering what constitutes well-being: the philosophical perspectives of hedonism and eudemonia (Caunt et al., 2013). The hedonic approach studies well-being in terms of maximising one's pleasurable moments through happiness, life satisfaction, and the absence of pain. Alternatively, the eudemonic approach – which evolved from Abraham Maslow's Hierarchy of Needs (Maslow, 1958) – considers well-being in terms of actualising one's inherent potentials through optimal functioning and personal growth (Dagenais-Desmarais & Savoie, 2012; Henderson, 2012; Straume & Vittersø, 2012; Henderson et al., 2013b; Bobowik et al., 2015). In recent years, some research has led to the suggestion that whilst distinct, both hedonia and eudemonia are important in contributing towards well-being (Henderson et al., 2013b). Well-being itself has been described as a dynamic and multifaceted concept (Bowling 2011; Henderson, 2012) the definition of which is continuing to evolve (Henderson, 2012), but includes an individual's potential coping resources (Schütte et al., 2014). However, due to the amorphous nature of well-being, it was decided that this research would concentrate on a specific aspect of well-being which has come to prominence: the concept of *subjective* well-being.

On a fundamental level, the term "subjective well-being" (SWB) has been used to describe "happiness and life satisfaction" (Hunter et al., 2013a), whilst anxiety, depression and other mental illnesses are the conditions (aside from alcohol and drug abuse) which are likely to have the biggest impact on SWB (Binder & Coad,

2013). In the west, the concept of SWB has become more prominent as the rise of individualisation and self-care has put the autonomous individual at the centre of discourses on well-being (Sointu, 2005; MacKian, 2009). In 2009, MacKian stated that SWB was generally premised on three components: the presence of pleasant emotion, the relative absence of unpleasant emotion, and personal judgements about satisfaction. These personal judgements draw on the individual's perception of what is important when making an assessment about how they think and feel about their lives (Carlisle et al., 2009; Hicks et al., 2013). In the UK, these aspects have put SWB at the forefront for government measures of population well-being. The Office for National Statistics (ONS), which is the UK's largest independent producer of official statistics (Office for National Statistics, 2014), also acknowledge that whilst both subjective and objective measures are important (Office for National Statistics, 2012) "asking people about their happiness" (Dolan et al., 2011) is a useful way to get respondents to rate their feelings (Tinkler & Hicks, 2011). Some argue that happiness represents "the truest measure of well-being" (Layard et al., 2013). SWB therefore fits with the narrative approach that has been utilised by this study, as the participants' narratives were used in order to explore their feelings and experiences. In terms of health, one way that women can maximise their well-being is through the use of various self-care strategies. Self-care at a basic level is a set of practises that an individual utilises to maximise their mental and physical health (MacKichan et al., 2011). Other ideas of what can constitute self-care, including how visiting a herbalist might fit into a self-care approach, are explored further in section 2.3.

### **1.1.5 Western Herbal Practice**

The final focus of this research carries on from women's experiences of distress and SWB to consider what western herbal practice (WHP) is, and what role it may have to play in the management of women's distress. In order to understand WHP, it is first necessary to place it within the wider context of Complementary and Alternative Medicine.

There is no universally accepted definition of the term Complementary and Alternative Medicine, or “CAM” (Hunt et al., 2010), but American and European societies commonly describe healthcare as being CAM according to whether or not it is delivered within mainstream health services (Little, 2006; Conway, 2011, p.46). In some countries, traditional (not biomedical) medicine is the mainstay of healthcare delivery, so that The World Health Organisation (2013) combines the concepts of traditional medicine and complementary medicine and may refer to CAM as T&CM (traditional and complementary medicine). As this research was carried out in the UK, the term CAM has been used throughout because in western societies it is the term that normally describes patients’ utilisation of healthcare other than modern biomedicine (Hunt et al., 2010; Adams et al., 2014), and is an area that has become increasingly popular in recent years (Rochelle & Marks, 2010). Mitchell & Cormack (1998, p.10) cite seven distinguishing features of CAM: individual assessment of symptoms; treatment of mind, body, and spirit; a broad definition of health; an emphasis on treatment of chronic disorders; relatively low risk of side effects; encouragement of self-management techniques by the patient; and an emphasis on the patient’s perspective. However, caution is recommended when using the term CAM due to the diversity of practice amongst therapies (Low, 2001; Meurk et al., 2013) and how users choose to access these therapies (Andrews et al., 2012). The term should also be used with caution as boundaries between CAM and biomedicine may change (Wieland et al., 2011) with some therapies (at least in part) moving into the realm of biomedical healthcare, such as the use of acupuncture for lower back pain (National Institute for Health and Care Excellence, 2009; Savigny et al., 2009) or the perception by some patients that osteopathy is “conventional” (Bishop et al., 2008). Falkenberg et al. (2012) therefore conclude that it is not useful to define CAM universally, and that each stakeholder should define exactly what they mean by the term CAM. Whilst herbal medicine in the UK largely falls outside mainstream health services and so can be considered a CAM therapy, due to the diversity of CAM therapies this study is looking at herbal medicine (and WHP) in its own right.

“Herbal medicines include herbs, herbal materials, herbal preparations and finished herbal products that contain as active ingredients parts of plants, or other plant materials, or combinations ” (World Health Organisation, 2000). There can be some overlap in usage: for example, *Matricaria recutita* L. (chamomile) can be used in the treatment of mild anxiety (Amsterdam et al., 2009), but is better known not as a medicine but as a pleasant tasting tea (Wong, 2009, p.200). In the UK (as elsewhere) users of herbal medicine can choose to grow, harvest, and use either fresh or dried plants in a process described by ethnobotanists as indigenous folk medicine (Wahlberg, 2010). However, they are more likely to buy herbal preparations (either raw plant material or finished products) described as over the counter (OTC) products (Ipsos Mori, 2009), or may choose to go and see a therapist that practises one of a number of herbal traditions (Ernst, 2007; Bishop et al., 2008). Due to variation in these traditions, this research has concentrated on the practice of western herbal medicine (WHM).

In the west, the earliest surviving record of herbal medicine is generally thought to be a collection of medicinal plants listed on the Ebers Papyrus, written in Egypt in about 1550 BCE (Eldin & Dunford, 1999, p.8; Capasso et al., 2003, p.9; Aboelsoud, 2010), although there is archaeological evidence which suggests the use of plants as medicines thousands of years before this time (Hardy et al., 2012). Medicinal plants’ long history of use, along with the view that they are seen as being natural (Bunsiriluck, 2013; Pirotta et al., 2014; Nissen, 2015), has been cited as a reason for the belief amongst many consumers that most herbal medicines are relatively safe (Ang-Lee et al., 2001). Today, the OTC market is the most common way that people gain access to medicinal plants (Lee, 2005). In the UK the majority of herbal medicines are bought from high street stores rather than following a consultation with a herbalist: 67.7% of users compared to 8.1% (Damery et al., 2011), whilst self-treatment with herbs is common way of treating symptoms associated with distress such as “depressive disorders” (Solomon & Adams, 2015). The usage of herbal medicine in the UK remains popular. In 2008 35% of British adults surveyed claimed to have used herbal medicine at some stage (Ipsos Mori, 2009), and by 2013 the UK market for all herbal/traditional products was valued at over £463 million

(Euromonitor International, 2015). Although herbs can be sourced in a number of ways by consumers (Ernst, 2007), this study concentrated on an area that has received little attention in the past and so requires more investigation: the experiences of those that had visited a herbalist practising in the western tradition.

The practice of using herbal medicine in the west traces its roots back to the Greco-Roman period, and has evolved over the centuries, incorporating plants and ideas from other healing traditions (De Vos, 2011; Tobyn et al., 2011, p.32). In recent years, the boundaries between these traditions have become more blurred as the expansion of global communication, transportation and trade now means that plants from all over the world are regularly to be found in use within the framework of different herbal medicine traditions (Herbal Medicine Regulatory Working Group, 2003; Nissen, 2010; Wahlberg, 2010). In the UK, the traditional indigenous form of herbal medicine is today referred to as WHM as a way of distinguishing it from other herbal practices (such as Traditional Chinese Medicine and Ayurveda) that have become popular (Nissen, 2008; Nissen, 2015), and other CAM therapies that may use plant materials therapeutically such as naturopathy (Lin et al., 2009) and aromatherapy (Fismer & Pilkington, 2012). What the herbal traditions share is that they provide a system of healthcare made up of complex interventions (such as diet, exercise and supplements), but which use medicinal herbs as a primary modality (Zick et al., 2009).

The UK's largest professional body of western herbal practitioners is The National Institute of Medical Herbalists (NIMH), which was founded in 1864 (as The National Association of Medical Herbalists) making it the oldest professional body of herbal practitioners in the world (Chevallier, 1996, p.25; Conway, 2011, p.20). The NIMH report that "medical herbalists are health care providers trained in western orthodox medical diagnosis who use plant based medicines to treat their patients" (National Institute of Medical Herbalists, 2012). The second largest professional body – The College of Practitioners of Phytotherapy (CPP) – echoes this assertion, but appears to put more emphasis on "scientific research" (College of Practitioners of Phytotherapy, 2012). The use of the term "phytotherapy" is a considered one: it evolved in the UK in the late 20th century and is presented as the "integration of

traditional European herbal medicine practice with modern scientific understanding of the physiological actions of botanical medicines” (Hamblin et al., 2008). However, despite the slightly different presentations, both professional bodies emphasise not only the healing power of herbs, but also the importance of patients being given time to discuss their problems with a herbalist. A number of practising herbalists are members of both professional bodies, and both professional bodies were (until June 2015) associate members of The European Herbal & Traditional Medicine Practitioners Association (EHTPA): The EHTPA is an umbrella organisation for professional bodies (such as The NIMH and CPP), which focuses on the development of standards and training, and strengthening the identity of the profession (European Herbal & Traditional Medicine Practitioners Association, 2014).

Whilst there has been little research into the practise of WHM (Denham et al., 2011) and its effectiveness as actually practised by herbalists (Vickers & Zollman, 1999; Walker, 2006), there is research that reports what takes place during a consultation. At a fundamental level, WHP involves the use of whole plants or parts of plants (World Health Organisation, 2000; Van Marie, 2002), using a combination of herbs (Lee, 2005; Topps & Busia, 2005; Brock et al., 2012), and the individualisation of herbal combinations in treatment (Green et al., 2007; Denham et al., 2011; Brock et al., 2012). The treatment is based around a detailed case history of the patient and usually involves a one-to-one consultation which lasts roughly between 30 and 75 minutes (Walker, 2006; Casey et al., 2008; Cottingham et al., 2015). The consultation normally occurs in some type of CAM clinic, or in the practitioner’s or patient’s home (Conway, 2011, p.241), with an emphasis placed on the importance of the patient’s story, or narrative (Stewart, 2010; Nissen & Evans, 2012). Conway (2011, p.42) described how a ritual occurs when the patient tells their story as the herbalist “first listens, then offers an interpretation of the story, perhaps weaving it into a complementary or alternative story of their own creation”. This then leads to a “master narrative” for the patient to ascribe to (Conway, 2011, p.42).

Other elements of the consultation can vary, leading to some diversity of practice, compounded by the fact that some herbalists also practise other types of therapy (Nissen, 2010). This diversity, combined with a lack of research, means that what constitutes WHP is open to some element of interpretation. However, in addition to eliciting a case history, the consultation may include a physical examination (Casey et al., 2008; Nissen & Evans, 2012), lifestyle advice, which includes dietary advice (Casey et al., 2008; Denham et al., 2011; Rooney & Pendry, 2014), and suggestions for further pathological tests (Casey et al., 2008; Nissen & Evans, 2012). Unlike a lot of CAM therapies, as much of the consultation is taken up with talking, the actual treatment itself (the herbal prescription) is taken at home by the patient (Zeylstra, 1995). The herbs can then be in a variety of forms, including (among others) infusions, decoctions, creams, and tinctures, with tinctures being the preferred form of administration by most herbalists (Zeylstra, 1995; Brock et al., 2012) due to its convenience for patients, as well as the belief by some practitioners that it is more efficacious than using dried herbs (Brock et al., 2012). Tinctures are formed by macerating plant material in an ethanol/water mix (Brock, 2012) in order to obtain a concentrated liquid herbal extract (Casey et al., 2007). Whilst tinctures may be of a single herb, herbal practitioners are likely to formulate a prescription using a combination of herbs individually prescribed for the patient (Casey et al., 2007; Denham et al., 2011), in contrast to most OTC preparations.

The NIMH claim that a herbalist is a “genuine, caring partner in health”, that visiting one can be “a life changing experience”, patients are given time to discuss “their physical, emotional and spiritual well-being in depth”, and this in turn gives them a “sense of freedom and empowerment” (National Institute of Medical Herbalists, 2012). Both the NIMH and the CPP give the impression that the therapy is “holistic”, using the term “in the sense of an active integration of different facets or sensitivities (i.e. mind, body, spirit) within a healthcare practice” (Meurk et al., 2013). The statements made by the herbalists’ professional bodies sound, as one might expect, impressive. What is less clear is where the information on what occurs in a consultation is obtained, and whether the experience of the patient matches the claims of the profession. What is also overlooked by the professional

bodies, and much of the research, is the diversity of herbal practice that can occur from a variety of elements that may, or may not, occur during the consultation (Nissen, 2010; Nissen, 2011). Historically, herbal medicine was taught in the style of an apprenticeship, or at a number of private schools (Isbell, 2008). In recent years there has been a move in the west towards university courses for herbal medicine (World Health Organisation, 2013), particularly in the UK (McCabe, 2008) where one of the requirements formed at the time of proposed statutory regulation of herbalists was that they be trained to degree level (Pittilo et al, 2008). Standards of education for herbalists are now laid down by The EHTPA's core curriculum (European Herbal & Traditional Medicine Practitioners Association, 2007) in a similar way that The General Medical Council outlines standards for biomedical education and training (General Medical Council, 2013). These historical differences in background and training may help to explain why WHP is diverse and still evolving (Denham et al., 2011; Nissen, 2011). An example of this diversity has been provided by Evans (2008) whose research showed that whilst WHP may traditionally use the concept of "vitalism" – which is the idea that herbal medicine can stimulate the human body's own powers of self-defence and self-regeneration (Grant, 2004; Nissen, 2011) – many herbalists are now more likely to utilise biomedical understandings of illness instead.

Many patients in the UK only have experience of medical treatment via the NHS – the main provider of healthcare, which provides treatment mainly based on a biomedical paradigm that is largely free at the point of delivery and is paid for by taxpayers (Rochelle & Marks, 2010). It therefore follows that many patients do not necessarily know what to expect when they walk through a herbalist's door for the first time (Eldin & Dunford, 1999, p.27), compounded by the apparent diversity of practice. The paucity of research into the patient experience of the treatment process of WHP highlighted that this was an area that warranted further investigation as part of this research.

## **1.2 Aims and Objectives**

### **1.2.1 Research Aim**

To investigate how women experience and understand distress, as well as the role of consulting with a herbalist who practises WHM for distress related conditions.

### **1.2.2 Research Objectives**

(i) To survey herbalists practising WHM, in order to report their approaches to the treatment of distress

(ii) To collect the narratives of women who have a history of distress, and who are consulting with a herbalist who practises WHM

(iii) To analyse and compare narratives for themes related to their experience of distress, and seeing a herbalist as part of their self-care strategy

(iv) To repeat the collection and analysis of patient narratives as part of the longitudinal study to see if their experiences – and narratives – change over time

(v) To report the above findings through a thesis, journal articles and conference papers.

## **1.3 Structure of the Thesis**

### **1.3.1 Chapter Outline**

Following this introductory chapter, this research is laid out over a further six chapters.

**1.3.2 Chapter 2 – A Review of the Literature:** provides a literature review of what has been reported about women's experiences of distress. The review then considers the role that self-care strategies may have in the management of distress,

including the utilisation of guided self-care and considers the role that a herbalist may play in guided self-care. The literature review then continues to consider any potential that herbal medicine products may have for the treatment of symptoms associated with distress, but also highlights that taking herbal medicine would only be one part of visiting a herbalist. The review looks at women's experiences of WHP within the paradigm of CAM, and considers the paucity of research with regards to the patient experience of WHP – particularly when considering women and distress. Finally, the chapter considers the significance of this research in relation to the current literature.

**1.3.3 Chapter 3 – Methodology, Methods and Demographics:** outlines the research design for this study. It firstly considers the theoretical approach to this research, and discusses the decision to use a constructionist (as opposed to a positivist) approach. The methodological approach is then detailed, along with sampling and recruitment, data gathering, data management, and the decision to utilise thematic analysis. The chapter then considers the rigour of the study, and outlines steps taken to help ensure the credibility of the research design, including transparency, reflexivity, and triangulation. The chapter ends by presenting the demographic data for both the practitioners and their patients.

**1.3.4 Chapter 4 – Women and Distress:** introduces the presentation of the data from the fieldwork. After reporting how the herbalists viewed their approaches to treating distress, the chapter focuses on the women and their varied experiences of distress, but also highlights where there are similarities between their experiences. The chapter then focuses on the elements of distress that were reported as being significant to the participants, including the distress of bereavement and the distress of ill health, and then looks at how distress can manifest itself: in particular the experiences of anxiety and depression (including suicidal thoughts). The chapter ends by discussing the impact that distress can have on the individuals' lives.

**1.3.5 Chapter 5 – Isolation and Social Acceptability:** focuses on different ways that women can become isolated when unwell, particularly physical and social isolation. The chapter then considers how feelings of embarrassment, shame, and guilt can add to individual's distress, and lead to greater isolation as withdrawing is utilised as a self-care process. The need to deliberately use isolation is considered within the context of the social acceptability of distress; particularly stigma, the felt need to put up a front, inability to cope, and a desire to protect others.

**1.3.6 Chapter 6 – Results From The Herbal Therapeutic Process:** begins by considering the self-care practises reported by the participants, and how they related to WHP. The focus then shifts to the consultation, described as the herbal therapeutic process. The process is both individual and flexible, but revolves around three areas for the participants: being heard, being held (emotionally), and being treated. The chapter explores the different aspects that make up each of these three areas, using the participants' narratives to illustrate and how it felt when seeing a herbalist and taking the herbs. The chapter then considers the narratives from T2 to consider whether increasing usage of WHP had a positive impact on their distress or not.

**1.3.7 Chapter 7 – Discussion:** considers the results and places them within the context of the wider literature. In particular, the discussion considers what the experience of distress is like for women, concentrating on feelings of shame (associated with a loss of agency), and guilt (associated with an inability to cope with societal roles). The discussion then considers what aspects of the herbal therapeutic process the participants found most useful, but places these against less successful encounters as a way of emphasising best practice. Thoughts then turn to what aspects of WHP have the potential to overcome the issues of women's distress: in particular, the ways in which WHP can help with feelings of empowerment. The chapter then considers any limitations of this research, any suggestions for future research, before ending with an overall conclusion.

## **CHAPTER 2: A REVIEW OF THE LITERATURE**

### **2.1 Introduction**

This chapter provides a review of the literature concerning the different areas that are of relevance to the current study: women's experiences of distress; the use of narratives of distress; self-care strategies for distress, and the potential role of western herbal practice (WHP) for distress. In the first instance, as this research is investigating women's experience of distress, the review considers what has been reported about women's distress within the literature. It highlights how women's distress can be experienced both as a loss of self and a loss of agency, be expressed via the use of metaphors, and potentially lead to feelings of shame, guilt, stigma and/or isolation. As the participant's narratives are being used to elicit their experiences, a review of the use of narratives – both by those living with distress, and across different research disciplines – follows on from women's experiences of distress. This then leads into the next stage of the research, which investigates women's experiences of WHP for distress. The literature review considers the use of self-care, and how self-care may either be utilised on an individual basis or may include the judicial use of therapists (including utilising the services of a herbalist). This is followed by a review of the literature which considers the potential for medicinal herbs to be used within treatment of distress, before considering what is known about women's experiences of WHP as a form of complementary medicine. The chapter ends by highlighting gaps in the literature, and considers the significance of this research.

### **2.2 Women's Experiences of Distress**

Women's experiences of distress are diverse (Emslie et al., 2007; Danielsson et al., 2011). In spite of this, this review of the literature shows that there are patterns to distress including feelings indicative of women's experiences of distress, which include fatigue (Danielsson & Johansson, 2005; del Mar Garcia-Calvente et al.,

2012), fear (Reynolds, 1999; Allan & Dixon, 2009), anxiety (Singer & Hunter, 1999; Singer, 2012), and low mood (Allan & Dixon, 2009; Newton et al., 2012). These have previously been described as “internalising disorders” (MacKenzie & Fowler, 2013). However, looking at such descriptions associated with distress only provides part of the picture as it does not give an idea of what the wider experience of distress might be for women, and does not show the impact that distress can have both on their ability to function, and everyday lives.

### **2.2.1 Loss of Self and Loss of Agency**

An individual’s view of the self and identity are both important concepts for understanding experiences of distress. The view of the self has been described as an individual’s reflexive capacity to imagine themselves, and is “an inner and private phenomenon, unique to the individual, unknowable directly to others” (Kelly, 1992). The individual’s concept of self may be distinct from their identity, where “identity” is “the label imposed by others on self... it is the public knowable aspect of the person” (Kelly, 1992). An individual’s identity can take on extra relevance in times of distress when an individual attempts to display a version of their private experience to an audience in a public space (Murdoch et al., 2013). In 1951, Parsons helped to formulate the concept of “the sick role” (Parsons, 1951, p.211), an identity whereby the person who was ill was not regarded as being responsible for their situation and so was given exemption from some of the activities and obligations of everyday life (Moreira, 2004; Armstrong, 2014). Whilst both concepts of the self and identity are important when considering an individual’s experience of distress, in recent years concepts of the self have risen to prominence in understanding these experiences.

In 1983, Kathy Charmaz helped to put the individual’s concept of self at the centre of discourses of distress when she described how distress might be experienced by those living with chronic illness as a “loss of self” (Charmaz, 1983). Skaff & Pearlin (1992) also defined a loss of self as “the constriction of self-identity or loss of the essence of oneself”, what Charmaz later described as a loss of the ways that people

know, define, and feel about themselves (Charmaz, 2011). The work by Charmaz also highlighted how a loss of self due to distress could affect those with distress in a number of ways: for example, stigma associated with chronic ill-health can not only cause feelings of low self-esteem but also lead the individual to withdraw from social activities (Lawton, 2003). Whilst illness does not necessarily always lead to a loss of self (Pierret, 2003), Radley & Billig (1996) argued that the individual's view of their state of health would invariably affect their identity in relation to others.

The idea that a loss of self can help characterise distress has continued to be reported by research across a range of disciplines, and for a range of situations that can cause distress. One area of research has been concerned with the effects of the menopause. Not only can the menopause lead to unpleasant physical symptoms, such as hot flushes and a loss of libido (Green et al., 2007; Brown et al., 2015), but distress associated with the unwanted symptoms can negatively affect women's self-esteem and sense of control (Bunsiriluck, 2013), which in turn can lead to them feeling like they have lost a sense of who they once were (Reynolds, 1999; Singer & Hunter, 1999; Singer, 2012). Living with depression is another situation where women who described feelings of "struggling with life" have also felt that they have lost a sense of who they were, linked to "gendered expectations of successful womanhood" (Edhborg et al., 2005; Fullagar, 2008; Fullagar & O'Brien, 2012). Some research has gone further to suggest that if women feel that they have "failed" to make themselves well when living with distress (Cosgrove & Riddle, 2003) they can be critical of the self, and experience feelings of "self-loathing" (Granek, 2006; Allan & Dixon, 2009). These feelings of failure in relation to gendered expectations of successful womanhood lend weight to the argument that women's perceptions of how others will see them is related to the societal role that they think they are expected to aspire to.

Neoliberal societies prioritise personal responsibility for one's own circumstances, where agency is of primary importance (McCoy & Peddle, 2012). Women's societal role which, it is argued, is commonly expected within neoliberal societies (Fullagar, 2008) stems from the stereotypical expectation that women have a greater interest in the feelings and emotions of others compared to men (Roter et al., 2014). This

interest in others is then translated to assume that women are likely to assume the role of a “care-giver” (Lafrance & Stoppard, 2006; Hunter et al., 2013b; Creighton et al., 2015): in the UK, someone who provides regular or ongoing care and support to a family member or friend who is physically or mentally ill (National Health Service Choices, 2013) is commonly referred to as a “carer” (Arnsberger et al., 2012). This caring role can extend to family or friends who do not have a clinical diagnosis but are less able to take care of themselves (such as children and the elderly). Figures from The United Nations report that across the globe women are more likely to take on the role of a carer than men (Pierret, 2003; Carmona, 2013). The situation is similar in the UK where, in 2011, 58% of the 5.78 million unpaid carers in England & Wales were women (Office for National Statistics, 2011a). Their role as carers means that these women are more likely to find themselves living in financial poverty, or having to deal with poor health compared to those that do not have a carer role (Office for National Statistics, 2011a; Carmona, 2013).

The nature of the caring role can mean that women are likely to be self-sacrificing and put the needs of others before the needs of themselves (Hampton, 1993; McMullen, 1999; Lafrance & Stoppard, 2006). This can result in feelings of becoming “engulfed” as described by Skaff & Pearlin (1992) who found that women in their study of carers were more likely than men to have feelings of a loss of self. Another effect of adopting a self-sacrificing, carer role is that the desire to protect those around them can make it difficult for women with distress to admit how they are feeling – especially to close friends and family, who women can feel need protecting from the individual’s negative thoughts (Allan & Dixon, 2009; Rüscher et al., 2014). The seemingly inextricable link between women’s perceived societal roles and their well-being (Sointu, 2011) has led to the argument that distress can be linked to women trying to “be all things to all people” (Fullagar, 2011), so that resisting gendered norms and putting themselves first can be an important part of the battle to recover from circumstances such as living with depression (Fullagar & O’Brien, 2012).

Another aspect of women’s distress that can affect an individual’s view of the self is the idea that distress can cause a loss of personal agency (Kemp, 2003; Pritzker,

2003), where agency is defined as the degree to which people experience themselves as able to affect events in their own lives (Lysaker et al., 2010). Agency as applied to patients and their behaviour has shifted in recent years from the sick role described by Parsons (1951) which withdrew responsibility from the patient, to a position in which patients are encouraged to take more of an active role in decisions about their health and well-being. The concept of patient empowerment is thought to be rooted within civil rights and women's movements (Rissel, 1994), and is a process by which people are helped to use autonomous decision making in order to better self-manage their condition, gain control over their health and remain socially integrated (The Lancet, 2012) – the concept of self-care is discussed further in section 2.3.

Armstrong (2014) has argued that a rejection of the Parsonian model of a passive sick role has led to a more powerful sense of individual autonomous action for patients. However, McKenzie-Mohr & Lafrance (2011) when investigating the experiences of women who had lived with depression argued that a loss of agency could be perceived as removing blame on the part of the individual. They further suggested that women are placed in a precarious position when talking about distressing times to others, and walk a "tightrope" between recognising their agency, whilst rejecting any notion of blame for their circumstances (McKenzie-Mohr & Lafrance, 2011). The societal expectation in the west for individuals to be "autonomous and in control" (Sointu, 2005) can result in the situation where women with distress also have to contend with the stigma of their distress. For example, having to live with conditions such as depression and anxiety can be seen as a sign of personal weakness that they should be able to overcome (McKenzie-Mohr & Lafrance, 2011): as discussed (above), an inability to cope can lead to women feeling like a failure (Cosgrove & Riddle, 2003). These feelings can exacerbate distress as low self-esteem can affect how women perceive that others view them (Hedelin & Jonsson, 2003) and provides an example of the point raised by Charmaz (1983) that distress can affect individuals in a number of areas of their life. Feelings of losing control can sometimes be perceived by women to be linked to circumstances in their lives, such as distress around the time of giving birth (Haga

et al., 2011; Chadwick et al., 2014), negative feelings related to giving up work to have children (Haga et al., 2011), or going through an early menopause (Singer, 2012). By contrast, there may be no discernible external cause for feelings of distress, which can then also lead to feelings of being unable to cope with experiences of depression (Fullagar & O'Brien, 2012) or anxiety (Willgoss et al., 2012) and exacerbate feelings of a loss of control. This can, in turn, exacerbate their distress and again lead to women feeling like they are “a failure” (Allan & Dixon, 2009).

These examples of women's experiences of distress support the idea that the sense of self is not static and can be disrupted by distress (Saha et al., 2011). Conversely, over the past thirty years mental healthcare has focused on a recovery paradigm (Jarchow, 2014; Feeney & Collins, 2015), which emphasises that a sense of self can also be regained via recovery from distress. It is now recognised that individuals can develop meaningful and purposeful lives, despite having experienced mental illness (Anthony, 2000) – including distress (Timander et al., 2015) – as distress and recovery (or post-traumatic growth) “are not mutually exclusive” (Soo & Sherman, 2015). Relevant to the current research, one of the ways that individuals can feel better, and develop a better sense of self is by sharing stories, or narratives (McLean et al., 2007; Pasupathi et al., 2009; Goldie, 2012).

### **2.2.2 The Use of Narratives in Distress and Recovery**

It has been argued that language makes thoughts and concepts possible and not the other way around: language predates concepts and provides a means of structuring the way the world is experienced (Andrews, 2012). By formulating narratives, individuals engage with language, and their supposed past and future (Goldie, 2012), and share stories to help to create and share with others a sense of self and journey (McLean et al., 2007; Pasupathi et al., 2009; Goldie, 2012). As was considered in section 2.2.1, a sense of self is provided by the ways that people know, define and feel about themselves (Charmaz, 2011), but the concept of a sense of self is not static (Saha et al., 2011). In 1982, Bury outlined the idea that

chronic illness can cause “biographical disruption” by affecting “taken-for-granted assumptions and behaviours”, leading to “a fundamental re-thinking of the person’s biography and self-concept”, and a resultant “mobilisation of resources, in facing an altered situation” (Bury, 1982). Whilst Bury’s original work has been critiqued for failing to take into account that illness may already be part of an individual’s biography, so that what may be a disruptive experience for some may be part of everyday life for others (Williams, 2000a), it does support the notion that illness can cause a loss of self (Charmaz, 1983), and also a loss of personal agency (Kemp, 2003), at least initially. The idea of biographical disruption continues to be used and adapted when considering experiences of distress, such as the work by Locock et al. (2009) which suggested that those living with Motor Neurone Disease (usually a terminal illness) can experience a “biographical abruption” as the diagnosis leads to feelings of “a death sentence” and of being denied a future. In times of crisis, narratives have particular relevance as one of our most powerful forms for expressing suffering and experiences related to suffering is the narrative (Hydén, 1997). What may then be collectively referred to as illness narratives, or patient narratives, are storied accounts told by people about their conditions (Pool & Geissler, 2005, p.52; Thomas, 2010).

As well as expressing suffering, narratives may be used in other ways. Narratives are of relevance to the individual patient because whilst illness can cause a breach in the individual’s sense of identity, narratives can help the individual make sense of changes in their self and in their relationship with their surroundings (McLean et al., 2007; Frost, 2009; Lysaker et al., 2010; Nosek et al., 2012). Under conditions of adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of self identity (Bury, 2001) or to develop new and more useful stories of the self (Lafrance, 2009, p.189) – what Williams (1984) described as “narrative reconstruction”. This process of reconstruction is important in determining the extent to which recovery occurs (Scrignaro, et al., 2011). Examples include Ridge & Ziebland (2006) who described participants recovering from depression moving from a place of “not knowing” to becoming more aware of themselves and their place in the world, whilst adults who

construct more meaningful narratives of personal experiences not only show higher levels of well-being (Sales et al., 2013), but can surpass their level of functioning before the distress occurred (Hefferon et al., 2009).

The process of narrative reconstruction also necessitates the process of rumination. This act of reflecting back on events can manifest itself in different forms: it may be positive and so help reduce distress, or negative and so increase distress (Soo & Sherman, 2015). In 1984, Lazarus and Folkman proposed a cognitive theory of psychological stress and coping. One aspect of this theory was concerned with how individuals might behave when faced with a stress that they perceived they were unable to cope with. The theory suggested that individuals had two methods of trying to cope available to them when faced with distress. Problem-focused forms of coping revolved around deliberate efforts to solve a situation, whilst emotion-focused forms of coping included distancing, avoidance, seeking social support, and positive reappraisal (Folkman et al., 1986; Folkman & Lazarus, 1988). Positive rumination matches the positive reappraisal of emotion-focused coping (Jin et al., 2014), although problem-focused coping has also been positively associated with recovery from distress (Scrignaro et al., 2011), and so both may be of relevance to those such as the women spoken to for this study.

Narratives can also form part of the herbal consultation (Stewart, 2010; Nissen & Evans, 2012) and are utilised in other medical practices as narratives may be used as a means of “bringing the person back into medicine”, both as an end in itself and for potential therapeutic benefits (Conrad & Barker, 2010). Narratives can therefore not only provide stories of distress but also (and of relevance to this research) stories of recovery.

### **2.2.3 Metaphors of Distress**

Some research has described distress with words such as anxiety and depression, but these terms have the issue of remaining associated with clinical diagnoses without necessarily giving an insight into what women’s distress can actually feel

like. Whilst some have argued that much of the research conducted into experiences associated with distress has been medically oriented and so not paid attention to women's subjective experiences (Edhborg et al., 2005; Allan & Dixon, 2009; Hunter et al., 2013b), a growing body of research has utilised narratives in order to give the opportunity to reveal distress from women's perspectives (Granek, 2006), and so provide a more nuanced account of the issues surrounding women and distress (Chadwick et al., 2014). One issue with narratives can be the difficulty that individuals find when trying to describe emotions. However, one common way of describing mental illness that would otherwise be difficult to express in words is to use metaphors (Hedelin & Jonsson, 2003). "The essence of metaphor is understanding and experiencing one kind of thing in terms of another" (Lakoff & Johnson, 1980, p.5) and is used cross culturally (Schoeneman et al., 2004) as a tool to better express individuals' experience of the self and their world (Levitt et al., 2000). For example, Mallinson & Popay (2007) found that metaphors of depression were shared across ethnic groups in the northwest of England.

Whilst there are various metaphors that women can utilise to help describe their distress, some metaphors (used by both women and men) appear repeatedly in the literature, the first of which is the idea of darkness. Thought to be one of the earliest, and long lasting metaphors (McMullen, 1999), darkness is often used when trying to describe negative emotions across cultures (Pritzker, 2003): "the black struggle" (Styron, 1990; Schoeneman et al., 2004), "a black cloud" (McMullen, 1999; Rhodes & Smith, 2010), "black and gloomy" (Fullagar, 2008; Fullagar & O'Brien, 2012) and "a dark hole" (Granek, 2006) or "a black hole" (McKenzie-Mohr & Lafrance, 2011) are typical examples, whilst Winston Churchill famously used the metaphor of a "black dog" to describe his episodes of depression (Parker, 2002). A second common metaphor is the idea of being weighed down, with examples including "I feel burdened" (McMullen, 1999), "carrying a burden" (Levitt et al., 2000), or "an overwhelming sense of weight" (Fullagar, 2008; Fullagar & O'Brien, 2012). Feelings of being weighed down can lead to people feeling "paralyzed" (Granek, 2006); what Fullagar (2011) has also described as a form of "stasis". Other

metaphors appear to take the ideas of darkness and weight, but place them within a more fluid context.

McMullen (1999) reported how the majority of metaphors used in her research centred round “depression is descent”. The idea of movement up and down has emerged in other research: Pritzker (2003) considered how the idea that “sadness is down” is used in opposition to the idea that “happiness is up”. McKenzie-Mohr & Lafrance (2011) took the description of a black hole to consider how women could use a gravity metaphor, which can describe a descent into depression (being pulled down by an external force) as well as a struggle to ascend (regaining agency). Hedelin & Jonsson (2003) used women’s metaphors in a similar way to describe mental health as an ascending or descending spiral, whilst Fullagar & O’Brien (2012) reported women using words such as “descending”, “crashing”, or “falling” into depression, before moving on through “an undulating journey” to a point where depression “lifted”. Whilst life is often metaphorically viewed as a journey (Pritzker, 2003), the use of the word “undulating” is an important one in women’s stories of distress, as recovery is not necessarily a linear journey of moving through sequential stages (Fullagar, 2003), but can be seen as “a repeated and incomplete process” (Locock et al., 2009). Narratives of recovery could include feelings of getting “lost in a foggy haze” (Granek, 2006), or feelings of having to “fight” (McKenzie-Mohr & Lafrance, 2011) or “battle” (Fullagar & O’Brien, 2012), which gives an impression of a difficult journey with the possibility of set-backs on the way.

Reisfield & Wilson (2004) highlight the ubiquitous use of violent metaphors in western society (such as “wars” on drugs, poverty, illiteracy and teenage pregnancy). This is particularly the case with regards to cancer: in 1971, Richard Nixon (then president of The United States of America) “declared war on cancer” (Drake, 2011). Political rhetoric aside, metaphors of battle (along with metaphors of journey) are frequently reported by those who are living with cancer (Gibbs & Franks, 2002). Whilst the idea of fighting against cancer has been described as “an enabling metaphor” (Reisfield & Wilson, 2004), the use of battle metaphors has also been cautioned against as it risks stigmatising those who are perceived to have lost their battle (Sontag, 1991, p.180; Reisfield & Wilson, 2004). However, their usage

does help to give an impression of the possible physicality of distress: Granek (2006) described how distress can lead to diverse feelings such as being “fragmented” or “in a knot”. These metaphors also suggest that distress can also lead to somatisation (Pritzker, 2003), and is supported by the work of Mallinson & Popay (2007) who found across ethnic groups in the northwest of England shared somatic metaphors of depression such as having “a heavy head” or being “gripped by emotion”.

#### **2.2.4 Shame, Stigma and Isolation**

Feelings of shame or embarrassment are linked to feeling exposed and experiencing a perception of reduced self-worth (Crowe, 2004). Whilst shame and embarrassment are not the same, there is no consensus in the literature about how they differ. In 2014, Crozier carried out a review of the literature in order to help differentiate the terms. Whilst there is still some contention over the differences, and each instance will be unique to the individual, a review of the empirical data (taken from Crozier, 2014) suggested that embarrassment is likely to be a transient and less severe emotionally painful experience. It represents a perceived flaw in the individual’s persona or public self in relation to social evaluation, and can be seen as a minor breach of standards. In addition, embarrassment tends to be worse in the presence of others. By comparison, shame is likely to be a persistent, intense experience. It represents a perceived flaw in the individual’s core or sense of self in relation to self-evaluation, and can be seen by the individual as a major breach of standards. In addition, shame can occur with no audience present.

Similar to shame and embarrassment, the terms shame and guilt are sometimes used interchangeably (Tangney et al., 1996; Kim et al., 2011) and their exact usage is also a matter of some debate. In spite of these issues, a review of the literature provided some working definitions. Kim et al. (2011) and Tangney et al. (2014) have helped to unpick the differences: whilst shame represents a perceived flaw in the individual’s sense of self, guilt involves focusing on a specific behaviour with an outward focus towards others. Shame is thought to lead to feelings of diminished

worth, helplessness and exposure, whilst guilt leads to feelings of remorse and regret. Shame is also considered to be a more painful emotion than guilt, and can lead to a desire to withdraw or escape, whereas guilt is more likely to lead to a desire to apologise or confess.

Rather than feelings of embarrassment due to distress, much of the literature talks of women's feelings of embarrassment being due to physical conditions that are associated with distress. These conditions share visible signs that the individual feels are embarrassing, such as chronic skin conditions (Mizara et al., 2012; Sampogna et al., 2012), menopausal symptoms (Singer & Hunter, 1999; Nosek et al., 2010; Smith et al., 2011; Brown et al., 2015), or chronic obstructive pulmonary disease (COPD) where those living with COPD have reported feeling embarrassed due to the physical symptoms associated with the illness, but have also felt embarrassment due to feelings of anxiety (Willgoss et al., 2012). Other narratives help to show the complex nature of women's experiences: Hunter et al. (2013b) described how some female burns victims reported few concerns over the appearance of their bodies, but also had counter-narratives which suggested they were worried about their scarring being visible in public.

There are few qualitative studies aimed at understanding how shame is experienced by women with distress (Sari & Gençöz, 2015), though some research has suggested that emotional distress can be linked to feelings of shame, and associated guilt (but not embarrassment). Shame has been reported by both women and men of all ages when living with depression (Danielsson & Johansson, 2005; Danielsson et al., 2009; Danielsson et al., 2011; Holm & Severinsson, 2014; Sari & Gençöz, 2015). Danielsson et al., (2011) argued that being normal was important for self-esteem and that shame was linked to "the opposite feeling of not fitting in". Danielsson & Johansson (2005) considered that women verbalised their distress more than men, but it was men who were more likely to feel shame linked to "losing face", and that women were more prone to feelings of guilt. Women's feelings of guilt have been associated with self-blame, where individuals deem themselves responsible for having feelings of depression (Danielsson et al., 2009), but also responsible if their depression impacts on others (Vallido et al., 2010). Whilst there may be some

differences in how women and men experience feelings of shame and/or guilt, these feelings have been linked to stigma.

The word stigma comes from the Greek word “stig”, which means “to prick” and refers to the practise in Ancient Greece of tattooing slaves who tried to escape (Scambler, 2009). Today, the usage of the word stigma denotes a mark of disapproval that allows “insiders” to identify and disassociate from “outsiders” (Scambler, 2009). Mental illness stigma relates to the devaluing and disgracing by the general public of individuals with mental illness (Fleming et al., 2009; Abdullah & Brown, 2011; Stubbs, 2014), which may be perceived (the anticipated negative views of others) or enacted (Boardman et al., 2011). Research consistently shows that there is stigma surrounding mental health problems (including distress) for both women and men, as well as for other conditions linked to distress (Cromby et al., 2013, p.7; Angermeyer et al., 2014).

Despite figures which suggest that general attitudes towards mental illness in the UK are improving (National Health Service Information Centre, 2011), some research indicates that public attitudes have not improved in recent decades (Angermeyer et al., 2014) so that stigma can still be attached to a number of situations and conditions associated with distress. For example, symptoms associated with the menopause can lead to embarrassment and affect the individual’s self-image (Reynolds, 1999) which, combined with the fact that the menopause is generally not spoken about (Bunsiriluck, 2013), can lead to the perception that the menopause can be seen as “taboo” (Singer & Hunter, 1999; Bunsiriluck, 2013). Physical conditions can be particularly susceptible to being stigmatised if the illness does not have any obvious external signs. One example is chronic fatigue syndrome (McInnis et al., 2014) as the individual may feel that their condition has become a “contested illness” (Conrad & Barker, 2010; Bock, 2013) and so experience the need to justify how they are feeling. Feelings of a contested nature are also true of women’s distress (Lafrance, 2009. p.181), as distress is often surrounded with moral ambiguities about whether the person concerned is the blameless victim of a condition they cannot control (reminiscent of Parson’s sick role) or is “putting it on” (Heller et al, 1997, p.18). The stigma that can be attached

to mental and emotional conditions such as distress (Henderson et al., 2013a; Evans-Lacko et al., 2014; Whitley & Campbell, 2014) can be made worse if the condition requires on-going pharmaceutical treatment (such as anti-depressants) as the perceived dependence on drugs can also carry its own stigma (Fullagar & O'Brien, 2012). In addition to not necessarily having any external signs and so being "contested", and as well as the potential need for on-going pharmaceutical treatment, distress (along with mental health problems in general) is often stigmatised due to the perception by some that it is "beyond control" (Sallinen et al., 2011). A combination of these factors can lead to women who are living with distress also experiencing feelings of isolation and a loss of self (Fleming et al., 2009).

Isolation is a further feature that is apparent within research that explores women's descriptions of distress (Fullagar, 2008; Jarchow, 2014). Negative emotions can lead to women expecting that they will become isolated which, if realised, can lead to them feeling that the isolation confirms their own lack of self-worth (Hedelin & Jonsson, 2003). Actual instances of isolation are sometimes linked to stigma as negative reactions from others can lead to women feeling invisible and alone (Edhborg et al., 2005; Chadwick et al., 2014). These feelings can exacerbate women's distress which, in turn, can lead to them disclosing less about how they are feeling, and so result in increased isolation (Reynolds, 1999; den Heijer et al., 2011). Isolation can also be used as a way of coping with distress. This can be achieved in one of two ways. The first involves women avoiding stressful situations (Ussher & Perz, 2013), though the downside of this strategy is that the avoidance of social situations can ultimately exacerbate their isolation (Willgoss et al., 2012). The second strategy is to put up a façade to cover their distress – typically described metaphorically in the literature as "putting on a mask" (Allan & Dixon, 2009; Holm & Severinsson, 2014), "hiding face" (Dong et al., 2013), "saving face" (Hunter et al., 2013b) or "maintaining face" by "putting on a front" (Pollock, 2007) and so attempting to "blend in" (Whitley & Campbell, 2014). Whilst this strategy might allow individuals to keep up a veneer of social acceptability by not avoiding social situations, the experience of hiding one's own feelings can still be isolating.

What becomes clear from the literature is that women's distress is not a condition that is simple to categorise, or predict what the experience of distress is going to be like for each individual. What is clearer is not only the negative impact that distress can have on women's well-being and their ability to function, but also how distress can potentially lead to an increased sense of isolation. However, women's narratives of distress also include stories of recovery, so it is important to understand the processes that women utilise in order to overcome their distress and return to a place of well-being.

### **2.3 Self-Care and the Expert Patient**

The emergence of subjective well-being (as highlighted in section 1.1.4) has put the autonomous individual at the centre of discourses on well-being (Sointu, 2005; MacKian, 2009). As patients are seen to have increasing autonomy (as discussed in section 2.2.1), this has led to self-care being promoted in recent years as part of a patient centred approach in the management of health conditions (Lucock et al., 2011), with the result that the majority of health care is undertaken by individuals (MacKichan et al., 2013). Self-care skills and knowledge stem from lay experience (Rijken et al., 2008) and form a deliberate action that individuals engage in to maintain good health (World Health Organisation, 2009), to manage medical conditions (Arcury et al., 2012) and so experience feelings of enhanced control and increased resilience (Seebohm et al., 2013). However, the terms "self-care", and "self-management" are subject to a variety of interpretations (Pratt et al., 2009). Self-care has been broadly defined as those behaviours that are practiced by the individual and directed at relieving symptoms, maintaining health, or preventing ill-health (MacKichan et al., 2011), whilst self-management has been described as putting patients in direct control of managing their conditions (Crepaz-Keay, 2010; Dorflinger et al., 2013), and refers to the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition (Barlow et al., 2002). As there is a marked degree of overlap between the terms self-care and self-management, a

review of the literature in this area has considered research that used either/or both of these terms to describe how an individual may cope with symptoms of distress.

In the UK, public health campaigns have increasingly focused on developing responsibility for health care to the individual through the development of the “expert patient”, empowered by the state to self-manage (Reeves et al., 2008; Broom et al., 2012; Raffaetà & Nichter, 2015). This emphasis on self-care has been partly driven by the costs of providing healthcare: over the course of the past fifty years, public spending on the NHS has risen from 3.4% of GDP to 8.2% of GDP – equivalent to a seven-fold increase in real terms (Appleby, 2013). This coincides with a time of recession where the NHS itself is experiencing budget pressures (National Health Service England, 2014) which has resulted in funding cuts of over 8% for NHS mental health services from 2010 to 2015, despite a rise in demand for these services (Community Care, 2015). However, whilst self-care is seen as important, those self-care practices adopted by people with less well-defined health problems (such as distress) are little understood (MacKichan et al., 2011). What is known is that patients have consistently demonstrated a desire to play an active role in the healthcare decision making process (Brown et al., 2002), and that health care providers can play an important role by not only providing information, but also enhancing motivation for patients to engage in self-management techniques (Dorflinger et al., 2013).

### **2.3.1 Individual Self-Care**

Lazarus and Folkman’s (1984) cognitive theory of psychological stress and coping (introduced in section 2.2.2) was described as transactional as “the person and the environment are viewed as being in a dynamic, mutually reciprocal, bidirectional relationship” (Folkman et al., 1986). The theory proposed that when faced with a stressor, an individual initiates a primary appraisal, where the potential threat is assessed in order to decide if it is of significance/potential harm to the individual. If it is decided that the stressor is of significance, the theory postulated that the

individual would then undertake a secondary appraisal in order to decide what actions were available to them (Folkman, 1984). One option involves the utilisation of the individual's personal (self-care) resources, but requires sufficient motivation for the act of self-care to actually take place. In 1985, Deci & Ryan proposed a self-determination theory (SDT) in which they distinguished between different types of motivation (Ryan & Deci, 2000). Basic Needs Theory (BNT) is a sub-theory of SDT (Adie et al., 2008; Vansteenkiste et al., 2010), which contends that humans function and develop effectively as a consequence of the social environment and its potential to satisfy basic psychological needs (Lovell et al., 2015). BNT proposes that people have basic innate needs across three areas: autonomy; competence, or mastery; and relatedness, or connectedness with others (Adie et al., 2008; Bernard et al., 2014; Lovell et al., 2015). It has been argued that meeting these needs is essential to achieve well-being, with the emphasis on autonomy fitting with an individual self-care approach (Garn et al., 2012).

What patients do to self-manage a condition can obviously vary (Marley, 2011; MacKichan et al., 2013). Whilst those who feel stressed or anxious (along with those dealing with back pain) are more likely to use self-care practices than those reporting other problems (MacKichan et al., 2011), it has been suggested that distress associated with chronic health problems can make self-care more difficult due to feelings of apathy, hopelessness and fatigue (Ludman et al., 2013). Exercise, pet ownership, engaging in social activities and a high level of perceived social support have all been shown to have an effect on maintaining psychological well-being (McHugh & Lawlor, 2011; González-Herero & García-Martín, 2012; Mariti et al., 2013; Garcia et al., 2015). Spirituality – which reflects an individual's intrinsic nature to connect with the essence or meaning of life (Visser et al., 2010; Iwatani et al., 2013) – has also been shown to help increase well-being (Bennett & Shepherd, 2013). Whilst a lack of methodological rigour has been criticised, there is a body of evidence which suggests that spirituality can play a role in helping women to deal with distress (Visser et al., 2010; Kidwai et al., 2014), although this may in part be due to women who have spiritual experiences also reporting higher levels of social support (Bennett & Shepherd, 2013; Hovey et al., 2014).

Having a high level of perceived social support from friends has been strongly related to lower levels of psychological distress (Arnberg et al., 2012; Hameed et al., 2013; Horwitz et al., 2015) and general health (Holden et al., 2015). As well as facilitating social interaction, it has also been suggested that participating in mutual self-help groups can improve well-being by increasing feelings of control and resilience (Seebohm et al., 2013). Information sources for individuals wishing to utilise self-care strategies vary (Perry & Pescosolido, 2015) though social support networks, independent research, and trusted health care providers are reported to be the main sources of information (Brown et al., 2002; MacKichan et al., 2011). It is claimed that women are more likely than men to talk about things that are “bothering them” (Breslin & McKay, 2012), with their partners (Perry & Pescosolido, 2015) and mothers having an influence on their self-care decisions (Brown et al., 2002; Perry & Pescosolido, 2015). It has also been reported that women were more likely to try relaxation techniques than men, but also appear to engage in physical activity at a similar level to men (Breslin & McCay, 2012). Whilst there are a range of self-care strategies available to the individual, this research has concentrated on one specific area: women who choose to visit a herbalist.

### **2.3.2 Guided Self-Care**

Although self-care is often used at an individual level, the utilisation of different types of therapy is also evident (MacKichan et al., 2011; Arcury et al., 2012): Kabirian et al. (2011) described how patients can use “internally oriented behaviour” (which utilises their own resources) or “externally oriented behaviour” (which involves seeking assistance). Khan et al. (2007) have described a form of self-management that involves patients taking control of their healthcare, facilitated through contact with a therapist, a process described as “guided self-help”. It has been suggested that self-care is more effective when it is combined with support from a therapist (Coote & MacLeod, 2012), an example of which is psychotherapy: one of a number of talking therapies commonly used to treat emotional/mental problems such as distress (National Health Service Choices,

2015). Within these talking therapies, aside from any active treatment, one benefit for the patient is that active engagement with the therapist has the potential “to offer the patient a profound sense of being understood” and consequently a feeling of “being held” emotionally (Ginot, 2001). The suggestion that self-care is more effective when carried out in conjunction with a therapist has been supported by a recent review of self-care interventions which reported that guided self-care can have the potential to reduce the symptoms of distress, but self-care based solely on providing information to those with distress is less likely to be effective (Matcham et al., 2014). One argument for why this may be the case is that whilst guided self-care can be useful, patients can feel abandoned if they perceive that their therapist has placed the onus on the patient to take care of themselves (Kielmann et al., 2010; Broom et al., 2014). However, this perception can be ameliorated by the patient feeling they have flexible access to their healthcare professional (Kielmann et al., 2010).

Although other self-care strategies are available Broom et al. (2012) suggested that self-responsibility often required the dutiful use of assistance, whether biomedical or complementary in orientation. Whilst patient empowerment may then be shaped by the patient’s own activity, it is also acknowledged that the individual may have dependence on others (Aujoulat et al., 2012). The utilisation of the services of a therapist is not then viewed as limiting a sense of autonomy and agency (Meurk et al., 2013). Patients value the personal choice in deciding on which treatments to use, whether they be biomedical or complementary, as part of an integrative healthcare approach (Broom et al., 2012). The choice of therapies in a pluralistic medical marketplace has resulted in self-care being an on-going process, where patients constantly query the effectiveness of what they choose to do (Broom et al., 2014). It has the potential benefit of being able to help restore feelings of empowerment and autonomy, but can also run the risk that it can put added pressure on individuals by giving them the expectation that they should be able to cope with their situation (Broom et al., 2014).

Rather than choosing one type of therapy, individuals will try different therapies (Broom et al., 2014), particularly if a biomedical approach is perceived to have not

offered a solution to their problem (Staples, 2012). It is argued that health care professionals need to participate in a dialogue with women, which places an emphasis on sharing rather than simply giving information (Brown et al., 2002; Kennedy, 2003). This supports the need for health care professionals to be patient centred by acknowledging and responding to each patient's desired level of participation in the decision making process (Brown et al., 2002): an area that it is argued makes herbal medicine practice distinct from biomedical practice (Little, 2011) and can help facilitate recovery (Scrignaro, 2011). In other CAM practices, self-care talk did not demonstrate the marked asymmetry which pervades biomedical consultations. For example, Paterson et al. (2012) described acupuncture patients and practitioners initiating interactive discussions, with practitioner advice and support being individualised in terms of the patient's life world and/or the therapist's diagnosis.

In terms of its relevance to this research, what emerged from the literature was that self-care paints a complex picture, where individuals who are feeling a loss of agency due to distress have a variety of strategies available to them that may (or may not) be used at different times. Whilst individual techniques may be utilised, women may choose to seek the services of a therapist. As with OTC remedies, the practitioner may be from a biomedical paradigm (such as a doctor) or be from a CAM background (such as a herbalist). Whilst the picture is complex, CAM is known to be a self-care strategy that can be utilised for dealing with distress (Lo-Fo-Wong et al., 2012; McPherson and McGraw, 2012). The selective usage of herbal medicine is also known to be part of the distressed patient's self-care arsenal (Eichhorn et al., 2011; Arcury et al., 2012), and so the next part of the literature review has focused on whether there is any evidence to support the use of western herbal medicine (WHM) in the treatment of distress.

#### **2.4 Herbal Medicine and Distress**

Whilst CAM has been identified as having a role to play in the treatment of symptoms of distress such as anxiety, stress and depression (Smallwood, 2005;

Bystritsky et al., 2012; McPherson and McGraw, 2012), there is a growing body of evidence from clinical trials on safety and efficacy showing that herbal medicine in particular has a role to play in a number of conditions which may be associated with distress. Studies have shown that *Melissa officinalis* L. (lemon balm) can have a beneficial effect on both anxiety and sleep with no apparent side effects (Kennedy et al., 2002; Cases et al., 2011). An extract of *Ginkgo biloba* L. (maidenhair tree) has been shown to have a dose-dependent anxiolytic effect on those living with generalised anxiety disorder (GAD) with good tolerability, and no apparent adverse impact on vigilance and cognitive functioning (Woelk et al., 2007). *Passiflora incarnata* L. (passion flower) has the ability to reduce anxiety without inducing sedation or changing psychomotor function (Movafegh et al., 2008). *Matricaria recutita* L. (chamomile) has an anxiolytic effect on those living with mild to moderate GAD (Amsterdam et al., 2009) and also those with premenstrual syndrome (Sharifi et al., 2014). *Rhodiola rosea* L. (rhodiola) has undergone a number of preliminary studies which suggest that it can be useful for those living with a range of conditions associated with distress including fatigue and depression (Hung et al., 2011). *Scutellaria lateriflora* L. (skullcap), which has a tradition of use for anxiety and sleep disorders (Gao et al., 2008), has recently been shown to have the potential to reduce symptoms of anxiety and enhance mood without harmful or unpleasant side effects (Brock et al., 2014).

Research also suggests that herbal medicine can be of use for symptoms that have a known comorbidity with distress. *Eschscholzia californica* Cham. (Californian poppy) can be useful for the treatment of pain along with associated insomnia (Chamberland, 2014). *Uncaria tomentosa* (Wiild. ex Schult.) DC. (cat's claw) has been shown to have the potential to reduce fatigue and improve quality of life in cancer patients (de Paula et al., 2015). Some research has suggested that conditions such as the menopause, which can cause hot flushes, sleep disturbances, anxiety, and depression in women (Terauchi et al., 2012) can be treated safely and effectively with herbal medicine (Bommer et al., 2011; van Die, 2011). This is supported by research looking at specific herbs, an example of which is *Actaea racemosa* L. (black cohosh) which has been reported as being beneficial for

menopausal symptoms (Rostock et al., 2011; van Die, 2011; Wuttke et al., 2014). *Valeriana officinalis* L. (valerian) has also been studied as a herb which can improve the quality of sleep for both postmenopausal women (Taavoni et al., 2011) and those undergoing cancer treatment (Barton et al., 2011) but without having a tranquilising effect. Apart from *V. officinalis*, a recent review of research into herbal treatments for insomnia also found that *M. recutita* and *P. incarnata* had been reported as having promising effects (Taslaman, 2014), whilst *V. officinalis* has also been shown to help ease insomnia when taken in conjunction with herbs such as *Humulus lupulus* L. (hops) (Morin et al., 2005).

The greatest amount of research has been carried out on the effects of *Hypericum perforatum* L., (St. John's wort) in part due to its popularity for the treatment of depression (Alsanad et al., 2014; Davis et al., 2014), although it has been used in WHP to treat other conditions for over a thousand years (Watkins et al., 2011). *H. perforatum* has been demonstrated to be as effective as orthodox antidepressants for mild to moderate depression but with fewer side effects (Linde et al., 2005; Kasper et al., 2010; Russo et al., 2014) and has been shown not only to be safe over time (Singer et al., 2011), but could also work out to be more cost effective than orthodox anti-depressants (Solomon et al., 2013). In addition, research has reported that the herb may also be protective against side effects from certain types of chemotherapy (Peron et al., 2013). However, whilst the herb itself is thought to be safe, some research has urged caution when using *H. perforatum* due to the danger that it can alter the drug metabolism of pharmaceuticals (Davis et al., 2014) such as anti-cancer drugs (Alsanad et al., 2014), anti-coagulants, immunosuppressive drugs, and the oral contraceptive pill (Russo et al., 2014).

Overall, there is encouraging evidence for the use of herbal medicines in the treatment of conditions associated with distress such as depression, anxiety and insomnia (Sarris et al., 2011; Arya & Verma, 2012; Saki et al., 2014), though there has been a call for more rigorous research to back up preliminary findings (Sharma et al., 2012; Saki et al., 2014). In spite of these encouraging results, it should be noted that these studies have generally concentrated on the pharmacological actions of a single herb, and not a combination of herbs selected for an individual as

would be prescribed by herbal practitioners: a limitation which has come in for some criticism (Sarris et al., 2010; Taslaman, 2014). However, research into how herbal medicine is used by western herbal practitioners for treating menopausal symptoms showed that herbal treatment led to a reduction in symptoms, which included psychological symptoms of anxiety and depression (Green et al., 2007). What remains unclear is how herbs such as these are utilised by patients themselves, and whether the overall experience of visiting a herbalist practising WHM for the treatment of distress is positive or not.

## **2.5 Women's Experiences of Western Herbal Practice as a CAM Therapy**

Much of the research which has investigated the patient experience of CAM (for both women and men) has not concentrated on one specific modality. However, some of the features reported with regards to the patient experience of CAM have commonality with WHP, and so were considered as part of the review of literature.

### **2.5.1 Patterns of Use**

Statistically, women make more use of health services than men (Farrimond, 2011). In the UK, women are the main users of primary healthcare, with the number of consultations with NHS general practitioners being higher for women compared to men, except in the very young or very old (National Health Service Information Centre, 2009). This trend is similar for CAM use (Hunt et al., 2010; Harris et al., 2012; Meurk et al., 2013; Keshet & Simchai, 2014) with women using CAM more than men, although there is some research that shows this trend is also reversed amongst older adults (McLaughlin et al., 2012). Overall, the research suggests that whilst women utilise any form of healthcare more than men, the tendency is amplified when it comes to using CAM (Bishop & Lewith, 2010). These figures are further supported by research which shows that women are the main users of herbal medicine (Ipsos Mori, 2009; Nissen, 2015). A review of herbal medicine usage in the UK shows that estimates of average prevalence rates are variable

(27.3% - 57.8%). The range of results can partly be explained by the range of methods used (face to face interviews through to postal questionnaires), the sample size (98 through to 11,545), and whether the research targeted the general population or specific groups (such as breast cancer patients). However, even the most modest figures indicate that the usage of herbal medicine makes it a popular CAM therapy (Posadzki et al., 2013), and there is evidence to suggest that women can also take responsibility for themselves by utilising the services of a herbalist that practises WHM as a type of guided self-care (Nissen, 2013).

The literature suggests that apart from being female, CAM users are also more likely to be better educated (Wyatt & Furnham, 2010; Hunt et al., 2010; Harris et al., 2012), “middle-aged” (Sirois, 2008; Harris et al., 2012) or described as “not young” (Wyatt & Furnham, 2010), and have chronic health conditions (Hunt et al., 2010; Singer & Adams, 2014). Users of WHM are similarly reported as more likely to be better educated (Gardiner et al., 2007), of higher UK socio-economic class (Vickers et al., 2006), and middle-aged (Gardiner et al., 2007; Damery et al., 2011), although some research has stated that those from a wide range of ages are likely to use WHM (Vickers et al., 2006).

The literature also suggests that people resort to CAM either because they are dissatisfied with conventional health care (“push” factors) or because they have a natural attraction to complementary health care (“pull” factors) (Vincent & Furnham, 1996; Andrews et al., 2012; Terry et al., 2012). However, the push and pull factors have been investigated in more detail since Vincent and Furnham (1996) first proposed them. Dissatisfaction with biomedicine is still cited as a push factor in why people use CAM (Sharples et al., 2003; Richardson, 2004; Gollschewski et al., 2008) along with concerns over the use of pharmaceuticals (Sharples et al., 2003; Richardson, 2004; McCaffrey et al., 2007; Meurk et al., 2013). However, the motivations to use CAM may change over time: consumers are becoming more likely to be attracted to CAM therapies rather than dissatisfied with biomedical treatment per se (Sirois, 2008). For example, concern over the use of pharmaceuticals is often accompanied by the more positive perception that CAM therapies are more natural and/or safer (Cartwright, 2007; Hill-Sakurai et al., 2008;

Joos et al., 2012; Meurk et al., 2013). This also reflects reported views of herbal medicine, which suggests that users view herbs as being natural (Lynch & Berry, 2007; Ipsos Mori, 2009) and relatively safe (Evans, 1993; Ang-Lee et al., 2001; Vickers et al., 2006; Lynch & Berry, 2007). Whilst factors that can influence women's decision to utilise CAM services are generally referred to as "push" and "pull", this does tend to suggest a dichotomy with respects to patient choices, where some suggest the situation is in reality more nuanced.

Research has suggested that patients pick and choose which modality to use and emphasise the "value of personal choice" (Broom et al., 2012). Meurk et al. (2013) report that women's use of CAM did not constitute a rejection of biomedical practice; instead it formed part of their integrative healthcare approach, and the opportunity to participate in a shared decision making process (McCaffrey et al., 2007). In choosing which therapies to use, patients are likely to continually question whether they find any chosen treatment effective (Cartwright & Torr, 2005; Broom et al., 2014). When assessing the effectiveness of their treatment, patients may also be aware of the value of the psychological component of the therapeutic encounter (Cartwright & Torr, 2005), and take the view that empirical results are more important than scientific validation (Gollschewski et al., 2008). It has also been reported that, in the case of WHP, patients use it "simply because it works better" (Little, 2009).

### **2.5.2 The Patient Experience**

Once an individual has made the decision to consult with a CAM practitioner, a popular aspect of the encounter is reported to be the provision of a good therapeutic relationship with the practitioner (Wyatt & Furnham, 2010; Nissen et al., 2012; Ernst, 2013), which suggests that there is a healing potential residing in the interactions that occur between patient and practitioner (Conway, 2011, p.39). There are claimed to be different aspects to the success of this therapeutic relationship. First to consider are the characteristics that patients value in their practitioner: as well as being professional and knowledgeable, patients like their

practitioner to be supportive, empathetic, and caring (McCaffrey et al., 2007; Cheshire et al., 2013). These characteristics can be connected to the patient feeling like they are being actively listened to by the practitioner (Wyatt & Furnham, 2010; Nissen et al., 2012), which are sometimes linked to the ideas of continuity of care (Bishop et al., 2011) and having more time than in a typical biomedical encounter (Bishop et al., 2011; Berger et al., 2012; Nissen et al., 2012; Singer & Adams, 2014). The length of western herbal consultations has also been reported as being valued by patients, and whilst much of the consultation is taken up with talking rather than active treatment, this process is considered important by the patient (Evans, 1993; Little, 2009; Little, 2011; Nissen, 2013). Patients of CAM have reported wanting to feel like they have a connection with their practitioner (Smithson et al., 2010). Other aspects of the therapeutic relationship which are valued by patients include a personal approach with a focus on the individual (Bishop et al., 2008; Berger et al., 2012), and good provision of information from the practitioner (Brown et al., 2002; Gollschewski et al., 2008; Wyatt & Furnham, 2010). This information can include self-care advice (Luff & Thomas, 2000; Richardson, 2004) and shared explanations of health and illness (Cartwright & Torr, 2005). The provision of information, such as advice on diet and lifestyle, has also been reported as a feature of WHP (Green et al., 2007; Stewart, 2010). Wyatt & Furnham (2010) have suggested that women place “more importance on the practitioner explaining diagnoses and discussing treatments with high patient involvement”, which may be a factor in their overall greater usage of CAM compared to men.

It has been reported that users of WHP find themselves part of an evolving and complex therapeutic relationship (Green et al., 2007; Nissen, 2013). By utilising patient narratives, herbalists aim to create a collaborative partnership which can help patients explore underlying reasons for being ill and, in doing so, help foster a shared understanding of illness causation (Little, 2009; Little, 2011). Reaching a shared understanding helps to justify the NIMH claim that a herbalist is a “caring partner in health” (National Institute of Medical Herbalists, 2012). Other aspects of the patient experience of WHP that have been reported by the literature include the suggestion that the treatment process is both flexible and tailored to the

individual (Green et al., 2007; Hamblin et al., 2008; Nissen, 2011; Nissen, 2013). WHP has also been described as “patient centred” where the focus of the practitioner’s attention is on the patient rather than the disease (Nissen, 2010; Nissen, 2015), and the practitioner aims to provide three conditions that can be therapeutic in themselves: empathy, congruence, and unconditional positive regard (Rogers, 1979). Looking at areas other than the presenting complaint as part of the case history (Stewart, 2010) also helps to give WHP its holistic credentials.

Research has reported that a combination of factors from the therapeutic relationship in CAM practices has the potential to result in a sense of autonomy and empowerment for the patient (McLaughlin et al., 2012; Nissen et al., 2012; Meurk et al., 2013). This has also been reported as a feature of WHP where feeling like the individual is being heard (Nissen, 2013) can help the patient to frame (or reframe) their view of their particular situation (Nissen, 2013). It has been argued that this, in turn, can help women to question their traditional gender role, help them to feel worthy of attention and care (Nissen, 2013), and so feel empowered (Little, 2009; Joos et al., 2012). However, the idea that the experience of using CAM can be empowering for women has been critiqued in recent years. Whilst it is accepted that women can experience feelings of control when utilising the services of a CAM practitioner (Smithson et al., 2010; Brenton & Elliott, 2014), it has been argued that they still face the challenge of trying to live for themselves rather than having the perception of needing to live to serve others (Sointu, 2011). This has led to the argument that whilst women may feel personally empowered, they are seeking control within what remains a patriarchal society (Brenton & Elliott, 2014; Keshet & Simchai, 2014); that is to say that women focus on personal empowerment rather than collective action to change gender relations (Keshet & Simchai, 2014). Whilst it may be considered important to challenge gendered assumptions (LaFrance, 2009, p.187), at a pragmatic level, personal empowerment may be all that an individual is seeking.

Whilst descriptions of the patient experience sound impressive, there have been reasons cited why patients may discontinue the use of CAM – described as “the mechanism of exit” (Bishop et al., 2011). These reasons include a perception that

the particular therapy is either too “foreign” or (paradoxically) is too like biomedical treatment; or that there is a lack of anticipated patient involvement and/or independence (Nissen et al., 2012). Whilst there has not been a large amount of research which has looked at WHP (and particularly the patient experience of WHP), the research that exists suggests that WHP has a high level of patient satisfaction.

### **2.5.3 Previous Research Looking at Western Herbal Practice**

The research that has been carried out into the practice of WHM (Evans, 1993; Van Marie, 2002; Little, 2006; Nissen, 2008; Casey, 2009; Evans, 2008; Stewart, 2010) has had some limitations, but provides a base of knowledge which suggests what WHP may look like for patients.

Evans (1993) used a questionnaire to discover new patients’ expectations of treatment and how these changed over the space of four months. A total of 108 forms were received from patients who were about to visit a member of The National Institute of Medical Herbalists for the first time. A follow-up questionnaire was received from 86 patients within the timescale of the research. Whilst the research did not include any interview data to elicit patient experiences, it did help to highlight a number of useful points at a time when there was virtually no research into the usage of WHP. The perception of those going to see a herbalist was that herbal medicine was safe, whilst the practice was seen as holistic. In addition to initial views, those that completed the second questionnaire also indicated a high level of satisfaction, which included the reporting of symptom relief. However, Evans reported that overall improvements in the participants’ quality of life were associated more with overall feelings of emotional well-being rather than physical changes (Evans, 1993).

Van Marie (2002) did not look at WHP from a patient’s perspective, but did question how herbalists may approach their practice by analysing data from 87 members of two UK professional bodies, and also interviewing 36 herbalists to

ascertain their views. Whilst Van Marie argued that changes in the form of herbalist education (to university degrees in the UK) had been implemented within a scientific framework as a strategy for moving towards professionalisation, he also noted that such changes had not (at the time) radically affected professional practises. This gave an insight into WHP, but the form of the research meant that the patients' experience of WHP was not investigated.

Little (2006) identified a lack of research into the patient experiences of WHP, and so interviewed nineteen adults to investigate their stories. The research showed that those interviewed were pragmatic in their choice of therapy: they were more likely to use WHP for "everyday healthcare" rather than acute complaints. The overall experience was judged by the participants to be effective (all the participants reported positive experiences and that they would visit their herbalist for common medical complaints in the future), and reinforced their initial feelings of confidence linked to herbal medicine's long tradition of use. In addition to the effect of the herbs, participants also found the overall experience to be enhanced by a positive patient-practitioner relationship founded on shared understandings of health and illness, and empowerment. Whilst Little's research and subsequent papers helped add to the knowledge base of the patient experience of WHP (Little, 2006; Little, 2009; Little, 2011) there were some limitations. Little carried out qualitative interviews with patients over a small geographical area (only fourteen herbalists practising in the area) who had physical complaints, and excluded those living with mental illness.

In order to try and overcome these limitations, this current study recruited herbalists from a large geographical area, and sought women who were living with distress.

Nissen (2008) interviewed female patients and obtained patient narratives as part of an ethnography investigating the practice and use of WHM. She discovered that the herbalists in her study helped to support patients through listening to their stories, which was mirrored by the patient interviews which had central themes of being able to tell their story, and feelings of being listened to. These stories were

negotiated and co-constructed by the practitioners and the patients. This resulted in the patients' stories of healing not only including use of herbal medicine, but also a responsibility for self-care and the reframing of the patients' personal experiences. Nissen argued that the "partnerships of healing" positioned women as experts in knowing and caring for themselves, but also offered new resources for personal change and promoted their autonomy. Nissen also followed on from Van Marie (2002) to suggest that there was a tension between the approaches of science and holism, but the complexity and flexibility of the herbal encounter led to a plurality of practice. As with Little (2006), Nissen's work helped to add to the knowledge of women's experiences of WHP, but also had some limitations. The use of an ethnographic approach was novel, but she had a limited response to her initial practitioner survey, and so could only interview six practitioners (all women) and nine patients in depth (all described as white, middle-class, and only one who was not British). However, the relatively small numbers were offset by the methodological approach as the ethnography combined the data with participant observation in various settings. Nissen highlighted that it would be useful in the future to consider utilising longitudinal patient narratives to further explore the patient's perspective of WHP.

Casey (2009) used a mixture of quantitative and qualitative methods to interrogate practitioners in order to investigate the practice of WHM in Australia, where WHP is popular. Similar to the results of Van Marie (2002), Casey found that whilst WHP was increasingly being influenced by biomedical science, the practice of prescribing herbs retained a predominantly traditional approach – although there were a number of differing approaches to practice amongst her participants. Casey's work also supported that of Little (2006), as it found that rather than assuming a primary healthcare role, herbalists were predominantly treating chronic conditions. Like Van Marie (2002), what Casey's research did not investigate was what the experience of WHP felt like for the patients.

Like Casey (2009), Evans (2008) looked at WHP in Australia – particularly how the practice was adapting to increasing popularity in contemporary Australian society. Her research did not look at WHP from a patient's perspective, but included

interviews with sixteen herbalists that helped to further show what the herbal consultation might look like. In particular, she highlighted the complex nature of the consultation, and that there might be a variety of approaches to diagnosis. The importance of the herbalist getting the patients to “tell their story” was highlighted, which could then be analysed by the herbalist using a mixture of traditional and biomedical understanding. Getting to the root cause was seen as important by the herbalists: this holistic approach meant that there was a marked degree of individuality reported in terms of the treatment options. Differences in practise were emphasised by the herbalists’ views on “vitalism”: some herbalists were reticent to use the term as their view of illness corresponded to a more biomedical view, whilst some felt vitalism was central to their practise. Whilst the research gave an idea of what WHP might appear like to the patient, it did not investigate the actual patients’ experience.

Stewart (2010) carried out qualitative interviews, but specifically looked at the experiences of three girls (and their mothers, and herbalists) who were living with Asperger’s syndrome. As well as interviews, the research also utilised an online diary to elicit views. Whilst the numbers were relatively low, they were appropriate for the use of in-depth, hermeneutic phenomenological analysis. The overall experience of visiting a herbalist was again seen to be beneficial by the participants, but there were issues within the patients’ group over treatment compliance, and financial issues suggested that there were potential problems with regards to the access of herbal treatment as it is generally a privately funded form of healthcare. Whilst the research utilised innovative forms of data capture and analysis for WHP, the choice of participants made it less easy to relate its findings to a wider population, although the isolation of Asperger’s syndrome did have relevance for this research.

This current study has focused on female patients who were living with distress, who were consulting with herbal practitioners based in the south-east of the United Kingdom that practised in the western tradition of herbal medicine. This research project has aimed to extend the knowledge with regards to the experience of seeing a western herbalist by talking to twenty-six of the main users of herbal medicine

(women), with a common complaint that has not been investigated before (distress), consulting with both female or male herbalists, within a large geographical area (the south-east of the UK). In addition, this study has utilised patient narratives from two separate interviews within a longitudinal design.

## **2.6 Significance of this Study**

Whilst the relatively large number of patients, large geographic area, and longitudinal narrative approach are novel for studies into the patient experience of WHP, this research has aimed to make a significant contribution to knowledge in a number of other areas. In the first instance, it has explored women's experiences of distress. Despite conflicting research into gendered experiences of distress (Essau et al., 2010; Harryson et al., 2012; Kinglerlee, 2012; Springer et al., 2012), the individual remains central to how distress is experienced. A review of the literature supports the suggestion by Emslie et al. (2007) that there is an increasing body of qualitative work investigating women and distress, but much of the research into distress has ignored listening to the voices of those who actually have distress (Allan & Dixon, 2009; Nosek et al., 2010; Newton et al., 2012). As women continue to receive more treatment for distress (National Health Service Information Centre, 2007), more research is required into how women experience, narrate, and attempt to manage their distress. In particular, the review of the literature has highlighted the need for a greater understanding into women's feelings related to distress. This research has therefore utilised the patient narratives of women living with distress in order to look for further insights into this area.

The second area of investigation centres round women's experiences of WHP. Paterson & Britten (2008) report that whilst patients of therapies such as acupuncture want a holistic approach from their therapist, they claim that not much is known about how patients actually experience healthcare that is based on holistic principles. Whilst some research has investigated the users of CAM (Cartwright & Torr, 2005; Stratton & McGivern-Snofsky, 2008; Jeswani & Furnham, 2010), CAM therapies and their users are not homogenous (Low, 2001), and so the research

cannot necessarily be extrapolated to users of WHP. The paucity of research into the patient experience of the treatment process of WHP highlights that this is an area that requires more investigating (Joos et al., 2012; Nissen, 2013; Sibbritt, 2014).

Ultimately, this research has investigated whether utilising the services of a herbalist practising WHM has a role to play in women's management of distress. Despite the financial and emotional costs of distress (Chonody & Siebert, 2008; National Institute for Health and Care Excellence, 2011; Panayiotou & Karekla, 2013), the report that women commonly experience distress (National Health Service Information Centre, 2007; Essau et al., 2010), and the suggestion that herbal medicine has the potential to be of use in conditions associated with distress (Sarris et al., 2011; Arya & Verma, 2012), there is currently no research into the usage of WHP in the UK for the treatment of distress as actually experienced by distressed women. However, a pilot study by Green et al. (2007) has demonstrated that herbal medicine as practised by western herbal practitioners has the potential to be effective in reducing symptoms of the menopause, and that these symptoms include those associated with distress, such as pain, anxiety, and depression. This research is utilising patient narratives to better understand the reasons why women with distress seek the services of a herbalist practising WHM, what the experience of seeing the herbalist is like, and whether or not they feel they gain any benefits from seeing a herbalist for their distress.

## **CHAPTER 3: METHODOLOGY, METHODS AND DEMOGRAPHICS**

### **3.1 Methodology**

#### **3.1.1 Background to the Methodology**

A review of the literature in chapter 2 has shown that more research needs to be conducted into women's own experiences of distress (Allan & Dixon, 2009; Nosek et al., 2010; Newton et al., 2012); also that there is a relative lack of research into the patient experience of WHP (Joos et al., 2012; Nissen, 2013; Sibbritt, 2014), and no research looking exclusively at women's experiences of WHP for distress. The aim of this research was therefore to investigate how women who were living with distress experience their distress, and the process of consulting with a herbalist who was practising WHM. This chapter considers the methodology behind this research, the different methods available, and the methods then chosen to undertake this research, before considering sampling, recruitment and the demographics of both the herbalists and (the main participants) their patients.

#### **3.1.2 Overview of Approach**

This qualitative, longitudinal piece of research initially used a structured questionnaire (including some open questions) to investigate thirty-two purposively sampled herbalists' approaches to treating distress. These herbalists were then used as gatekeepers to provide access to twenty-six patients (described as participants for the purposes of this research), who were interviewed using in-depth, one-to-one, semi-structured interviews at two points in time: firstly when the participants initially entered the study (T1), and secondly approximately six months later (T2). This research was longitudinal in order to see if the participants' experiences of distress and WHP changed over time, but also allowed both the participants and the interviewer to reflect on the original conversations, fill in missing pieces of information, and helped provide assurances that the participant's words were accurately described (Thomas & Magilvy, 2011). The interviews aimed

to obtain participant narratives concerning experiences of distress, experiences of visiting a herbalist, and whether the participants felt that visiting a herbalist could help women living with distress. The qualitative data from the participant interviews has been analysed thematically (discussed further in section 3.3.1).

### **3.1.3 Theoretical Position**

Rigour needs to be addressed throughout the research process in order to build trust that the research is credible (Bradbury-Jones, 2007; Thomas & Magilvy, 2011). The first task to increase the credibility of any research is to consider its coherence, which describes the “fit” between the research question, the philosophical perspective and the methods adopted (Yardley, 2000). Qualitative researchers have a responsibility to make their theoretical position clear in order that they may carry out their research in an appropriate manner (Madill et al., 2000), but also to allow readers to understand how the research questions were explored (Tong et al., 2007; Petty et al., 2012a).

Ontology is traditionally understood as the study of what it is to be, or exist (Lawson, 2004) so that “ontological positions specify the relationship between the world and our human interpretations and practices” (Braun & Clarke, 2013, p.27). Realism is the view that there is an objective order of reality which can be known by the human observer, whilst relativism is the view that everyone’s experience represents equally valid ways of making sense of the world (Seller, 1988). Realism and relativism therefore represent two polarised ontological perspectives on a continuum between objective reality at one end and multiple realities on the other (Andrews, 2012). Following on from ontology, epistemology is a branch of philosophy which looks at the nature of knowledge, the different kinds of knowledge that are possible and their limits (Pool & Geissler, 2005, p.163). The central concern of epistemology is what then counts as legitimate knowledge (Braun & Clarke, 2013, p.28), with the two poles being represented by positivism (which aligns with a realist view of reality) and constructionism (which aligns with a relativist view of reality). What is important when considering carrying out any type

of research is that the research method is appropriate for the theoretical position (Braun & Clarke, 2013, p.31): Brooks et al. (2015) argue that researchers using any form of analysis should be upfront about their epistemological approach in order to show that the methods match the theoretical assumptions. The approach used for this research is outlined below.

Positivism has emerged as being grounded in empirical observations in order to view an objective reality (Tebes, 2005; Petty et al., 2012a). This objective view has been used by the biomedical model to assume that diseases are universal and invariant to time or place (Conrad & Barker, 2010). Conversely, constructionism has been adopted by different disciplines and with different approaches (Brickell, 2006), but stems from the view that truth, knowledge and reality are actively created, and emphasises the cultural and historical aspects of phenomena (Yardley, 2000; Conrad & Barker, 2010). What various types of constructionism do share is a rejection of a strictly positivist conception of illness as the mere embodiment of disease (Conrad & Barker, 2010). However, constructionism has itself been criticised as being unable to deal with the “real” world (Brickell, 2006). For example, Ussher & Perz (2013) argue that feminist constructionism has positioned pre-menstrual syndrome as a normal part of women’s experience, but that this can deny the reality of suffering for some women.

Due to criticisms of both a purely positivist or constructionist stance, some research adopts a position that falls between the two. Various terms have been used to describe this position, including contextual constructionism (Andrews, 2012), contextualism (Braun & Clarke, 2013, p.30), and critical realism (Ussher & Perz, 2013). Whilst theoretical approaches can differ, they all accept that knowledge will be true in some contexts (Braun & Clarke, 2013, p.31). However, whilst they acknowledge the existence of an independent reality, such as the materiality of the body (Ussher & Perz, 2013), they deny that there can be direct access to that reality through research (Andrews, 2012). Knowledge emerges from various contexts (Braun & Clarke, 2013, p.31) that are then represented from the perspective of the researcher (Andrews, 2012) and so are “co-constructed” (Petty et al., 2012a), which mirrors what Smith (2011) described as a “double hermeneutic” whereby the

researcher tries to make sense of the participant, who is trying to make sense of what has happened to them (Smith & Osborn, 2014).

Broadly speaking, the theoretical approach chosen to underpin this research was constructionism, as it was accepted that there were multiple realities available to the participants that could have then been related to others through their narratives. However, whilst there were multiple realities evident, the researcher for this study was also aware of the criticism by Cosgrove (2000) that constructionism's denial of a single reality had the potential to negate women's agency and so their ability to resist gendered constructions of distress. Although events may be reported differently to a different audience at a different time, this does not make them any less "true" (Greenhalgh & Hurwitz, 1999). The researcher chose to accept the interviewee's stories as being valid, but also utilised the idea of Smith's double hermeneutic – the reporting and interpretation of their stories may have been one of many possibilities, but that did not make the story invalid, or affect the ability of the interviewee to have control over their own life. However, it did highlight the importance that any interpretation from the researcher remained grounded in the data.

#### **3.1.4 Methods of Analysis Considered**

Following on from the theoretical position, one of the foremost questions when conducting any type of research is what form of analysis to use (Shukla et al., 2014). The data from the interviews was interpreted thematically: thematic analysis (TA) is a method for analysing patterns within a set of data (Braun & Clarke, 2013, p.178) and is discussed further in section 3.3.1. However, before selecting to use TA, other analytical methods were considered. TA was chosen over the use of grounded theory (GT), as TA uses prior theory to help look for novel theoretical insights from the data, but this is generally eschewed in the early stages of GT (Riessman, 2008, p.74). TA also attempts to keep the "story" intact for interpretive purposes, whereas GT thematically codes segments (Riessman, 2008, p.74). TA was chosen over Interpretative Phenomenological Analysis (IPA), as TA has a more flexible

approach (Braun & Clarke, 2012b), which can be used to focus on what a phenomenon, event or social interaction looks like to the individuals of interest (their lived experience) across the dataset. IPA also enquires about what things feel like for participants, but tends to work with smaller numbers of participants (Rivas, 2012; Smith & Osborn, 2014), which may not have been able to capture the variety of stories of distress that were sought for the current research within a reasonable timescale (Close, 2013).

Once it was decided to use TA, it was then necessary to consider which type of TA to employ, as there are various approaches to choose from (Braun & Clarke, 2012a). For the basis of this research, the analysis adopted an inductive approach. That is to say that (in line with the theoretical position of the researcher) an inductive approach to analysis was utilised as it involves detailed readings to derive themes from the data through interpretations by the researcher (Braun & Clarke, 2013; Thomas, 2006). For this research, the aim was to try and ensure that any analysis was firmly rooted within the participants' narratives.

## **3.2 Data Collection**

### **3.2.1 Methods of Data Collection Considered**

"Research is about knowing, understanding and exploring the world... there is no one privileged way to do this" (Walsh, 2011). Bearing Walsh's assertion in mind, different methods of data collection were considered as a way of obtaining the participants' narratives for this research. There has been much debate with regards to the differences and appropriateness of qualitative versus quantitative research. Some have argued that the two approaches do not necessarily create a dichotomy: quantitative research can make qualitative judgements, and qualitative research can use quantification (Walsh, 2011). Whilst there can be some overlap in approaches, a review of the two approaches showed some distinctions that helped to choose which to use for this particular study. Quantitative approaches often start with a hypothesis, which can then be tested using accepted statistical

measures (Britten, 2011; Silverman, 2011, p.4), measure the effectiveness of an intervention (Britten, 2011) and lead to generalisation for a wider population (Mason, 2010; Bölte, 2014) where inferences are made about the unobserved based on what has been observed (Polit & Beck, 2010). However, whilst quantitative data can be used to ask questions about “how many” or “how much” (Green & Thorogood, 2014, p.5), qualitative research can ask questions regarding the “what”, “how” or “why” of a phenomenon (Green & Thorogood, 2014, p.5) lead to deeper, contextualised understanding of the human experience (Polit & Beck, 2010; Petty et al., 2012a; Bölte, 2014), and so better suited the aims of this research. Zick et al. (2009) have also highlighted the usefulness of qualitative methods as a way of obtaining patient experiences of herbal practice’s complex interventions.

Once it was confirmed that a qualitative approach would best suit the research question, the focus then shifted to what particular qualitative methods would best gather the required narratives. Focus groups were initially considered for the data collection, as it is argued that focus groups can give more control to the participants (Wilkinson, 2004; Webb & Doman, 2008), and initiate interaction among participants to give insights that would otherwise remain hidden (Ho, 2006). However, due to the nature of the research topic, focus groups were rejected as it was considered that some participants might have felt more able to disclose personal details in a one-to-one situation (DiCicco-Bloom & Crabtree, 2006; Webb & Doman, 2008), whilst focus groups would also have run the risk of being dominated by certain participants at the expense of other’s views (Ho, 2006; Petty et al., 2012b). In fact, some of the narratives did involve the disclosure of distressing events (such as bereavement, abortion, racism, and abuse), which may have been withheld within a focus group, or if disclosed, the forum may not have allowed sufficient support to be given to the individual.

The decision to then use in-depth, one-to-one, semi-structured interviews was made for a number of reasons. Firstly, individual in-depth interviews are widely used in healthcare (DiCicco-Bloom & Crabtree, 2006) as they can explore the complex experiences of participants and the meanings they attribute to them (Tong

et al., 2007; Rabionet, 2011; Petty et al., 2012b), and are an excellent way of eliciting personal narratives. Semi-structured interviews were chosen over a more structured design as the probable variety of participants and their stories precluded the use of a standardised interview schedule due to its lack of flexibility (Barriball & While, 1994). Conversely, an unstructured interview was also precluded as this research needed to cover specified topics (Cohen & Crabtree, 2006). Compared to an unstructured interview, the use of a semi-structured interview allowed some standardisation of questions through the use of a topic guide, which facilitated comparability amongst the participants (Barriball & While, 1994; Cohen & Crabtree, 2006). In addition, the topic guide was prepared beforehand (Cohen & Crabtree, 2006), which allowed the interviewer the opportunity (if required) to focus on specific areas of interest (Rabionet, 2011). This ability to focus was useful as it allowed for “probing” which could be utilised to clarify relevant points, explore sensitive issues, elicit valuable information, explore apparent inconsistencies within the narrative, and help stimulate participants’ recall of events (Barriball & While, 1994). In addition, the flexibility of the semi-structured interview allowed the interviewer to tailor questions to the comments of the interviewee and so investigate emerging themes that may not have been anticipated (Banister et al., 1994, p.51; DiCicco-Bloom & Crabtree, 2006; Tong et al., 2007). Over the course of this research, the iterative nature of the process allowed the topic guide to be amended as new themes emerged from the participants’ narratives (DiCicco-Bloom & Crabtree, 2006; Petty et al., 2012b). It was these narratives that ultimately provided the data for this research.

### **3.2.2 The Use of Narratives**

The concept of narrative is used in different ways in different academic disciplines (Ridge, 2009, p.28). In the disciplines of psychology and sociology, narratives are extended accounts of lives in context that develop over the course of single or multiple interviews (Riessman & Quinney, 2005). On a basic level, narratives have been described as “storytelling” (Frank, 2010), but McLean et al. (2007) go further

to describe them as “situated stories” in order to emphasise the fact that “any narrative account of personal memory is created within a specific situation, by particular individuals, for particular audiences, and to fulfil particular goals” (McLean et al., 2007). These stories are then also influenced by social and cultural conventions by which individuals organise, interpret and represent their past experiences (Pasupathi et al., 2009; Sales et al., 2013). Narratives have multiple and shifting perspectives because personal narratives are just that; they have their origins in the experience of a particular person and they represent the perspective and interpretation of that person (Skultans, 2000). Narratives can therefore never represent the world as it is, but only as it is experienced (Skultans, 2000), but they are important if we consider individuals to be the only valid tellers of their own lives. Indeed, Holma & Aaltonen (1997) argue that life is simply a biological phenomenon before it has been interpreted through narrative. Narratives therefore fit with the constructionist stance of this research that has used the participant’s stories in order to explore their personal experience of distress and WHP. Narratives are also interwoven with time (Murray, 1999) and have a finite and longitudinal time sequence (Greenhalgh & Hurwitz, 1999). This research involved two interviews with each participant, approximately six months apart, in order to investigate whether the women’s narratives changed over time, as well as to help increase the rigour of the study (rigour is discussed further in section 3.3.2).

Narratives are also useful within the context of research, as they are used by researchers as a way of understanding participants’ experience in health (Granek, 2006; van der Riet et al., 2012), and their understanding (and response to) socially and culturally accepted norms (Shukla et al., 2014). Due to its fluid nature, the narrative does not claim to be the illness itself, but can become the experience of the illness (Frank, 1995, p.22). Narratives were therefore used for this study because it was the patient’s unique experience of illness and treatment which was being sought (Lewis, 2011), particularly in relation to how the women experienced their distress, how they experienced WHP, and how they felt their distress would be affected (if at all) by WHP.

### **3.2.3 Sampling and Recruitment**

The first step of actually collecting the data was to consider what sampling strategy to use. A purposive sampling design was used as it explicitly selects participants who share particular characteristics relevant to the study (such as women living with distress who are consulting with a herbalist), and who are likely to generate appropriate and useful data (Tong et al., 2007; Petty et al., 2012b; Green & Thorogood, 2014, p.121). This study initially involved making contact with thirty-two herbalists practising WHM within a ninety mile radius (Free Map Tools, 2014) from Charing Cross, which is traditionally used to measure distances from the centre of London (British Broadcasting Corporation, 2008). The herbalists were mainly recruited from membership of the two biggest UK professional bodies, The National Institute of Medical Herbalists (NIMH) and/or The College of Practitioners of Phytotherapy (CPP). In addition, one was a member of a separate professional organisation, and one was technically not a member of a professional body as they had not (at the time of inclusion to this research) renewed their membership. However, all the herbalists recruited were eligible for inclusion onto a register of herbalists for the proposed statutory regulation of the profession (Pittilo et al., 2008) – although whether the UK government will proceed with statutory regulation has recently been thrown into doubt (Walker, 2015).

Once it had been decided to use a purposive sampling design, this research specifically utilised maximum variation sampling (Abrams, 2010), which aimed to include the widest practical range of herbalist socio-demographic background, and experience of practise (Marshall, 1996). Because the participants were recruited via the herbalists, it was hoped to also achieve a similar level of variation amongst their patients. As the recruitment of herbalists progressed, it was noticed that whilst there was variety in the background of the herbalists, the majority described themselves as white British. The sampling then attempted to recruit herbalists from a wider ethnic background (more information on the demographics of the herbalists can be found in section 3.5.1). An information sheet was sent to prospective herbalists, a copy of which can be found in Appendix 1. Once they had been given time (at least twenty-four hours) to read the information sheet, the herbalists were

contacted by the researcher and given the opportunity to ask any questions they may have had about the study. If the herbalist was prepared to be part of this research, a meeting was arranged with the researcher at a time and place to suit the herbalist. The initial meeting with the herbalists involved officially obtaining consent, and then utilised a short (approximately 15 minute) survey which included some open questions in order to establish their demographics, some details about their type of practice (part-time or full-time; sole practice or part of a clinic; length of practice), and how the herbalist viewed their practise of WHM with particular reference to distress – a copy of the survey can be found in Appendix 2. Whilst not the main aim of the study, it was intended that the data from the survey would help to put the patient experience into context, and help provide information on the herbalist's approach to treating women with distress, as well as add to the knowledge base of what WHP looks like. It was intended to recruit both male and female herbalists, those that worked part-time or full-time, on their own or in a clinic, with a wide range of experiences (in terms of years in practise), and who practised in a variety of socioeconomic geographic locations. The results from the survey can be found in section 3.5.1.

The recruited herbalists acted as a link between the researcher and the participants. Acting as gatekeepers, the herbalists gave eligible patients a verbal outline of the research project. Due to the research question any male patients were excluded at this stage, along with anyone less than 18 years of age in order to minimise potential safeguarding issues. Those patients that showed an interest in participating were then given a participation information sheet by their herbalist, a copy of which can be found in Appendix 3. The patients were encouraged to read the information sheet, which included the researcher's contact details in order for them to have the opportunity to ask any questions they may have had about the study. The researcher was not given any details of patients that had received information sheets. This was to ensure that the patients could not be contacted directly by the researcher without first agreeing in principle to participate, and chose to take part in the study without any coercion. Once contact with the researcher was made and it had been established why the patient was consulting

with a herbalist, they were then invited to attend an interview, provided that they were willing to take part and they met the inclusion criteria. The inclusion criteria for the interview stage was any female patient aged 18 or over, who contacted the herbalist due to conditions associated with emotional distress (defined by participants, but including issues such as stress, anxiety, depression, or insomnia), or with a condition that has known comorbidity with distress such as pain (Edwards et al., 2006) or chronic ill health (Okoro et al., 2014). Ultimately, the aim was to purposively recruit a maximum variation sample of 25-30 women, directly via the herbalists, that had some homogeneity (women with a history of distress), but also reflected a wide socio-demographic mix. A demographic breakdown of the participants recruited can be found in section 3.5.2.

#### **3.2.4 Data Collection Process**

It is considered important to outline the context in which research interviews take place (Tong et al., 2007). The herbalists were surveyed once, whilst their patients were interviewed at two points in time (T1 & T2) approximately six months apart. In all cases only the interviewer and interviewee were present, apart from one participant who had her young son with her. However, some interviews took place when pets were also present in the room. As Mao et al. (2014) have suggested that issues with travel and other demands on an individual's time can be a barrier to research participation the interviews were conducted at a time and place to suit the interviewee. It was also envisaged that the participant being in control of when and where the interview occurred would place them more at ease. Interviews were conducted in a variety of locations: of the T1 interviews, twelve were conducted at the participant's home, ten at a University of Westminster campus, three at their herbalist's clinic, and one in a public place. Of the T2 interviews, fourteen were conducted at the participant's home, eleven at a University of Westminster campus, and one via Skype. The patient interviews varied in time between 39 minutes (T2) and 2 hours and 25 minutes (T1). The average time of a T1 interview was 1 hour and 22 minutes, and the average time of a T2 interview was 1 hour and 10 minutes.

The shorter duration of the T2 interviews was due to their nature: the T2 interviews were partly used as a way of clarifying and further exploring themes raised during the T1 interviews. However, the durations are not markedly different as some T2 interviews also resulted in deeper narratives emerging as the participants had already met the researcher, knew what was to be expected, and so often seemed more at ease. As well as being used to help clarify and explore themes raised in the T1 interviews, the T2 interviews also gave the opportunity to explore whether the participants' experiences of using WHP for their distress changed over time. In total, the participant interviews that provided the data on women's experiences of distress and WHP for this research comprised of just under sixty-six hours of interview time, and equated to 593,863 words. Expenses of £20.00 were offered to cover costs such as travel or childcare that were incurred as a result of taking part in the interview. The remuneration was set at a level to avoid it acting as an incentive to take part in this research, but acknowledged the value of the participants' time.

In line with best practise, the herbalist surveys and participant interviews started with an introduction about the process (Baumbusch, 2010) including a reiteration of the nature of the study, what was expected of the participant, assurances of confidentiality (all herbalists have been allocated a code in order to anonymise any quotes from the herbalists' surveys; all participants have been given an alias) which included the option to withdraw at any stage, a reminder of the use and scope of results, and confirmation of the participant's consent (DiCicco-Bloom & Crabtree, 2006; Rabionet, 2011). In addition, all participants (including the herbalists) were given a list of various free/low cost support groups and helplines before the interview commenced, in case the discussion of distressing events caused upset to the individual (a copy of the list can be found in Appendix 4). This process was important in order to help reduce the risk of unanticipated distress to the participants (DiCicco-Bloom & Crabtree, 2006).

In order to elicit a narrative, it is considered advisable to start with a broad and open-ended question, which reflects the nature of the research (DiCicco-Bloom & Crabtree, 2006). Open questions were used as much as possible during the interviews in order to give the participant space to tell their story. The participant

was encouraged to start her narrative at the beginning of her story of distress (whether it was a recent occurrence, or linked to events further back in time). The interviews therefore began with the open question: "Going back to when you first noticed something wasn't right, can you tell me your story of seeing the herbalist?" It was hoped that the question would give the participant the opportunity to begin their narrative at any point in their life history, and to include any aspects of their life that they felt were relevant. In order to ensure that the different areas from the research question were covered, the topic guide included questions concerning the experiences of distress, seeking help, visiting the herbalist, taking herbs, and hopes for the future. A copy of the T1 interview topic guide can be found in Appendix 5. The T2 interview topic guide was developed as themes emerged from the participants' narratives, but varied between participants as specific questions were included which could clarify and further explore responses from an individual's T1 interview. In spite of the variation, an outline T2 interview topic guide can be found in Appendix 6. Again in line with best practise, at the end of the interview the interviewee was thanked for their time and reminded of what would happen next in the research process (Baumbusch, 2010).

To help with accuracy (Cohen & Crabtree, 2006; Tong et al., 2007; Rabionet, 2011), the interviews were audio recorded with a digital voice recorder for later transcription, either by the researcher or by a professional transcriber, so that verbatim excerpts could be used to find meaning from the narratives through a process of organising and describing rich data (Braun & Clarke, 2006). The transcripts were "cleaned", with any possible identifying data removed or altered to protect identities. Due to the challenge of capturing the spoken word in text form (DiCicco-Bloom & Crabtree, 2006) the cleaned transcripts were then sent to the participants for approval, to amend any section that they did not agree with or felt needed clarification, or to add additional information. In addition to aiding accuracy, the process also reiterated to the participants the control that they had in ensuring that they were satisfied with their own personal narrative. This proved useful as one participant contacted the researcher after receiving her cleaned T2 transcript in order to add some points that she felt did not fully come across in the

interview. These points helped to elaborate her story, and became an important part of the research data (utilised in section 7.3.5). It was also useful when one participant indicated that she would like to withdraw her data (outlined below).

A question which was considered before undertaking the interviews was whether it would be suitable for the main researcher, who is a man, to be someone that interviewed women about their stories of distress. Whilst it may be appropriate for feminist research to be carried out by men (Banister et al., 1994, p.122), few studies have dealt with cross-gender methodologies, particularly men interviewing women (Berliner & Falen, 2008). Whilst the recruitment method meant that the participants self-selected to take part in the study (as outlined in section 3.2.3), in order to help overcome any potential issues, the interviewer was trained in interview techniques in order to remain sensitive to the interviewees' needs and interests (a copy of the researcher's training log can be found in Appendix 7). However, despite the safeguards that were put in place to help ensure the well-being of the participants (in terms of ensuring that the women understood the research process, and the interviewer remained sensitive to their needs) one participant (in addition to the twenty-six presented here) asked to have her data withdrawn from the research process after her T1 interview. When she received her cleaned transcript, she contacted the researcher to voice her concern that the narrative had "revealed too much" about herself. Despite clarifying how her data would be anonymised and amending passages that she had voiced concerns over, the participant indicated that she would like to withdraw from the process. In line with the assurances made in the participation information sheet, the participant was informed that her decision did not present a problem, and all data including the interview recording, transcript, field notes, and any initial analysis were removed from the process and physically destroyed/electronically deleted. Reflecting back on the incident, the researcher and his Director of Studies considered that whilst it was disappointing to lose the data, it reiterated the need to continually safeguard the participants' well-being, and also reinforced the importance of integrity throughout the research process. Of the twenty-six women that were happy for

their T1 data to be included in this research, all twenty-six also completed their T2 interview and allowed the resultant data to also be included.

### **3.3 Analysis**

#### **3.3.1 Thematic Analysis**

TA was originally described as a process rather than a method (Boyatzis, 1998, p.4), but was clearly defined as a distinct method by Braun & Clarke in 2006 (Braun & Clarke, 2013, p.178), and is now described as a way of identifying and analysing patterns of meaning in a data set (Attride-Stirling, 2001; Braun & Clarke, 2006; Alhojailan, 2012). Whilst Braun & Clarke originally wrote about TA in relation to psychology, they have argued that it is a general method of analysis that can be applied to a number of different disciplines, including the health and social sciences (Braun & Clarke, 2006; Braun & Clarke, 2012a). However, whilst “just a method”, one of the strengths of TA is its flexibility (Braun & Clarke, 2013, p.178), which makes it a useful method for early career researchers (Riessman, 2008, p.73; Braun & Clarke, 2006; Braun & Clarke, 2012b). The flexibility means it can be used to identify themes at a superficial level, but also move to analysing at a deeper level (Boyatzis, 1998, p.4; Braun & Clarke, 2013, p.178), and can manage themes produced by many participants (Bishop et al., 2011). Crucially, TA can locate data within the wider social context, but is also flexible enough to make sense out of seemingly unrelated material, and to capture contradictions and complexities within the data (Boyatzis, 1998, p.4; Braun & Clarke, 2013, p.180). This ability to capture the complexity of narrative accounts means that TA lends itself to a constructionist approach (Shukla et al., 2014). In addition, TA was utilised for this research as it is widely used to analyse verbal interviews (Joffe, 2011; Clarke & Braun, 2013) in areas such as healthcare where it has the ability to identify, report, and analyse data reported by participants (Floersch et al., 2010; Joffe, 2011; Vaismoradi et al., 2013), such as patients’ subjective experiences of different therapies (Joffe, 2011).

Whilst some claim that there is no clear agreement about what TA is and how to go about doing it (Buetow, 2010; Vaismoradi et al., 2013), and whilst there are few guides on how to carry out TA (Joffe, 2011; Vaismoradi et al., 2013), there is now some consensus amongst the literature of what a thematic analysis should look like, helped in no small part by the contributions of Braun & Clarke (2006; 2013). However, there are different ways in which TA can be approached (Braun & Clarke, 2012b; Brooks et al., 2015), which necessitates some transparency on the part of the researcher. The process of data analysis for this research (taken from Aronson, 1994; Boyatzis, 1998; Braun & Clarke, 2006; Fereday & Muir-Cochrane, 2006; Floersch et al., 2010; Joffe, 2011; Alhojailan, 2012; Braun & Clarke, 2012a; Braun & Clarke, 2012b; Petty et al., 2012b; Rivas, 2012; Braun & Clarke, 2013; Vaismoradi et al., 2013) was:

- Utilisation of an inductive/constructionist approach, where coding and theme development were directed by the content of the data, to explore how the participants perceived their experiences.
- Immersion in the data by transcription, and then repeatedly listening to and reading of the transcripts.
- Utilisation of a process of “memoing” (Graneek, 2006); making notes of the researcher’s thoughts, observations, and reflections of the transcripts, highlighting items of potential interest.
- Utilisation of a coding process to name, extract, and list emerging themes with the aid of NVivo 10 analysis software.
- Utilisation of a process of “constant comparison” (Floersch et al., 2010) to combine codes, and so develop themes from across the entire data set.
- Utilisation of an iterative (Petty et al., 2012b), “zigzag approach” (Rivas, 2012) of simultaneous data collection and analysis in order that emerging themes could lead to a possible revision of interview questions throughout the process.

- Repetition of the process for new transcripts, using themes from the interviews to create a consolidated list, until a point of where a “saturation of themes” (Tong et al., 2007; Mason, 2010; Rivas, 2012) was reached. This was the point where no new codes emerged, and the participants’ narratives added to the existing themes, but no new themes emerged.

Whilst the utilisation of a “zigzag approach” may sound random, upon reflection the process felt more like a spiral, as the researcher continually covered the same ground (moving from the transcripts, to the codes, to emerging themes and back again); but with each pass would obtain a deeper understanding of the data, which ultimately led to the outcomes presented in chapter 6, and the themes presented in chapter 7.

### **3.3.2 Rigour**

Discussions of the quality of social and cultural research often begin with the ideas of validity and reliability, which derive from the scientific (positivist) tradition (Prion & Adamson, 2013). Validity refers to whether the reported results are true (Seale, 2012), whilst reliability refers to the possibility of generating the same results when the same measures are administered by different researchers to a different participant group (Yardley, 2008). However, the scientific discussion of validity and reliability makes assumptions that sit uncomfortably with many conceptions of qualitative social and cultural research (Seale, 2012) because of the assumption that the research can and should be objective (Braun & Clarke, 2013, p.279), when it is acknowledged that qualitative research by its very nature is subjective (Boyatzis, 1998, p.15). In addition, from a constructionist perspective, the purpose of the research is to offer just one of many possible interpretations of a phenomenon (Yardley, 2000): in this instance, an interpretative account of the participants’ experiences gained by analysing exchanges between the researcher and the participants (Harvey, 2014). However, if reliability is thought of more broadly as being about the trustworthiness (or rigour) of the methods of data collection and analysis, then some version of reliability is applicable (Thomas & Magilvy, 2011;

Braun & Clarke, 2013, p.279). Similarly, validity corresponds to the degree to which research is accepted as sound, legitimate and authoritative by people with an interest in research findings (Yardley, 2008).

Credibility is the term sometimes used in place of validity as it refers to the fit between the experiences of the respondents and the researcher's representation of them (Bradbury-Jones, 2007; Thomas & Magilvy, 2011; Prion & Adamson, 2013). Whilst qualitative research does not necessarily seek the generalisation for a wider population that typifies much quantitative research (Mason, 2010; Bölte, 2014), generalisation of concepts can occur when researchers provide "detailed descriptions that allow readers to make inferences about extrapolating the findings to other settings" (Polit & Beck, 2010) – a process known as "transferability" (Polit & Beck, 2010; Petty et al., 2012b). What is therefore accepted amongst qualitative researchers is that some way of evaluating the quality of research employing qualitative methods is necessary (Yardley, 2000).

This research also needed to ensure that the process was "transparent", achieved by detailing the process of data collection and analysis (Yardley, 2000; Tong et al., 2007; Rivas, 2012) as outlined previously, and in this section. Credibility was also increased by the use of triangulation, which traditionally refers to a process whereby two or more methods of data collection or sources of data are used to examine the same phenomenon, and is underpinned by an assumption that seeking to depict "the truth" of participants' experiences is worthwhile (Braun & Clarke, 2013, p.285). Whilst the theoretical approach of this research did not accept that there was one truth to discover, it was still considered desirable to employ triangulation of data in order to increase credibility (Yardley, 2000).

There were four separate approaches used within this research process in order to increase credibility. The first approach was a process of triangulation that involved allowing the participants to "check" their transcripts. The primary goal of interpretation is not the passive repetition of what the interviewee says; the researcher's task is to offer a telling at some different level of discourse (Josselson, 2011). However, it is important that themes emerge from the data, and that

developing a conceptual analysis of participants' stories still create a sense of their presence in the final text (Braun & Clarke, 2006). To try and overcome potential misinterpretation by the researcher, and so help triangulate the data, the participants were given transcripts of the interviews to read (as in Emslie et al., 2007) in order to confirm their accuracy and so add to the validity of the process (Fox & Ward, 2008).

Whilst semi-structured interviews are commonly only conducted once for an individual participant (DiCicco-Bloom & Crabtree, 2006), the second approach to increase credibility for this research was the use of a longitudinal design. Longitudinal research has the advantage that it can highlight changes in attitudes, behaviours and relationships within a population (Stidham et al., 2014) – particularly in a “total population design” (Bauer, 2004) as the relatively short timescale can allow the majority of the group (in this instance, all of the group) to be re-interviewed. As well as seeing if the experiences of WHP changed over time, the longitudinal design also allowed both the participant and the interviewer to reflect on the original conversation, could be used to fill in missing pieces of information, helped to provide assurances to the participants that their words were accurately described, and so helped with the rapport (and openness) between the researcher and the participant (Tong et al., 2007; Thomas & Magilvy, 2011), which ultimately led to better data being elicited.

The third approach to increase credibility involved the use of reflexivity. “Reflexivity” is the term used for explicit consideration of specific ways in which it is likely that the study may be influenced by the researcher (Yardley, 2008). It is widely acknowledged that the researcher has an effect on the research and vice versa (Cutcliffe, 2003). As Fischer (2009) put it, it is not possible to view without viewing from somewhere. As the role of an interviewer can affect the interview process (DiCicco-Bloom & Crabtree, 2006), and analysis of qualitative material is necessarily influenced by the researcher's perspectives (Attride-Stirling, 2001; Yardley, 2008; Joffe, 2011), reflexivity is often an important part of the transparency of the study. Specifically, it should be noted that the researcher already had a BSc (Hons) degree in herbal medicine, and had previously carried out fieldwork looking

at perceptions and usage of WHM at an NHS general practitioner (GP) surgery as part of an MSc in medical anthropology. Whilst this background allowed the researcher some insights into the area being studied, it was necessary to remain aware of how this background could influence the interpretation of the research. The researcher was aware that his background as a herbalist could mean that he would already have a pre-conceived idea as to what constituted WHP and the therapeutic encounter. In addition, his previous research also had the potential to give the researcher ideas about what the current participants would say, which would lead to certain parts of the narrative being given prominence over other areas that were unexpected. To help overcome this, the researcher kept a reflexive diary in order to help reflect back on the interview process (Tong et al., 2007), to record details of the nature and origin of any emergent interpretations (Vaismoradi et al., 2013), and to record thoughts and reflections after each interview. In addition, the researcher was mindful of the fact that all emerging codes/themes had to be grounded in the current data, and not from previous experiences/preconceptions. An example was the researcher's perception of what constituted herbal treatment from having his own part-time practice: what emerged from the data was that herbal practice is diverse, so that some forms of treatment that the researcher would not have originally considered as part of the herbal therapeutic process emerged from the interviews.

The final approach to help ensure credibility of this research was analyst triangulation. This form of triangulation has been criticised for adopting a realist approach that assumes there is an accurate reality in the data (Braun & Clarke, 2012b; Ando et al., 2014). However, due to the early stage of the researcher's career, his Director of Studies was given copies of all cleaned transcripts, all of his supervisory team were given sections of selected transcripts and subsequent coding, and the researcher fed back emerging themes via a workshop to his supervisors and colleagues. The process proved to be useful: it allowed the supervisory team to highlight clarifications or modifications of codes that might have been needed, such as the need to form codes that allowed for both positive and negative reports (an example was to use the code "sleep" rather than

“insomnia”). In addition, the supervisory team were also able to help to identify potential themes in the data that may not have been captured by the codes – this included challenging the code “embarrassment”, which subsequently became the code “feelings” and allowed the researcher to distinguish between distinct feelings of embarrassment, shame, and guilt (discussed in section 5.3). This process gave the researcher confidence he was achieving a consistency and coherence of analysis (Fox & Ward, 2008; Yardley, 2008). A coding system to identify emerging themes was prepared with the aid of NVivo 10, a software programme designed to aid the organisation and analysis of electronic data sources (QSR International, 2013). An example of coding for a section of transcript can be found in Appendix 8. A list of final codes and their explanations can be found in Appendix 9, with a breakdown of how these codes fed into the categories of self-care, distress, and the herbal therapeutic process can be found in Appendices 10, 11, and 12.

### **3.4 Ethics**

Questioning participants about any aspect of their personal lives, but particularly talking about areas that may be distressing, requires the researcher to consider any ethical or moral issues involved (Rabionet, 2011). With this in mind, ethical approval for the study was sought and received (App. No. 11\_12\_20) from the Research Ethics sub Committee on 6th June 2012. The School of Life Sciences ethics filter form, the ethics application, and the approval letter, can be found in Appendix 13.

In terms of anonymity, all participants (including the herbalists) were given an identifying number to replace their name upon inclusion to the research process, and any other possible identifying data (such as job title or place of residence) were removed from the transcripts. The participants were given pseudonyms for the purposes of writing up the research, and any mention of their herbalist in the write-up has disguised the herbalist’s gender. In addition, for specific instances where the participant voiced a concern over anonymity, all mention of names (including pseudonyms) has been removed.

### 3.5 Demographics

This section contains the demographic data gathered from the herbalists and (subsequently) the participants recruited for this study. The demographic data is also compared to any available information from the professional bodies, and data from previous studies in order to situate this research in relation to the wider literature.

#### 3.5.1 Demographics from the Herbalists' Survey

As was reported in section 3.2.3, the herbalists that were recruited for this research all practised within a ninety mile radius from the centre of London, and were purposively sampled in an attempt to get as great a variety of practice as possible. The demographics from the survey that was conducted on the herbalists when they first entered this research process can be found in Table 3.1. The responses to the open questions of how the herbalists viewed their practice and their approaches to treating distress can be found in section 4.2.

**Table 3.1:** Demographic Breakdown of the Herbalists

Herbalist Characteristic	Gender	Age Range (Years)	Ethnicity	Highest Herbal Qualification	Member of:	Time in Practice (Years)	Total Practice Deprivation
	Male n=7 (22%)	<26 n=1 (3%)	White British n=26 (81%)	Certificate n=5 (16%)	NIMH n=19 (59%)	<10 n=13 (41%)	Up to 20% n=2 (6%)
	Female n=25 (78%)	26-35 n=7 (22%)	White Other n=4 (13%)	Diploma n=4 (13%)	CPP n=7 (22%)	11-20 n=12 (37%)	25-40% n=5 (16%)
	–	36-45 n=4 (13%)	White Irish n=1 (3%)	Degree n=19 (59%)	NIMH/ CPP n=4 (13%)	21-30 n=6 (19%)	45-60% n=9 (28%)
	–	46-55 n=11 (34%)	White/Asian n=1 (3%)	PG Diploma n=1 (3%)	Other n=1 (3%)	>30 n=1 (3%)	65-80% n=13 (41%)
	–	56-65 n=7 (22%)	–	Masters n=2 (6%)	None n=1 (3%)	–	85-100% n=3 (9%)
	–	>65 n=2 (6%)	–	PhD n=1 (3%)	–	–	–
<b>Total</b>	n=32 (100%)	n=32 (100%)	n=32 (100%)	n=32 (100%)	n=32 (100%)	n=32 (100%)	n=32 (100%)

Table 3.1 highlights a number of features related to the diversity of the herbalists. Although there has not been a lot of research into western herbal practice, chapters 1 & 2 outlined what a typical herbal consultation may look like. Whilst some of the research that has been carried out has not always been explicit about the demographics of the practitioners utilised for the research, some papers have included demographic information about herbal practitioners and/or patients, a synopsis of which has been produced by Nissen & Evans (2012) and is used here for comparison. The NIMH and CPP were also contacted to request demographic data for their members: whilst this is not routinely recorded, the NIMH were able to provide some information with regards to herbalist gender and age, and the CPP provided information about herbalist gender.

In the UK, the suggestion that herbalists are more likely to be women aged between 41 and 50 years of age was in part supported by the current research. The majority (twenty-five) of herbalists recruited were women, with just over a third falling within the age range of 46 to 55 years. The NIMH estimated that 75% of their members were women (the CPP reported that 76% of their members were women), whilst the NIMH also confirmed that almost half (46%) of their members fell within the age range of 50 to 64 years.

A large majority of practitioners were white, with twenty-six describing themselves as “white British”, despite an effort by the current study to recruit herbalists from a variety of ethnic backgrounds. The shift of herbal training from apprenticeships and private schools to universities was apparent in the number of practitioners who had degrees in herbal medicine. Other routes of training were generally only mentioned by those that had been practice over a longer period – the table also shows that there was a degree of variation in the experience of the herbalists from five who had been in practise for 5 years or less, to one who had been in practise for over 30 years. The final column of Table 3.1 shows the level of deprivation in the area that the herbalist practised. This research aimed to recruit herbalists from a variety of areas (rural, suburban and urban) and from a range of social and economic backgrounds (from more affluent areas to more deprived areas). The figures were taken from ONS neighbourhood statistics (Office for National Statistics, 2011b): the

total deprivation figure is an average that takes into account a neighbourhood's deprivation figures for income, employment, health, education, crime, living environment, and barriers to housing services, with 100% being the highest level of deprivation.

As not all of the herbalists recruited were able to provide participants to take part in the main body of the research, table 3.2 provides demographic data for the seventeen herbalists whose patients were actually spoken to. The figures show that these herbalists' data was similar to those in table 3.1, although they represented a group that was slightly more mature, were more likely to be a member of NIMH only, and tended to work in areas that suffered with slightly less deprivation.

**Table 3.2:** Demographic Breakdown of the Herbalists Who Were Able to Recruit Participants

Herbalist Characteristic	Gender	Age Range (Years)	Ethnicity	Highest Herbal Qualification	Member of:	Time in Practice (Years)	Total Practice Deprivation
	Male n=4 (24%)	<26 n=0 (0%)	White British n=14 (82%)	Certificate n=2 (12%)	NIMH n=12 (71%)	<10 n=6 (35%)	Up to 20% n=2 (12%)
	Female n=13 (76%)	26-35 n=3 (18%)	White Other n=3 (18%)	Diploma n=2 (12%)	CPP n=2 (12%)	11-20 n=7 (41%)	25-40% n=2 (12%)
	–	36-45 n=0 (0%)	White Irish n=0 (0%)	Degree n=10 (60%)	NIMH/ CPP n=3 (18%)	21-30 n=4 (24%)	45-60% n=7 (41%)
	–	46-55 n=8 (47%)	White/Asian n=0 (0%)	PG Diploma n=0 (0%)	Other n=0 (0%)	>30 n=0 (0%)	65-80% n=4 (23%)
	–	56-65 n=5 (29%)	–	Masters n=2 (12%)	None n=0 (0%)	–	85-100% n=2 (12%)
	–	>65 n=1 (6%)	–	PhD n=1 (6%)	–	–	–
<b>Total</b>	n=17 (100%)	n=17 (100%)	n=17 (100%)	n=17 (100%)	n=17 (100%)	n=17 (100%)	n=17 (100%)

As well as the figures outlined in table 3.1, some other statistics emerged from the survey of all herbalists. A smaller percentage of herbalists spoken to for the current research practised part-time compared to previous studies, but were still in the majority with half of the current herbalists seeing fewer than six patients a week. As the deprivation figures suggest, the location of herbal practice could be diverse: thirteen of the current herbalists worked in a multi-disciplinary CAM clinic, twelve worked from home, six in a herbal training clinic, and two in an NHS setting or retail

outlet. The higher percentage of practitioners that were employed by a training clinic for the current study compared to previous studies may in part be due to the fact that the researcher was based at a university that had a training clinic for herbal medicine students (and he also had ties with another training clinic in the area), but may also reflect that – with the exception of Lincoln – all the other EHTPA validated western herbal training clinics fell within this research’s geographical area. Nissen (2010) reported that 67% of her participants supplemented their income from sources other than herbal medicine; the current research asked a different question, but showed that fourteen of those spoken to practised at least one other therapy in addition to WHM.

In terms of patients, in line with previous studies, the current research found that that the majority of herbalists (thirty) treated more women than men (though the current study did not attempt to quantify the amount). Whilst Nissen’s survey (2010) showed that the majority of complaints treated by those surveyed were either “women’s health complaints” or “gynaecological complaints”, other conditions were either categorised as “obstetric complaints” (which were in the minority) or “miscellaneous complaints”. The current survey used an open-ended question to ask the practitioners what they felt were the three most common complaints that they were asked to treat, and so provided a wider list of conditions. What the survey suggested was that whilst herbalists treat a wide range of complaints, there is a triad surrounding distress (reported by twenty-five of the herbalists), hormonal/gynaecological problems (twenty-four), and (to a lesser extent) digestive complaints (fifteen). However, it should be noted that the herbalists were aware of the nature of this research at the time of the survey, so it may be that herbalists who treat distress regularly were more inclined to participate.

The current study also tried to make it clearer as to what a typical herbal encounter might look like for the patient. What was clear from the current survey (and in line with previous research) was that the mainstay of WHP is the tincture (ethanol/water based concentrated liquid herbal extract), as it was the only form of herbal medicine that was used by all the herbalists, though infusions, external

creams & ointments, tablets/capsules, and decoctions were also popular. The patients' average daily adult dosage of tincture (equivalent to a 1:1) was most likely to fall within the range of 5-15ml daily.

### 3.5.2 Demographics from the Participants' Survey

After their survey, the herbalists that were recruited for this research acted as gatekeepers to try and recruit women who were visiting them whilst living with distress to take part in the study. In order to determine whether the women recruited for this research had the desired level of diversity, and to compare the current participants with those from previous studies, demographic data was also collected from all the participants. An outline of the demographic data which was gathered at the time of the participants' T1 interview is presented in Table 3.3.

**Table 3.3:** Demographic Breakdown of the Participants

Participant Characteristic	Age Range (Years)	Ethnicity	Highest Qualification	Employment Status	Relationship Status	Carer Status	Total Deprivation of Neighbourhood
	<26 n=1 (4%)	White British n=20 (77%)	GCSE n=7 (27%)	Student n=1 (4%)	Single n=5 (19.5%)	Current n=9 (35%)	Up to 20% n=3 (12%)
	26-35 n=4 (15.5%)	White Other n=4 (15%)	A Level n=3 (12%)	Corporate n=1 (4%)	Co-habiting n=2 (7.5%)	Previous n=9 (35%)	25-40% n=7 (27%)
	36-45 n=4 (15.5%)	White Irish n=1 (4%)	HND n=1 (4%)	Sales n=2 (7%)	Married n=14 (54%)	Never n=7 (27%)	45-60% n=8 (31%)
	46-55 n=5 (19%)	Black British N=1 (4%)	Degree n=7 (27%)	Admin n=3 (12%)	Separated n=1 (4%)	Desired n=1 (3%)	65-80% n=4 (15%)
	56-65 n=7 (27%)	-	PG Diploma n=1 (4%)	Arts n=3 (12%)	Divorced n=2 (7.5%)	-	85-100% n=4 (15%)
	>65 n=5 (19%)	-	Teaching Qual. n=2 (7%)	Education n=3 (12%)	Widowed n=2 (7.5%)	-	-
	-	-	Masters 5 (19%)	Health n=4 (15%)	-	-	-
	-	-	-	Unemployed n=4 (15%)	-	-	-
	-	-	-	Retired n=5 (19%)	-	-	-
<b>Total</b>	n=26 (100%)	n=26 (100%)	n=26 (100%)	n=26 (100%)	n=26 (100%)	n=26 (100%)	n=26 (100%)
<b>Average</b>	56.75	-	-	-	-	-	-

The women that were interviewed were all recruited by herbalists whose demographic data is outlined in Table 3.2. Due to this, the patients presented in table 3.3 all came from a similar geographical area (within a ninety mile radius from

the centre of London) but were also recruited from a variety of geographic locations (urban, suburban and rural). The women themselves in part reflected the demographics of other herbal patients that have been reported in the literature. Whilst their mean age (56 years and 9 months) matched the suggestion that herbal patients are more likely to be “middle-aged” (Gardiner et al., 2007; Damery et al., 2011), the women also supported Vickers et al. (2006) as they incorporated a wide range of ages, from 25 years up to 79 years at the time of their T1 interview.

Unlike research which would suggest that the participants were likely to be better educated (Gardiner et al., 2007), their level of education was diverse: half were below graduate level, whilst half were graduate level or above. Similarly, whilst research has suggested that they were more likely to be of higher socio-economic class, the total deprivation figures from The ONS suggest that the women came from a wide variety of social backgrounds. However, it should be noted that this research included eight patients that had attended two herbal training clinics, where the treatment was offered at a discounted rate, and so may have attracted some users that would otherwise have been unable to afford to visit a herbalist. Similar to the herbalists, the majority (twenty) of the women described themselves as white British, the rest coming from a variety of (predominantly white) ethnic backgrounds.

The majority of the women (sixteen) were married or cohabiting, whilst five described themselves as single; the rest were either separated, divorced, or widowed. Their occupations were also diverse, ranging from those in a home maker role, through administrative roles, up to those employed at a professional level, and included those that had retired. In addition to any employment, nine of the participants also found themselves in a caring role, which was subsequently found to be of potential significance (discussed further in section 5.4.4). These nine found themselves responsible to a greater or lesser degree for the care of others: one was caring for her partner, two were caring for their mother, three were responsible for children, two had responsibility for children in addition to their mother, and one was employed to take care of children. Of those that did not have a caring role at the time of their inclusion to this research, nine had previously been

responsible for the care of children and/or parents, whilst seven did not report having ever been responsible for the care of others. In addition, one participant had not been a carer, but was looking to take on the role with her partner by applying to adopt children.

**Table 3.4:** Patterns of Participant Usage of Western Herbal Practice at T1

	<b>Seen a Different Herbalist Previously</b>	<b>Not Seen a Different Herbalist Previously</b>	<b>TOTAL</b>
<b>New Patient at T1</b>	4	5	9
<b>Existing Patient at T1</b>	7	10	17
<b>TOTAL</b>	11	15	<b>26</b>

In addition to the participant demographics outlined above, table 3.4 illustrates the usage patterns of WHP by the participants: of the twenty-six participants, nine were new patients at T1, though four of the nine had prior experience of visiting a herbalist (including one naturopath). Seventeen had been visiting their herbalist at T1 for some time, whilst seven of these also had previous experience of visiting a different herbalist. In addition to the data provided in table 3.4, of the fifteen participants who had not seen a herbalist prior to the herbalist they were seeing at T1, eleven reported having some experience of using herbs to treat themselves. This helps to show that the participants reported ongoing use of WHM, and that once they had had experience of visiting a herbalist, they were likely to continue using WHP.

Despite the lack of diversity in terms of ethnicity, the women represented individuals from a complex variety of backgrounds. What the demographics do not show is that as well as the women coming from a variety of backgrounds, the women were also complex with regards to the diversity of their stories of distress. As the first task of the researcher after recruiting the women was to elicit their narratives of distress, chapter 4 introduces the women and their stories in more depth.

## **CHAPTER 4: WOMEN AND DISTRESS**

### **4.1 Introduction**

This chapter initially reports how the herbalists recruited for this research viewed their practice and their approaches to treating distress. It then introduces the women who participated in the interview stage of this research, and outlines the reasons that contributed to them initially consulting with a herbalist. It looks at the events that the women reported as distressing: in order to achieve this, the chapter outlines the complaints that were presented to the herbalist at the time of the first consultation, but also considers any other stories of distress that were spoken of. Stories of the most common reasons for feelings of distress (bereavement and ill health) are outlined, before considering the feelings that the participants associated with their distress. These feelings centred round anxiety and low mood, to the point of where some felt it appropriate to talk of suicide. The chapter then looks at how the participants' distress could potentially lead to feelings of a loss of self and have a negative impact on their lives, before attention turns what reported aspects of distress require further investigation in the next chapter.

#### **4.1.1 Themes**

Six themes are presented in this chapter concerning women and distress:

1. Comments from the herbalists' survey show that when women with distress choose to visit a herbalist practising WHM, they are unlikely to know what to expect due to the diversity of practice
2. Women with distress will frequently visit a herbalist due to feelings of desperation, often linked to dissatisfaction with biomedical treatment options
3. Women's stories of distress are diverse, but frequently centre round experiences of bereavement and/or ill health

4. Women's experiences of distress often involve feelings of anxiety and/or low mood, but also the feeling of a loss of agency
5. In order to communicate their distress, women will often use metaphorical language
6. Feelings of distress commonly have a profoundly negative impact on a woman's wellbeing, but can also extend beyond the individual and have a negative impact on those around them.

## **4.2 Comments from the Herbalists' Survey**

As well as the closed questions which gave the results in section 3.5.1, the survey that the herbalists completed upon inclusion to this research also included open questions with regards to how they described their practice, their herbal approaches to treating distress, and any other areas that they would consider when treating distress. This information is useful to situate the data from the participants' interviews. From the herbalists' responses, four themes emerged (outlined in sections 4.2.1 to 4.2.4): the holistic nature of WHP; the individual approach to treatment; the importance of the therapeutic relationship in addition to any herbal treatment; and the diversity of practice. As outlined in section 3.2.4, the herbalists have each been given a code (e.g. herbalist code 100) in order to anonymise any quotes used.

### **4.2.1 A Holistic Therapy**

Twenty-three of the thirty-two herbalists surveyed either mentioned treating holistically or looking for underlying reasons why a patient would be suffering with a particular problem. As well as an overall holistic approach, some herbalists gave examples of providing recommendations to patients other than the use of medicinal plants. Twenty-one spoke about giving dietary advice as part of their consultation (eleven spoke of dietary advice specifically when treating those with

distress), and twenty-seven spoke about giving lifestyle advice (eighteen spoke of lifestyle advice specifically when treating those with distress).

#### **4.2.2 Individuality of Treatment**

In line with a patient centred approach, twenty-eight of the herbalists spoke of the need to treat patients on an individual basis – reinforced by the question on herbal approaches to distress, when twenty-nine highlighted the difficulty to answer the question as they felt that their approach “depends really on the individual” (herbalist code 170). After initially highlighting the need to treat the patient on an individual basis, the herbalists then either spoke about specific herbs that they would often choose (eighteen), or particular actions/effects that they would look to utilise from various herbs (twenty-six). The specific herbs did not appear to follow a particular pattern – possibly because the western herbal pharmacopeia is large, and the individual needs of a patient can vary. One herbalist typified the difficulty that they found in coming up with a standard herbal formula:

*Well there's lemon balm, there's St John's wort, erm there's... But then there's rosemary, there's damiana for example. But the thing is it also depends on what else is going on, there's oats as well. It depends really on the individual.* (herbalist code 170)

Due to the possible variability of an individual's distress, herbalists also found themselves considering a wide range of herbal actions that might be appropriate when treating distress, examples of which include herbs with sedative effects, or those with an antispasmodic action. Each action has a number of potential herbs that could be considered to achieve the desired effect, the selection of which formed the basis of each patient's individual herbal prescription.

#### **4.2.3 Importance of the Therapeutic Relationship**

Aside from the herbal prescription, another aspect which stood out when the herbalists described their practise was the importance that they put on building a

good therapeutic relationship – mentioned by twenty-three of the herbalists, and described by one as “a partnership” (herbalist code 130). Following on from the desire to build a good therapeutic relationship, twelve herbalists spoke about the need to help empower their patients, whilst nineteen also spoke about the importance of listening as part of the consultation process. Some felt that listening, acknowledging and validating the patient was “essential as part of the approach of a holistic herbalist” (herbalist code 260) and “as important – for distressed patients particularly – as the herbal medicine” (herbalist code 140). As one herbalist explained:

*The first thing you’ve got to do is respond to the distress, and you’ve got to show yourself... I had a patient on Friday who was in complete distress. She was in that situation where she thought she was going mad, and what came to me was the best thing that I could be was just to explain to her that, given what she was experiencing, what was happening was completely normal.*

(herbalist code 040)

Whilst the herbalists reported talking to their patients about distress, their responses also highlighted that the herbalists were not trained counsellors, though there was an acceptance that elements of counselling could become part of western herbal practice, and an important part of the therapeutic relationship. As one herbalist put it:

*Although we’re not qualified to do any counselling – but sometimes you know it’s just helping people see through their problem just by externalising it isn’t it? So listening and caring can be enough to help.*

(herbalist code 190)

#### **4.2.4 Diversity of Practice**

A number of elements of the consultation highlighted the variety of practises that the herbalists spoke of. For example, only seven herbalists mentioned carrying out physical examinations as part of their practise, though the number in reality may have been higher as there was not a specific question with regards to physical examination as part of the questionnaire. Sometimes the thought processes of the

herbalist could follow a route which they considered to be relatively orthodox scientific/biomedical, such as one herbalist who described how they would use herbs “on a very scientific basis” and would utilise their knowledge of the plants to try and establish “which would be the best combination of phytochemicals in various combinations” (herbalist code 420). Alternatively, some herbalists used phrases which were less likely to be used within a biomedical model, although the herbal actions may still have had a scientific basis. This was summed up by one herbalist who considered their herbal approach to dealing with distress:

*If you think about herbal actions, you might think about depuratives, alteratives, tropho-restoratives – I mean old names but they do have a meaning which is not covered in the rest (other therapies). (herbalist code 390)*

What emerged from the responses was that whilst there was some commonality among the ways in which the herbalists spoke about their various practises and their approaches to treating distress, there were also some noticeable differences. For example, twenty-two of the herbalists did not mention about using a traditional “energetic” approach when prescribing herbs, which relates to a process that has its roots in traditional humoral medicine where qualities such as heat, cold, dry, and humid are used to help match herbs to an individual patient (Firenzuoli & Gori, 2007). However, of the herbalists that did mention energetics, six spoke about how they liked to use an energetic approach, whilst four highlighted that they did not use an energetic approach. Also, of the herbalists that did talk about particular herbs that they might use, there was again variation; a good example was the use of *Hypericum perforatum* L. (St. John’s wort) – some herbalists spoke of its usefulness, whilst others reported how they did not find it particularly effective in their practise.

One final aspect that was frequently mentioned by the herbalists (twenty) was the need to be aware of their professional boundaries, and when to refer patients on to other healthcare professionals if they felt that their particular skills were insufficient to meet the individual patient’s needs. What all the apparent variations did was to support the idea that patients (even if they have visited a herbalist before) may not

know what to expect when they walk through a herbalist’s door for the first time. Reasons why the participants would choose to visit a herbalist therefore became the first focus from the participants’ narratives.

### 4.3 Reasons for Visiting a Herbalist

The reasons given for consulting with a herbalist were diverse, with half seeking the services of a herbalist because they were dealing with the effects of distress, eight seeking help for conditions which the participant reported was exacerbated by stress, whilst four were seeing a herbalist for physical conditions that they felt were having a negative impact on their well-being. The fact that half the women were primarily living with some form of distress is unsurprising as the practitioners recruited for this research were actively seeking women with distress when they were acting as gatekeepers. However, the top three conditions that the practitioners reported treating most often upon their inclusion into this research process (as reported in section 3.5.1) – distress, gynaecological problems, and digestive complaints – in part reflected those reported by the patients. An outline of all the body systems that the participants reported had an issue at the time that they first consulted with their particular herbalist is presented in Table 4.1.

**Table 4.1:** Participants’ Body Systems Affected at Time of First Consultation

Body System	Number of Participants Reporting
Nervous System	20
Gynaecological System	11
Musculo-Skeletal System	6
Integumentary (Skin) System	4
Digestive System	2
Respiratory System	2
Cardiovascular System	1

Table 4.1 illustrates how the participants could present to the herbalist with a variety of concurrent problems. As well as the systems affected, the participants’

specific presenting complaints did bear some resemblance to the conditions that the herbalists reported treating. As with the herbalists, the top two primary problems presented were feelings associated with distress, followed by hormonal or gynaecological problems. There then followed a spread of conditions from skin complaints through to digestion problems, musculo-skeletal problems, respiratory problems, and chronic fatigue. All the participants described instances that they found extremely distressing, either at the time of first visiting their herbalist or at a different point in time. In order to help introduce the participants and their stories further, Table 4.2 not only outlines the nature of the participants' distress when they first went to see their herbalist, but also highlights any other notable stories of distress that emerged from their narratives. The stories were diverse, but included stories of anxiety, depression, ill health, and bereavement.

**Table 4.2:** Participants' Stories of Distress

<b>Participant</b>	<b>Stories of Distress</b>
01	On-going musculo-skeletal problem, which had previously led the participant to be house bound. Also had a history of panic attacks and cancer.
02	Chronic fatigue syndrome coupled with a history of panic attacks, which had forced the participant to have to give up work.
03	On-going menstrual problems were exacerbated by stress, but participant also had a history of distress, relationship problems, and an eating disorder.
04	Extreme menopausal symptoms which were exacerbated by the side effects of pharmaceuticals after having cancer. Also had a history of depression.
05	Looking to generally improve her health after having pneumonia, this was then followed by a diagnosis of cancer.
06	Looking to generally improve her health in order to be able to cope with her role as a carer.
07	Initial gynaecological problem soon resolved, but became apparent that participant was living with depression and experienced financial stress and relationship problems.
08	Current bout of eczema had been much worse in the past, and also coincided with the participant having severe depression. Has also had a history of suicide attempts.
09	Was feeling run down coping with the menopause and depression. Had a history of severe depression, relationship problems, and problems with fertility.

10	On-going menopausal symptoms and thyroid dysfunction. Also had to cope with anxiety, and a history of bereavement.
11	Living with anxiety; also had a previous history of debilitating period pain, depression, extreme anxiety and panic attacks.
12	A history of depression and systemic lupus erythematosus; the participant also had stories of suicide attempts, abuse, and bereavement.
13	Aside from an initial skin complaint, the participant also spoke openly about trying to cope with the suicide of her son.
14	Whilst having on-going depression, participant also had numerous distressing stories, including bereavement, abusive relationships, and cancer.
15	History of chronic fatigue syndrome, but also having to deal with a family member with dementia, and becoming very ill after a medical emergency.
16	Musculo-skeletal misalignment thought to be linked to an underlying problem that was perceived as being ignored by the biomedical profession.
17	Initial problem of polycystic ovary syndrome not considered distressing compared to bereavement, and had had a particularly traumatic and unsettling year.
18	Current symptoms linked to the menopause could be distressing; also had a history of bereavement and family member with dementia.
19	Did not see her diverticular disease as that stressful compared to previously having to deal with bereavement, and having had cancer.
20	Living with the after-effects of a traumatic childbirth, but also had a history of psoriasis.
21	Current bout of anxiety/insomnia placed against a background of a nervous breakdown and distressing experience of biomedicine.
22	Persistent cough and insomnia affected participant's well-being; had a history of depression and anxiety linked to bereavement.
23	Was dealing with arthritis that affected her ability to do some of the things she most enjoyed. Previously had two notable episodes of severe depression she associated with difficult circumstances.
24	Eczema perceived by the participant to be due to stress stemming from bereavement.
25	On-going history of anxiety/panic attacks and irritable bowel syndrome. Participant resistant to the perception that her doctor was trying to label her as depressed.
26	Initial complaint subsequently diagnosed as panic attacks. Participant felt let down by biomedicine after a number of distressing instances.

#### 4.4 Desperation: Feelings When First Visiting a Herbalist

Various reasons were spoken of by the participants as to why they had chosen to visit a herbalist. Whilst all of the participants reported having experience of CAM (in addition to visiting a herbalist), and some reported feeling an affinity for herbal medicine, the main driving force for going to a herbalist was dissatisfaction with treatment options that they had already tried. In all but four of the cases, the participant had tried biomedicine before visiting a herbalist, but had found some aspect of the treatment that they were not happy with. Whilst these figures would appear to suggest that the participants' distress was normally apparent to their GP, the narratives did also provide examples where this was not the case. There could be multiple factors that could lead to an individual feeling that their distress was invisible to the biomedical gaze. Table 4.3 presents the various reasons given by the participants why their distress may have remained invisible from a biomedical point of view. These reasons may have occurred in combination, and include the four who initially visited a herbalist rather than their GP.

**Table 4.3:** Instances Where Participants' Distress Was Invisible to Biomedicine

Reason for Invisibility	Number of Instances
Participant stopped visiting their GP/practitioner due to the perception that their distress was not acknowledged	9
Participant decided not to visit their GP in the first instance	6
Participant stopped visiting their GP due to concerns over treatment	6
Participant stopped visiting their GP due to a rejection of the biomedical label/diagnosis	4

The reasons for not choosing to visit a GP could vary: two had previous experience of CAM and preferred going to a complementary therapist over their GP; one decided to try using her herbalist instead of the GP as her husband had had such positive results from seeing the herbalist; one was looking to optimise her health to help her in her role as a full-time carer. However, even when an individual chose to

visit their GP, they would sometimes subsequently remove themselves from the biomedical process. This decision would often be due to feelings of marginalisation as the individual felt that their distress/situation was not fully appreciated or acknowledged by their GP/consultant. Beth's quote in section 1.1.2 illustrated how her irritable bowel syndrome (IBS), which she felt was not considered serious by her consultant, was having a massive impact on her well-being. Wendy provided another example where she experienced such severe menopausal symptoms after treatment for breast cancer that she found herself having suicidal thoughts (explored further in section 4.6.4). In spite of the severity of the symptoms on her well-being, her oncologist "was horrible and said 'Well you just have to get on with it'".

In some instances, an individual would choose not to continue with the biomedical process due to concerns over the proposed treatment. The treatment option that was being eschewed was frequently the use of pharmaceuticals, such as the case of Nicola who described being given a topical application by her GP that she considered "so toxic" she wouldn't use it. However, sometimes another option was sought due to fear: Judith "was a bit floored" by a diagnosis of an overactive thyroid and found the treatment options "frightening", whilst Fay emphasised her hatred for hospitals which was not helped by a traumatic time at a hospital accident and emergency department (A&E) after collapsing at work, attributed to exhaustion resulting from a combination of stress and insomnia:

*I said to them "Put me in a taxi, I'll go home, go to the doctor's, fine". I knew what was going on to that degree. And instead, they phoned up A&E, and got me carted off to (hospital). And for me that was the worst thing they could've possibly done, because it put absolute panic stations in for me. It was not the place I wanted to be, it was completely unfamiliar. I hate hospitals – I absolutely hate hospitals. I hate them even more when I'm in that state. So my stress levels went orbital – not even through the roof, they were orbital.*

In some instances, participants would indicate that they felt biomedical labels (particularly a diagnosis of depression – discussed further in section 4.6.2) were not relevant to them/their situation. Eve provided an example where she did not

collect anti-depressants which had been prescribed for her by her GP as she made a distinction between feeling “really low” and feeling “clinically depressed” after her mother died (discussed in section 4.5.1). Margaret appeared to share this view, and succinctly summed up her feelings on the matter when she explained that sometimes “you’re depressed because you’ve bloody well got something to be depressed about”.

One reason for visiting a herbalist was a feeling of wanting to get to the underlying cause of a particular problem, such as Kate who had an on-going musculoskeletal problem that she found quite hard to get to “the root of the problem” and provided another example where she felt that she was not being listened to by her GP. Whilst there were a number of factors that led the participants to visit a herbalist, it was primarily due to an unsatisfactory biomedical outcome. This situation was exemplified by Hayley who was frustrated when having to keep going to her GP for antibiotics to manage her diverticulitis and being told that she had “got to put up with it” due to old age. As Hayley said “Well, I wasn’t about to put up with it so I thought I’d try something different”.

Feelings of fear, frustration, marginalisation and a lack of control could combine so that when the women first went to see a herbalist, they were often feeling desperate. Over half of the participants’ narratives included words that suggested feelings of desperation at the time of their first consultation. Yvonne had been struggling for some time to cope with the effects of chronic fatigue but had not found an effective treatment. Her narrative gave an impression of distress as she described trying to find someone that could help her with her symptoms, and ended up seeing “a load of different advisors, medical practitioners, anybody, everybody”. A similar story was reported by some of the other participants: Pippa had originally been living with debilitating period pain, but felt frustrated after visiting three different GPs when “none of them could do anything” and “wouldn’t offer any advice”. Despite there being issues reported with biomedical practitioners in some narratives, other participants could appreciate the efforts that were being made, but were still frustrated at how they were feeling. Gemma had gratitude for biomedical services, especially after a traumatic time when her child was born.

However, some months later, she was still dealing with the effects of anxiety and insomnia after the traumatic events surrounding the birth, and described how her distress felt:

*I was still not sleeping, and I think it was because I always felt like I was about to burst. Just felt stressed like – when I say felt my physical experience of stress, I felt like something was always about to go wrong. I was just waiting for something to go wrong and something bad would happen, but it just felt like if you took a pin and you pricked me with the pin I would burst open... that's how my stress felt.*

Isobel was living with menopausal symptoms when she first went to see her herbalist, but also having to cope with the demands of a young family meant that she had also got to the point of feeling desperate:

*I remember sitting here just thinking, and (herbalist) probably thinking "What on earth am I going to do with you?" But yeah, just feeling very, very unable to cope. And depressed, feeling very, very low, tearful, not being able to cope with anything.*

As Isobel's quote illustrates, the events going on in the participants' lives could lead to feelings of a loss of control. That is not to say that going to see a herbalist was necessarily equated with relinquishing control by the participants. The decision to utilise the services of a herbalist had the potential to help the participants feel like they were regaining some control, by replacing feelings of a loss of control with those of hope. As Wendy put it, visiting a herbalist was a positive thing because she was "doing something".

#### **4.5 Instances of Distress**

Whilst the participant's narratives showed how they were feeling around the time of their first consultation, what was also striking about their narratives was the number of times that they also included instances of distress that were distinct from when they went to visit the herbalist. Every one of the participants spoke of notably distressing instances in addition to any reason why they first consulted with their herbalist. Sometimes these stories were used to illustrate differences in how

the participant was feeling at the time of seeing their herbalist, compared to another instance of distress that stood out for them. Hayley considered what it felt like to be stressed at work, compared to when her mother had been taken seriously ill some years earlier:

*My job gave me huge amounts of stress in that I was responsible for very, very high level events because I used to run them and people spend thousands of pounds on their event and it's down to you getting it right... so it was all on my shoulders. But that was good stress. The adrenaline rush was fantastic and I thrived on it, but there are different types of stresses I guess and the stress when my mum was ill for example was a different one. That was fear that she would die and it was a month of it and I lost half a stone just in stress alone although I was eating what I thought normally.*

Sometimes the stories of distress would be distinct from the story of seeing a herbalist, such as when Eve described how she felt more drawn to complementary medicine than to biomedicine, but included an instance of depression that had not been previously mentioned:

*Don't get me wrong, because I do take conventional medicine for my migraines, and I have taken conventional medicine when I went through a period where I was really severely depressed... I felt when I was severely depressed – it's like I wanted something quickly to sort of kick into my system and make me feel better.*

Whilst the reasons for visiting a herbalist, and other reported instances of distress, were diverse, some patterns of distress did emerge from the narratives. These were stories that revolved around bereavement, ill health, anxiety, and low mood/depression – all of which could have a profoundly negative impact on the individual's well-being and everyday life. These are discussed in more detail below.

#### **4.5.1 The Distress of Bereavement**

Of all the stories of distress, bereavement was the experience that was most often talked about. From the narratives, over half of the participants mentioned bereavement, whilst eleven spoke of feelings of distress related to bereavement. A

history of bereavement did not necessarily equate to an individual reporting depression, although all the instances of bereavement were associated with negative feelings. Eve spoke of her father's death at T1, but had also lost her mother shortly before T2, and reflected on her feelings:

*When I lost my dad, I know what a real clinical depression is now and I would say to you I feel really, really low but I wouldn't say to you I feel clinically depressed.*

What exactly constituted clinical depression was raised by a number of the participants, but rather than attaching a label, what was important to the individual was how they were feeling at the time. Margaret described having to be treated for a nervous breakdown after the death of her parents, but stated "I'm not so sure that it was depression so much as just sheer exhaustion and grief". Whilst there could be a desire to resist a label of depression, what was clear was the impact that how Margaret felt had on her ability to function as she needed time in a psychiatric unit to recover, illustrating just how dramatic an effect bereavement can have on an individual. The narratives clearly showed that loss was one of the most distressing events that the participants had had to endure – particularly the loss of a partner, parent or child. Zoe described how after her parents died she no longer felt like she had the "safety net" of having them around, whilst Carol described the result of losing her parents as not having "that natural thing to fall back on". Jade also described her situation after her mother had died:

*I think that's one of the hardest things when you deal with, the hardest thing to deal with in some ways in life, is death... I think it's really changed my approach to everything really, from the point of view of, like I appreciate things 10,000 times more than I used to, because I don't know (slight pause). I think until you've actually really lost someone that's close to you, you can't begin to imagine...*

Three features stood out from the narratives which described the distress of bereavement. The first was how the women's emotional distress was so great that they could also experience the somatisation of their distress. Jade explained how she thought that she would never fully get over the death of her mother, and how (years later) her grief "comes and goes in waves" that she described as "a physical

thing... a real visceral feeling". Carol spoke of a physicality to her emotional distress from the loss of her husband which she described as feelings of "lacerating pain". Hayley described how she felt when her mother died after a protracted illness as "a continual churning in your gut that never goes away and it's stress, it's fear and it's terror". Hayley's emotions were so extreme, that she found it comparatively less distressing when she was diagnosed with cancer some years later:

*But that was quite stressful, but didn't seem as stressful as my mum for some odd reason, but I don't know why because it was happening to me, and I could be dying. But I felt more stressed with my mum's thing.*

Hayley's feelings suggested that she found it easier to cope with distressing instances that happened to her rather than to somebody else, and helped to highlight the second aspect of bereavement that could be particularly distressing, which was the lack of control and so feelings of helplessness that were experienced when someone close to the participant died. One of the aspects that Jade found most difficult to deal with after her mother died was that grief was something that was beyond control, and that "no matter how much you might want to, wish it away, make it go away, eat it away, drink it away, whatever you try, it doesn't go away". In order to help illustrate the intensity of their distress which was associated with bereavement, the third feature of some of the narratives was to use descriptions and metaphors of disintegration. Carol described the effect of her husband dying on both her and her children, and how the entire family was "blown to bits". Similarly, when Margaret's parents died she described how she "just broke up into little pieces", whilst Eve "fell apart" after her father died.

Whilst it was possible to learn to live with the loss of a loved one, the process of doing so was difficult. In the wake of her son's suicide, Nicola considered how she "came to pieces" and that it was "almost a miracle" that she survived the ordeal. However, she made it clear that whilst she might be "learning to live with" the death of her son, she would never say that she had "come to terms with it" (which was a phrase the interviewer inadvertently used). This helped to illustrate that the distress of bereavement was something that could be difficult to "learn to live

with”, and was emphasised by the fact that some of the participants became visibly upset when talking of the loss of loved ones, though the bereavement may have happened decades previously. However, whilst bereavement was seen as one of the most distressing situations to have to endure, as Hayley’s quote (which compared having cancer to the death of a parent) showed, ill health was another factor that could lead to distress.

#### **4.5.2 The Distress of Ill Health**

Ill health was a major factor connected to distress: nine participants reported instances of previous periods of ill health that were distressing, in addition to the reason that they originally went to see their herbalist. Lucy had spent over eight years trying to cope with chronic fatigue, a condition that she found distressing:

*There’s a great debate with chronic fatigue – are you depressed and therefore you get chronic fatigue, or does chronic fatigue make you depressed? Well my experience is that chronic fatigue makes you depressed, because you’re stuck, unable to do the things you love doing, and that’s really frustrating and depressing.*

Others had also considered the possible link between emotional and physical symptoms, with some concluding that physical symptoms could be affected by their state of mind. Wendy related that how she was feeling would affect her menopausal symptoms: the more she worried about her hot flushes, the worse that they got. This was echoed by Eve, who had a chronic cough that she felt was worse when she was stressed. These narratives were important as they raised the point that not only can being physically ill lead to distress, but that being distressed can have an impact on an individual’s physical well-being. However, similar to the somatisation of distress when dealing with bereavement, it is sometimes difficult to separate the two: Beth described originally going to see her herbalist as her digestive system was “falling apart” due to living with IBS. Whilst the symptoms from her digestion were distressing, Beth found that distress could also adversely affect her digestion, and so felt that there was a connection between the two.

*I think they're so intertwined for some reason, my brain got accesses really closely connected, which is really irritating because sometimes I can just get angry about something, and I just wanna be able to get angry about something without it affecting my digestive system, but that doesn't seem possible, so it's always been digestion that's at the crux of it.*

Another of the things that Beth's narrative illustrated was that, similar to bereavement, the experience of ill health can lead to feelings of distress partly due to a loss of control. As Lucy said when it comes to being ill "you don't have any choice. You can't say 'Oh I don't think I'll be ill today'". During times of illness, the loss of control meant that the individual's body could almost feel like it had become alien to them. Lily described how having systemic lupus erythematosus meant that she would sometimes "get all these weird symptoms – symptoms that even I cannot believe sometimes, and doctors definitely don't believe". A certain level of incredulity was also spoken of by Yvonne who was living with chronic fatigue that gave her "bizarre" symptoms that she often could not understand.

A diagnosis of cancer was always distressing for the individual concerned. At T2, Judith had been diagnosed with cancer and had originally refused treatment, but after being unable to find a CAM practitioner that would agree to treat her in place of biomedical treatment, she had consented to an operation. In spite of this, she still described how she was "really *really* scared" about going to hospital. Vicki was unaware that she was seriously ill when she was first diagnosed with cancer, and explained that when she went to get her test results she took her daughter (who was twelve at the time) and left her outside the consulting room whilst Vicki had her appointment because she thought that she would "only be ten minutes":

*I had no idea why I was going. Because I'd had a blood test and the results weren't right, I just thought I was just going to be, I don't know, chatted to and given some pills that would make my bloods be right. Didn't occur to me I was really ill.*

Pain was another feature that could cause distress: Hayley found that frequent attacks of diverticulitis were upsetting as the pain either "had to be borne" or required frequent doses of antibiotics. Pippa also described the distress of painful periods where "one day a month I wouldn't be able to get out of bed I was in so

much pain, and that was obviously not good for work because you'd have to take a day off". Taking time off of work appeared to exacerbate Pippa's distress as she not only had to deal with her period pain, but the situation also made her feel "a bit pathetic phoning in for something which is meant to be a natural biological occurrence for half the population".

Whilst bereavement and ill health were the two distressing instances that were most often spoken about by the participants, their narratives included (as would be expected) a wide range of issues, from pets being ill and times of financial hardship, through to relationship problems and periods of abuse. Distress is sometimes described as an ill-defined concept, but despite the diversity of the stories, what was clear was that distress had a huge impact on the participants' well-being, self-concept, and daily functioning. Crucially, what the women interviewed also spoke of, was what their experience of distress felt like.

## **4.6 The Experience of Distress**

### **4.6.1 Anxiety**

The participants' experiences of distress commonly centred on feelings of anxiety (depression was distinct from anxiety, though the two often went hand in hand, see section 4.6.2). A lack of discernible cause for feelings of anxiety were reported by a number of participants, though there were also instances of stressful times leading to feelings of anxiety, whilst Judith and Yvonne both reported feelings of anxiety which they thought were (at least in part) attributable to a pathophysiological mechanism: in their cases "a thyroid going completely wonky".

The manifestation of feelings of anxiety could range in severity: Fay described anxiety as adrenaline waves that were similar to feelings of waiting to go for an interview or an exam, but could carry on for days without any discernible external stressor. Whilst feelings of anxiety could be an on-going problem, anxiety could manifest itself in an acute form as panic attacks. Both of these forms of anxiety could be distressing, but in different ways: Beth described anxiety as being more

frustrating because it lingered on, whereas with a panic attack there was a “little crescendo and then boom, you’re done, and then you just get over it”. But whilst the duration of a panic attack could be something that was short-lived, the severity of the attack could be profound, as Anna described:

*I got so panicky, I couldn't breathe – I was passing out from lack of air. And (husband) rushed me into hospital again – we went into A&E, they did all the tests, they did everything, and they said “Everything's fine!” And I said “Give me some oxygen – I need oxygen”, and they said “But you don't need it – your oxygen levels, we've just taken it, they're 100%. You're 100% saturated – your oxygen levels are fine”. And I said “But I can't breathe”, and they said “Well we think it's just you panicking – you're having a panic attack”.*

The fear described by Anna was reported by other participants as being a result of panic attacks, and helped to illustrate just how debilitating a panic attack could be. Pippa described how she felt when she had a panic attack: “I suddenly found my hands were shaking, my heart was going, my legs were like jelly”. Pippa's symptoms match some of those which were described by other participants, including dizziness, over-breathing, and racing heartbeat/palpitations. The variability of the symptoms associated with panic attacks was reported by Zoe, but what linked her experiences of panic attacks was the loss of control that she felt, which resonated with the loss of control that affected the participants when they were talking about other instances of distress. However, with the case of panic attacks, the loss of control that Zoe spoke of would then ultimately lead to her feeling frightened. Pippa described how having recurring panic attacks was “really terrifying” – a feeling of fear which was epitomised by Eve:

*I just had this terrible fear. And I remember saying to my husband “You know what? If someone said to me now, stand up against that wall and I'm gonna shoot you...” I said “that fear would be nothing to what I felt”.*

Feelings of anxiety could also affect an individual's sleep pattern – Anna described being “alert one hundred percent” because she felt that her “central nervous system wouldn't shut down”. Being unable to sleep could then exacerbate anxiety: a lack of sleep was reported by a number of participants as being particularly

problematic when combined with distress, as it made everything more difficult to cope with. Isobel explained how having to act as a carer for her children and elderly mother meant that she would sometimes have very disturbed sleep “and those are the times where perhaps I have a day of feeling just not coping physically very well”. Gemma was caring for a young child, and felt that a resultant lack of sleep helped to explain her distress:

*I think that was a big part... just feeling on edge and stressed out because I think my body had got to the point where it was just so used to running on cortisol from lack of sleep; that was why I felt like I was going to just explode.*

As with other types of distress, the outcome of the feelings of anxiety was a negative impact on the individual’s life. Kate summed up how she felt about living with anxiety when she described it as “a blockage” that prevented her from being able to do all the things that she wanted to do with her life. Jade recounted how her GP diagnosed her with generalised anxiety disorder after she had been trying to deal with anxiety that was “through the roof” for a number of weeks and meant that she had to keep walking out the office at work to go to the toilet because she felt like she “couldn’t even focus”, felt “absolutely beside” herself and was “just falling apart”. Pippa described how she felt impelled to change her job in order that she could work from home after her level of anxiety reached a point where she found it difficult to cope, and provided another example from the narratives of how big an impact anxiety could have on an individual’s life:

*I’ve started making my life smaller and smaller because I thought I was just having a rest “Oh, I’m just having a rest and this will go away and it’ll be fine” but because I stopped doing stuff, my anxiety – when I started to do normal things like go to the shop – started to get really massive. I was in (supermarket) and I was like “I can’t be in here”... And that’s when I went to see (herbalist) because I was like “This is getting out of control – soon I won’t want to leave the house”. And I started to feel nervous when I was at home, in my own house – it’s ridiculous.*

Pippa’s description of her life becoming smaller helps to illustrate that anxiety can be so severe that it can lead to feelings of – and actual instances of – isolation (isolation associated with distress is considered further in chapter 5). What was

also clear from the narratives was that the negative emotions associated with anxiety could also lead to individuals feeling low.

#### **4.6.2 Low Mood**

Aside from feelings of anxiety, the women often spoke of instances of low mood, which were sometimes (but not always) associated with a clinical diagnosis of depression, as clinical depression is recognised by a markedly low mood over an extended period of time (as explained in section 1.1.2). Pippa had given some thought to the different experiences of anxiety and depression. She described the sometimes complex relationship between these different aspects of distress, and described her mental health as “almost like peeling an onion, it’s so layered”. She surmised that depression and anxiety were “at the opposite end of the spectrum” but were still linked together:

*So I think depression – like numbing out of stuff – is one way of coping with a problem, and then anxiety’s almost the opposite reaction, to get hyperly stimulated by a problem.*

Actual experiences of depression, which were reported by over half of the participants, varied in their duration and intensity. Sometimes having a low mood was seen as part of the individual’s make-up: Carol described herself as “not an even keel person... you know, patchy bits of depression”. However, some felt their feelings of low mood could be attributed to various causes, such as the instances of bereavement reported in section 4.5.1. Diane described her instances of depression as “circumstantial and not clinical” as whilst she had “a tendency to be up and down”, she felt that she would not be prone to depression in “a normal life” – it was circumstances that led her to feel how she had felt. Whilst the distinction could be less important if the individual clearly needed help, the difference between circumstantial depression and a clinically diagnosed depression could be of great significance for the individual. Beth and her partner wanted to adopt children, but she was concerned that a history of anti-depressant use on her medical record might prejudice her chances of being able to adopt in the future, so

that when her GP prescribed a low dose of anti-depressants for her, she just “popped that prescription in a cupboard”. As she described it:

*Cos I’m not actually depressed. I’ve got a low mood, but I think that’s because I’m off sick, I’m at home, I’m feeling really useless, my dog died a couple of weeks ago – it’s all a bit crap really. And I think that’s a reasonable thing, to feel a bit down about it, but I’m not like, thinking that all is doom or anything like that. I don’t think it warrants medication yet, so I’m steering clear of that this time.*

Margaret, who explained in section 4.4 that sometimes “you’re depressed because you’ve bloody well got something to be depressed about”, recounted a description that had been given to her by a GP that she felt summed up her experience of depression:

*If you have a sleep and you get up and you feel better then it’s probably not depression. With depression you sleep and you wake up and you don’t feel any better – you want to go back again. Yeah, that’s true – that’s how it is.*

In the instance of Nicola when her son committed suicide, being labelled (or not labelled) with depression was less important as she clearly needed help for the way that she was feeling. Despite the fact that Nicola did not receive pharmaceutical treatment for depression, she was obviously living with the effects of depression. She spoke of how she felt at the time, and in hindsight was surprised that she had not been prescribed anti-depressants by her GP. Speaking to her GP after the event, she found out that he would have given her anti-depressants if she had asked for them, but as she had not he had felt it appropriate to refer her to bereavement counselling instead. Nicola was unsure why she had not asked for anti-depressants, though at T2 she reflected back that despite being “half mad” at the time, she must have known that she would either have had to take anti-depressants for the rest of her life, or would have had to stop them at some point and then deal with the trauma that she was feeling.

### 4.6.3 Metaphors of Distress

Whether the individual felt that there was a discernible reason for their low mood or not, there were some features from the narratives that seemed to epitomise depression, one of which was the depth of the low mood. In order to help illustrate how they were feeling, the participants would sometimes make use of metaphors. One metaphor that was frequently used was to describe their emotions by using colour (or a lack of colour). Beth, who felt that she was not depressed, despite being prescribed anti-depressants by her GP described herself as “feeling a bit grey”, but was “not in a black hole of doom, or anything like that”. But “black” did describe how some of the other participants had felt when they had experienced depression, such as Zoe who described what it was like when an on-going musculo-skeletal problem took away her ability to walk for a period of time, and described it as “a really black, black, *black*, black place”. Other participants similarly described their low mood as feeling like they were in a “dark tunnel” or were under a “black cloud”. Teri described how her recovery from depression felt like moving from having “a big black cloud looming over me, stopping me from thinking straight”, to feeling at T2 “so much lighter and like that cloud, that big blackness has gone”. In this instance, lightness not only described the escape from something dark, but also suggested a weight had been lifted which was a metaphor also used by Rachel who described how she found it more difficult to cope with life events generally when she had “the weight of the world” on her shoulders.

A number of the participants also referred to themselves in terms of being physically broken despite talking about emotional feelings. Following the death of her husband (reported in section 4.5.1), Carol described feeling as though she had “shattered”, whilst Margaret described how she felt when she had a nervous breakdown, and said she “just broke up into little pieces”. In fact, a number of participants used the analogy of crashing, but sometimes in different ways. For example, Jade described a time when the relationship that she was in was “about to car crash”, whilst Zoe used the term a bit more literally to describe a period her life when she was unable to walk and so “just crashed”. Vicki was given an analogy by

her herbalist to illustrate what was happening in her life, and was likened to a computer where:

*It all looks great on the surface, but you've got all these other programs going on in the background. Yeah, you get to a point and then the computer crashes.*

A number of the participants also described “falling” into distress. Vicki reported how a combination of trying to cope with domestic affairs whilst being treated for cancer meant that when she was “ill and tired, the whole thing spirals downwards”. Eve described how she had to get to a certain point before she could pick herself up: what she described as having “to reach that edge”, whilst Zoe also described feelings of “being pushed over the brink”. The use of metaphors of movement also allowed the participants to describe a sense of journey, that is to say they were able to move from one state (such as darkness) to another (such as light). Even when talking in terms of disintegration, whilst it clearly illustrated the destructive effect that distress could have on an individual, it also allowed the possibility of being made whole again. That is not to say that the process of recovery was easy, or that distress would not have a lasting effect on the individual. For example, when Nicola’s son committed suicide, she described how “it was as if a jigsaw had been flung up in the air and all the bits had come down, and they had to be put together – not the same, but somehow”.

Metaphors were also useful to help describe another feature of depression that was frequently quoted, which were the physical sensations associated with it. These sensations were in addition to any emotional feelings of being down. Carol described feeling “paralysed”, whilst Judith described how there were instances when she “got deeper and deeper” into “the mire”. Rachel described her feelings of depression thus:

*The dark mood feels more – I describe it like chewing gum where you feel everything is really stretchy and slow and it's fuzzy and I feel like held by chewing gum and it's all sticky and stretchy. Stretchy not in a good way, sort of slow and (grr) holding me, holding me down as if you're in a quagmire.*

The idea of “being stuck” was also spoken about by Diane:

*It was physical and mental I just felt – I think I described as being stuck together as if I couldn't move, literally so I couldn't put one foot in front of the other, and very helpless.*

In addition to the idea that depression is associated with an extremely low mood to the point where it can lead to physical symptoms, Diane's description (above) hinted at another feature of severe depression which was spoken of in other narratives of distress: a feeling that the individual had lost the ability to control what was happening. These feelings of losing control, and so feelings of helplessness, could be difficult to bear. After her son's death, as Nicola put it, she thought she was "going potty":

*I wasn't going mad really, because I felt so helpless and out of control that, because I'd never felt like that before I couldn't think what else it could be. But I had to feel in my bones that it was just a response to something that shouldn't have happened really. As a mother you think you will outlive your children. It never occurs to you for a second they will go first and certainly not that they would actually kill themselves... After (son) died, it was as if I came to pieces, and it was a physical feeling as I was told. I remember clearly, it was as if the skin that keeps the body in, just sort of dissolved and I was leaking out and everything else was leaking into me – it was horrendous. I felt helpless, I felt like a baby, awful, awful experience. God, I wouldn't wish it on anybody, no.*

Nicola's narrative stood out as it showed how difficult it could be to cope with a situation that was extreme in its level of emotional trauma, and clearly showed the depths of despair that the participants' narratives could descend to. Whilst the circumstances behind her story were unusual, the level of distress was something that was not uncommon amongst many of the participants' narratives. In fact, the level of distress could be so great that some of the participants who had experienced extreme lows, either as a result of personal circumstances or due to the effects of depression, felt it appropriate to talk of suicide.

#### **4.6.4 Talk of Suicide**

Eleven of the participants spoke of suicide during their interviews, but were grouped into those that spoke of suicide as a way of illustrating the severity of their

distress, and those that spoke of instances where they had seriously considered and/or attempted suicide. Those that spoke of dying but were clear that they would not have killed themselves, sometimes used talk of death to show how distressed they actually were. Beth, for example, felt particularly frustrated when her consultant did not appear to take the symptoms of her IBS seriously as she was not experiencing anything that he considered to be a severe pathology:

*I felt like I didn't have a chance to say to him "No offence, but I realise I'm not dying, but this is affecting every single aspect of my life – I can't stay like this for another three months. I can't". So, I mean I wouldn't commit suicide or anything, but like I don't know what I'd do – it's just (sighs). Well – it's not a life. Considering there's supposedly nothing wrong with me, it's not a life.*

In some instances, it was not the fact that the participant particularly felt like they wanted to commit suicide, but just a realisation that death would (at least in theory) be one solution to how they were feeling. Four of the participants spoke of death as being a release from the fear that they were feeling as the result of panic attacks. As Zoe said "I don't think I was suicidal, I was not suicidal. I did not try to take my own life, but I think I thought if I died it would solve it". Diane and Rachel spoke of how their mood had led them to the point that they thought of suicide, but both were still insistent that they would never actually commit suicide. The thought that someone could be depressed enough to consider taking their own life, but that in reality suicide was not an option was something that three of the participants spoke of. However, why they could feel so bad to consider suicide but still know that they would not take their own life was something that they found difficult to rationalise. Rachel tried to explain how she felt when she was particularly down:

*I was feeling very down, to the point where, I would feel perhaps even suicidal – I know I won't ever commit suicide, I know that, somewhere deep inside but the thought would cross my mind. It's a bizarre sort of thing to try and explain that you can feel so down and desperate but knowing fine well that you're not going to do it, if that makes sense, but it's the sort of that would just be the easy way out.*

Diane also spoke of a specific instance that stood out for her where one night when she was living with depression, she had been walking alone around the area that she lived, and eventually found herself by the river:

*I walked along this lane and stood on the edge of the river and thought "Why can't I commit suicide?" I knew I wouldn't funnily enough, which is a good thing, so I know I'm not a suicidal person. I felt I can't get more depressed than I am and yet I can't jump in the river, so I was kind of stuck... I still don't understand what makes some people suicidal and some people not, because I don't think it's the degree of the depression...*

In spite of Diane considering that the degree of depression was not necessarily an indicator of what would make an individual actually attempt suicide, five of the participants spoke of having serious suicidal thoughts. Three of these were women who had not attempted suicide but who had got to a point of desperation. Two of them had been living with extreme insomnia as part of their distress, and this was a contributing factor as to why they were feeling so desperate. As Wendy reflected, she could understand why forcing people to stay awake had been used as a form of torture:

*I virtually got suicidal at one point because I was just so tired. I could barely stand up at some times and if it hadn't been for (husband) I think I probably would've done something... I would've done something silly I think because I just got so desperately low.*

For Wendy, it was the physical symptoms that she was experiencing after having to come off of hormone replacement therapy and so dealing with the effects of the menopause that were causing her not to be able to sleep. However, in the case of Nicola, it was the anguish of losing her son that meant her mind would not switch off:

*I mean I was in such a state, I could have quite happily have killed myself because it was so painful. I mean horrendously painful and... Cos you have thoughts going round in your head all time. You're lucky if you get an hour's sleep. Of course you want that to stop. Unless you're a masochist, you want it to stop.*

Whilst Wendy and Nicola had been desperate enough to consider suicide, they were in a position that they had a level of support which helped them through the

desperate times. For Wendy it was the support of her husband (and also her herbalist), whilst for Nicola (as well as the support of her friends and family) it was the bereavement counselling service that her GP had recommended.

Unlike the other participants, Lily and Sam had both attempted suicide when they were younger. By the time that she started seeing her herbalist, Lily had had chance to look back at her suicide attempts, and decide that it was something that she no longer felt was appropriate:

*I remember the moment thinking "Okay I don't do suicide any more" but I haven't quite learned the wanting to live. I've stopped wanting to die, which is a big step, I've sort of not quite made the wanting to live. It's a different thing; it's not the same as not wanting to die.*

Sam had also attempted suicide on more than one occasion when she was younger and living in an environment of abuse, but felt that she "grew out of that". However, when she went through a spell of severe depression as an adult, coupled with the stress of having to cope with on-going eczema, some of her suicidal feelings resurfaced:

*When this depression started I thought a lot about killing myself – yeah, all the time. And if I hadn't have had children, I think I would have done a long time ago, but I didn't want to leave them – and certainly not in that way.*

Sam spoke of feelings of responsibility towards her children and not wanting to leave them as a reason for not committing suicide, although she had attempted suicide when she was younger. There was no clear reason that would prevent someone attempting suicide, though feelings of responsibility to protect others (considered further in section 5.4.4) was spoken of by Diane:

*I do remember about the suicide thing I thought of my cat, how I would never be able to explain to my cat if I didn't come home. And my father who knew absolutely nothing and my dad was in his eighties I think at the time, late seventies maybe, and the fear, the idea that I could never explain to them what had happened...*

Whilst talk of suicide naturally stood out within a narrative, it should be remembered that the majority of the participants did not talk of suicidal thoughts,

and over half of those that did were insistent that they would not actually commit suicide. However, what these narratives did show was the extreme depths of distress that women can experience, whether that be due to circumstances, ill-health, or feelings such as anxiety and depression that have no discernible external cause. What also emerged from the narratives was the impact that living with distress (whatever the cause) could have on the participants' views of themselves.

#### **4.6.5 Loss of Self**

A number of participants spoke about distress changing the way that they viewed themselves. Pippa described how experiencing anxiety and panic attacks had changed the way that she viewed herself "in a negative light", whilst Judith explained how chronic menopausal symptoms had "knocked the confidence" out of her and made a big difference to how she viewed herself. Beth also described how distress had changed the way that she viewed herself, and how she felt that she wanted to get back to how she used to feel prior to her anxiety/IBS problems:

*Feel like I'm trying to get back to how I was pre 1993, because that I feel like was me, and everything else since then has been sort of, I don't know – marred by a cloud...*

Beth's description was similar to a number of the participants in as much that she described feelings of having lost her sense of self. Anna saw her role changing to one of a patient when she started experiencing anxiety and panic attacks, but "hated" the fact that she no longer felt like herself, and stated that she "felt lost" in the role. Una felt that having to change her life in order to care for her partner could make her feel like she was being "swallowed up" by the situation and was "losing a piece" of herself, but rationalised that feelings like that were normal under the circumstances, and she would only really feel like that if she was having a bad day. At T2, Una considered that her and her partner's circumstances had improved, although the situation was still having an impact:

*I suppose I still feel like I've lost that piece and I don't know whether I'll get that piece back, because it is like what our life was*

*going to be and our life – even though everything is good here, and it's fine and we've come through it – it's not the same. And it'll never be the same. So I might have lost a piece but that's okay really, because (partner)'s lost a piece too. I feel like we've lost the life that we would have had but now we have a different life, it's just going to be different. So, yeah, we just have to change it.*

When Scarlett was living with distress, a combination of factors – which included moving out of the family home, the breakdown of a relationship, and bereavement – left her “feeling sad and empty and not feeling myself”. For Teri on-going circumstances, such as financial issues and problems with close family relationships also took its toll, so that when she first went to see her herbalist, she told the herbalist that she had “completely lost” herself. Having to cope with on-going musculo-skeletal problems was something that Kate found frustrating, particularly as she felt like it was difficult to get to the root cause of the problem. Being told by medical practitioners that she was “fine” just added to her frustration and led to her feeling “lost” as she contemplated how she was going to be able to get back to how she had been feeling before she became ill. Yvonne summed up not only how living with chronic fatigue (also known as myalgic encephalomyelitis or ME) had affected how she felt, but also what she was able to do:

*And I do remember saying to somebody that I felt like the ME had taken my personality – it had taken who I thought I was, because to a degree sometimes we define ourselves by who we are in the workplace, who we are in our social group, and gradually all those things were being taken away.*

Ultimately, the diverse causes and feelings of distress resulted in a negative impact on the individual's life. However, Yvonne's narrative helped to illustrate how the impact could not only be profound, but also extend beyond the boundaries of the individual.

#### **4.7 Impact on Life**

One of the things that the participants reported across the narratives was the way that how they were feeling, either physically or emotionally, could have a negative

impact on what they were able to do. Aside from the distress as a result of being physically unwell or due to some emotional/mental upset, the participants' distress could therefore be compounded by not being able to live their everyday lives in the way that they wished. Some of the greatest impacts due to ill health were reported by those who were living with chronic fatigue. Yvonne spoke about times when her fatigue was so great that "you can't shower... if you have managed to shower you can't lift the hairdryer". This level of fatigue would then have an impact on all areas of the individual's life. Yvonne also described "a time when I was desperately trying to hang on to work life, social life and they were all gradually slipping away". Lucy described what the experience of chronic fatigue felt like for her:

*So your whole life just literally concertinas in on itself, and if you have very little energy... it's physically difficult to do things. What tends to happen is the things that go first is all the things that you find pleasurable and fun. So very often all the things in your life that were pleasurable and fun have disappeared, and you're left with trying to cope with the absolutely essential survival things, like trying to keep on top of your bank statements, and trying to feed yourself. So anything other than survival becomes sort of extra.*

Whilst physical symptoms could have an impact on an individual's life and so contribute to their distress, their effect was no more dramatic than mental distress, as Eve illustrated:

*With a clinical depression, the obsession just took over. I couldn't eat, couldn't sleep, couldn't do anything – couldn't look after my children, didn't want to do anything, didn't want to get up, didn't want to get dressed, didn't want to go out, nothing, nothing at all.*

Eve's narrative illustrated the impact that mental distress could have on an individual's well-being and ability to carry out everyday functions. Sam also spoke of the difficulty in performing basic functions when she was living with depression, as "sometimes it was all I could do just to get out of bed and wash myself... Sometimes I didn't wash myself, I just sat around and it was terrible". Health problems could also make it difficult to hold down a job. Sam described how living with depression prevented her from working in the same way that a physical illness could: at one point she used to work one day a week on a vegetable stall, but her

depression meant that “I was ill more times than I went there” and so she “lost quite a few little part time jobs like that”.

The impact that being ill and distressed could have was not limited to the lives of those living with distress, but could also affect those around them. Not only did Sam’s depression lead to her not being able to hold down a job, but when she was “very ill” her husband also lost jobs as he would have to leave work at short notice in order to be able to care for their children when Sam was unable to. The situation meant that her husband at times needed to take “some pretty awful jobs”. The pressure of work coupled with a wife that was chronically depressed also affected his mood, though he only spoke of it to his wife after she had started to recover as he did not want to make her feel any worse. Sam was convinced that how she felt had actually affected “everybody in the family... in lots of ways”:

*I mean my children suffered in a way, because I did the things I had to absolutely do, but I couldn't do more than that – like I couldn't always take them out in the holidays because if I was depressed they just had to play in the garden... So I didn't take them out very often, yeah. And I still feel quite bad about that, to this day actually – it's quite upsetting to think of how I used to be, yeah (participant gets upset).*

Like Sam, Anna also spoke about how her problems with panic attacks affected her family and meant that her husband had to take time off of work when she was ill, a situation that she described as “a domino effect”. Linking back to Hayley describing how her mother’s illness was harder to bear than her own (section 4.5.1), the effect of illness and distress on those around them was something that Lucy considered to be worse than actually having a chronic illness:

*It was much harder for my husband, cos he was looking after the household, trying to earn enough money to support us, and worrying about me, and having no social life with me because suddenly his partner wasn't able to go out or do the fun stuff he wanted to do.*

So the distress not only affected the individual but, like ripples in a pond, could spread outwards and affect those around them (a realisation of this fact and attempts by the participants to protect others is considered further in section

5.4.4). The participants were then left with a situation that distress not only affected them as an individual, but affected what they were capable of doing, how they acted, and so affected their family and friends. The effect on others was something that could be difficult to come to terms with, and could make the participants question how others viewed them. This was particularly relevant for Beth, as she felt that the way that social workers would view her would affect the chances of her and her partner being able to adopt children. She tried to view herself through the eyes of a social worker and concluded that she was “just a big fat disaster”, which gave her a harsh view of herself as she felt that if they were turned down for adoption it would be entirely her fault. As she explained:

*So that's really hard, because I feel like I could end up denying him the chance of a family because, I'm not good enough to adopt.*

#### **4.8 Summary**

Distress, which the participants' narratives suggest may commonly be presented to a herbalist (and the herbalists also reported commonly treating), paints a complex picture. The experience of distress for the participants has been typified by feelings of anxiety and low mood: these feelings can range from feelings of a chronic underlying stress, through to feelings that are so extreme the individual is unable to function. The narratives have shown that life events can play a part in engendering these feelings, with bereavement and ill-health being the two that stood out in the participants' stories. However, a range of events can lead to distress, including feelings of anxiety and/or depression with no discernible cause. How distress can present itself can be highly variable: physical illness can lead to emotional distress; feeling distressed can lead to physical symptoms; distress can contribute towards insomnia, whilst insomnia can lead to distress. Within this complex picture, metaphors can help to illustrate the severity of an individual's distress, which might otherwise be difficult to describe. However, metaphors are also useful as they can show similarities across diverse experiences of distress: how an individual can feel lost within the dark (which can be equated with a loss of self and/or agency),

weighed down (which bears similarities to descriptions of literally being unable to move when ill and/or depressed), or physically broken and in pieces (and so in need of mending). Metaphors are also used to describe stories of recovery as each metaphor had an opposite that could be strived for – darkness could be banished, weight lifted, or broken pieces put back together.

What appeared throughout the narratives was the negative impact that distress could have – not only on the individual, but also those around them, with the effects moving out into other spheres such as the workplace or social circles. However, one other potential problem that also appeared but has not been fully explored within this chapter is the suggestion that distress can be isolating. Many of the narratives described how physical or emotional distress could lead to the individual's world getting smaller, but that this isolation might remain invisible in many instances where individuals tried to manage the impact on their wider social sphere. Feelings of isolation were so common, that the idea of isolation due to distress and the reasons for this isolation form the subject of chapter 5.

## **CHAPTER 5: ISOLATION AND SOCIAL ACCEPTABILITY**

### **5.1 Introduction**

Chapter 4 introduced the participants and their experiences of living with distress. The chapter also highlighted one area that required further investigation as it was spoken of by all the participants: the association between distress and isolation. The participants' stories were diverse, so that the extent of the isolation could vary, and the reasons for the isolation were also different, but all such experiences had the potential to add to the distress of the women. The form that the isolation took could be broken down into three broad categories, although they could also occur concurrently, which blurred the lines between them. These categories were: physical isolation and social isolation (considered together in this chapter), and isolation as a coping strategy. What follows in this chapter is a review of the main types of isolation (including associated feelings of embarrassment, shame and guilt), followed by consideration of an underlying contributor to isolation – the social acceptability of distress – and how the participants reacted to perceptions of stigma surrounding their distress.

#### **5.1.1 Themes**

Five themes are presented in this chapter concerning isolation and social acceptability:

1. Distress can lead to physical/social isolation
2. Whilst distress can lead to isolation, isolation can be used as a way of coping with distress (though the isolation is not always helpful)
3. Women frequently experience feelings of embarrassment, shame and guilt due to their distress
4. Feelings of embarrassment, shame and guilt are linked to individuals feeling that their distress is not socially acceptable

5. Perceptions of stigma associated with distress can lead to women trying to “put up a front” – partly to hide their inability to cope, and partly to protect others.

## **5.2 Isolation**

### **5.2.1 Physical and Social Isolation**

Circumstances (such as being unemployed or being ill) have the potential to encourage physical and/or social isolation. A further example from the narratives of how a woman could become physically removed from public life involved taking the role of a full-time mother. Sam spoke of how living with depression had led to her becoming physically isolated, but felt that even if she had been well, she would not have wanted to go out to work when her children were young as she wanted to be with them. This was in contrast to most of her women friends who went back to work, which left her feeling “a bit isolated... well quite a lot”. Gemma also reflected on how much her world had shrunk since she had given birth and become a full-time mother. A combination of factors, such as the fact that many of her relatives lived abroad, most of her friends had jobs, and caring for a young child meant that she spent a lot of time at home – all of which contributed to her physical and, subsequently, social isolation. In particular, she was aware that the environment that she was in meant that she no longer had the opportunity to “have great conversations with many people through the day” as her child was only starting to learn how to talk.

The role of being a carer was not limited to looking after children. Four of the participants spoke of having responsibility to care for their mother at T1, whilst one had given up work to care for her partner when he became ill. Being physically, and so socially, isolated from friends and family was also not limited to those who had taken on the role of a carer. Between T1 and T2, Beth had moved house and so found herself in a situation where she was not only unable to work, but was living in an area that she did not know very well, with very few friends or family close by.

Anna also spoke of a similar situation where, although she had lived in her current house for a number of years, she had not formed many relationships in the area, which meant that when she became unwell it was difficult to have contact with her close family and friends who also lived some distance away.

As was discussed in section 4.7, distress could have a negative impact on the individual's life, including their ability to work. This inability to work could in turn exacerbate their distress, as over half of the participants spoke of how not being able to work had the potential to have a negative impact on their well-being, which could further impact on their ability to work. Beth provided an example where the physical symptoms of her IBS, coupled with her associated emotional distress, led to her feeling isolated as she was unable to work. Yvonne also spoke of desperately trying to hang on to her work when she first started to live with chronic fatigue. The inability to work could also adversely affect the individual's finances. Being financially restricted emerged in over half of the narratives, as it affected how the women were able to conduct their lives – including their ability to be able to afford a range of complementary therapies.

Whilst individual cases of ill health were different, all resulted in the individual's worlds becoming smaller as they were less able to physically do everyday tasks such as going to work, shopping, or socialising. The process of being physically ill was itself clearly distressing, but the impact that the symptoms could have on the individual's ability to function would also at times add to their distress. Lucy described how the symptoms of her chronic fatigue meant that she was unable to do the things that she loved doing, which she found "really frustrating and depressing" and resulted in the fact that her life "just reduced down to a very small set of circumstances and experiences". It was not only missing things that the women loved doing that could be frustrating, but also apparently mundane things that could once be taken for granted, such as three participants (Beth, Isobel and Zoe) who spoke of missing being able to do the food shopping. Vicki provided an example describing how she felt when she underwent chemotherapy:

*And when you're ill, you're tired, so you can't do anything. You just feel.. No, you can't be bothered, so you don't achieve – it's not*

*a question of achieving and ticking things off, but you just don't do anything, so you don't go anywhere, you don't do anything. It's boring. But... that's what you've got to do – you've got to rest, but it's pretty tedious.*

Physical isolation associated with mobility problems were keenly felt by nearly a quarter of the participants. The negative impact it could have was succinctly summed up by Kate, who spoke of her on-going musculo-skeletal problems and exclaimed that “I couldn't do my life”. In particular, Kate's feeling of not being able to do her life was again linked to the fact that she was unable to work, which was a situation that she felt she had to defend against questions from her family:

*I'm like “I can't work! I can't think, I can't read, I can't do anything”. So it was a constant struggle of getting a job and working and not being able, and finding the right solution.*

The fact that Kate felt she had to defend her inability to work to other people, highlighted that being unable to work was socially unacceptable, especially in Kate's case as her condition had no outwardly visible signs and could be construed as malingering, which is considered within a wider context in section 5.4.

The narratives showed isolation could be exacerbated if the individual had physical symptoms that were visibly noticeable, and so led to them feeling self-conscious about their appearance. Menopausal symptoms were mentioned by four of the participants. Isobel spoke of how her hot flushes made her feel:

*And depressed, feeling very, very low, tearful, not being able to cope with anything and socially didn't want to go out, didn't want to do anything, because I just felt, every time I sat down my face would just whoosh, and I couldn't be anywhere without feeling very uncomfortable. I'd have choking fits, I felt as if my throat was closing in, yeah, they were quite all consuming really.*

Isobel's feelings were echoed by Wendy whose menopausal symptoms also meant that she did not want to socialise as she found that the anxiety of socialising tended to make her hot flushes worse, whilst having a hot flush would make her feel embarrassed and so exacerbate the anxiety. Judith also voiced concerns with regards to what others thought of her when she was living with the menopause and a thyroid dysfunction. How she felt affected her social life, as the inability to control

her symptoms meant that she was unable to commit to social events “unless they were willing to let me tell them at the last minute”.

Skin conditions were another visible problem that was spoken about by a fifth of the participants in terms of isolation. Carol described her skin when it was particularly bad as “completely raw and sticky, horrible”, which led her to wear lots of scarves over the area in an attempt to hide it “because it looked so odd”. Gemma also spoke of a time that she used clothing to hide her skin when living with psoriasis, but was unable to hide the fact that her hands looked like they “had third degree burns on them”. She described how she perceived that fellow commuters used to look at her with pity. This made her feel “just awful”, as she explained:

*That was just really upsetting because, like I didn't feel like I actually needed to be pitied, but the looks on their faces were with pity. It's a long train ride as well – forty minutes of somebody sitting opposite you with a look of pity on their face is a bit like “I know I've got this – please stop looking at me”.*

As well as purely physical symptoms, emotional symptoms such as anxiety and low mood could contribute to isolation, and was reported by over four-fifths of the participants. Judith described how feelings of anxiety would make her “retreat into myself” as the fear of getting “a bit panicky” and “not be able to cope with it” when in public resulted in her feeling that her world became smaller. Pippa did have a network of friends where she lived, but surmised that they were unaware that she was feeling socially isolated as her living with anxiety “coincided with when I've got married and when I've moved, so I think maybe they think I've just settled down into married life and don't want to know my friends any more”. Una also considered how others viewed her situation after she had to become a full-time carer for her partner. She felt that there was a lot of support when the incident first occurred, but “that stops after a period of time and then you are on your own”, which she partly attributed to others feeling that she was able to cope with the situation, although that was not necessarily always the case. Eve spoke of her previous experience of depression: one of the features that she associated with being depressed was feelings of fatigue, so that everything she did she described as “such an effort” and meant that she felt like she wanted to withdraw into herself

and just go back to bed. This physical withdrawal from everyday life appeared to be a feature that was particularly associated with feelings of anxiety and/or low mood. Sam summed up her isolation when feeling depressed:

*It was like anything, anything at all that happened just made me... want to run and hide and go to bed, which I did quite often, yeah.*

What became clear from the narratives was that the effects of isolation could become extreme. Nicola spoke of the time after her son committed suicide, and described how she became “semi-agoraphobic” as her “GP delicately put it”. Whilst Nicola tried to put a humorous slant on the situation, it was clear that she found it almost impossible to function in the wider world at the time. She described how she was in such a state, that some time afterwards she felt “surprised that the planet was still spinning on its axis” as she had been so “cocooned” from everything going on around her.

Feelings of isolation could be ameliorated to a certain extent if the individual had some form of support to hand, such as Pippa’s husband who she described as “an absolute angel”, or Isobel’s close friends who were described as “amazing, lovely, lovely girlfriends”. However, in some instances, the availability of support was not enough to overcome feelings of distress. This situation was illustrated by Lucy, who explained how the physical symptoms of her chronic fatigue meant that she had to give up a lot of the things that she loved doing, but that it was especially true for social situations, which she found “most exhausting”. This left her in a catch-22 situation as she felt that she would “desperately need support, and want stimulation of other people”, but “if they turn up to see you, often you don’t have the energy for it”. The utilisation of technology had the potential to be of benefit when dealing with isolation, as it could help overcome physical/geographical isolation that an individual might be experiencing. However, how the participants used technology to keep in touch with friends and family had a marked degree of variation. Rachel was not very keen with talking on the telephone, and would use it to talk to friends who were living in a different country, but did not talk to them as much as she would if she was able to talk to them face to face. Conversely, Scarlett found the telephone useful when she was living with a low mood after a

relationship finished, partly because she was living away from the majority of her friends and family. She also found it easier to talk to friends on the phone as she could hide her facial expression, which could help control how much she revealed about how she was feeling (or felt was acceptable to reveal). Sometimes the use of telephones to maintain contact with others was variable, and would depend on how the individual was feeling at the time. Vicki considered how difficult it could be for people to say the right thing when they wanted to support her after she was given a diagnosis of cancer. As she described it, there was nothing that they could say to make it better, but whilst she sometimes appreciated people phoning up, sometimes she would think to herself “I don’t want to talk to you today”.

What the narratives suggested was that sometimes, even when social interaction was available, there was no guarantee that it would be the type of support that was wanted or useful. What they did show was that there was a split in those that were experiencing isolation, between those that felt isolated as they perceived that opportunities for social interaction had been taken away from them, and those that had the choice of whether they wanted to socially interact with others but chose not to. In some cases, the impulse to isolation could lead to further withdrawal, such as the quote from Sam (above) who described wanting to “run and hide”. Using isolation as a coping strategy is the topic of section 5.2.2.

### **5.2.2 Isolation as a Coping strategy**

The participants would sometimes talk of other negative feelings (such as embarrassment, shame and guilt) that were associated with their distress (discussed further in section 5.3). One way of dealing with these sorts of feelings was for the individual to remove themselves from social situations, and was spoken of by nearly three-quarters of the participants. In these situations, whilst feelings such as embarrassment were undesirable, the individual could at least help alleviate the embarrassment by removing themselves from the situation, and so help regain some element of control. Isobel explained how experiencing hot flushes whilst out shopping made her feel so bad that she started doing her grocery shopping online.

Beth spoke of how important it was to be able to retain some control when dealing with her IBS:

*If I go anywhere, I have to go in my car on my terms – I don't go on coaches or anything like that, because I have to be independent. I have to be able to get home myself, and leave when I want... I don't want anyone to rely on me, and I don't want to rely on them because I need to make sure that if I need to go home – or because I'm running late because I'm stuck in flipping bathroom again – that it's not going to affect anyone.*

Beth's desire to retain some control was linked to the embarrassment that she felt about her physical symptoms, which she described as "mortifying". Using isolation as a coping strategy was not only utilised by those that had physical symptoms which were obvious to others, but was also used as a strategy by those that were feeling emotionally distressed. Examples include Carol, who spoke of going "deep inside" herself and not wanting to talk about how she was feeling, whilst Judith described how she "retreated from life quite a lot". Putting her needs above the needs of others was also something that was described by Lily, when she spoke of the moment between T1 and T2 when she "crashed", which was a point where she felt she had to give up a lot of her responsibilities and take care of herself.

Some participants reported negative aspects to choosing to isolate themselves. That is not to say that some of the participants did not have a genuine desire to withdraw from others as a way of coping when they were experiencing distress, but that there could still be a negative aspect to the isolation. As Rachel put it when describing what the experience was like for her when she was feeling down:

*So really withdrawing and I know when I'm well that I do need that as well because of my job, I'm always with people all the time and there are times when I just kind of go "Oh, leave me alone, I don't want to talk to anyone", but it's a very different wanting to be alone. And wanting to be alone and at the same time feeling very lonely because of that, and not wanting to be alone, if that makes sense, but not really knowing how to step out.*

Rachel's narrative showed that some aspects of using isolation as a coping strategy could be undesirable. Pippa's narrative went further to show how the isolation that began as a coping strategy could become a source of distress:

*Once your coping mechanism becomes to walk away from a situation “Oh, I’m really stressed here, I’m going to start walking away to the bus stop to go home or to the car or wherever” and that relieves the stress you’re feeling and the anxiety, then every time you’re in a stressful situation you want to walk away because you know that’s going to make you feel really good getting away. But then you can’t always do that. For example at a funeral or at a wedding you can’t just go “Yeah, I’m just going to bugger off now” during the vows. So once that becomes your only coping mechanism then you start using it all the time because you can’t tolerate sitting with the anxiety. And then you either stop going to stuff, or you start leaving things really immediately and the point where you feel like you want to leave becomes sooner and sooner. So before it’s like during the thing, and then it’s like on the way to thing, and then it’s before you leave the house to the thing. So it starts to eat away, starts to take little chunks further on. So, yeah, so that’s what happened. So then my life became really, really small. And then I thought “This is not good – I can’t get out and do stuff”.*

Whilst being able to withdraw from social situations could help an individual to cope with feelings such as embarrassment, it did not always result in them regaining control. Sam went to see her herbalist with on-going eczema, but spoke of a time when it was particularly bad – a situation that was exacerbated by Sam also having a history of depression. Whilst she used a coping strategy of isolation, it was not something that she necessarily felt she had much control over:

*I remember standing at the front door being totally unable to open it and go out and just crying my eyes out, because I just couldn’t. I just couldn’t, because I just felt “Yeah, everybody’s looking at me and saying horrible things about me”. So, yeah, it was a way of coping but it was also I just couldn’t, sometimes I just couldn’t do it.*

For Sam, her strategy of isolating herself could help with feelings of embarrassment, but she also had to contend with feelings of shame (discussed further in section 5.3). These were linked to her history of depression after a traumatic childhood, and meant that she “couldn’t bear the thought of being looked at – with or without the eczema”. This also provided an example of the perception by the individual that aspects of their private self could be visible to others (considered further in section 5.3). For Sam, her attempt at dealing with how she was feeling at the time was to

avoid going out in public as much as possible. However, in some ways Sam's strategy of isolation became counter-productive as it made feelings of loneliness worse. The result was a further loss of control as a combination of factors meant that Sam no longer felt able to affect her isolation.

There was a further reason why some of the participants felt the need to isolate themselves, whether due to a physical or an emotional complaint, which was the perception by the individual that what they were experiencing was not acceptable to others. This was most noticeable when the narratives spoke of physical symptoms that could lead to isolation. When Beth was speaking about her digestive symptoms, she described them as "embarrassing or socially unacceptable". However, whilst some participants could feel very uncomfortable about any physical symptoms that they may have been living with, the narratives also suggested the notion that some elements of emotional or mental distress could also be perceived as socially unacceptable (discussed further in section 5.4). This perception was often associated with feelings of embarrassment, shame and guilt, outlined in section 5.3.

### **5.3 Embarrassment, Shame and Guilt**

Feelings that commonly accompanied distress were those of embarrassment, shame, and/or guilt. Feelings of embarrassment were invariably linked to physical symptoms, and were mentioned by almost a third of the participants. As described in section 5.2.2, Beth did not want anyone "within a ten mile radius" when dealing with her IBS, as having to keep going back and forth to the bathroom felt "mortifying". Another example was Eve, who first went to see her herbalist with a persistent cough, which she found embarrassing when she unexpectedly found herself having a coughing fit. Her spasms of coughing could be so violent and uncontrollable, that it could sometimes lead to urinary incontinence and so resulted in her not wanting to go out. One feature of embarrassment in these instances was that it could be alleviated by the individual removing themselves from public gaze.

Isobel explained that how she felt about her menopausal symptoms would differ depending on the circumstances:

*But the night sweats that's different because you're in your own space away from anybody aren't you? The issue is when you're out and about and you're dealing with everyday life, that's the hard things with hot sweats.*

Whilst embarrassment is often considered to be distinct from feelings of shame (outlined in section 2.2.4), it was sometimes difficult to differentiate between the two within the participants' narratives, as talk of shame was only mentioned infrequently. When being ashamed was spoken of, it was sometimes used interchangeably with descriptions of embarrassment, such as Scarlett describing at one point how she "felt very embarrassed almost and like probably quite ashamed". Whilst the concept of shame was not frequently mentioned by the participants, their narratives did include instances that gave an impression of feelings of shame. Shame often accompanied instances where the individual felt that a judgement was being made of them. Whilst physical symptoms could be embarrassing for the individual, physical problems with no obvious external sign could induce feelings of shame. As noted in section 5.2.1, Kate found herself having to justify not being able to work to family and friends as her musculo-skeletal problems were not immediately apparent. Zoe also spoke of her musculo-skeletal problems, and looked back to a time when the condition had a big impact on her mobility:

*I can put things in my diary. God to put things in my diary, I know the chances are I'll be able to go, is amazing for me. Because I used to put things in my diary and I used to say to the person "Oh by the way don't think I'm really odd but I might not be able to come because my legs might not work on that morning". And that was what I really feared, because then people would just think I'm a nutter.*

As in Zoe's case, the lack of external signs meant that mental/emotional distress could also result in feelings of shame and of being judged. Fay explained that feeling anxious for no reason could be seen as "inappropriate", but the anxiety could then be exacerbated by the perception that others would consider the anxiety to be "ridiculous". She described how the views of others could make the

individual feel upset, no matter how thick their skin was. As Fay put it “I don’t care if you’re a rhino; it’s still not very nice”. In some instances, feelings of distress could remain hidden: Beth described how she thought that others perceived her as being “super-duper calm” in a crisis, whereas inside she likened herself to the painting *The Scream* by Edvard Munch, thinking “Oh my God! What am I gonna do now?!” What Beth described, was a situation where her private self was able to remain hidden, and so distinct from her public identity (the idea of “putting up a front” is discussed further in section 5.4.2). However, in cases where an individual perceived that their emotional distress was visible to others, they were more likely to have feelings of embarrassment and/or shame. These feelings could make their distress worse, in a similar way to Isobel (above) describing how it was more distressing to experience physical symptoms of the menopause in public than when at home. Yvonne described having a panic attack whilst attending a conference, and spoke of worrying what others might think. Her feelings at the time meant that she felt the need to get out of the situation that she was in, but was compounded by:

*Fear that I would attract attention in getting out of the room – I think I was scared I was going to collapse on my way out. So the relief when I finally made it to the door and was able to hide in the ladies toilet for a bit and try and calm down.*

Yvonne’s narrative helped to illustrate how private feelings of distress could be exacerbated by the individual’s perception that those elements of their private self were escaping out into the public space, and so could affect their identity. Pippa provided an example of how distress (due to living with anxiety) could not only affect perceptions of the (private) self, but also of (public) identity. Pippa was keenly aware of how she felt at T1 compared to what she had been like in the past, when she had been employed doing what she described as “a really scary job”:

*After I did that job I was like, “Oh, I can deal with anything now because I’ve dealt with a screaming bunch of drunk people in the middle of (urban area) on a Saturday night, yeah, I can handle anything”. So then suddenly being afraid to go into the supermarket, or to go in the car to visit my mum was really hideous – and having to admit that to people was quite hideous.*

Not only did Pippa's distress feel "hideous", but admitting to others how she was feeling was described in the same terms. She explained how it felt "really exposing" to tell somebody about her problem and how she thought that "it reveals your inner life to admit a mental health condition", which risked others having "a lesser view of you" as "it would reflect other areas of your life". Concern about the views of others is also discussed in section 5.4. Scarlett explained how her concerns had to be overcome when she first went to see her herbalist whilst living with a low mood combined with issues concerning food. She described that before her first visit she was "really nervous", "very embarrassed", and "quite ashamed" of herself for feeling the way that she did. In particular, she felt that how she was feeling was "quite a selfish thing" as when she thought about "all the other bad things in the world", she was "much better off than everybody else". This led her into a cycle of feeling bad, but then "feeling guilty for feeling bad". What became clear from Scarlett's narrative was that whilst the herbalist was initially a stranger, and so a member of the "public", they provided a space where "the emotional things were allowed to be said", which resulted in Scarlett leaving the first visit "feeling positive" that her situation "would be alright". The role of the herbalist in helping women living with distress is considered in chapter 6. Scarlett's narrative also showed a further area that could be a feature of the participants' distress, which was a feeling of guilt.

For Scarlett (above), much of her guilt came from comparing her distress to how (she perceived) others were feeling – a type of "social comparison" (considered further in section 7.5.4). In this instance, Scarlett felt that she was "much better off than everybody else". Wendy also had to come to terms with how she was feeling when menopausal symptoms affected her mood. She reasoned that because she was financially secure, had "a nice house" and "nice friends", and she had survived cancer, that "it was so silly to be so low". In particular, Wendy felt "a bit stupid" that she "wasn't able to cope". Wendy's narrative was typical of the participants' narratives in that whilst she felt guilty for feeling bad when she was apparently comfortably off, the thing that she felt worst about was being unable to cope and the impact that this might have on others (considered further in section 5.4). Anna

also reported that living with anxiety left her feeling like “this whole scene has made me feel guilty that I’ve let everyone else around me down” including family, and elderly neighbours that she used to take shopping. Lucy was another participant who reported similar feelings when she was living with chronic fatigue:

*So you might have endless time lying on the sofa and thinking about trying to sum up the energy to make a cup of tea, and that might become the sort of focus. How do you pull yourself together to get up and make a cup of tea? Or do you wait till somebody who comes, who you can persuade to make you a cup of tea? But they’re probably busy, and you’re already feeling guilty because they’re probably taking care of things that you can’t do that you would normally do. So, it changes, and it changes the relationships you have with all the people around you.*

The narratives also showed that the participants felt bad when living with distress because feelings of being unable to cope left them with the idea that they were not able to “pull their weight” – whether at work, but particularly within their domestic situation (an inability to cope with different roles is considered further in section 5.4). One example was provided by Sam who reflected back on a troubling time for one of her children and explained how she felt that “if I was more able to cope at that time I would have been able to stop that happening to him”. Whilst Sam was able to rationalise that she would probably not have been able to protect her son, it did not stop her feeling bad:

*As a parent you always feel really responsible and I do feel – I still think about that a lot. I feel very guilty about that. But I know there’s nothing I could have done but do you know what I mean? I just do feel quite sad about what happened to his life.*

Overcoming these feelings of guilt could be an important step in starting to deal with their distress. Lucy considered how she felt it “very un-trendy” to suggest putting oneself first, but that sometimes it was necessary in order to be responsible for one’s own well-being. Others also spoke of the need to look after themselves, such as Eve who described how she used to feel guilty if she was not well and needed to go to bed, but reasoned that if she was not well and needed to rest: “What’s wrong with that?” Fay also explained how she managed to ignore “the little guilty voice that’s going ‘You’ve got to do this, you’ve got to do that’”.

Feelings of embarrassment, shame and/or guilt could all be features of living with distress, and could exacerbate the feelings of isolation which were outlined in sections 5.2.1. However, whilst these feelings could be a feature of distress, they also hinted at the perception by some that their distress was not socially acceptable (the topic of section 5.4).

#### **5.4 The Social Acceptability of Distress**

All of the participants considered whether distress was likely to be seen by others as “socially acceptable”. Twenty-three of the participants spoke in terms which suggested that they felt their distress, whatever the cause, lacked social acceptability. Half of the participants spoke of feeling the need to put on a brave face: the way in which they described the process varied, but included phrases such as “putting up a happy barrier” and putting on “a good front”. The reasons why the women felt the need to put up a front and so hide how they were feeling to others varied, but some spoke of a stigma that they perceived was attached to their condition. This was especially true when an individual felt like they were unable to cope with their situation. In addition to feelings of stigma and/or an inability to cope, some of the participants also spoke of instances in which they tried to protect those around them from the effects of their distress. The areas of stigma, an inability to cope, and a desire to protect others are the topics explored in this section.

##### **5.4.1 Stigma**

Stigma denotes a mark of disapproval that allows “outsiders” (such as those with mental illness) to be identified and (potentially) ostracised. Instances of enacted stigma were not common, but as the participants’ narratives were their personal accounts of distress, part of their story sometimes saw the participants considering how others might view their distress. A lack of understanding of what distress was like was spoken about by Lucy, who described the time she had chronic fatigue as

“a curious twilight zone that other people don’t understand generally”. She described that period of her life as “the troubles” and acknowledged that unless someone had been through their own troubles, it was “very difficult to relate to someone who has”. Judith described how it felt to live with menopausal symptoms, thyroid dysfunction, and resultant anxiety. It was a particularly lonely time for her, but whilst she had some people that she could talk to about how she was feeling, she felt that she still risked being stigmatised as “other people get very tired of hearing what’s wrong with you when it goes on for so long”. Teri also felt that a lack of understanding of what her distress was like could lead to her becoming a burden to others. Her narrative included a section when she remembered how she had felt when she was living with a low mood, but was unaware of the reasons behind her low mood. She described how she felt that “friends don’t want to hear you whingeing and whining on and saying how terrible you feel when you don’t know why”, and was concerned that if she did disclose how she felt, that she would lose all her friends.

A lack of understanding was spoken of by Fay, who felt that when she was experiencing anxiety and insomnia some might be sympathetic, whilst others would have the attitude of “Oh well, just pull it together love”. She considered why there might be a difference in attitude, and felt that it was partly due to the lack of physical signs of how she was feeling, whereas with a broken leg “you get all the sympathy of the world”. However, she also felt that dealing with mental health was “a sticky one for society”, and that a combination of not being able to see physical symptoms, and a lack of a clear fix (like a plaster cast for a broken leg) could lead to the perception that mental health problems were “uncontrollable”, which made them “more complicated and more scary”. Scarlett also spoke of how her herbalist had helped her to “normalise” her issues with food, but felt that this was an area she had found difficult to discuss as she thought that “eating disorders are quite taboo to talk about”.

Jade’s view was that despite work by mental charities to help break down the stigma of mental illness, there remained a reluctance to talk about issues such as distress, which would contribute to individual’s isolation. This idea was supported

by Pippa's narrative, as she also felt that the stigma she perceived to be associated with mental health issues would only be overcome once people began to understand mental illnesses and so could begin to "normalise" them rather than suggesting that there was something abnormal about an individual who was living with issues such as distress. Pippa felt that her own experiences had helped her to gain a greater understanding of those with mental conditions, though some of the terms Pippa used to describe herself were disparaging. For example, she described herself as feeling vulnerable and pathetic telling people about how she felt, because she did not want to appear like one of "those people" where any "minor thing will upset them", but at times ended up feeling like "Little Miss Special Needs".

Whilst the participants' narratives spoke more about a fear of stigma due to a lack of understanding from others rather than actual instances of stigma, the fear was understandable: Sam provided an example of losing friends because her depression prevented her from socialising with them, whilst Yvonne was "dropped from people's social circles for being what they thought unreliable". The fear linked to the perception that there was a stigma to mental illness – coupled with wanting to protect their inner self – would often lead those with distress feeling the need to put up a front in order to hide their "true" self.

#### **5.4.2 Putting Up a Front**

As well as the instances outlined in section 5.3, Lily also provided an example of putting up a front: when talking about her personal situation, Lily described how she had become "hardwired into putting up a happy barrier", which was something that she thought was done by "most people who suffer any sort of mental issues". Whilst Lily's views were based on her personal opinion, putting up a front to hide their distress was often reported by the participants, despite the fact that hiding their true feelings from others risked causing increased isolation. Sam put up a front in order to hide the fact that she did not always feel strong enough to socialise when she was living with depression.

*I know I lost friends because of it, because I couldn't go out, they would want me to go out and do this and do that and I was always saying "No". Or I'd say "Yes" and then at the last minute I'd have to phone them up and say "No actually I can't, because I'm ill" and make excuses because I couldn't.*

Sam gave the impression that she was trying to hide her distress by coming up with a "better" (more socially acceptable) illness. The interviewer pointed out during the interview that it sounded as if her perception had been that "being depressed wasn't ill enough". Sam agreed with the point as she explained how "I'd make up all kinds of things. I'd have to sit there thinking 'Now what can I say?'"

Teri described how she was "able to function fairly normally" in public when she was living with a low mood, so that nobody apart from her husband knew what she was going through. It was only when she got back home to her "bolthole" that she felt able to put her guard down. She considered how, at the time, she did not want to admit to herself how she was feeling, and so definitely did not want to admit to others what she was going through. Rachel also spoke about trying to conceal how she was coping when she was feeling low, and would only admit to how she was feeling to certain people:

*I don't want to be asked, I want to choose who I speak to about these things so I don't want the occasion to even arise for somebody to go "Are you okay?" And even if they do, I will say "Yes I am".*

Jade explained how she did not want to let others know how she was feeling when she was given a diagnosis of generalised anxiety disorder by her GP. Despite the fact that she worked in an area that included supporting those with mental health conditions, she reported how she "would never in a million years" have announced the diagnosis at work. Jade not only felt like she would not get the necessary support from her colleagues, but also felt that she would not feel comfortable to say that she was struggling. Despite Jade's reservations, at one point she did relate how she was feeling to "one colleague I felt comfortable to confide in" because there came a time where "this breaking point between your inside and outside just has to meet – you can't hold it in any more". Jade's narrative highlighted that an

individual's decision to put up a front when experiencing distress was not a straightforward one. As well as concerns over stigma (which may not materialise) and wanting to protect their inner self, other factors could lead to the putting up of a front. One of these was the desire by some to hide any sign of being unable to cope.

### 5.4.3 Not Able to Cope

Chapter 4 highlighted that a loss of control was one of the features of distress that emerged from the participants' narratives. However, the perception of losing control and the resultant inability to cope was one aspect that those with distress attempted to hide in front of others. In part, an inability to be able to cope was linked to feelings of shame due to the individual having a perception that they were not able to pull their weight. Jade (in section 5.4.2) did not want to admit that she was struggling at work, whilst Pippa also considered why she sometimes felt the need to put up a front, and spoke of how she thought that "it reveals your inner life to admit a mental health condition". She surmised that revealing her distress to colleagues would not only have revealed something of her inner life, but would also have led to others judging her:

*Sometimes with a mental health condition you feel like by saying it, it almost exposes something else beneath the social veneer that you show to everybody every day in the workplace. You're very efficient: "I'm very good at my job, I'm very organised, very confident", and suddenly saying (puts on a small voice) "But I'm scared of this", undermines your whole social persona. So either you feel like you're faking it, because "No, but you're fine, you're all right, you always do this, you're the union rep, you speak up in union meetings, you argue with all the managers when they do unfair things, and you're now afraid to go to the supermarket?" Or it's like "Now you're just making a fuss and you want special attention" or you feel like "Wow, that's really pathetic for somebody that was that capable to suddenly not be", and it feels quite exposing to share it with other people. That you might think they would have a lesser view of you in other areas in your life – it would reflect other areas of your life...*

Yvonne related how when she first started having panic attacks whilst at work that she thought they would be seen as “a sign of weakness”. Judith also avoided making social arrangements when living with the menopause as she knew that her symptoms meant there was a good chance that she would not be able to attend. She found the situation particularly upsetting where her family were concerned, which contributed to her having a negative view of herself:

*I think it does change the way that I viewed myself, because I didn't feel that I was capable anymore... Like I say I didn't take on anything – I couldn't even say yes I'd go and look after the grandchildren. I felt really fairly useless.*

Judith's view that she was “fairly useless” as she felt that she was no longer capable suggested that she felt her condition had also undermined her role within the family. Judith's narrative had resonance with that of Zoe in section 5.3, who could not commit to social events in case her legs were not working on the day. Zoe feared that her seemingly random instances of being unable to walk would lead to others thinking that she was “a nutter”.

The idea of not wanting to be considered “a nutter” relates back to the “sticky” problem of mental health issues – in particular, the desire not to be seen as unable to cope. Una spoke of when she had to deal with her partner suddenly being taken ill, and how she did not want to seem like she was not coping; but also admitted that she could not help but show it sometimes. Vicki also spoke of trying to hide her emotions, and described how when she became distressed she would lose her temper “in a big way”. However, she described how she would only lose control of her temper when she was at home:

*Well I don't want to lose my temper when I'm out in the shops or being seen, she says sounding like Hyacinth Bucket, you know (puts on a posh voice) “What would my public say?” So you know, in the privacy of your own home... I don't think anybody really loses it when they go out do they? Or they try not to.*

Vicki's narrative provided another example of somebody who was hiding their distress in order to present an identity that she felt was socially acceptable to portray in public. Isobel spoke of a further aspect related to feelings of not being

able to cope. Isobel considered herself fortunate to have some “very, very good girlfriends” that she was able to talk to because her husband ran “his life fantastically smoothly and he wants everyone to be coping around him”. This situation led her to not want to be seen as not coping, in particular because she did not want to “expose” herself to her closest family members. Not only was Isobel illustrating how those with distress may put up a front to those closest to them, it also hinted at why they may sometimes feel the need to do so: in Isobel’s case, her decision was to appear to be coping in order to protect those around her from her distress.

#### **5.4.4 Protecting Others**

Carol spoke about not wanting to talk to people when she was feeling down, and stated that “there’s that taboo about not dumping on other people”. Whilst some of the narratives spoke of the perceived stigma associated with mental illness and the need to put on a brave face, Carol’s quote appeared to suggest that it was not socially acceptable to burden others with one’s problems, no matter what the reason. This position appeared to be accepted by Teri who explained why she did not tell her best friends “all your woes and your worries and your problems” when her mood was very low “for fear of them running away down the street screaming”. Whilst Teri feared losing her friends if she opened up to them, part of her decision not to talk was also from a desire not to burden them with her problems.

As reported in section 3.5.2, eighteen of the participants had (or previously held) the role of a carer. The role carried an expectation of being able to cope, as the individual had a responsibility for the well-being of others. This responsibility manifested itself in the narratives as a desire by the participants to protect others from their own distress. This desire to hide their distress was not always limited to those that they felt a responsibility for, but was most keenly felt in relation to family and friends. Wendy described how she felt when she was recovering from cancer and dealing with severe menopausal symptoms. Whilst she would talk to family and friends about how she was feeling, she still felt the need to put on “a good

front” in order that they did not know the true extent of her distress. It was only when she let her daughter read the cleaned transcript from her T1 interview that her daughter realised just how low her mother’s mood had been. Being unable to cope was the thing that Wendy found particularly difficult: she described how she felt “a bit of an idiot” for not being able to do so. However, she also revealed that part of the reason she had not told her children how bad she felt was because they had their own lives to deal with, and she “didn’t really want to lumber them with a silly mother”. Judith also described how she did not talk much about how her menopausal/thyroid symptoms affected her as she did not “want to bore everybody” with how she was feeling. At T2, Judith had received a diagnosis of cancer, but also appeared to not want to “lumber” her family with the burden of the news:

*I have told my family of course, but it took me quite a long time to tell them. And then I didn’t tell them in clear terms. I told them more that there’s a possibility that it could be this or that... My daughter is pregnant, and I really didn’t want to upset her – she’s due to have her baby in October and I just didn’t think it was a good time for her to be worrying about me.*

The impact of a combination of trying to cope with distress and care for others could be profound, and was clearly illustrated by Eve, who explained the circumstances leading up to what she described as “a real clinical depression”.

*Well the thing was, at that time, I had my dad who was ill with terminal cancer; my husband had had a horrific road traffic accident and had to learn to walk again, spent fourteen months at home; my children were young; I had to go out and get two jobs – I had to do two jobs to make ends meet. So I had him, I had my dad, young children, and it was after... My father died, and then my husband resumed back to work, and it’s almost like I’d kept going, and then I had nothing to focus on any more, and the focus then became me.*

In this instance, Eve’s role as a carer meant that she felt she “couldn’t be ill” because “too many people rely on you”. However, when things became too much, she felt the shame linked to the perception that others judged her, in addition to the guilt of no longer being able to care for others:

*When I was depressed, I remember people thinking “Hmm, not her – how can she be depressed? She’s always the one that’s coped so well”. And I remember saying to my husband, “I don’t wanna cope any more – I don’t wanna pretend I don’t wanna cry when I do wanna cry, and I don’t wanna pretend to cope when I can’t cope!”*

A desire to protect others was one of reasons why distress could be so isolating. Whilst the decision not to disclose what was going on in the participant’s life was a decision made by the individual, it could have negative consequences. Diane described how her father had been “a terrible worrier” when he was alive, so that her mother had always discouraged Diane from concerning her father. Later in life, this situation meant that she felt unable to speak to her father when she was in a relationship with an alcoholic. It also meant that when she was depressed to the point of standing at the edge of a river considering whether or not to commit suicide (described in section 4.6.4), her father “knew absolutely nothing” about how she was feeling. Gemma spoke about keeping things from those close to her, but reflected on how it could be counter-productive. In Gemma’s case, she had not told her close family (apart from her husband) when she was pregnant, but subsequently found that she did not have immediate support when she miscarried as she had “really kept it a secret”. When she rang up her sister to ask if she could look after her son whilst Gemma went into hospital, her sister “was like ‘Oh my God – I didn’t even know you were pregnant!’” which resulted in them both feeling upset. Putting up a front to hide one’s true feelings to close family members was summed up by Scarlett who described how difficult she found it to stay with her parents when she was feeling down:

*It was really hard being really upset in their company. I don’t know, you feel like you’re acting your life to a certain extent. You kind of play the parts and you do the things that you normally do, but you don’t feel stuff in the same way and you don’t like, yeah. It feels like an act. Definitely...*

## **5.5 Summary**

Periods of distress can be a lonely time for women who are experiencing them. Beyond the more obvious physical isolation due to ill-health, women can feel

socially isolated which is particularly problematic when the cause of their distress is not visible to others. This invisibility is sometimes due to a deliberate act where the individual attempts to hide their distress by putting up a front to the outside world, and in some cases to those that are closest to them. The decision by some women to hide their distress can be linked to feelings such as embarrassment, shame and/or guilt, often centred round feelings of an inability to cope with their situation and/or role, coupled with a desire to protect others from their distress. Chapters 4 and 5 have described many of the issues experienced by women living with distress. The next chapter will consider one way the participants tried to cope with their distress, by looking at the role that a herbalist may be able to play.

## **CHAPTER 6: RESULTS FROM THE HERBAL THERAPEUTIC PROCESS**

### **6.1 Introduction**

The previous two chapters have introduced the herbalists and the women who have participated in this research project, examined what the women's experience of distress was like, focused on how this experience can be isolating, and considered reasons for this isolation. This chapter focuses on which processes the participants reported they used in order to help cope with their distress. Medical practitioners have the opportunity to impact on how women perceive their distress. However, as section 4.4 highlighted, these women were likely to visit a herbalist after trying biomedical treatment but finding some aspect of the experience to be unsatisfactory. This chapter will therefore consider what the participants did when they felt that biomedicine was unsatisfactory in some respect, before concentrating on the process of visiting a herbalist to investigate the participants' experiences of WHP, and whether usage of WHP was perceived by the participants to be beneficial (and any reasons why). It will end with a review of the participants' T2 narratives in order to investigate the outcomes of ongoing usage of WHP.

#### **6.1.1 Themes**

Three main themes are presented in this chapter concerning results obtained from the herbal therapeutic process:

1. Women often use a number of self-care strategies before visiting/alongside visiting a healthcare professional
2. There are a number of features of WHP which were reported as being of particular benefit to the participants:
  - a. The accessibility of the herbalist and having time to talk helped the women feel like they were "being heard"

- b. Building rapport and having a supportive therapeutic relationship helped the women to feel that they were “being held”
  - c. A holistic, individual and flexible approach from the herbalist was felt to be an important part of “being treated”
- 3. In addition to the features outlined above, certain aspects of the herbal therapeutic process stood out as being particularly pertinent to women who are living with distress:
  - a. Flexibility allowed the herbalists’ approach to be adapted for diverse stories of distress
  - b. A successful therapeutic relationship could help provide support and so empower women who may have experienced feelings of embarrassment, shame and/or guilt associated with their distress
  - c. As well as providing emotional support (similar to therapies such as counselling), the herbalists also provided an active treatment for distress (the herbs) that the women could use outside of the consultation.

## **6.2 Self-Care**

Whilst all the women spoken to had been to see a herbalist when faced with physical or mental/emotional problems, they were more likely to try helping themselves in the first instance. All of the women spoken to had tried different strategies in the past to cope, which could range from hobbies as a source of enjoyment, through to self-medicating with over the counter (OTC) remedies, or choosing to visit different types of therapists. Table 6.1 (overleaf) lists the most commonly quoted self-care processes.

What the data presented in table 6.1 does not show is the importance that the women placed on these various self-care techniques. As Isobel reported “those are snippets of sanity really, the painting, the dog walking, the yoga are the things that I think probably keep it all together for me, because I’m doing something for myself and feeling strong about that”. Whilst an individual would choose a course of

action that suited them, some of the participants were particularly passionate when talking about things they did in order to help themselves.

**Table 6.1:** The Most Common Self-Care Processes Reported by the Participants

<b>Self-Care Strategy</b>	<b>No. of Participants That Utilised (n=26)</b>
Using CAM (other than WHP)	26
OTC Remedies (e.g. herbs/supplements)	22
Exercise	14
Nature (Being Outside)	12
Diet	11
Company of Animals	9
Activities to Distract the Mind	9
Yoga	9
Meditation	6
Gardening	6
Positive Thinking Techniques	6
Breathing Techniques	4
Spiritual Practice	3
Sleep	3
Holidays	3
Giving up Commitments	2

Nicola described herself as sounding like “a bit of an evangelist” when she described how learning to control her breathing when she started to meditate could help her overcome feelings of panic – something that she was particularly impressed with as she thought that it was such a simple technique. As well as meditation, those that practised yoga were keen to extol its virtues, and led Diane and Una to train as yoga teachers because they were so impressed with the benefits that they had felt from practising it.

Exercise was generally felt to be beneficial. Vicki enjoyed walking as it got her out of the house and gave her the opportunity to meet people, but explained how “I don’t really care much about looking at green leaves and doing all that”. However, most of those that spoke of exercise would often speak of wanting to combine it with being out in the natural environment. Jade spoke of how she felt that “spending quiet time in nature is essential” to help maintain her well-being, whilst

Nicola felt that gardening and “connecting with nature” “helped actually keep my sanity” after her son died.

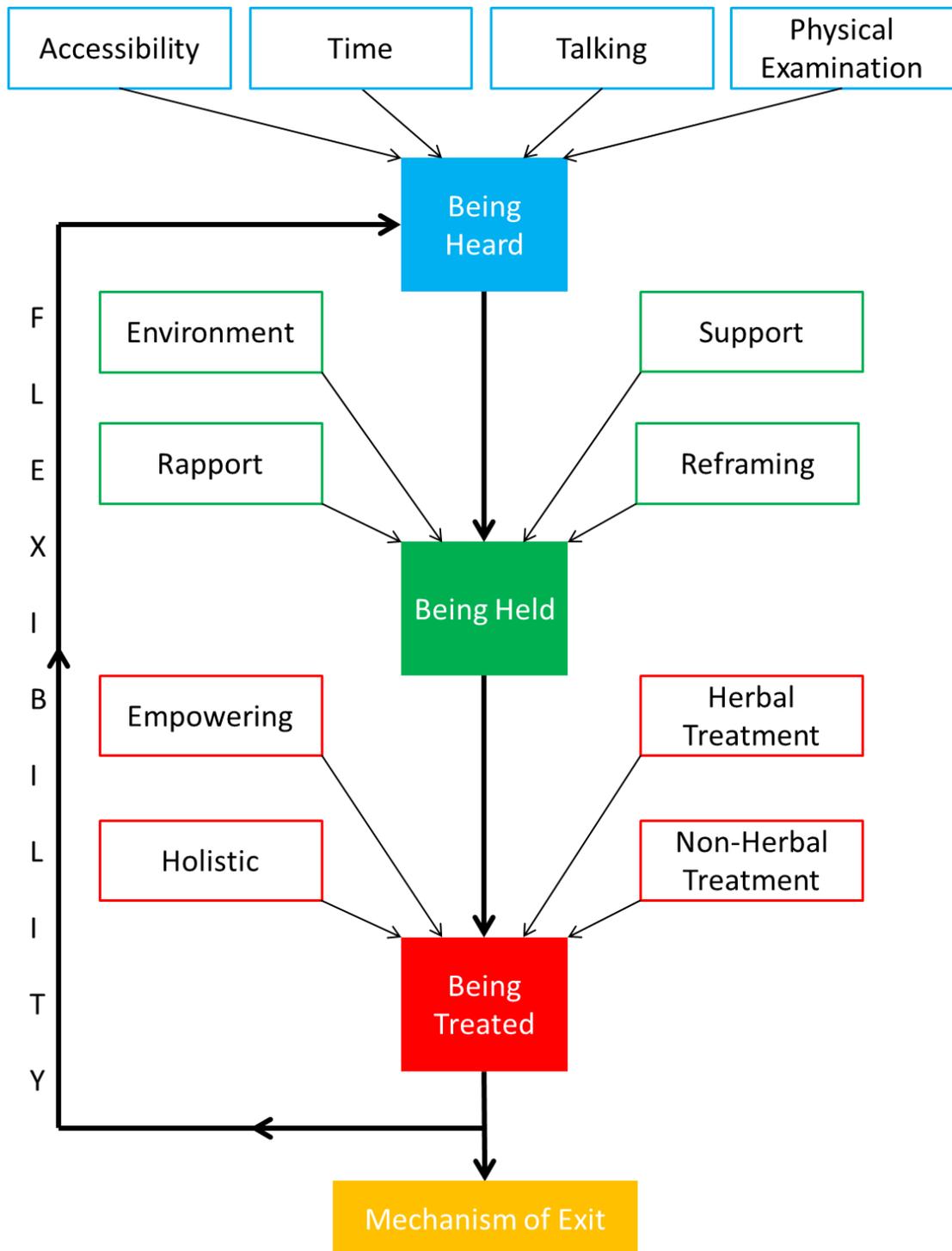
Apart from techniques that they were able to undertake, when an individual decided that they needed some external help to cope with how they were feeling, the interviews showed that the GP was the most common source of help when self-care strategies failed to be effective in the first instance. All but four of the participants (reported in section 4.4) went to a GP for their problem before deciding to visit a herbalist. Ultimately, the women decided to utilise the services of a herbalist because they perceived that their GP (or other biomedical practitioner such as a consultant) was unable to provide a solution that satisfied them.

### **6.3 The Herbal Therapeutic Process**

Once the women had made the decision to consult with a herbalist, they entered an ongoing process described for the purposes of this study as the herbal therapeutic process. Whilst each participant’s experience was different, there were a number of features that were common to most stories of visiting a herbalist. A typical herbal therapeutic process for distress (as reported by the participants) is illustrated in Figure 6.1 (overleaf).

The process has a number of distinct sections, although whilst figure 6.1 has tried to simplify the process, in reality the structure is less linear and the distinction between the stages can become blurred. For example, feelings of empowerment can occur at a number of points throughout the process. The first area represents the part of the process where an individual has the opportunity to feel that their distress is “being heard”. This process may include time to tell their story, feel that they are being actively listened to, and are being assessed physically which can help support their story. The second area represents the process of “being held” (initially defined in section 2.3.2), where the individual seeks to feel understood and supported through their distress. This may be helped by an appropriate therapeutic environment and a building of rapport with the herbalist which, in turn, has the

potential to lead to a feeling of being supported, and can result in the patient viewing their distress in a different light.



**Figure 6.1:** A Typical Herbal Therapeutic Process

The third area represents how the individual feels like they are “being treated” to help their distress. This treatment is likely to be herbal, but may include non-herbal interventions – including the need for referral to another healthcare professional. The treatment may be seen by the patient as being holistic, that is it takes into account all the information from when the patient was being heard, and may include other aspects to help their distress such as dietary and/or lifestyle advice. This process may be seen as empowering the patient to feel that they can better cope with their own distress. As the process is ongoing, these areas are continually being attended to, and may be modified over time as circumstances dictate. Alternatively, the patient may leave the process once they feel that it is no longer appropriate: either because they feel that have reached a point where they no longer need to visit the herbalist, or because they feel that the process has been unsuccessful for some reason.

The different areas of the herbal therapeutic process will now be considered in more detail.

## **6.4 Being Heard**

### **6.4.1 Accessibility**

All of the participants spoke of the idea of being heard, with twenty-four of the twenty-six participants reporting universally positive experiences. In order to feel like their story was being heard, the first part of the herbal therapeutic process that needed to be in place was that the patient needed to feel that their herbalist was readily available. Generally, the herbalists were seen as being accessible by the participants: the majority had universally positive reports in terms of accessibility. The most obvious benefit that was spoken of in terms of accessibility was that the participants felt it was easy to contact their herbalist outside of the consultation itself. This was particularly important, as it allowed for questions to be quickly answered and so helped the individual to feel like they were being heard, but also (underlining the amorphous nature of the the herbal therapeutic process) being

held and supported. Vicki wanted to emphasise that her herbalist was “very accessible”, and that she could contact the herbalist via text, phone or e-mail “anytime”. In line with other narratives, Wendy spoke of how she felt that if ever she took a herb that didn’t agree with her, she could just ring up the herbalist and ask for advice, but Wendy was particularly impressed with how quickly her herbalist would respond to her. Wendy described the herbalist as “instant and the GP isn’t – that’s important”. What became clear was that being accessible had the potential to help patients feel like they were being attended to.

Being accessible for the consultation itself could also be important, especially if it was not easy for the participant to travel. In this instance, being able to see the herbalist outside of their normal consulting room was useful, and was spoken of by almost a quarter of the participants. In most cases reported, the herbalist would offer the option of home visits as was described by Pippa when she was living with anxiety. Anna also had her consultation at home when she was experiencing panic attacks, and described how it was “very reassuring” to know that the herbalist would travel to see her. Eve described how she looked for a herbalist in her area as she did not have the time to travel far, and so was pleased that whilst her herbalist practised in a clinic that was fairly local, the herbalist was happy to carry out the consultation at the herbalist’s home as it was more convenient.

The T2 interviews showed that the accessibility that the participants enjoyed was not just at the start of the herbal therapeutic process. Zoe had seen her herbalist for a number of years, but described how she knew that when she contacted her herbalist that the herbalist “would be there for me” to provide advice and support, and so act as a type of emotional safety-net. Anna described her feelings of ongoing accessibility:

*It’s not just those one off periods, it’s continuous, it’s ongoing – I’m now one of (herbalist’s) patients, and (herbalist) hasn’t sort of dismissed me and said “I’m not talking to you on the phone, or advising you any more”. (Herbalist’s) always there at the other end of the phone for advice, which I think is very amazing... Doesn’t say “Oh I’m going to charge you for the call” or anything like that. It’s all part and parcel of the treatment package, which is why I recommend (herbalist) to people, you know?*

Four of the participants spoke of instances where they found that their herbalist was less accessible. For two of these, the issue of accessibility was not a particular problem, but was mentioned because the herbalist worked from a larger clinic. However, an ongoing lack of accessibility could lead to a less satisfactory experience of the herbal therapeutic process. One participant at T1 had decided to stop seeing her herbalist, partly due to perceived issues with accessibility. Whilst she found that she was normally able to contact her herbalist if she had the need of a repeat prescription, when she contacted her herbalist after not taking the herbs for a while, the herbalist initially refused to dispense the prescription because the participant had not had a recent consultation. Whilst the participant thought that needing a consultation was “fair enough”, she also felt that she had not been fully informed of the situation so that she could have arranged to have a consultation beforehand. Under the circumstances, the participant described the situation as being particularly stressful:

*You know sometimes it's so difficult when you're stressed out just to hold yourself together, let alone focus on "I must take my medicine, I've got to do this, I've got to go to work", all these different things. And I felt like I'd finally got myself up in a good mental position to want to commit to taking care of myself again, and all of a sudden (herbalist) was saying they wouldn't give me the medicine, and I was just really pissed off to be honest with you.*

A perceived lack of accessibility was also the main reason why Beth had decided to stop seeing her herbalist by T2. Whilst she found the herbalist easy to get hold of, she was told that after the initial consultation she did not need to have any follow up consultations, which was a situation that she was not comfortable with:

*I found it strange that (herbalist) was like "Oh yeah, once you've seen me, you don't really need to see me again". Like you just e-mail (herbalist) if you need anything, which I found strange – not only from a business point of view of (herbalist) making money, but from a clinician's point of view you need to see your patients. I mean what if I'd turned yellow and I hadn't noticed? If I was just e-mailing (herbalist), no-one knows. I could have something horrible going on and it would take someone to look at me to see that. I don't know; I just found that odd.*

Beth's narrative showed that she felt the need to be properly supported in a medical sense, but to fully achieve this required physical interaction as well as being contactable via the phone or computer. Other participants' narratives suggested that if Beth's herbalist had been physically accessible, she was likely to receive the checks and support that she desired. One of the main aspects of the herbal therapeutic process that was spoken of by the participants was linked to the idea they felt that they had time to tell the herbalist their story.

#### 6.4.2 Time

One aspect of feeling like they were being heard (which was mentioned by twenty-two of the participants) was having time, and was generally seen as one of the strengths of the herbal consultation – especially in contrast to the perceived lack of time that the participants had with their GP (which was spoken of by seventeen of the participants). Having time was spoken of across the T1 and T2 narratives as follow-up consultations also gave the participants sufficient time to feel attended to. Lucy described how she did not feel rushed when she went to her herbalist, which was something that she felt was important for someone who was unwell, whilst Zoe considered that despite the fact that her herbalist must have had time parameters “they never let the patient feel it's an issue”. The majority of the time was taken up with talking, but this was perceived as being an important step for the herbalist to ascertain a clear picture of the patient's medical history. As Hayley said:

*First of all we had a long chat and on the initial interview (herbalist) didn't take any blood pressure readings or pulse or anything because I think we just spent the time talking, because (herbalist) wanted to find out what had been happening and what I'd been doing about it.*

However, whilst having time to spend with the herbalist was generally seen as a good thing, the length of the process was mentioned as something that could be problematic. The issue was only spoken of by two of the participants, and was only spoken of by those that had experience of attending teaching clinics, where the herbalist had the additional responsibility of having to oversee the training of

students as well as be present during the consultation. Rachel spoke of how the added responsibility could sometimes result in her consultation being delayed, or could mean that she had to wait a long time for her herbal prescription. This could affect her experience depending on the sort of day she was having: she described how if she was having a busy day and felt that she needed to “shoot off”, delays meant that she would “get a little ‘Arghh!’” In these instances, she found the staff at the clinic to be flexible, so that if she was particularly busy, she could go and run some errands before returning later in the day to pick up her herbs. Margaret’s experience was slightly different. She generally found that her appointments were on time, but felt that even if they were slightly delayed “it wouldn’t matter because you’ve got a comfortable seat”, which also hinted at the importance of the therapeutic environment (discussed further in section 6.5.1).

Having time would not necessarily lead to a successful encounter – the key point for the participants was to feel that their story was being heard. Carol felt that her herbalist not only gave her time, but was also listening to her, and so “engaged” with her story. As Isobel put it, when she first went to see her herbalist, she “poured it all out and they were just incredibly receptive to it all”. Hayley’s narrative (above) showed that in order to feel like she was being heard, much of the time was not spent undergoing physical examination or receiving active treatment, but was spent talking.

### **6.4.3 Talking**

Much of the consultation was spent with the patient answering the herbalist’s questions; the depth of this questioning could come as a surprise to the participant. Lucy explained how her herbalist asked her questions that she did not necessarily think were relevant at first, but realised that questions on areas such as diet and lifestyle were important, and were another example of being heard as the questions made her feel that she was “being properly considered in the broadest sense”. This was echoed by other participants such as Beth, who felt that the consultation was “thorough”, whilst Margaret described the experience of not only talking but also

being properly listened to as “a luxury”. What these narratives began to show was that not only was having time to talk in-depth an important part of the consultation for the herbalist to obtain information and so treat the patient holistically, but was also important in making the patient feel heard, valued, and so cared for. Teri also spoke about having the time to chat to the herbalist, and thought that it was one of the reasons that she had felt able to open up and told her herbalist “very personal things” that she was surprised she could discuss with someone who she initially described as “a total stranger”. Teri’s narrative began to suggest that having time to talk not only enabled her to feel like she was being heard, but also that she felt safe enough to disclose “very personal things” that she might have otherwise found difficult to talk about. The idea of safety and being held (defined in section 2.3.2) is considered further in section 6.5.

As well as helping the participants to feel valued, being heard could also be perceived as being an important step in the treatment process. Margaret thought that the herbalist listening was a vital part of the process as the herbalist’s conclusions about what course of action to take were only reached after listening to her. In that respect, having her information taken into account meant that Margaret felt like she was having an active input into the treatment process. Rachel also related how she felt that she was always part of the process, whilst Sam thought the consultation was based around her, so that not only did she feel like she was the centre of attention, but she also felt like she was the expert for her situation. The impression of being made to feel like an expert (feelings of empowerment are discussed further in section 6.6.4) was especially important for those participants who reported that their views had largely been ignored by biomedical practitioners. As Lily put it, she experienced joy that her herbalist did not accuse her of making up her symptoms and make her feel “like a whiney woman or a neurotic”. Similarly, Zoe described her herbalist as “non-accusatory”, and that the herbalist would “always support me and respect me and take my word for it and won’t dismiss it”. Scarlett described how her herbalist came across when she first went for a consultation:

*I just remember (herbalist) seeming so calm, like they had this real sense of calm and they just had a little notepad, and it was very open. And they didn't really write loads down – they didn't really say loads.*

In spite of not saying much and not taking many notes, the result was that Scarlett's herbalist gave her the impression that she had a space in which "emotional things were allowed to be said". This impression was in contrast to her experiences of seeing her GP, but allowed Scarlett to talk about her problems openly which was "quite a big thing" for her as she described how there was "a lot of stuff that I hadn't really talked about", and had resonance with Teri's narrative (above) which revealed the importance of having a safe space within which to talk.

Sometimes the herbalist gave reassurance to the participant by accepting the story of their illness and so helped them to frame their narrative. This not only meant that the individual was heard, but they also felt emotionally held because of the perception that the herbalist had validated their story. Zoe related how she would generally not talk to other people about her musculo-skeletal condition, but described her herbalist as somebody "who does understand" as they had been treating her from before she had received a diagnosis. Not only did Zoe feel that her herbalist understood her, but also that the herbalist would trust her when she described her symptoms. This was echoed by Yvonne who reported having a herbalist who was supportive and reassuring as there was never a sense of disbelief when she reported how she felt. As well as framing their story, sometimes the herbalist would go further and help the participant to re-evaluate, or "reframe" their story, which is considered further in section 6.5.4.

#### **6.4.4 Physical Examination**

Whilst Hayley reported in section 6.4.2 how she had not received any physical examination during her first visit to her herbalist, she described how physical examination did take place on subsequent visits. Some form of physical examination was reported by the majority of the participants, from measurements of pulse and blood pressure, through looking at physical symptoms, to full systemic

examinations. Of the participants that did not report any physical examination, two reported that no physical examination took place, whilst two spoke of having had experiences of physical examination with herbalists aside from their current herbalist. Physical examination was more likely to occur at an initial consultation as part of the holistic overview, but could also be used over time to monitor physical symptoms. Participants were also more likely to talk of physical examination if they attended a training clinic, as it formed part of the students' programme. What was clear was that physical examination is a common part of the herbal therapeutic process. As a way of gathering more information about the patient's condition, physical examination was another way that the herbalist could listen to the patient's body, and had the potential to add to the patient experience.

Eve spoke about how she was surprised at the thoroughness of her herbalist, as she had not had her blood pressure taken by any other complementary therapist before. Both Beth and Hayley had abdominal examinations performed, but remarked on how the herbalist asked permission to perform the examination, and was careful not to hurt the participant. The narratives spoke of the participants being impressed with the herbalist's level of skill and professionalism. Teri in particular was impressed with the way her physical examination was carried out: the herbalist took her blood pressure and pulse in both arms, and explained to Teri why it was important to check both arms and encouraged the patient to feel her own pulses. As Teri put it:

*And again I felt that's really thorough, and I just thought you just feel like you're really being looked after. You feel like the person really cares. It's not just a quick "Oh, yeah, I'll take your blood pressure, oh, right, that's..." and write it down.*

Teri went on to describe how her herbalist's way of feeling her pulses, as well as looking at her tongue was influenced by Chinese herbal medicine (CHM). Almost a third of the participants reported that they had seen herbalists that had used techniques other than WHP in their diagnosis, treatment, or both. The use of iridology (studying the iris to determine a patient's health) as a diagnostic technique was mentioned by three of the participants; three spoke of diagnostic techniques

that were taken from CHM. What this showed was that western herbalists not only have access to herbs traditionally used in different healing traditions, but can also adopt practises from other CAM therapies/traditions, and incorporate them into their practice – both as diagnostic tools within the consultation, but also as treatment options (considered further in section 6.6.3). Whilst all of the areas in this section helped the participants to feel like they were being heard, and were described in the narratives as being an important part of the herbal therapeutic process, the participants also spoke of the desire to feel supported, or held.

## **6.5 Being Held**

### **6.5.1 Environment**

“Being held” involves the patient having a sense of being understood and emotionally supported. As Teri and Scarlett’s narratives in section 6.4.3 revealed, an important part of a herbal therapeutic process that was deemed to be successful was the feeling of being emotionally held within a safe environment as it allowed them the opportunity to open up, which let them feel like their story was being heard and understood. Their comments not only suggested that the therapeutic environment could be an important part of the experience of seeing a herbalist, but in some instances feelings associated with the herbal therapeutic process began before the consultation commenced. Over three-quarters of the participants mentioned the therapeutic environment during their interviews. All of the comments made with relation to the environment were positive: typically they were described with words such as “nice”, “comfortable” and “safe”, and gave the impression of the consulting space as a place of sanctuary. Just under a fifth of the narratives included the herbalist travelling to a home environment in order to conduct the consultation (plus one that took place at the herbalist’s home). The option of having a home visit was valued for its convenience, coupled with the fact that the patient felt relaxed in their own environment.

The overall appearance of the therapeutic setting could also be important, and was usually considered when the participant had experience of visiting more than one herbal clinic. At T2, both Margaret and Nicola considered what it was like going to a modern clinic having originally been seen in a more traditional setting. Whilst a modern clinic had the feeling of “more like being in a hospital” as Nicola put it, both suggested that they still liked a more traditional setting. Margaret described her old clinic as “the nice little domestic thing, this old building” whilst Nicola described her old clinic as somewhere “a bit tatty and dingy, but we loved it”. Both Margaret and Nicola’s experiences were that whilst they preferred the traditional setting, they were also content with a more modern environment. However, Beth felt that one clinic she attended was “too official”, and that the feeling she had of going to a hospital was something that she did not like. She preferred the setting of the herbalist that she was seeing at T1, which whilst being modern, was “all nice and clean and friendly”. The impression of a friendly atmosphere was mainly spoken about by those that attended clinics where there was a reception area and receptionist, but again gave the impression of a place of sanctuary. As Nicola put it:

*Oh, it’s still a lovely experience to go. I was there in March, it always is lovely because it’s just so calm and you feel that everybody’s on your side in the sense that they want to do what’s best for you.*

### **6.5.2 Rapport**

As well as feelings of being physically held within the therapeutic environment, some of the participants gave the impression of being metaphorically held by establishing a rapport with their herbalist. Whilst it could not guarantee a successful herbal therapeutic process overall, having a rapport with the herbalist was a necessary element for a successful therapeutic relationship. At T1, all but one of the participants reported positive feelings towards the herbalist that they were seeing at the time. Much of the positive response was due to how the personality of the herbalist came across. For example, both Fay and Lucy described their herbalists as “personable”, whilst both Eve and Wendy described their herbalists as “bright and bubbly”. Being “personable” had the advantage that it could make the

participant feel brighter: as Diane described it, it felt as if her herbalist's "whole personality gave one a lift the minute one walks into the room – it's quite extraordinary". However, there were other aspects of the herbalists' personality that were valued by the participants. Words such as "polite", "caring", and "professional" were often used: Nicola described her herbalist as "a sweetie" but that whilst the herbalist was knowledgeable, they would "wear their knowledge lightly" so as not to be overbearing. Ultimately, she thought that her herbalist had "a very good manner". These feelings were generally reinforced over time – at T2, all but two of the participants reported having good rapport with their herbalist.

There were a number of words that were repeated across the narratives that seemed to indicate they were an important part of the rapport between the participants and their herbalists. One was based around the idea of "collaboration", which was spoken of by ten of the participants. Isobel described her menopausal symptoms as "an ongoing thing that we're sorting out together", whilst Beth described that going to see a herbalist made her feel like she was "working with them" and described the herbalist as "a guide" towards getting her better. These feelings of collaboration also helped to engender feelings of empowerment within the participants (discussed further in section 6.6.4). Scarlett's herbalist appeared to make deliberate use of the idea that they were working collaboratively, by getting Scarlett to help dispense her herbal prescription. Scarlett, who had already told her herbalist that she had an interest in the actions of medicinal plants, felt that involving her in the the act of dispensing was an important stage of the herbal therapeutic process:

*I don't know I want to use the word tactic, but I think it was also about me engaging with what I was going to take, and yeah I think it was brilliant. I think it's great – it was a great idea to do.*

Another word that was used by some participants to help describe the rapport that they had with their herbalists was "trust". Over half of the participants either spoke of trusting, or having faith in, their herbalist. Partly, this trust was down to the fact that the herbalist was seen as being a professional, which was apparent to the participants from the herbalists' level of knowledge. Pippa thought that her

herbalist had received an adequate amount of training, so she trusted them. Zoe reported being particularly impressed with her herbalist's level of knowledge, and trusted the medicine that her herbalist recommended because she felt that "brand (herbalist)" was very important. Margaret felt that it was important to have an ongoing relationship with her herbalist, because the herbalist's knowledge extended to her and her history, so that Margaret trusted the herbalist's "acuity" to look after her.

In a similar way to Scarlett being involved in helping to prepare her herbal prescription, all of the participants spoke of instances where their herbalist had told them which herbs they were taking and why. For Rachel this led to a feeling of being involved, which was also a way of helping to build trust: her herbalist would not only explain to her the actions of the herbs in her prescription, but would also explain changes to her prescription. The importance of trust was epitomised by Wendy, who became so distressed when living with chronic menopausal problems that she got to the point of having suicidal thoughts. However, whilst her physical symptoms were not able to be controlled by her herbalist, she still found that the therapeutic relationship she built up (coupled with the herbalist's accessibility) held her and helped her to cope with the difficult time:

*It's just my faith in them really that kept me going, the fact that I knew that I could just pick up the phone and talk to them any time. (Herbalist) would always be there if I wanted to talk, that's what kept me going, yeah.*

One aspect that could affect the rapport between the participant and the herbalist was mentioned by just over a quarter of the participants, and was that of the herbalist's gender. Lily felt that when she first made an appointment at her clinic to see a herbalist, she "didn't care who it was" – male or female. However, six of the participants thought that the gender of the herbalist could affect the herbal therapeutic process, with five talking of instances where seeing a male herbalist could potentially be an issue. Gemma was surprised when one herbalist spoke of helping her with her gynaecological problem as she had previously seen male naturopaths that had used western herbs, but the subject had not been broached,

which led Gemma to wonder whether it was “not something you think of when you’re a man”. Anna had seen both male and female herbalists and was happy with both therapeutic relationships, but felt that with the female herbalist they could “relate to each other female to female” as she was dealing with gynaecological issues at the time, whereas the male herbalist she saw more as a “father figure”. This view was echoed by other participants such as Lucy who had seen a number of therapists, both male and female, but thought that when she had a gynaecological issue, seeing another woman could be an advantage as they might have “a good deal of understanding and experience” in an area that a man would not. Similarly, Beth had also seen both male and female herbalists, but felt that when it came to gynaecological symptoms “what’s the point in trying to describe it to a guy? Because he’s not gonna understand... it’s such a specific type of pain”.

Whilst some participants felt that male herbalists would not be able to fully empathise when it came to treating female specific medical conditions, for Rachel it was more of an issue when she went to a training clinic where she did not choose the practitioner and ended up talking to a relatively young male student. Whilst part of her presenting complaint was gynaecological, she was also “going to talk about not feeling so well emotionally”, but the fact that the herbalist was a young man made her “hold back”. In this instance, she would have felt “much more relaxed” with “a young woman... a more mature woman actually” as she felt that an older woman would be more understanding of her situation. Beth reported another situation where, whilst she was generally happy to see a male herbalist, at one stage she attended a larger clinic where there were predominantly male herbalists:

*It was weird. It was like a big group of men in white coats... It felt much more like being in a doctors’ surgery, and I find that quite uncomfortable – probably because I’ve had so many bad experiences at the doctor.*

Whilst some of the participants felt that the experiences of female herbalists would make them better able to appreciate female specific medical problems, the decision whether to see a male herbalist or not largely came down to a matter of choice on

the part of the individual. This was not normally an issue as most herbalists practice privately where the individual can choose who to see, though it could be more problematic in a larger clinic with predominantly male herbalists, or a training clinic where the patient may not feel they have any say in who is actually present during the consultation.

The views of the participants that were seen at a training clinic were variable. Some felt that having students present was not an issue as they were “not very obvious”; some initially found a number of students being present “a bit of a shock”; whilst some felt that their “personal preference would have been if they hadn’t been there”. The instances where those attending training clinics did appear to have a good rapport were those instances where the participant had the opportunity to be seen by the same herbalist supervisor over time. This was clearly illustrated by Sam at T2:

*When I first started for the first two or three sessions, I think it was a different leader for the group every session. But for the last two, I've seen the same person. She asked me if I wanted to come back and see her again the first time I saw her and I think also – that was it – because the leaders before they were all men. And the woman that I saw, she just got more involved with me kind of thing. She asked me different questions... Yeah, I had more of a rapport with her. I don't know if it's because she's a woman and I'm a woman – I don't know but I just felt more like that. And then she said “Do you want to come back when I'm here again?” Which nobody had asked me that before. So that was quite good and I've seen her a couple of times now and I feel more connected to the process now in that way. Although it's all been good but just seeing her a couple of times it feels more continuous.*

Sam's description included something that most of the participants enjoyed, as they paid to see their herbalist privately – continuity of care (another aspect that was often reported to be in contrast to seeing a GP). By having continuity of care, Sam felt more able to build rapport with the herbalist, helped by the fact that the herbalist “got more involved”. Feeling that the herbalist was involved was another example of collaboration, which also led to some participants reporting feelings that the herbalist was helping to support them.

### 6.5.3 Support

Whilst taking herbal medicine was generally seen to be a good thing, it was only part of the participants' experience of WHP. Unlike buying OTC herbs, the herbalist themselves could provide "added value" (discussed overleaf), and so were vital in determining whether the participant felt like their experience was positive or not. One of the main features of distress that was highlighted in chapter 5 was the potential for women with distress to feel isolated. Certain aspects of the herbal therapeutic process (such as accessibility) were helpful in making the participants feel like they were less alone. Feelings of support were also reported throughout the herbal therapeutic process, and could start before the participant had met the herbalist. Eve remembered that the first time she phoned up her herbalist, she felt that the herbalist seemed "sympathetic and seemed like they understood". Isobel spoke of how her initial consultation had a big impact, even before she'd taken the herbs:

*I immediately felt there was someone – whether it was (herbalist) or just their way I don't know – but the way they were, I felt they were with me immediately. (Herbalist) understood me and, "We'll go from here, we'll work from here", and so I left feeling elated.*

Once the herbal treatment was underway, the participants reported ongoing feelings of support. Margaret felt that seeing her herbalist was "a type of doctoring" and appreciated having her health monitored periodically. Yvonne considered herself "lucky" to have met her herbalist, who she described as being "on her team", and gave her "a great sense of relief and support". Pippa reported that the support from her herbalist was continual over time, which helped Pippa to monitor her progress, and so was another example of participants feeling empowered (discussed further in section 6.6.4). As well as having support, Pippa reported that the herbal therapeutic process was also flexible enough (discussed further in section 6.7) that she was able to strive to overcome her feelings of anxiety:

*So you start to notice those things because you've got someone to feed them back to, and you start to notice your progress. So having that – somebody who's met you at the very beginning and*

*then is seeing how you've moved on – and somebody that you think "Maybe I should try this". Because you've got the support from (herbalist) to go "Oh, I tried it, it didn't work" or "I tried it and it did kind of work", and then you can work on maybe tweaking the mix that you're taking, and you've got a plan.*

Carol explained how working with her herbalist led to her feeling like they had a partnership. Whilst Carol primarily visited her herbalist due to having eczema, she felt that the eczema was an external sign of her internal distress. Rather than just having symptomatic treatment, Carol felt that her herbalist would help her to "grow again" and described them as being "like the gardener, I think, with the watering can". Having a good rapport with their herbalist was generally evident across the narratives. Teri related how she was particularly impressed with her herbalist, and reported how "I can't praise them enough" as the herbal treatment combined with a positive therapeutic relationship had "worked brilliantly". The importance of the therapeutic relationship meant that Teri felt supported as the herbalist wanted "to listen and help you get to the bottom of things", which resulted in the situation that "you suddenly don't feel alone". Whilst Teri obviously had a good relationship with her herbalist, positive feelings towards the herbalists were common, and were epitomised by Beth at T1 when she considered the different aspects of the therapeutic relationship and summed up by describing her herbalist as an "all round good egg".

Whilst there was almost universal agreement that taking herbal medicine had beneficial results, the therapeutic relationship had the potential to give the encounter "added value" as Pippa described it. In some circumstances, the added value of having a good therapeutic relationship was seen to be more important than the herbs themselves, as Isobel explained:

*I think the most important thing is feeling you have the support, and the results – the results have been incredible. And feeling that support is ongoing, that's the most comforting thing, the most important things that come from it I think.*

Other participants gave examples of how a herbalist could add value over and above the herbs. Vicki was one participant who felt that seeing her herbalist had

been a positive experience, although personal circumstances meant that she was the one participant who had not had the opportunity to take her herbs. Whilst Vicki had not taken the herbal treatment, the fact that she had received support, understanding and a listening ear, were the positive aspects that encapsulated her experience “in a nutshell”. It was also illustrated by Wendy, who saw her first herbalist for a year and a half with no improvement in her symptoms. The herbalist appeared to give Wendy something more than just a treatment, which led her to persevere with the process:

*I think I must have seen them about eighteen months before they retired probably and every time I went I just went with hope, because I thought “I’m doing something”. If I’d sat here and I wasn’t doing anything to try and help the situation, I just don’t know what I would’ve done.*

Whilst feelings of support were reported by the participants as being a vital part of a successful therapeutic encounter, this is further evidenced by the unusual instances where feelings of support were not received from the herbalist. Fay described how she had spoken to a herbalist that ran a shop before finding her current herbalist, but chose not to make an appointment with them because she found them “abrupt”, with an approach that “was very much like a GP”. She explained how she preferred the approach of her herbalist, which was “much more personal”. Beth had changed herbalist by T2, partly because she felt unsupported when she was told that she no longer needed to have any consultations. However, she also described how she had previously felt when she’d attended a clinic with male herbalists that felt “too official... like going to the hospital”. She reported that the clinic was “very expensive”, but summarised by saying that whilst “the stuff that they gave me was good, the overall experience wasn’t as satisfying”. Vicki had also seen a herbalist prior to the herbalist she was seeing T1, which had been a less satisfying experience. The herbalist had been geographically closer and “very nice”, but Vicki felt that they “just didn’t click”. Whilst Vicki took the herbs that were prescribed for her because she had paid for them, she felt that the overall herbal therapeutic process was not what she was looking for. In part, this was because she felt that she did not “get much back” from the herbalist, whereas the subsequent

herbalist “gave the impression that (herbalist) was actually listening to you, and thinking, and actually they’d assimilated” – a combination of being heard, and being held.

One participant gave a comprehensive narrative which showed that whilst herbal treatment may be helpful, the overall herbal therapeutic process may not be a positive experience. Ongoing gynaecological problems were having a negative impact on her well-being, so that she “really reached out to” her herbalist as she did not know how to deal with it. She described how she “felt very trusting” in her herbalist’s knowledge, but the therapeutic relationship was not always as good.

*At different times I’ve found (herbalist) to be very helpful and their character very easy to get along with, and at other times I’ve found certain aspects of their communication and interaction skills somewhat inappropriate, but I don’t know if that’s just their personality. But (herbalist)’s also been very helpful, so it’s been very mixed to be honest.*

Ultimately, the variable nature of the therapeutic relationship resulted in the participant walking away from what she felt was an unsuccessful herbal therapeutic process:

*So there’ve been several kind of bumps, so I didn’t really feel that I could go back. I didn’t really feel like I wanted to go back to (herbalist), even though I don’t doubt that they’re an extremely knowledgeable person, and I think they’re doing the best that they can. But there were just certain things that were kind of stressing me out about seeing them, and I thought that’s not really the point.*

#### **6.5.4 Reframing**

One further aspect that could contribute to a successful herbal therapeutic process was the idea that once the herbalist had heard the patient’s story and helped frame it, they could hold the story and then help the patient to reframe it; essentially helping the participant view their story in a different light. Whilst reframing was distinct from the herbal treatment, it had the potential to help the participant cope better and so reduce their distress. However, the process of the herbalist helping

an individual to view their condition differently was not universal across the narratives.

What the narratives revealed was that the herbalists were less likely to be involved in reframing patient narratives if the patient was seeing the herbalist purely for a physical condition which had a clear underlying cause – especially if the participant did not associate the condition with embarrassment/shame. For those with mental/emotional problems or physical problems that were associated with distress, the time spent talking with a herbalist had the potential to help reframe their story and so cope with how they were feeling. However, those participants that were receiving or had already received some form of talking therapy (such as counselling) would often report having already found different ways of looking at/coping with their circumstances.

Anna reported how her herbalist had not discounted her symptoms, but made her rethink the reasoning behind her palpitations. At T1, she reported being told by A&E staff that she was “just panicking for nothing”, but still reported that her heart was at the root of her problem. By T2, she realised that her symptoms were related to anxiety after her herbalist – along with other CAM practitioners – had pointed out that the symptoms she was describing were not emanating from her heart. This led to her having a better understanding of how she was feeling, where the apparently dismissive message from the A&E staff had failed to get through. The participants would sometimes report that rather than challenge their diagnosis, the herbalist would help them reframe their situation by suggesting different reasons for why certain situations had occurred. Isobel’s herbalist accepted the symptoms that Isobel reported related to the menopause, but helped her view the situation differently so that she could feel empowered to engage more in self-care:

*Really holding onto the fact that it’s all a natural process and it’s okay to feel down and this is why I’ve been feeling down and this is why I’ve been feeling like I have – physically, mentally, everything else – and just have the veils taken away. It’s like, just feeling there’s lots I can do about this situation.*

After Eve had reported to her herbalist what had been going on in her life and what her symptoms were, the herbalist explained that whilst Eve had been trying to carry on and cope with everything that had been thrown at her, she had reached the stage where she had burnt herself out. As well as using colloquial language, some participants reported their herbalist using metaphors to help them view their situation differently – such as Vicki reported in section 4.6.3. Teri described her herbalist as being someone that had “taken the lid off the box” when the herbal therapeutic process led to Teri realising that (after going to see the herbalist for a minor medical issue) she was actually feeling very down. She described how the herbalist not only helped her to see how low her mood had become, but then helped her to feel better. This process of recovery involved the use of herbal medicine, but also the herbalist helping Teri to view the things that were making her feel low differently:

*My particular herbalist is a lovely person, very patient, very intuitive, has a brilliant way of making you see things in a different way – flipping the coin and helping you to just change your mind about coping or just seeing an alternative side of the problem. And on many occasions it's made me think, because of what (herbalist)'s said and the way they've said it, “Oh, gosh, yes, I didn't think of that, that's a good point. Why did I see it that way when it's so obviously this way? How daft of me”*

Teri's narrative helped to show the complex nature of the herbal therapeutic process, that figure 6.1 has tried to simplify. In this instance, the process of being heard also helped Teri to feel like she was being held and supported, whilst the act of holding and reframing had a therapeutic outcome. The fact that there was a therapeutic outcome leads into the different ways that the participants reported that they were actively treated (discussed in section 6.6).

## 6.6 Being Treated

### 6.6.1 Holistic

In terms of treatment, all of the participants spoke of the holistic nature of the herbal therapeutic process. In part, the holistic approach was perceived to have begun at the start of the process, where the herbalist had the time to take a full medical history. This holistic approach was seen as important: Nicola surmised that the other participants in the research would have spoken of the importance of a holistic approach, and felt that it was one of the key differences between seeing a herbalist and seeing a doctor: “GPs can just be looking at little bits of you at different times, whereas the (herbalist) looks at all of you”. The holistic approach was seen as important by Eve, because she said that:

*I want to maybe be able to get down to the root cause, because without dealing with the root cause, then I'll be taking medicine for ever.*

Treating the root cause was a frequent wish of the participants, though Judith stood out as one participant who was less sure whether WHP was able to deliver that aspect. At T2, she explained how she felt that whilst using herbal medicine “had dealt successfully with the thyroid problem” that she had been experiencing, she was unsure whether WHP would be capable of “getting to the real problem that created it in the first place”.

Whilst the participants were convinced that their herbal encounter was a holistic process, there was still some degree of variation in the approach of the herbalists. This was highlighted by Beth, who considered the differences between the herbalist that she was seeing at T1, compared to a herbalist that she had previously seen. Her previous herbalist had “gone through the whole body” in order to “build up a whole picture” when taking her medical history, whilst she felt like her current herbalist did not do that, but was “targeting the problem” – which she was comfortable with at the time as she did not have any major concerns apart from her presenting complaint. Beth’s current herbalist also saw another of the participants, who did report a full history being taken. This suggested the possibility that the

herbalist was not only treating the patient as an individual, but was also flexible in their approach to the patient, depending on the patient's circumstances.

As well as taking a full medical history, the time could also be used by the herbalist to investigate other aspects of the patient's life. This in-depth questioning was also seen as being an important part of a holistic approach, as was explained by Isobel:

*I mean (herbalist) really asked, and family life, everything, and how I dealt at school, how I dealt with friends, how I dealt with... I just felt at the end of the however many hours it was, that they really knew me, they had a very real picture of who I was and who I'd been, which makes who you are now.*

Isobel's narrative helped to illustrate how the participants generally appreciated the depth that the process involved, as it helped to make them (and their story) feel validated. This in-depth, holistic approach was also extended to the treatment process, as the participants often reported being given individual advice and self-care techniques by the herbalist in addition to any herbal treatment. The participants reported that diet routinely came up in conversation during the consultation: four-fifths of the participants reported talking with their herbalists about diet. The importance of dietary advice was considered by Gemma at T2. She discussed how, in addition to her main presenting complaint, her herbalist had also offered to address problems that she was having with pre-menstrual syndrome (PMS) which had emerged as part of the full medical history:

*The biggest thing I found influencing it though was the diet. It was like eighty percent or ninety percent diet, and the rest of the other percentage was what it took... for which I used herbs.*

Gemma's narrative not only began to show the holistic nature of the herbal therapeutic process in terms of treatment, but also how the process was flexible enough to consider other aspects that were bothering the participant, and incorporate them into the overall treatment package. At T2, Gemma reported that a combination of "diet, exercise, and the herbal medicine" meant her PMS "got very resolved" despite the fact that it was not the reason she went to the herbalist in the first place. Other examples of the herbal therapeutic process being able to impact on areas aside from the main presenting complaint included Eve, who found that

there was an unexpected improvement in her persistent headaches. Nicola felt surprised that her herbalist had resolved her skin condition so quickly, but was also surprised when the herbalist said “we might be able to help with your arthritis” as using herbs for her arthritis “had never occurred” to her.

As well as herbs and diet, lifestyle was another area that was seen by the participants to add to the herbalists’ holistic approach: over half reported talking about lifestyle advice with their herbalist. Of the advice given, the need for exercise was the most common, and was mentioned by almost a quarter of the participants. This was followed by advice on sleep, and what was described by the participants as “general lifestyle advice”. However, rather than only giving general lifestyle advice, the herbalists’ advice could be very specific to the individual. For example, Eve spoke of her herbalist advising that she consider purchasing a dehumidifier to help with her persistent cough; whilst Sam was given advice with regards to washing her skin and her clothes to help with her eczema. Isobel summed up how she felt about her herbalist’s approach to treating holistically:

*And they went through so many things, what I was eating, my whole attitude, everything, and immediately gave me stuff... I left feeling that they were going to sort me out.*

Isobel’s narrative showed that an integral part of being treated was being given “stuff” to take away after her first visit. All of the participants spoke of their experience of having herbs prescribed for them by their herbalist.

### **6.6.2 Herbal Treatment**

Whilst aspects such as a good therapeutic relationship were important for a successful herbal therapeutic process, a good knowledge of medicinal herbs was seen by the participants as a pre-requisite for being a good herbalist. Not only did all the participants talk of the impressive knowledge level of their herbalist, but this knowledge was one of the reasons why the participants chose to consult with a herbalist rather than self-treating with herbs. Partly, this was down to concerns over the safety of self-prescribing. Wendy described the practise as potentially

“dangerous” as “you’re not seeing anybody to tell you if you’re doing the right thing” whilst Sam felt that she did not have enough time to research the herbs to ensure that she was taking the correct amount of the herb, with no contraindications. Some felt that herbs, being natural, were relatively safe: Isobel thought that the body could process and so cope with herbs much better than a pharmaceutical, whilst Hayley felt that “natural herbs” could be dealt with by the liver and kidneys “quite happily”. However, a quarter spoke of instances when they thought that herbs might not necessarily always be safe.

The idea that herbs are relatively safe was partly supported by the participants, as nearly three-quarters reported not having ever had any unwanted effects from taking herbs. However, the remaining participants did talk of having experienced unwanted effects from taking herbs. The majority of the unwanted effects were minor, such as stomach cramps, and were sometimes attributed by the participants to the body getting used to the herbs when they were first taken, although Jade reported an adverse reaction to one herbal supplement (that had been recommended by the herbalist), which she had subsequently needed to stop taking as she felt it caused ongoing feelings of anxiety. In times of possible adverse reactions, the experience of the herbalist had the potential to be reassuring and useful. At one point, Kate (who also had low blood pressure) felt that her “tincture was too strong” as she was “feeling quite weak”, but advice from her herbalist over the phone led to her reducing the intake and resolving the issue.

One aspect of visiting a herbalist that was particularly valued, was that they were seen to be able to use their herbal knowledge in order to ensure that the best combination of herbs were utilised for the participants. When Fay first went to see her herbalist, she was already self-treating with OTC herbs, which were appraised by the herbalist who was reported as saying “well you’re more or less taking the right herbs, but they’re just of the wrong kilter”. So the perception of the participants was that the herbalists used their knowledge and ensured that the correct herbs, in the correct quantity were used. They then felt that this, in turn, would lead to the most effective (and safe) combination of herbs. Lucy was prepared to sometimes self-treat using herbs, but as she summed up:

*Usually if I've got a problem, I will go to (herbalist), because they'll give me something that's exactly what I need, rather than just randomly, throwing something at a situation.*

Once the herbalist had decided on a herbal prescription, unlike a lot of other CAM therapies such as chiropractic or acupuncture, the active treatment was taken away in order to be taken by the participant. In terms of the form that the herbs took, all of the participants spoke of taking a tincture at some stage, although they were not necessarily taking a tincture at T1. In addition to being prescribed a tincture, just over a third reported being given dried herbs to take at some point (either as powder or to make into an infusion), four mentioned external preparations, whilst one patient also reported being given a throat spray at one point, and one patient had moved from tinctures to tablets due to concerns over the possible effect of alcohol on her liver. The dose of the herbs also had some flexibility. Two participants reported being prescribed drop doses: one because she was “too sensitive” to take a higher dose, and one who reported being prescribed a combination of herbs with homeopathic remedies. A pattern of 5 ml three times a day was more typical, though there could again be some variation: the amount taken could be less, or the herbs only taken twice or once a day (particularly if the participant was being weaned off of a higher dose).

One of the first features that was mentioned was the taste of the herbs, and was spoken of by twenty-two of the participants – usually in negative terms. The taste was spoken of as being bearable by over a third of the participants, though exactly how palatable the herbs were could vary. Participants that had taken herbs for a while were aware that the flexibility of the prescription meant that there could be some variation in the taste. Some participants were of the impression that a conditioned response to an unpleasant taste could be an important part of the treatment. Hayley reported that her herbalist had told her the bitterness of the tincture was designed to educate her palate to avoid the sweet things which were bad for her. Pippa described how the taste of her “emergency mix” for when she was feeling anxious, whilst being “horrible”, had become “a comforting taste” which her body associated with feeling better and more in control. Overall, the

participants accepted the taste of their herbal medication. As Zoe said, “as long as it does the job, I don’t care what it tastes like”.

The participants’ narratives suggested that for feelings associated with distress (such as anxiety and low mood), herbal medicine could “do the job”. Diane explained how having experienced depression in the past, she felt that “I think if I wasn’t taking herbs I would probably have bits of depression”. Margaret had a similar story: she described the herbs she took as “helpful per se”, but had originally sought the services of a herbalist when her GP had suggested that she needed to take antidepressants. Margaret’s herbalist gave her a mix that included *Hypericum perforatum* L. (St John’s wort), which Margaret reported led to an improvement in her mood. Other participants mentioned specific herbs that they felt were key to their well-being. Lily took *Scutellaria lateriflora* L. (skullcap): she explained how she thought that she would not need the herb if she was “not in a low state”, but could “definitely see the difference” in her mood if it was added to her tincture when she was feeling low.

As reported in chapter 4, one of the situations that could particularly exacerbate feelings of distress was a lack of sleep. Fay was one of the participants who were taking herbs at T1 in order to help with difficulties in sleeping. She described how “within a couple of weeks my sleep pattern was much better, the quality of sleep was much better”. Like Fay, others found that the effects from a lack of sleep could be profound. However, in these instances, herbs were reported as being effective: Isobel, Rachel and Wendy all spoke of the impact of insomnia due to menopausal symptoms, but also the beneficial effects of taking herbs. Gemma was another participant who found that taking herbs appeared to have positive effects:

*My sleep’s really altered, I’m sleeping much better. I don’t have that feeling of being like I’m going to pop – that’s gone. I have so much more energy now than I had before, my body feels fantastic, I just feel really healthy.*

In some instances, participants described a physicality to the actions of the herbs. Lily described how taking herbs when her mood was low felt “like someone from behind holding you up and lifting the pain away for a bit”. Some herbalists

appeared to acknowledge the physicality that the herbs could provide, and dispensed tinctures for their patients that the herbalists typically described as “a hug in a bottle”. This description seemed to reflect the views of some participants. Jade described that whilst having a bottle of herbal medicine “might not fix the whole problem straight away”, it felt “like a support”; but rather than drinking or comfort eating, taking the herbs “felt like a positive thing”. As Fay described it:

*The first few times I took it I could literally feel the base of my back kind of warming up and... when I went to bed it was like getting a hug in bed it was just beautiful, really nice... you feel like, even if you haven't put your feet up, you feel like you're in the big comfy chair with your feet up.*

Some of the narratives also gave an idea of timescale when it came to taking the herbs. In some instances, the participants would report how the herbal medicine could take some time to have an effect. Isobel reported that her herbalist initially informed her that the herbal mix would take three months to help improve her menopausal symptoms. This timescale was an initial concern for Isobel, but she was impressed with the eventual results:

*I was just thinking “Oh God, I need something now”, and in literally three months' time it kicked in and my hot flushes and night sweats and everything just started to fall away, which is incredible.*

What also became clear from the narratives was that the time that the participants reported it took the herbs to have an effect was variable. Both Anna and Pippa described having “an emergency mix” that they could take whilst feeling anxious, which would have “an immediate reaction”. Most of the participants did not speak of an immediate reaction, but they did sometimes find the speed of the results from taking herbs surprising. Nicola reported how she had initially visited her herbalist for a skin complaint, and that a combination of tincture and “a very, very simple cream” had left her “very pleasantly surprised that by the time I went back in three weeks it had all cleared up”. Rachel was feeling run down when she first went to see her herbalist, but also received treatment for menopausal symptoms coupled with a low mood. At T1 she described how “when I first started taking them within three days some of the physical symptoms were gone”, and also that approximately

six weeks after her first visit “I certainly felt much more uplifted and clearer in my head... much more positive”. Rachel’s narrative helped to show how herbs could work relatively quickly for some conditions, but take longer for others. This variability could also exist between participants with seemingly similar circumstances: Margaret described when she first took *H. perforatum* that “it took a couple of months before any improvement was shown”. Diane’s experience of taking *H. perforatum* in her tincture was different, as she was surprised at the speed of the results:

*And (herbalist) said don’t expect them to work suddenly, but actually they did – within days I started feeling better, and I just got brighter and brighter and brighter and I felt really full of energy in a very short space of time.*

What the participants’ narratives showed was that at T1, taking herbal medicine prescribed by a herbalist was generally reported as being effective for feelings and conditions associated with distress, and that all the participants (even if they were new patients) would have had time to see any beneficial effects from visiting their herbalist by T2. There were only three instances reported at T1 where the patient did not have an entirely positive response to the herbs (although the herbs were still seen as having some benefits). Eve felt that her presenting complaint (chronic cough) had not been affected by taking the herbs (although she had noticed a welcome improvement in other symptoms such as headaches and insomnia). Jade reported (above) having been recommended one herb that she attributed to feelings of anxiety. Vicki had not tried taking her herbs at T1, but did report feeling positive that they would help her to recover from being run down after having pneumonia and cancer.

Another aspect that the narratives elicited with regards to taking the herbs was whether the expectation of taking the herbs would lead to a positive reaction. Half of the participants touched on whether something other than the medicinal properties of the herbs had a role to play in any perceived success of their herbal treatment. Zoe spoke in terms of having an expectation response when she reflected on whether the mere presence of herbs in her cupboard could have a

positive effect on how she was feeling, and whilst she admitted that she had not thought about it before, she considered that it “might be an important part of it”. Others also considered whether an expectation response was important. Jade wondered whether having a bottle of tincture to turn to was in itself helpful, but was clear that the important point was that “it was helpful”. Pippa thought that the herbs from her current herbalist were effective because “I can just feel it”, though she was also accepting of the idea that when treating physical conditions, “psychosomatic things can really help”. So rather than seeing an expectation response as detracting from the herbs, the participants that commented on the idea accepted it as another part of the herbal therapeutic process. The process could also extend to the daily ritual of taking the herbs. As Carol explained:

*Seeing the bottle, putting the bottle on the side so the bottle represents, it becomes something, opening it up... You know it's a whole process from being given this thing, this is what it is, taking it and taking it twice a day... It's a remedy.*

What the narratives demonstrated was another example of the flexibility of the herbal therapeutic process (which is looked at further in section 6.7), with marked degrees of variation between the participants' stories in terms of the form that the herbal treatment could take, the combination of herbs, the dosage, and when the herbs were taken. This flexibility of treatment also extended to the participants describing how the herbalists could use the herbs in combination with other treatments, or decide that a referral of the patient was necessary. Whilst the participants had a variety of narratives due to the individual nature of their treatment, their stories showed that they generally had a positive response to taking herbal medicine. These experiences meant that the participants were keen to continue taking the herbs due to the beneficial effects that were reported. Zoe felt that the herbs were “a major part” of her “support system”, and whilst she did not want to use the word “dependent”, she “wouldn't like to try without them”. As Rachel also explained, “If I was to go somewhere and I'd forgotten my herbs, I think I'd be pretty devastated”.

### 6.6.3 Non-Herbal Treatment

As was reported in section 6.4.4, some therapists were trained in more than one therapy. In these instances, not only could the herbalist use techniques from different disciplines to aid their diagnostic skills, but could also use other techniques when treating the patient. Whilst virtually all the participants reported that their herbalist only used herbs as an active treatment, one practitioner was also trained in Traditional Chinese Medicine (TCM). In this instance the herbalist would not only use TCM techniques when diagnosing, but would also use herbs in a way more familiar with CHM in addition to techniques like acupuncture as part of their treatment regimen. One herbalist was trained in a number of CAM therapies, and so their treatment was variable as they could use a combination of WHP, meditation, healing, and homeopathy.

One other treatment outcome, which was spoken of by eleven of the participants, was the willingness of the herbalists to refer patients on to other healthcare practitioners where appropriate. The reasons why a herbalist might refer a patient could vary. The most common reason (spoken of by a quarter of the participants) was due to having conditions which required biomedical treatment. In some cases, the participant did not talk of specific instances, but merely highlighted their confidence that the herbalist would refer if necessary. This was particularly spoken of by Nicola, who had witnessed herbal students' practical exams. The students had been specifically asked when they would refer patients, which had highlighted to her the importance of appropriate referrals, but also gave her confidence in the depth of their knowledge combined with clear professional boundaries:

*I understood that it's vital that if you say got someone like me who's not too keen on going to the GP, if it's really necessary you obviously have to steer them in that direction and that it's vital you don't give the impression that you are some sort of shaman who can sort out anything. So obviously that has to be got across in the training.*

There were also specific instances reported which reinforced the suggestion that the herbalists had clear professional boundaries, where a herbalist had advised the participant to seek the services of another practitioner such as a dentist or a

podiatrist. Diane in particular spoke of the time that her herbalist had refused to treat her before she had had a lump examined in order to ensure that it was not a sign of a serious medical condition. As well as referring on to different healthcare practitioners, four of the participants spoke of herbalists advising them to seek the services of different herbalists with specific expertise. Beth was advised to see a different herbalist when her recovery “plateaued”, whilst Diane was advised at one point to see a herbalist that had greater experience of dealing with cancer patients. That is not to imply that any of the herbalists made any claims to be able to treat cancer: Vicki was adamant that her experience of herbalists was that they treated individual patients, and not specific conditions such as cancer, whilst Judith explained how she had been unable to find a herbalist that would be willing to treat her cancer in place of biomedical treatment.

#### **6.6.4 Empowering**

All of the participants spoke of some aspects of the herbal therapeutic process that they found gave them feelings of empowerment. These feelings could occur before the first visit to the herbalist. Wendy’s narrative of visiting the herbalist “with hope” in section 6.5.3 raised an important point. Some of the participants’ distress surrounded feelings of shame due to a loss of control, linked to feelings of an inability to cope. Wendy clearly showed that one aspect that she found helpful when she first went to visit a herbalist was the fact that she was regaining some element of control by taking the decision to seek help after feeling desperate due to her menopausal symptoms. These feelings of desperation were frequently spoken of by the participants (reported in section 4.4) and were instrumental in them seeking the services of a herbalist. The feelings of desperation that many of the participants spoke of as a feature of their distress before visiting a herbalist helps to explain why the participants reported positive feelings at the start of the herbal therapeutic process, as these feelings of desperation could be replaced with those of hope.

Diane described how visiting the herbalist to help with her arthritis and tendency to depression had given her optimism that she would be able to cope without the need to resort to taking pharmaceuticals. At T1, Gemma described how she was “really excited” that the herbalist had explained to her that (in addition to her presenting complaint) they should be able to treat her PMS symptoms using herbs. This instilled feelings of confidence as she realised that “there’s things that I’ve been putting up with that I think are normal that I don’t actually have to put up with”. These feelings were echoed by Nicola, who described how seeing her herbalist enabled her to be “proactive” when it came to problems with her health such as arthritis: she felt that herbs and yoga to manage her symptoms was preferable to taking painkillers once the symptoms occurred. These feelings of being proactive and taking control were summed up by Rachel when she described visiting the herbalist to help with her menopausal symptoms and a tendency to have depression:

*From that basis on I could move out into the world and do the things that feel right for me again and being more myself again, and being more proactive and doing things that are good and nice and nurturing.*

What Rachel’s quote introduced was the suggestion that visiting a herbalist not only helped to lift her mood, but by being able to regain feelings of control, she could engage more with other self-care techniques, which ultimately helped her to feel like she had regained a sense of self. Another aspect of the herbal therapeutic process which could feel empowering and was mentioned by all of the participants was the sharing of knowledge by the herbalist. Not only could this involve informing the participant about the herbal prescription as a way of forming trust (reported in section 6.5.2), but could also involve advice of diet and lifestyle changes for the participant to implement themselves (reported in section 6.6.1).

Section 6.5.2 provided examples where the herbalists explained to the participants which herbs were prescribed for them and why. In addition to this, a quarter of the participants spoke of being able to suggest specific herbs. For Anna, the fact that she was so sensitive to herbal treatment meant she needed to be able to try drop

doses of the herbs and then tell her herbalist if she could tolerate the herb in her tincture or not. Other participants had some knowledge about the herbs, and so felt that they were able to make suggestions to the herbalist. Lucy had read up about herbal medicine, so that whilst she acknowledged that she was not a herbalist, she had “an idea of what the starting point might be”. Lucy’s herbalist ultimately decided what went into the tincture, but Lucy liked the fact that the herbalist was “not an autocratic practitioner”. Margaret also described how “every now and then” her herbalist would suggest reducing the amount of *H. perforatum* in her tincture, but that she would make it clear she did not want to reduce the amount of support from the herb, so it would stay the same.

Whilst some participants felt that they were able to suggest specific herbs to go into their tincture, it was more usual for the participant to let the herbalist choose the herbs, with input in terms of how the participant was feeling. Teri was always asked about how she had been getting on since her previous consultation, and felt that her input was important in deciding if the mixture needed to be changed or not. In section 6.4.3, Sam described how she had been made to feel like “the expert” in her consultation. This sentiment was echoed by Rachel, who always felt that she was part of the decision making as to what herbs she would take as she was always asked the question “Is that still working for you? How are you getting on with it?” It was this feeling of being valued that could help the herbal therapeutic process to feel like a collaboration, which could empower the participants. This was summed up by Beth, who had not always felt that previous herbalists had given her much say when it came to treatment options. However, as spoken of in section 6.5.2, the herbalist that she was seeing at T2 felt like “a guide” and always made Beth “really feel like it’s your choice”, which was empowering because:

*I feel like it’s the right balance of control in-between practitioner and patient because I think sometimes I’m not very assertive, and so I’ll nod along with things sometimes, when I’d rather say something but I’m a bit too shy or scared to say it.*

Feelings of empowerment could be boosted by the herbalist, by them letting the participant know that they were doing the right things to help themselves. Fay

described how she discussed her lifestyle changes with her herbalist, who confirmed that generally she had “been doing the right things”, which made Fay feel positive. Teri felt that she was starting to come to the end of her herbal therapeutic process at T2, and recounted how her herbalist had made a specific point of acknowledging the role that Teri herself had played:

*And (herbalist) did say to me that I should be very, very proud of myself for going through that, and said that “It’s quite amazing that you are now where you are because you would have had to dig very deep emotionally, under lots of layers, to get yourself back to this situation. And don’t underestimate the way that you feel now because it really is a very big thing compared to how you were – I’m really, really pleased and happy for you and really, really don’t underestimate it”. And that was a really good thing to say, because I hadn’t really thought about it, and it did really bring it home to me about the whole process that I’ve been through with her and how great it really does feel.*

## **6.7 Flexibility**

Section 4.3 illustrated the diverse range of stories of distress that were recounted by the participants. Although the variety of stories could have been considered problematic for the herbalists to deal with, their patient centred approach meant that they were able to adopt a flexible position which could concentrate on the needs of the individual. This flexibility was illustrated by Beth (in section 6.6.1) when she described how her herbalist at T1 had used an approach that focused on her immediate problem, though a more general approach was reported by another of the same herbalist’s patients. This degree of flexibility was important as not only could the herbalists provide individualised treatments for a range of conditions associated with distress, but their treatment could also be adjusted as they accompanied the participants through their journeys of distress.

Having a companion on their journey was particularly important for the participants as they frequently spoke of feelings of desperation before visiting their herbalist – often due to perceptions of being marginalised (as outlined in section 4.4). These feelings were often spoken of after the participants felt that the cause of their distress had not been able to be dealt with through individual self-care or

adequately handled by their biomedical encounters. One of the advantages that the participants felt WHP had over biomedicine was that its flexibility meant that it also had a subtlety which was appropriate for dealing with diverse feelings of distress. Diane felt that this subtlety was an advantage with regards to her mood, as when she went to visit her GP she felt that “it’s black and white again, either you’re depressed or you’re not depressed – you can’t just have something added to a mixture that might help your mood”. Fay agreed with the view that visiting a herbalist (along with other patient centred CAM therapists) had an advantage over biomedicine as she felt that “formulaic doesn’t work”, but that herbalists:

*They seem to work much more with the person in seeing how they as a person are doing on that treatment or on that particular course and are willing to adjust it. And also look into other avenues to adjust things... even if it means that that person needs to go on some other course or seek some other medical attention or whatever it is – they seem much more open to that.*

The flexibility to alter the herbs that were in the individual’s herbal prescription was spoken of by twenty-four of the participants, and was universally seen as a good thing as it helped to reinforce the notion that the herbal prescription was specific to the individual. Flexibility was also acknowledgement by some participants that “everybody’s body is different” as Pippa put it, and so some “tweaking” was always likely to be necessary. Nicola considered how the herbs that she was given were “very suited” to her, but was aware that there were lots of different herbs that could potentially be used, and knew that one herb that was in her mix would not be used on a patient with a “dodgy tummy”.

Lucy reflected on the fact that she did not know what dose her herbalist might prescribe for someone else, but that she was being prescribed herbs at a dose that was within her limits. Flexibility of the dosage gave the opportunity for the participants to feel that they were only taking as much medicine as was needed. At T2, Anna spoke of how as she got “better and better” the dose got “less and less” to the point where she would end up taking a “maintenance dosage” – the idea being that the herbalist would take her off the herbs gradually. This process was clearly

illustrated by Judith, who was taking herbs in order to try and keep her thyroid hormone levels within normal parameters. As she described it:

*I take a little tincture in the morning, and when I started I was taking it three times a day, and then we gradually cut it down as the (hormone) figures went up, and (herbalist) advised me how much to cut down until we were down to one dose a day, and the figures were still okay. And then if I feel like things aren't right I'll ring (herbalist) and they'll either tell me to increase it again, or maybe "Come in and see me and we'll change the mix".*

The flexibility could also extend to having different herbal mixes for different situations. Fay reported having two separate herbal mixes ("a morning tonic" and "an evening tonic") that she took at different doses as well as at different times. Whilst she described both mixes as "nurturing", the morning tonic was designed to help boost her energy levels, whereas the evening tonic was designed to be more relaxing. Lucy described how she had a separate "pain medication", to her main mix. She liked the flexible approach that was tailored specifically to her, and felt that it was a better way for her to work "than a doctor who's just gonna give me a blanket dose of something".

The flexible approach also had the ability to make the participants feel like they had a role to play in deciding the herbal outcomes (also mentioned in section 6.6.4). Pippa felt that she had some input: she could mention symptoms that were of concern, and the herbal prescription could be altered in light of her reporting. Similarly, if she felt that a particular mix suited her, she felt comfortable saying "This has worked really well, don't change anything". However, experiences could again vary as the herbalist's approach could be different. At T2, Beth had gone back to a previous herbalist because she liked the herbalist's personal approach and "that they're going to offer you more than one option". This was in contrast to other herbalists that she had seen where she was made to feel "if you don't do it this way, then it won't work".

## 6.8 Participants' Views of Western Herbal Practice for Distress at T2

Ongoing feelings of being cared for as reported in section 6.5.3 were apparent across the narratives partly because, with the possible exception of those attending a training clinic, the participants always saw the same herbalist. As Zoe explained, she liked the continuity of her relationship with the herbalist, and described the process of seeing her herbalist as “a journey”. This section considers whether the journey of visiting a herbalist over time led to continual benefit in the treatment of distress or not. Of the twenty-six participants, all of them were able to complete their T2 interview and provide an update on their experiences of distress and visiting a herbalist. The outcomes that the participants reported in terms of treatment were variable, but broke down into five categories. These categories are outlined in Table 6.2, with a description of results following on from section 6.9 to section 6.10.

**Table 6.2:** Participants' Views at T2

<b>Participants' Views</b>	<b>No. of Participants</b>
<b>No Longer Visiting the Herbalist (n=10)</b>	
Stopped Due to Circumstances	5
Felt That Herbalist Not Needed	4
Unable to Find a Suitable Herbalist	1
<b>Still Visiting the Herbalist (n=16)</b>	
Reached a plateau	7
Continual Improvement	6
An Undulating Journey	3
<b>Dropped Out of Process (n=0)</b>	0
<b>TOTAL</b>	<b>26</b>

## 6.9 No Longer Visiting a Herbalist at T2

From the T2 narratives, ten participants reported that they had stopped going to visit their herbalist. The reasons for stopping seeing the herbalist varied, but could be broken down into five that stopped going due to circumstances, four who felt they no longer needed their herbalist at T2, and one who had been unable to find a

suitable herbalist after after giving reasons for no longer visiting her first herbalist at T1.

### **6.9.1 Stopped Due to Circumstances**

The five participants who stopped visiting the herbalist due to circumstances did so for a variety of reasons: the upheaval of moving house, bereavement, falling pregnant, lack of money, and a relationship breakup. What these five participants shared was a desire to visit their herbalist again in the future once their circumstances were different, and underlined the positive experiences reported at T1. These were typified by the narratives of Vicki and Gemma. As at T1, personal circumstances at T2 meant that Vicki had not taken the herbs that her herbalist had prescribed, though she still reported that the herbalist had given her “excellent advice” and that she would be prepared to visit them again – especially for an ongoing condition such as chronic stress. Vicki was keen to make it clear that her herbalist was very accessible and that “I could ring her anytime... there was no problem whatsoever”, but the fact that Vicki had not utilised the herbs “was entirely my fault really for not doing it”. Gemma had stopped seeing her herbalist at T2 as Gemma had fallen pregnant. Gemma’s herbalist had advised her with regards to the safety of taking herbs when pregnant: Gemma had taken the advice and chose to stop taking any herbs at that stage as she thought that “it might not be safe”. Whilst not taking herbs at T2, Gemma reported ongoing positive results before becoming pregnant, and indicated that she would see her herbalist again: she was experiencing insomnia at T2 and explained that “if I felt like this and I wasn’t pregnant, I’d go and see them straight away”.

### **6.9.2 Herbalist Not Required**

Of the four participants who felt that they did not need to visit their herbalist at T2, three shared a similar story. Isobel had improved to the point that whilst she still felt she needed to take herbs for her menopausal symptoms, she was at the stage

where she no longer felt like she needed to visit the herbalist and so was self-treating with OTC herbs and supplements. The success of her experience was illustrated by the fact that Isobel reported that she would visit the same herbalist again, and that if she was feeling low, the herbalist would be “probably the first person that would pop into my mind”. Judith provided another example, as she had also not felt the need to see her herbalist because she could manage her symptoms with a repeat prescription from the place that the herbalist worked. Judith had not considered contacting her herbalist when she was diagnosed with cancer between T1 and T2, but thought it “quite probable” that she would go back to the herbalist once she had finished her course of cancer treatment.

Lily’s story was different as she had stopped taking her herbs by T2, and then “came to a grinding halt” where she had to give up a lot of her responsibilities in order to be able to cope with how she was feeling. However, whilst this might appear to be an example of a setback, Lily described how the process was “healthy” for her:

*It may not sound healthy, it may sound counterintuitive, but the way I learn and deal with things is from crises. If I don’t have a crisis I go round looking for one. My body needs stopping points and starting points and the crisis is like a full stop.*

Lily reflected back on how she had managed to carry on with the pressures she felt she had been under for so long – particularly helping to organise local groups, and helping to care for her parents when they were alive. She remembered that she had been visiting her herbalist for a number of years, and surmised that the process had been successful in helping her through the difficult times as “I didn’t realise how much it was helping me until I stopped and crashed”. Lily was another participant who indicated that she would return to the same herbalist – in her instance because she thought “I will need it” once she had gone “through this bottom feeding phase”. What Lily’s narrative also illustrated was that recovery from distress is not necessarily a linear process, but whilst her story could be considered to illustrate a relapse, by stopping treatment Lily was able to relinquish responsibility that she might have otherwise felt hard to do.

### **6.9.3 Unable to Find a Suitable Herbalist**

At T2, the participant who had stopped seeing her herbalist at T1 had not returned to the herbalist, but had not visited another one either. She reported part of the reason was down to circumstances, as she had been through a rough time looking after her pet who had been ill and died between T1 and T2, but she had also been unsuccessful in finding another herbalist. When she had made attempts to find someone, she found that either there was nobody local to her, or when she did contact a herbalist, they were “rubbish at getting back to me”. The frustration that the participant felt was exacerbated by her reporting that she had found benefits from taking herbal medicine and that “I’m really convinced that it did a world of good”. Whilst she indicated that she would visit a herbalist in the future, she expressed a desire to be able to get a recommendation “of somebody who knows somebody who does stuff that would be good for me”. What became clear from the participant’s narrative was that if the positive aspects of the herbal therapeutic process were not in place, a herbal encounter was unlikely to be effective in the treatment of women with distress. As she put it, when she was going through a rough time, visiting her herbalist “felt like a rollercoaster and I just needed something a bit more steady in a herbalist to be honest”.

### **6.10 Still Visiting a Herbalist at T2**

From the narratives, sixteen participants reported still visiting a herbalist at T2 (although two were not visiting the same one as at T1). The reported degrees of success varied, but could be broken down into seven who felt they were in a similar situation to T1, six who reported improvements from T1, and three who reported mixed results, though they felt the overall process had been positive.

#### **6.10.1 Reached a Plateau**

Seven of the participants reported a similar situation to T1 at the time of their T2 interview. However, all seven were women who had been seeing their herbalist for

a while before their T1 interview and had reported a positive experience at T1. In that respect, whilst their situation was the same, this was viewed by the participants as a good thing as they felt that the herbal therapeutic process was continuing to work for them. Diane explained how there was generally “nothing new there” with respect to her mood and arthritis when she visited her herbalist. However, whilst she felt that she could have a repeat prescription of her herbs, she found that visiting her herbalist gave her ongoing support and added benefit as “I like the people – I find the place therapeutic as well”. Lucy felt like her situation post chronic fatigue had remained stable since T1, so that she continued to use her herbalist “as and when I need her”. Lucy’s narrative gave the impression that she was the one participant who appeared to most utilise the services of her herbalist in a similar way to a GP, though she was clear that there were a number of therapists available to her (including her GP) and that “I’m choosing which treatments I use when”.

Rachel was continuing to take herbs at T2 for her menopausal symptoms, but which also included “something in there for my moods”, which she felt had “made a huge, huge difference”. Whilst her treatment was ongoing, Rachel appeared happy to stay on the herbs for the time being due to concerns over what would happen if she stopped. As she said: “I don’t want to stop taking them just to see ‘Oh how am I doing without them?’” Yvonne reported a similar situation. She had been receiving treatment for chronic fatigue for a number of years, and so was aware that she was likely to be taking herbs for the foreseeable future. However, she reported confidence in the herbs and reported that “I do think it works, and I think psychologically knowing I’ve got it works” so that Yvonne described how having them was fundamental:

*I see it as necessary to have quality herbs that have been ideally prescribed specifically for me in my cupboard, as other people think it’s necessary to have milk in the fridge. So that relationship has strengthened – so that’s changed, and the types of herbs that I now take have changed.*

### 6.10.2 Continual Improvement

Six of the participants were still seeing their herbalist at T2, and reported feelings of continual improvement from T1. Of these six, three reported improvements in feelings of anxiety or low mood, whilst three reported fewer physical symptoms. Of the three who reported improved mental well-being, Anna described how her feelings of anxiety had started to improve, so that the amount of herbal medicine she required had reduced to the point where she was “able to drink it as a little tea, as a maintenance thing”. Fay described how her treatment process for anxiety had “just been working much better” from T1 so that whilst she felt that she was “not quite there yet” in terms of stopping the herbal treatment, she had got to the point where she had discussed with her herbalist “a point where I don’t take them all the time”. Teri described how taking herbs had “definitely” improved her palpitations, but that the overall process of overcoming her feelings of low mood had taken “a couple of years”. However, at T2 Teri had got to the point where she began to feel “Ah, I’m back”, which she described as “a really good feeling”.

Hayley had started visiting her herbalist just before T1 for treatment with diverticulitis. At T2, she was very pleased that she had remained asymptomatic throughout and had not experienced a “flare up”, but reported ongoing feelings of support from both the herbs, and the herbalist:

*I take a teaspoonful of gut medicine every night before I go to bed – just as a reinforcement and as a kind of comfort blanket, if you will. So I’ve got enough medicine now to last me for six months, when we’ll be in touch again and I’ll see her and see how we’re getting on. If I get into trouble in the meantime I’ll contact her, but I don’t intend to and I don’t expect to.*

Sam reported a sudden improvement in the eczema on her legs between T1 and T2, which led her to conclude that “the herbs have worked. I believe that definitely”. She also described how she felt that, apart from a change in her symptoms, her overall experience had improved after she started seeing the same herbalist at her clinic (reported in section 6.5.2). Wendy had also seen improvement in her menopausal symptoms: at T1 she reported seeing her herbalist every two weeks, but at T2 this had reduced to once a month. Wendy explained how not having to

see her herbalist as often was tangible “progress”, and considered how she felt compared to when she was at her lowest: “When I was so low then I couldn’t see a light at the end of the tunnel, but now I can”.

### **6.10.3 An Undulating Journey**

Three participants reported having seen improvements at T2, though their journey had not been a straightforward, continual improvement. At T2, Beth had stopped seeing the herbalist she had been visiting at T1 for help with her IBS and related anxiety. Instead, she had decided to return to a herbalist that she had visited previously in an area that she used to live. This decision was partly driven by feelings of a lack of accessibility (and so support) with the herbalist she was visiting at T1 (as reported in section 6.4.1), coupled with the perception that the herbalist’s dietary advice had a lack of flexibility. Difficulty in sticking to the diet, and a feeling that she had “started reaching a plateau again” all contributed to Beth switching herbalist to one that she had previously had a positive therapeutic relationship with. However, whilst she had not had an entirely satisfactory encounter with the herbalist she was visiting at T1, at T2 Beth reported a positive experience with her original herbalist and some improvement in her symptoms. She summed up her position by explaining how she felt that she still had “a long way to go, but I’m doing a lot better”.

Pippa’s narrative at T2 also illustrated how recovery from distress was not necessarily a linear process. She described how after her T1 interview her levels of anxiety had improved, but there came a stage where she was not seeing many further improvements. At that point she decided to start taking the pharmaceutical antidepressant (citalopram) that had previously been prescribed for her by her GP as “I need to be doing everything possible – I can’t let my life just tick by slowly”. Pippa, in conjunction with her herbalist, had decided to reduce her herbal medication to see how she got on with the pharmaceutical treatment. However, at T2 Pippa felt that a combination of reducing the herbal medication, an injury which meant she had not been able to do other things which she felt helped her feelings

of distress (such as walking the dog), and the possibility of having to move house had led to her anxiety getting worse. After considering her situation, Pippa concluded that “actually, the herbal meds were making more of a difference than I realised” – not only with her feelings of anxiety, but also with her “anxious stomach” as she could “eat the stuff that usually would make my stomach upset” because the herbs “were doing such a good job”. She concluded that the herbal treatment “was definitely having an effect”, and whilst “I’m almost at a step back at the moment, but maybe on my way to a step forward” it was because “sometimes progress doesn’t come in a constant form” and “it’ll probably take another couple of years” to get to where she wanted to be. Pippa was also clear that part of the process that she had found useful was the role of her herbalist as a non-judgemental source of support: after reviewing her cleaned T2 transcript, she contacted the researcher to clarify her thoughts.

*When I made the decision to take the citalopram my herbalist was very supportive and understanding and made it easy for me. She made room for this treatment and after a month or so suggested we gradually lower the herbal medication so I could see if citalopram alone would resolve my issues so I would not be taking the herbal medication unnecessarily... My herbalist put me first as a patient rather than feeling she had to protect her profession first and try to dissuade me from looking at other treatment options. This can only improve the trust in this relationship.*

### **6.11 Summary**

The herbal therapeutic process is a complex one: the different sections outlined in this chapter come together in a continually evolving way to result in the overall patient experience. The process can be seen as one of a number self-care processes available to women who find themselves living with distress. The patterns of use of WHP by the participants showed that their overall experience of WHP was positive. This was illustrated by eleven of the participants visiting a herbalist before the herbalist they were seeing at T1 (including Gemma who had seen a naturopath who had used herbal medicine), whilst all of the twenty-six participants indicated that they would be prepared to visit a herbalist in the future. As well as the patterns of

use, the participants' narratives have also shown that WHP can be of benefit to women who are living with distress: the narratives illustrated that the participants perceived herbal medicine to be effective, and their experience was (in almost all cases) enhanced by a good therapeutic relationship. This underlines the point that one of the main strengths of WHP (and makes it distinct from many other therapies) is that patients receive a combination of a supportive relationship, and an ongoing active treatment to take away (plus the safety net of an accessible practitioner). The importance of these elements was reinforced as when some were lacking from the herbal therapeutic process, the experience was likely to be less good, and could result in a mechanism of exit. Whilst WHP would therefore appear to be a suitable process with which to help women on their journey of distress, it is still important to take the elements of the herbal therapeutic process that are particularly useful, and to place these findings with a wider social context. These points will be discussed in chapter 7.

## CHAPTER 7: DISCUSSION

### 7.1 Introduction

The results from the previous three chapters have added to what is known about women's experiences of distress and WHP in a number of key areas. These areas will be discussed in depth throughout this chapter, although the main findings of this research (and its original contribution to knowledge) are summarised in this section.

This research has expanded on the understanding of women's experiences of distress, whilst also providing original contributions to knowledge in this area. Initially, this research has helped to reiterate findings from existing literature that women's stories of distress are diverse. In spite of this diversity, this research has highlighted feelings that the participants commonly experienced with their distress (such as isolation, anxiety and low mood). The current research findings would caution against the tendency within the literature to view women's distress in terms of "internalising disorders" (The European Union Health & Consumer Protection Directorate-General, 2004) as the stories collected here included numerous examples that are classified as "externalising disorders", including instances of self-harm. Whilst varied experiences of distress occur along a continuum, this research has also confirmed the profound impact that seemingly everyday distress can have on women's well-being and everyday lives. In line with previous research, the participants' narratives have shown a frequent use of metaphors in order to communicate distress (McMullen, 1999), but have also elaborated on the analogies commonly reported within existing literature to show that a variety of metaphors were used to describe distress, and for feelings other than depression. This research has also extended the knowledge regarding women's use of metaphors of distress as, unlike previous research, the concept of disintegration was of importance to the participants: it also allowed subsequent descriptions of being made whole again, which were useful in providing narratives of recovery from distress.

As outlined in section 2.2.4, previous research has reported how women living with distress run the risk of finding themselves isolated (Fullagar, 2008; Jarchow, 2014), which has been supported by these findings. In addition, this research has confirmed that women may also isolate themselves (including instances of “putting up a front”) both as a way of trying to cope with their distress, but also as a way of protecting their private, inner self from the public arena within which they portray their identity. In this respect, the participants displayed examples of “performativity” (Schlichter, 2011) that extended beyond the idea of gender to include all interactions with others. A further area in which this research adds to the literature of distress and isolation, is by having shown that whilst some literature argues that women’s distress is over-pathologised (Henderson, 2012), everyday distress could be disabling for the participants who had not contacted their biomedical practitioner (or who had subsequently removed themselves from the biomedical process). In these instances, despite the potentially profound impact of their distress, the participants would be flying under the radar of the medical gaze, which could contribute to them feeling invisible and marginalised. Feelings of marginalisation were further alluded to by the participants when they reported stories which – despite the assertion that general attitudes towards mental illness in the UK are improving (National Health Service Information Centre, 2011) – provided instances of perceived and/or enacted stigma.

While previous research has shown that women’s distress can be associated with feelings of embarrassment (Hunter et al., 2013b), shame (Sari & Gençöz, 2015) and/or guilt (Vallido et al., 2010), this research has shown that the participants particularly associated embarrassment with assumed outwardly visible signs of physical illness. The participants commonly reported feelings of both shame and guilt when living with mental/emotional distress. This research has contributed to the knowledge surrounding understandings of the shame and guilt associated with distress by highlighting that it was not uncommon for the participants to experience feelings of shame and guilt concurrently, with links to a sense of control and societal role. For the participants, shame was invariably linked to expectations of autonomy which are commonplace within neoliberal societies (McCoy & Peddle, 2012); whilst

feelings of guilt were associated with perceptions of the impact that distress had on others, which were linked to expectations of women's traditional role within society of being self-sacrificing carers (Lafrance & Stoppard, 2006). Following on from the feelings of shame due to a loss of autonomy, this research has added to the knowledge of women's distress: whilst the participants' distress often resulted in feelings of a loss of self (Charmaz, 1983), they were particularly centred around feelings of a loss of agency as it was feelings of losing control (and the perception that to do so was socially unacceptable) that impacted on perceptions of the self.

In terms of patient experiences of WHP, this research has also made some important contributions to the (currently limited) literature on the subject. The results from the longitudinal element of this study have helped to show that continual use of WHP over time can be beneficial for women living with distress (as reported by these participants). This conclusion was strengthened as all the participants who completed the T1 interview process came back to also complete their T2 interviews. The demographics of the participants which were outlined in section 3.5.2 have helped explore further the type of people who use WHP, whilst their descriptions of visiting a herbalist in chapter 6 has also helped to clarify what the experience of WHP looks like from the patient's perspective. In addition, the research has helped to show that rather than completely rejecting biomedical treatment when choosing to visit a herbalist, the participants were likely to continue visiting their GP (and other therapists) as part of a pluralistic approach to healthcare.

Apart from describing what occurred when visiting a herbalist, the participants have reported which aspects of WHP they found most useful – especially in relation to distress. Feelings of support and empowerment which were instilled by the herbalists were often highlighted as being particularly important by the participants – in some instances, more important than the herbal treatment/prescription itself. In particular, the narratives have added to the understanding of how visiting a herbalist can instil feelings of support by highlighting the importance of accessibility. These features of being able to offer support and empowering approaches in addition to herbal treatments meant that WHP helped the

participants to deal with some of the feelings associated with distress, including those of isolation, anxiety, low mood, and shame, whilst not labelling them with a pathology (such as depression) that the individual may have been resistant to. The narratives also illustrated the collaborative nature of the therapeutic relationship. This relationship helped the herbalists to journey with the participants from a place of distress that could be hidden, back to the wider society.

As well as adding to existing literature with regards to what WHP looks like, the participant accounts in this thesis have also challenged findings from previous research. Whilst the participants reported that visiting a herbalist had the potential to be empowering, this research has disagreed with literature (Nissen, 2013) which claimed that visiting a herbalist can help women resist stereotypical gendered relations by empowering them through the use of self-care strategies. Rather than taking care of the self as opposed to taking care of others, the participants' narratives have shown that they would use self-care processes alongside their role of caring for others and, in some instances, use self-care in order to be able to facilitate this role. This research has also extended the knowledge of WHP in one crucial area: unlike previous research (Little, 2006; Nissen, 2008), the participants' stories have included negative accounts of WHP. Whilst these negative stories were not common amongst the participants, their elicitation helped to highlight important aspects of WHP by illustrating how a failure of these could result in the participant concluding that their visit to a herbalist had been unsuccessful.

This final chapter is going to consider the wider picture of women, distress, and visiting a herbalist within the context of existing literature on the subject, in order to expand on the points made in this section and underscore the significance of this research. It will also consider any limitations of the research and areas of possible future research, before finally providing an overall conclusion to the research question of how women describe and understand their experiences of distress, and the role that WHP has to play for women who are living with distress.

## **7.2 “As If a Jigsaw Had Been Flung Up in the Air” – Experiences of Distress**

One of the first areas of literature reviewed as part of this research were the epidemiological and economic figures concerning experiences such as distress within the UK (outlined in section 1.1.2). Whilst the figures were alarming, they risked losing sight of the effects of distress on individual women, which can be (as the participants’ narratives have shown) so devastating at a personal level. The narratives have highlighted which circumstances that can lead to distress were most common for these participants; particularly the loss of loved ones (Thomas et al., 2014) or being physically unwell (Okoro et al., 2014). As well as specific life events contributing to their distress, the narratives have also reiterated that distress can occur with no external cause that the participants could discern (Henderson, 2012). The feelings that the participants associated with their distress were variable, but included those that have previously been reported: stress, anxiety, anger, low mood, anorexia, fatigue and insomnia (Butt et al., 2008; Ridge et al., 2011; Herlofson et al., 2012; Suh et al., 2012; Haun et al., 2014). These states associated with women’s distress have been described in terms of pathologies such as anxiety and depression, or “internalising disorders” (The European Union Health & Consumer Protection Directorate-General, 2004). The participants’ narratives have in part supported the suggestion that women’s distress is characterised by internalising disorders. However, whilst their stories included numerous instances of anxiety and depression, there were also variations across the narratives. Externalising disorders such as anger against others (Brownhill et al., 2005) were not spoken of, but the participants did sometimes report externalising their distress through narratives of feeling anger, and also of suicidal thoughts. The fact that some of the participants had serious suicidal thoughts, and two had a history of suicide attempts, has helped to highlight that it is not always useful to create a dichotomy between internalising disorders that are meant to typify women’s experiences of distress, and externalising disorders. The participants’ circumstances were all very different and so, as has previously been suggested (Emslie et al., 2007; Addis, 2008; Danielsson et al., 2011), their stories of distress were diverse. Nevertheless, what the narratives did share was a sense of patterns in women’s distress (as above) and the certainty

that women could be profoundly affected by their distress, regardless of whether or not they are diagnosed with a mental disorder.

Some research has not only suggested that normal sadness is increasingly being pathologised (Henderson, 2012), but that psychiatric diagnoses make “gendered assumptions” that pathologises femininity (Ussher, 2010). This research has provided narratives to support the suggestion that distress (for the women spoken to) felt over-pathologised. In these instances, the participants would reject biomedical labels/diagnoses such as depression. However, whilst some participants may have considered that their distress did not always warrant a biomedical diagnosis, there was a perception amongst others that their distress was overlooked or not considered serious. This research has added to the debate by showing that one potential problem for the participants was that for instances of everyday distress, although they did not feel that a biomedical/pharmaceutical approach to treatment was appropriate, they could still find themselves struggling and so in need of some sort of help. The form of help that all the participants utilised (visiting a herbalist) is considered further in sections 7.6 – 7.9.

Although some participants felt that their distress was not always considered to be a serious problem, this study (in line with previous research) uncovered the profound effect that distress can have on an individual and their ability to narrate a life affirming story – what Bury (1982) originally conceptualised as a kind of “biographical disruption”. Distress occurs along a continuum, so that for some, their experience of distress might be “normal feelings of vulnerability, sadness, and fear” (The National Comprehensive Cancer Network, 2008 cited in Bultz et al., 2009). Rather than the distress among women who use WHP being a mild condition, this research agrees with previous studies (Edhborg et al. 2005; Fullagar, 2008; Rhodes & Smith, 2010), that no matter how common distress is, it can leave women struggling to complete everyday tasks. As well as physical conditions such as chronic fatigue, which could mean the participant would be unable to do seemingly simple tasks like taking a shower, mental conditions such as anxiety and depression could also leave the individual unable to look after themselves: in severe cases, unable to get out of bed. This inability to function could then impact on all

areas of the participants' lives, from being unable to work or socialise with others as they had before, through to being unable to look after those who were meant to be in their care.

In order to help communicate their distress, which can be difficult to put into words, the participants would often use metaphorical language to describe how they were feeling. Similar to previous research (McMullen, 1999; Pritzker, 2003), darkness (or an absence of colour) was frequently used by the participants to illustrate feelings of low mood. In addition to talk of darkness, participants also spoke of feeling burdened such as having "the weight of the world" on their shoulders, which again matched some examples of women documented in the literature (Levitt et al., 2000; Fullagar & O'Brien, 2012). In some instances, participants could report how suffering with feelings such as a low mood could leave them physically stuck, as if they were "in a quagmire", which had resonance with previous descriptions of those with distress feeling paralysed (Granek, 2006), or in a form of stasis (Fullagar, 2011). The idea of "crashing" into distress (Fullagar & O'Brien, 2012) was mentioned by the participants, but (unlike previous research) the narratives would also sometimes include analogies with a kind of disintegration, further elucidating our understanding of women and distress. In these instances, the individual would describe breaking into pieces and so be in need of mending. The fact that the participants' metaphors of disintegration allowed for the possibility of being mended did correspond with previous research which described "an undulating journey" (Pritzker, 2003) and post-traumatic growth as potential ways of recovering from distress (Soo & Sherman, 2015). This journey could be from a place of darkness and weight to a place of lightness, or could (for some of the participants) involve being put back together, such as Nicola describing how she felt like a jigsaw that had been flung up in the air.

### **7.3 "Life Just Literally Concertinas In" – The Isolation of Distress**

The next theme to emerge from the participants' narratives agreed with other research that showed that whilst isolation could be distressing (Burton et al., 2011)

distress could also lead to further isolation (Fullagar, 2008). The isolation could not only be caused by physical conditions which could lead to distress, but feelings of anxiety, fear, and low mood could also cause isolation. The participants' narratives have reiterated that isolation associated with distress could add to the profound impact that it had on the individual's well-being, such as Lucy describing how her life had concentrated in on itself.

Research has reported that not only do higher levels of perceived social support have a positive effect on distress (Arnberg et al., 2012; Hameed et al., 2013; Horwitz et al., 2015), but the reverse is also true: low levels of support can lead to increased distress (Allen et al., 2012). It has also been shown that social support can have a positive impact on the sort of experiences reported by the participants for this research, including anxiety and low mood (Dour et al., 2014) resulting from the sort of events spoken of, such as dealing with breast cancer (Huang & Hsu, 2013; Kroenke et al., 2013). The narratives support this previous research, as the importance of having someone to confide in was frequently spoken of. Conversely, section 5.2 showed how a lack of understanding from family members could contribute to feelings of isolation, but that those outside of the individual's immediate friends and family can also be important. Nicola's use of bereavement counselling provided an example of the potential for self-help groups to provide support (Seebom et al., 2013), whilst Wendy's churchgoing not only indicated the importance of spirituality for some (Bennett & Shepherd, 2013), but that spiritual behaviour could also be beneficial if it included having a supportive network (Bennett & Shepherd, 2013; Hovey et al., 2014).

Whilst social support is generally beneficial, section 5.3 highlighted that there is no guarantee that the type of support offered would be what was wanted or useful. This problem has also been raised by research that has showed that whilst social support can predict post-traumatic growth (Yu et al., 2014), providing support is not necessarily enough – how the support is provided determines the outcome of that support (Feeney & Collins, 2015). For example, women who had survived breast cancer only found support which was pertinent to their situation correlated with their recovery (McDonough et al., 2014). Lucy also explained (in section 5.3) how

being in desperate need of support could conflict with the fact that her chronic fatigue meant she did not have the energy to actually pursue such support. If the available support was not felt to be appropriate by the individual, one common experience of living with emotional distress was a feeling of wanting to withdraw from social life. The lack of support could also extend to healthcare professionals, as a lack of perceived support or understanding from GPs/consultants could contribute to increased isolation and marginalisation, but was one example (outlined in section 6.5.3) where visiting a herbalist could have a positive impact.

The narratives have helped to support other research, which has reported that as well as being a consequence of distress, isolation can be used as a way of trying to cope with distress, frequently with the opposite results women were trying to achieve (Ussher & Perz, 2013). A number of the participants described how experiencing feelings such as anxiety and low mood would make them “want to run and hide”. Pippa gave a clear description in section 5.2.2 to show how turning away from a situation could relieve anxiety, but how the need to avoid situations that were perceived as being stressful could increase to the point where Pippa’s life “became really, really small”. By acting in this way, the participants could attempt to keep their private self separate from the public world, though they risked the outcome that their lives would concertina in. Pippa’s narrative was an example that supported the research by Willgoss et al. (2012), which illustrated how avoiding social situations might initially help with feelings of distress but would ultimately lead to further distress associated with increased isolation. As well as isolation being a result of distress, literature (Allan & Dixon, 2009; Holm & Severinsson, 2014; Garthwaite, 2015) which has shown that those living with distress might use isolation by putting up a front to hide their distress has also been supported by this research. The reasons behind a decision to put up a front were complex, but were in part linked to feelings of stigma associated with distress.

#### **7.4 “Pull It Together Love” – The Stigma of Distress**

Whilst there is a stigma that commonly surrounds mental health problems in general (Cromby et al., 2013, p.7), feelings of distress are also problematic for the individual due to the lack of visible signs or apparent reasons for feeling so bad. Because of the stigma surrounding distress, distress is necessarily a contested state that women find themselves in (Lafrance, 2009. p.181). The narratives did uncover perceived stigma for conditions that had a lack of visible signs. These feelings were in addition to those of some participants who felt that others did not see distress as a serious problem. This perception could then encourage them to feel that they should indeed “pull it together love” as Fay put it. However, negative reactions from others as reported by the participants were not universal (Benoit et al., 2015): stigma was not reported by the participants as being commonly enacted and, in line with previous research (Whitley & Campbell, 2014), the fear of stigma was more prevalent than enacted stigma. There were occasional examples of being stigmatised within the narratives, though the stigmatisation was more likely to be centred around a perception by the individual that others felt they were unable to cope (and consequently unreliable). Examples of enacted stigma, such as Sam losing friends when she was unable to socialise whilst living with depression, provided evidence of the type of situation that participants feared. Whilst the reaction from others was not certain, being dropped from social circles did result in the individual becoming isolated, whilst the fear of stigma provided one of the reasons why participants would want to isolate themselves or put up a front.

One aspect of Lazarus and Folkman’s (1984) cognitive theory of psychological stress and coping was concerned with how individuals might behave when faced with a stress that they perceived they were unable to cope with. For the participants, there were two methods of trying to cope available when faced with the problem of distress coupled with perceptions of an associated stigma, described in section 2.2.2. as problem-focused forms of coping and emotion-focused forms of coping. By putting up a front, the participants appeared to adopt a problem-focused approach as they attempted to manage the problem and seem “able to function fairly normally”. A desire to “appear normal” and so “blend in” (Whitley &

Campbell, 2014) did not just help to guard the individual against negative comments from others: putting up a front was also used as a way of portraying a public identity that was distinct from private thoughts and feelings (Murdoch et al., 2013). As Scarlett said (in section 5.4.4) she felt like she was “acting” her life. Researchers have argued that gender is a malleable concept (Annandale & Hammarström, 2010), and is better understood as a performative accomplishment (Gringeri et al., 2010; Schlichter, 2011). Scarlett’s comment suggests that this “performative accomplishment” extends beyond the realm of gender into other aspects of the individual’s identity (Goffman, 1956, p.8). Within this act, there are a number of roles, the idea of which is looked at further in section 7.5.5.

A problem-focused approach is reliant on the individual feeling like they can regain some sort of control over the situation, which can then be managed. The participants’ narratives frequently spoke of a loss of control (discussed further in section 7.5.3). In instances where there were feelings of a loss of control, an emotion-focused approach could lead to a desire to protect the private, inner self from the public and so meant that some of the participants would avoid talking about how they were feeling to others. An emotion-focused approach could also result in participants attempting to distance themselves from distressing situations.

If the level of distress became so great that the participant felt they would not be able to hide it in public, they would sometimes withdraw from public life. Even when out of the public gaze, some would continue to try and retain an air of social acceptability by putting up a front and inventing reasons in addition to their distress as to why they were unable to attend social events. These actions had some resonance with previous research (Garthwaite, 2015), which described how those on sickness benefit would try to look ill in order to appear “genuinely sick”. In this current research, anxiety and panic provided examples where participants had to work hard in order to hide their private self. The loss of control associated with panic attacks were something that the individual would try to cover up – sometimes literally, such as Yvonne feeling the need to “hide in the ladies toilet”. Yvonne’s narrative illustrated how, despite their best efforts to cope, the participants could

experience a range of negative feelings associated with distress; particularly embarrassment, shame, and guilt.

## **7.5 Embarrassment, Shame and Guilt**

This section moves on from the fact that the participants would sometimes use isolation as a way of coping with perceptions of distress and stigma, to consider the feelings that emerged when the participant felt that their distress was socially unacceptable: embarrassment, shame, and guilt. This research has added to the knowledge in this area by not only showing that women with distress experience both shame *and* guilt, but has also provided reasons why these distinct emotions can occur. Two further themes emerged from the narratives: the problem of the autonomous individual (associated with shame and discussed in section 7.5.3), and the problem of women's "role" within society (associated with guilt and discussed in section 7.5.5).

### **7.5.1 "I Don't Want Anyone To See Me Like That" – Embarrassment**

The first feeling that was spoken of when the participants considered the social acceptability of their distress was that of embarrassment. Embarrassment, which are transient feelings that represent a perceived flaw in the individual's public identity made worse by the presence of others (Crozier, 2014), have primarily been shown in previous research to be linked to physical conditions that are associated with distress such as hot flushes (Smith et al., 2011) and skin conditions (Sampogna et al., 2012; Hunter et al., 2013b). This current study has helped to support research (Crozier, 2014) which has highlighted the difficulty in separating out terms such as embarrassment and shame as they could be used interchangeably within narratives; though the narratives do support the suggestion that feelings of embarrassment are primarily linked to more physical problems (Crozier, 2014). Whilst visible symptoms (such as a skin condition or having a hot flush) could be embarrassing, this embarrassment could be relieved to a certain extent by

protecting the private self and moving out of the public gaze or (in some instances) covering up the visible sign: Isobel recounted how she found hot flushes to be worse than night sweats because they could occur in public, whilst Beth described wanting to be alone when dealing with her IBS symptoms because “I don’t want anyone to see me like that”. As well as feelings of embarrassment, the narratives also illustrated that the participants could experience separate feelings of shame.

### **7.5.2 “Little Miss Special Needs” – Shame**

Shame is a persistent feeling that represents a perceived major flaw in the individual’s sense of self and can lead to feelings of regret (Crozier, 2014). Pippa illustrated how distress could be perceived as a flaw in the sense of self when she described trying to hide her feelings of anxiety at work as she felt that admitting she had a problem to others would be “really exposing” and reveal the “inner life” that she was trying to keep private. Pippa did not know why she was experiencing feelings of anxiety, which matched the research by Danielsson & Johansson (2005) who reported that women can feel shame associated with distress when they perceive that they do not have a valid reason for feeling distressed. However, having a clear reason for feeling distressed – such as Wendy living with insomnia due to her menopausal symptoms – did not necessarily stop the participant feeling “a bit stupid” that they were not able to cope. The key aspect to Wendy’s story was whether she felt the reasons for her distress (which led to talk of suicidal thoughts in her narrative) were “valid”.

Wendy’s narrative showed how individuals would sometimes compare their own distress to the distress of others. In 1954, Festinger proposed a theory of social comparison processes, of which the first two hypotheses were that people have a desire to evaluate their opinions and abilities; and that due to an absence of objective, non-social means, people evaluate themselves with the opinions and abilities of others (Festinger, 1954; Sabiston & Pila, 2014). Upward social comparisons are made with others who are perceived to be better off, whilst downward social comparisons occur with those who are perceived to be less

advantaged (Sabiston & Pila, 2014). Whilst upper social comparisons can be used when individuals are seeking to self-improve, they may have a discouraging effect (Sabiston & Pila, 2014), and be associated with negative self-approval (Mitchell & Schmidt, 2014). In Wendy's case, whilst she appeared to be comparing herself to those who were less advantaged, she was actually using upward social comparison, as her perception was that others were coping better than she was, and that she should have been more in control of her circumstances.

Wendy feeling "a bit stupid" helped to illustrate that feelings of shame could sometimes be recognised within the narratives when participants described themselves in disparaging terms. These included Pippa feeling "pathetic" that she could not cope with her anxiety, which resulted in her self-depiction of "Little Miss Special Needs". Whilst Pippa's self-depiction attempted to put a humorous slant on how she felt, it still presented an example of "self-defeating humour" (Martin et al., 2003) where the humour was at her own expense. Some participants worried how they would appear in the eyes of others, which led to self-disparaging terms such as being seen as "mad" or "a nutter". The aspect that could cause participants to feel "pathetic" was consistently associated with a loss of control and an inability to cope, commonly reported within existing literature as a loss of agency (Kemp, 2003; Pritzker, 2003), which is considered further in section 7.5.3.

Previous research has claimed that distress is characterised by a loss of self (Charmaz, 1983; Skaff & Pearlin, 1992; Charmaz, 2011). Similar to the research by Skaff & Pearlin (1992), the narratives included instances where the women felt like they were losing aspects of their personality. Whilst this research therefore agreed with the literature which states that distress is characterised by a loss of self, it has added to the debate by showing that the feelings of a loss of self that the participants experienced were invariably linked to an inability to cope. That is to say, if there was not a loss of agency, the perception of self would be less likely to be affected.

Whilst some research has reported that women may experience shame linked to depression (Danielsson et al., 2009; Danielsson et al., 2011; Peters, 2013; Holm &

Severinsson, 2014; Sari & Gençöz, 2015), some has also considered that it was men who were more likely to feel shame linked to “losing face” and a perceived loss of autonomy (Danielsson & Johansson, 2005; Mitchell & Schmidt, 2014). This research has not compared the experiences of women and men, but has shown that feelings of shame were commonly experienced by the participants when living with distress. Sari & Gençöz (2015) also considered the effect that depression might have on women who had a caring role: they reported that failing to be “a good mother” would predominantly lead to feelings of shame. McKenzie-Mohr & Lafrance (2011) suggested that a loss of agency can help remove blame on the part of the individual. However, this research has shown that the feelings of shame felt by the participants that were linked to a loss of agency could occur concurrently with those of blame. Why the participants should carry these feelings are linked to the notions of autonomy and personal responsibility.

### **7.5.3 “I Hate Playing That Role” – Loss of Autonomy**

In 1951, the notion of Parsons’ sick role gave patients exemption from some of the activities and obligations of everyday life (Moreira, 2004; Armstrong, 2014). Today, neoliberal societies prioritise personal responsibility for one’s own circumstances, where agency is of primary importance (McCoy & Peddle, 2012). This has led to a rejection of the Parsonian model of a passive sick role for a more powerful sense of individual autonomous action for patients (Armstrong, 2014; Raffaetà & Nichter, 2015). This shift of emphasis from what Sointu (2005) described as the “body politic” to the “body personal” has led to the advent of the “expert patient”, empowered by the state to self-manage (Broom et al., 2012). Increased patient autonomy has led to the promotion of self-care (Lucock et al., 2011) which, in the UK, has partly been driven by increasing costs of providing healthcare (Appleby, 2013) or “healthcare austerity” (Raffaetà & Nichter, 2015). Patient empowerment has also extended to the idea of what it means to be well, as the rise of individualisation and self-care has put the autonomous individual at the centre of discourses on well-being (Sointu, 2005; MacKian, 2009), leading to prominence for

subjective well-being as it puts the emphasis on personal judgements about satisfaction (Carlisle et al., 2009; MacKian, 2009). This onus on the individual also pervades the area of mental health, typified by The World Health Organisation's definition of mental health, which pronounces that mental health is "a state of well-being in which an individual realises his or her own abilities, can cope with the normal stresses of life, can work productively and is able to make a contribution to his or her community".

Putting the onus on the individual to be in control of their health and well-being is ostensibly designed to empower the patient. However, this onus provides a similar problem to the enabling metaphor of fighting against cancer (Reisfield & Wilson, 2004) as the metaphor could stigmatise those who were seen as having lost the fight (Sontag, 1991, p.180). Broom et al., (2014) asserted that whilst self-care has afforded empowerment and autonomy for women, it has also proliferated a moral burden that compels them to action, so that those who do not recover are viewed as "failed patients" (Timander et al., 2015). As Vicki said when describing how she had not felt in a position to take the herbs she had been prescribed by her herbalist, it "was entirely my fault really for not doing it".

Danielsson et al. (2009) have suggested that women can feel guilty and blame themselves for feelings of depression – also described as a form of "self-stigma" (Rüsch et al., 2006). The narratives from this research have partly rejected the suggestion by Danielsson et al. (2009) as the participants were more likely to emphasise underlying causes for how they were feeling: as Margaret said "you're depressed because you've bloody well got something to be depressed about". What the narratives have shown is that women are likely to feel shame from living with distress. This shame is related to the individual's loss of agency: rather than being empowering, the emphasis on personal responsibility results in a feeling of having failed to win the fight against distress. However, rather than feeling blame for being distressed, the participants felt shame for not being able to cope. As Anna said when she was unable to cope with her feelings of anxiety "Suddenly I've become the person that's helpless, and I *hate* playing that role".

The participants' narratives did, in part, support the research by Danielsson & Johansson (2009) which reported that women living with depression were prone to feelings of guilt. However, whilst some participants did express feelings of guilt, they were not linked to feelings of blame for being depressed. Rather, these feelings were linked to a specific set of circumstances, where the participant not only felt shame for being unable to cope, but also felt guilt for the effect that their inability to cope had on others that were around them (Vallido et al., 2010).

#### **7.5.4 “You Always Feel Really Responsible” – Guilt**

Whilst it has been reported that shame can lead to regret (Crozier, 2014), guilt is the emotion that is more likely to be associated with feelings of regret and a desire to apologise or confess, but (unlike shame) involves focusing on a specific behaviour rather than a perceived flaw in the individual's sense of self (Kim et al., 2011; Tangney et al., 2014). Danielsson & Johansson (2005) considered that women were more prone to feelings of guilt than men, whilst women's feelings of guilt have been associated with self-blame, where individuals deem themselves responsible for having feelings of depression (Danielsson et al., 2009), but also responsible if their depression impacts on others (Vallido et al., 2010). The instances of guilt within the participants' narratives were always spoken of in relation to the impact of their distress on others. The feelings of guilt almost always revolved around people that the participant felt responsible for.

Instances of guilt were normally related to close family members. The relationship typically saw the participant as a child, parent, or partner, but the relationships all shared one common theme – as part of the relationship, the participant had taken on some form of caring role. This relationship of caring for others helped to explain why being unable to cope in the workplace was not generally associated with guilt, as there was not the same level of connection or feeling of responsibility towards colleagues. Whilst the participants' stories were varied, they kept showing how the individual wanted to care for and protect those around them (Vallido et al., 2010): as Sam said (in section 5.3) “as a parent you always feel really responsible”.

Feelings of guilt, and a desire to care for those around them would often lead participants to try and avoid worrying those closest to them by not disclosing their distress. This approach of putting up a front to protect others matches coping strategies employed by carers in other research (Papastavrou et al., 2009). Wanting to protect others, and the importance that the caring role has in women's experiences of distress has also been previously considered by other researchers, and so is discussed in section 7.5.5.

### **7.5.5 “How Can She Be Depressed?” – Women's Societal Roles**

In order to understand why the participants might feel guilty for letting others down, it is necessary to revisit the research which considered the role of women within a wider social context. In the 1970's, feminist research argued that the female role as it was socially constructed was conducive to mental illness (Doyal & Pennell, 1979, p.227). This position persists within the literature as some writers maintain that women's emotions are deemed to be a sign of pathology – especially in relation to men's (Ussher, 2013) – and that women who step outside the confines of the female role are likely to be vilified (Lafrance, 2009, p.174). It has been further argued that women's societal role in neoliberal societies (Fullagar, 2008) stems from the stereotypical expectation that women have a greater interest in the feelings and emotions of others compared to men (Roter et al., 2014), and results in women being constructed as subservient and nurturing (Lafrance, 2009, p.174). Whilst some women may reject this stereotypical view, others often see themselves as central to the health and well-being of the family unit (Lewis & Ridge, 2005), whilst figures have shown that the majority of unpaid carers in the UK are women (Office for National Statistics, 2011a). Previous research has reported that being a female carer is a predictor of poor self-assessed health status (Arnsberger et al., 2012), and that whilst caring for loved ones can be rewarding (Wong & Ussher, 2009), carers frequently experience feelings that would meet biomedical criteria of distress (Smith et al., 2014; Thomas et al., 2014; Raffaetà & Nichter, 2015) to the point where women caring for partners who were diagnosed with prostate cancer

experienced greater distress than the patients themselves (Couper et al., 2006). Societal roles are also used to help explain why women carers can experience greater distress than male carers, as women try to live up to expected standards of caring associated with their stereotypical role (Perz et al., 2011). This burden of care on women helps to support the suggestion that, although more than 35 years has passed since Doyal & Pennell (1979) wrote about it, the female role is still conducive to mental illness.

Whilst this research is unable to comment on women's experiences compared to men, the demographics of the participants (outlined in section 3.5.2) did show that having a caring role was commonplace: eighteen of the twenty-six participants reported taking on (to a greater or lesser extent) the care of others at some point, whilst nine were carers at the time they entered the research process. However, the fact that seventeen of the participants did not report being in a caring role at the time of their inclusion to this research, and eight of the participants did not report having ever had a caring role suggested that women's roles in society might have moved on since Doyal and Pennell's (1979) work. Whilst some may feel that women are expected to fulfil a societal role of being a carer – and whilst many of the participants had done so at some point – the narratives showed that the participants were not limited to that role. The demographic data from the women showed that their roles could also include those such as being a full-time student, or being in full-time employment. The range of opportunities that were offered to the participants would appear to be a good thing – the opportunity to go to university, or hold down a job and earn a wage could be seen as being empowering for the participants. The issue for the participants came back to idea of empowerment and personal responsibility – no matter what their "role", an inability to cope due to distress was always shameful. However, the participants narratives also showed that when the individual found their role to include caring for others (as was frequently the case), they also had to contend with feelings of guilt as their inability to cope then impacted on the lives of others. This rejects the suggestion that perceptions of having failed to be a good carer would lead to feelings of shame (Sari & Gençöz, 2015).

The current study has therefore provided a contribution to knowledge, and helped to further illuminate women's experiences of distress, as not only has it shown that feelings of both shame *and* guilt are commonplace, but has provided reasons for why this might be the case. The impact on the women who found themselves in this situation could be profound, and was clearly illustrated by Eve in section 5.4.4 when she described how she had to cope with the demands of a terminally ill parent, young children, and a partner who had been involved in a severe road traffic collision, whilst having to hold down two jobs in order to make ends meet. However, when things became too much, she felt the shame linked to the perception that others judged her, in addition to the guilt of no longer being able to care for others. She recalled that "I remember people thinking 'Hmm, not her – how can she be depressed? She's always the one that's coped so well'".

For Eve, as for all of the participants, there came a point in her narrative when she chose to visit a herbalist. From a narrative point of view, the decision to visit a herbalist can be viewed as part of a process designed to achieve a "narrative reconstruction" (Williams, 1984) – as Nicola said, the jigsaw "had to be put together – not the same, but somehow". This process of reconstruction is important in determining the extent to which recovery occurs (Scrignaro, et al., 2011), as it is now recognised that individuals can develop meaningful and purposeful lives, despite having experienced mental illness (Anthony, 2000). Recovery from mental illness includes that of distress (Timander et al., 2015), as distress and recovery (or post-traumatic growth) "are not mutually exclusive" (Soo & Sherman, 2015). Patient centred therapies, such as WHP (Little, 2011) have been shown to help facilitate this process (Scrignaro, et al., 2011). Whilst chapter 6 has shown that visiting a herbalist was felt to be useful by the participants, it has also been necessary to consider what aspects of the herbal therapeutic process were particularly effective for women who were living with distress.

## **7.6 “I Just Went With Hope” – Visiting the Herbalist**

In terms of WHP, this research has added to the literature describing the users and features of WHP (in particular, what WHP looks like to the patients). In line with previous research (Ipsos Mori, 2009; Nissen, 2010), the herbalists reported that the majority of users of WHP are women. However, the demographics of the participants for this particular research (presented in section 3.5.2) have not followed some patterns that have previously been reported. In particular, the demographic data did not correspond with research that suggested patients are more likely to be better educated (Gardiner et al., 2007); of a higher UK socio-economic class (Vickers et al., 2006); or predominantly middle-aged (Gardiner et al., 2007; Damery et al., 2011). Patients’ motivations to consult with a herbalist practising WHM are under-researched (Nissen & Evans, 2012). Whilst not a key aim of the research, the participants’ narratives did show a variety of push and pull factors in terms of their decision to use WHP. However (as outlined in section 4.4) the majority of participants had seen a doctor, and reported feelings of desperation before visiting their herbalist as they felt that their issues had not been resolved. This suggested that dissatisfaction with biomedicine (Sharples et al., 2003; Richardson, 2004; Gollschewski et al., 2008), along with concerns over the use of pharmaceuticals (Sharples et al., 2003; Richardson, 2004; McCaffrey et al., 2007; Meurk et al., 2013), were the most important factors in the decision to use WHP. However, table 4.3 also revealed that the participants might look for an alternative to biomedicine if they rejected pathological labels which they felt were not appropriate to their situation, or (conversely) felt that their distress was not considered serious from a biomedical perspective. Ultimately, this research has tied in with the findings by Little (2009) that the patients she spoke to were looking for “more effective healthcare”. The features of WHP that the participants felt was lacking when visiting a GP are the focus of this section (and sections 7.7 – 7.9).

Meurk et al. (2013) claimed that visiting CAM practitioners in general did not necessarily constitute a rejection of biomedical practice. This research has added to these findings by illustrating that the participants did not turn their backs on biomedicine when specifically choosing to visit a herbalist: whilst all of the

participants reported a desire to use WHP in the future, they also indicated that they would continue to use the services of their GP. This supports the assertion by Little (2009) that a “simplistic dichotomy” of push/pull factors does not always mirror reality for the patients. Patients may choose different therapists as part of a pragmatic integrative healthcare approach within a pluralistic medical marketplace (Cartwright & Torr, 2005; Broom et al., 2012), and so commonly use CAM alongside biomedicine (Pirotta et al., 2014; Solomon & Adams, 2015). Once a participant visited a herbalist, in line with recent research (Cottingham et al., 2015), there was also a chance that the herbalist would refer the patient on. This referral could be to the participant’s GP if the herbalist had any concerns over their ability to be able to safely treat the individual, or to a different type of therapist if they felt the therapist was better able to meet the participant’s needs. In addition, the decision to visit a herbalist was not associated with a loss of autonomy by the participants, but agreed with previous research into CAM (Broom et al., 2012; Mitchell, 2014) that the act of visiting a herbalist was empowering because the individual was being proactive in their healthcare. As Wendy said, “I just went with hope, because I thought ‘I’m doing something’”.

What the herbal consultation looked like had some degree of variation amongst the participants’ narratives, but did again help to support previous research and confirm what a typical herbal therapeutic process might look like from the patient’s perspective. The description of the herbs themselves by the participants helped to support the suggestion that non-native as well as British herbs were used as part of the treatment (Nissen, 2010; Wahlberg, 2010). The participant narratives supported what was reported by the herbalists, and had been reported in the literature (Zeylstra, 1995; Brock et al., 2012), that tinctures were the most common form of herbal medicine. In addition, the tinctures were almost always made using a combination of herbs individually prescribed for the patient (Casey et al., 2007; Denham et al., 2011), but the herbs could change over time. In that respect, the herbal treatment was not only individual, but also flexible. This flexibility was an important feature of WHP for the participants’: the individual prescription could change as the participant’s circumstances changed, and did not require a definitive

diagnosis but could address areas that were of concern to the individual participant. In order to ascertain what was concerning the individual, the herbalists and participants also confirmed that the one-to-one herbal consultations involved a detailed (sometimes referred to as “holistic” by the participants) case history taking which typically lasted between 30 and 75 minutes (Walker, 2006; Casey et al., 2008; Cottingham et al., 2015). The herbalists and participants’ narratives also showed that the consultation could sometimes (though not always) include physical examination (Casey et al., 2008; Nissen & Evans, 2012) and lifestyle advice, which included dietary advice (Denham et al., 2011; Rooney & Pendry, 2014). However, the use of further pathological tests as reported by Casey et al. (2008) and Nissen & Evans (2012) was less apparent, with only one instance spoken of by Fay (although further biomedical tests may have been carried out if the herbalist referred the participant back to their GP).

### **7.7 “You Suddenly Don’t Feel Alone” – Feeling Supported Within Western Herbal Practice**

A review of the literature revealed that there has not been a large amount of research into the patient experience of WHP: the findings from this study help to add to this body of knowledge. In many respects, this research helps to support the findings by previous researchers and provides further evidence that WHP can be effective. In line with previous research (Evans, 1993; Little, 2006, Nissen, 2008) there were improvements in emotional well-being that were not only attributable to the herbal medicines themselves. The participants’ narratives from this research highlighted a number of areas within the herbal therapeutic process that were particularly important. Little’s research findings (2006; 2009; 2011) reported how the therapeutic relationship could lead to feelings of a patient-practitioner collaboration founded on shared understandings of health and illness. Nissen (2008; 2010; 2013) similarly spoke about “partnerships of healing” in which herbalists could help support patients through rough times. This research supports

these findings, as the participants' narrative clearly showed the importance of a good therapeutic relationship.

There have been various aspects previously reported that can help promote a good therapeutic relationship: the work of Rogers (1979) was highlighted in section 2.5.2 suggesting three conditions that can be therapeutic in themselves: congruence, unconditional positive regard, and empathy (Rogers, 1979). The participants' narratives have provided examples of the herbalists' ability to provide all three. Congruence implies genuineness and transparency on the part of the practitioner, highlighted by the rapport that the herbalists could create with the participants. Section 6.5.2 explained how the herbalists were generally seen as "professional", but that they still came across to the participants as genuine, which led to a number of participants describing how they trusted their herbalist. Unconditional positive regard requires a positive, accepting attitude, and was of particular importance to those who felt that their distress had been questioned by their GP/consultant (reported in section 6.4.3). Empathy requires the practitioner to sense accurately the feelings and personal meanings of the client, typified by Isobel's quote in section 6.6.1: "they really knew me; they had a very real picture of who I was".

Whilst different aspects of the herbal therapeutic process helped to form the therapeutic relationship, one of the most significant to the participants was the accessibility of the herbalist. Flexible access to healthcare professionals has been highlighted as an important step in providing feelings of support and also encouraging self-care (Kielmann et al., 2010), but has not been extensively commented on within the literature concerning WHP. Feeling that the herbalist was easy to contact helped to engender feelings of support within the participants as well as a feeling that they were not alone in their journey of distress. The possibility of home visits was especially important for those whose feelings of distress meant that they found it difficult to venture out, and so provided a level of support that would not otherwise have been available to them.

High levels of accessibility and a high perceived level of support were of particular relevance to the participants for this research due to the feelings of marginalisation

and isolation that frequently accompanied their distress. The narratives emphasised the difference that some participants felt between visiting their herbalist and visiting their GP: seventeen of the participants spoke of having sufficient contact time with their herbalist in comparison to their GP. In cases of isolation, the availability of someone to talk to who was not a close family member (that may have been perceived as needing protection from the individual's distress) was especially helpful.

The longitudinal, narrative approach of this research (which is novel in the field of WHP) helped to show that the participants' feelings of support could deepen over time. The narratives helped to illustrate one final important aspect of accessibility (which could also be less satisfactory when visiting a GP) was related to continuity of care. Seeing the same herbalist was another aspect of the herbal therapeutic process that the participants reported was important as it helped to build the rapport that was vital to instil feelings of support, but this was not always guaranteed if the participant was attending a herbal training clinic. Whilst the participant's experience could still be positive, seeing the same herbalist could help the individual feel "more connected to the process".

The combination of accessibility, having a rapport helped by continuity of care, and feeling supported helped build a good therapeutic relationship which was described within the narratives as "the most comforting thing" and gave "added value" on top of the herbs. As Teri put it when describing how it felt to go and visit her herbalist, "You suddenly don't feel alone".

As well as feelings of support from a positive therapeutic relationship, one area that previous research has also spoken about that had particular relevance for this study was the idea of the herbalists being able to empower their patients, as it could be particularly important for women who are living with distress.

## **7.8 “Flipping the Coin” – Empowerment Within Western Herbal Practice**

In terms of empowerment, this study has added to existing research (Broom et al., 2012; Mitchell, 2014) that the act of visiting a CAM therapist is empowering in itself by showing that this was also the case for the participants when visiting a herbalist. Not only were the participants doing something in order to help themselves, and taking the decision to choose a particular therapy within a pluralistic medical marketplace, but could (with the possible exception of a training clinic) also choose their particular practitioner. The herbalist had an important role to play in empowerment, which can in part be understood in terms of Basic Needs Theory (BNT), which was described in section 2.3.1. Whilst BNT is thought to be an important part of achieving well-being (Garn et al., 2012), it is argued that the three innate needs (autonomy, competence, and relatedness) can be enhanced by the positive contribution of others (Lovell et al., 2015). Feeney & Collins (2015) argue that assisting other’s strengths and abilities relevant to coping with adversity is a vital process of “fortification”. This assertion has resonance with research which contends that self-care is more effective when it is combined with support from a therapist (Coote & MacLeod, 2012), but that self-care based solely on providing information to those with distress is less likely to be effective (Matcham et al., 2014) as patients can feel abandoned if they perceive that their therapist has placed the onus on the patient to take care of themselves (Kielmann et al., 2010; Broom et al., 2014).

Once the patient had stepped through the herbalist’s door, both Little (2006; 2009; 2011) and Nissen (2008; 2010; 2013; 2015) emphasised the importance of the herbalist having the ability to help empower their patients: Little described how a collaborative approach and “shared understanding” could be empowering, whilst Nissen spoke about “partnerships of healing” in which herbalists could reframe women’s personal experiences and reposition them as experts in knowing and caring for themselves. In this way, Nissen argued that herbalists could empower their patients by encouraging them to have a responsibility for self-care which also helped to promote autonomy, and has also been recognised as a useful approach to the treatment of women with distress outside the field of CAM (McKay, 2010). The

participants for this research described feelings of empowerment that were instilled by their herbalists, and appeared to meet the requirements of BNT. The participants repeatedly reported feelings of empowerment (outlined in section 6.6.4), which illustrated how the rapport that developed between the herbalists and their patients led to feelings of connectedness or support. The supportive environment was used to help instil feelings of autonomy, as the participants were made to feel like “the expert”. What Beth described as a “balance of control” had the added benefit that it could lead to feelings of competence. These feelings were especially important in terms of self-care: as Nicola said, visiting the herbalist “galvanised” her into being a bit more proactive to do things to help herself, which relates back to Nissen’s “partnerships of healing”.

Within the “partnerships of healing”, Nissen (2013) particularly investigated how herbalists had the potential to reframe women’s discourses about their bodies by employing “technologies of the self”. That is to say that herbalists’ encouragement of self-care techniques could empower the women and help them regain agency by prioritising their own needs over the needs of others. In this respect, the herbalists critically engaged with the women, and challenged their traditional gender roles. Nissen’s work has relevance for this research in two aspects. Firstly, some participants made reference to the fact that whilst they thought it “very un-trendy” to suggest putting their own needs over the needs of others, sometimes it was necessary in order to be responsible for their own well-being. However, the second aspect highlighted how Nissen’s argument can be problematic. Whilst the participants’ narratives (and previous research) have helped to show that their traditional gender roles (of being a nurturing, self-sacrificing carer) can be detrimental to their health and can exacerbate their feelings of distress, how much self-care processes can help to overcome this role is less clear. The participants in this research did engage in a variety of self-care processes, but those that found themselves in a caring role tended to do so alongside their responsibilities. That is to say that their chosen self-care techniques helped them to cope with their traditional gender role but, as Keshet & Simchai (2014) suggested, did not challenge gender relations. Whilst some narratives showed that it was possible to overcome

gendered norms and place the needs of the individual over the needs of others, most narratives suggested that this would only occur when the individual was incapable of coping.

This research has helped to support that of Nissen (2013), which claimed that the herbal therapeutic process included talk which frequently encouraged self-care practises in a variety of ways. The participants' narratives showed that the holistic approach typically adopted by the herbalists meant that suggestions about diet, lifestyle, and other possible self-care strategies were frequently mentioned. As well as "general lifestyle advice", recommendations could be very specific to the individual and their personal circumstances. This advice can be important for patients as expectations of being an "expert patient" (Reeves et al., 2008; Broom et al., 2012) combined with a proliferation of information sources (Raffaetà & Nichter, 2015) can lead to individuals looking for "information filters" (in this instance, the herbalists) who they can trust (Raffaetà & Nichter, 2015). Aside from her technologies of the self, Nissen mentioned one other aspect of the therapeutic encounter which she considered could help to empower: the process of reframing the women's discourses meant that their physical and emotional experiences were witnessed and validated. The participants' narratives from this research have shown that having time to tell their story was important to them, and was frequently mentioned in relation to the relative lack of time the participants had experienced when visiting their GP. Again, having the time to be heard helped to overcome some of the isolation and marginalisation that was frequently associated with the participants' distress. However, the participants' less positive experiences (discussed further in section 7.9) have shown that having time to tell their story was not necessarily always enough – as well as being heard, a successful herbal therapeutic process also involved the participant being held (described in section 6.5).

A number of the herbalists that were surveyed as part of this research made mention of the fact that they were not counsellors. In spite of this fact, there was a recognition amongst both practitioners and patients, that some aspects of the herbal therapeutic process made use of counselling skills – in particular witnessing

and validating the stories of the person that had come to visit them. This process of acknowledgement has been criticised as lacking from some healthcare professionals when dealing with women who are living with distress (Vallido et al, 2010), but highlighted as a strength of WHP (Nissen, 2008). The participants' narratives showed that visiting a herbalist was invariably seen as a place of sanctuary – a “safe haven” (Feeney & Collins, 2015) in which comfort, reassurance and assistance allowed the individual to say things that they might not have been able (or at least comfortable) to say to those around them. As well as hearing the stories, the herbalist could also reframe narratives by assisting in redefining adversity as a mechanism for positive change (Feeney & Collins, 2015). Sometimes this involved the herbalist challenging the way the participant viewed a situation. As Teri said, her herbalist had a way of “flipping the coin and helping you to just change your mind about coping or just seeing an alternative side of the problem”. One of the most important ways that the herbalist could flip the coin was by letting the individual know that “it’s okay to not be okay sometimes and to ask for help”. This could help “normalise” the individual’s distress and in doing so, the herbalist not only helped to remove the stigma associated with the distress, but also gave the individual permission to adopt a position that was more akin to Parson’s sick role.

McKenzie-Mohr & Lafrance (2011) wrote that women with distress walk a tightrope between recognising their agency, whilst rejecting any notion of blame for their circumstances. The participants in this research have suggested that herbalists have the potential to both help restore agency to the individual, whilst also removing blame and stigma for their distress. These features, combined with a sense of accessibility (outlined in section 6.4.1) and support (outlined in section 6.5.3) meant that the herbalists were skilled at journeying with the participants through their distress. They became facilitators of resilience by helping to remove perceptions of personal responsibility from the individual (Boardman et al., 2011) and so could be seen as a form of “social safety net” (Perry & Pescosolido, 2015) for the women who were walking McKenzie-Mohr & Lafrance’s (2011) tightrope. This combination – alongside herbal treatment, that the participants reported (in section 6.6.2) to be

effective – provides the reasons why these narrative have shown that WHP has the potential to help women living with distress.

### **7.9 “A Real Mixed Bag” – Illuminating Western Herbal Practice**

Whilst this research has shown that visiting a herbalist can be useful for women who are living with distress, and whilst it agrees with previous research that the therapeutic relationship, having a good rapport, and feeling empowered were important parts of the herbal therapeutic process, it also adds to the knowledge of the patient experience of WHP in one crucial aspect. The results from the research by Little (2006) and Nissen (2008) reported universally positive experiences from the participants: this research also elicited narratives that included negative experiences, and by illustrating what can lead to an unsuccessful herbal therapeutic process has helped to throw the positive aspects into relief.

Section 7.7 has shown the importance of accessibility as part of WHP. However, a lack of accessibility could cause issues with the herbal therapeutic process for the participants. One such participant had tried to contact some herbalists after deciding that she no longer wished to visit her herbalist at the time, but found that she was unable to get the help she needed as the herbalists she had reached out to were “rubbish at getting back to me”. Beth had also changed herbalist between T1 and T2, primarily because she felt that she needed more contact with her herbalist in order to feel “properly considered in the broadest sense” as Lucy put it. Judith also showed how being able to see the herbalist was important when her narrative revealed that she had received a diagnosis of cancer, but had carried on having a repeat herbal prescription from the location that her herbalist practised without the herbalist realising that her medical history had changed.

Feelings of having a rapport with the herbalist were crucial to a good therapeutic relationship and so a successful herbal therapeutic process. Instances where participants reported contacting herbalists but felt that they “just didn’t click” would result in what Bishop et al. (2011) described as a “mechanism of exit”.

Sometimes the participant could be more definitive as to why the therapeutic relationship was less successful, such as Zoe who felt that one herbalist she visited was more interested in modes of treatment other than herbal medicine. Another example was Beth, who had stopped visiting one herbal clinic because she found that “a big group of men in white coats” felt “too official” and left her with the impression that “they were a bit up themselves”. However, Beth also described how “the stuff they gave me was *very good* – so that was a bonus”. The fact that she felt the herbal medicine was a bonus provided an interesting comparison to Pippa (in section 7.7), who thought that the therapeutic relationship provided “added value” to the herbs. In Beth’s narrative, it was the herbs that were providing an added value to the therapeutic relationship. The one participant who reported a less successful therapeutic relationship at T1 also reported that problems with rapport were the main reason why she chose to stop seeing the herbalist. Whilst she felt that the herbal medicine had been useful, it was not enough to get her to continue with the process as she thought it had been “a real mixed bag”, which again highlighted the importance of the skills of the herbalist in fostering a positive therapeutic relationship and, ultimately, a successful herbal therapeutic process.

### **7.10 Limitations**

Section 3.3.2 considered the importance of rigour within any research process, including qualitative research such as this current study. Part of a rigorous process necessitates a process of reflection in order to consider any limitations of the research. A critical review has highlighted seven areas that need to be considered due to their limitations.

A strength of this research is that it spoke to a relatively large number of participants, recruited over a large geographical area, and from a larger number of herbalists than has previously been used in similar studies. The initial sampling of the herbalists was purposive (Green & Thorogood, 2014, p.121) in order to find practitioners that were likely to be able to provide access to suitable participants,

but utilised maximum variation sampling (Abrams, 2010) in order to try and recruit the widest possible range of herbalist socio-demographic background. However, the sampling process had two limitations. Initially, the sampling of the herbalists was not randomised – it was down to the researcher to try and find the variation that was wanted. Whilst the recruitment did provide herbalists from a variety of backgrounds, there was a risk that the lack of randomisation may have inadvertently introduced some element of bias (although the fact that the researcher was aware of the potential issue helped to ameliorate the risk to a certain extent). The second issue with sampling was the lack of ethnic diversity of the herbalists. Although this was identified as an issue at the time, attempts to recruit herbalists from a wider range of ethnic backgrounds failed. Whilst research (Ipsos Mori, 2009; Nissen, 2010) has shown that the herbal users were likely to be predominantly white and British, failing to get a wider mix of ethnic diversity amongst the herbalists may have resulted in the relative lack of ethnic diversity amongst the participants. This lack of diversity has consequences for how generalisable the concepts from the research are (discussed below).

The next three limitations relate to the recruitment of the participants themselves. The first limitation relates to the fact that only women were recruited for this research. Whilst the research question meant that it was women's narratives that were required for the data, the researcher noted that a number of herbalists reported having patients that "would have been ideal to talk to" if the research had also utilised the narratives of men. Whilst these "lost" participants did not fulfil the recruitment criteria for the research, their stories may have added to the knowledge with regards to the patient experience of WHP (discussed further in section 7.11). The second issue with recruitment was that the herbalists acted as gatekeepers for the participants, and so chose which patients would be given information packs about the research. Whilst this process ensured that the participants met the recruitment criteria, it did run the risk that the herbalists might have introduced an element of bias by recruiting patients who they thought had "good" (and so positive) stories to tell. Whilst the narratives have thrown up less positive experiences of WHP, only one participant had any issues with their

herbalist at the time of their inclusion into the research process. The final limitation with regards to recruitment relates to a lack of recruitment at the start of the research process when the inclusion criteria specified that the participants should be new patients. The low numbers necessitated a broadening of the inclusion criteria to include existing patients. Whilst these stories were helpful in meeting the aims of the research, talking exclusively to new patients may have revealed more of a journey between T1 and T2 for the participants, rather than those who felt they had not experienced much change as they had been visiting their herbalist for a significant period of time before their inclusion into the research process.

The next limitation concerns the process of triangulation. Whilst some triangulation was utilised for this research (as outlined in section 3.3.2), there was no way of confirming whether the participants' stories of what occurred during the herbal therapeutic process corresponded to those of the herbalists. A constructionist approach to this research accepted the participants' stories as being valid, but greater use of the practitioners' view (discussed further in section 7.11) could have also helped to increase the validity of the research.

The final limitation of the research comes from an appraisal of the research design employed. Chapter 3 described the "fit" between the research question, the philosophical perspective and the methods adopted (Yardley, 2000) in order to help increase the credibility of the research. The decision to use a qualitative approach fitted with the aim of the research (that wanted to explore women's experiences), the philosophical perspective of constructionism, and the narrative approach used. However, a decision to eschew a quantitative approach meant that the research was unable to measure the effectiveness of WHP for women's distress that could then lead to generalisation for a wider population. In spite of this, whilst the outcomes described are only valid for these participants, this research has achieved the aim of providing a deeper, contextualised understanding of the human experience, whilst the transparency of the process should allow for a certain degree of transferability: "detailed descriptions that allow readers to make inferences about extrapolating the findings to other settings" (Polit & Beck, 2010).

### **7.11 Recommendations For Future Research**

The findings from this research, whilst helping to answer the research question, also help to pose more questions within the areas of distress and WHP which would provide useful areas of future research. This research has expanded on previous research that has shown women's distress can be problematic because women can suffer both feelings of shame and guilt, by exploring the differences between these emotions, and suggesting reasons that lay behind them. It would be useful to conduct qualitative research into women's experiences of distress to specifically look for instances of shame and/or guilt, and (if present) to investigate women's personal understanding as to why they experience these negative emotions.

This research has also looked exclusively at women. Some research has suggested that men are more likely than women to experience feelings of shame linked to losing face and a perceived loss of autonomy (Danielsson & Johansson, 2005; Mitchell & Schmidt, 2014). As this research has claimed that women also experience shame linked to distress for similar reasons, it would be interesting to compare women and men's experiences in this area. Previous research (Danielsson & Johansson, 2005; Danielsson et al., 2009) has also argued that women were more prone to feelings of guilt than men. This research has added to this area by suggesting that women's guilt is linked to their stereotypical societal role as a carer, but has been unable to investigate whether men also feel guilt in any way and (if so) the feelings behind that guilt.

Previous authors have highlighted that there is a relative lack of research into the patient experience of WHP (Joos et al., 2012; Nissen, 2013; Sibbritt, 2014). Whilst this research has added to literature in this area, the popularity of herbal medicine in the UK (Ipsos Mori, 2009; Posadzki et al., 2013; Euromonitor International, 2015) reinforces that the patient experience of WHP still requires further investigation. Limitations discussed in section 7.10 help to signpost areas of research that would be productive. Whilst the majority of users of WHP are women, the herbalists for this research emphasised that it has the potential to be of use for men as well: studies that include both women and men would be useful to see if their

experiences of WHP differ. This research, along with other studies, has suggested that WHP can be used for a range of conditions, so investigating patients' experiences of WHP for conditions other than distress would also be useful. Section 7.10 also emphasised the limited ethnic background of the participants. Whilst other herbal based healing traditions are available within the UK, this research has suggested there are a group of people who have been underrepresented within the current study, and that investigating their experiences in the future would be productive.

Finally, section 7.10 also reflected on limitations of the methods used for this research. Further investigation of both practitioner and patients' views into the experience of WHP (possibly with the use of focus groups) may yield greater understanding of some of the areas highlighted by this research. In addition, the use of a more quantitative approach (possibly as part of a mixed methods approach) would be able to provide greater validity and reliability from a positivist perspective.

## **7.12 Overall Conclusion**

This research has shown that, in line with the definition from The National Comprehensive Cancer Network (2008, cited in Bultz et al., 2009), "distress is a multifactorial unpleasant emotional experience" which "extends along a continuum" and includes problems severe enough that they "can become disabling". The participants' stories of distress were therefore diverse in terms of the reasons behind their distress, as well as the feelings associated with it. In spite of this, some features were commonly spoken about such as insomnia, anxiety, and feelings of a low mood. The range and intensity of the participants' experiences could sometimes be difficult for them to get across: in these instances, metaphors formed an important part of how they spoke of their distress. Whilst the use of metaphors could help the participants' distress be described within the narratives, their distress was not necessarily apparent to others as the participants could experience feelings of isolation (sometimes linked to not meeting biomedical/social

criteria for distress) or may have chosen to try and hide their distress. The issue for the participants was not therefore one of language with which to communicate their distress, but a reluctance to do so due to perceptions of stigma surrounding mental health and an inability to cope. These feelings helped to highlight the problem that the participants found when trying to be well and enjoy good mental health: the expectation – which begins with the WHO (2010) definition of mental health – that they should be autonomous and (as an individual) “work productively” and be “able to make a contribution to his or her community” meant that the participants felt stigmatised and ashamed when they “failed” to be well. In addition, those who found themselves with a caring responsibility also had to deal with feelings of guilt as they struggled with a “role” that they felt was expected of them as a nurturing, self-sacrificing carer. The overall impact resulted in lives that concentrated in on themselves as individual participants attempted to keep their private self safe from the public arena. These feelings of isolation could be exacerbated if the participant felt marginalised by an unsuccessful biomedical encounter. Examples of marginalisation included individuals rejecting biomedical diagnoses of distress (such as “depression”), avoiding the use of pharmaceuticals (particularly anti-depressants), but also feelings that their everyday distress was not always considered serious from a biomedical point of view.

Whilst the participants’ stories of distress were diverse, their narratives have shown that their experiences of WHP were also varied in terms of the reasons why they first chose to visit a herbalist, their experiences of what occurred during the consultation, and the outcomes of their visits (although visiting a herbalist was generally viewed as being positive). However, as with the stories of distress, there was some commonality amongst the narratives of visiting a herbalist, which helped to form the descriptions of the herbal therapeutic process within chapter 6. Importantly for the participants, the skills that the herbalists demonstrated could help them to overcome some of the features of distress. When the onus on the individual resulted in feelings of shame for the person who was unable to cope, the herbalist could listen, acknowledge and validate stories, accept that the individual’s distress was justified, and allow them a place of sanctuary in which to adopt a sick

role. However, rather than just allowing the individual to be sick (and so relinquish all responsibilities), the herbalist also gave them tools to help themselves and so regain some feelings of control and empowerment. In doing so, the herbalists could help the participants to feel supported – which was also helped by the herbalists being accessible and providing continuity of care throughout the process. In addition, the herbalists could help to reframe the individual’s narrative by assisting them view things differently. These skills were in addition to any benefits that the participants found from taking the herbs themselves, and so provided “added value”. Ultimately, the flexibility of the herbal therapeutic process meant that the participants’ narratives led to the conclusion that their herbalists were skilled at accompanying and supporting them through their journeys of distress to a point where they could regain the lost agency which was such a feature of distress.

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## **APPENDICES**

### **Appendix 1 – Participation Information Sheet for Herbalists**

# **Herbalist Information Sheet**

## **How Women Experience Herbs and Herbal Practice**

**Lead Researcher:** Adrian (AJ) Yates

**Research Supervisor:** Julia Green, PhD

Hello. I am a PhD student at the University of Westminster in London, and have received sponsorship from a charity to gather experiences of women receiving herbal treatments from herbal practitioners in the UK. This sheet is designed to outline the research that I hope you will consider helping me with. Please take time to read it – I shall contact you within the next few days to answer any further questions you may have, and to discuss your participation.

### **What is the Purpose of the Study?**

You are being invited to help in a study which uses patient narratives to investigate women's perceptions and experience of western herbal medicine, and western herbal medicine practice. The study is keen to know more about the emotional aspects which may be considered in the consultation either as a focus or as part of the wider treatment plan. There is growing evidence from numerous studies to show that western herbal medicine can be useful for a number of medical conditions that have an association with stress, anxiety, or feeling down, but there is little research on the patient's experience of their use. Practitioners are known to take great care to consider both the physical and emotional feelings shared by the patient and address emotional aspects in the treatment plan – this study is particularly interested in the emotional support of patients. The aim of the research is to investigate the patient's experiences, and how they may change over a period of time.

It is hoped that the study will help highlight the benefits of seeing a practitioner of western herbal medicine, as opposed to using herbs from other sources.

### **What Will Your Part of the Study Involve?**

1. Following your agreement to take part, you will be asked to take part in an interview (of about 20 minutes' duration) about you, your practice, and your approaches to treatment.
  
2. I would like to ask you to identify suitable patients who may be at any stage of treatment – a new patient, in on-going treatment, or even having been treated in the past, and encourage their participation in the study. **Please note:**
  - The study is asking you to give up a little of your time to be interviewed (as outlined overleaf), at a time and place to suit you.
  - Participation is entirely voluntary.
  - Your responses will be anonymous. No individuals involved will be identifiable from any collated data, written report of the research, or any publications arising from it.
  - You have the right to withdraw at any time without giving a reason.
  - You do not have to answer particular questions in the interview if you do not wish to do so.
  - You have the right to ask for your data to be withdrawn and for personal information to be destroyed. However, please note that it will not be possible to withdraw data after any publication of the study results.
  - You do not have to pass on the details of the study to any patient and for any reason if you do not wish to do so.
  - All personal data will be kept in a locked filing cabinet at the researcher's premises or at The University of Westminster.
  - Any typed up information will be kept on computer, will be coded, and will be password protected. It will not contain any information that could identify you or your patients, as this information will be coded separately.
  - As talking about issues surrounding being ill can occasionally bring upsetting feelings to the surface, all participants in the study will receive at the start of their interview a list of specific support groups and helplines that can be used to get more help if personal issues come up that they would like to discuss further. However, if a patient became excessively upset, they would also be referred back to you as a matter of course.
  - If you wish you can later receive information on the results of the research.
  - Your consent is conditional on the university complying with its duties and obligations under the Data Protection Act 1998.

- Any questions prior to, during, or after the study can be directed to the lead researcher (AJ) via email at: a.yates@my.westminster.ac.uk or by telephone on: 07983 978821 or to the lead supervisor, Julia Green, via e-mail at: j.green3@westminster.ac.uk or by telephone on: 020 7911 5000 ext 64597 or to the research supervisor, Julie Whitehouse, via e-mail at: j.whitehouse01@westminster.ac.uk or tel: 020 7911 5000 ext 64592
- Any complaints about your experience with the research can be directed to the School of Life Sciences research director, Taj Keshavarz, via e-mail at: t.keshavarz@westminster.ac.uk or by telephone on: 020 7911 5000 extension 3800.

If you are prepared to help in this study, you shall be asked to read and sign an *Informed Consent Form for Herbalists* before helping. This information sheet is for you to keep for your records. You will also receive a copy of the consent form for your records.

**Please remember:** Participation is entirely voluntary – you only have to sign the consent form if you are prepared to help, and may withdraw from the study at any time without having to give a reason.

Thank you very much for your time:  
A.J. Yates

## Practitioner Survey

### \*\*\*CONSENT FORM...?\*\*\*

**What is your highest educational qualification in herbal medicine?**

- Diploma
- BSc
- MSc
- Other  Specify: \_\_\_\_\_

**Where was the qualification obtained?** \_\_\_\_\_

**When was the qualification obtained?** \_\_\_\_\_

**Which professional body/bodies of herbal practitioners do you belong to?** (Tick all that apply):

- NIMH
- CPP
- Other  Specify: \_\_\_\_\_

**How long have you been in practice?**

- Up to 5 yrs
- 6 – 10 yrs
- 11 – 15 yrs
- 16 – 20 yrs
- 21 – 25 yrs
- 26 – 30 yrs
- Over 30 yrs

**Do you practice?**

Full Time   
Part Time

**Where do you practice? (Tick all that apply):**

Home   
Herbal clinic   
“CAM” clinic   
NHS setting   
Retail outlet   
Other  Specify: \_\_\_\_\_

**What is the average length of your consultations?**

Initial consultation: \_\_\_\_\_(minutes)

Follow-up: \_\_\_\_\_(minutes)

**How many appointments do you normally have a week?**

Up to 5   
6 – 10   
11 – 15   
16 – 20   
Over 20

**Would you normally see...?**

- More women than men
- More men than women
- About equal

**Do you practise any other therapies apart from WHM?**

- No
  - Yes  Specify: \_\_\_\_\_
- 

**What form do your herbal medicines normally take? (Tick all that apply)**

- Tincture
- Infusion
- Decoction
- Tablet
- External
- Other

Specify: \_\_\_\_\_

**What would be the average (internal) daily adult dose?**

- Equivalent to 1:1 FE:
- Up to 5 ml
  - 5 – 15 ml
  - 16 – 30 ml
  - Over 30 ml

**What are the most common three reasons for people consulting with you?**

Record verbal responses via the digital voice recorder.

**How would you describe your practise of herbal medicine?**

Record verbal responses via the digital voice recorder.

**Which herbal approaches would you use for treating distress?**

Record verbal responses via the digital voice recorder.

**Are there any other aspects would you consider when treating distress?**

Record verbal responses via the digital voice recorder.

**Gender:**

Male

Female

Other

Specify: \_\_\_\_\_

**Age:**

Up to 25

26 – 35

36 – 45

46 – 55

56 – 65

Over 65

**Ethnicity:**

White British	<input type="checkbox"/>	White Irish	<input type="checkbox"/>
White other	<input type="checkbox"/>		
Indian	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>
Bangladeshi	<input type="checkbox"/>	Other Asian	<input type="checkbox"/>
Black Caribbean	<input type="checkbox"/>	Black African	<input type="checkbox"/>
Black Other	<input type="checkbox"/>		
Chinese	<input type="checkbox"/>		
Mixed:			
White & Black	<input type="checkbox"/>	White & Asian	<input type="checkbox"/>
White & Other	<input type="checkbox"/>		
Other	<input type="checkbox"/>	Specify: _____	

**Venue:** Do you have any views on suitable places to interview your patients?  
 EG: University of Westminster/practitioner's clinic/elsewhere...?

**Thank you very much for your time! 😊**

## Participation Information Sheet for Patients.

### How Women Experience Herbs and Herbal Practice.

**Lead Researcher:** Adrian (AJ) Yates.

**Research Supervisor:** Julia Green, PhD.

Hello. I am a PhD student at the University of Westminster in London.

This sheet explains the research that you have been asked to take part in.

Please take time to read it, but feel free to contact me and ask any questions you have that are not answered by this sheet.

You can also contact me to say that you want to take part in the research.

#### **What is the Purpose of the Research?**

You are being asked to take part in research which looks at patient ideas about herbal medicine, especially patients who have been through a rough time and feel stressed out. Research has shown that herbal medicine can be useful for these types of people, but there is little research on the view of the patient.

This research will look at your views, and how they may change over time.

#### **Who Can Take Part?**

This research is interested in women's **experience** of seeing a herbalist.

This means that if you are seeing a herbalist for **any** reason and have experience of feeling stressed, anxious, or just down, then you can take part in this research.

#### **What Will the Research Involve?**

- Chosen patients will be asked to take part in two interviews.
- These interviews will let them talk about their experience of being ill, being stressed and about using herbal medicine.
- The first interview would take place within the next few weeks (at a time and place that suits you), and the second one about six months later.

- The interviews will take roughly 1 hour (sometimes less, although I would allow 1½ hours to be safe), and will be voice recorded.
- I may also write some notes during the interview.
- The interviews shall be written up, and a copy of the interview shall be sent to you so that you can make sure you are happy with it.
- Expenses of up to £20 per interview are available if needed, for any costs (such as travel) that may occur due to you being interviewed (a receipt **must** be provided to claim back the costs).

**Please note:**

- The research will take up some of your time (the interviews).
- You do not have to take part if you do not want to.
- Your responses will be anonymous. No-one will be able to be identified from the interview, or any reports that come from it.
- You have the right to withdraw at any time without giving a reason.
- You have the right to ask for your interview to be withdrawn and for personal information to be destroyed. However, please note that it will not be possible to do this once the research is published.
- You do not have to answer any question in the interviews if you do not want to.
- All personal information will be kept in a locked filing cabinet at the researcher's premises or at The University of Westminster.
- Any typed up interviews will have all names removed. They will be kept on computer, and will be password protected. They will not contain anything that could identify you from your personal information.
- A write-up of the interview will be sent to you to check. You have the right to change or remove anything you want.
- Please remember that talking about yourself and your illness can make you feel upset. Everyone who is interviewed will receive a list of groups that can be used to get more help if wanted.
- If you want to, you can receive information on the results of the research.

- The information you provide shall be used in a PhD thesis. It may also be used in conference or media reports and/or publications related to this research.
- Any questions at any time can be put to the lead researcher (AJ) via email at: [a.yates@my.westminster.ac.uk](mailto:a.yates@my.westminster.ac.uk) or by telephone on: 07983 978821  
Or to the research supervisor (Julia Green) via e-mail at: [j.green3@westminster.ac.uk](mailto:j.green3@westminster.ac.uk) or by telephone on: 0207 911 5000 extension 64597.
- Any complaints about the research can be put to the university's School of Life Sciences research director (Taj Keshavarz) via e-mail at: [t.keshavarz@westminster.ac.uk](mailto:t.keshavarz@westminster.ac.uk) or by telephone on: 020 7911 5000 extension 3800.

If you want to take part in this research, you shall be asked to read and sign an **Informed Consent Form for Patients** before doing so.

This information sheet is for you to keep.

You will also receive a copy of the consent form.

**Please remember:** Taking part is voluntary – you only have to sign the consent form if you want to take part, and may withdraw from the research at any time without having to give a reason.

Your consent is conditional on the university complying with the Data Protection Act 1998.

If you want to take part in this research, please inform me via e-mail at:

[a.yates@my.westminster.ac.uk](mailto:a.yates@my.westminster.ac.uk)

or by telephone on: 07983 978821

or return the enclosed form in the pre-paid envelope, saying how you wish to be contacted.

Thank you very much for your time.

A.J. Yates

## **How Women Experience Herbs and Herbal Practice.**

I want to take part in the above research.

Please contact me on the details below, to answer any questions that I may have, and/or to recruit me for the research.

I prefer to be contacted by: telephone / e-mail / post

(delete as appropriate).

Name:

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Address:

---

---

---

Telephone number:

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E-mail address:

---

## Appendix 4 – List of Support Groups for Participants

### Support Groups and Helplines

Action on Addiction:

Advice and help for those living with, or who know someone living with, an addiction:

Telephone: 0300 330 0659

Website: [www.aona.co.uk](http://www.aona.co.uk)

British Association of Counselling & Psychotherapy:

Information about therapy, and contact details for therapists:

Telephone: 01455 883300

Website: [www.itsgoodtotalk.org.uk](http://www.itsgoodtotalk.org.uk)

Citizens Advice Bureau:

Free advice on a range of subjects:

Telephone: 08444 111 444

Website: [www.adviceguide.org.uk](http://www.adviceguide.org.uk)

Cruse Bereavement Care:

Grief counselling service:

Telephone: 0844 477 9400

Website: [www.cruse.org.uk](http://www.cruse.org.uk)

Debt Advice Foundation:

Advice for financial debt problems:

Telephone: 0800 043 40 50

Website: [www.debtadvicefoundation.org](http://www.debtadvicefoundation.org)

MIND:

Support for those living with, or who know someone living with, all manner of mental health issues:

Telephone: 0300 123 3393

Website: [www.mind.org.uk](http://www.mind.org.uk)

Pain Concern:

Support for those living with chronic pain:

Telephone: 0300 123 0789

Website: [www.painconcern.org.uk](http://www.painconcern.org.uk)

Rape Crisis:

Support for those that have been sexually abused:

Telephone: 0808 802 9999

Website: [www.rapecrisis.org.uk](http://www.rapecrisis.org.uk)

Samaritans:

Confidential emotional support service:

Telephone: 08457 90 90 90

Website: [www.samaritans.org](http://www.samaritans.org)

Self Help UK: Provide a list of self-help organisations, and patient support groups and charities across the UK:  
Website: [www.self-help.org.uk](http://www.self-help.org.uk)

Women's Aid: Support for those suffering from domestic violence:  
Telephone: 0808 2000 247  
Website: [www.womensaid.org.uk](http://www.womensaid.org.uk)

Women's Consortium:  
Counselling and personal development to empower women:  
Telephone: 07814 960 713  
Website: [www.womensconsortium.org.uk](http://www.womensconsortium.org.uk)

*Please note: these represent a range support groups and helplines available, and their inclusion is not a recommendation. All information correct at time of printing.*

## **T1 – INTERVIEW TOPIC GUIDE**

### **A. THE STORY UNINTERRUPTED**

'Thinking about <reason for seeing herbalist> - going back to when you first noticed something was not right, in your own words, can you tell me your story of seeing a herbalist?'

### **B. GETTING THE DETAILS**

**Take care not to ask questions that have already been covered and so appear disinterested.**

#### **Experiences of seeking help:**

'Can you tell me something about seeking help?'

'Who did you turn to?'

'Did you know anything about herbal medicine beforehand?' 'Where did you get this information from?'

#### **Seeing the herbalist:**

'Can you tell me what it was like finding a herbalist?'

'What made you choose that herbalist?'

'Imagine you're explaining what seeing a herbalist is like to someone who knows nothing about herbal medicine – how would you describe the experience of going to see a herbalist?'

'What did you discuss during the consultation?'

'Were there things you didn't, or felt you couldn't, discuss?'

'How did you *feel* during the consultation?'

'Was it just talking, or was there any physical examination?'

'How was it similar/different to seeing other healthcare workers?'

If different – 'What was different about it?'

'Do you feel you had a part to play in deciding what happened, both during and after the consultation?'

'What is your view of the herbalist themselves?'

**Role of the herbs:**

'Can you tell me a bit about how you have found taking the herbs?'

'Do you know what you are taking and why?'

'Have there been any problems taking the herbs?'

'Do you think the herbs have been beneficial, or have they had any unwanted effects?' 'Does the taste make a difference?'

'How would you feel about buying herbs from a shop, or online, to treat yourself?'

'As you're seeing a herbalist, what more do you feel you get from seeing a herbalist rather than self-prescribing?'

'Has the herbalist suggested anything other than herbs to help you?' (e.g. diet and lifestyle)

**The story – early on to now:**

'What life was like before <reason for seeing the herbalist>?'

'Can you think back to a time before things were rough?'

'What happened next?'

'When did you notice something was not right?'

'Can you tell me a little bit more about that?'

'What was it like when things were rough?' 'What happened next?'

'Was there a time when things started to get better?'

'What happened next?'

'How are things today?'

**Distress:**

'Tell me something about feeling stressed/rough....'

'What impact has it had on your life?'

Embarrassment...?

'That sounds like it must be upsetting – are you okay to tell me a bit more about that?'

'How have people reacted...?' 'Has it affected those around you – work/social life et cetera?'

'Has it affected the way you see yourself?'

'Do you have any theories about why things got hard for you?'

(e.g. childhood trauma, birth, genetics, stressful life events...)

**Self-care...**

'Is there anything else that you do to help cope with your problems?'

Personal coping strategies:

- e.g. diary keeping, financial, hobbies, distractions (food/drink), ruminating, positive thinking, peace of mind, physical activity, yoga, nature-based activities, acupuncture, courses, CAM, sex, illicit drugs et cetera)
- 'Which have been the most helpful or least helpful?'

**Consider if appropriate to the individual interviewee...**

'What has been the most healing aspect of your journey?'

'Which aspects of seeing a herbalist have you found the most useful?'

'And the least useful?'

'Have any other things you've tried been useful?'

**The future:**

'How do you view the future?'

'Would you use WHM for different problems in the future?'

**Closure:**

'Do you have any advice for someone going through similar issues to the ones you've had?'

## T2 – TOPIC INTERVIEW GUIDE (292)

### A. THE STORY UNINTERRUPTED

#### **The last six months:**

'So how have you been since I last saw you?'

'How have you been feeling?'

'What happened next?'

### B. GETTING THE DETAILS

**Filling in gaps from the first interview. If a narrative of distress was not obtained, consider enquiring again.**

#### **Distress:**

*'You mentioned feeling "a bit pathetic" or "humiliating" or "Little Miss Special Needs" if **not coping** – do you still feel like that?'*

#### **Seeing the herbalist:**

*'You had seen a different herbalist once before – were the experiences similar or different in any way?'*

*'You said that you were made to feel **part of the solution** – was that an important part of the experience?'*

*'It was interesting that you said you felt it was difficult to talk to your GP about mental health stuff: different with herbalist?'*

***:" makes you feel like part of a bigger thing rather than just you and your problem"***

*'It sounded like removing yourself from stressful situations was a good way of coping with anxiety in the short term, but the **isolation became counter-productive**. Is herbalist still helping?'*

*'I suppose one of the things that stood out about herbalist as that it sounded like she made you feel cared for – is that the case?'*

**Role of the herbs:**

*'How have you found taking the herbs?'*

*'Because when we last spoke you were in a dilemma whether to also take citalopram or not...'*

**'ANY DIFFERENCE BETWEEN T1 AND T2?!'**

*'Do you think the herbs have had any unwanted effects?'*

*'You spoke about the taste, but it was interesting that the emergency had a horrible taste, but it also became a comforting taste...'*

**Self-care...**

*'Is there anything else that you have done to help cope with your problems?'*

*Diet was mentioned last time.*

*Being with/walking the dog!*

**Consider if appropriate to the individual interviewee...**

*'What has been the most healing aspect of your journey?'*

*'And the least useful?'*

*'Have any other things you've tried been useful?'*

**The future:**

*'You said that going through a rough time would mean that you are likely to come out the other side stronger as you would be more yourself and less likely to find yourself in a similar situation – so how are you viewing the future now?'*

*Was "cautiously optimistic"...*

**Social persona altered...?****Closure:**

*'Do you have any advice for someone going through similar problems to the ones you've had?'*

*'Now that you've used it, what is your view of herbal medicine?'*

*'What is your view of seeing a herbalist?'*

*'Would you use herbal medicine again?' **For distress...?***

*'How have you found taking part in the research?'*

*'Do you think being interviewed here by a man could have affected your story in any way?'*

## **Appendix 7 – Researcher Training Log**

**27.9.11** – University of Westminster UT1: Induction

**3-5.10.11** – University of Westminster MSc module: Introduction to Qualitative Research Methods in Psychology I

**6.10.11** – University of Westminster UT3: Library Induction

**w/c 10.10.11** – University of Westminster Induction week

**27.10.11** – University of Westminster Endnote training

**26.11.11** – University of Westminster UT4: Advanced Information Searching and the Wider Research Context

**7-9.11.11** – University of Westminster MSc module: Introduction to Qualitative Research Methods in Psychology II

**16.11.11** – University of Westminster UT2: Induction Part II

**13.1.12** – University of Westminster invigilation/demonstration training

**16-18.1.12** – University of Westminster MSC module: Advanced Qualitative Research Methods in Psychology

**16.1.12** – University of Westminster introduction to marking with Liz Oldham

**14.2.12** – University of Westminster Refworks training

**22-23.3.12** – University of Oxford Health Experiences Research Group Qualitative Research Methods Programme: Introduction to Qualitative Interviewing

**31.3.12** – CPP Seminar: Re-imagining the Profession

**24.4.12** – University of Westminster: Invigilation of Exams

**2.5.12** – College of Medicine Workshop: From Prescriber to Guide? The Herbal Self-Care Option

**11.5.12** – University of Westminster introduction to NVivo with Tim Lomas

**14.6.2** – University of Westminster UT6: Transferring to PhD

**2-3.7.12** – University of Westminster UT5: Teaching in Higher Education

**18-19.10.12** – University of Oxford Health Experiences Research Group Qualitative Research Methods Programme: Analysing Qualitative Interviews

**11.12.12** – University of Westminster: Postgraduate Certificate of Special Study in Supporting Learning induction

**17.1.13** – University of Westminster: Postgraduate Certificate of Special Study in Supporting Learning: observed teaching session

**29.1.13** – University of Westminster: Postgraduate Certificate of Special Study in Supporting Learning: feedback from observation

**27.3.13** – University of Westminster: Supporting Academic Writing workshop

**12.4.13** – Volunteer room manager/attendee: The International Society for Complementary Medicine Research

**16.4.13** – Bournemouth University: narrative workshop

**14.6.13** – University of Westminster Graduate School workshop – A Beginner's Guide to Research Grants

**1-2.7.13** – Volunteer administrator and organiser for CAMSTRAND conference at The University of Westminster

**25.9.13** – Research Council for Complementary Medicine 30<sup>th</sup> Anniversary Conference: From Hierarchy of Evidence to Good Practice

**8.10.13** – University of Westminster Presentation: Living or Just Surviving?

**12.11.13** – Attainment of Postgraduate Certificate of Special Study in Supporting Learning from The University of Westminster

**13.11.13** – Participated in focus group as part of research project: Business Case for Diversity in Science, Engineering, Technology, Mathematics and Medicine at The University of Westminster

**27.11.13** – University of Westminster lecture: The Neuroscience of Laughter

**22 & 29.1.14** – University of Westminster: NVivo training

**4.2.14** – University of Westminster: Student Centred Learning workshop

**18.6.14** – Award for best PowerPoint presentation: CAMSTRAND conference at The Christie NHS Foundation Trust, Manchester

**16.1.15** – College of Medicine: Student Strategy Meeting at Guy's Hospital, London

**18.2.15** – University College London: Qualitative Health Research Symposium  
'Enriching Qualitative Inquiry in Health'.

## Appendix 8 – Example of Coding from Page 1 of Cleaned Transcript 232

Text p.1

**Interviewer:** So thinking about going and seeing the herbalist, going back to when you first noticed something wasn't right, in your own words can you just tell your story of seeing a herbalist?

**Patient:** About (age) years old, just feeling suddenly, not a build-up really, just suddenly one day having hot flushes then the next day just more and more and more, very quickly just becoming not being able to function – just thinking there's something terribly wrong, thinking I couldn't be having menopause, because I was too young. So I went to the doctors, had some blood tests and he said "You've begun your menopause and we'll get you on HRT" and I didn't want to be on HRT. So I came away and had a think about it and I'd been on the pill for a *long* time, and lots of other health things, I just didn't want to start taking other huge hormonal thing into my body, so started thinking very seriously about other alternatives. Went into homey, well, looked into homeopathy and just thought it's not going to, I pooh-poohed it quite early on. And then someone told me about (herbalist) and I came to see her and we talked for a long, long time and she gave me some stuff that she said is going to take three months to work, and I was just thinking "Oh God, I need something now", and in literally three months' time it kicked in and my hot flushes and night sweats and everything just started to fall away, which is incredible. And so on the whole I'd say, this is about 2 years ago – I'm (age) now – so in times of high stress when I've got like 20 people staying in the house and Christmas and loads of kids, or when I'm feeling very, very run down, it doesn't work. I get my serious hot flushes back and my night sweats, I'm up all night with them, but I'd say on the whole it's unbelievable. Yeah, so it really, really does work.

Okay, so it came on quite suddenly.

Yeah, very.

And was your GP the first person you went to see?

**GP,** first person, did the blood test and yeah, and they were just, they just said "Right, get you straight onto.." They didn't really give me any other information, no other choices, they just said "HRT – because you're young and you shouldn't have to do this", and I just came away thinking "Well actually this is the most natural body process, and actually if it is the menopause, I want to get over it and move on", sort of thing. So that was a very negative response from a doctor I thought.

And then when you'd been to see the doctor, where did you turn to next to seek help? Did you speak to anybody else, or what did you do?

**Well** I did go home and I looked on the Internet and whatever, but just went, talk through my family. My mother had a very, very easy, she had an early menopause and very easy and she said "I just remember a few hot flushes" and I think my mum is very good at pushing things aside anyway, but she said "Just go, deal with it, couple of years' time you'll be over it, just not a problem". And I spoke to, I've got six girl cousins, my mum is an identical twin, and all the cousins we're all incredibly similar in lots of things that have happened to us, and they all just said "We've all had early menopause, just it's not a problem, but don't.." you know. So I said that I was having *huge* amounts of hot flushes during the day and night sweats and they were saying "Oh well we didn't, we didn't". So I just thought "Right, I've got to do something", because they were just laughing at me thinking "Why are you bothering doing anything?" But no, I just thought, "I've always looked into.." When I've hurt, I did a lot of sports when I was younger, so I've always done preventative medicine, as in going to cranial osteopath every two months and everything else, so I just thought, and I spoke to him about it and he suggested the clinic as well, he just, I think he might have even suggested (herbalist) and just through him really, I just thought "Right, I'll come and see her".

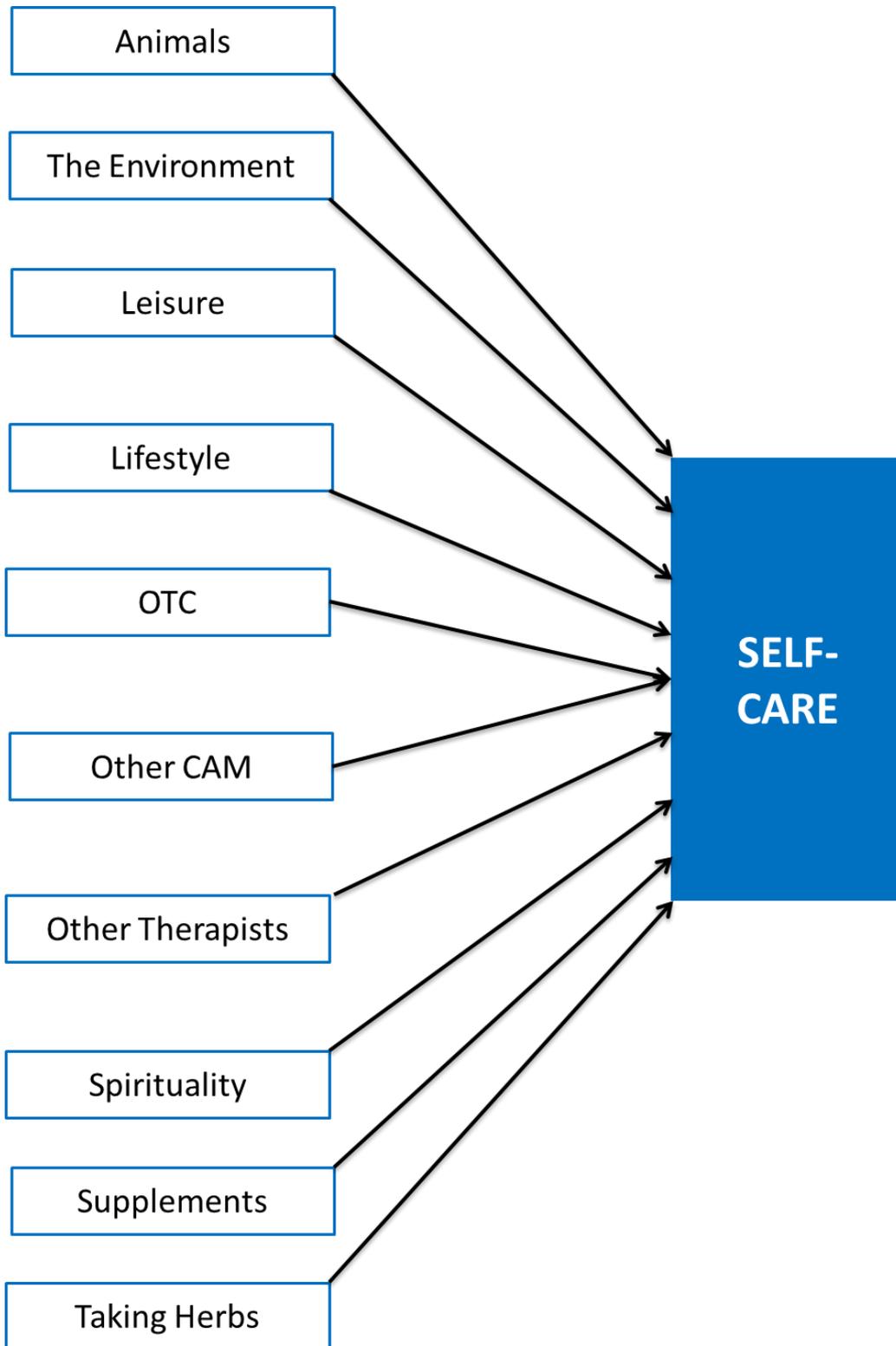


## Appendix 9 – Explanation of Final Codes

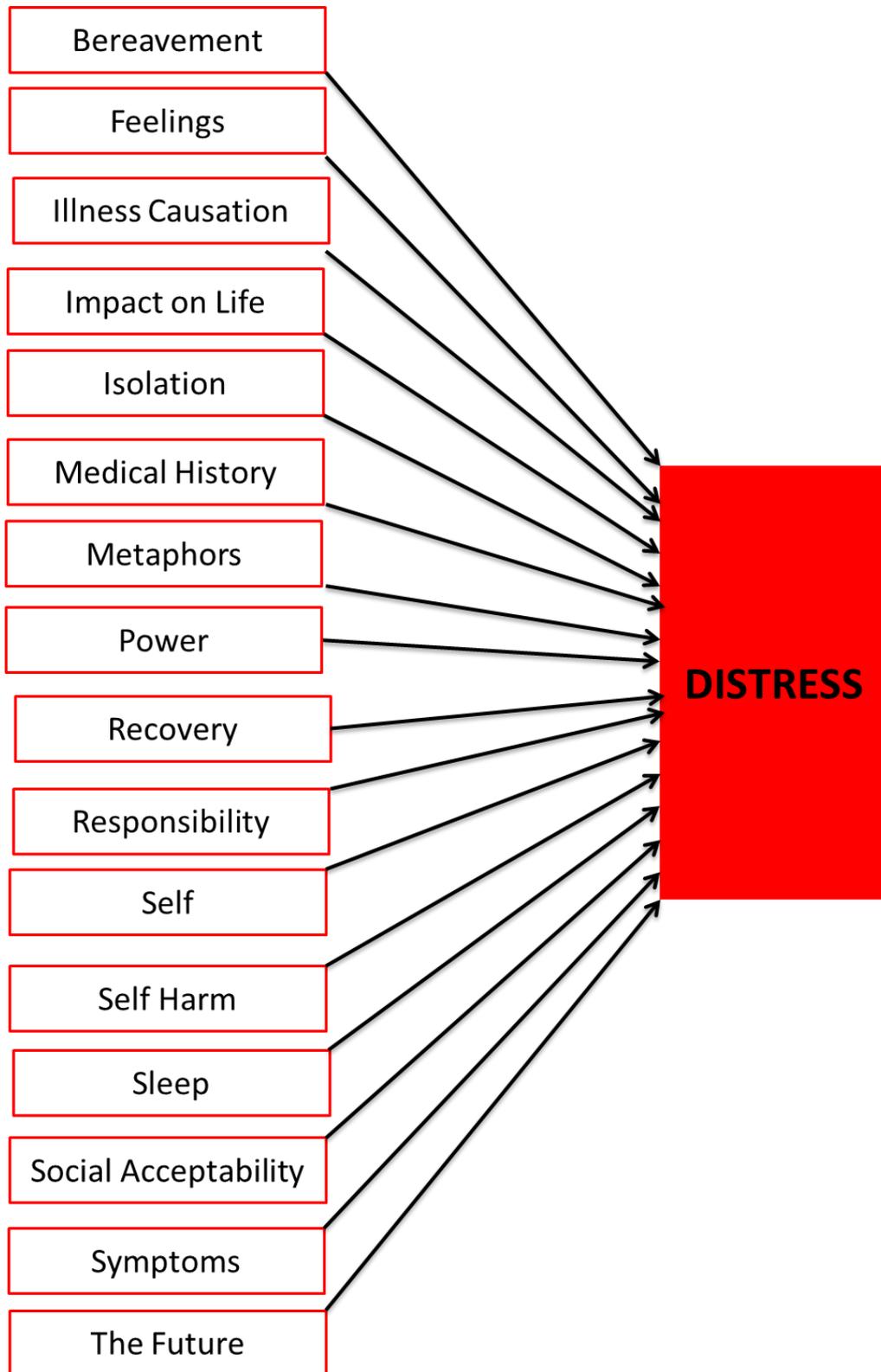
1. Accessibility – accessibility (or not) of therapists
2. Age – mention of age and ageing
3. Animals – talk of animals, including pets
4. Before the herbalist – any experiences/views of herbal medicine before actually consulting with the current herbalist
5. Being heard – relating to feelings of being listened to, or not being listened to
6. Bereavement – relating to the death of another
7. Biomedicine – experiences of all aspects of biomedical treatment such as seeing a GP, taking medicine etc.
8. Blame – talk of blame (or lack of) for condition/situation
9. Childhood – events from childhood
10. Diet – talk of views about diet, or discussion of diet with herbalist
11. Distress – descriptions of feeling stressed, anxious, down, afraid et cetera.
12. Empathy – feelings of empathy with/from others
13. Environment – talk of the outside world and/or nature
14. Feelings – talk of feelings/emotions
15. Finances – talk of money
16. Gender – talk of gender differences or similarities
17. Historical – events from the past
18. Holism – views on treating the whole person rather than treating symptomatically
19. Humour – any instances of humour, including chuckling
20. Illness Causation – thoughts on why they are ill and/or distressed
21. Impact on Life – effects that their condition/distress has had on them
22. Individuality of Treatment – specificity (or not) of treatment
23. Isolation – instances around isolation (or lack of isolation)
24. Knowledge – talk of sources of knowledge, and expertise (or lack of) from therapists
25. Leisure – talk of spare time, pastimes, hobbies, etc.
26. Lifestyle – talk of lifestyle choices, or advice received/not received
27. Medical history – events concerning historical medical events
28. Metaphors – descriptions that use metaphor (such as the use of colour)
29. Not western herbal practice – talk of herbal practises that fall outside the remit of WHM
30. OTC – experiences of using over the counter remedies/supplements etc.
31. Other CAM – experiences of other types of CAM therapies
32. Other cultures – talk of different/similar cultural practices
33. Other therapists – experiences of seeing other therapists

34. Pharmaceuticals – experiences of orthodox medication
35. Physical Examination – any mention of physical examination
36. Placebo – consideration of the effects, or lack of effects, from placebo
37. Power – talk of having/not having, losing, or regaining power/control
38. Professional Boundaries – talk of professional limitations
39. Push/pull Factors – any talk of push/pull factors
40. Recovery – any talk of recovery or setbacks
41. Reframing – having views altered
42. Regulation – thoughts on regulation of CAM
43. Relationship – talk of relationships with others
44. Responsibility – feelings of responsibility, or lack of responsibility, towards others
45. Self – views of the self or feelings of a loss of self
46. Self-care – other strategies for coping
47. Self-harm – talk of harming, or choosing not to harm, self
48. Sexuality – any mention of sex and sexuality
49. Sleep – talk of sleep or insomnia
50. Social acceptability – talk of feelings with regards to awkward social situations
51. Spirituality – talk of or thoughts on spirituality
52. Supplements – any reports of supplements from therapists
53. Support – support (or lack of support) from family, friends, etc.
54. Symptoms – reports of specific symptoms
55. Taking Herbs – experience of what taking herbal medicine is like
56. Taste – mention of positive or negative experiences of taste
57. Temperaments – talk of humoral/astrological traits
58. The Consultation – the story of what occurred during the consultation
59. The Future – expectations of what the future holds
60. Therapeutic Environment – talk of physical surroundings of clinical settings
61. Therapeutic Relationship – views on therapeutic relationships
62. Time – talk of time, or lack of time
63. Views of others – talk of others viewpoints
64. Work – any talk of employment

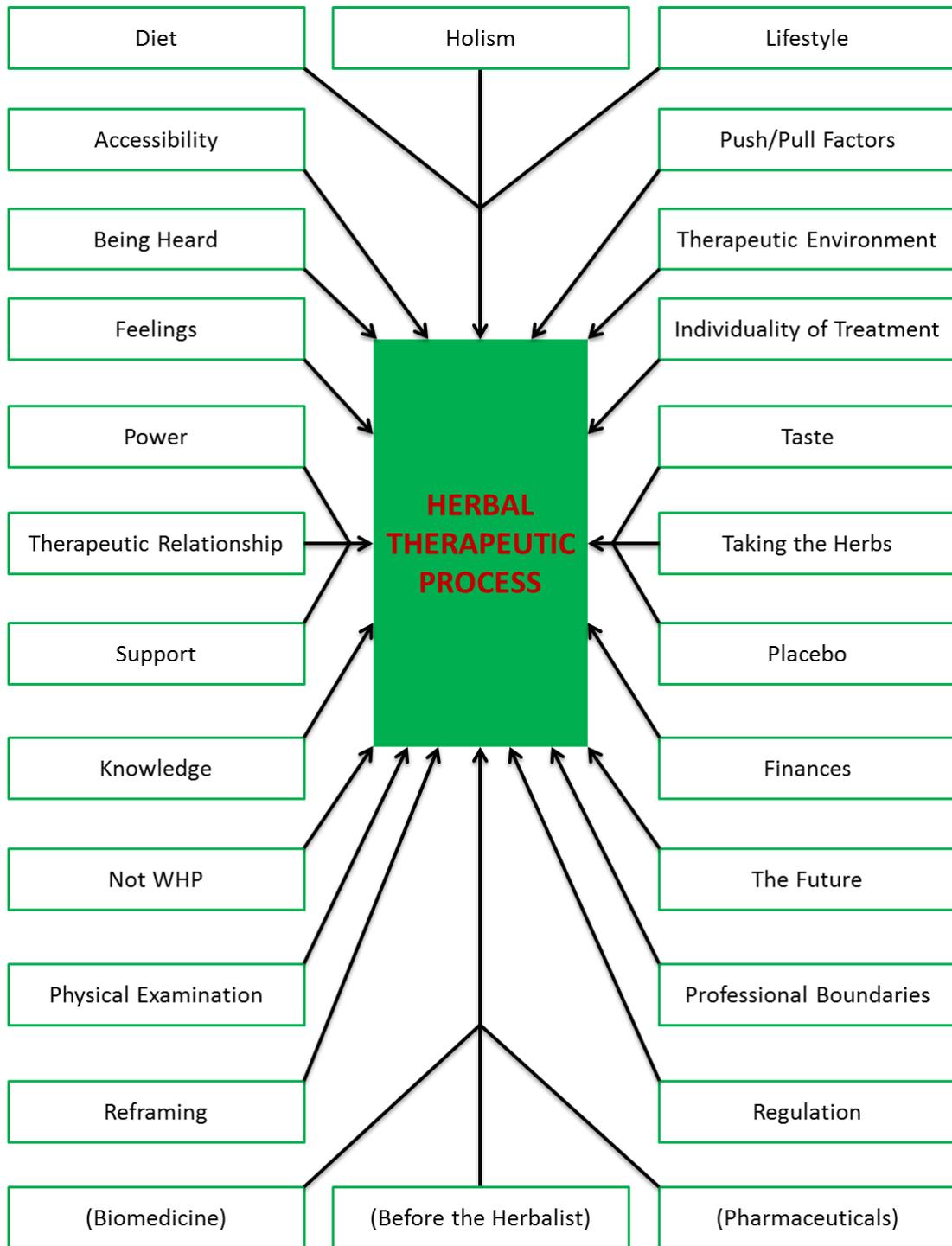
**Appendix 10 – Codes Feeding Into Category of Self-Care**



**Appendix 11 – Codes Feeding Into Category of Distress**



**Appendix 12 – Codes Feeding Into Category of Western Herbal Practice**





Does work include the *in vivo* use of animals?\*

Yes  No

If yes, please enter Home Office project number and the certificate of designation number of the institution where the work will be done:

\*NB no one is permitted to do *in vivo* research with animals on UoW premise

Your research is classified as Class 3B, if an outside body requires the scrutiny of the University's RESC to ensure that the research conforms with general ethical principles and standards. Please complete parts A and B of the Research Ethics Approval Form. Submit parts A and B to Huzma Kelly. If you are doing this please check the box:

If you need to submit **any** forms to Huzma Kelly, Senior Research Officer, then you may not commence work until you receive the approval of the University's RESC. When you receive approval please lodge a copy of the approval letter with the School Office.

**1.4 Declaration.** The information on this form is true and to the best of my knowledge correct. If you are a student your supervisor must sign the declaration to demonstrate that they have read and approved your application.

**Signature:**

**Name:** Dr Julia Green

**E-mail Address:** j.green3@westminster.ac.uk

**Dept:** School of Life Sciences

**Telephone Number:** x64597

**RISK OF HARM** [this tick list is a quick guide to the classification of your work only. The exact classification should be determined using the University of Westminster Code of Practice Governing the Ethical Conduct of Research 2009 ([http://www.wmin.ac.uk/docs/Ethics%20Code%20of%20Practice%202009\\_2.doc](http://www.wmin.ac.uk/docs/Ethics%20Code%20of%20Practice%202009_2.doc))].

		Yes	No	N/A
1	Is pain or more than mild discomfort likely to result from the study		x	
2	Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	x		
3	Will the study involve prolonged or repetitive testing?		x	
4	Will the study involve raising sensitive topics (e.g. sexual activity, drug use, revelation of medical history and/or illegal activities)	x		
5	Does your work involve any material containing human cells (e.g. blood, urine, saliva, body tissues) from living or deceased persons? (Such work must take account of the Human Tissue Act).		x	
6	Will DNA samples be taken from human participants? (Such work must take account of the Human Tissue Act).		x	
7	Does your study raise any issues of personal safety for you or other researchers involved in the project? (Especially relevant if taking place outside working hours or off University premises)	x		
8	Does your study involve deliberately misleading the participants (e.g. deception, covert observation)		x	
9	Does your work involve administration of a non-food substance in abnormally large amounts or one that is known to cause allergic reaction(s) in some people?		x	

**PARTICIPANTS**

**Does your work involve any of the following:**

		Yes	No	N/A
10	Human participants in health settings (e.g. private patients in private clinics)	x		
11	Human participants in health settings (e.g. NHS patients in NHS clinics/hospitals)		x	
12	Human participants who are in the care of a social worker		x	
13	Expectant or new mothers	x		
14	Refugees		x	
15	Minors (under the age of 18 years old)		x	
16	Participants in custody (e.g. prisoners or arrestees)		x	
17	Participants with impaired mental capacity (e.g. severe mental illness, brain damaged, sectioned under Mental Health Act, lowered or reduced sense of consciousness)		x	

<b>INFORMATION TO PARTICIPANTS</b>				
		<b>Yes</b>	<b>No</b>	<b>N/A</b>
<b>18</b>	Will you provide participants with a Participant Information Sheet prior to obtaining consent which can be taken away by the participant?	<b>x</b>		
<b>19</b>	Will you describe the procedures to participants in advance, so that they are informed about what to expect?	<b>x</b>		
<b>20</b>	Will you obtain consent for participation? (normally written)	<b>x</b>		
<b>21</b>	Will you tell participants that they may withdraw from the research at any time and for any reason?	<b>x</b>		
<b>22</b>	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	<b>x</b>		
<b>23</b>	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	<b>x</b>		
<b>24</b>	Will you debrief participants at the end of their participation (e.g. give them a brief explanation of their study)?	<b>x</b>		

If you have answered **NO** to questions 1-17 (inclusive) and **YES** to questions 18-24 (inclusive) then the project is probably Class 1.

If you have answered **YES** to any of the questions 1-17 (inclusive) or **NO** to any of the questions 18-24 (inclusive) then the project is either Class 2 or 3A.

Any documents for consideration by the University's RESC should be sent to: Huzma Kelly, Senior Research Officer (Policy and Governance), Academic Registrar's Department, Copland Building, New Cavendish Street.

University of Westminster

Research Ethics sub-Committee

Application for Research Ethics Consideration

COVER SHEET

(To be completed by all applicants)

<b>Section 1 – PROJECT AND APPLICANT DETAILS</b>  <b>To be completed by all applicants</b>
--

<b>1.3 Project Title:</b> How women use and experience herbs and western herbal practice for distress: Implications for health care and self-management approaches
--

<b>1.4 Applicant Details</b>	
<b>Name:</b> A.J. Yates	<b>Email Address:</b> a.yates@my.westminster.ac.uk
<b>Contact Address:</b> 66 Brill Place Bradwell Common Milton Keynes MK13 8LR	<b>Telephone Number:</b> 01908 234443
<b>Please check the relevant box:</b>  <input type="checkbox"/> Undergraduate <input checked="" type="checkbox"/> Postgraduate x MPhil/PhD Student <input type="checkbox"/> Staff	

<b>1.5 Supervisor/Dean of School/ School Research Director details</b> Supervisor – Julia Green; Dean of School – Jane Lewis; School Research Director – Taj Keshavarz  Please note that all applicants with a supervisor(s) must ensure that the supervisor signs the
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declaration at the bottom of this page if completing Part A only or in **Section 10.3** if completing Part B

All staff must ensure that their Dean of School, or School Research Director (or nominee), as appropriate, signs the declaration at the bottom of this page if completing Part A only or in **Section 10.3** if completing Part B

**Name:** Julia Green

**Email Address:** j.green3@westminster.ac.uk

**School/Centre/Unit:** Life Sciences

**Telephone Number:** x64597

**NOW COMPLETE PART A**

## PART A

### Section 2 – Project Details

**2.1** Please provide a description of the background to your study including a literature review (250 words maximum):

It has been stated that there are gender differences within mental health. Research suggests that common mental disorders are more prevalent amongst women than men (19.7% and 12.5% respectively), and that women are more likely to suffer from common mental disorders that can cause emotional distress (NHS Information Centre, 2007). Mental health is the foundation for individual well-being and the effective functioning of a community (WHO, 2010), but in the UK, common mental health disorders account for one in five of all work days lost and cost UK employers £25bn each year (NICE, 2011).

Herbal medicine has the potential to be of use in conditions associated with distress, such as depression, anxiety and insomnia (Sarris *et al*, 2011). In 2008, 35% of British adults surveyed claimed to have used herbal medicine at some stage, the majority of which were women (Ipsos Mori, 2009). However, there is little research into how the users of western herbal medicine (WHM) experience herbs and the practice of herbal medicine, or how these experiences may change over time. As patients are increasingly seen as experts in their own condition (NHS Choices, 2012) this proposed study aims to use patient narratives at two different points in time in an attempt to discover how women experience herbs and herbal practice for distress, and therefore suggest the most meaningful approaches to herbal treatment for this group from a herbal practitioner, or other self-management techniques.

**2.2.** Please provide a brief description of your study (250 words maximum):

The research shall study women in and around the Greater London area who are suffering from distress – either as a primary complaint, or associated with another condition – that are seeking the services of a herbalist who practices WHM. By using the theme of narrative, the study shall use qualitative research methods (particularly semi-structured interviews) at two set points in time, to consider how distressed women perceive and experience their distress, their reasons for using WHM, what contribution the women perceive the consultation and treatment with WHM may or may not make to their well-being, and whether these experiences change over time.

The research shall analyse the narratives using interpretative phenomenological analysis (IPA) as IPA is an inductive approach where participants are experts on their own experiences; so the participants are to be recruited because of their expertise in the phenomenon being explored. IPA shall then be used to give the researcher's interpretation of the results, thereby attempting to gain an insider perspective whilst acknowledging that the researcher is the primary analytical instrument. Being explicit of this fact will allow for a more reflexive process in which the interviewer can consider how their own preconceptions and prejudices may be affecting the data extracted from the interviews.

**2.3.** What are the specific aims of the study? (250 words maximum):

**Research Aims**

- Determine how women define and narrative their distress.
- Discover which factors influence emotionally distressed women’s decision to consult with a herbalist practicing WHM.
- Investigate what contribution the women perceive the consultation and treatment with WHM may or may not make to their well-being.
- Ascertain whether these perceptions and experience of distress, well-being, and WHM, change over time.
- Consider implications of the findings on the way in which women utilise WHM, with particular reference to distress and well-being.
- Provide recommendations on the role (if any) of WHM for the management and self-management of distressed women.
- Publish an outline of the research in a journal concerned with WHM in order that the findings might help inform practice.

**2.4.** Please outline the design and methodology of your study [attach extra information as necessary] (250 words maximum in total):

**Sampling**

**Practitioners:** A variation sample of up to 20 herbal practices shall be recruited via a short interview with herbalists.

**Patients:** The herbalists shall introduce the researcher to a total of 25-30 female patients around the time of their first consultation. An information sheet shall be issued to the patients by the herbalist. Sampling for the interviews will be purposive in order to achieve diversity of participants, with the inclusion criteria being women aged eighteen years or above, contacting the herbalist due to conditions associated with emotional distress or with a condition that has known comorbidity with distress.

**Interviews**

The research intends to use one-to-one, semi-structured narrative interviews at two points in time – one within approximately a fortnight of the participant commencing herbal treatment, and one approximately six months later. The interviews shall last 1-2 hours, and shall be digitally audio-recorded for the purposes of transcription and analysis. The interviews shall take place at a location that is convenient for the participant. Questions shall be used to initiate patient narratives based around the research question. Themes emerging from the narratives will guide subsequent interviews.

**Data Analysis**

The data shall be transcribed by a professional transcriber (once a confidentiality agreement has been signed), and sent to the participants for verification. The data will then be analysed using IPA. Findings will be written up for a PhD thesis, where it is hoped to make recommendations on how best to meet the needs of distressed women seeking to use WHM.

## 2.5 Timescales

Start Date (DD/MM/YY): 01/10/11

Estimated duration of work: Four years

<b>Section 3</b>				
<b>RISK OF HARM</b>				
		<b>Yes</b>	<b>No</b>	<b>N/A</b>
<b>1</b>	Is pain or more than mild discomfort likely to result from the study		<b>x</b>	
<b>2</b>	Could the study induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	<b>x</b>		
<b>3</b>	Will the study involve prolonged or repetitive testing?		<b>x</b>	
<b>4</b>	Will the study involve raising sensitive topics (e.g. sexual activity, drug use, revelation of medical history and/or illegal activities)	<b>x</b>		
<b>5</b>	Does your work involve any material containing human cells (e.g. blood, urine, saliva, body tissues) from living or deceased persons? (Such work must take account of the Human Tissue Act).		<b>x</b>	
<b>6</b>	Will DNA samples be taken from human participants? (Such work must take account of the Human Tissue Act).		<b>x</b>	
<b>7</b>	Does your study raise any issues of personal safety for you or other researchers involved in the project? (Especially relevant if taking place outside working hours or off University premises)	<b>x</b>		
<b>8</b>	Does your study involve deliberately misleading the participants (e.g. deception, covert observation)		<b>x</b>	
<b>9</b>	Does your work involve administration of a non-food substance in abnormally large amounts or one that is known to cause allergic reaction(s) in some people?		<b>x</b>	
<b>PARTICIPANTS</b>				
<b>Does your work involve any of the following:</b>				
		<b>Yes</b>	<b>No</b>	<b>N/A</b>
<b>10</b>	Human participants in health settings (e.g. private patients in private clinics)	<b>x</b>		
<b>11</b>	Human participants in health settings (e.g. NHS patients in NHS clinics/hospitals)		<b>x</b>	
<b>12</b>	Human participants who are in the care of a social worker		<b>x</b>	
<b>13</b>	Expectant or new mothers	<b>x</b>		
<b>14</b>	Refugees		<b>x</b>	
<b>15</b>	Minors (under the age of 18 years old)		<b>x</b>	
<b>16</b>	Participants in custody (e.g. prisoners or arrestees)		<b>x</b>	
<b>17</b>	Participants with impaired mental capacity (e.g. severe mental illness, brain damaged, sectioned under Mental Health Act, lowered or reduced sense of consciousness)		<b>x</b>	

INFORMATION TO PARTICIPANTS				
		Yes	No	N/A
18	Will you provide participants with a Participant Information Sheet prior to obtaining consent which can be taken away by the participant?	x		
19	Will you describe the procedures to participants in advance, so that they are informed about what to expect?	x		
20	Will you obtain consent for participation? (normally written)	x		
21	Will you tell participants that they may withdraw from the research at any time and for any reason?	x		
22	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	x		
23	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	x		
24	Will you debrief participants at the end of their participation (e.g. give them a brief explanation of their study)?	x		

**If you have answered NO to questions 1-17 (inclusive) and YES to questions 18-24 (inclusive), you do not need to complete the Full Research Ethics Approval Form (Part B). Please keep this form for your records.**

**If you have answered YES to any of the questions 1-17 (inclusive) or NO to any of the questions 18-24 the Full Research Ethics Approval Form (Part B) MUST be completed.**

**If you are applying for external Ethical Approval, please send a copy of the Conditions/Approvals letter to Huzma Kelly, Secretary Research Ethics sub Committee; Senior Research Officer (Policy and Governance), Academic Services Department, 101 New Cavendish Street, London, W1W 6XH.**

## PART B

**N.B.** Please ensure you have completed the Cover Sheet and Part A, and check that you need to complete Part B before proceeding with further details below.

### Section 4 – Risk Assessment and Hazard Analysis

**4.1** Describe any potential hazards which may cause harm or distress to the participants, psychologically or physically, in the study and/or any potential harm to the community, environment etc:

The herbalists shall be interviewed to gain stakeholder information for the research, to discover their approaches to treating distressed women, and to confirm their willingness to be considered as gatekeepers. Whilst it is unlikely that the study will cause them any psychological distress, talking about their practise and treatment of distress has the potential to be stressful. However, any risk is anticipated, and shall be managed as outlined in section 4.2. It is not anticipated that there shall be any risk of physical harm.

The herbalists' patients that meet the inclusion criteria of the study will be invited to take part in the main interview stage of the research. Discussion of topics such as their previous medical history, experience of distress, and why they are using herbal medicine have the potential to lead to some distress on the part of the individual participant, but these risks are anticipated and will be managed as outlined in section 4.2. It is not anticipated that there shall be any risk of physical harm.

It should also be noted that this current study raises personal safety issues with regard to the interviewer, as interviews may take place in participants' homes. There is also the possibility that talking to interviewees about potentially upsetting subjects may lead to the interviewer undergoing some emotional distress. These risks are also anticipated, and will be managed as outlined in section 4.2.

It is not anticipated that there shall be any potential to cause harm to the wider community or the environment.

**4.2** Give details of any measures taken to reduce the risk of such harm or distress to the participants, psychologically or physically, in the study (e.g. COSHH or other risk assessment forms – any such forms should be attached to this application form):

In order to minimise the potential risk of causing psychological distress to the participants or researcher, the researcher shall:

- Follow the school ethics guidelines and, accordingly, provide all participants with a participation information sheet and consent form, before interviews commence.
- Only interview participants in their homes if there is no other suitable venue available.
- Have an enhanced Criminal Records Bureau check in place (already obtained).
- Be first aid trained (qualification already gained) – no physical harm to the interviewees is anticipated, but is a precaution as the interview may occur with no other medically trained persons present.
- Follow the Researcher Safety Protocol guidelines as set out by the Social Research

Association. This includes leaving the interviewer's itinerary and appointment times with a dedicated colleague, carrying a mobile phone at all times, and confirming the interviewer's safety with the dedicated colleague at the end of the interview.

- Utilise a personal safety device (such as those provided by *Skyguard*) to ensure personal safety whilst working alone.
- Provide all participants with contact details for a variety of support groups, and free and low-cost counselling options, at the start of the interview process (attached).
- Be trained in qualitative interview techniques prior to any interviews taking place (booked with The University of Oxford Health Experiences Research Group).
- Maintain sensitivity and respect for participants' narratives.
- Inform participants that they can stop the interviews at any time without question or penalty, and can also withdraw some (or all) of their data at any point up to publication of the thesis without question or penalty.
- Observe the participants for signals of distress during their interview and then enquire about any such distress.
- Contact the participants a few days after the interview to thank them for their participation (and also check if the interview has raised any concerns).
- Provide the patients with a transcript of the interview for checking; this will also provide another opportunity to check on the patients.
- Be aware of his own emotional well-being. Any emotional issues arising from the interviews shall be discussed with his supervisors (Professor Damien Ridge is a trained counselor and psychoanalyst) and/or taken up with the university's PhD tutor (Miriam Dwek), or student counseling service.

**4.3** Outline the extent to which these risks are balanced against the potential benefits to education and/or the contribution to scientific knowledge:

The risk of inadvertently causing distress is relatively low, but cannot be ruled out as the research question involves interviewing distressed women. However, due to the nature of the research question, the need to find patient narratives means that discussion of potentially distressing areas is unavoidable.

The potential benefits outweigh this risk, because despite the financial and emotional costs of distress (NICE, 2011; Chonody & Siebert, 2008), the reporting that women suffer from emotional distress more than men (NHS Information Centre, 2007; Essau *et al*, 2010), and the suggestion that herbal medicine has the potential to be of use in conditions associated with distress (Sarris *et al*, 2011), there is currently no research into the usage of western herbal medicine (WHM) and WHM practice for the treatment of distressed women. This study proposes to provide recommendations on the role (if any) of WHM for the management and self-management of distressed women, and lead to the publishing of an outline of the research in a journal concerned with WHM in order that the findings might help inform practice.

The study also intends to add to the debate into the ways in which women experience distress. Although it is reported that women suffer from emotional distress more than men, it has been argued that there is little or no difference in the incidence of common mental disorders between men and women, but it is their *experience* of distress which is different (Danielsson & Johansson, 2005; Danielsson *et al*, 2009; Gibson, 2011). This has led to the suggestion that some symptoms in both women *and* men may be neglected if they do not match the gendered assumptions of the medical practitioner (Ussher, 2010; Annandale & Hammarström, 2010).

**4.4** What criteria will be employed for deciding the end point at which the study will stop because of unjustifiable further risk of harm or distress, psychologically or physically, to the participants?

The participants will be aware that they can stop the interview and/or withdraw from the study at any time without question or penalty.

If the participant is becoming noticeably distressed, they will immediately be given the opportunity to stop the interview at that point, and withdraw completely from the study if they wish. If the participant suddenly becomes too distressed to continue with the interview, the interviewer shall stop the interview and withdraw them completely from the study.

Any case of distress for the participants shall be discussed with the research supervisors. If the supervisors decide that study is causing too much distress for the participants, then the decision shall be taken to halt the study.

**4.5** What monitoring mechanisms will be in place to decide when some or all participants should be withdrawn from the study i.e. explain what your procedures and criteria for detecting and addressing these issues are (such as a half-way point check)? Also what procedures are to be used, and subsequent observations made, on participants for the purpose of detecting any harm or distress, psychologically or physically, to the participants arising from the study?

See Sections 4.2 & 4.4

Having carried out the training in interview techniques, the interviewer shall continually monitor the participants throughout the interview process.

The participants shall have contact details for the researcher, so that if they feel distressed at any point throughout the research process, they can discuss this with the researcher, who shall then discuss any issues with his supervisors. If they wish to do so, participants can immediately withdraw from the study without question or penalty, with the option of withdrawing some (or all) of their data.

## **Section 5 – Informed Consent of Participants, Recruitment of Participants**

**5.1** It is an expectation that written consent will always be obtained from participants. Have you obtained or will you be obtaining written consent?

X Yes (Please attach a consent form which will be used for your study, failure to do so may result in a delay in consideration by the UREC)

No (if you think this does not apply please justify your reasons)

**5.2 Is there a Participant Information Sheet?**

Yes (Please attach a Participant Information Sheet which will be used for your study, failure to do so may result in a delay in consideration by the UREC)

No (if you think this does not apply please justify your reasons)

**5.3 How and where will you make contact with the participant(s) in order to recruit them?**

The herbalists shall act as gatekeepers and shall be directly approached with an information pack about the study (a covering letter is attached). After a period of time (of at least 24 hours) the herbalists shall be contacted to see if they have read & understood the information pack, have any questions about the study, and will then be asked to fill in a consent form to agree to take part in a short interview (to ensure a maximum variation sample of herbal practice), and also to allow access to their patients.

The potential participants for the patient interviews shall be contacted via their herbalist, who shall give them a participation information sheet at the time of their first consultation. The patients shall be given time (at least 24 hours) to read the information sheet, and shall also be given the researcher's contact details in order to have the opportunity to ask any questions they may have, and/or to express an interest in taking part in the research. Once contact with the researcher has been made and it has been established why the patient is consulting with a herbalist, they shall then be invited to attend an interview, provided that they are willing to take part and they meet the inclusion criteria of the study. Before the interview stage actually commences, the researcher shall confirm that the participant has read and understood the information sheet. The participant shall then be asked to sign a participant informed consent form. As the patient's educational background will not be known, both the participant information sheet and consent form for patients have been devised using The British Dyslexia Association's dyslexia style guide.

**5.4 How will consent be obtained and stored?**

Please note, storage at home or on personal lap tops may be considered insufficient to the requirements of the Committee.

Consent will be obtained via two written consent forms, signed by the participant and the researcher, after confirmation by the researcher that the participant has read and understood the participation information sheet. One copy of the consent form will be for the participant to keep, the other form will be stored in a locked filing cabinet at the researcher's premises. The filing cabinet is already used to hold confidential patient information, and is only accessible by the researcher.

**5.5.** Is parent/guardian consent required for any participants less than 18 years of age?

Yes

No

**5.6.** How will this be obtained?

Being less than 18 years of age will exclude participants from this study.

## **Section 6 –Expenses and Conflict of Interest**

**6.1.** Will expenses be paid to participants?

Yes (If yes, how much?)

A maximum allowance of up to £20 to cover the costs of travel, refreshments and child-care for participating in the research will be paid to the patients if required.

A maximum allowance of up to £20 may be offered to the herbalists to cover the cost of hire of a room at their clinic, if this is where the participant wishes to be interviewed.

No

**6.2.** Will a reward separate from expenses be made to participants?

Yes (If yes, please give more details)

No

**6.3.** Will any of the participants be known to you? If so please indicate your relationship with them?

Yes (If yes, please give more details).

Some of the herbalists that act as gatekeepers may be known to the researcher in a professional capacity. However, the patients will not be known to the researcher.

No

**Section 7 – Confidentiality of Information, Data Protection and Freedom of Information**

**7.1** Who will you be sharing information with? Please tick the relevant box(s):

	Yes	No	N/A
Others, please specify:		x	
Others on the project	x		
External collaborators		x	
Commercial organisations and funding councils		x	
Participants	x		
Research Councils/Funding bodies		x	
Charities		x	
Sponsors		x	
Other Higher Education Institute		x	

Other please specify: N/A

**7.2** Will the study include:

Named participants

x Participants whose names have been separately coded

Anonymous participants

**7.3 – How will you store and make secure the data and/or material of human origin collected in the study?**

Coded data files and any hand written field notes will be stored in a locked filing cabinet at the researcher’s premises, accessible only by the researcher.

**7.4 If the investigation involves storage of computerised data which might enable a participant to be identified, please name the person in charge of computer system security for the study?**

The researcher will be responsible for computer system security for the study. The interview data shall be encrypted before being sent for transcription, with the resultant transcripts “cleaned” of any identifying data. The transcripts shall be password protected and worked with on a university desktop or laptop computer. Password protected data will also be digitally stored on the university’s “H” drive, and on an external hard drive that will be stored in a locked filing cabinet at the researcher’s premises, accessible only by the researcher.

The cleaned transcripts shall be coded, but the coding shall be separate to any coding of personal data so that it will be impossible to match participants to transcripts if they were to fall into the wrong hands.

**7.5 Does the study include use of, or planned publication of, photographs or videos either of individuals or any human material?**

Human material            Yes  No

Individuals                Yes  No

If yes to either of these, please provide a copy of the consent form which participants will be asked to sign for this purpose (please attach a copy to your application).

**Section 8 – Funding and links with external organisations**

**8.1 If your work involves research which includes working with or being facilitated by those external to the University, please provide details of any organisations/individuals involved**

Contact Name	Contact Name
Address	Address
Telephone Number	Telephone Number
Please provide a copy of any agreement between the organisations/individuals (this should be attached to your application form, failure to do so may delay your application for approval, as it is	

good practice to receive agreements with facilitators/collaborators in advance).

**8.2** Is this study initiated/sponsored?

Yes

If yes, give the **name** of the organisation/individual: *Make My Day Better* charity.

What benefits will you receive, if any, for conducting this research by the organisation or individual named above, please state:

PhD scholarship

### Section 9 – Insurance

(If uncertain about answering any questions in this section, please contact the University's insurance officer; Procurement Manager Andrew Rance)

**9.1** Are manufacturers of any of the products used (for testing) providing insurance cover?

Yes (If yes, please enclose a letter confirming insurance cover, including the names of all covered)

No

N/A

**9.2** Are all of the investigators/researchers either employees or students of the University of Westminster?

Yes

No

If no, please provide evidence of insurance cover, including:

- list of all people involved in the investigation
- details of the form this cover will take
- 

**9.3** Does the investigation involve the use of equipment or non-food substances?

Yes

No

If yes, please give details of *manufacturer's indemnity*:

**9.4** Does the investigation involve the use of equipment or non-food substances which are manufactured on site but are not covered by insurance?

Yes

No

If yes, appropriate insurance cover must be arranged and written confirmation of such cover must be attached to this form.

**Section 10 – Declarations. *This Section should be read carefully and must be completed by all applicants***

*All students must ensure that the supervisor signs the declaration at Section 10.3*

*All staff must ensure that their Dean of School, or School Research Director (or nominee), as appropriate, signs the declaration at Section 10.3*

**10.1 Data Protection Act and Freedom of Information Act**

**I understand that**

- the information provided on this form is subject to the Data Protection Act 1998 and the Freedom of Information Act 2000.
- this form may be disclosed as a result of a Data Protection Act Subject Access Request
- this form may be disclosed as a result of a request for information under the Freedom of Information Act 2000.
- I must ensure that any subjects selected for study are made aware of their rights and our obligations under the Data Protection Act 1998.
- I must ensure that sponsors are made aware that the University of Westminster is subject to the Freedom of Information Act 2000.

**10.2 Applicant declaration**

The information I have given on this form is true and to the best of my knowledge correct:

Name of Applicant: A.J. Yates

Signature

Date: 14<sup>th</sup> March 2012

It is the responsibility of the Principal Investigator/researcher to refer to the University of Westminster 'Code of Practice Governing the Ethical Conduct Research' and to consult their Supervisor/Dean of School/ School Research Director

**10.3 Supervisor/Dean of School/ School Research Director (or nominee) declaration**

In accordance with the University's **Code of Practice Governing the Ethical Conduct of Research**, I agree that

(a) the applicant named in 1.2 and 10.2 above should submit their proposal to the University Research Ethics Committee (UREC) for consideration

(b) The information given on this form is true and to the best of my knowledge correct:

Name of Supervisor/~~Dean of School/ School~~  
Research Director: Julia Green

Signature

Date: 14<sup>th</sup> March 2012

**Send the completed form to:**

**Huzma Kelly**

**Senior Research Officer (Policy and Governance)**

**Academic Services Department**

**Research Office**

**101 Cavendish Street**

**University of Westminster**

**London**

**W1W 6XH**

**Email:** [h.kelly01@westminster.ac.uk](mailto:h.kelly01@westminster.ac.uk)

## **GLOSSARY**

**A&E:** Accident & Emergency – name given to a department within NHS hospitals in the UK that initially deal with patients who have physical trauma or a medical emergency.

**BNT:** Basic Needs Theory – a sub-theory of self-determination theory, which contends that humans have three basic innate needs: autonomy, competence, and relatedness, and that meeting these needs is essential to well-being.

**CAM:** Complementary and Alternative Medicine – an umbrella term commonly used to describe healthcare practices that fall outside mainstream (biomedical) health services.

**CHM:** Chinese Herbal Medicine – a branch of TCM (q.v.) that uses crude plant material as a base for its medicines within traditional Chinese concepts of anatomy, physiology and pathology.

**Chronic fatigue syndrome** – ongoing medical condition of unknown origin which causes persistent fatigue, with possible periods of (relative) remission and relapse. Also known as ME (q.v.)

**COPD:** Chronic Obstructive Pulmonary Disease – a collection of ongoing lung diseases including chronic bronchitis, and emphysema.

**CPP:** College of Practitioners of Phytotherapy – the second largest professional body of herbalists in the UK.

**EHTPA:** The European Herbal & Traditional Medicine Practitioners Association – an umbrella organisation for European herbal professional bodies, which focuses on the development of standards and training, and strengthening the identity of the profession.

GAD: generalised anxiety disorder – an on-going condition in which the individual feels anxious about a wide range of situations and issues, rather than one specific event.

Gatekeeper: an individual or individuals who facilitate researcher access to the researcher's desired group of participants.

GDP: gross domestic product – a standard measure of the value of final goods and services produced by a country during a set period minus the value of imports.

GP: general practitioner – a doctor (in the UK usually employed by the NHS) who looks after the health of people in their local community, and so deals with a wide range of health problems or can refer on to more specialist practitioners.

IBS: irritable bowel syndrome – ongoing medical condition of unknown origin thought to be linked to increased sensitivity of the gut, which can cause bouts of bloating, abdominal cramps, diarrhoea and/or constipation.

Little Miss<sup>TM</sup>: a series of characters (along with Mr. Men<sup>TM</sup>) originally created by the British author Roger Hargreaves and now owned by Sanrio Company Ltd. Each character has a personality and physical attributes based on their name.

ME: myalgic encephalomyelitis – another term for CFS (q.v.) indicating the probability of individuals having muscle pain and/or inflammation of the brain and spinal cord.

Neoliberalism: a term primarily associated with a resurgence of economic ideas in the 1970s and 1980s that advocated a laissez-faire approach by governments in order to encourage free trade. The term has expanded to include other areas of society: neoliberal social policy prioritises personal responsibility for one's own circumstances.

NHS: National Health Service – the main provider of healthcare within the UK which provides treatment mainly based on a biomedical paradigm, and is largely free at the point of delivery as it is paid for via government taxation.

NIMH: National Institute of Medical Herbalists – the largest UK based professional body of herbalists, which was originally formed in 1864 and claims to be the oldest professional body of herbal practitioners in the world.

ONS: Office for National Statistics – the UK's largest independent producer of official statistics.

OTC: Over the Counter – used as a way of describing herbs, supplements, and other medicines that are purchased directly by the consumer rather than obtained via a practitioner.

Phytotherapy: a term devised in the 20<sup>th</sup> century to describe herbal medicine that claims to combine traditional herbal practice with a scientific understanding of the physiological actions of herbs.

PMS: pre-menstrual syndrome – a range of physical, psychological and behavioural symptoms that can occur in the two weeks before a woman's monthly period.

Somatisation: the cultural patterning of psychological and social distress into mainly physical signs and symptoms.

SWB: subjective well-being – an experience of well-being based on the individual's perception relating to the presence of pleasant emotion, the relative absence of unpleasant emotion, and personal judgements about satisfaction.

Systemic lupus erythematosus – an autoimmune disorder that can affect different systems of the body and so lead to a variety of symptoms among individuals, more commonly fatigue, joint pain, and rashes (including photosensitivity).

TCM: Traditional Chinese Medicine – a broad base of traditional medical practices sharing common concepts formed in China, of which CHM (q.v.) is one part.

Tincture: an ethanol/water mix which is macerated with plant material in order to obtain a concentrated liquid herbal extract.

UK: United Kingdom – sovereign state comprising of the island of Great Britain, Northern Ireland, and many smaller surrounding islands.

Vitalism: a concept used in WHM whereby herbal medicines are used to stimulate the human body's own powers of self-defence and self-regeneration.

WHM: Western Herbal Medicine – historically, the traditional form of medicine in the UK that uses crude plant material as a base for its medicines.

WHP: Western Herbal Practice – the process of providing western herbal medicine by practitioners, from consultation, through to diagnosis, prescribing of herbs, and other advice.