Existential Distress Among Parents of Children with Cancer or Chronic Illness: Screening and a Meaning-Based Intervention

By

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I declare that this thesis is my own account of my research and contains as its main content work which has not previously been submitted for a degree at any tertiary education institution.

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ABSTRACT

Parents of children with cancer or a chronic illness not only face practical challenges in the management of their child’s condition, but also experience intense psychological and existential distress in the period after diagnosis that can have detrimental effects in the long run if left undetected. To date, neither the option of using an ultra-short screening tool for measuring parents’ distress, nor a meaning-based intervention to reduce parents’ distress, have been investigated. The current research comprised two studies. Study 1 aimed to evaluate the accuracy of an adaptation of Mitchell et al.’s (2010) Emotional and Help Thermometers in detecting the level of distress. Mitchell et al.’s instrument consisted of four emotion thermometers – Distress, Anxiety, Depression, Anger – and a Need Help thermometer. Our adaptation added the “Crushed Universe” thermometer designed to measure existential distress. All six thermometers were compared against a battery of assessment tools that measure depression, anxiety (Depression, Anxiety and Stress Scale-21 items), loss of meaning (Sense of Coherence-13 items), and post-traumatic stress (Impact of Events Scale-Revised). Participants were main caregivers whose children were diagnosed with cancer or chronic illness (n = 172). The thermometers had good diagnostic accuracy in predicting various forms of distress, and the Crushed Universe Thermometer was able to predict parents’ sense of meaningfulness and post-traumatic stress.
symptoms. The Crushed Universe Thermometer was also the optimal thermometer in predicting depression, anxiety, and stress. Study 2 aimed to evaluate the applicability and efficacy of a meaning-based intervention in reducing parents’ distress in relation to the context, particularly meaning-related distress. Participants were two mothers, one with a child with cancer, the other with a chronic illness. In both cases, contextual stressors influenced participants’ distress more than the child’s illness. Together, the results suggest that existential distress is a significant component of psychological distress for parents of chronically-ill children.
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Chapter 1: Introduction

Paediatric cancer and chronic illnesses affect a significant number of children globally and in Singapore. Globally, 215,000 children below 14 years old, and 85,000 children between 15 and 19 years old are diagnosed with cancer (Auste, 2017). In Singapore, about 90 to 100 (about 1%) of children and adolescents below 15 years old are diagnosed with cancer each year (KK Women's and Children's Hospital, KKH, 2014). In terms of the most common cancer type, global and Singapore data coincide; leukaemia is the most common cancer type, followed by brain tumours and lymphomas (Kaatsch, 2010; KKH, 2014). On the other hand, the picture of paediatric chronic illness is not as clear. The number of children diagnosed with chronic illness ranges from five to 1,100 per 10,000 live births, depending on the type of chronic illness, among which, premature births has the highest incidence rates, occurring at 11.1% of live births worldwide (Blencowe et al., 2012). These illnesses require long-term and often invasive treatments (e.g., chemotherapy, organ transplantations, blood transfusions, long-term care, etc.). Apart from the financial burden these treatments pose on parents, they also experience emotional and psychological burdens when witnessing their child experiencing pain and discomfort from the treatments. In the long run, a significant portion of them develop mental health difficulties associated with caring for their children. The current thesis will discuss these burdens in detail, with the aim of emphasising the importance of distress screening among parents, and the feasibility of implementing a psychological intervention to reduce their distress.

1.1 Distress and Mental Health

The diagnosis of cancer or a chronic illness in a child can produce multiple forms of distress for parents. Reports of post-traumatic stress disorder (PTSD), depression, and anxiety
are commonly reported among parents (Cabizuca, Marques-Portella, Mendlowicz, Coutinho, & Figueira, 2009; Santacroce, 2003; Vrijmoet-Wiersma et al., 2008).

The term “distress”, according to the National Comprehensive Cancer Network (NCCN), refers to the:

“…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.” (NCCN, 2014)

This definition highlights the importance of viewing parents’ internal challenges from the perspective of different lenses.

Among the various perspectives is an oft-investigated one, the mental health perspective, due to its prevalence and potential long-reaching consequences. Another perspective is the resource and coping perspective, where it is suggested that parents’ reported mental health problems are linked to greater resource depletion than gain, and unhelpful or inappropriate coping strategies (Hobfoll, 1989; Katz, 2002). The last perspective is the meaning-making perspective, which relates to parents’ struggle in attempting to adjust to the changed world following the child’s diagnosis (Pelchat, Lefebvre, & Levert, 2007).

1.1.1 Mental Health Perspective

There is consistent evidence of mental health problems in parents of children with cancer, and other chronic illnesses (Dahlquist, Czyzewski, & Jones, 1996; Fauman et al., 2011; Pelchat
et al., 2007), particularly for parents who had recently received the diagnoses. The constructs commonly investigated by researchers are depressive symptoms, anxiety, and PTSS.

1.1.1A Depression

Parents of children with cancer report higher levels of depressive symptoms than parents of healthy children. These symptoms are maintained if parents initially react to the stressful event of their child’s diagnosis with moderate to severe levels of distress (Manne et al., 1996; Noll et al., 1995).

Factors contributing to the maintenance of depression in parents of ill children include child behavioural problems, lack of spousal assistance, and increased or shifts in responsibility in the household (Manne et al., 1996; Pelchat et al., 2007). The impact of these factors is that parents’ coping skills are tested as their physical, emotional, and cognitive resources are stretched, leading to fatigue and possibly burnout (Lindström, Åman, & Norberg, 2010; Norberg, 2010). Research on the effects of fatigue has linked it with reduced concentration, and impaired judgement due to limitations in information processing (van der Linden, Frese, & Meijman, 2003; van der Linden, Frese, & Sonnentag, 2003). With continued exposure to such an environment, individuals’ beliefs about the world, the situation, and their selves, may be adversely affected (Greening & Stoppelbein, 2007). In a study of maternal depression and treatment adherence to asthma therapy, high levels of depressive symptoms in mothers from lower socio-economic backgrounds were related to lower asthma treatment adherence, more negative beliefs about the illness, and low levels of self-efficacy regarding asthma treatment (Bartlett et al., 2004). The authors suggested that depression may compromise mothers’ ability to care for their children.
1.1.1B Anxiety

Anxiety is generally highest around the time of diagnosis, and reduces to near normal levels around five years’ post-diagnosis (Vrijmoet-Wiersma et al., 2008; Wade, Taylor, et al., 2006). The intensity of the anxiety symptoms in parents at six months’ post-diagnosis predicts later psychosocial functioning. Anxiety may be due to parents’ fear of their child’s future, as well as the repercussions of the diagnosis. For parents of children with cancer, a notable concern of many parents is the fear that their child will die, or that the cancer will recur (Edwards & Clarke, 2004). Highly anxious parents are also at higher risk of developing PTSS (Pai et al., 2007).

1.1.1C Post-traumatic stress symptoms (PTSS) and post-traumatic stress disorder (PTSD)

PTSS is common in parents of children with chronic and/or life-threatening illnesses. Among the symptoms, re-experiencing the event and hyper-arousal were most often endorsed, especially if parents had faced similar losses in the past (Granek et al., 2014; Pöder, Ljungman, & von Essen, 2008).

Although both PTSS and PTSD are reported by parents, a higher incidence of PTSS seems to be reported than PTSD (Kazak et al., 2004). While at least one parent met criteria for re-experiencing in 98.7% of 150 families in Kazak et al.’s study, only 20% of these families had at least one parent qualify for a diagnosis of PTSD. The results imply that parents’ distress is expressed on a continuum, and though they may not meet full criteria for PTSD, they experience symptom clusters of PTSD that may be distressing for them. Therefore, it is important to consider parents who report distress but do not present with all the symptoms required for a diagnosis of PTSD. Hence, a method for screening different levels of distress is necessary to provide the healthcare team with a multi-dimensional view of parents’ distress.
PTSS or PTSD develops via several mechanisms, such as characteristics of the situation in which the cancer was diagnosed, and parents’ appraisal of their child’s diagnosis and implications as threatening (Balluffi et al., 2004; Ehlers & Clark, 2000). Parents who continue to appraise their situation as threatening and highly distressing are more likely to develop PTSD. This is more likely to be observed in parents who have a history of unresolved, traumatic, or unexpected loss, and may manifest itself in generalized hyper-vigilance about the health of other family members, or an avoidance of the implications of the diagnosis such as the severity of the child’s condition or the treatment procedures (Granek et al., 2014).

1.1.1D Overall psychological distress

Gender differences in levels of distress are also present among parents of ill children. Mothers tend to report higher levels of depressive symptoms than fathers (Manne et al., 1996; Pelchat et al., 2007). Although the gender differences can partially be attributed to higher rates of depression in women than men (Kurzthaler & Sperner-Unterweger, 2009), other explanations could include mothers having to endure greater stress from caring for the child and the emotional effects of the child’s disabilities due to their proximity of care to the child, and the different roles that mothers and fathers take in caring for the sick child (Glasscoe & Smith, 2011; Tehee, Honan, & Hevey, 2009).

Nonetheless, fathers also report difficulties of a qualitatively different nature. In a longitudinal study of parents living with paediatric cancer, fathers tended to report difficulties balancing work and care for the child, as well as providing emotional support for their spouses, whereas mothers reported difficulties associated with managing the child’s behavioural problems, and structuring and planning activities for the family (Svavarsdottir, 2005). Pelchat et al. (2007) and Chesler and Parry (2001) attributed these gender differences to gender identity as prescribed
by social norms and personal interpretations of gender roles. The findings on gender differences highlight a fundamental issue that has been overlooked by the mental health perspective.

Contributing another level of complexity to understanding parents’ distress is the role of culture. While there is a sparsity of literature surrounding cultural influences on parents’ distress and coping in the face of serious paediatric illness, the general consensus is that across cultures, parents of ill children report higher levels of distress than parents of healthy children. Nonetheless, some differences do emerge, particularly in terms of illness representations (“attributions and beliefs regarding the aetiology, treatment, and clinical course of a disorder that are typically embedded within a context”; Gray, Szulczewski, Regan, Williams, & Pai, 2014, p. 254), style of communicating (verbal and non-verbal) both about death or the illness, and parents’ personal meanings of pain and suffering, illness, dying, and death (Wiener, McConnell, Latella, & Ludi, 2013). For example, Banerjee et al. (2011) studied the cultural beliefs and coping strategies of South Asian immigrant parents to Canada, regarding their child’s cancer diagnosis. The authors found that South Asian parents, having had less exposure to paediatric cancer, viewed it as incurable, rare, unspeakable, and as an illness to be understood through religion, yet also having a strong sense of trust in their healthcare professionals. Their coping strategies reflected their beliefs, in their perseverance in engaging in religious practices and prayers, trusting their healthcare professionals, and seeking support from fellow South Asian parents whose children had cancer. Similarly, in a questionnaire study of mothers of young children with chronic illnesses, Krulik et al. (1999) found cultural differences relating to mothers’ difficulties with sense of competency, role restriction, and depression. Specifically, compared to mothers from the United States, mothers in Japan had fewer problems of sense of competency, but more difficulties with role restriction and depression. The authors postulated that difficulties in role
restrictions among Japanese mothers was due to disproportionate shifting role of mothers in juggling home and workplace against little change in fathers’ involvement in the family. These studies suggest that culture may provide a broad framework that influences how parents react to their child’s diagnosis and adjust to it.

Perhaps more importantly, however, the findings on gender and cultural differences highlight a fundamental issue that has been overlooked by the mental health perspective. The psychological distress parents face in response to their child’s illness is more complex than merely distress related to treatment management; a poorer prognosis of their child’s illness might be associated with higher existential distress due to parents’ fears of losing their child, which might correspond with parents’ ascribed meanings of their identities as parents and the death of a child within their cultural context.

1.1.2 Resources and Coping

The previous section highlighted that the demands of caring for a child with cancer or chronic illness places a lot of stress on parents. These demands can be broadly categorised into practical, emotional and cognitive demands. Practical demands include the increase in responsibilities for parents – to make important treatment decisions that can impact the child’s life and future, financial arrangements, and juggling the care of the ill child with the needs of other children in the family. Emotional and cognitive demands, on the other hand, revolve around parents trying to understand and make sense of their child’s illness, reconciling the implications of their child’s illness with prior beliefs of their world, while also managing their distress, fear and anxiety towards theirs and the child’s future.
The emotional and cognitive demands parents face will be considered in this review. The theoretical frameworks that will be considered are Antonovsky’s Sense of Coherence Theory (1979), Hobfoll’s Conservation of Resources Theory (1989), and Lazarus and Folkman’s Transactional Theory of Stress and Coping (1984). These frameworks underpin the concepts of stress, resources, and coping that parents experience when caring for their ill children.

According to Lazarus and Folkman (1984), stress results when the demands of the situation outweigh the resources available to the individual. Successful coping with a situation occurs when there is a fit between the coping strategy adopted, the nature of the situation, and resources that are available and appropriate for the situation. Thus, based on Lazarus and Folkman’s (1984) model of stress and coping, it seems likely, in general, that people with more resources would be expected to manage stress better. Resources such as education, socioeconomic status, size and quality of support networks and personal qualities such as optimism are some of the common factors to well-being (Yali & Lobel, 2002).

Resources are seen as the basis on which individuals’ outlook in life is formed and thereafter maximised (Antonovsky, 1979, 1987), as primary sources of motivation and well-being (Hobfoll, 1989), and as a helping hand in times of stress (Lazarus & Folkman, 1984). Thus, resources are instrumental in providing a base for individuals to navigate their lives. However, while the theories acknowledge the importance of resources, they also have different perspectives on the roles that resources play. Antonovsky (1979, 1987) viewed resources as the impetus to moving individuals forward in life. This means that the quality and type of resources, and the life experiences that the resources lead individuals to, shape their general orientation to life. Hobfoll (1989), on the other hand, views resources as being central to the maintenance of psychological well-being; thus, the more resources individuals have, the wider their possible
repertoire of resource selection, the more buffered they are from stress. Lastly, Lazarus and Folkman (1984) view resources as the foundation of coping, and their ability to influence coping, which in turn mediates stress. These three models, while presenting slightly different perspectives of resources, nonetheless come together to provide a comprehensive picture of how resources, coping, and adjustment to stress play reciprocal roles in interacting and influencing each other. Thus, using the three models discussed above, the next section discusses the role of resources, the relationship between resources and coping, and the relationship between coping and adjustment to stress. Given the centrality of resources to adjustment and stress in Hobfoll’s Conservation of Resources (COR) Theory, the section on the relationship between coping and adjustment to stress pertaining to the theory will be discussed between the role of resources, and the relationship between resources and coping.

### 1.1.2A Antonovsky’s Sense of Coherence Theory

#### 1.1.2 A1 Role of Resources

Taking on the view that stress is ubiquitous and idiosyncratic across individuals, Antonovsky (1979, 1987) preferred to conceptualise resources on a more general level that met the various types of stress that individuals face. He named these Generalised Resistance Resources (GRRs) and defined them as “any characteristic of the person, the group, or the environment that can provide extended and continued experience in making sense of the countless stimuli with which one is constantly bombarded and facilitates the perception that the stimuli one transmits are being received by the intended recipients without distortion.” (Antonovsky, 1979, p. 121). Based on this definition, three main points about GRRs arise: Firstly, GRRs can come from within the individual (i.e., bio-physiology, personality, emotional intelligence, values and attitudes, etc.), the individual’s ties to his or her immediate environment
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(i.e., family and friends), and to the larger community (i.e., culture and society; Cowley & Billings, 1999). Therefore, the stronger a person’s personal ties are to others, the deeper his roots in the society, and the stronger his flexibility in understanding stressors, the stronger his GRR (Antonovsky, 1990). Secondly and related to the first point, the more deeply rooted and firmer GRRs are, the greater their ability to buffer the individual against stress. Lastly and most importantly, GRRs play the dual and reciprocal function of providing individuals with a set of life experiences that form a generalised, pervasive orientation towards life and, in doing so, allow for the possibility to mobilise these resources to resolve tension. Antonovsky’s view converges with research on resilience among caregivers, in that the interaction of three interrelated factors – social and cultural characteristics, quality of the care relationship, and the caregiver’s psychological characteristics (i.e., attachment style, personality traits, etc.) – serve to buffer caregivers’ resilience to stress (Cherry et al., 2013).

Antonovsky called the individual’s resultant generalised, pervasive orientation towards life the Sense of Coherence (SOC), and defined it as:

“A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that 1) the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable, and explicable; 2) the resources are available to one to meet the demands posed by the stimuli; and 3) these demands are challenges, worthy of investment and engagement.” (Antonovsky, 1987, p. 19)
There are thus three corresponding components of the SOC – (1) Comprehensibility, (2) Manageability, and (3) Meaningfulness. Taken together, the SOC has cognitive, instrumental, and motivational components.

GRRs interact with SOC to maintain or improve individuals’ well-being. GRRs contribute towards individuals’ life experiences characterised by consistency and predictability, opportunities to shape outcomes, and a balanced stress load, thus contributing towards a strong SOC (Antonovsky, 1987). A strong SOC, in turn, gives the individual greater flexibility in selecting and combining various GRRs to overcome the stressor (Antonovsky, 1987). In other words, the role of GRRs is not to prevent the individual from experiencing stress per se, but to help the individual to maintain or improve his or her well-being. Studies on caregiver burden for individuals with dementia or terminal stage cancer, or parental well-being or attitudes towards caring for a child with autism, irregular food intake, or developmental disabilities, found that individuals with high SOC report higher levels of well-being, more positive attitudes, less emotional distress and greater acceptance of their family members’ illnesses (Andrén & Elmståhl, 2008; Mak, Ho, & Law, 2007; Oelofsen & Richardson, 2006; Ray, Suominen, & Roos, 2009; Tang & Li, 2008). However, a more important question is, how do GRRs contribute towards the various outcomes of these caregivers? Next, we will discuss the relationship between GRRs and coping. In addition, having established that GRRs play an integral and reciprocal role in building individuals’ SOC, we also look at how the SOC influences coping.

1.1.2 A2 Relationship between Resources and Coping

Among the GRRs that Antonovsky pointed out, coping was considered one. To the extent that coping pulls a person towards the healthier end of the continuum, it is considered a GRR.
Antonovsky described three important qualities of coping that influence its effectiveness: rationality, flexibility, and far-sightedness. Rationality refers to the accurate, objective assessment of the extent to which a stressor is considered a threat. Flexibility refers to the availability of alternative plans and the individual’s willingness to consider them. Flexibility also requires constant evaluation and revision of a strategy to be effective. Lastly, farsightedness refers to the individual’s ability to anticipate the implications of implementing a particular coping strategy. Thus, the higher the coping strategy is on the three elements of rationality, flexibility and far-sightedness, the more effective it will be, and the more it will buffer an individual’s SOC.

Among the three components of SOC, Manageability concerns the allocation of appropriate resources to overcome the stressor. Bergh and Bjork (2012) conducted a longitudinal study on the course of SOC for parents with a child diagnosed with cancer. They found that mothers’ reported levels of Manageability and Meaningfulness were lower than fathers, and tended to decrease between the period immediately after diagnosis and during treatment. Similarly, Manor-Binyamini (2012) found that mothers tended to report lower Manageability scores than fathers in a sample of ultra-orthodox and secular Jewish parents of adolescents with developmental disorders. Apart from gender differences, what is of interest here is that Manageability seems to be an important predictor of stress. This is a noteworthy finding, as it suggests that parents’ confidence in the availability and effectiveness of their resources is associated with their ability to cope with their child’s illness.

1.1.2 A3 Relationship of Coping with Adjustment and Stress

Dabrowska (2008) investigated the relationship between SOC and coping in fathers of children with developmental disabilities. She found that fathers who reported lower levels of
SOC tended to use avoidance coping strategies, while fathers with higher levels of SOC tended to adopt more approach coping strategies such as confrontation, positive reappraisal, and problem-solving. In addition, she found that fathers of children with Down’s syndrome reported lower levels of Meaningfulness than fathers of normally developing children and fathers of children with autism. Dabrowska’s results extended Oelofsen and Richardson’s (2006) study, who found that parents of preschool children with developmental disabilities tended to report lower levels of SOC, higher parental stress, and poorer health than parents of normally developing children. These studies highlight that apart from the common constructs of coping and parental stress affecting the well-being of parents of ill children, SOC also plays an important role in these parents’ well-being.

Among the three components of the SOC, Meaningfulness is seen as playing a central role in maintaining an individual’s SOC due to its motivational properties (Antonovsky, 1987). Regardless of the level of a person’s Comprehensibility and Manageability, Antonovsky believed that not caring about, or playing an active role, in one’s own outcome, led the individual to lose his understanding of his life, and a failure to recognise the resources at his disposal. Taking on the motivational role in an individual’s outlook in life, Meaningfulness pushes the individual towards an active and committed engagement in activities associated with his life.

Comprehensibility, playing a cognitive role that emphasises the individual’s appraisal of predictability, explicability and structure of a situation, is necessary to decide how much and what resources can be harnessed. Lastly, Manageability, playing an instrumental role, facilitates individuals’ knowledge to access and harness resources. With the inter-related dynamics between the components of SOC, Antonovsky postulated that successful coping depended on SOC as a
whole, and hence suggested that SOC is a unitary construct, and stable over time (Antonovsky, 1987).

However, there is evidence against Antonovsky’s view of the SOC as a unitary construct, and its stability over time. Among the limited studies examining individual components of the SOC, studies such as Bergh and Björk’s (2012), found instability in the levels of various components of parents’ SOC. Specifically, Bergh and Björk found decreases in levels of Comprehensibility and Meaningfulness in parents of children with cancer from the point of diagnosis to treatment. Similarly, described above, Dabrowska (2008) found better utility of individual SOC components than the whole construct. These results have several implications.

Firstly, that Comprehensibility and Meaningfulness in Bergh and Björk’s (2012) study were found to be the components affected by the child’s diagnosis, suggests that resources are not the first areas to be threatened during a stressor. Rather, the process of making sense of the child’s illness and its implications, and reconciling it with their values and beliefs, seems to occur before the resources are appraised and mobilized. It was interesting to note that parents’ reported levels of Manageability in Bergh and Björk’s study remained constant over time, which could be as long as 105 months for some parents. The findings of this study and its implications contrast with Hobfoll’s (1989) stand that distress is created when individuals perceive a threat to their resources. Instead, the SOC theory suggests that rather than the threat of resources, it is individuals’ understanding of the situation, and their perception that they are not able to play as active a role in shaping the outcome as they would like, that creates the distress.

Secondly, finding that parents of children with developmental disorders or cancer report lower, or decreasing levels of SOC, questions Antonovsky’s assertion that SOC is stable over
time. While this has not been conclusively determined by any research to our knowledge, it does lead one to wonder if support that aims at facilitating parents’ understanding of their child’s illness, as well as helping them get back in touch with their values and beliefs, would halt or slow down the decrease in SOC levels.

1.1.2 Hobfoll’s Conservation of Resources Theory

1.1.2 B1 Role of Resources

In Hobfoll’s COR Theory, resources take a central and motivational role in individuals’ well-being in which they are motivated to protect their current resources and acquire new ones. According to COR Theory, resources can be anything that is valued by the individual or that serves as a means for the attainment of other things. These include the possession of objects (either due to their attractiveness, monetary value, or rarity), personal characteristics, status, or energies (e.g., time, money, or knowledge; Hobfoll, 1989). Stress is created when there are threats to resources, or during the actual loss of resources.

Nonetheless, Hobfoll’s initial definition of resources drew some criticisms. Halbesleben, Neveu, Paustian-Underdahl, and Westman (2014) found issue with the term ‘value’, saying that it implies that a resource must lead to a positive outcome to be considered one, which confounds the nature of a resource with outcome. Instead, the authors suggested that the definition of resources should take on a goal-directed focus, such that any resource that facilitates goal attainment is a resource. Hobfoll’s later writings, however, clarified that rather than focus on ideographically-valued resources like SOC and the Transactional Theory of Stress, the COR Theory emphasizes the utility and value of primary, shared resources, or resources that are universally or at least widely agreed to be important to people, such as social support, money, health, love, and intelligence (Hobfoll & Wells, 1998). Hobfoll’s nomothetic approach to
resources also emphasised COR Theory’s departure from other stress theories such as Lazarus and Folkman’s (1984) Transactional Theory of Stress in its focus on objectivity. That is, rather than conceptualising the maximal utilisation of resources as a purely cognitive endeavour, COR Theory viewed it as a behavioural process based on the individual’s experience. Furthermore, the small component of cognitive appraisal in COR Theory is more an objective stock-taking of resources based on the individual’s current situation and social climate, than an ideographic appraisal of the situation and resources (Hobfoll, 2011). However, looking into the paediatric illness literature, studies have found parents reporting a reshuffling of their priorities (Pelchat, Levert, & Bourgeois-Guérin, 2009; Wray & Maynard, 2005) as a result of their child’s illness. Families reported giving higher priority to family relationship and well-being than career progression and other material possessions, not necessarily due to a lack of resources, but from a re-examination of values and beliefs.

According to the COR Theory, resources that complement each other tend to cluster together, forming what Hobfoll (2011) called resource caravans, such that possessing one major resource usually means possessing a variety of other resources related to it. Resource passageways, on the other hand, refer to the “environmental conditions that support, foster, enrich, and protect the resources of individuals, families, and organizations, or that detract, undermine, obstruct, or impoverish people’s resource reservoirs” (Hobfoll, 2012, p. 229). For example, research has shown that parents with higher education levels or income tend to report lower levels of distress (Bartlett et al., 2004; Sahler et al., 2005; Savage & Bailey, 2004). Furthermore, the resource of self-efficacy is likely to be linked with optimism and social supports, whereas the lack of self-efficacy is linked with possessing poorer social support and quality of coping strategies (Hobfoll, 2001).
1.1.2 B2 Relationship between Resources and Coping

The COR Theory asserts that resources play instrumental and guiding roles in supporting coping strategies, which in turn influence individuals’ adjustment. In the former role, resources provide support to confront difficulties. In the latter role, resources guide individuals in their assessment of situations and assess their ability to cope, as well as the likelihood of success of coping strategies (Ito & Brotheridge, 2003). Thus, the more resources are available to the individual, the more flexibility they provide to him to critically confront the situation (i.e., proactive coping, or control strategies), while those with less resources tend to take a more conservative approach, to adopt defensive strategies (Hobfoll, 2001). Thus, COR Theory assumes that individuals take a linear approach to managing stressful situations.

Proactive coping, or control strategies, take the form of active problem-solving, positive thinking, and help-seeking (Ito & Brotheridge, 2003). Research on parents’ reactions to manage their child’s illness indicates that parents reporting increased seeking of social support ask for help particularly from family and friends, as well as looking to each other and within their nuclear family to make changes (Ångström-Brännström, Norberg, Strandberg, Söderberg, & Dahlqvist, 2010; Baum, 2004). Often, this means restructuring the family in terms of employment decisions and care of the other children and household (Long & Marsland, 2011). These responses are active movements towards the utilisation of resources readily available to the family, to try to stop the depletion of resources caused by the child’s diagnosis.

Defensive strategies on the other hand take the form of reducing or stopping effort and their resources in order to conserve them (Grandey & Cropanzano, 1999). Hobfoll (2001) suggested these are particularly employed when individuals find themselves possessing insufficient resources. Parents of ill children report isolation and withdrawal from social others
or family (Aho, Tarkka, Åstedt-Kurki, & Kaunonen, 2009; Sen & Yurtsever, 2007), sometimes purposefully for a variety of reasons—conserving time, energy, avoiding facing difficult questions, or feeling isolated in their situation. These strategies may be employed on either a permanent or temporary basis. While temporary forms of defensive strategies might be beneficial to distance from the stress, they are also maintaining factors for mental health problems in the long run, as the individual’s resources continue to remain under threat with no further accumulation of resources.

However, some research suggests that the relationship between resources and choice of coping strategies is more complex than Hobfoll postulated. These relate to firstly, the assumption that control strategies are more adaptive than defensive strategies, and secondly, Hobfoll’s stand that resource gains are primarily due to access to resources rather than other factors.

With regard to the superiority of control over defensive strategies, evidence suggests avoidance coping might be useful in specific situations such as short-term and uncontrollable ones like awaiting medical reports and diagnoses (S. E. Taylor & Stanton, 2007). Park (1997) also found that cognitive avoidance coping strategies such as denial used in the short term played a buffering role in allowing the individual to process or make sense of the stressor. Related to the previous point, is the role of cognitive appraisals in the use of avoidance coping strategies, which implies subjectivity in making choices about the availability of resources or the severity of the situation. In contrast, Hobfoll strongly emphasized that stressors and assessments of individuals’ available resources were based on the objective reality shared by people within groups, organizations, and cultures, and also on circumstances where clear stressors and challenges are occurring. Later studies in COR Theory were also more in line with the role of appraisals in allocation of resources. In raising the possible explanations of relative insignificance of threat, or
that the resources required outweigh the amount of resources individuals have, Ito and Brotheridge implied that cognitive appraisals of the severity of the situation (i.e., primary appraisal; Lazarus & Folkman, 1984), and the availability of resources (i.e., secondary appraisal), were in play.

Secondly, Butler’s (2007) study on posttraumatic growth (PTG) suggests that resource gains can occur in the context of resource loss. This is when individuals examine their values and beliefs to view the situation in a new light. The emotional turmoil creates an impetus for individuals to gain resources. This view contradicts Hobfoll’s view that resource access is necessary to acquire or protect resources. PTG research suggests that sometimes the situation itself provides access to resources. Furthermore, where COR Theory left off in explaining the occurrence of PTG in severe stress, the SOC Theory explains PTG via the engagement of the individual’s values through Meaningfulness. In addition, in later writings tangential to the Transactional Theory of Stress, Folkman and Moskowitz (2004) coined the term “meaning-focused coping”, a form of coping that drew on individuals’ values, beliefs, and goals to manage stress, thus suggesting that values may be an alternative form of motivation, and resource, for individuals to manage stressors.

1.1.2C Lazarus and Folkman’s Transactional Theory of Stress and Coping

1.1.2 C1 Role of Resources

While Antonovsky placed GRRs centrally as managers of stress, Lazarus and Folkman conceptualised resources as preceding and influencing coping. However, like the SOC, the Transactional Theory of Stress posits that the greater the generalisation of resources to other aspects of the individual’s life, the more valued this resource would be.
Among several categories of resources ranging from intrapersonal ones such as health and psychological resources, to external ones such as social support and material resources, Lazarus and Folkman (1984) conceptualise beliefs as a key resource, where, the more pervasive a belief is in various aspects of the individual’s life, the more deeply rooted it would be. Some of these deeply rooted beliefs also come to form schemas about how we think the world is supposed to be, something Janoff-Bulman (1992) coined as the assumptive world. These deeper-seated beliefs also manifest as individuals’ SOC, forming the lens through which they view the world (Antonovsky, 1979). Furthermore, within the literature on stress and coping, in particular the paediatric illness literature, there is an underlying dependence on viewing beliefs as a factor influencing parents’ abilities to manage stress (e.g., Alderfer et al., 2009; Clarke, McCarthy, Downie, Ashley, & Anderson, 2009; Lazarus & Folkman, 1984). This suggests that while beliefs can function as resources – facilitating coping – they also form individuals’ general outlook on life and thereby drive actions.

Indeed, according to Park and Folkman (1997), beliefs comprise one of three components that shape individuals’ global sense of meaning in life. These beliefs include beliefs about the world, the self, and the relationship between the self and the world. Beliefs about the world include their estimates of how benevolent the world and other people are, and that there is justice and fairness. Beliefs about the self include individuals’ evaluations of their self-worth, and the extent to which they believe they have control over their environment and outcomes. This belief of the self, as well as individuals’ existential beliefs about their faith in religion, fate, or some natural order in the universe, are seen by Lazarus and Folkman (1984) as being fundamental to influencing individuals’ views on stress and their ability to cope.
1.1.2 C2 Relationship between Resources and Coping

As discussed earlier, resources influence coping processes. While Lazarus and Folkman (1984) agreed that resources available to individuals play a large role in their coping, they encouraged that “greater attention be given to the actual coping processes through which the person manages the demands of a stressful encounter” (p. 170), which appraisals and reappraisals mediated. The authors proposed that factors such as the accuracy of the individual’s appraisal of the situation and its flow of events, as well as a match between coping options and actual demands, and between a selected coping strategy and other personal agendas such as values, goals, commitments, etc, influenced the effectiveness of coping. Later research by Cheng (2001), refined Lazarus and Folkman’s requirements for coping effectiveness. She proposed the concept of coping flexibility, and conceptualised it as “(a) variability in cognitive appraisal and coping patterns across stressful situations, (b) a good fit between the nature of coping strategies and situational demands, and (c) subjective evaluation of effectiveness in attaining the desired goals”. Thus, where Lazarus and Folkman (1984) discussed factors associated with coping effectiveness, Cheng (2001) emphasised the role of cognitive appraisal in coping flexibility and hence, coping effectiveness.

Lazarus and Folkman (1984) identified three types of appraisal – primary and secondary appraisal, and reappraisal. Primary appraisal refers to evaluation of the nature of the event as belonging to one of three types: irrelevant (i.e., the event has no implication for an individual’s well-being), benign-positive (i.e., the individual construes the event as bringing about benefits or increasing his or her well-being), or stressful (i.e., includes potential harm or loss, threat, and challenge). As the nature of the current study relates to a stressful and highly relevant issue of critical childhood illness, the ensuing discussion will focus on the third type of primary appraisal.
Secondary appraisal on the other hand, refers to the evaluation of what might and can be done about the event, and the availability of necessary resources. Secondary appraisals work together with primary appraisals in evaluating the threat of the situation to the individual’s well-being and resources; and if threatening, whether the situation is a threat or a challenge (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Contributing to the discussion on the role of appraisals, is Ehlers and Clark’s (2000) cognitive theory of PTSD. A central assertion of their theory was that individuals’ interpretations of events and their aftermath as threats were maintenance factors of PTSS. To prepare for the potential loss, stress appraisals of threat drive individuals to prepare for it, which might lead the individual to get caught in continuous attempts of dealing with the stressful event. Supporting this view, are findings from parents’ experiences of their child’s illness, where reports of PTSD were associated with perceptions that their child might die (Balluffi et al., 2004) or realising the severity of the child’s illness and distressing thoughts about the child’s future (Forinder, Claesson, Szybek, & Norberg, 2015).

Among other factors that influence appraisal (i.e., resources, situational and environmental demands), Lazarus and Folkman (1984) also discussed the role of commitment in influencing individuals’ cognitive appraisals. Commitment reflects areas important and meaningful to the individual. During stressful situations, commitment influences appraisals through three pathways: Firstly, by guiding individuals towards valued goals and activities, and away from those that threaten them; Secondly through sensitising individuals to situational cues that may facilitate or compromise their achievement of goals. Lastly, commitment influences appraisals through their relationship with vulnerability. The deeper an individual’s commitment,
the greater his or her vulnerability to the stress. This last point explains why paediatric illnesses are great sources of stress for parents.

The concept of commitment is echoed in the SOC Theory, existential theories of meaning, and Park’s cognitive theory of meaning-making (Park & Folkman, 1997). While commitment in the existential field and Park’s meaning-making theory will be discussed in their respective sections on meaning-making, Antonovsky (1987) placed commitment in the centre of his definition of the Meaningfulness component. In SOC Theory, an activity or course is only considered meaningful to the individual to the extent that he is committed to it. This then influences the individual’s persistence towards pursuing the cause or activity.

Reappraisal refers to a changed appraisal based on new information from the environment and/or the person. It usually occurs after coping has been engaged. The concept of reappraisal, particularly positive reappraisal, is of interest in the cognitive and meaning-making field. This will be discussed further in the meaning-making section.

In summary, the relationship between resources and coping is mediated by appraisals. Primary appraisals might serve as the starting point in accessing the relevance of the situation to the individual and its level of threat, but secondary appraisals involve evaluating the available resources and coping options. These translate to the various coping strategies that then mediate the relationship between adjustment and stress.

1.1.2 C3 Role of Coping in Adjustment to Stress

Within the Transactional Theory of Stress framework, Lazarus and Folkman (1984) conceptualized emotion-focused and problem-focused coping. In more recent work, however, a
third type of coping was conceptualised: meaning-focused coping (Folkman & Moskowitz, 2004; Park & Folkman, 1997). These three types of coping will be discussed below.

Emotion-focused coping refers to cognitive and behavioural actions aimed at reducing the negative emotions associated with the stressful event (Folkman & Moskowitz, 2004). It is used predominantly when situations are perceived as uncontrollable, or when the individual has decided that nothing else can be done to change the problem (Lazarus & Folkman, 1984). Mothers of children with chronic illnesses may utilize emotion-focused coping strategies by turning to their social support networks as an outlet to express their emotions. Consequently, they report lower levels of loneliness and helplessness than fathers (Pai et al., 2007).

There are mixed results with regard to the efficacy of emotion-focused coping. Early research on coping reported almost unanimously that emotion-focused coping led to poorer outcomes than problem-focused coping (Folkman & Moskowitz, 2004). Later research extended investigations of individual strategies that make up emotion-focused coping. For example, emotion-focused coping strategies include behavioural and cognitive avoidance, seeking social support, emotional expression, emotional processing, and cognitive reappraisal (Austenfeld & Stanton, 2004). Austenfeld and Stanton (2004) reported that among these strategies, avoidance strategies in the form of suppression of emotions, cognitive and behavioural avoidance, led to negative outcomes, whereas Aldao, Nolen-Hoeksema, and Schweizer (2010) event with their found that coping strategies such as emotional expression, and cognitive reappraisal led to more positive outcomes. Emotional processing, on the other hand, had inconsistent outcomes – Stanton and Low (2012) for example, found that among women with Stage IV metastatic breast cancer who reported more emotional processing also reported increases in depressive symptoms and lower quality of life. However, if the participants reported high levels of emotional
expression and processing, they reported a reduction in depressive symptoms over time. Stanton and Low’s study underscores the complexity of emotion-focused coping.

Problem-focused coping refers to the direct addressing of the problem that is causing distress, and includes defining the problem, generating alternative solutions, weighing the alternatives, choosing the best solution, and acting on it. Due to its function of directly confronting the problem, problem-focused coping is suggested to be the most effective in distress management when the sources of stress are controllable (Lazarus & Folkman, 1984). However, Riley and Park (2014) found that within the context of chronic stressors, there are areas still amenable to problem-solving efforts. In the context of parents of ill children, research examining the efficacy of teaching mothers problem-solving skills also showed significant reductions in mothers’ reports of depression and anxiety (Sahler et al., 2005), thus suggesting that even in the uncertain landscape of paediatric illness where emotion-focused coping might be used more often for emotional regulation, problem-focused coping also has its place. In relation to the current research, some areas amenable to problem-solving efforts might include finding temporary substitute carers for the other children when parents are at work or with the sick child in hospital, transport to and from hospital appointments, or financial difficulties (Stuber, 2010).

Apart from problem-and emotion-focused coping, Folkman and Moskowitz (2004) proposed meaning-focused coping, which consists of cognitive strategies to manage a stressful situation. The relevance of meaning in coping was first considered by Park and Folkman (1997), where the authors proposed that distress related to stressful events not amenable to change could be managed by changing the meaning of the event, an occurrence they named “meaning-making” (p. 124). A core mechanism of the meaning-making process was cognitive reappraisal, which drew on individuals’ values, beliefs, and goals. Meaning-focused coping also manifested in the
form of goal revisions, focusing on strengths gained from life experiences, and reordering of priorities (Guo, Gan, & Tong, 2011).

The concept of meaning-focused coping is not new, and though it was proposed by Folkman and Moskowitz (2004) as a form of coping, before then, it had never been formally categorised as such, and there is still a lack of research investigating the role of meaning-focused coping in stressful situations. However, elements of meaning-focused coping such as benefit-finding, sense-making, and cognitive reappraisal (Schwarzer & Knoll, 2007) are contained in various research studies investigating issues of loss, trauma and bereavement. In addition, other lines of research, such as Yeh’s (2004) investigation of Taiwanese parents’ coping strategies while caring for their child with cancer, also highlighted the dearth of a broad coping taxonomy that captures individuals’ process in finding meaning during stressful periods. Although Yeh attributed this gap to a lack of cross-cultural consideration in the research literature, the idea of meaning-focused coping only recently caught the attention of researchers in the coping field.

There is converging evidence from various sources of research relating to the relationship between meaning-focused coping and quality of life. This relationship has been found in patients in the terminal stage of illness (Breitbart, Gibson, Poppito, & Berg, 2004; Breitbart et al., 2010; Greenstein & Breitbart, 2000), parents of children with autism or other disabilities (Samios, Pakenham, & Sofronoff, 2008), and caregivers of adult individuals with debilitating illnesses and disabilities (Tang & Li, 2008). These authors found that in engaging in meaning-focused coping, individuals go through a process of re-evaluating and re-aligning their lives and goals to make sense of the occurrence of serious and life-threatening conditions for themselves and their loved ones. Interestingly, in Gattino, Rollero, and De Piccoli’s (2014) study on the relationship between coping strategies and quality of life, the factors of positive reframing and acceptance on
the Brief COPE were significant predictors of the physical, psychological and environmental dimensions of quality of life, but not for social relationships. This suggests that meaning-focused coping has generalisation effects in first influencing individuals’ way of perceiving their circumstances, which then lead to personal changes in their mental and physical health. Changes in mental and physical health then provide the resources for individuals to exert changes to their environment. As supported by Park, Folkman, and Bostrom’s (2001) study on HIV-infected men, meaning-focused coping increases the health and reduces rate of mortality for these men, suggesting that meaning-focused coping can conserve individuals’ resources to buffer them from stress.

How does meaning-focused coping work in increasing quality of life? The literature has currently not arrived at a clear picture. Nonetheless, research on meaning-focused coping or benefit-finding have found that despite the negative emotions inevitably aroused by these situations, there are episodes where positive emotions have been experienced, and found to be associated with active coping, search for meaning, and positive reappraisal (Folkman, 1997). In Breitbart et al.’s (2004) meaning-centred psychotherapy for patients with terminal illness, triggering positive experiences in sessions was one way of allowing the patients a glimpse of what their lives still had to offer, and gave them courage to move on and complete any unfinished business. At the end of therapy, Breitbart and colleagues found that despite still reporting pre-test levels of depression and anxiety, patients reported higher levels of quality of life as compared to the waitlist group. Such studies suggest that positive emotions increase the salience of alternative perspectives, thus facilitating a process of reappraisal that reduces distress related to quality of life. This can facilitate the transformation of threat appraisals to challenge appraisals, thereby motivating and sustaining coping efforts over time.
The role of reappraisal in reducing quality of life-related distress highlighted two issues: firstly, that quality of life and psychological adjustment are two separate pathways to well-being; secondly, the two pathways leading to well-being either utilise different types of coping, or, more interestingly, reflect a more complex interplay between the different types of coping. Riley and Park (2014) discussed the role of reappraisal somewhat differently in their study of how problem- and meaning-focused coping might interact in the face of chronic stress. They found a positive and significant relationship between problem-focused coping and adjustment (i.e., levels of post-traumatic stress symptoms and depressive symptoms), but could not find any relationship between meaning-focused coping and adjustment. The authors suggested that meaning-focused coping might have preceded problem-focused coping in altering individuals’ appraisal of their stressors, which then led the way to seeking solutions. Although to date Riley and Park’s (2014) study remains the only one investigating and suggesting this, we cannot rule out this possibility, as meaning-focused coping does have the element of positive reappraisal, which can lead to a new direction in approaching problems.

Emotion-, problem- and meaning-focused coping have been described as predictors and possible mediators of individuals’ adjustments to stress. Nonetheless, with the uncertain nature of serious paediatric illnesses with regard to the length of treatment, mortality rate, and impact of the illness on the child and the family, they bear the hallmark of chronic stressors in which adjustment might be through a process of meaning-making. The next section, therefore, will discuss parents’ distress from the meaning-making perspective.

1.1.3 Meaning-Making

The uncertain nature of paediatric cancer and chronic illnesses call for strategies that go beyond solving problems and reducing negative emotions to those that enable parents to derive
meaning from their situation. Possessing a sense of meaning is related to: 1) quality of life (Breitbart et al., 2004), 2) lower reports of mental health problems (Besier et al., 2011; Delavari, Nasirian, & Baezgar Bafrooei, 2014; Sahler et al., 2005), and 3) satisfaction in life (Besier et al., 2011; Joshi, Marszalek, Berkel, & Hinshaw, 2014). These studies underscore the importance of meaning as a source of well-being. Conversely, the absence of meaning is related to 1) mental health problems such as depression, anxiety, or PTSD (Park, 2008), 2) disruption of individuals’ beliefs in the world (Janoff-Bulman, 1989), and 3) existential crisis (Frankl, 1963). Referring back to Hobfoll’s (1989) and Antonovsky’s (1979, 1987) work on resources, the absence of meaning as a buffer presents an increased risk of resource loss spirals and disequilibrium, exacerbated by threats to meaning or resources in other aspects of individuals’ lives. What, though, is meaning?

While the literature is replete with studies investigating the meaning construct and its process, there are variations in the definition of ‘meaning’. Frankl (1963) views meaning as the basic reason for Man’s survival, an innately human quality that is influenced by the individual’s values in order to satisfy his or her purpose in life. The satisfaction of this purpose leads to a greater quality of life regardless of the individual’s circumstances. This assertion relates to the three tenets of Frankl’s Logotherapy: meaning in life, will to meaning, and freedom of will. Antonovsky (1979, 1987) uses the adjective – ‘Meaningfulness’ – implying that life, or life events, are only as significant as the individual feels they are important and makes sense to them not only cognitively, but more so, emotionally. Park (2010), on the other hand, conceptualises global meaning as providing an overall cognitive framework made up of values, beliefs and goals, to make sense of their world. Specifically, Park is concerned with a cognitive equilibrium where individuals’ interpretation of the situation matches their global meaning. Lastly, Ehlers
and Clarke (2000) come from the point of view that disrupted and threatening beliefs individuals have about their world and their part in it arise from interpretations of events and their sequelae as threats, thus leading to PTSD.

In sum, meaning pervades all areas of an individual’s life, and is primarily an important source of motivation in overcoming various difficulties. In the following discussion, the theories of meaning-making will be contrasted with each other. The issues inherent in meaning-making – 1) the process of meaning making; and 2) the role of tension in meaning-making – will be discussed in the context of these theories.

1.1.3A Process of Meaning-Making

Meaning is a complex construct that has been conceptualised differently in different theories. Inherent in the different conceptualisations is the characteristic of meaning-making, as well as the mechanisms by which these processes operate. These two aspects of meaning-making will be discussed below.

1.1.3 A1 Characteristics of Meaning-making

The goal of meaning-making in the cognitive perspective is to reduce discrepancies between situational meaning and global meaning. According to the cognitive field, meaning-making is both automatic and deliberate. It is automatic during the process of reducing cognitive discrepancy or cognitive processing of stressful events, such as in the form of intrusive thoughts, (Ehlers & Clark, 2000). On the other hand, meaning-making is a deliberate process when the individual actively engages in meaning-focused efforts such as positive re-appraisals, goal revisions (or accommodation; Folkman, 1997; Janoff-Bulman & Frantz, 1997), engaging in spirituality and positive experiences (S. T. Cheng, 2012; J. M. Holland, Currier, & Neimeyer,
2006; Venning, Eliott, Whitford, & Honnor, 2007). Logotherapy, however, conceptualises meaning-making as a deliberate effort, even a responsibility. The first tenet of Logotherapy, meaning of life, states that meaning is inherent in every moment of the individual’s life, and the individual’s action gives the event its meaning. Indeed, in Breitbart et al.’s (2011) Meaning-Centred Group Psychotherapy (MCGP) with patients nearing the end of life, meaning was conceptualised as a ubiquitous phenomenon which never ceases to exist, regardless of the circumstances. The participants were encouraged to assume responsibility for the remaining time they had left, to make each moment count. In essence, meaning-making was seen as a continuous process where the participant was making a conscious effort to make sense of each moment that presented itself.

1.1.3 A2 Mechanisms of Meaning-Making

The underlying motivation of Logotherapy and the cognitive models with regard to meaning-making is different. In Logotherapy, the three tenets emphasise making the best out of the limits of the situation, while the cognitive models firstly seek closure of discrepancies (Park & Folkman, 1997), and secondly seek a more benign interpretation of the event so as to reduce the intensity and frequency of distressing intrusive thoughts and other trauma-related symptoms (Ehlers & Clark, 2000).

Logotherapy strongly emphasises the use of values in meaning-making (Frankl, 1963). Specifically, Logotherapy delineates three values which Frankl asserted were the sources of meaning: creative values (i.e., engaging in life through work, deeds, dedication to causes), experiential values (i.e., connecting to life through love, relationships, nature, art, and humour), and most importantly, attitudinal values (i.e., the stand the individual takes when facing a situation over which he or she has no control of; Breitbart & Applebaum, 2011). On the other
hand, the cognitive perspectives highlight the importance of reappraisals in meaning-making – either by changing the appraised meaning of the situation to align with their global meaning (i.e., assimilation), or by changing the individual’s global beliefs and goals (i.e., accommodation; Janoff-Bulman & Frantz, 1997; Park & Folkman, 1997). Thus, cognitive reappraisals target both the automatic and deliberate processes of meaning-making.

Values are conceptualised as objects – living or otherwise - “features, or conditions” that facilitate the progress of individuals towards fulfilling their potentials, while also integrating them more fully into the world (Adams, 2003, p. 66). Indeed, the three values of creativity, experience, and attitude, serve the purpose of engaging the individual with life through active involvement, or even passive enjoyment of life (Breitbart & Applebaum, 2011). In particular, attitudinal values engage the individual in the second tenet of Logotherapy: freedom of will. Ramin, Dadkhah, Bahmani, and Movallali (2014) utilised attitudinal values in their intervention with mothers of children with hearing impairment. They found that mothers reported coming to the knowledge that although they could not change the circumstances of their lives, they were still able to change the way they coped and responded to events in their lives.

The characteristic of attitudinal values in encouraging individuals to actively take a stand in life, holds similarities to Park and colleagues’ (2005, 2010; 1997) concept of reappraisal in its outcome of changed perspectives. However, whereas Logotherapy encourages change in attitudes via engaging in affective and motivational elements of values (Hitlin & Piliavin, 2004), Park’s (2008) meaning-making model engages in a continuous process of reappraisal, while Janoff-Bulman (1989) suggests individuals engage in either assimilation or accommodation depending on the impact of the situation on their assumptive worlds. Departing slightly, Ehlers and Clark (2000) postulate that meaning-making through re-appraisal operates via a process of
identifying the intrusive thoughts associated with the event, identifying the personal meanings of the event and the pertinent parts of the thoughts that require ‘updating’, and finally updating the intrusive thoughts with the new information (Ehlers, 2010). Thus, re-appraisal in Ehlers and Clark’s model is achieved through an objective assessment of information related to the event, and more importantly, through integrating the new information with possible alternative appraisals that are more benign.

1.1.3B Role of Tension in Meaning-Making

Across the theories, tension is seen as a catalyst towards meaning making. However, the benignity or malevolence of tension is viewed differently in the various theories. The third tenet of Logotherapy, the will to meaning, represents the internal tension that pulls the individual towards a life imbued with his or her own values, and is seen in a positive light (Frankl, 1963). The tension is borne from a need for a unique meaning and purpose in one’s life and is the anchor that guides one’s actions and decisions (Fabry, 1968). In fact, Barnes (2000) argued that tension should be welcomed rather than avoided, and is integral to achieving meaning in life.

However, tension is viewed differently in other theories. In SOC, tension is a ubiquitous obstacle to be overcome by the individual, and is only welcomed to the extent that it gives the individual the opportunity to actively shape his or her outcome. According to cognitive theories, cognitive dissonance, the uncomfortable tension resulting from a discrepancy between expectations and the experienced reality, is created (Festinger, 1962; Gawronski, 2012). Such cognitive discomfort is also experienced in the realm of meaning in the cognitive perspective (Janoff-Bulman, 1992; Park, 2008). Citing evidence from their investigations on victims of natural disasters, assaults (both sexual and physical) and traumatic losses, Park (2010) argued that the tension between reality and individuals’ understanding of the world pushes them to
search for meaning either by looking within themselves (through evaluating their behaviour, values, beliefs, and goals), or by looking at the environment. An equilibrium, or a state of having made meaning, is reached when individuals are able to reconcile the event with their global beliefs and goals (Park, 2008). Thus, while Frankl (1963) thought of meaning-making as an integral and ongoing process of growth that should be encouraged, Park (2008) viewed meaning-making as a response to cognitive discomfort, thereby triggering a series of attempts that lead to cognitive equilibrium.

Logotherapy’s conceptualisation of tension as an opportunity for meaning-making leads us to question if parents of children with cancer or chronic illness could be helped to view their situation as an opportunity for change. Bateman (2011), in her study of the lived experiences of mothers of children with autism, asserted that the liminal experience provided a fertile medium to facilitate meaning-making and benefit-finding for mothers. Bjork, Thomas, and Inger (2005) also reported similar results in families of children with cancer. They found that despite a “broken life world”, family members strove to be hopeful and maintain close relationships with one another. These studies suggest that while the uncertainty of the child’s illness is an uncomfortable state to be in, it nonetheless provides fertile ground for parents to grow, and to spur them on to find meaning.

1.2 What has been Done in the Field?

The diagnosis of cancer or a chronic illness in a child brings about a wide range of different types of distress that can be exacerbated or reduced by parents’ access to resources, their coping abilities, as well as the meanings they make of the situation. With so many variables combining to influence parents’ adjustment, the question to answer is how do we identify the parents who need support, and what kinds of support do they require? Just as importantly, we
need to answer how can these parents’ distress be reduced? The discussion now shifts to more practical issues: the screening of distress, and provision of support in the form of an intervention, to parents.

1.2.1 Distress Screening

Distress screening has been identified as the sixth vital sign in cancer care (Bultz & Johansen, 2011; J. C. Holland & Bultz, 2007). The rationale for this is that distress, when unattended, has far-reaching implications in areas such as increased medical attention and attendance in the emergency room for the patient, strain on the medical team, and increased economic burden to the medical system (J. C. Holland & Bultz, 2007). In recognising the potential costs of neglecting distress screening, many countries such as the United Kingdom (Mitchell, Kaar, Coggan, & Herdman, 2008) and United States (Bultz & Johansen, 2011; J. C. Holland & Bultz, 2007) have developed their own set of clinical practice guidelines to improve psychosocial care for cancer patients (J. C. Holland, Watson, & Dunn, 2011). Nonetheless, the translation and reality of distress screening is not equally present. Zebrack, Kayser, Sundstrom, and Savas (2015) investigated the fidelity of distress screening protocols administered at two tertiary cancer treatment centres – National Cancer Institute-Designated Comprehensive Cancer Programme and Academic Comprehensive Cancer Programme – comprising of five clinics in all. Across a 12-week period, rates of adherence (measured as the presence of a scanned copy of the screening instrument, regardless of level of completion) to the distress screening protocols ranged from 47% to 73% of the patients, while levels of acceptability by the doctors ranged from 56% to 90%. Rates of adherence corresponded with rates of acceptability by doctors. The results from this study suggest that while distress screening has been written into official patient care guidelines, the practice of distress screening is still not carried out by all.
Taking the issue further, if there is still a push for distress screening for cancer patients, what more for parents of ill children? Answering the call to care for parents’ distress, several pockets of researchers have designed screening tools to assess this (Grootenhuis, Haverman, van Oers, Limperg, & Maurice-Stam, 2014; Haverman et al., 2013; Kazak et al., 2001; Rodday, Terrin, Chang, & Parsons, 2013). Nonetheless, there is a lack of consensus as to which is the most ideal. This can be attributed to some outstanding issues. Firstly, the focus of the screening tools differs among researchers. Kazak and other colleagues (2012; 2012), in recognising the impact of psychosocial factors on the family and the possibility of PTSS as a result of psychosocial difficulties, designed the 15-item Psychosocial Assessment Tool (PAT). On the other hand, Rodday et al. (2013) targeted parents’ emotional distress, thus launching the seven-item Parent Emotional Functioning (PREMO) Screener. Lastly, Grootenhuis et al. (2014) and Haverman et al. (2013) acknowledged parents’ emotional and psychological difficulties. Choosing to use the umbrella term of “distress” to screen for parental difficulties due to its non-stigmatising connotations, they developed and tested the validity of the 29- to 36-item Distress Thermometer for Parents (DT-P). A more detailed description of the PAT and DT-P will follow in Study 1.

A second challenge to reaching a consensus on screening tools is the criteria they should follow. Taking into account the constraints faced by parents and the medical staff, it is necessary to have a short screening tool that encapsulates all the family’s difficulties, and also is easy for medical personnel to score and interpret (Mitchell et al., 2008). In their study of cancer specialists’ and non-specialists’ preference to screen for distress and other mood-related problems, Mitchell et al. (2008) found that medical staff preferred to use their clinical judgement to identify individuals who might be feeling distressed, rather than using an objective screening
measure. The medical staff interviewed also suggested using screening measures that consisted of between one and three questions. In response to recommendations by the medical personnel, Mitchell and colleagues tested the comparative accuracy of a multifaceted Emotion and Help Thermometer screening tool against the more well-validated Hospital Anxiety and Depression Scale.

1.2.2 Provision of Support

In 2003, the task force set up by the American Academy of Paediatrics to guide the development of public policy and assist paediatricians to promote well-functioning families found that family functioning and parents’ emotional distress or relationship quality with each other have a strong influence on children’s physical, emotional, cognitive and social development (Pediatrics, 2003).

The findings of the task force agree with studies from the traumatic brain injury (H. G. Taylor et al., 2001), childhood developmental disability (Trute, Hiebert-Murphy, & Levine, 2007), and oncology fields (Pai et al., 2007), showing converging evidence that parents’ distress and appraisal of their children’s condition were related to the child’s functioning and recovery. In particular, H. G. Taylor et al. (2001) investigated whether the family’s adjustment to their child’s traumatic brain injury is primarily predicted by child behavioural problems or parents’ adjustment. They found a bi-directional relationship between parents’ distress predicting child behaviour problems at 12 months, suggesting a complex relationship between parental functioning and child outcomes within the context of paediatric illness. Thus, being at the centre of the child’s care, parents’ psychological well-being is therefore paramount in facilitating their child’s recovery.
In response to calls to support parents, various interventions centred around the cognitive-behavioural therapy (CBT) paradigm have been developed and implemented with parents (Pai, Drotar, Zebracki, Moore, & Youngstrom, 2006). Among them, some have focused on enhancing mothers’ problem-solving skills (Sahler et al., 2005), family-centred cognitive-behavioural techniques such as reframing (Kazak et al., 2005; Stehl et al., 2009), and improving parents’ coping skills (Backhaus, Ibarra, Klyce, Trexler, & Malec, 2010; Wade, Carey, & Wolfe, 2006). A description of each of these interventions is beyond the scope of this research. However, Kazak et al.’s (2005) Surviving Cancer Competently Intervention Programme – Newly Diagnosed (SCCIP-ND) and Sahler et al.’s (2005) Problem-Solving Skills Training (PSST) will be covered in more detail in Study 2.

Cognitive-behavioural therapy (CBT) has been found to be effective in treating depression, anxiety, and PTSD among the general clinical population. The main thrust of CBT is that maladaptive thought processes lead to unhelpful behaviours and corresponding emotions. Hence, CBT targets amending individuals’ thought processes through cognitive restructuring and behavioural change (Ameli & Dattilio, 2013). However, cognitive restructuring does not address the notion of shattered world views, loss of meaning in individuals’ lives, as well as a constant appraisal of threat in their surroundings, postulated to contribute to the development of PTSD (Larsson, Hooper, Osborne, Bennett, & McHugh, 2015). This gap has spawned a separate series of interventions which target more than thought processes among many populations, but among the medically ill population, has until now only been tested among adult patients (Breitbart et al., 2010; V. Lee, Robin Cohen, Edgar, Laizner, & Gagnon, 2006), family members, or professional caregivers of adult patients (S. T. Cheng, 2012; Fillion et al., 2009). Given that parents of ill
children face an unprecedented and unexpected situation that threatens their world view and values, an intervention that addresses these threats may facilitate reduction of existential distress.

In addition, recent research has also indicated interest in targeting values in psychotherapeutic interventions. Among them, is the Acceptance Commitment Therapy (ACT; Hayes, Luoma, Bond, Masuda, & Lillis, 2005) that has been found to be efficacious relative to control conditions in reducing anxiety and depression (Powers, Zum Vörde Sive Vörding, & Emmelkamp, 2009). However, ACT has not been tested among caregivers, particularly parents of ill children. A more detailed discussion of ACT and its emphasis on values in reducing distress will follow in Study 2.

Thus, in the current context, introducing an intervention that helps repair parents’ world view and enables them to make sense of their challenging life experiences and to seek meaning out of them, is considered valuable to reducing their meaning-related distress.

1.3 Present Study

Keeping in mind the multi-faceted distress parents of chronic and/or life-threatening illnesses face, which includes the meaning dimension, the current thesis aims to fulfil the following objectives: Firstly, to develop and validate a short and simple screening tool to assess specific aspects of parents’ emotional distress, with a particular interest in the meaning aspect and whether screening for it would provide information about parents’ distress over and above the information provided by the screen for overall distress(Study 1). Secondly, to explore the possibility and feasibility of incorporating a meaning-focused intervention into care of distressed parents of ill children (Study 2).
Chapter 2: Study 1 Introduction

The paediatric literature suggests that parents of children with cancer or chronic illness report levels of distress similar to, or higher than, their ill child (Noll et al., 1995; Quittner et al., 1998). If untreated, this can have negative long-term repercussions for the ill-child and the family. The National Comprehensive Cancer Network (NCCN) has defined distress as:

“(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 with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from 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.” (National Comprehensive Cancer Network NCCN, 2014).”

Distress thus takes on a multi-faceted experience, where, apart from usual indicators of distress such as anxiety and depression, an existential and/or spiritual element has also been identified. This underscores the need for a screening tool that attends to other types of emotional distress, including existential/spiritual distress. The ensuing paragraphs will discuss the literature surrounding parents’ distress – its prevalence and impact on parents, available screening tools to identify distressed parents, and finally introduce the overarching aims and hypotheses of the study.

2.1 Prevalence and Impact of Distress Among Parents of Ill Children

Research has suggested that the prevalence of distress varies in accordance to the illness or disability of the child. Dunn et al. (2012) found that up to 11% of mothers and 9% of fathers
of children with cancer reported post-traumatic stress symptoms (PTSS) six months after the child’s diagnosis, while about 22.8% of parents of children with chronic illness reported symptoms of post-traumatic stress disorder (PTSD; Cabizuca et al., 2009). Manuel, Naughton, Balkrishnan, Paterson Smith, and Koman (2003) found that out of a sample of 270 mothers, 30% of them reported symptoms of depression relating to their child’s care. Other lines of research have also found that moderate to severe depressive symptoms reported by parents of children with cancer predicted PTSS three to six months later (Manne et al., 1996). There is little doubt that children may be left vulnerable to difficulties in adjustment when their parents are experiencing distress. Vrijmoet-Wiersma et al. (2008) suggested that parents’ distress might affect the quality of emotional support for the children, communication with the child and medical personnel, as well as their coping strategies, thus affecting the child’s well-being.

If parents’ distress is left undetected or unattended, short- to medium- term problems could range from non-compliance with treatment on the child’s part, negative communication patterns between family members, to poor communication and rapport between parents and healthcare personnel, which could have long-term consequences for the child’s adjustment to the sickness and to life (Besier et al., 2011; Dahlquist et al., 1996; Pediatrics, 2003). Nonetheless, to date, psychosocial screening for parents remains a procedure that is seldom employed (Kazak et al., 2012).

2.2 Types of Psychosocial Screening Tools

Among attempts to answer the call for psychosocial screening tools, Kazak et al.’s (2001) Psychosocial Assessment Tool (PAT) has been prominent in the paediatric illness literature. Created initially to measure the psychosocial distress in families in the paediatric oncology population, the PAT, a 15-item psychosocial screening tool, has been used in other paediatric
chronic illness populations such as sickle cell disease (Karlson et al., 2012) and kidney transplants (Pai et al., 2012). The PAT has also been validated in other countries such as Australia (McCarthy et al., 2009) and Canada (Barrera et al., 2014). The PAT has undergone several revisions from the time of its creation to address the needs of the populations being administered to, and has been found to maintain its psychometric validity and reliability.

Nonetheless, being a 15-item screening tool, the PAT and its variants have been found to take about 10 minutes to complete, which may be burdensome to parents who are already distressed.

While some may argue that 10 minutes is not very onerous to complete a questionnaire, implementing short screening tools that take less than five minutes for patients or caregivers to complete, as well as for clinicians and hospital staff to administer (NSW, 2011) is gaining increased attention. Physicians and hospital staff are often too pressed for time to formally assess the emotional and psychological well-being of caregivers of the patients, preferring to rely on their clinical judgement to identify individuals who may be feeling distressed (Mitchell et al., 2008). How accurate are the medical staff in identifying distressed patients? Sollner et al. (2001) investigated the accuracy of oncologists in identifying such patients by comparing patients’ reports of distress on the Hospital Anxiety and Depression Scale (HADS), Hornheide Questionnaire (measuring patients’ psychosocial problems), Questionnaire to Assess the Need for Psychosocial Support (screening for social and financial problems, perceived social support and interest in supportive counselling), and the Freiburg Questionnaire for Coping with Illness (screening for minimising of problems and treatment compliance), against the oncologists’ assessments of the patient based on the dimensions of level of distress, quality of perceived support from their social network, need for psychotherapeutic support, and need for counselling by a social worker. The study team found not only poor concordance between oncologists’
assessments with patients’ reports on the screening instruments, but also that oncologists’
estimations of patients’ distress showed sensitivity and specificity ranging from 36.7% to 80.2%
and 32.8% to 87.6%, respectively, depending on the cut-off values of the HADS to detect
moderate or severe distress. The results suggested that relying on subjective judgement by
medical personnel could result in many distressed individuals not being identified and referred
for support.

The NCCN and various proponents of cancer distress screening have identified the one-
question Distress Thermometer (DT; Roth et al., 1998) as the screening tool of choice. The DT
has been found to be more efficient and as accurate as the more commonly used 14-item Hospital
Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), and has been found to
maintain reasonable psychometric properties across different populations (Tuinman, Gazendam
Donofrio, & Hoekstra Weebers, 2008; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008).
However, while the DT can accurately identify true positives, it is less able to differentiate
between distressed and non-distressed individuals, possibly because one item is insufficient to
obtain a comprehensive and sufficient indication of a person’s distress.

The Emotional and Help Thermometers (Mitchell, Baker-Glenn, Granger, & Symonds,
2010; ET and HT, respectively) comprise a five-item scale presented in a visual-analogue format
on an 11-point scale, where 0 – none and 10 – extremely, answering to NCCN’s call for a more
holistic measurement of distress. It comprises the initial assessment of level of “distress” and
adds three scales, which measure emotional states such as anxiety, depression, and anger, plus a
fifth thermometer measuring the level of help an individual requires. Mitchell et al. (2010)
administered the ET and HT to 130 cancer patients in the UK and found that with a cut-off score
of 4 on each thermometer, patients with distress, depression and/or anxiety symptoms in the past
seven days were detected with reasonable accuracy, and each of the mood thermometers enhanced the accuracy of the DT. The combined thermometers also did not greatly extend the time taken by participants to complete, as completion did not take more than two minutes. A particular strength of the ET and HT in this study was their ability to identify individuals with depression and anxiety (Mitchell, Baker-Glenn, Granger, et al., 2010). These findings endorse the combination of the Distress Thermometer and Emotion Thermometers (Mitchell, Baker-Glenn, Granger, et al., 2010). The promising initial results of the ET and HT were supported by the administration of the thermometers to a population of adult cardiac patients in the UK (Mitchell et al., 2012), as well as to a sample of adult cancer patients in Singapore (Beck, Tan, Lum, Lim, & Krishna, 2014). However, although the Singapore study showed results of the Distress, Depression and Anxiety Thermometers corresponding to Mitchell et al.’s study, it only utilised these thermometers instead of the whole range [e.g., Depression Thermometer against the Mini-International Neuro-psychiatric Interview (MINI) depression subscale; the Anxiety Thermometer against the MINI generalised anxiety disorder subscale; and the Distress Thermometer against the MINI depression and generalised anxiety disorder subscales]. This suggests that while the ET and HT show promise in distress screening, more research is needed for its validation.

The NCCN acknowledged that the diagnosis of cancer could invoke a sense of hopelessness, and confrontations with the concept of death, which resulted in existential distress among patients. They thus recognised the need to address existential distress among patients. With parents’ description of changes in the family caused by the presence of illness in the family, one convergent aspect starts to appear: life is certainly drastically different from how they used to know it. This brings to mind an image of lightning striking one’s personal world, resulting in a
chaotic universe where nothing makes sense anymore, and individuals’ sense of meaning and their place in the world is threatened (Bjork et al., 2005; Santacroce, 2003). In keeping with the present study’s aim of measuring various aspects of distress as suggested by the NCCN’s definition, a thermometer measuring parents’ existential distress, named the Crushed Universe Thermometer (CrushedUniT), was added to the Mitchell at al. (2010) instrument. In the current study, the thermometers are collectively named the modified ET and HT.

Typically, the ET and HT have been validated against the HADS (Zigmond & Snaith, 1983). Although the HADS has been used in studies validating the use of the Distress Thermometer (DT) among parents of chronically ill children, it was created largely with the hospital or medically ill population in mind, as suggested by its exclusion of somatic symptoms to prevent confounding of symptoms as well as symptoms relating to serious mental health problems. It therefore appears less relevant for assessing individuals who are neither sick themselves nor in hospital (Bjelland, Dahl, Haug, & Neckelmann, 2002; Snaith, 2003).

In the current study, therefore, the modified ET and HT were validated against the Depression, Anxiety and Stress Scale (DASS-21 and DASS; Lovibond & Lovibond, 1993). The DASS has been administered to a variety of populations (i.e., clinical and non-clinical, older adults, young adolescents, etc), cultures (e.g., China, Taiwan, Iran), and languages (Mandarin, Malay, Tamil, etc), including parents of children with cystic fibrosis, as well as tests on existential meaning (R. C. K. Chan et al., 2012; Gloster et al., 2008; Henry & Crawford, 2005; Mascaro & Rosen, 2008; Sahebi, Asghari, & Salari, 2005; Szabó, 2010; M. G. Wong & Heriot, 2008). Parents of children with cancer or a chronic illness are in exceptional circumstances that place them in the grey area between a distressed and normal healthy population (Vannatta & Gerhardt, 2003). While there have been calls to develop measures for parents of children with
cancer or a chronic illness, to date, only a small number of measures have attempted to meet this call (Devine et al., 2014; Kazak et al., 2001; Pai et al., 2008; Streisand, Braniecki, Tercyak, & Kazak, 2001). Thus, the choice to use the DASS was borne out of the need to use a measure that has been administered to a wide range of populations, in particular the normal population. The use of the DASS also matches the multi-faceted nature of distress, represented by the modified ET and HT.

Trauma researchers have cautioned that threats to individuals’ beliefs, values, goals, and assumptions about the world can predispose them to post-traumatic stress symptoms (PTSS) or, in more severe cases, post-traumatic stress disorder (PTSD; Ehlers & Clark, 2000; Janoff-Bulman & Frantz, 1997). In addition, chronic exposure to stressors with no sources of relief or aid can also drain available resources, which may exacerbate distress (Hobfoll, 2001). Faced with a life-threatening illness, or one that does not have a cure in sight, parents endure a lot of uncertainty while managing their lives and their child’s illness, which can have implications for the presence and levels of PTSD (Santacroce, 2003). Thus, to validate the Crushed Universe thermometer (CrushedUniT), the Impact of Events Scale-Revised and the Sense of Coherence-13 items were used to measure the presence of PTSD and resources – both internal and external – possessed by parents in the study.

2.3 Present Study

In light of the potential distress parents of children with cancer or chronic illness may face, and the corresponding lack of psychosocial distress screening tools particularly in the area of existential distress, the current study served three aims: 1) validating the modified ET and HT among parents of children with cancer or a chronic illness; 2) validating the efficacy and validity
of the CrushedUniT among parents of children with cancer or a chronic illness; and 3) determining the optimal thermometer and its cut-offs to measure various psychological outcomes.

The hypotheses for the present study were thus as follows:

H1: Short screening measures would discriminate parents with distress (indicated by cut-off scores on the DASS, IES-R Total score, and SOC-13 Total score) from parents who were not distressed;

H2: The CrushedUniT would predict PTSS as defined by the Impact of Events Scale-Revised Total score, over and above the Distress, Anxiety, Depression, Anger and Need Help Thermometers;

H3: The CrushedUniT would predict crisis of meaning as defined by the Meaningfulness subscale in the Sense of Coherence Scale-13 Items, over and above the other thermometers.
Chapter 3: Study 1 Methods

The current study validated the modified ET and HT among parents of children with cancer or chronic illness. Singapore has two main paediatric hospitals that treat children with cancer or chronic illness, and one Volunteer Welfare Organisation (VWO) set up to address the needs of families of children with chronic illnesses. As such, the current study consisted of multiple sites. These were: Club Rainbow Singapore (CRS), KK Women’s and Children’s Hospital (KKH), and the National University Hospital of Singapore (NUH).

Club Rainbow Singapore is a Volunteer Welfare Organisation for children with chronic illness aged 0 to 21, and their families. Chronic illness groups under their purview are categorised under seven major illness groups: blood disorders (e.g., Thalassemia Major/Minor, Haemophilia, etc.); congenital heart disease; biliary atresia; spina bifida; premature babies (e.g., cerebral palsy, chronic lung disease, etc.); genetic disorders; and others (e.g., asthma, eczema, etc.). Premature birth was considered a category of chronic illness at CRS because of its relation to several disabilities or chronic illnesses such as cerebral palsy, chronic heart or lung diseases, etc. At CRS, children may not become beneficiaries of the organization upon diagnosis; rather, each family joins CRS at different times of their child’s illness journey, depending on the stage at which they are found by healthcare personnel (i.e., medical social workers, doctors, nurses, etc.) to require additional support, or if they wish to seek assistance. Thus, some families may join CRS sometime after their child’s diagnosis, while others may join CRS immediately after their child’s diagnosis.

KK Women and Children’s Hospital and NUH, on the other hand, are the only two hospitals in Singapore with paediatric illness wards. Although there were considerations to
include the paediatric chronic illness wards at KKH and NUH, unfortunately this was not possible. Therefore, participants recruited from KKH and NUH were from the paediatric oncology wards. Participants from the cancer population included parents of children from various types of cancers, including brain tumours. At the two hospitals, families are automatically referred to the Children’s Cancer Foundation (CCF) for assistance upon diagnosis (KKH) or shortly after diagnosis (NUH).

3.1 Participants

A total of 172 participants were recruited for Study 1, over the three data collection sites. 78.9% (n = 120) were recruited from CRS, while 17.4% (n = 30) and 12.8% (n = 22) participants were recruited from KKH and NUH respectively. Background characteristics of the participants and their children are shown in Table 1, grouped according to either cancer or chronic illness. For simplicity, the method for recruitment and data collection for the hospitals will be described together, as they follow the same procedures. Informed Consent Forms for each institution can be found in Appendices A to C.

3.1.1 Club Rainbow Singapore (CRS)

One hundred and twenty participants were recruited from CRS. Of the participants, 85% (n = 102) were mothers, 10.8% (n = 13) were fathers, and 4.2% (n = 5) were grandmothers, aunts, or stepfathers of the child. Within these participants, 6.7% (n = 8) had another child under the purview of CRS. The mean age of the parents was 42.9 (SD 9.4) years. Thus, the total number of children among the parents was 128. The children who the parents were reporting distress about, were on average 133.5 (i.e., 11.1 years old; SD 73.7) months old, while their second child was on average 98.9 months old (i.e., 8.2 years old; SD 55.7); 54.4% (n = 68) were boys while 45.6% (n
= 57) were girls (three parents did not complete the information on their child’s gender). The demographic and medical variables of the participants and their children are shown in Table 1.

The participants were recruited mainly at the main office of CRS, and at the CRS branch offices at KKH and NUH when they turned up for their child’s medical appointments. All the participants recruited needed to be able to understand English or Mandarin. For participants who could not read English or Mandarin, the questions were read out to them.

3.1.2 KK Women and Children’s Hospital (KKH) and the National University Hospital of Singapore (NUH)

Thirty participants were recruited from KKH, of whom 22 were females, and eight were males. Of the females, 20 were mothers and two were grandmothers. All of the males were fathers. Twenty-two participants were recruited from NUH, of whom 15 were mothers and 7 were fathers. Participants were recruited between four and 16 weeks after their child’s diagnosis. 69.2% (n = 36) were boys while 30.8% (n = 16) were girls. The demographic and medical variables of the participants and their children are shown in Table 1.

Of the participants recruited from KKH and NUH, 67.3% (n = 35) were Singaporeans, while the rest were from other countries such as Southeast Asia, Asia, and the Middle-East.

There were significant differences in the demographic variables between parents of children with cancer or chronic illness. Parents of children with cancer were younger, more likely to be married, had higher education and income than parents of children with chronic illness. Children with cancer tended to be younger, and were recruited within a shorter time since diagnosis.
Table 1

Demographic and Medical Variables

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cancer (n = 52)</th>
<th>Chronic Illness (n = 120)</th>
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<tr>
<td></td>
<td>Parent/Caregiver</td>
<td>Parent/Caregiver</td>
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<tr>
<td>Type of caregiver [n (%)]</td>
<td></td>
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<tr>
<td>Mother</td>
<td>35 (67.3)</td>
<td>102 (85.0)</td>
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<tr>
<td>Father</td>
<td>15 (28.8)</td>
<td>13 (10.8)</td>
</tr>
<tr>
<td>Others</td>
<td>2 (3.8)</td>
<td>5 (4.2)</td>
</tr>
<tr>
<td>Age [mean (SD)]*</td>
<td>37.9 (7.3)</td>
<td>42.93 (9.41)</td>
</tr>
<tr>
<td>Marital status [n (%)]1*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>1 (1.9)</td>
<td>9 (7.5)</td>
</tr>
<tr>
<td>Married</td>
<td>48 (92.3)</td>
<td>91 (75.8)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>3 (5.8)</td>
<td>18 (15.0)</td>
</tr>
<tr>
<td>Education [n (%)]2*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary school or less</td>
<td>2 (3.8)</td>
<td>51 (42.5)</td>
</tr>
<tr>
<td>Secondary school</td>
<td>11 (21.1)</td>
<td>42 (35)</td>
</tr>
<tr>
<td>Diploma</td>
<td>13 (25.0)</td>
<td>18 (15.0)</td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>26 (50.0)</td>
<td>6 (5.0)</td>
</tr>
<tr>
<td>Monthly combined income [n (%)]3*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>13 (25.0)</td>
<td>86 (71.67)</td>
</tr>
</tbody>
</table>

1 2 parents from the chronic illness population did not enter marital status.
2 3 parents from the chronic illness population did not enter education.
3 14 parents from the cancer population and 5 parents from the chronic illness population declined to enter their monthly income.
Table 1. Continued

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cancer (n = 52)</th>
<th>Chronic Illness (n = 120)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parent/Caregiver</td>
<td></td>
</tr>
<tr>
<td>Medium</td>
<td>4 (7.7)</td>
<td>15 (12.5)</td>
</tr>
<tr>
<td>High</td>
<td>21 (40.4)</td>
<td>14 (11.70)</td>
</tr>
<tr>
<td>Child</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age [mean (SD)]*</td>
<td>92.69 months (58.80)</td>
<td>133.5 months (73.7; first child); 98.9 months (55.7; second child)</td>
</tr>
<tr>
<td>Time since diagnosis [mean (SD)]*</td>
<td>2.17 months (1.05)</td>
<td>11.29 years (16.38)</td>
</tr>
<tr>
<td>Diagnostic category [n (%)]†</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ALL</td>
<td>17 (9.4)</td>
<td></td>
</tr>
<tr>
<td>Other leukaemia</td>
<td>13 (7.2)</td>
<td></td>
</tr>
<tr>
<td>Hodgkin’s Lymphoma</td>
<td>1 (0.6)</td>
<td></td>
</tr>
<tr>
<td>Solid tumour</td>
<td>18 (10.0)</td>
<td></td>
</tr>
<tr>
<td>Brain tumour</td>
<td>3 (1.7)</td>
<td></td>
</tr>
<tr>
<td>Blood disorders</td>
<td>9 (7.0)</td>
<td></td>
</tr>
<tr>
<td>Congenital heart disease</td>
<td>10 (7.8)</td>
<td></td>
</tr>
<tr>
<td>Liver</td>
<td>9 (7.0)</td>
<td></td>
</tr>
<tr>
<td>Spina bifida</td>
<td>3 (2.3)</td>
<td></td>
</tr>
<tr>
<td>Premature</td>
<td>7 (5.5)</td>
<td></td>
</tr>
<tr>
<td>Genetic disorders</td>
<td>17 (13.3)</td>
<td></td>
</tr>
</tbody>
</table>

(continued)

*4 parents from the chronic illness population did not complete their child’s diagnosis.
Table 1. Continued

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Cancer (n = 52)</th>
<th>Chronic Illness (n = 120)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neurological problems</td>
<td>28 (21.9)</td>
<td></td>
</tr>
<tr>
<td>Renal</td>
<td>6 (4.6)</td>
<td></td>
</tr>
<tr>
<td>Colon</td>
<td>7 (5.5)</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>28 (21.9)</td>
<td></td>
</tr>
</tbody>
</table>

*significant difference between populations, \( p < .01 \).

3.2 Materials

Singapore is a multi-lingual and multi-racial society where, although English is the official language, Mandarin, Malay and Tamil are recognized as the Mother Tongue of the respective races. Taking this into account, there was the consideration that there would be pockets of participants who were unable to understand English. Thus, a decision was made to include a second language to include as many participants in the study as possible. It was initially considered to include all the Mother Tongue versions of the questionnaires so as to maximise recruitment. However, only the Mandarin version was included in the end, for the following reasons. Firstly, we were unable to find validated Malay and Tamil versions of each of the questionnaires; secondly, taking into account cultural differences in language expression within the same language, the author, being a Singaporean Chinese with limited knowledge of Malay and Tamil, would not have been able to make an informed decision about the applicability of the questionnaires in the Singaporean context. Thus, being more familiar with Mandarin, the decision was made to include only English and Mandarin versions of the questionnaires.
The validity of the Emotion and Help Thermometers with the inclusion of the Crushed Universe Thermometer was assessed by comparing the scores of the screening tool with the English and Mandarin versions of the DASS (42-item and 21-item versions depending on participants' language preference; Lovibond & Lovibond, 1993; Zuo & Chang, 2008), the IES-R (Weiss & Marmar, 1997; Wu & Chan, 2003), and the SOC-13 (Antonovsky, 1987; Shiu, 1998).

3.2.1 Modified Emotion and Help Thermometers

The screening tool (both English and Mandarin versions) was a set of five emotion thermometers (Distress, Anxiety, Depression, Anger, Crushed Universe) and a Help thermometer that required parents to rate their levels of distress on a scale from 0 to 10, where 0 = No Distress, 10 = Extreme Distress. The emotion thermometers (with the exception of the Crushed Universe thermometer) and help thermometers were adapted from Mitchell, Baker-Glenn, Granger et al. (2010), while the Crushed Universe thermometer was created for the present study to test for the presence of meaning among participants. Based on the recommendation by the National Comprehensive Cancer Network (NCCN) in 2007 (NCCN, 2007; as cited by Mitchell et al., 2010) The Mandarin version of the thermometers was translated by the author, and checked by five Mandarin speaking individuals from Singapore, who were not accredited translators. Differences in opinion regarding the translated emotion terms were discussed and resolved.

Cronbach’s alphas for the English ET and HT and Mandarin ET and HT were 0.884 and 0.868, respectively.

3.2.2 Depression, Anxiety and Stress Scale-21 Items (DASS-21)

The DASS-21 (Lovibond & Lovibond, 1993) is a 21-item self-report measure that contains three subscales – depression, anxiety, and stress. Participants were asked to rate how
often they had experienced each symptom over the past week (e.g., Depression: “I couldn’t seem to experience any positive feeling at all”; Anxiety: “I was aware of dryness of my mouth”; Stress: “I found it hard to wind down”). Each item on the DASS-21 was rated on a 4-point Likert scale, ranging from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). The total score of each subscale indicates the severity of clients’ levels of depression, anxiety and stress from normal to extremely severe.

The DASS-42 (Zuo & Chang, 2008) was chosen for the Mandarin version because the language structure of Chinese Mandarin is more similar to that of Singapore's. Although a DASS-21 was available in Mandarin, it followed the Cantonese language structure, which may pose problems for Singaporean users. The DASS-42 was validated by R. C. K. Chan et al. (2012) among individuals who had experienced the 2008 Sichuan earthquake, as well as a community sample of undergraduate student volunteers from Beijing. They found Cronbach’s alphas of above 0.90 for each of the DASS subscales, and factor analyses demonstrated a three-factor structure that matched the constructs of depression, anxiety, and stress. The DASS-42 also showed sensitivity to the effects of a large-scale disaster (the Sichuan earthquake), where participants who had undergone the disaster reported significantly higher levels of distress on each of the subscales than the community samples.

Cronbach’s alphas for the English DASS-21 Depression, Anxiety, and Stress subscales were 0.884, 0.856, and 0.883 respectively. The Cronbach’s alphas for the Mandarin DASS-42 were 0.963, 0.944, and 0.945, respectively.
3.2.3 Impact of Events Scale-Revised (IES-R)

The IES-R (Weiss & Marmar, 1997 for English version; Wu & Chan, 2003 for Mandarin version) (Weiss & Marmar, 1997) is a 22-item questionnaire that was developed to assess the subjective effects of stressful life events on individuals (McDonald, 1997). It is a revised version of the older 15-item IES (Horowitz, Wilner, & Alvarez, 1979). The Mandarin version of the IES-R (CIES-R) was developed in Hong Kong and validated on patients from Accident and Emergency Departments, and patients who had undergone motor vehicle accidents (K. S. Chan & Wu, 2004; Wu & Chan, 2003). The CIES-R demonstrated good psychometric properties that were comparable to that of the IES-R. It also showed construct validity as a measure of psychological distress, and subscale homogeneity in the CIES-R Total score.

Parents completed the IES-R and CIES-R in relation to their child’s illness as the traumatic event. The IES-R and CIES-R comprise the total symptom scores and subscale scores of intrusive thoughts (e.g., “I thought about it when I didn’t mean to”), avoidance (e.g., “I avoided letting myself get upset when I thought about it or was reminded of it”) and hyper-arousal (e.g., “I was jumpy and easily startled”) related to their child’s illness. Participants were asked to rate how distressing each of the symptoms was over the past seven days. Each item on the IES-R was rated on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely). Scores on the IES-R can be interpreted by the individual subscales. The individual subscale scores were obtained by averaging the total subscale score, reaching a highest possible score of 4, and a lowest possible score of 0. The IES-R Total score is obtained by adding all the item scores, reaching a highest possible score of 88, and a lowest possible score of 0. The current study utilised the IES-R and CIES-R Total score in its analysis as parents’ overall PTSS symptoms were of interest.
Cronbach’s alphas for the English IES-R and Mandarin IES-R were 0.944 and 0.962, respectively.

3.2.4 Sense of Coherence Scale-13 Items (SOC-13)

The SOC-13 (Antonovsky, 1987 for English version; Shiu, 1998 for Mandarin version) is a 13-item self-report questionnaire that comprises three dimension – comprehensibility (i.e., how events around the individual make sense to him/her); manageability (i.e., whether the individual has the resources to meet the demands posed by the events); and meaningfulness (i.e., whether the event is a challenge that is worthy of investment and engagement). The Mandarin version of the SOC-13 was developed in Hong Kong and implemented on a variety of populations such as public health and critical care nurses, patients with diabetes, and parents of children with autism (Mak et al., 2007; Shiu, 1998, 2004; Yam & Shiu, 2003). The studies showed high internal validity of Cronbach’s alphas between 0.76 and 0.85.

The SOC-13 comprises five items measuring Comprehensibility (e.g., “Do you have the feeling that you are in an unfamiliar situation and don't know what to do?”), four items measuring Manageability (e.g., "How often do you have feelings that you’re not sure you can keep under control?") and four items measuring Meaningfulness (e.g., "How often do you have the feeling that there's little meaning in the things you do in your daily life?"). Each item on the SOC-13 was rated on a 7-point Likert scale, with two anchoring phrases with 7 representing strongest SOC and 1 representing weakest SOC. Thus, the highest possible SOC-13 Total score would be 91, while the lowest possible SOC-13 score would be 13. For each of the subscales, the highest and lowest possible scores would be 35 and 5 for Comprehensibility; and 28 and 4 for Manageability and Meaningfulness, respectively.
Cronbach’s alphas for the English SOC-13 subscales of Comprehensibility, Manageability, Meaningfulness and Total were 0.665, 0.696, 0.506, and 0.824, respectively. The Cronbach’s alphas for the Mandarin SOC-13 subscales of Comprehensibility, Manageability Meaningfulness and Total were 0.775, 0.780, 0.546, and 0.885, respectively.

3.3 Procedure

3.3.1 Ethics Approval

Approval for the study was obtained from four management or Ethics Boards – Murdoch University’s Human Research Ethics Board (ethics approval code: 2012/008), CRS’ Management Council, KKH’s SingHealth Centralised Institutional Review Board (ethics approval code: CIRB 2013/237/D), and NUH’s National Healthcare Group’s Domain Specific Review Board (ethics approval code: 2013/00708). Each site had different management styles and Ethics Boards, which led to a slight difference in the recruitment procedure between Club Rainbow Singapore and the hospitals. These differences will be explained in detail in their respective sections.

3.3.2 Data Collection Procedures

3.3.2A Club Rainbow Singapore (CRS)

Discussions regarding the feasibility of the study, and data collection and participant identification process, commenced at CRS with a Senior Social Worker and Programmes Manager, and finally with the social work team as well as the director of CRS. These discussions revolved around the team’s concerns with crisis management in the event that participants reported high levels of distress such as suicidal ideation, abuse, or serious mental health issues of the participant or beneficiary. As it was a clinical priority for the social workers at CRS to be kept abreast of their members’ emotional and psychological well-being, summarised/finalised
scores of the participants’ responses on the emotion and help Thermometers as well as the assessment battery were made known to the social workers. This was reflected in the Informed Consent Form and verbally explained to the participants. It was also resolved that the social workers would be notified immediately if there were participants who reported high levels of distress, abuse, or serious mental health issues during the study.

A pilot study of the thermometers was conducted at CRS. Parents were mass-administered the thermometers at a Caregivers Appreciation event. Parents were given the opportunity to opt out of the exercise if they wished. Due to the nature of the administration of the thermometers, it was not possible to debrief the pilot participants individually. Thus, the group was debriefed about the significance of each thermometer’s score and their cut-off, and attendants were strongly encouraged to speak with their social worker if they reported scores above the cut-off. Although no formal analysis of the pilot study data was undertaken, it was observed that the feedback from the pilot study possibly allowed for more dialogue between the author, the social workers, and the participants. Between the author and the social workers, there was a clearer understanding of the purpose of the thermometers and demarcation of the author’s and social workers’ duty of care to the participants. The social workers’ concerns that the study would overlap with the latter’s care for the families were resolved. The social workers were able to use the scores as indicators of the participants’ well-being. Parents who were not active with CRS were able to use the thermometers to seek support from their social workers.

Data collection commenced a week after the pilot study. A shared Google Document was set up between the social workers and the author, where the social workers would indicate their appointments, and time of appointments. The author was on-site on the days of the appointments. The social workers made first contact with the participants, informing participants about the
research study being carried out at CRS and providing them with the Information Sheet. The author then entered the room with the participants after they expressed interest to their social worker in taking part in the study. The author then answered any questions the participants had, and also reminded the participants that their social workers would be provided a summary of their scores, and that they were free to withdraw from the study at any point. Participants were asked to express their consent in writing when all their questions were answered.

Participants were administered a set of questionnaires which consisted of the Emotion and Help Thermometers, DASS (21-items or 42-tens depending on language preference) IES-R and SOC-13. While the ET and HT were always the first to be administered, the DASS, IES-R and SOC-13 were counterbalanced into six versions to reduce fatigue and practice effects. Participants who could understand but had limited literacy in English or Mandarin had the questions read out to them. On average, participants took less than two minutes to complete the thermometers, and 20-30 minutes to complete the whole set of questionnaires.

Upon completion of the questionnaires, the participants’ scores were entered into a Microsoft Excel spreadsheet, and the participants were debriefed. Specifically, participants’ scores on the thermometers and the assessment battery were explained to them, and any questions they had were answered. Although the participants were aware that their social workers would have a summary of their scores, those who reported high levels of distress were also strongly encouraged to discuss their distress with their social workers.
3.3.2B KK Women and Children’s Hospital (KKH) and the National University Hospital of Singapore (NUH)

Discussions first commenced with the respective heads of departments of the Psychological Medicine and Paediatric Oncology wards. These discussions, like that at CRS, revolved around issues of crisis management, flow of information and duty of care, and recruitment method. Specifically, the hospitals were concerned about issues of referral, and overlap in the care of the participants with the CCF social workers.

Discussions were held with CCF after the heads of departments agreed to collaborate on the research, and logistics issues such as recruitment method were also discussed. The CCF social workers were recommended to be the referral body for the research as they were the agency most in contact with the families, and therefore in the best position to identify and refer eligible families to the study.

The CCF social workers identified parents who had received their child’s diagnosis of cancer in the past four to eight weeks, and informed them about the study. These parents were provided an information sheet about the study, which included the potential risks and benefits of the study, their rights and responsibilities, and the contact numbers of the author and Principal Investigator.

Parents were asked by the CCF social workers during their next appointment about their interest in taking part in the research. For parents who indicated interest in the study, the social workers, with the parents’ permission, provided the author with their contact number. The author then called up these parents to arrange an appointment.
Appointments with the parents usually took place when the child was hospitalised for treatment, or when the child returned for treatment or outpatient visits. When the child was hospitalised, the author met the participants in the wards and administered the questionnaires there. During outpatient visits, the author met participants in one of the available consultation rooms and administered the questionnaires.

After the commencement of the recruitment, a few changes were made. Firstly, it had initially been decided to recruit only Singaporean parents into the study. However, recruitment remained slow and feedback from the hospitals was that there had been several children of various nationalities diagnosed with cancer, in comparison with Singaporean children. This was especially the case at NUH, which is a teaching and research hospital with state-of-the-art technology and internationally-renowned doctors. As such, the decision was made to open the study to international patients, who came from various countries in Southeast Asia, the Middle-east, and Europe.

Secondly, it was originally agreed that the participants would be recruited four and eight weeks from their child’s diagnosis; however, the recruitment rate during this period was very slow. Feedback from the CCF social workers suggested that the majority of parents were still feeling overwhelmed by their child’s diagnosis and its implications, and that they had not given thought to participating in the study. By the time they indicated interest in the study, these parents were past the recruitment cut-off date. As such, it was decided that the period since diagnosis be lengthened to between four and sixteen weeks to maximise the recruitment rate. The decision to increase to 16 weeks was informed by Kazak et al.’s (2003; 2005) research, where they recruited recently diagnosed families within the same time frame.
As with the CRS sample, participants first completed the emotion and help thermometers, then moved on to counter-balanced copies of the assessment battery. Their scores were similarly entered into a Microsoft Excel spreadsheet and tabulated. Participants were then debriefed, and any questions they had were answered. Permission was sought from the participants to inform their CCF social workers if they reported any concerns or issues about their child’s treatment. When permission was given, the social workers were then given a summary of the session. All participants were enthusiastic about letting their social workers know about the session. They were encouraged to speak to their social workers about their scores, especially those who reported high levels of distress.

3.4 Data Analysis

A power analysis was conducted to determine the minimum sample size. Based on Cohen’s (1992) calculations, to obtain a minimum power of 80% and a medium effect size of 0.30, a minimum of 85 participants were needed.

Sensitivity, specificity, positive predictive values and negative predictive values were calculated to assess the modified ET and HT’s diagnostic accuracy at NCCN’s recommended cut-offs of 4, and receiver operating characteristics (ROC) curves were used to assess the discriminating ability of the thermometers in detecting various types of distress among the participants.

To analyse the diagnostic accuracy, cut-offs needed to be established for the assessment battery. For the DASS (both English and Mandarin versions), the study used the cut-offs of 10 and above for Depression, 8 and above for Anxiety, and 15 and above for Stress (Lovibond & Lovibond, 1993). The decision to use cut-offs that indicated mild levels of depression, anxiety,
and stress was borne from the study’s purpose to optimise the cut-off needed to detect parents who needed assistance.

With regard to the IES-R Total score, Weiss (1997) advised that there is no cut-off for the scale. However, as several cut-offs for the IES-R have been investigated and tested, and it has sometimes been used to identify clinical cases of PTSD (Samuelson, Lundberg, & Fridlund, 2007), the current study chose to use the cut-off of 33 recommended by Creamer, Bell, and Failla (2003) because it yielded an overall diagnostic power of 0.88, and had a “sensitivity of 0.91, a specificity of 0.82, positive predictive power of 0.90, and negative predictive power of 0.84” (p.1494). This cut-off was used for both the English and Mandarin versions of the IES-R.

The SOC-13 faced the same constraints as the IES-R. Antonovsky had asserted that as health occurs on a continuum, no cut-off should be established for any of the SOC scales. However, Holmefur, Sundberg, Wettergren, and Langius-eklöf (2015) found that the SOC-13 Total scores could be separated into three strata that “confirms the theoretical hypothesis regarding the SOC construct that a population can be divided into 25% having the lowest SOC scores, 50% having scores in the middle, and 25% having the highest scores” (p. 1462). As such, the study used the cut-off of 58 and above proposed by Holmefur et al. (2015) to identify individuals with SOC from the medium range and below. This cut-off score was used for both the English and Mandarin versions of the SOC-13.

Hierarchical multiple regression analyses were conducted to test Hypotheses 2 and 3. Population Type and Time Since Diagnosis were controlled to minimise their possible confound. Mitchell et al.’s (2010) thermometers and the CrushedUniT were then separately entered into the
regression equation. Pearson’s Product Moment Correlation $r$ was computed to find out the correlations between the variables.

For all the institutions, scores were entered into the Statistical Package for the Social Sciences (SPSS) Version 22 software to be analysed. The diagnostic accuracy of the thermometers when NCCN’s recommended cut-off of 4 was used, as well as all the regression analyses, were conducted using SPSS. Diagnostic accuracy based on the ROC analyses was conducted using the MedCalc statistical software.
Chapter 4: Study 1 Results

4.1 Results

In this section, the results of the current study will be presented in the following order: (a) the diagnostic accuracy of the thermometers; (b) the efficacy of the CrushedUniT in predicting PTSS and Meaningfulness beyond the original ET and HT; and (c) the optimal combination of thermometers to predict various forms of distress.

4.1.1 Diagnostic Accuracy of Thermometers

Findings from calculation of the sensitivity, specificity, negative and positive predictive values based on NCCN’s recommended cut-off of 4 for all thermometers including the CrushedUniT (Table 2), and ROC analysis (Table 3), are reported. The thermometers were compared against the DASS subscales (i.e., Depression, Anxiety and Stress), the IES-R Total score and SOC-13 Total score.

4.1.1A Diagnostic Accuracy of Thermometers Against Depression

Based on the NCCN’s recommended cut-offs of 4, the thermometers had reasonable sensitivity ranging from 61.7% to 93.7%, but comparatively lower specificity ranging from 35.1% to 75.3%. The CrushedUniT demonstrated similar levels of sensitivity and specificity (61.7% and 75.3% respectively). The rule-out accuracy was the best for the AnxT (NPV = 81.8%).

Based on the ROC analysis, all the thermometers were statistically significant in their ability to identify parents reporting depression as defined by the DASS Depression subscale. The optimal thermometer recommended by the analysis was the DT (ROC = 0.782, Se = 62.1%, Sp = 79.2%) at a cut-off of above 5. In comparison, the DepT was less accurate (ROC = 0.755. Se =
75.8%, Sp = 66.2%) at a cut-off of above 4. The CrushedUniT demonstrated the best rule-in accuracy (PPV = 82.9) at cut-off of above 3.

### 4.1.1B Diagnostic Accuracy of Thermometers Against Anxiety

Using the NCCN’s recommended cut-off of 4 for all thermometers, the thermometers showed reasonable sensitivity ranging from 61.2% to 90.4%, and lower specificity ranging from 33.8% to 79.4%. The AnxT showed the best sensitivity (90.4%) but the lowest specificity (33.8%), while the CrushedUniT showed more equivalent and reasonable sensitivity (61.2%) and specificity (79.4%). In terms of rule-in and rule-out accuracy, the CrushedUniT (PPV = 81.8%) and the DT (NPV = 75%) performed the best respectively.

Based on the ROC analysis, against DASS-defined Anxiety, all the thermometers demonstrated discriminatory abilities of anxiety in the same range. Their ROCs ranged from 0.709 (AngT) to 0.790 (DT). The thermometer with the best rule-in accuracy was the HT (PPV = 84.1%) at a cut-off of more than 5. The rule-out accuracy of the thermometers were modest, ranging from 55.3% (HT) to 69.5% (DT). The CrushedUniT showed improved diagnostic accuracy in terms of sensitivity, specificity, rule-in and rule-out accuracies when the cut-off was at more than 1.

### 4.1.1C Diagnostic Accuracy of Thermometers Against Stress

At the pre-determined cut-off of 4 against DASS-defined Stress, the thermometers demonstrated good sensitivity of between 63.5% (CrushedUniT) and 92.8% (AnxT). The specificity of the thermometers was comparatively weaker. The AnxT had the weakest specificity (34.7%), and the CrushedUniT had comparatively the highest specificity (78.7%).
The CrushedUniT showed the highest rule-in accuracy (PPV = 79.2%) and the AnxT the highest rule-out accuracy (NPV = 78.8%).

The ROC analysis found reasonable discriminatory ability of the thermometers in identifying parents reporting stress as defined by the DASS-Stress subscale (ROC from 0.678 to 0.757). With the highest ROC, the DT also demonstrated the best rule-in accuracy, PPV = 83.6%. The HT showed the best rule-out accuracy, NPV = 73.6%.

4.1.1D Diagnostic Accuracy of Thermometers Against Post-Traumatic Stress Symptoms

Using 4 as the pre-determined cut-off score, the thermometers demonstrated good sensitivity against IES-R Total scores. The AngT, DT, DepT and HT showed high sensitivity (84.3% - 95.5%), while the CrushedUniT showed the weakest sensitivity (Se = 68.5%). Nonetheless, the CrushedUniT showed the strongest specificity (Sp = 80.5%) and rule-in accuracy (79.2%). The rule-out accuracy of the AnxT was the highest (NPV = 87.8%).

Using the ROC analysis, all the thermometers except for the AngT demonstrated reasonable discriminatory ability in identifying PTSS defined by the IES-R Total score. At a cut-off of more than 1, the CrushedUniT showed the best rule-in accuracy (PPV = 77.4%), and improved rule-out accuracy (NPV = 73.5%) compared to a cut-off of 4.

4.1.1E Diagnostic Accuracy of Thermometers Against Overall SOC

For the SOC-13, higher scores indicate better preparedness for life challenges, hence indicating more positive outcomes, while lower scores indicate difficulties in preparedness, indicating more negative outcomes.

At the NCCN’s recommended cut-off of 4, the sensitivity of the thermometers ranged from low to moderate. The AnxT showed the weakest sensitivity (Se = 34.2%) in identifying
parents with moderate to high levels of SOC, while the CrushedUniT showed the strongest sensitivity (78.9%) and rule-out accuracy (NPV = 74.6%). The AnxT had the strongest specificity (81.9%). The HT had the highest rule-in accuracy for identifying parents with high SOC (NPV = 65.0%).

Using the ROC analysis, the thermometers demonstrated modest ability to identify parents reporting high levels of SOC. The ROCs ranged from 0.606 (AnxT) to 0.684 (CrushedUniT). The AngT demonstrated the strongest rule-in accuracy for identifying parents with high SOC (PPV = 69.3) and the CrushedUniT demonstrated the highest rule-out accuracy (NPV = 72.0%). The CrushedUniT’s optimal cut-off was more than 1.

Overall, the diagnostic accuracy results as shown in Tables 2 and 3 below, indicated that the modified ET and HT possessed reasonable ability, as well as modest to good levels of rule-in and rule-out accuracies, to detect a variety of psychological distress among parents of children with cancer or chronic illness. Thus, H1 was supported.

The next analysis on the efficacy of the CrushedUniT will report findings answering H2 and H3.
Table 2

*Diagnostic Accuracy for Emotion and Help Thermometer (≥ 4) Against the DASS subscales, IES-R Total, and SOC-13 Total*

<table>
<thead>
<tr>
<th></th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>CrushedUniT</th>
<th>HT</th>
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<tbody>
<tr>
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<td></td>
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</tr>
<tr>
<td>Sensitivity</td>
<td>89.5%</td>
<td>93.7%</td>
<td>85.3%</td>
<td>76.8%</td>
<td>61.7%</td>
<td>83.2%</td>
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<tr>
<td>Specificity</td>
<td>44.2%</td>
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<tr>
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<td>66.4%</td>
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<tr>
<td>NPV</td>
<td>77.3%</td>
<td>81.8%</td>
<td>73.6%</td>
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<td>61.7%</td>
<td>69.8%</td>
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<tr>
<td>Sensitivity</td>
<td>89.4%</td>
<td>90.4%</td>
<td>79.8%</td>
<td>76.9%</td>
<td>61.2%</td>
<td>83.7%</td>
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<tr>
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<td>79.4%</td>
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<tr>
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<tr>
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<td>60.7%</td>
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<td>67.9%</td>
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<tr>
<td>Sensitivity</td>
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<tr>
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<td>34.7%</td>
<td>48.0%</td>
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<th>AngT</th>
<th>CrushedUniT</th>
<th>HT</th>
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<tr>
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<td>68.5%</td>
<td>84.3%</td>
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<td>47.0%</td>
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<tr>
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<td>63.0%</td>
</tr>
<tr>
<td>NPV</td>
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<td>87.8%</td>
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<td>73.6%</td>
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<tr>
<td>Against SOC-13 Total</td>
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<td>52.6%</td>
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<td>78.9%</td>
<td>51.3%</td>
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<tr>
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<td>81.9%</td>
<td>76.6%</td>
<td>67.0%</td>
<td>50.5%</td>
<td>77.7%</td>
</tr>
<tr>
<td>PPV</td>
<td>62.1%</td>
<td>60.6%</td>
<td>64.5%</td>
<td>59.7%</td>
<td>56.6%</td>
<td>65.0%</td>
</tr>
<tr>
<td>NPV</td>
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<td>66.7%</td>
<td>67.7%</td>
<td>74.6%</td>
<td>66.4%</td>
</tr>
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*Note.* PPV = Positive predictive value; NPV = Negative predictive value
### Table 3

**Diagnostic Accuracy of Emotion and Help Thermometers Against the DASS subscales, IES-R Total, and SOC-13 Total Based on ROC Analysis**

<table>
<thead>
<tr>
<th></th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>CrushedUniT</th>
<th>HT</th>
</tr>
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<tbody>
<tr>
<td><strong>Against DASS-Depression</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area under ROC; 95% CI</td>
<td>0.782</td>
<td>0.736</td>
<td>0.755</td>
<td>0.666</td>
<td>0.757</td>
<td>0.722</td>
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<tr>
<td>(0.713 – 0.841)</td>
<td>(0.664 – 0.800)</td>
<td>(0.684 – 0.817)</td>
<td>(0.590 – 0.736)</td>
<td>(0.685 – 0.819)</td>
<td>(0.649 – 0.788)</td>
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<tr>
<td>Delong standard error</td>
<td>0.034</td>
<td>0.038</td>
<td>0.037</td>
<td>0.041</td>
<td>0.035</td>
<td>0.039</td>
</tr>
<tr>
<td>Optimum cut-off</td>
<td>&gt; 5</td>
<td>&gt; 4</td>
<td>&gt; 4</td>
<td>&gt;2</td>
<td>&gt; 3</td>
<td>&gt; 6</td>
</tr>
<tr>
<td>Sensitivity; 95% CI</td>
<td>62.1</td>
<td>84.2</td>
<td>75.8</td>
<td>75.8</td>
<td>56.4</td>
<td>53.7</td>
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<tr>
<td>(51.6 – 71.9)</td>
<td>(75.3 – 90.9)</td>
<td>(65.9 – 84.0)</td>
<td>(65.9 – 84.0)</td>
<td>(45.8 – 66.6)</td>
<td>(43.2 – 64.0)</td>
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<tr>
<td>Specificity; 95% CI</td>
<td>79.2</td>
<td>52.0</td>
<td>66.2</td>
<td>50.7</td>
<td>85.7</td>
<td>84.4</td>
</tr>
<tr>
<td>(68.5 – 87.6)</td>
<td>(40.3 – 63.5)</td>
<td>(54.6 – 76.6)</td>
<td>(39.0 – 62.2)</td>
<td>(75.9 – 92.6)</td>
<td>(74.4 – 91.7)</td>
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### Table 3. Continued

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<th>AngT</th>
<th>CrushedUniT</th>
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</tr>
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<tbody>
<tr>
<td><strong>Against DASS-Depression</strong></td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>PPV; 95% CI</td>
<td>78.6</td>
<td>68.3</td>
<td>73.4</td>
<td>65.4</td>
<td>82.9</td>
<td>80.9</td>
</tr>
<tr>
<td>(67.7 – 87.3)</td>
<td></td>
<td>(59.1 – 76.6)</td>
<td>(63.6 – 81.9)</td>
<td>(55.8 – 74.2)</td>
<td>(71.5 – 91.2)</td>
<td>(69.1 – 89.7)</td>
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<tr>
<td>NPV; 95% CI</td>
<td>62.9</td>
<td>72.8</td>
<td>68.9</td>
<td>62.9</td>
<td>61.5</td>
<td>59.7</td>
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<td>(57.1 – 79.2)</td>
<td>(49.7 – 74.9)</td>
<td>(51.6 – 70.7)</td>
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<tr>
<td>Area under ROC; 95% CI</td>
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<td>(0.662 – 0.799)</td>
<td>(0.635 – 0.776)</td>
<td>(0.688 – 0.821)</td>
<td>(0.661 – 0.798)</td>
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<tr>
<td>Delong standard error</td>
<td>0.034</td>
<td>0.040</td>
<td>0.038</td>
<td>0.040</td>
<td>0.034</td>
<td>0.038</td>
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<tr>
<td>Optimum cut-off</td>
<td>&gt; 3</td>
<td>&gt; 5</td>
<td>&gt; 4</td>
<td>&gt; 3</td>
<td>&gt; 1</td>
<td>&gt; 5</td>
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Table 3. Continued

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<tbody>
<tr>
<td><strong>Against DASS-Anxiety</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sensitivity; 95% CI</td>
<td>82.7</td>
<td>63.5</td>
<td>72.1</td>
<td>67.3</td>
<td>68.0</td>
<td>55.8</td>
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<td>(62.5 – 80.5)</td>
<td>(57.4 – 76.2)</td>
<td>(58.0 – 76.8)</td>
<td>(45.7 – 65.5)</td>
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<tr>
<td>Specificity; 95% CI</td>
<td>60.3</td>
<td>70.6</td>
<td>66.2</td>
<td>64.7</td>
<td>78.0</td>
<td>83.8</td>
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<td>(58.3 – 81.0)</td>
<td>(53.7 – 77.2)</td>
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<td>(66.2 – 87.1)</td>
<td>(72.9 – 91.6)</td>
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<tr>
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<td>76.6</td>
<td>74.5</td>
<td>82.5</td>
<td>84.1</td>
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<td>(72.8 – 89.9)</td>
<td>(73.3 – 91.8)</td>
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<td>(45.2 – 65.1)</td>
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<th>DepT</th>
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<th>HT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Against DASS-Stress</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Area under ROC; 95% CI</td>
<td>0.757</td>
<td>0.715</td>
<td>0.738</td>
<td>0.678</td>
<td>0.746</td>
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<td></td>
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<td>(0.641 – 0.781)</td>
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<td>(0.602 – 0.747)</td>
<td>(0.674 – 0.810)</td>
<td>(0.659 – 0.797)</td>
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<th>AngT</th>
<th>CrushedUniT</th>
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<td>&gt; 4</td>
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<td>&gt; 2</td>
<td>&gt; 2</td>
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<td>66.7</td>
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<td>74.5</td>
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<td>56.9</td>
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<td>(59.7 – 84.7)</td>
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<th>AngT</th>
<th>CrushedUniT</th>
<th>HT</th>
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<tbody>
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<td><strong>Against IES-R Total</strong></td>
<td></td>
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</tr>
<tr>
<td>Area under ROC; 95% CI</td>
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<td>0.674</td>
<td>0.796</td>
<td>0.716</td>
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<td>(0.675 – 0.810)</td>
<td>(0.720 – 0.847)</td>
<td>(0.599 – 0.744)</td>
<td>(0.727 – 0.853)</td>
<td>(0.642 – 0.782)</td>
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<td>0.037</td>
<td>0.035</td>
<td>0.041</td>
<td>0.033</td>
<td>0.039</td>
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<tr>
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<td>&gt; 5</td>
<td>&gt; 4</td>
<td>&gt; 4</td>
<td>&gt; 3</td>
<td>&gt; 1</td>
<td>&gt; 6</td>
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<tr>
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<td>61.8</td>
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<td>79.8</td>
<td>68.5</td>
<td>74.2</td>
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<td>(65.3 – 84.6)</td>
<td>(40.6 – 62.9)</td>
<td>(56.3 – 77.4)</td>
<td>(48.9 – 70.8)</td>
<td>(66.2 – 85.4)</td>
<td>(70.6 – 88.6)</td>
</tr>
<tr>
<td>PPV; 95% CI</td>
<td>73.3</td>
<td>65.8</td>
<td>72.4</td>
<td>64.9</td>
<td>77.4</td>
<td>74.6</td>
</tr>
<tr>
<td></td>
<td>(61.8 – 82.9)</td>
<td>(56.4 – 74.3)</td>
<td>(62.5 – 81.0)</td>
<td>(54.3 – 74.4)</td>
<td>(67.0 – 85.8)</td>
<td>(62.0 – 84.7)</td>
</tr>
</tbody>
</table>

(continued)
<table>
<thead>
<tr>
<th></th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>CrushedUniT</th>
<th>HT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Against IES-R Total</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NPV; 95% CI</td>
<td>65.0</td>
<td>78.2</td>
<td>75.7</td>
<td>64.1</td>
<td>73.5</td>
<td>61.5</td>
</tr>
<tr>
<td>(54.6 – 74.4)</td>
<td></td>
<td>(65.0 – 88.2)</td>
<td>(64.3 – 84.9)</td>
<td>(52.5 – 74.7)</td>
<td>(62.9 – 82.4)</td>
<td>(51.7 – 70.7)</td>
</tr>
<tr>
<td>Area under ROC; 95% CI</td>
<td>0.641</td>
<td>0.606</td>
<td>0.671</td>
<td>0.676</td>
<td>0.684</td>
<td>0.677</td>
</tr>
<tr>
<td>(0.564 – 0.712)</td>
<td></td>
<td>(0.529 – 0.680)</td>
<td>(0.596 – 0.741)</td>
<td>(0.601 – 0.745)</td>
<td>(0.609 – 0.753)</td>
<td>(0.601 – 0.746)</td>
</tr>
<tr>
<td>Delong standard error</td>
<td>0.042</td>
<td>0.044</td>
<td>0.042</td>
<td>0.042</td>
<td>0.039</td>
<td>0.042</td>
</tr>
<tr>
<td>Optimum cut-off</td>
<td>≤ 3</td>
<td>≤ 4</td>
<td>≤ 4</td>
<td>≤ 2</td>
<td>≤ 1</td>
<td>≤ 4</td>
</tr>
<tr>
<td>Sensitivity; 95% CI</td>
<td>47.4</td>
<td>42.3</td>
<td>62.8</td>
<td>55.1</td>
<td>69.2</td>
<td>55.1</td>
</tr>
<tr>
<td>(36.0 – 59.1)</td>
<td></td>
<td>(31.2 – 54.0)</td>
<td>(51.1 – 73.5)</td>
<td>(43.4 – 66.4)</td>
<td>(57.8 – 79.2)</td>
<td>(43.4 – 66.4)</td>
</tr>
</tbody>
</table>

(continued)
Table 3. Continued

<table>
<thead>
<tr>
<th>Against SOC-13 Total</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>CrushedUniT</th>
<th>HT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specificity; 95% CI</td>
<td>76.6</td>
<td>76.6</td>
<td>73.4</td>
<td>79.8</td>
<td>65.6</td>
<td>75.5</td>
</tr>
<tr>
<td></td>
<td>(66.7 – 84.7)</td>
<td>(66.7 – 84.7)</td>
<td>(63.3 – 82.0)</td>
<td>(70.2 – 87.4)</td>
<td>(55.0 – 75.1)</td>
<td>(65.6 – 83.8)</td>
</tr>
<tr>
<td>PPV; 95% CI</td>
<td>62.7</td>
<td>60.0</td>
<td>66.2</td>
<td>69.3</td>
<td>62.5</td>
<td>65.1</td>
</tr>
<tr>
<td></td>
<td>(49.1 – 74.9)</td>
<td>(45.9 – 72.9)</td>
<td>(54.2 – 76.8)</td>
<td>(56.3 – 80.4)</td>
<td>(51.4 – 72.7)</td>
<td>(52.4 – 76.4)</td>
</tr>
<tr>
<td>NPV; 95% CI</td>
<td>63.8</td>
<td>61.6</td>
<td>70.4</td>
<td>68.2</td>
<td>72.0</td>
<td>67.0</td>
</tr>
<tr>
<td></td>
<td>(54.2 – 72.6)</td>
<td>(52.1 – 70.4)</td>
<td>(60.4 – 79.2)</td>
<td>(58.7 – 76.8)</td>
<td>(61.2 – 81.2)</td>
<td>(57.2 – 75.8)</td>
</tr>
</tbody>
</table>
4.1.2 Efficacy of the Crushed Universe Thermometer in Comparison with Other Thermometers

Hierarchical multiple regression analyses were conducted to determine the efficacy of the CrushedUniT in predicting IES-R Total scores (measuring PTSS) and SOC-Meaningfulness, while controlling for population type (i.e., parents of children with cancer or chronic illness) and time since diagnosis. Population Type and Time Since Diagnosis were simultaneously entered into Block 1, the original set of thermometers (i.e., DT, AnxT, DepT, AngT, and HT) were simultaneously entered into Block 2, and the CrushedUniT entered into Block 3 as the independent (or predictor) variables.

4.1.2A Efficacy of Crushed Universe Thermometer Over Other Thermometers in predicting IES-R Total Score

The hierarchical multiple regression (Table 4) revealed that in Model 1, Population Type and Time Since Diagnosis did not contribute significantly to the regression model, \( F(2,158) = 0.714, p > .05 \). Population Type and Time Since Diagnosis accounted for 0.9% of the variation in IES-R Total. In Model 2, the inclusion of the original thermometers accounted for 35.2% of the variance in IES-R, and this change in \( R^2 \) was significant, \( F(5, 153) = 16.22, p < .01 \). Higher scores on the thermometers were associated with higher IES-R Total scores. Including the CrushedUniT in Model 3 explained an additional 2.4% of the variation in IES-R Total. The \( R^2 \) change was also significant, \( F(1, 152) = 5.931, p < .05 \). When all the independent variables were included in the final model, only the DepT and CrushedUniT were significant independent predictors of IES-R Total. The most important predictor of IES-R Total was the CrushedUniT (\( \beta = 0.237, p < .05 \)).

The correlations between the variables (Table 5) corresponded with the results of the regression analysis. The thermometers had significant medium to large correlations with IES-R Total. Among them, the DepT and CrushedUniT had the largest correlation with the IES-R
Total, $r = 0.518$ and $r = 0.547$, $p < .01$ respectively. Time Since Diagnosis had a small but statistically significant relationship with the AngT, $r = 0.243$, $p < .01$.

Table 4

_Hierarchical Multiple Regression Analyses of Modified ET and HT on IES-R Total Score_

<table>
<thead>
<tr>
<th>Model</th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>Sig. of R² change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Model 1</td>
<td></td>
<td></td>
<td>0.009</td>
<td>0.491</td>
</tr>
<tr>
<td>Population type</td>
<td>0.040</td>
<td>0.693</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td>0.064</td>
<td>0.524</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 2</td>
<td></td>
<td>0.352</td>
<td>&lt; 0.0001</td>
<td></td>
</tr>
<tr>
<td>Population type</td>
<td>0.025</td>
<td>0.788</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.040</td>
<td>0.637</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT</td>
<td>0.058</td>
<td>0.572</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxT</td>
<td>0.159</td>
<td>0.123</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>0.305</td>
<td>0.003</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.144</td>
<td>0.103</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>0.044</td>
<td>0.629</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Model 3</td>
<td></td>
<td>0.377</td>
<td>0.016</td>
<td></td>
</tr>
<tr>
<td>Population type</td>
<td>0.031</td>
<td>0.729</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.053</td>
<td>0.525</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT</td>
<td>-0.006</td>
<td>0.954</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxT</td>
<td>0.162</td>
<td>0.110</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>0.210</td>
<td>0.049</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.095</td>
<td>0.286</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>0.033</td>
<td>0.713</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>0.237</td>
<td>0.016</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5

*Correlation between Thermometers, Population Type, Time Since Diagnosis, and IES-R Total Score*

<table>
<thead>
<tr>
<th></th>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>IES-R Total Scores</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Type</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since Diagnosis</td>
<td>0.622**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>IES-R Total Scores</td>
<td>0.061</td>
<td>0.086</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT</td>
<td>-0.036</td>
<td>0.000</td>
<td>0.459**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxT</td>
<td>-0.066</td>
<td>0.017</td>
<td>0.452**</td>
<td>0.646**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>-0.032</td>
<td>-0.020</td>
<td>0.518**</td>
<td>0.667**</td>
<td>0.656**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.375**</td>
<td>0.243**</td>
<td>0.383**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>0.127</td>
<td>-0.028</td>
<td>0.438**</td>
<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
<td>0.477**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.006</td>
<td>0.153</td>
<td>0.547**</td>
<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>0.540**</td>
<td>1</td>
</tr>
</tbody>
</table>

*p < .01 (2-tailed)
4.1.2B Efficacy of Crushed Universe Thermometer Over Other Thermometers in predicting SOC-13 Meaningfulness

A similar three stage hierarchical multiple regression was conducted with the SOC-13 Meaningfulness subscale as the dependent variable. The regression statistics are reported in Table 6 below.

In Model 1, Population Type and Time Since Diagnosis accounted for 7.3% of the variance in SOC-13 Meaningfulness, $F(2,158) = 6.247, p < .01$, which reflected a significant $R^2$ change. When the original thermometers were added into the regression model (Model 2), they accounted for an additional 9.9% of the variation of the model, resulting in significant $R^2$ change, $F(5,153) = 3.64, p < .01$. In Model 3, adding the CrushedUniT resulted in an additional 5.9% variation in SOC-13 Meaningfulness, which was a significant $R^2$ change, $F(1, 152) = 11.76, p < .01$. Higher scores on the thermometers were associated with lower SOC-13 Meaningfulness scores. When all the independent variables were included in the final model, only Population Type and the CrushedUniT were significant predictors of SOC-13 Meaningfulness. The CrushedUniT was the most significant predictor of SOC-13 Meaningfulness ($\beta = -0.37, p < .01$).

Table 7 summarises the correlations between the variables. SOC-13 Meaningfulness had a small to medium correlation with all the thermometers and Population Type. It had the highest correlation with the CrushedUniT, followed by the HT. The results corresponded with the regression analysis. Time Since Diagnosis had a small but statistically significant relationship with the AngT, $r = 0.243, p < .01$.

Overall, the results supported H2 and H3 in that the CrushedUniT contributed statistically significant variance in the prediction of IES-R Total score and SOC-13 Meaningfulness. Population Type also contributed significant variance in predicting
Meaningfulness, suggesting that the parents of children with chronic illness reported lower levels of sense of meaningfulness than parents of children with cancer.

Table 6

Hierarchical Multiple Regression Analyses of Modified ET and HT on SOC-13 Meaningfulness

<table>
<thead>
<tr>
<th>Model 1</th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>Sig. of R² change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population type</td>
<td>-0.292</td>
<td>0.003</td>
<td>0.073</td>
<td>0.002</td>
</tr>
<tr>
<td>Time Since Diagnosis</td>
<td>0.038</td>
<td>0.700</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Model 2</th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>Sig. of R² change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population type</td>
<td>-0.287</td>
<td>0.006</td>
<td>0.172</td>
<td>0.004</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.057</td>
<td>0.546</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT</td>
<td>0.021</td>
<td>0.853</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxT</td>
<td>-0.018</td>
<td>0.878</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>-0.185</td>
<td>0.104</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>-0.013</td>
<td>0.900</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>-0.164</td>
<td>0.112</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Model 3</th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>Sig. of R² change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population type</td>
<td>-0.298</td>
<td>0.003</td>
<td>0.231</td>
<td>0.001</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.037</td>
<td>0.688</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DT</td>
<td>0.121</td>
<td>0.295</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxT</td>
<td>-0.022</td>
<td>0.842</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>-0.036</td>
<td>0.758</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.064</td>
<td>0.516</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>-0.147</td>
<td>0.141</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.371</td>
<td>0.001</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 7

Correlation between Thermometers, Population Type, Time Since Diagnosis, and SOC-13 Meaningfulness

<table>
<thead>
<tr>
<th></th>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>SOC-13 Meaningfulness</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Type</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since Diagnosis</td>
<td>0.622**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SOC-13 Meaningfulness</td>
<td>-0.266**</td>
<td>-0.144</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>DT</td>
<td>-0.036</td>
<td>0.000</td>
<td>-0.227**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AnxT</td>
<td>-0.066</td>
<td>0.017</td>
<td>-0.171**</td>
<td>0.646**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>-0.032</td>
<td>-0.020</td>
<td>-0.284**</td>
<td>0.667**</td>
<td>0.656**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.375**</td>
<td>-0.243**</td>
<td>-0.269**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>0.127</td>
<td>-0.153</td>
<td>-0.315**</td>
<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
<td>0.477**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.006</td>
<td>-0.028</td>
<td>-0.398**</td>
<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>-0.540**</td>
<td>1</td>
</tr>
</tbody>
</table>

**p < .01 (2-tailed); *p < .05 (2-tailed)
4.1.3 Combination of Thermometers in Predicting Types of Distress

The same hierarchical multiple regression analyses were used to determine the optimal combination of thermometers, while controlling for population type and time since diagnosis. Population Type and Time Since Diagnosis were simultaneously entered into Block 1. Block 2 comprised the original set of thermometers simultaneously entered into the model. The CrushedUniT was entered into Block 3.

The results will be presented according to the type of distress predicted.

4.1.3A Combination of Thermometers in Predicting Depression

In Model 1, Population Type and Time Since Diagnosis did not contribute significantly to the regression model, $F(2,158) = 1.631, p > 0.05$. They accounted for 2% of the variation in DASS-Depression. In Model 2, the thermometers accounted for an additional 34.6% of variance in DASS-Depression and resulted in a significant $R^2$ change, $F(5, 153) = 16.735, p < .01$. Model 3 included the CrushedUniT which resulted in a significant $R^2$ change of 6.3%, $F(1,152) = 16.856, p < .01$. Higher scores on the thermometers were associated with higher DASS-Depression scores. The final model (Model 3) showed that controlling for Population Type and Time Since Diagnosis, the CrushedUniT represented the variance of the other thermometers in accounting for DASS-Depression. The results are summarised in Table 8.

Table 9 shows the correlations between the thermometers, Population Type, Time Since Diagnosis and DASS-Depression. Time Since Diagnosis had a small but statistically significant relationship with the AngT, $r = 0.243, p < .01$. The medium to large correlations between the thermometers and DASS-Depression corresponded with the results of the regression analysis. The CrushedUniT had the largest correlation with DASS-Depression, also corresponding with the regression analysis.
Table 8

*Hierarchical Multiple Regression Analyses of Modified ET and HT on DASS-Depression*

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>( \Delta R^2 )</th>
<th>Sig. of ( R^2 ) change</th>
</tr>
</thead>
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<td><strong>Model 1</strong></td>
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<td>0.020</td>
<td>0.199</td>
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<td>0.486</td>
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<tr>
<td>Time since diagnosis</td>
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<td>0.385</td>
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</tr>
<tr>
<td><strong>Model 2</strong></td>
<td></td>
<td></td>
<td>0.367</td>
<td>0.346</td>
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<td>Time since diagnosis</td>
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<tr>
<td>AnxT</td>
<td>0.097</td>
<td>0.34`</td>
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<tr>
<td>DepT</td>
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<td>0.069</td>
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<tr>
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<td>&lt;0.0001</td>
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<td>Time since diagnosis</td>
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<td>DT</td>
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<tr>
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<tr>
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<td>0.784</td>
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<td>AngT</td>
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<td>0.515</td>
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<tr>
<td>HT</td>
<td>0.103</td>
<td>0.229</td>
<td></td>
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<tr>
<td>CrushedUniT</td>
<td>0.383</td>
<td>&lt;0.0001</td>
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Table 9

**Correlation between Thermometers, Population Type, Time Since Diagnosis, and DASS-Depression**

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<th></th>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>DASS-Depression</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
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<tbody>
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<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>Time since Diagnosis</td>
<td></td>
<td>0.622**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<td>0.000</td>
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<tr>
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<td>-0.020</td>
<td>0.514**</td>
<td>0.667**</td>
<td>0.656**</td>
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<td>AngT</td>
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<td>0.243**</td>
<td>0.428**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
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<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
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<tr>
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<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>0.540**</td>
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</table>

**p < .01 (2-tailed); *p < .05 (2-tailed)**
4.1.3B Combination of Thermometers in Predicting Anxiety

The first model showed that Population Type and Time Since Diagnosis contributed significantly to the regression model, $F(2, 158) = 4.034, p < .05$, accounting for 4.9% of the variation in DASS-Anxiety. When the original ET and HT were entered into the model (Model 2), they resulted in a significant $R^2$ change of 0.367, $F(5,153) = 15.396, p < .01$. In Model 3, the CrushedUniT appeared as a significant predictor ($\beta = 0.305, p < .01$). It accounted for 4% of the variance in Model 3, which reflected a significant $R^2$ change, $F(1, 152) = 10.288, p < .01$. Higher scores on the thermometers were associated with higher DASS-Anxiety scores. The final model (Model 3) showed that controlling for Population Type and Time Since Diagnosis, the CrushedUniT represented the variance of the other thermometers in accounting for DASS-Anxiety. The results are presented in Table 10.

The correlations between the variables (Table 11) corresponded with the results of the regression analysis. The CrushedUniT had the largest correlation with DASS-Anxiety. The DASS-Anxiety had medium to large correlations with all the thermometers. In addition, Time Since Diagnosis had small but statistically significant correlations with DASS-Anxiety and AngT, $r = 0.205, p < .01$ and $r = 0.243, p < .01$, respectively.
**Table 10**

*Hierarchical Multiple Regression Analyses of Modified ET and HT on DASS-Anxiety*

<table>
<thead>
<tr>
<th>Model 1</th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>ΔR²</th>
<th>Sig. of R² change</th>
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<tr>
<td>CrushedUniT</td>
<td>0.305</td>
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</table>
Table 11

Correlation between Thermometers, Population Type, Time Since Diagnosis, and DASS-Anxiety

<table>
<thead>
<tr>
<th></th>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>DASS-Anxiety</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
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<tr>
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<tr>
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<td>0.646**</td>
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</tr>
<tr>
<td>DepT</td>
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<td>-0.020</td>
<td>0.471**</td>
<td>0.667**</td>
<td>0.656**</td>
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</tr>
<tr>
<td>AngT</td>
<td>0.375**</td>
<td>0.243**</td>
<td>0.437**</td>
<td>0.495**</td>
<td>0.409**</td>
<td>0.409**</td>
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<tr>
<td>HT</td>
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<td>0.153</td>
<td>0.502**</td>
<td>0.598**</td>
<td>0.595**</td>
<td>0.595**</td>
<td>0.477**</td>
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<tr>
<td>CrushedUniT</td>
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<td>-0.028</td>
<td>0.560**</td>
<td>0.652**</td>
<td>0.690**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>0.540**</td>
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</tr>
</tbody>
</table>

**p < .01 (2-tailed); *p < .05 (2-tailed)
4.1.3C Combination of Thermometers in Predicting Stress

Model 1 showed that Population Type and Time Since Diagnosis did not significantly contribute to the regression model, $F(2, 158) = 0.871, p > .05$. They only accounted for 1.1% of the variance in DASS-Stress. Model 2 contributed 35.1% additional variance to the model, which was significant, $F(5,153) = 18.157, p < .01$. In Model 2, the DT was a significant predictor of DASS-Stress ($\beta = 0.240, p < .05$). However, the significance of DT disappeared when the CrushedUniT was added in Model 3. Model 3 included the CrushedUniT, which did not significantly contribute to the final model, $F(1,152) = 3.197, p > .05$. The CrushedUniT only contributed 1.3% of the variance to the final model. Higher scores on the thermometers were associated with higher scores on DASS-Stress. The final model showed that none of the thermometers were significant independent predictors of DASS-Stress, suggesting that stress can be collectively predicted by all the thermometers in Model 2. The results are shown in Table 12.

The correlations in Table 13 showed medium to large correlations between the thermometers and DASS-Stress. The correlation results corresponded with those of the regression analysis in demonstrating that any of the thermometers can be used to predict DASS-Stress. Time Since Diagnosis had a small but statistically significant correlation with the AngT, $r = 0.243, p < .01$. 
Table 12

*Hierarchical Multiple Regression Analyses of Modified ET and HT on DASS-Stress*

<table>
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<tr>
<th>Model</th>
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<th>p</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
<th>Sig. of $R^2$ change</th>
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<td>Population type</td>
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<tr>
<td>Model 2</td>
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<td>AngT</td>
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<td>0.052</td>
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<td>HT</td>
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</tr>
<tr>
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<td>0.059</td>
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</tr>
<tr>
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<tr>
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<td>CrushedUniT</td>
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Table 13

Correlation between Thermometers, Population Type, Time Since Diagnosis, and DASS-Stress

<table>
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<th>Population Type</th>
<th>Time since diagnosis</th>
<th>DASS-Stress</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
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<tr>
<td>Time since Diagnosis</td>
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<td></td>
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<td>DASS-Stress</td>
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<td>DT</td>
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<td>0.000</td>
<td>0.538**</td>
<td>1</td>
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</tr>
<tr>
<td>AnxT</td>
<td>-0.066</td>
<td>0.017</td>
<td>0.456**</td>
<td>0.646**</td>
<td>1</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>DepT</td>
<td>-0.032</td>
<td>-0.020</td>
<td>0.480**</td>
<td>0.667*</td>
<td>0.656**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.375**</td>
<td>0.243**</td>
<td>0.441**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HT</td>
<td>0.127</td>
<td>0.153</td>
<td>0.487**</td>
<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
<td>0.477**</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.006</td>
<td>-0.028</td>
<td>0.526**</td>
<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>0.540**</td>
<td>1</td>
</tr>
</tbody>
</table>

**p < .01 (2-tailed); *p < .05 (2-tailed)
4.1.3D Combination of Thermometers in Predicting SOC-13 Comprehensibility

In Model 1, Population Type and Time Since Diagnosis did not contribute significantly to the regression model, $F(2, 158) = 0.841, p > .05$ (Table 14). They contributed 1.1% of the variance in SOC-13 Comprehensibility. Model 2 contributed an additional 14.3% towards the model [$R^2_{change} = 5.182, p < .01$]. The CrushedUniT was added in Model 3. It did not contribute significantly towards SOC-13 Comprehensibility ($R^2_{change} = 0.009, p > .05$), $F(1, 152) = 1.658, p>.05$. Higher scores on the thermometers were associated with lower SOC-13 Comprehensibility scores. The final model showed that none of the thermometers were significant independent predictors of SOC-13 Comprehensibility. However, because Model 2 was significant, SOC-13 Comprehensibility could be collectively predicted by all the thermometers. The results are presented in Table 14.

The correlations in Table 15 showed small to medium correlations between the thermometers and SOC-13 Comprehensibility. The correlation results corresponded with those of the regression analysis in demonstrating that any of the thermometers can be used to predict SOC-13 Comprehensibility. A small but statistically significant correlation was found between Time Since Diagnosis with the AngT, $r = 0.243, p<.01$. 

Table 14

Hierarchical Multiple Regression Analyses of Modified ET and HT on SOC-13 Comprehensibility

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>ΔR²</th>
<th>Sig. of R² change</th>
</tr>
</thead>
<tbody>
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<td>Model 1</td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Population type</td>
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</tr>
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<td>Time Since Diagnosis</td>
<td>0.113</td>
<td>0.267</td>
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<td></td>
</tr>
<tr>
<td>Model 2</td>
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<td></td>
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</tr>
<tr>
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<tr>
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</tr>
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<td>AnxT</td>
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<tr>
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<td>0.200</td>
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</tr>
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</table>
Table 15

Correlation between Thermometers, Population Type, Time Since Diagnosis, and SOC-13 Comprehensibility

<table>
<thead>
<tr>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>SOC-13 Comprehensibility</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
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<tbody>
<tr>
<td>Population Type</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td></td>
<td></td>
<td>0.622**</td>
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</tr>
<tr>
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<td>0.033</td>
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<tr>
<td>DT</td>
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<td>0.000</td>
<td>-0.312**</td>
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<tr>
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<td>0.017</td>
<td>-0.288**</td>
<td>0.646**</td>
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<td>DepT</td>
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<td></td>
<td>-0.032</td>
<td>-0.020</td>
<td>-0.323**</td>
<td>0.667**</td>
<td>0.656**</td>
<td>1</td>
</tr>
<tr>
<td>AngT</td>
<td></td>
<td></td>
<td>0.375**</td>
<td>0.243**</td>
<td>-0.281**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
</tr>
<tr>
<td>HT</td>
<td></td>
<td></td>
<td>0.127</td>
<td>0.153</td>
<td>-0.321**</td>
<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
</tr>
<tr>
<td>CrushedUniT</td>
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<td></td>
<td>-0.006</td>
<td>-0.028</td>
<td>-0.349**</td>
<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
</tr>
</tbody>
</table>

**p < .01 (2-tailed); *p < .05 (2-tailed)
**4.1.3E Combination of Thermometers in Predicting SOC-13 Manageability**

In Model 1, Population Type and Time Since Diagnosis contributed significantly to the regression model in contributing a significant $R^2$ change of 5.2%, $F(2,158) = 4.298, p<.05$, towards SOC-13 Manageability. In Model 2, the original ET and HT contributed an additional 18.1% of variation which was significant, $F(5,153) = 7.231, p < .01$. The final model (Model 3) included the CrushedUniT, which contributed an additional variance of 0.6% which was not a significant $R^2$ change, $F(1,152) = 1.183, p>.05$. Higher scores on the thermometers were associated with lower scores on SOC-13 Manageability. The final model showed that the AngT was the optimal thermometer to predict SOC-13 Manageability ($\beta = -2.22, p<.05$). The results are presented in Table 16.

The correlations in Table 17 showed small to medium correlations between the thermometers and SOC-13 Manageability. The AngT had the largest correlation with SOC-13 Manageability, thus corresponding with the regression analysis in showing that the AngT is the optimal thermometer to predict SOC-13 Manageability. The AngT also had a small but significant correlation with Time Since Diagnosis, $r = 0.243, p<.01$. 
### Table 16

*Hierarchical Multiple Regression Analyses of Modified ET and HT on SOC-13 Manageability*

<table>
<thead>
<tr>
<th></th>
<th>β</th>
<th>p</th>
<th>R²</th>
<th>ΔR²</th>
<th>Sig. of R² change</th>
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<td></td>
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<td></td>
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<td>0.052</td>
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<tr>
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<td></td>
<td>&lt;0.0001</td>
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<td>0.233</td>
<td>0.181</td>
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<tr>
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<td>0.671</td>
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<td>0.936</td>
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<td>0.126</td>
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<tr>
<td>AngT</td>
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<td>0.012</td>
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<tr>
<td>HT</td>
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<td>0.512</td>
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<td><strong>Model 3</strong></td>
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<td>0.239</td>
<td>0.006</td>
<td>0.279</td>
</tr>
<tr>
<td>Time since diagnosis</td>
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<td>0.620</td>
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<tr>
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<td>0.725</td>
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<tr>
<td>AnxT</td>
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<td>0.516</td>
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</tr>
<tr>
<td>DepT</td>
<td>-0.120</td>
<td>0.305</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>AngT</td>
<td>-0.218</td>
<td>0.028</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>HT</td>
<td>-0.060</td>
<td>0.546</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.117</td>
<td>0.279</td>
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</tr>
</tbody>
</table>
## Table 17

*Correlation between Thermometers, Population Type, Time Since Diagnosis, and SOC-13 Manageability*

<table>
<thead>
<tr>
<th></th>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>SOC-13 Manageability</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
</thead>
<tbody>
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<td></td>
<td></td>
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<td></td>
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<tr>
<td>Time since Diagnosis</td>
<td>0.622*</td>
<td>1</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SOC-13 Manageability</td>
<td>-0.221**</td>
<td>-0.120</td>
<td>1</td>
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</tr>
<tr>
<td>DT</td>
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<td>0.000</td>
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</tr>
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<td>-0.066</td>
<td>0.017</td>
<td>-0.273**</td>
<td>0.646**</td>
<td>1</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>DepT</td>
<td>-0.032</td>
<td>-0.020</td>
<td>-0.363**</td>
<td>0.667**</td>
<td>0.656**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
<td>0.375**</td>
<td>0.243**</td>
<td>-0.411**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
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</tr>
<tr>
<td>HT</td>
<td>0.127</td>
<td>0.153</td>
<td>-0.355**</td>
<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
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</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.006</td>
<td>-0.028</td>
<td>-0.363**</td>
<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>0.540**</td>
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</tr>
</tbody>
</table>

**p < .01 (2-tailed); *p < .05 (2-tailed)
4.1.3F Combination of Thermometers in Predicting Overall Sense of Coherence

Model 1 showed that Population Type and Time Since Diagnosis contributed a variance of 4.5% to SOC-13 Total, which was a significant $R^2$ change, $F(2,158) = 3.748, p < .05$. Model 2 included the original ET and HT, which contributed an additional 18.4% of variation to the model. The inclusion of the original ET and HT resulted in a significant $R^2$ change, $F(5, 153) = 7.317, p < .01$. The final model (Model 3) included the CrushedUniT, which contributed an additional variance of 2.4%, which was a significant $R^2$ change, $F(1,152) = 4.834, p<.05$. Higher scores on the thermometers were associated with lower scores on SOC-13 Total. The final model showed that the optimal thermometer for predicting SOC-13 Total was the CrushedUniT. The final model also showed that Population Type remained a significant predictor of SOC-13 ($\beta = -0.216, p<.05$). The results are presented in Table 18.

The correlations in Table 19 support the findings from the regression analysis. Population Type had a small but significant correlation with SOC-13 Total, and the CrushedUniT had the largest correlation with the SOC-13 Total. Time Since Diagnosis had a small but statistically significant correlation with AngT, $r = 0.243, p<.01$.

Overall, the different types of distress were each predicted by only one thermometer. In particular, the CrushedUniT was the most representative predictor of most forms of distress. This was with the exception of the SOC-13 Manageability, which showed the optimal thermometer to be the AngT. An interesting finding was the contribution of Population Type to SOC-13 Meaningfulness and SOC-13 Total Scores. The results will be discussed in the next section.
### Table 18

**Hierarchical Multiple Regression Analyses of Modified ET and HT on SOC-13 Total Score**

<table>
<thead>
<tr>
<th></th>
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<th>p</th>
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<th>$\Delta R^2$</th>
<th>Sig. of $R^2$ change</th>
</tr>
</thead>
<tbody>
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<td>0.045</td>
<td>0.026</td>
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</tr>
<tr>
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<tr>
<td><strong>Model 2</strong></td>
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<td>0.214</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>AngT</td>
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<td>0.114</td>
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</tr>
<tr>
<td>HT</td>
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<td>0.221</td>
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<td>0.634</td>
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</tr>
<tr>
<td>AnxT</td>
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<td>0.262</td>
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</tr>
<tr>
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<td>-0.042</td>
<td>0.716</td>
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</tr>
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<td>-0.111</td>
<td>0.260</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.235</td>
<td>0.029</td>
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</tbody>
</table>
Table 19

*Correlation between Thermometers, Population Type, Time Since Diagnosis, and SOC-13 Total Score*

<table>
<thead>
<tr>
<th></th>
<th>Population Type</th>
<th>Time since diagnosis</th>
<th>SOC-13 Manageability</th>
<th>DT</th>
<th>AnxT</th>
<th>DepT</th>
<th>AngT</th>
<th>HT</th>
<th>CrushedUniT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population Type</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>0.622**</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>SOC-13 Manageability</td>
<td>-0.205**</td>
<td>-0.082</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>DT</td>
<td>-0.036</td>
<td>0.000</td>
<td>-0.328**</td>
<td>1</td>
<td></td>
<td></td>
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<tr>
<td>AnxT</td>
<td>-0.066</td>
<td>0.017</td>
<td>-0.291**</td>
<td>0.646**</td>
<td>1</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>DepT</td>
<td>-0.032</td>
<td>-0.020</td>
<td>-0.379**</td>
<td>0.667**</td>
<td>0.656**</td>
<td>1</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>AngT</td>
<td>0.375**</td>
<td>0.243**</td>
<td>-0.375**</td>
<td>0.495**</td>
<td>0.401**</td>
<td>0.409**</td>
<td>1</td>
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<td></td>
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<tr>
<td>HT</td>
<td>0.127</td>
<td>0.153</td>
<td>-0.386**</td>
<td>0.598**</td>
<td>0.537**</td>
<td>0.595**</td>
<td>0.477**</td>
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<td></td>
</tr>
<tr>
<td>CrushedUniT</td>
<td>-0.006</td>
<td>-0.028</td>
<td>-0.428**</td>
<td>0.652**</td>
<td>0.538**</td>
<td>0.690**</td>
<td>0.467**</td>
<td>0.540**</td>
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**p < .01 (2-tailed); *p < .05 (2-tailed)
Chapter 5: Study 1 Discussion

Parents of children with cancer or chronic illness face significant distress. The current study had three aims: to validate the modified Emotion and Help Thermometers (ET and HT) among parents of children recently diagnosed with cancer or chronic illness; to test the ability of the CrushedUniT to identify parents reporting PTSS and/or facing a crisis in their sense of meaning in life; and to explore the optimal combination of thermometers in predicting various forms of distress.

The results from the study supported the hypotheses. Firstly, with the exception of the SOC-13 Total score, the thermometers showed reasonable to good sensitivity but low specificity in identifying parents reporting distress (H1). Secondly, the Crushed Universe Thermometer (CrushdUniT) was found to predict IES-R Total score (measuring PTSS) and SOC-13 Meaningfulness over and above Mitchell et al.’s (2010) original set of Emotion and Help Thermometers (ET and HT), thus supporting H2 and H3. Lastly, each type of distress had its optimal combination of thermometers, among which, the CrushedUniT was a significant predictor for most of the types of distress. Together, the results indicate that the CrushedUniT identified a different dimension of distress faced by parents – that is, one that included an existential aspect that concerns parents’ sense of meaning.

This section integrates the results from the diagnostic accuracy and regression analyses of the modified ET and HT, and relates them to the various forms of distress parents face, with a focus on their meaning-related distress.

5.1 Results from the Diagnostic Accuracy Analyses

The Distress Thermometer (DT) was the optimal thermometer for detecting depression. The current study demonstrated that at a cut-off of greater than 5, the DT showed
a greater ROC value, specificity and rule-in accuracy (PPV) than the DepT. This result departs from past research findings of the DepT and AnxT having better diagnostic accuracy in the form of larger AUCs, higher sensitivity and specificity over the DT (Beck et al., 2014; Gil, Grassi, Travado, Tomamichel, & Gonzalez, 2005; Mitchell, Baker-Glenn, Granger, et al., 2010; Mitchell, Baker-Glenn, Park, Granger, & Symonds, 2010). The results suggest that in this sample, parents of ill children might experience depression as a general form of distress rather than as a disorder. Evidence from cross-cultural research supports that Asians may report depression symptoms differently from their Western counterparts. Instead of reporting psychological symptoms such as feelings of guilt, worthlessness, or irritability, Asians showed a tendency to report somatization symptoms such as headaches, sleeplessness, or changes in appetite (Kalibatseva & Leong, 2011; Kim, 2012). Thus, parents might have conceptualised symptoms of depression as an overall emotional upset rather than specifically as depression.

With regard to anxiety, findings were mixed. While the Anxiety Thermometer (AnxT) had the best sensitivity at cut-off of 4, its predictive accuracy in other aspects and according to the ROC analysis was not as favourable as other thermometers. Instead, in terms of rule-in accuracy, the CrushedUniT at the cut-off of 4, and the Help Thermometer (HT) at a cut-off greater than 5 were better screeners of DASS-Anxiety than the AnxT. While sensitivity and specificity are important tools to understand the qualities of a screening tool, the rule-in and rule-out accuracies (PPV and NPV) reflect the likelihood that individuals actually have the difficulties (or not) when the test shows a positive (or negative) result, and are thus more applicable to our use of the thermometers in relation to the current population (Lalkhen & McCluskey, 2008). The results with regard to detecting DASS-Anxiety contrast with past research finding the AnxT to be the optimal thermometer (Beck et al., 2014; Mitchell, Baker-Glenn, Granger, et al., 2010; Schubart, Mitchell, Dietrich, & Gusani, 2015). Finding that the
HT is the optimal thermometer for detecting anxiety converges with the results of the regression analyses, and suggests that when children are diagnosed with cancer or a chronic illness, parents’ anxieties might be related more to the availability and access to resources than about their child’s illness per se. The importance of resources to parents’ well-being supports theories emphasising the buffering effects of resources against stress (Antonovsky, 1987; Mak et al., 2007).

The CrushedUniT performed well in the detection of PTSS (measured by IES-R Total score) and overall orientation to life (measured by SOC-13 Total score). It possessed the strongest specificity and rule-in accuracy in detecting PTSS, and the strongest sensitivity and rule-out accuracy in detecting overall orientation to life. In particular, the CrushedUniT was identified by the ROC analysis to be the optimal thermometer in detecting these two constructs. The performance of the CrushedUniT thus reflect the disruption of parents’ worldviews and threatened perceptions of life when their child is diagnosed with cancer or a chronic illness. The results of the CrushedUniT’s diagnostic accuracy corresponded with the regression analyses that were subsequently run, and will be discussed in detail below.

5.2 Efficacy of Crushed Universe Thermometer in Comparison with Original Thermometers

The CrushedUniT was not only found to contribute increased predictive ability beyond the original thermometers in predicting IES-R Total and SOC-13 Meaningfulness, but was also the optimal thermometer in predicting SOC-Meaningfulness and, to a smaller extent, the IES-T Total. The results support the use of a “Crushed Universe” screening tool to measure the presence of PTSS or crisis in meaning among parents of ill children. The results are aligned with Janoff-Bulman’s Assumptive Worlds Theory (1992) in that receiving a diagnosis of cancer, or living with a child with chronic illness, shatters parents’ assumptions of the world as benevolent, meaningful, and that they are worthy. The diagnosis of a chronic
and/or life-threatening illness in a child represented a loss to parents on many fronts in not just the potential physical death of their child, but perhaps may also be symbolic of their hopes and expectations of the future and of their child.

Firstly, in support of H3, the CrushedUniT had overall greater predictive ability than the original ET and HT in predicting SOC-Meaningfulness, and was the optimal thermometer in doing so. The results support past research findings of a “broken life world” (Bjork et al., 2005, p. 268), as well as parents’ loss of meaning upon their child’s cancer diagnosis (Collins et al., 2016; Grootenhuis & Last, 1997). The findings also support research among parents of children with disabilities, where it was found that parents continue to seek meaning for their children’s disabilities many years after the diagnosis (Y. J. Lee, Park, & Recchia, 2015). Convergence of the current study’s findings with past research’s conceptualisation of parents’ experience of their child’s diagnosis also lends support to the face validity of the term “Crushed Universe” to describe the thermometer. Anecdotal evidence of participants’ understanding of the term “Crushed Universe” revealed responses such as “My life has changed a lot”, “My life is not the same anymore” and “End of the world”.

The prediction of SOC-13 Meaningfulness was not only enhanced by the CrushedUniT, but also the population type. Specifically, parents of children with chronic illness reported lower levels of SOC-13 Meaningfulness than parents of children with cancer. This finding supports studies on the experience of parents of children with chronic illness. In particular, past research demonstrated that given the nature of chronic illness as one that is long-term and either not curable or posing limitations in individuals’ daily functioning, parents faced on-going and long-term stressors in terms of the child’s treatment management, the family’s functioning, and their own adjustment to each phase of the child’s illness or life (Coffey, 2006). Two seemingly opposing yet complimentary implications arise from the on-going stressors and reminders of their child’s illness. The first was that chronic grief and
sorrow were reported amongst parents (George, Vickers, Wilkes, & Barton, 2006; Gordon, 2009), and the second was that despite their distress, parents continuously sought to find meaning from their child’s illness at each point of their child’s life (Y. J. Lee et al., 2015; Nabors et al., 2013). Together, these converging pieces of evidence suggest that parents’ sense of meaning is dynamic, and can be tested when their child’s illness takes a turn, thus highlighting the importance of regular screening to monitor their psychological well-being.

Inherent in Population Type was the demographic characteristics for both populations. These included parents’ age, marital status, monthly combined income, their child’s age, and time since diagnosis. These differences could have been underlying factors influencing the prediction of SOC-13 Meaningfulness and SOC-13 Total. While the differences could have been due to the discrepancy in sample size, the proportion of parents of children with chronic illness was greater than that for parents of children with cancer. Furthermore, it was interesting that these variables predicted only SOC-13 Meaningfulness and SOC-13 Total, and not the other forms of distress. These results correspond with Coffey’s (2006) findings above, and also be explained by Antonovsky’s assertion that a chronic drain on individuals’ generalised resistance resources – i.e., strain on family functioning, individuals’ perspectives of difficulties, support from surrounding others, etc. – can lead to eventual reductions in their SOC levels.

Secondly, the CrushedUniT was a significant predictor of IES-R Total over and above the other thermometers, and was the optimal thermometer in combination with the Depression Thermometer (DepT). The results suggest that apart from experiencing shattered assumptions, PTSS among parents is experienced as emotional distress in the form of depression when their child is diagnosed with cancer or a chronic illness. Such a suggestion is supported by research findings – both within the field of paediatric oncology or in the general population – that PTSS is co-morbid with emotional disorders such as depression and/or
anxiety (Greening & Stoppelbein, 2007; Hynan, Mounts, & Vanderbilt, 2013), which can be maintained through individuals’ interpretations of the events (Ehlers, Clark, Hackmann, McManus, & Fennell, 2005; Kleim, Ehlers, & Glucksman, 2012).

5.3 Optimal Combinations of Thermometers

The study also sought to identify the optimal combination of thermometers to predict other forms of distress. Except for SOC-13 Manageability, the CrushedUniT was the optimal thermometer in predicting the other forms of distress in parents. This suggests that at least among parents of ill children, their distress contains a dimension of existential distress. This perspective converges with the proposition by several researchers in the meaning-making field. Firstly, meaning researchers advocate that sense of meaning is a core, organising construct in the maintenance of psychological well-being, the loss of which leads to significant psychological distress (Frankl, 1963; Park & Folkman, 1997; P. T. P. Wong, 2016). However, because it is such a fundamental component of individuals’ psychological make-up, it is often not a prominent feature of psychological distress (Brown, Roach, Irving, & Joseph, 2008). While distress associated with meaning might be seen as an undercurrent of other types of distress, the current research shows the pervasiveness of meaning distress among parents. This thus underscores a need for future research to make measurement of meaning distress a focus.

The hierarchical regression found the CrushedUniT to be the optimal predictor of anxiety. This was a different finding from Mitchell et al. (2010), who found that a combination of the AnxT and DepT added to the accuracy of predicting anxiety. The study’s findings also differ from other research investigating the ET and HT (e.g., Beck et al., 2014), as well as the DT (e.g., Akizuki, Yamawaki, Akechi, Nakano, & Uchitomi, 2005; K. A. Donovan, Grassi, McGinty, & Jacobsen, 2014; Grootenhuis et al., 2014; Haverman et al., 2013). Particularly for the DT, studies have found reasonable sensitivity for the detection of
anxiety, depression, and overall distress (K. A. Donovan et al., 2014). There are several possible reasons for the departure of the current findings from the literature. Firstly, as far as we are aware, the current study is the first to implement the modified ET and HT with parents of children with cancer or a chronic illness. Thus far, studies have only been conducted on the validity of the DT on parents of a chronically ill child (e.g., Haverman et al., 2013). It could hence be possible that the modified ET and HT are detecting distress that were not otherwise reported by parents in previous studies. In this study, that the CrushedUniT predicted anxiety among parents, suggests that an existential component underlies parents’ reports of anxiety. Such an explanation is supported by research reporting parents’ uncertainty about the future – relapse, achieving milestones, the future, etc. (Lin, Yeh, & Mishel, 2010; Santacroce, 2003). Furthermore, meaning of life has also been found to partially mediate the relationship between anxiety and mental health among a non-clinical sample of Taiwanese adults, further supporting the important yet underlying role of meaning in maintaining psychological well-being (Shiah, Chang, Chiang, Lin, & Tam, 2015). Secondly, K. A. Donovan et al.’s (2014) meta-analysis of the literature regarding the DT suggested that different translations of the DT led to different levels of diagnostic accuracy of the instrument as well as cut-off scores. A proportion of participants in the present study used the Mandarin version of the ET and HT, which might have contributed to differences in the results. Thirdly, the current study used the DASS instead of the HADS because the population of interest were caregivers rather than patients. Lastly, given that the population of interest were parents and carers and not the patients themselves, the findings might reflect inherent differences in the experiences of parents from patients.

With regard to Manageability, or individuals’ confidence that resources were available to them to meet the demands of stressful situations, the AngT was the optimal predictor. This suggests that parents’ perspectives of the availability of their resources had an
element of anger. Sen and Yurtsever (2007) found that families of children with chronic illnesses reported anger related to accepting their child’s illness, as well as difficulties accessing emotional and social support from family members and friends. The experience of anger also has implications for parents’ choice of coping strategies. Miedema, Hamilton, Fortin, Easley, and Matthews (2010) found that parents of children with cancer reported experiencing difficult emotions such as anger, yet coped with it through avoidance strategies, which ultimately contributed further to stress within the family. These convergent lines of research suggest that parents’ experiences of anger may be associated with on-going and anticipated future challenges associated with their child’s illness, and the risk of unhelpful choices of coping strategies as a result of their emotional distress, which also impacted their perceptions of accessibility to resources and ability to harness them.

5.4 Limitations

While the current study shows interesting results that are worthy of deeper investigation, it also faces some limitations. These limitations include the small sample size particularly among parents of children with cancer, the lack of equivalence between the cancer and chronic illness sample in terms of time since diagnosis and the circumstances under which they were recruited, and the choice of SOC-13 in assessing meaning.

A small sample size from parents of children with cancer could have affected the statistical power needed for the AnxT and DepT to predict or be optimal thermometers of depression and anxiety, and the lack of statistical significance of the AngT in its diagnostic accuracy. Furthermore, while finding that the CrushedUniT was a significant predictor of almost all forms of distress was noteworthy and corresponds with theories on meaning, it was also puzzling that the single AnxT and DepT did not independently predict anxiety and depression respectively. The current study met with difficulty in recruitment because of firstly, the low prevalence of paediatric cancer in the Singapore population, secondly, the
apprehension of parents in taking part in research due to lack of time, having other commitments, and lastly, the timeline of the research due to its being a doctoral thesis. It is highly recommended that future research includes a larger sample size to allow for greater statistical power.

The current study also faced a limitation with regard to the equivalence of the sample populations. The current study recruited parents of children newly diagnosed with cancer and parents whose children had been diagnosed with a chronic illness for a mean of 11 years, and a minimum of 2 months. The large variation in time since diagnosis between the samples might have resulted in the differences in their reported distress as reflected by the positive and statistically significant correlations between time since diagnosis and the AngT and DASS-Anxiety. Parents’ circumstances related to their child’s illness could also have led to differences in reports of distress, as the parents who were on active follow-up at CRS tended to be facing psychosocial issues in addition to difficulties with their child’s illness. While their distress might have been similar to parents of children with cancer, the psychosocial issues might have been possible confounds. Nonetheless, the impact of these differences were only observed in SOC-13 Meaningfulness and SOC-13 Total scores, thus suggesting that while parents of children with cancer or chronic illness face largely the same types of distress, the long-term implications of paediatric chronic illness takes a toll on these parents’ sense of meaning in life and preparedness towards life stressors.

The use of the SOC-13 might also have been a limitation. Firstly, a necessary step in determining predictive accuracy of tools is the establishment of pre-determined cut-offs of the test tool and the ‘gold standard’ tool (Hajian-Tilaki, 2013). However, the current consensus about SOC and its components is that being a measure of an individual’s general outlook on life, they are continuous constructs that have no cut-offs (Antonovsky, 1987). Although Holmefur et al.’s (2015) suggested cut-offs had a theoretical basis, their study and
its suggested cut-off point is, as far as we know, the first of its kind, and the comparatively poorer sensitivity and specificity of the thermometers to other types of distress in the current study suggest that the cut-offs may have either been unsuitable, or that the SOC concept really has no cut-offs or demarcations of low, medium or high levels. In relation to this issue, is also that one of the primary questions of this study was to investigate the accuracy of the CrushedUniT in identifying parents facing a crisis in meaning. Without the availability of cut-offs for the Meaningfulness subscale on the SOC-13, the closest the study got to answering the question was through the regression analysis. Future research could thus look into using other meaning-related subscales with established cut-offs to test the utility of the CrushedUniT.

Another limitation of the SOC-13 pertains to its psychometric properties showing lack of construct validity, and might be more stable as a 9-item questionnaire (Ferguson, Davis, Browne, & Taylor, 2015). Furthermore, given that a Mandarin version of the SOC-13 was used for the current study, there might have been differences in clarity of certain items. Ding, Bao, Xu, Hu, and Hallberg (2012) found that although the Mandarin SOC-13 was valid among women with cervical cancer in Mainland China, there were cultural differences in participants’ understanding and responses on certain items. The rating scale of the SOC-13 has also been suggested to be problematic for respondents due to their difficulty in applying a seven-point rating scale (Holmefur et al., 2015). Holmefur and colleagues thus proposed a five-point rating. The fourth reason for the drawback of the SOC-13 is the long-standing debate in the field about whether the SOC is a unitary concept or a three-factor construct (Eriksson & Lindström, 2005). The implication of this debate on the current study is that it might explain why the Comprehensibility subscale was collectively predicted by all the thermometers, rather than by a single thermometer.
5.5 Implications

The overall results suggest that parents of children with cancer and chronic illness face distress related to their sense of meaning and overall SOC that have the potential to continue many years after the initial diagnosis, and emotional distress that may be related to their SOC. The results have implications in the care for parents, categorised into short-, mid-, and long-term care.

In the short term, assistance for parents would be to firstly assist them in identifying their distress, and this can be done through the screening process and a debrief session. A screening process may be beneficial to parents in the sense that it helps them obtain the type of assistance they require, such as access to resources in the case of parents in the paediatric oncology population, or follow-ups with their social worker to discuss any emotional difficulties, as with parents of children with chronic illness.

Mid-term care would comprise parents receiving assistance with their emotional difficulties, such as in the form of psychotherapy or short-term interventions, as recommended by Applebaum and Breitbart (2013), Sahler, Sahler, Dolgin, Phipps, and Fairclough (2013), and Kazak et al. (2007). As Hocking et al. (2014) found, parents in the paediatric oncology population were keen on receiving interventions within six months of their child’s diagnosis, with a significant proportion of them favouring it within two months of diagnosis, most particularly if it matched the stage of parents’ adjustment, such as whether parents were acutely stressed, or if distress levels had stabilised. These results suggest that parents require some time to adjust to their child’s illness, and offering an intervention to them after the initial phase of emotional distress has stabilised would be beneficial.
Long-term care would then focus on parents living with their child’s illness, and approaching a new normal. In these cases, longer term interventions may be suitable for those parents who continue to report high levels of distress.

5.6 Conclusions

The overall results suggest that the CrushedUniT was the most optimal tool for predicting various forms of distress among parents of children with cancer or a chronic illness, suggesting that existential distress underlies parents’ reports of depression, anxiety, post-traumatic stress, etc. The AngT was predictive of SOC-13 Manageability, suggesting that experiencing anger might reflect parents’ perceptions of their accessibility to resources, as well as their ability to harness these resources. Furthermore, the results suggested that in the current sample, parents of children with chronic illness appeared to face greater vulnerability in their sense of meaning and overall preparedness for life stressors as compared to parents of children with cancer. The results demonstrate different patterns from those by past researchers, and could imply that the distress faced by parents of ill children may be qualitatively different from those of cancer patients. This warrants further research. The results also brought forth some implications in the form of comprehensive psychosocial care for parents of ill children. To make the first step, the next study (Study 2), using the modified ET and HT, embarked on an investigation of the efficacy of a meaning-based intervention for mothers of children with cancer, or with chronic illness.
Chapter 6: Study 2 Introduction

The diagnosis of cancer or a chronic (and potentially life-threatening) illness in a child brings distress in the form of shock and a gamut of other emotions to parents. Distress is multi-faceted, and covers psychological, social, and/or spiritual distress. Of particular interest in this study is the psychological distress that parents face when their child is diagnosed with a serious paediatric illness, and what interventions can be implemented to resolve their distress. This literature review will first describe the different facets of psychological distress that parents face, particularly focusing on the existential distress that parents might experience. Next, intervention models that have been implemented in the paediatric and adult caregiving literature and their relevance to parents of children with cancer or chronic illnesses will be described. The purpose of these discussions is to make a case for a meaning-based intervention, and to assess the feasibility of implementing such an intervention for parents of children with cancer or chronic illness.

6.1 Facets of Psychological Distress

Psychological distress is a facet of distress identified by the National Comprehensive Cancer Network (NCCN) as possessing three components – behavioural, emotional, and cognitive distress (NCCN, 2014). In the paediatric illness literature, behavioural distress refers to parents’ physiological reactions to the stress posed by the child’s illness and its implications (Kazak & Baxt, 2007; Muscara et al., 2015). Parents’ physiological distress can manifest as increased vigilance about the child’s symptoms, or ruminations about the child’s illness (Dunn et al., 2012; Perlesz, Kinsella, & Crowe, 1999; Wade, Taylor, et al., 2006). Emotional distress, on the other hand, has often been described in terms of depression, anxiety, and post-traumatic stress symptoms, and has been linked to higher rates among parents of children with cancer or chronic illnesses (PTSS; Dolgin et al., 2007; Malpert et al.,
Elevated emotional distress is found in parents at the time of diagnosis, and decreases three to six months’ post-diagnosis. However, a significant minority of parents remain emotionally distressed (Kazak et al., 2003; Manne et al., 2004; Manne et al., 1996). In particular, between 20% and 48% of parents reported symptoms of PTSD (Cabizuca et al., 2009; Kazak et al., 2004). For example, McCarthy, Ashley, Lee, and Anderson (2012) found that out of 63% of mothers and 60% of fathers of a child with cancer who met the criteria for Acute Stress Disorder (ASD) one week after their child’s cancer diagnosis, 48% and 40% of them respectively subsequently met the criteria of PTSD. These rates of parents’ stress symptoms were found to be higher than for paediatric intensive care unit admission and traffic injuries (32% and 12-23% respectively; Balluffi et al., 2004; Kassam-Adams, Fleisher, & Winston, 2009).

Parents’ distress over their child’s illness can also be exacerbated by their contextual experiences. Granek et al.’s (2014) study on the caregiving experiences of single parents of children with cancer found that the theme of cumulative stressors in the form of a history of family disruption or family trauma and disease, financial and housing difficulties, and physical and mental health problems, emerged for some parents. The authors proposed that the occurrence of family disruption or family trauma and disease predisposed participants to experience stressful events as more stressful and severe. Similarly, in a study of the experiences of working parents of children with chronic illness, George, Vickers, Wilkes, and Barton (2006) found that the chronic grief experienced by these parents was not only bound to their child’s diagnosis, but was triggered by hurtful and insensitive comments from other people, having to repeat their child’s history, and unhelpful experiences with medical personnel. The authors postulated that for these parents, distress related to managing both work and caring for their child is magnified. Such findings highlight that while the child’s
illness distresses parents, contextual stressors also play a significant role in exacerbating their distress.

Interestingly, while physiological and in particular, emotional distress, have been discussed extensively in paediatric caregiving literature, there are limited descriptions of cognitive distress, or what has been termed “shattered assumptions” (Janoff-Bulman, 1992). This term refers to the shattering of parents’ beliefs that the world is orderly, and that their child is safe. Bjork, Wiebe, and Hallstrom (2005) found reports of parents likening their child’s diagnosis to a “broken life world” (p. 268), suggesting that parents’ meanings in life were shattered or ruptured. For parents facing paediatric cancer or chronic (and potentially life-threatening) illness, it is not only the potential physical death of their child that they are facing, but also the symbolic death of their child in terms of their hopes and expectations of the child being healthy and having a ‘normal’ life trajectory, this defying the expected order of life events. In addition, with the feared loss of their child, parents’ identities as protectors of their child are threatened, contributing to a crisis in meaning (Lichtenthal & Breitbart, 2015). These physical and symbolic deaths, and threat to parents’ identities, have been described as existential distress, brought about by parents’ meaning ruptures. This form of distress is the focus of the current study.

Somewhat related to the concept of a loss of meaning is the current discussion in the psycho-oncology field on the construct of demoralisation. It is a condition characterized by hopelessness and helplessness. In extreme cases, it can lead to a loss of a sense of meaning and purpose in life (Robinson, Kissane, Brooker, & Burney, 2015). Demoralisation has also been associated with a desire for hastened death, and may occur when an individual’s coping strategies and available resources are no longer effective to cope with the situation (Tecuta, Tomba, Grandi, & Fava, 2015). While there is an overlap between demoralization and the distress parents face in terms of their threats to meaning, demoralization has been discussed
much more in the medically ill population than among healthy, non-medically ill people such as parents. It thus appears, at this point, that the experience of demoralization is specific to the psychological state that the patients experience, and the applicability of the construct to caregivers or parents requires further investigations (Tecuta et al., 2015).

6.2 Intervention Models

In light of the various forms of distress that parents face, there appears to be a need for psychological interventions that specifically target parents’ coping skills, their perceptions of their child’s illness, and the meanings parents make of their child’s illness. Interventions that target parents’ coping skills and perceptions of their children’s illness often take on a cognitive-behavioural approach (CBT). Interventions that target individuals’ sense of meaning have taken on the cognitive approach or the Logotherapeutic approach. This section discusses each of these models in turn.

6.2.1 CBT Intervention Models

Among the CBT intervention models are two widely cited ones – the Problem-Solving Skills Training (PSST; Sahler et al., 2005), and the Surviving Cancer Competently Intervention Programme-Newly Diagnosed (SCCIP-ND; Kazak et al., 2005). These two interventions target parents’ difficulties specific to their child’s illness, such as compliance to treatment, their child’s behavioural issues, and thoughts related to their child’s illness. These treatment models and their efficacy will next be discussed at depth.

The PSST (Sahler et al., 2005) is a predominantly behavioural intervention focused on building mothers’ problem-solving skills related to issues most commonly encountered in paediatric cancer. It has been found to be efficacious in reducing levels of depressive symptoms and PTSS through enhancing or sustaining mothers’ coping skills in the beginning stages of their child’s illness. In two multi-site randomised controlled trials (RCTs) of the
PSST, the intervention consistently demonstrated several strengths (Sahler et al., 2005; Sahler et al., 2013). Firstly, mothers who received the PSST reported significantly reduced levels of depression, anxiety, and PTSS, and increased levels of problem-solving skills, in comparison to mothers who were in the control group. These differences were maintained even at three-month follow-up. Secondly, the studies also compared treatment efficacy between English- and Spanish-speaking mothers, single and married mothers, and younger versus older mothers. Spanish-speaking mothers, single mothers, and younger mothers reported more significant improvements in their reported levels of depression, anxiety, and PTSS, as well as in their problem-solving skills than their counterparts. The authors suggested that the results were such because Spanish-speaking, single, and younger mothers were more likely to have been facing limitations in their access to resources, and the PSST had facilitated these mothers’ access to them. The results of these RCTs thus suggest that focusing on problem-solving is helpful in reducing mothers’ distress. Secondly, and more importantly, the problem-solving orientation is particularly helpful for individuals with limited resources, as it facilitates their abilities to resolve their difficulties through maximising available resources.

The SCCIP-ND (Kazak et al., 2005), on the other hand, emphasises the identification and restructuring of parents’ maladaptive beliefs about cancer, its treatment, and impact on the family, in order to reduce levels of PTSS. Thus far, three studies have been conducted on its efficacy with mixed results. Kazak et al. (2005) reported encouraging results from the pilot study, with parents receiving the intervention reporting declined levels of PTSS, while Stehl et al. (2009) reported no significant differences between the intervention and control groups. Warner et al.’s (2011) modification of the SCCIP-ND to specifically target parents’ anxieties and distress through a greater focus on cognitive restructuring of parents’ beliefs about self-care and communication, found mixed results. Specifically, they found significant reductions in reported distress, depressive symptoms, and the Burden subscale (i.e., deterioration of
child, stress levels, guilt, future outlook) on the Caregiver Quality of Life-Cancer Scale (CQOLC), but no significant changes in reported anxiety and other subscales of the CQOLC, such as Positive Adaptation (i.e., social support and spirituality), Disruption (i.e., impact on schedules and routines), and Financial (financial strain, concerns about the future finances). Warner et al.’s (2011) results suggested efficacy of the SCCIP-ND in reducing mainly emotional distress except for anxiety in parents, and that cognitive restructuring can modify parents’ meanings around the future severity of their child’s illness.

The differential effect of cognitive restructuring on aspects of parents’ quality of life suggests that the effect of cognitive restructuring on parents’ sense of meaning was only limited to a subset of their meaning distress, and that other forms of coping were needed to reduce it. Wiedebusch et al.’s (2010) study of parents of children with chronic renal failure found that although parents reported significant worries about the illness burden, they also engaged in meaning-focused coping through religion and trying to accept the illness. Wiedebusch et al.’s findings echo Grootenhuis and Last’s (1997) findings on a review of coping and adjustments among parents of children newly diagnosed with cancer. Given these findings, the results from Warner et al.’s (2011) study question the efficacy of cognitive restructuring in reducing the discrepancy between parents’ unhelpful beliefs and the reality that is impacting their quality of life.

The findings of the SCCIP-ND converge with meta-analyses of interventions implemented for parents of children with cancer (Pai et al., 2006) and chronic (and life-threatening) illness (Eccleston, Palermo, Fisher, & Law, 2012; Law, Fisher, Fales, Noel, & Eccleston, 2014). These meta-analyses found modest to no significant effects of CBT interventions (Pai et al., 2006), as compared to problem-solving based interventions such as the PSST (Eccleston et al., 2012). The differences in efficacy might be due to the nature of CBT approaches.
Coming from a tradition of objectivity, cognitive restructuring involves debunking dysfunctional beliefs with evidence to the contrary (Hofmann, Asmundson, & Beck, 2013). However, when the reality continues to differ from individuals’ restructured beliefs, the believability of the restructured beliefs remain unconvincing (Larsson et al., 2015). Larsson et al.’s (2015) suggestion is also corroborated by Butler, Chapman, Forman, and Beck’s (2006) review of meta-analyses of CBT. The authors found that while CBT was efficacious for various psychological disorders such as unipolar depression, generalised anxiety disorder, PTSD etc. (i.e., large effect sizes), moderate effect sizes were found for CBT’s efficacy to reduce distress related to contextual difficulties such as marital distress, childhood somatic disorders and chronic pain. Thus, the limited efficacy of CBT interventions in reducing parents’ distress might be due to the continued reality of their child’s illness and their inability to alleviate their child’s pain or suffering. CBT’s limited efficacy is in contrast to behavioural approaches such as the PSST that target specific problems and hence changes parents’ immediate environmental stressors. Furthermore, being limited in reconciling parents’ alternative beliefs with their lived experiences, the CBT approaches may have overlooked the aspect of guiding participants to connect with their inner resources and identify core values, and/or restore a greater sense of purpose. This is a particular strength of meaning-based approaches (Frankl, 1967; Hutchinson & Chapman, 2005). Interventions utilising meaning-based approaches and their efficacy will next be discussed in depth.

### 6.2.2 Meaning-Based Intervention Models

An intervention that targets personal meanings and engages individuals with their values and their relationship with the world can help to address existential distress in parents of children with cancer or a chronic illness. Given the lack of meaning-based psychological intervention literature on parents, the current study turns to the adult chronic PTSD and cancer patients’ literature for knowledge pertaining to addressing individuals’ sense of
meaning and values amidst situations that threaten their worldviews. Two interventions stand out in this respect: Cognitive therapy for PTSD (Ehlers et al., 2005), and the Meaning-Centred Group Psychotherapy (MCGP; Breitbart et al., 2004).

Cognitive Therapy for PTSD (CT for PTSD; Ehlers & Clark, 2000) targets personal meanings in traumatic situations. In contrast to traditional exposure interventions that view PTSD as a pathological fear structure associated with the trauma memory, and seek to extinguish this fear through repeated exposure to the trauma to increase habituation (Brewin & Holmes, 2003; Foa, Rothbaum, Riggs, & Murdock, 1991), Ehlers and Clark argue that individuals’ personal meanings of the most distressing part of their trauma memory and its sequelae are central to maintaining PTSD. Treatment identifies and modifies these meanings, then incorporates the modified meanings into the most distressing part of the trauma memory (Ehlers et al., 2005). So far, four RCTs have been carried out for CT for PTSD, and have consistently shown reduced PTSD symptoms in participants (Ehlers, Clark, Hackmann, & et al., 2003; Ehlers et al., 2010; Ehlers et al., 2013; Ehlers et al., 2014). In addition, in a systematic review and meta-analysis of psychological treatments for chronic PTSD, Bisson et al. (2007) reported two important findings supporting CT for PTSD. The first was that interventions specifically targeting the most distressing part of participants’ trauma memory and the personal meanings of the trauma received most support in showing significant reductions in PTSD symptoms (i.e., trauma-focused CBT, including CT for PTSD, and eye-movement desensitisation and reprocessing therapy; EMDR). The second finding was that evidence in support of trauma-focused CBT was stronger than EMDR in terms of the number of studies undertaken and the certainty with which clinical benefit was established.

Another way of assisting parents in seeking meaning from their child’s illness is through engaging their values. One such intervention that has been gaining increased attention in the psycho-oncology field is the Meaning-Centred Psychotherapy (Group and
Individual; MCP). The MCP used Frankl’s Logotherapy as its theoretical base to propose that a sense of meaning drives individuals’ motivation to continue living. It also adopted Logotherapy’s postulated sources of meaning – attitudinal values (i.e., the stand individuals take of their situation), experiential values (i.e., individuals’ encounters with life through art, nature, love, etc), and creative values (i.e., individuals’ engagements with life through their activities). The aim of the MCP was to help patients enhance or sustain their sense of meaning and purpose in life through addressing a sense of meaninglessness brought about by illness (Thomas, Meier, & Irwin, 2014; van der Spek, Vos, et al., 2014).

The MCP was originally developed by Breitbart and his colleagues (2004; 2012) for adult patients with advanced cancer, and later adapted for adult cancer survivors (van der Spek, van Uden-Kraan, et al., 2014). Three RCTs of the MCP were conducted, and demonstrated mixed results. While they shared common findings that the MCP improved participants’ sense of meaning and overall quality of life, they differed in terms of reductions in depression levels (group MCP and individual MCP), and hopelessness (individual MCP; Breitbart et al., 2012; Breitbart et al., 2015). Furthermore, at 2-months follow-up, the individual version showed that improvements during treatment in spiritual well-being, sense of meaning, and quality of life had disappeared, leaving insignificant differences between the treatment group and control group (Breitbart et al., 2012). In relation to the current study, would a meaning-based intervention similar to the MCP work with parents facing the potential death of their child? Breitbart and colleagues are planning to trial the MCP on caregivers of cancer patients ("Psychotherapy; Findings from Memorial Sloan-Kettering Cancer Center Broaden Understanding of Psychotherapy: Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C): Rationale and Overview," 2016), but there is still a need for meaning-based intervention for parents of children with paediatric cancer or chronic illnesses.
Parents’ description of a “broken life world” (Bjork et al., 2005, p. 268) when their child is diagnosed with cancer converges with literature that discusses parents’ coping through their search for meaning (Grootenhuis & Last, 1997; Lister, 2005; Wiedebusch et al., 2010). The search for meaning included drawing on their values, goals, beliefs, and religion (Folkman & Moskowitz, 2004; Frankl, 1963; Gawronski, 2012). In particular, values are seen as guiding mechanisms to life, leading individuals to live meaningful lives (Hitlin & Piliavin, 2004). Two approaches, Acceptance and Commitment Therapy (ACT; Hayes et al., 2005) and Logotherapy (Frankl, 1963), stand out in their emphasis on values.

Acceptance and Commitment Therapy (ACT; Hayes et al., 2005) and Logotherapy (Frankl, 1963) emphasise that individuals’ behaviours and attitudes need to be in line with their values to achieve a meaningful life (Sharp, Schulenberg, Wilson, & Murrell, 2004). These approaches share similarities, yet are fundamentally different in terms of their contextual frameworks. They view values as important and active ways of interacting with life, and motivate behaviours in ways that facilitate individuals’ search for meaning, thereby giving a sense of ‘alive-ness’ to their existence (Das, 1998; Hayes, Pistorello, & Levin, 2012). However, ACT takes on an individualised view of values, conceptualising them as a construct that has personal importance and significance to the individual (Hayes, Levin, Plumb-Vilardaga, Villatte, & Pistorello, 2013). This means that values come about because they are personally rewarding. In contrast, Logotherapy’s three broad categories of values (i.e., experiential, creative, and attitudinal values) suggest a bi-directional relationship between individuals and the values. That is, in engaging with these values, individuals are engaging with life and what it has to offer; and in turn, contribute back to life.

The difference in perspectives of the function of values may be explained by the context in which both the frameworks were developed. Logotherapy was borne out of Frankl’s experience from the Holocaust, where he witnessed the destruction that war brought
not only to individual people, but also to the quality of humanity. Frankl’s passion was to explain individual differences between what made some people succumb to becoming perpetrators or accomplices to mass violence, and what made others demonstrate their core qualities of being human. Logotherapy was thus conceptualised in a context when questions of life, death and existential distress were paramount. In contrast, ACT, being developed in the new millennium, emphasised pragmatism in the form of functional contextualism (Hayes, Strosahl, Bunting, Twohig, & Wilson, 2004). This means that instead of viewing the individual’s cognition or behaviour separately from the environment, ACT views the individual as the agent actively interacting with his or her values to produce behaviours and cognitions that influence his or her psychological well-being (Hayes et al., 2005). In light of the different contexts in which the two approaches were borne, and keeping in mind the balance between life and death parents face with their child’s illness, an interesting question would be whether Frankl’s approach to values might be more relevant to parents with an ill child than ACT.

As outlined above, many parents of children with cancer or chronic illness suffer from disrupted personal meanings and existential distress. It is therefore argued that an intervention that aims to reduce meaning distress may be beneficial for parents of children with cancer or chronic illness. Whether such an intervention is efficacious forms the overarching inquiry of this study.

6.3 Present Study

The overarching research question of this study is to explore the efficacy of using a meaning – and values-based treatment approach, named Meaning-focused Therapy (MFT) to enhance or repair the sense of meaning in parents of children with a chronic illness (Case 1) or cancer (Case 2). The study sought to answer the research question via two in-depth case studies that map out parents’ experiences of their child’s illness in their contextual reality;
assess the efficacy of the MFT through standardised outcome measures and qualitative observations; and evaluate the fit of the MFT to the participants via its delivery and receipt by the researcher and participants, respectively.
Chapter 7: Study 2 Methods

This section will describe how the study was carried out and analysed. To achieve this, the following aspects of the study’s method and their subsections will be discussed in detail: (a) the study’s design; (b) the description of the intervention; (c) the measures used; (d) a brief description of the participants; and (e) the procedure by which the study was carried out.

7.1 Study Design

Given the paucity of research on the benefits of a meaning-based approach in the established context, the current research seeks to map out parents’ experiences of their child’s illness as they undertake a meaning-focused treatment (i.e., the MFT). Furthermore, to have a full understanding of parents’ experiences, the study is also interested in describing them in the contextual reality of their lives, which includes their sense of meaning (current and shattered meanings) and values, and the additional stressors and challenges they face in their daily lives.

To my knowledge, although there is research exploring the lived experiences of parents of children with chronic illnesses or cancer (e.g., Ångström-Brännström et al., 2010; Bateman, 2011; Bjork et al., 2005), understanding parents’ caregiving experiences from their contextual reality through an intervention is the first of its kind. It is thus worth exploring parents’ caregiving experiences in relation to their contexts to build towards an amount of information that can allow generalisation to be drawn (Flyvbjerg, 2006; Yin, 1981). As of April 2016, electronic searches in the PsycINFO database using the keywords “psychological”, “psychotherapy”, “intervention*”, “parent*”, “of child”, “of p*diatric”, “illness”, “cancer”, “qualitative”, “context” yielded no results of interventions that targeted parents’ distress associated with their child’s illness as well as potential contextual stressors. Thus, there is a need to bridge this gap.
The current study thus adopted a case study research design. The case study method is an intensive approach that seeks to obtain in-depth knowledge about a particular case, including the case’s contextual information (Willig, 2013). While there is unanimity among various perspectives that the case study method requires in-depth, contextual information to enhance comprehensive understanding of the case, various case study theorists diverge in their approach towards the conceptualisation of a case, and how a case study should be carried out (Baxter, 2008). Yin (2003) emphasises the interaction between the case and its natural context (Barrett, 2014). Stake (1995), on the other hand, emphasises the internal dynamics of the case, viewing it as an “integrated system” (p.2). Finally, Merriam (2014) views the case study as an “in-depth description and analysis of a bounded system” (p.40), suggesting flexibility in studying cases.

In relation to the current study, participants’ contextual reality in the form of availability and accessibility of resources, and background history, play a role in their distress associated with their child’s illness. Given that illness within the family has ripple effects throughout the family system which could exacerbate or give rise to changes in parents’ distress or contextual situations, it is difficult to ascertain where the phenomenon starts or blends with the context, and also impossible to place or establish boundaries on the cases. Thus, the current study will utilise Yin’s (2003) definition of the case study.

The next components of the study design will be discussed: (a) data sources; and (b) data analysis.

7.2 Data Sources

The benefits of the MFT are explored from two perspectives. The first investigates the impact of the MFT on the participants’ existential and meaning distress (i.e., sources of parents’ distress and efficacy of the MFT in reducing their distress), and the second evaluates
the applicability of the MFT. The specific data sources that will be used to (a) analyse parents’ distress and the efficacy of the MFT, and (b) evaluating the fit of the MFT will be discussed.

7.2.1 Sources Analysing Parents’ Distress

The data sources of interest in analysing changes in the participants’ distress are grouped according to their sources of distress ([a] to [d]), their provision of a context for understanding participants’ distress ([e]), and provision of an objective measure of participants’ distress ([f]). These data sources are: (a) personal meanings; (b) values; (c) narrative of their experiences; (d) coping strategies; a context for understanding the participants’ distress through (e) their demographic information and relevant histories; and (f) standardised measures of their psychological outcomes pre- and post-intervention, and 3-month follow-up to assess if their distress was reduced after participating in the MFT.

7.2.1A Personal Meanings

The purpose of including participants’ personal meanings as a data source was to understand the meanings – lost or gained – participants derive from their child’s illness. The two specific areas of interest due to their impact on participants’ distress were the rupture of participants’ meanings, and coping with their child’s illness through meaning.

7.2.1B Participants’ Values

Analysing parents’ values served to help understand areas most closely held by them, and the impact when values clashed. The analysis of parents’ values was based on three indicators: (a) participants’ verbal expressions of their values; (b) their expression of it through their actions; and (c) observations of their emotional tone when they relate their experiences.

7.2.1C Narrative of Parents’ Experiences

The purpose of analysing parents’ narratives was to understand how they make sense of their world after their child’s diagnosis and its implications. This included their
descriptions of additional stressors, or other crises they might have been facing. These in turn influenced the meanings they prescribe to their child’s illness and their subsequent coping.

7.2.1D Parents’ Coping Strategies

Parents’ coping strategies were important in understanding their context and distress, and what alleviated it. Given that the efficacy of coping strategies is dependent on the flexibility by which individuals utilise them and whether these strategies are in line with their values, understanding this relationship can shed light on how the fit between these two variables might influence parents’ distress levels.

7.2.1E Demographic Information and Relevant Histories

Following the rationale of a case study approach, including participants’ demographic information and relevant histories provided a context to understand their responses to the intervention.

7.2.1F Standardised Outcome Measures

Standardised outcome measures were used to obtain objective scores of participants’ distress before and after the intervention, and at follow-up. A battery of standardised outcome measures was employed to assess participants’ depression, anxiety and stress levels, PTSD symptoms, general orientation to life, and engagement in coping strategies. In addition, a qualitative measure on participants’ sense of meaning about their child’s illness was used. The measures will be discussed in detail in the Measures section.

7.2.2 Evaluation of the Fit of the MFT

Following the argument that contextual reality plays a role in parents’ distress, evaluating the intervention included investigating whether, and how, the intervention fitted within the contextual reality of these parents (Hart & Bagiella, 2012). To achieve this evaluation, two broad areas of evaluation were used: (a) Delivery of Intervention; and (b) Receipt of Intervention. The specific criteria for the evaluation of the MFT are presented in
Tables 1 and 2, and discussed in detail in the Measures section. The reader is referred to Appendix D for the full checklist.

7.2.2A Delivery of Intervention

Assessing the researcher’s adherence to the treatment protocol ensured the validity and integrity of the treatment in meeting its objectives. The main constructs of the MFT – values and meanings – were assessed through the clarity and style of discussion. The data sources that were used to evaluate the delivery of the intervention were: (a) the values and meanings that were identified during the MFT; and (b) the process by which the values and meanings were discussed and presented.

7.2.2B Receipt of MFT

The purpose of assessing participants’ receipt of the MFT was to ensure that the intervention was received and understood by the participants as intended by the objectives of the intervention. Thus, data sources used to evaluate the receipt of the intervention were (a) participants’ engagement in the intervention; (b) the content of participants’ contributions during the intervention; and (c) the applications of concepts learnt from the MFT in between sessions.

7.3 Data Analysis

Two types of analyses were conducted in two areas. Firstly, qualitative analysis was used to analyse participants’ experiences of their child’s illness, as well as the feasibility of the MFT in meeting participants’ contexts and experiences. Secondly, quantitative analysis was used to analyse the scores on the standardised measures.

7.3.1 Qualitative Analysis

Thematic analysis was chosen for its theoretical freedom, which allowed flexibility in obtaining rich descriptions of participants’ subjective experiences. Thematic analysis is an
analytic method for “identifying, analysing and reporting patterns, or themes, within the data” (Braun & Clarke, 2006, p. 79), as comprehensively and as close to the participants’ words as possible (Guest, MacQueen, & Namey). It has been recommended for studies that aim to build knowledge for a specific phenomenon (Braun & Clarke, 2006). An inductive thematic analysis was used to address the parent’s expressions of their meanings and values in the wider context of their life experiences for themes. Particular attention was paid to their values, possible threats or ruptures to meaning, and methods of coping with difficulties. The results of the analysis also evaluated the fit of the MFT with participants’ contexts and experiences.

7.3.1A Thematic Analysis of Sessions

Participants’ responses regarding their experiences in caring for their child were analysed using the thematic analysis procedure described by Braun and Clarke (2006). Initial codes were generated based on participants’ reports of 1) their experiences in caring for their child, and 2) any changes (for better or worse) in their care of their child during the course of the intervention. Next, the codes were sorted into potential themes, and named as closely to participants’ words as possible. Themes generated during the course of the thematic analysis also served as a comparative guide to participants’ responses to the intervention. The researcher’s delivery of the MFT based on its respective ratings were compared to participants’ responses in the respective themes and analysed.

7.3.1B Analysis of MFT

The researcher’s delivery and participants’ receipt of the MFT were analysed using a set of criteria. The purpose of developing a set of criteria was to apply a structured approach to evaluate the fit of the MFT with participants’ experiences and contextual reality. This section will discuss the two sets of criteria.
7.3.1 B1 Delivery of Intervention

Two criteria were developed to evaluate the delivery of the intervention (Table 20). The first criterion evaluated whether the researcher kept to the objectives of the intervention. It sought to assess the fidelity of the MFT and hence its internal validity. The second criterion was the clarity by which meanings and values were presented to the participants. There were three objectives of the second criterion: (1) to evaluate the accessibility of the MFT across the participants; (2) to assess the way the concepts were presented to the participants; (3) to assess if the researcher’s presentations of the concepts had met the objectives of the MFT.

The study utilised a frequency analysis to assess the number of times values and meanings were identified to determine if the researcher kept to the objectives of the intervention. To analyse the clarity by which meanings and values were discussed, two analytic approaches were used. The first was a frequency count of the clarity of the presentation (assessed via a 5-point Likert scale; discussed in detail in the Measures section), and the second was an analysis of participants’ processing of the information. The analysis assessed participants’ engagement in the intervention, indicated by the strength of their responses, their tone of voice, and their emotional responses. A detailed description of the evaluation checklist is provided in the Measures section.
### Table 20

**Criteria for Delivery of MFT**

<table>
<thead>
<tr>
<th>Active ingredients</th>
<th>Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Values</td>
<td>- Were values discussed?</td>
</tr>
<tr>
<td></td>
<td>- Clarity of discussion?</td>
</tr>
<tr>
<td></td>
<td>- Purpose of discussing values the way it was?</td>
</tr>
<tr>
<td>Meaning</td>
<td>- Was meaning discussed?</td>
</tr>
<tr>
<td></td>
<td>- Clarity of discussion?</td>
</tr>
<tr>
<td></td>
<td>- Purpose of discussing meanings the way it was?</td>
</tr>
</tbody>
</table>

#### 7.3.1 B2 Receipt of Intervention

Four criteria were developed to evaluate participants’ receipt of the intervention (Table 21). Criterion 1 was participants’ attendance for the sessions. Criterion 2 was participants’ completion of the experiential exercises, the accuracy and quality of responses. Criteria 3 and 4 were participants’ engagement in discussions on values and meanings respectively. The criteria collectively assessed participants’ engagement and understanding of the constructs.  

Criterion 1 was assessed via frequency analysis for the number of times participants attended the sessions. Criteria 2, 3, and 4 were assessed using markers such as the length and depth of participants’ discussions of the experiential exercises, values and meanings, the extent to which their responses were in line with the topics, the extent to which prompting or clarifications needed to be made, and participants’ feedback of their experiences with the exercises and their reports of their lives in between sessions. Criterion 2 had an additional marker that utilised a frequency analysis for the number of times participants completed their experiential exercises. The transcriptions were analysed using the markers. A detailed
description of the evaluation checklist with its respective rating criteria is provided in the Measures section.

Table 21

*Criteria for Receipt of the MFT*

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Markers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendance</td>
<td>- Did the participant attend each session?</td>
</tr>
<tr>
<td>Completion of Experiential Exercises</td>
<td>- Did the participant complete his/her homework/experiential exercise?</td>
</tr>
<tr>
<td></td>
<td>- Did the participant require prompting for the homework/experiential exercise?</td>
</tr>
<tr>
<td></td>
<td>- Did the participant require clarification for the homework/experiential exercise?</td>
</tr>
<tr>
<td></td>
<td>- Were the participants’ responses in line with the topic of the homework/experiential exercise?</td>
</tr>
<tr>
<td>Engagement in Values Discussion</td>
<td>- Length of participant’s discussion on values?</td>
</tr>
<tr>
<td></td>
<td>- Depth of participant’s discussion on values?</td>
</tr>
<tr>
<td></td>
<td>- Application of values outside of session?</td>
</tr>
<tr>
<td>Engagement in Meanings Discussion</td>
<td>- Length of participant’s discussion on sense of meaning?</td>
</tr>
<tr>
<td></td>
<td>- Depth of participant’s discussion on sense of meaning?</td>
</tr>
<tr>
<td></td>
<td>- Awareness of sense of meaning outside of session?</td>
</tr>
</tbody>
</table>

7.3.2 Quantitative Analysis

Quantitative analysis was used to measure participants’ scores on the standardised objective measures. Visual analysis of the participants’ scores were used in the current study due to the small sample size.
7.3.3 Data Preparation

The intervention sessions were first transcribed orthographically. However, as Case 1 was conducted predominantly in Mandarin, the sessions were translated and also edited for grammar. Case 2 was also edited for grammar. Filler words were also removed to facilitate ease of reading the quotations.

Each session was videotaped. The intervention was conducted in Singapore. Sending the videos over to the researcher’s supervisor in Perth, Western Australia, for supervision, was not feasible due to ethical concerns of confidentiality. Thus, each session was transcribed, with as much description of the researcher and the participant as possible. Supervision for the intervention was conducted before each session commenced.

Participants’ responses on the standardised measures (described in detail below) before and after the MFT, and at 3-month follow-up, were entered into a Microsoft Excel spreadsheet.

7.4 Description of the Intervention

The section introduces the Meaning-Focused Therapy (MFT). The overall objective of the intervention was to reduce meaning distress by rebuilding or enhancing participants’ awareness of their values and sense of meaning, and use them as resources to cope with their child’s illness. It was achieved through discussions and experiential exercises. The following components will be discussed: (a) the conceptualisation of the MFT; (b) aims and objective of each session; and (c) the measures used to assess efficacy and feasibility of the MFT.

7.4.1 Conceptualisation of MFT

The underpinning position of the current study was that parents face meaning-related distress when their child is diagnosed with cancer or a chronic illness. Their distress could be compounded or be predisposed by contextual issues. The meanings parents gained from their child’s illness and the values that kept them going despite the threats, were considered
essential ingredients of the MFT. Thus, the primary purposes of the MFT were to target parents’ personal meanings that were threatened as a result of the child’s illness, and to identify areas of value to parents. Hence, an intervention that predominantly adapted elements from Breitbart and colleagues’ (2012; 2010; 2015) MCP, and Ehlers and colleagues’ (2000; 2005) Cognitive Therapy for PTSD, was adopted.

Firstly, parents’ interpretations of their child’s illness influence the degree of their distress. To target parents’ most distressing meanings, the MFT used Ehlers and Clark’s technique of targeting and modifying the personal meanings that were most threatening through continued exploration of these meanings and alternative interpretations.

Secondly, the possibility of losing the child, both physically and symbolically, also challenges parents’ values. To help participants become aware of their values, the MFT adapted MCP’s use of Logotherapy’s three values - experiential, creative, and attitudinal values in their experiential exercises. The goal was to help participants link the concepts with their experiences.

**7.4.2 Content of MFT Sessions**

The MFT was a four-week (1.5 hour weekly sessions) group intervention. This section provides an overview of each session’s topic and objective. The reader is directed to Table 22 for the content of each session, and Table 23, that lists the experiential and homework exercises for each session. The full protocol of the MFT is provided in Appendix E.

**7.4.2A Session 1: Overview of Intervention and Values Identification**

The purpose of Session 1 was to identify the most distressing aspects of participants’ experiences of their child’s illness, their values, and to introduce the construct of meaning. This was done using two activities. The first activity was participants’ introductions of
themselves, with a particular focus on their perspectives of life changes since the diagnosis, what they found most difficult with the illness and why, and the impact of their child’s diagnosis on them. The introduction was integral to Session 1 because it provided a non-threatening context for the researcher to identify two key areas: the distressing interpretations that participants had attached to their child’s illness, and participants’ values that were challenged or fulfilled throughout their experience. The second activity was the introduction of the experiential exercise where participants were asked about a time when caring for their child had been particularly meaningful. The experiential exercise was chosen because it provided participants with a meaningful experience from their current life in order to build hope for their future. The participants were then encouraged to go home to think of more examples and situations related to the exercise.

7.4.2B Session 2: Values and Attitude

Session 2’s purpose was to identify participants’ values, and their attitudes towards their child’s illness. Three activities were chosen to accomplish the exploration of values and attitudes. The first activity discussed how and what had kept participants going despite the difficulties. Leading in from Session 1, this activity provided a context to explore the values that led to a sense of meaning. The second and third activities utilised the experiential exercise to identify areas in their lives where they had choice and control, and how they had managed to keep going when faced with challenges in these areas. This experiential exercise aimed to identify participants’ strengths, and aid their discovery of how different attitudes give strength and meaning.

7.4.2C Session 3: Experiential Sources of Meaning

Session 3 built on participants’ values and purpose. This session explored areas where life had shown promise or meaning and, in turn, explored the experiential sources of meaning, particularly when caring for their child. To accomplish this purpose, the session utilised the
experiential exercise of asking the participants to reflect on times when their lives appeared to reinforce their sense of meaning. This experiential exercise allowed participants to learn that a sense of meaning can be obtained through experiences with love, or their surroundings.

A secondary reason for utilising this experiential exercise was to build participants’ awareness that there was more than one way to obtain a sense of meaning in life. Thus, a transition was created towards introducing creative sources of meaning. Creative sources of meaning were discussed to build on participants’ self-efficacy through thinking about past experiences where they had solved problems using alternative solutions. A homework exercise was introduced, where participants identified an area where they could try a new strategy and carry it out. This provided an opportunity for participants to apply the skills they had learnt during the interventions, and also planted the seeds for thinking about the future, the focus of Session 4.

7.4.2C Session 4: Creative Sources of Meaning and the Future

The purpose of Session 4 was for participants to explore their thoughts and plans for the future. The final session continued with the discussion of creative sources of meaning through exploring the homework exercises the participants had done between sessions.
Table 22

*Overview of Session Topics and Content*

<table>
<thead>
<tr>
<th>Session</th>
<th>Topic</th>
<th>Content</th>
</tr>
</thead>
</table>
| 1       | Introduction to intervention and values identification | - Introduction to format of MFT  
- Introduction of participants and their experiences in caring for child  
- Introduction of concept of meaning  
- Experiential exercise  
- Homework |
| 2       | Values and attitudinal sources of meaning  | - Discussion of adversities and how they were overcome  
- Experiential exercise |
| 3       | Experiential sources of meaning            | - Past experiences as a source of meaning  
- Values action as a prerequisite for building meaning  
- Introduction to creative sources of meaning  
- Experiential exercise  
- Homework exercise |
| 4       | Creative sources of meaning and the future | - Review of homework exercise  
- Discussion of plans for the future |
### Table 23

**Experiential Exercises**

<table>
<thead>
<tr>
<th>Session</th>
<th>Experiential Exercise</th>
<th>Homework Exercise</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Has there been any event while caring for your child, that made you think, “Ah, I know why I am here?” Tell me more</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>- What are some areas where you feel you have choice and control? - What kept you going when you met with difficulties in these areas?</td>
<td>Thinking of other examples and situations</td>
</tr>
<tr>
<td>3</td>
<td>In our first session, we talked about some of the challenges you face while managing your child’s illness. During this time, I wonder if there were times when things seemed better/more hopeful/brighter/you had felt like “This is worth it!” or “This is possible”?</td>
<td>If you think about the everyday now, how do you think you could use what you have discovered about your values, and apply it to your daily life?</td>
</tr>
</tbody>
</table>

### 7.5 Measures

The assessment phase consists of psychological outcome measures for the participants and an intervention feasibility checklist. To measure participants’ psychological outcomes, the same Emotion and Help Thermometers as well as the assessment battery administered in Study 1 were used. Additional self-report questionnaires were also administered. Only the English versions of the assessment battery were used and will be described in this section.
The intervention feasibility checklist measured treatment fidelity as well as how well the participant understood or took on board the discussions during the intervention.

7.5.1 Standardised Measures

7.5.1A Distress and Emotion Thermometers

The screening tool is a set of five emotion thermometers (Distress, Anxiety, Depression, Anger, Crushed Universe) and a Help thermometer that requires parents to rate their levels of distress on a scale from 0 to 10, where 0 = No Distress, 10 = Extreme Distress. The emotion thermometers (with the exception of the Crushed Universe thermometer) and help thermometers were adapted from Mitchell, Baker-Glenn, Granger et al. (2010), while the Crushed Universe thermometer was created for the present study to test for the presence of meaning-related distress among participants. Based on the recommendation by the National Comprehensive Cancer Network (NCCN) in 2007 (NCCN, 2007; as cited by Mitchell et al., 2010) a cut-off of 4 and above was used to indicate moderate levels of distress and higher in this study to recruit participants for the intervention phase.

7.5.1B Depression, Anxiety and Stress Scale-21 Items (DASS-21)

The DASS-21 (Lovibond & Lovibond, 1993) is a 21-item self-report measure that contains three subscales – depression, anxiety, and stress. Participants rated how often they had experienced each symptom over the past week (e.g., Depression: “I couldn’t seem to experience any positive feeling at all”; Anxiety: “I was aware of dryness of my mouth”; Stress: “I found it hard to wind down”). Each item on the DASS-21 is rated on a 4-point Likert scale, ranging from 0 (did not apply to me at all) to 3 (applied to me very much, or most of the time). The total scores of each subscale indicate the severity of participants’ levels of depression, anxiety and stress from normal to extremely severe.
7.5.1C Sense of Coherence Scale-13 Items (SOC-13)

The SOC-13 (Antonovsky, 1987) is a 13-item self-report questionnaire that comprises three dimensions – comprehensibility (i.e., how events around the individual make sense to him/her); manageability (i.e., whether the individual has the resources to meet the demands posed by the events); and meaningfulness (i.e., whether the event is a challenge that is worthy of investment and engagement). The SOC-13 comprises five items measuring comprehensibility (e.g., "Do you have the feeling that you are in an unfamiliar situation and don't know what to do?"); four items measuring manageability (e.g., "How often do you have feelings that you're not sure you can keep under control?") and four items measuring meaningfulness (e.g., "How often do you have the feeling that there's little meaning in the things you do in your daily life?"). Each item on the SOC-13 is rated on a 7-point Likert scale, with two anchoring phrases with 7 representing strongest SOC and 1 representing weakest SOC. Thus, possible SOC-13 scores ranged from 13 to 91, where lower scores indicated weaker SOC, and higher scores indicated stronger SOC.

7.5.1D Impact of Events Scale-Revised (IES-R)

The IES-R (Weiss & Marmar, 1997) (Weiss & Marmar, 1997) is a 22-item questionnaire that was developed to assess the subjective effects of stressful life events on individuals (McDonald, 1997). The IES-R scale comprises three subscales – intrusion (e.g., “I thought about it when I didn’t mean to”), avoidance (e.g., “I avoided letting myself get upset when I thought about it or was reminded of it”) and hyper-arousal (e.g., “I was jumpy and easily startled”). Participants were asked to rate how distressing each of the symptoms was over the past seven days or other agreed time period. Each item on the IES-R is rated on a scale of 0 (not at all), 1 (a little bit), 2 (moderately), 3 (quite a bit), and 4 (extremely). The individual subscale scores are obtained by averaging the total subscale score, reaching a highest possible score of 88, and a lowest possible score of 0.
7.5.1E Brief COPE Questionnaire

The Brief COPE (Carver, 1997) is a theoretically-driven 28-item questionnaire that measures individuals’ coping strategies. It comprises 14 discrete scales – active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame. Each scale is made up of two items rated on a four-point Likert scale, where 1 = I haven’t been doing this at all and 4 = I’ve been doing this a lot.

7.5.1F Open-ended Meaning Questionnaire

This questionnaire acted as a process measure to access the level of meaning parents attach to their child’s illness and their current situation. It contained a set of three questions assessing the meaning participants attach to receiving their child’s diagnosis and the management of their child’s illness. More specifically, the questions inquired if participants had made sense of their situation and what sense they had made, and if anything has changed, for the worse or better, for them.

7.5.2 Feasibility Assessment

7.5.2A Delivery of MFT

Frequency counts of the times values and meanings were identified were rated on a 5-point Likert scale that ranged from 1 (“Yes”) to 5 (“No”) with a midpoint of 3 (“Somewhat”). “Yes” meant that the values were addressed or identified explicitly (i.e., values were named); “Somewhat” meant that the values were brought up in an indirect fashion (i.e., tentative reflections or questions about participants’ values), and “No” meant that the researcher did not address or identify values or value-laden moments, or when the researcher’s questions or reflections did not name the values.
The ratings of the clarity by which values and meanings were presented to participants were graded on a 5-point Likert scale. The markers ranged from 1 (“Direct”) to 5 (“Vague”) with a midpoint of 3 (“Subtle”). “Direct” meant that the researcher had initiated the discussion with a direct discussion of the impact of the value on the participants. “Subtle” meant that questions or reflections of the participants’ responses were made to explore their underlying motivations. Lastly, “Vague” referred to the researcher using indirect means or examples to explore the participants’ values.

**7.5.2B Receipt of MFT**

The participants’ receipt of the MFT in terms of the completion of the experiential exercises was also rated on a 5-point Likert scale that ranged from 1 (“Yes”) to 5 (“No”) with a midpoint of 3 (“Somewhat”). “Yes” meant that the participants completed the experiential exercises, “Somewhat” meant that the participants had either confused the concepts or the experiential and homework exercises. “No” meant that the participants neither understood nor applied the concepts learnt in the MFT, or did not complete the experiential and homework exercises.

Markers (explained on Page 151) assessing the length and depth of the discussion utilised a 5-point Likert scale ranging from 1 (“Long/Thorough”) to 5 (“Short/Dismissive”) with a midpoint of 3 (“Attended to discussion, but did not elaborate”). For markers assessing participants’ behaviours outside of session, the scale ranged from 1 (“Discussed in detail”) to 5 (“Did not Mention”), with a midpoint of 3 (“Mentioned but did not elaborate”). Markers assessing the extent of prompting or clarification to the participants had the scale ranging from 1 (“All the exercises”) to 5 (“Little to no prompting/clarification”), with a midpoint of 3 (“Some prompting/clarification”).
7.6 Participants

A brief, overall description of the participants will be provided in this section. The Results section will provide detailed outlines of each case, including participants’ demographic background, presentation in sessions and relevant histories.

Two participants, both mothers, were recruited from Study 1. One participant was a mother of a child diagnosed with a chronic illness recruited from Club Rainbow Singapore (CRS; Case 1, Angie), and the other was a mother of a child diagnosed with cancer recruited from the National University Hospital of Singapore (NUH; Case 2, Tina). Both of them had reported scores above the cut-off of 4 on the Emotion and Help Thermometers, particularly on the Crushed Universe Thermometer, and also reported elevated levels of distress on the assessment battery.

7.7 Procedures

In this section, the following will be described: (a) ethics approval; (b) recruitment process; (c) format of the MFT; (d) completion of standardised measures; and (e) assurance of data integrity.

7.7.1 Ethics Approval

This study was approved by three Ethics Committees – Murdoch University’s Human Research Ethics Committee (for CRS), National Healthcare Group’s Domain Specific Review Board (DSRB; for NUH), and the Singhealth Centralised Institutional Review Board (CIRB; for KKH).

7.7.2 Recruitment

Participants were recruited from Study 1. Specifically, participants who reported elevated levels of distress (i.e., scores above cut-off of 4 on Emotion and Help Thermometers, or elevated levels on the assessment battery) in Study 1 were invited to participate in the MFT after they were debriefed of their scores. The potential participants were given an
information sheet describing the MFT, as well as its risks and benefits (refer to Appendix F for Information Sheet for NUH, and Appendix G for Information Sheet for CRS), and these were also verbally explained. Participants’ initial questions were also answered, and consent was sought to call them in a week’s time. Follow-up phone calls were made to answer questions and secure enrolment a week later. Participants’ formal consent was taken at the start of the first intervention session. Participants’ social workers at CRS and the Children’s Cancer Foundation (CCF) were notified when participants agreed to participate in the study.

No participants were recruited from KK Women’s and Children’s Hospital (KKH) for the study as all of the approached parents declined to take part. Reasons for declining participation were: not having time to attend the sessions, not being able to find carers for the child, and having other commitments apart from caring for the ill child. The recruitment for the current study at KKH was thus stopped as the recruitment deadline approached. The CIRB was notified of the change via an amendment, and approved.

It was initially intended that the MFT would be compared against a CBT intervention, and implemented in a between-subjects design with 60 participants. However, due to the low recruitment rate, a case study design was utilised. The respective Ethics boards were notified of the possibility of such an occurrence during the initial application process, and the study was approved.

7.7.3 Intervention

The intervention was initially intended to be a four-week (1.5 hour weekly sessions) group intervention. However, due to low recruitment rates and difficulties in scheduling common days because of differences in medical appointment schedules, parents’ working schedules and difficulties in finding carers for their child, the intervention became an individualised one. There was no change in the content and flow of the intervention. The time between each intervention session was modified to suit parents’ schedules, including
arranging the meeting to coincide with the child’s medical appointment requiring at least a
day’s stay (paediatric oncology population), or with the parent’s meeting with the CRS social
worker (chronic illness population). The sessions for the paediatric oncology population were
held in a consultation room at the hospital, and for the chronic illness population, in an
available meeting room at CRS.

7.7.4 Completion of Standardised Measures

Participants completed the standardised measures. The measures were administered
before and after the MFT, and at 3-month follow-up.

At the 3-month period, participants were contacted via phone calls to meet.

Appointments were made to coincide with their children’s appointments at the hospital to
reduce travelling time. The researcher met Angie when she attended her daughter’s medical
appointment at KKH, and Tina when she attended her daughter’s medical appointment at
NUH. Both participants completed the measures in a quiet room at the hospitals.

7.7.5 Assurance of Data Integrity

As this was part of a doctoral research programme, there were limited resources to
access independent raters to code data and rate treatment fidelity. Thus, the researcher herself
coded the data for the thematic analysis, and used the transcript to rate treatment fidelity.

Trustworthiness of the data was assured through two methods. First an audit was
conducted by the researcher’s supervisor. This involved the supervisor going through at least
20% of the coded and rated data. Differences between the researcher and supervisor’s coding
and the ratings were resolved through discussion. Second, the participants were engaged in
the proof-reading of the data analyses done to ensure the authenticity of the data to them.

Objections by the participants were taken into account and changed accordingly. All
intervention sessions were conducted by the researcher, and supervised by her supervisor.
Chapter 8: Study 2 Results

The results are presented in accordance to the two broad aims of the study: (a) the efficacy of the MFT, assessed through analysing changes in participants’ distress; and (b) the evaluation of the MFT’s feasibility, assessed through analysing the delivery and receipt of the intervention.

The findings of the cases are presented in a case study format. The participants’ case description will be presented in more detail, followed by their pre-test scores on the standardised measures previously described. Findings of the thematic analysis will be presented next, followed by participants’ post-test and follow-up scores.

The case studies were also about gaining an in-depth understanding of how the participants engaged in the intervention. The evaluation of the MFT also increased our understanding of their experiences and their engagement with the intervention.

Reflections

During the research process, I became aware of the dynamics between my dual role as both scientist and practitioner. While Psychology students are encouraged to adopt a scientist-practitioner approach, during the process, there were times when there were conflicts between the roles, particularly during the intervention process, yet also times where the roles facilitated each other, most notably during the data analytic process. The conflict between scientist and practitioner roles had the potential to bias the way the intervention was run. This was most evident in making a decision for how strictly to follow the intervention protocol, in favour of participants’ understanding of the principles of the intervention. I utilised both the transcribing of intervention sessions and supervision to manage this conflict. Firstly, transcribing provided a reflective process of each session. Secondly, supervision not only was a way to identify the conflict arisen from the transcribing process, but also, even before the intervention started, a way to reflect and discuss on the potential impact of the
conflict on the research process. The following paragraphs will explain the dynamics in more detail.

The conflict between scientist and practitioner was most salient in terms of how closely or loosely the intervention protocol was followed. This was particularly notable in two instances – adjusting the intervention to match participants’ style of communication and cognitive style, and when participants expressed a high level of psychological distress. The former instance was a challenge particularly when the two participants in the study differed so much in terms of ethnicity, life experiences, cognitive style, and age. Transcription firstly helped to raise my awareness of how the participants differentially responded to the intervention, and supervision helped to improve my ability to identify the nuances in each participant’s expression of values and meaning ruptures, and to develop alternative ways of questioning.

In the case where participants were experiencing high levels of psychological distress, as with Tina (explained in detail in Case 2), ethical considerations came into play. Tina’s safety and consequent ability to care for her ill daughter was called into question, and thus the call to focus on her distress rather than the particular goals of the intervention session.

It was interesting that while adjustments were made to the intervention protocol to match the abovementioned situations, the participants were able to maintain engagement in the intervention, and themes of values, meaning ruptures, and narratives of their experiences were able to be explored. It thus highlighted to me that in the context of conducting an exploration of an intervention, it is neither the activities nor keeping to specific goals of each session that determine the applicability or efficacy of the intervention. Rather, it is more important that the principles of the intervention are followed, and that reflections and queries are made in the way participants understand; activities and session goals are but tools and guidelines.
Where scientist and practitioner facilitated each other was in the development of the feasibility template of the intervention. While the scientist in me demanded that fidelity be assessed, the practitioner also wanted to assess participants’ receptivity to the intervention, and whether there was a qualitative difference in the way each participant understood and processed the intervention. Interestingly, it was an eye-opening and humbling experience to realise that however little change there was in participants’ reports of distress on standardised measures, their presentations and reports subtly changed. It was thus through this process that I realised fidelity is only half the story; explorations of intervention efficacy also need to account for participants’ receptivity to it.

Furthermore, the use of feedback between therapist and participant in each subsequent session also reconciled the role of scientist and practitioner. While the scientist takes feedback as a tool to check the trustworthiness of the data the practitioner used feedback to check for understanding of intervention content and rapport between participant and therapist. It was heartening to note that participants had reflected on certain aspects of the intervention, and also applied skills learnt in session outside of it. These suggested that however short a time the therapist had spent with the participant, certain aspects of the intervention had resonated within them.

It is thus with this hope and heart that I move forward in my role as both scientist and practitioner, to marry the two more than divide them.

8.1 Case 1

8.1.1 Case Description

8.1.1A Demographic Information

“Angie” was a Mandarin-speaking Chinese 46-year-old single mother of three, with two of her younger children diagnosed with a chronic illness. Her 15-year-old daughter was diagnosed with hypothyroidism when she was two years old (i.e. 2003), and her six-year-old
son had frequent episodes of rectal bleeding and bowel problems. Angie’s son was given a broad diagnosis of gastro-intestinal issues when he was three years old (i.e., 2013) as the doctors were unable to find a medical basis for his condition.

Angie reported that she worried more about her youngest son due to the uncertainty of his illness, which was exacerbated by her negative experiences with the hospital staff, and them not including her in their investigations of her son.

Additional potential stressors Angie faced at the time of the intervention were her accommodation and marital status, and financial difficulties. Angie was residing with her soon-to-be ex-husband with whom she shared the deed to their apartment, and her three children, aged 19, 15, and six. Angie had also been undergoing complicated divorce procedures prior to the intervention.

Angie and her family were also facing financial difficulties. She had been working part-time at a baking programme for women from low-income families to learn baking and sell their products, for the last four years. She received subsidies on her children’s medical bills from the hospital’s Medical Social Work department, and also received financial assistance and food rations from CRS.

However, Angie did not report significant stress from these areas during the intervention. Rather, she reported that time spent with her children, giving back to society, and behaving with integrity were more important than the difficulties mentioned above. Angie’s view with regard to these potential stressors and her values will be discussed in detail in the findings of the thematic analysis.
8.1.1B Presentation

Angie presented to the intervention as an energetic and outspoken lady. She was articulate in expressing her views on her values and principles in life, as well as in describing her past experiences. However, she found it challenging to accept praise and validation of her experiences. She reacted to these by talking about others who had undergone worse circumstances, by making jokes of the praise, or by changing the topic.

Angie participated actively in the intervention, and was diligent in completing the experiential exercises. It was observed, however, when it came to questions about her personal strengths, Angie tended to relate examples of what others had said about her.

8.1.1C Relevant History

Aspects of Angie’s history relevant to the analysis were of her overcoming difficulties in childhood and present potential stressors. Also of relevance was Angie’s access to sources of social support important to her.

Angie’s growing up years were marked by separation and lack of financial and social support. Her parents separated when she was young, and she was estranged from them. Angie was left under the care of her paternal grandparents to whom she was not close. At the age of 10, due to financial difficulties, Angie almost had to drop out of school. However, she managed to find a shop-owner (after going through a few blocks of industrial estates) who decided to pay for her school fees and meals in exchange for simple work at his shop for the next six years. Angie’s marriage was conflictual and required her to be the breadwinner in the family. Her husband was a compulsive gambler, and had racked up enormous debts with illegal money-lenders several times, which he depended on Angie to pay off. He went into hiding for a year once, when Angie finally decided that she could not pay off his debts to the money-lenders and provide for her children at the same time. When her husband went into
hiding, Angie had to negotiate with the money-lenders to reduce the interest rates, and also found a job distributing flyers that allowed her to simultaneously work and care for her children. In addition to his gambling addiction, Angie’s husband also expressed jealousy. He accused her several times of having extra-marital affairs, and had also gone to her workplace to accuse her boss of seducing her. As a result, Angie was not able to go back to her workplace for a year.

When Angie eventually decided to divorce, she met with unhelpful legal counsels who required that she pay their fees before commencing the divorce procedures.

While Angie did not receive social support from her husband, she had supportive children, particularly her eldest son, and her niece. She also received financial support and food rations from the abovementioned agencies.

**8.1.1D Pre-test Scores**

This section presents a summary of Angie’s pre-test scores. The breakdown of her scores are presented together with the post-test and follow-up test scores in Tables 24 and 25.

On the pre-test, Angie scored in the mild to high distress levels on all five of the emotion and help thermometers, based on the NCCN’s recommended cut-off of 4. In particular, Angie reported high levels of distress on the Distress, Anxiety, Depression and Help Thermometers (scores of 7 on Distress and Depression Thermometers; 8 on Anxiety and Help Thermometers), followed by moderate levels of distress on the Anger Thermometer and Crushed Universe Thermometer (scores of 6 and 5 on the Anger and Crushed Universe Thermometers, respectively).

The DASS-21 scores indicated depressive symptoms in the Severe range, anxiety symptoms in the Extremely Severe range, and stress symptoms in the Moderate range. On the
IES-R, Angie’s overall reported post-traumatic stress symptoms measured on the IES-R Total score was in the Moderate range. With regard to Angie’s sense of coherence, her reported levels of Comprehensibility and Manageability were in the Low range, while her reported level of Meaningfulness was in the Moderate range. Her reported level on the SOC-13 Total subscale was in the Low-Moderate range. For the SOC-13, higher scores indicate better preparedness for life challenges, while lower scores indicate difficulties in preparedness.

The Brief COPE measured Angie’s utilisation of coping strategies. She reported frequent use of Active Coping, Acceptance, Seeking Instrumental Support, Venting, Positive Reframing, and Planning (reported in descending order of frequency of utilisation). An interesting finding was a predominant use of Self-blame, which corresponded with her response on the open-ended meaning questionnaire.

On the open-ended meaning questionnaire, themes emerged relating to self-blame, uncertainty, and worry about Angie’s son’s illness. In particular, Angie’s response towards the question of the sense she made of her child’s illness corresponded with her scores on the standardised measures on the DASS-21, Brief COPE, and her Meaningfulness scores. Her responses reflected the extreme stress that she experienced, and the uncertainty and threat to her expectations of a medical system that she faced, when her son fell sick. However, despite the stress that Angie expressed, she persisted in following up with her son’s care with action, to “find out why, and what cause[d] him to [be] sick… check with doctor”. These were interesting findings that might be better explained through the analysis of the content of Angie’s sessions below.

8.1.2 Findings of Thematic Analysis

Themes related to Angie’s experiences were around her meaning rupture in not being able to act on her core value of being a good mother; resources; and choice of coping
strategies (Fig. 1). These themes also yielded sub-themes. For Angie, themes around the narrative of her experiences did not emerge and were therefore not included in the ensuing paragraphs. Although she faced stressors in the areas of her marriage and finances, to Angie, these stressors were firstly not expressed as significant sources of distress, and secondly did not lead to any other significant stressors in her life.
Figure 1. Thematic map of Angie’s experience showing relationship between core themes and sub-themes
8.1.2A Meaning Rupture

The rupture to Angie’s sense of meaning occurred when her son did not receive the quality of care that she expected from the doctors. This meaning rupture brought about feelings of powerlessness and not being in control, which was in direct contrast to how Angie conducts her daily life.

Angie’s reaction of feeling “all over the shop” and “not knowing what to do” represented a rupture to her understanding of a medical system in which she had placed her faith. That the doctors did not have “a more caring mind-set and attitude” to spend more effort in investigating her son’s illness, went against Angie’s expectations of what doctors should be like. In identifying that she had “given up” arguing with the doctors or asking them for information, and feeling “blur” and “useless” when doctors made decisions without consulting her, it seems that this meaning rupture was not only experienced on a meaning level, but also on an emotional level. Angie’s reaction in these responses suggest a level of passivity that she had to take up, which was at odds with her sense of agency, an important resource that will be discussed later.

Angie’s response to the rupture of her sense of meaning around the medical system was in sharp contrast to how she solved challenges in her daily life. Two occasions are noteworthy. The first was when Angie was left alone to raise her children and pay off the moneylenders, and the second was when she persisted in maintaining her work ethics despite a conflictual relationship with her boss. In both situations, while Angie acknowledged that the situations, in particular being a single parent, were “difficult”, they were “not the end of [her] life”. The difference between Angie’s response in the hospital setting and other areas of her life further highlight the additional distress that the rupture of meaning brings to Angie, over and above the original distress from her son’s illness.
8.1.2B Angie’s Core Value

8.1.2 B1 Being a Committed Mother – If They Are Good, then I am Good

Being a committed mother was a central theme and emerged as a core value for Angie. Underpinning this value was a desire to bring up healthy and responsible citizens of the world where she saw it as an imperative to “take care of them… guide them… teach them how to lead their life”, and her dedication to placing them as her priority “no matter what”. Angie played an active role in expressing her commitment, and had her “own way of looking after [her] children”. This included making her children a priority, even over-riding all other needs such as financial stability and other commitments.

Angie manifested her core value of being a committed mother in three ways, and that formed three sub-themes. These were: 1) Caring for her children’s health (in particular her youngest son); and 2) guiding children in life.

Caring for Her Children’s Health

Caring for her children emerged as a priority for Angie. During the intervention, this was mainly expressed in the context of her sick son. Caring for her children provided Angie with a deep sense of meaning, and was at times, a source of anxiety. She demonstrated her deep commitment to her children by taking on an active role in her son’s illness management in a variety of ways. One of the ways was to seek as much information as she could about her son’s illness and its management, and another was to advocate for him in treatment.

To Angie, caring for her children’s health meant setting in place precautions to prevent them from falling sick, or to maintain their health. This included Angie being an active partner with the medical team in her son’s treatment plan “on [her] part record[ing] how many times he has taken the medicine, and during the course of the fever whether he had diarrhoea or vomiting, or whether he had cough or flu”, and preparing for contingencies
should her son’s condition turn for the worse. Angie was also meticulous in enforcing her children’s daily dietary needs, and punctually administering medications.

Conversely, caring for her children’s health was also a source of anxiety for Angie. She identified that the “uncertainty” of her son’s illness and doctors being unable to tell her the cause of the illness or their treatment plans caused her the most distress. Angie expressed that seeing her son “suffer” and being unable to “help him” was the most difficult part of his illness for her. It placed her in a position where she was “unable to do anything” while “seeing him suffer”. The helplessness that came with the uncertainty was in stark contrast to her usual active and proactive mode of caring for her children. “Not being able to do anything” led Angie to perceive herself as a “useless mother”, and hence was a source of the rupture of her meaning system of being a good mother. An interesting point of mention was also that Angie’s view of herself as a “useless mother” when she was unable to alleviate her son’s suffering, converged with her pre-test report on the Brief COPE of utilising the Self-Blame coping strategy. The convergence of the results suggested that, to Angie, being an effective mother meant being able to care for her children, failure of which resulted in a threat or rupture to her sense of meaning.

**Guiding Children in Life**

Guiding her children in life provided Angie with a strong core purpose. Despite being a single mother and facing financial difficulties, Angie persisted in her resolve to “make sure that [her children] grow safely, and… be independent” “as long as [she is] alive”, and set examples for her children as to “what is right and what is wrong, what should be learnt and what should not be done”. Angie carried this value out via open communication and involvement in her children’s lives. She used these channels to pass down personal values, discipline her children and, at the same time, provide a safe and supportive environment for
her children to share their difficulties. Angie’s efforts to maintain open communication with her children and be involved in their lives seem to have a reciprocal impact on each other.

**Open Communication.** Open communication was a key means for Angie to guide her children. It meant transparent and structured means of conveying her expectations and needs to her children and their teachers, respectively. Communication was also an important tool for her to know how her children were faring in school, as well as to facilitate their learning there. It had a reciprocal impact on her relationship with her children and their teachers.

Angie was open in expressing her expectations and emotions to her children. Her emphasis on open communication with her children was:

“… regardless of what happens, good or bad, we will have to bring out the things, and we will have to share. Don’t just keep it to yourself. Because no matter what, when you keep it inside yourself you will suffer, and feel very uncomfortable, like how come my family members don’t understand me.”

This statement from Angie was representative of her view of family ties – to have open communication. Angie’s open communication with her children had a reciprocal effect. They shared with Angie their vocational choices, late assignment submissions, first foray into smoking and even their plans for “revenge”, allowing her the opportunity to correct or encourage them.

Angie’s open communication also extended to her relationship with her children’s teachers. She sought help from the teachers regarding her youngest son’s schoolwork, and also regularly communicated with the teachers to keep track of her children’s conduct at school. It was interesting to note that Angie’s open communication seemed to have a reciprocal effect on her children’s teachers. Angie described her relationship with them as “like friends”, keeping her updated via phone messages and calls about her children’s
activities and their progress in school. The result of such open communication was Angie’s increased involvement in her children’s lives.

**Involvement in Children’s Lives.** Angie was deeply committed to her children, and being deeply involved in her children’s lives was one aspect for her to express that. The extent to which Angie was involved in her children’s lives was demonstrated via two incidents. The first was when Angie took immediate action to prevent her daughter from exacting “revenge” on her friend when her arm was broken. Angie warned her sternly, “You never, never let me see you break this friend’s hand or leg… This is not the right thing.” Angie also informed her daughter’s teacher to “keep an eye” on her daughter after the incident, and occasionally checked in with her daughter’s friends on her conduct. The second incident was when Angie noted changes in her son’s behaviour in Secondary school due to suspected bullying in his extra-curricular activities. Once Angie understood the circumstances her son was facing, she made the decision to contact his school coach, and “[went] down to solve the problem”.

Angie also set an example for her children with regard to valuing family ties, overcoming challenges and leading a values-driven life. She considered setting an example for her children to be of utmost importance “because… if [parents] didn’t [set an example] well, [the children] don’t have an example to look at, to learn from. They will… lose their direction”.

It was also interesting to note here again that Angie’s involvement in her children’s lives was reciprocated, particularly by her eldest son, who made it a priority to set aside time for family outings, and showed concern for her well-being through messages and “willingly… follow [her] down. Then whatever [she buys], he will help [her] to take. Make sure [she is] not carrying the things… like [her] bodyguard”.
Thus, through open communication, Angie was able to build the rapport needed to allow herself to be involved in her children’s lives. Her involvement and intentions reinforced the value of open communication, enabling Angie to continue guiding her children. This was also demonstrated through the reciprocation shown by her children and their teachers.

8.1.2C Resources

Two themes related to Angie’s resources emerged from the data. They served as protective factors, or generated further resources to facilitate Angie’s management of difficulties. These resources were her sense of agency, and her openness to learning, experiences, and alternative solutions.

8.1.2 C1 Sense of Agency – Nothing Can Be Too Difficult, If I Dare to Face It

Angie’s sense of agency was a very salient value that was not only a guiding principle in her life to overcome challenges and fulfil other values as demonstrated above, but was also a resource to engage in effective coping strategies.

Apart from agency in caring for her children, Angie also displayed a sense of agency when dealing with challenges in her personal life. Despite the challenges to her physical, emotional and financial resources, Angie maintained her stance to pursue a better environment for herself and her children, and created a current status quo where she felt “released” and “free”. She stood her ground and insisted that her ex-husband pay the alimony of “at least $100… better than nothing”, and also stood up to the moneylenders to negotiate for longer grace periods, while simultaneously working and looking after her children. Angie’s behaviour of directly confronting challenges corresponds with her high scores on the Active Coping subscale on the Brief COPE, during the post-test and follow-up sessions.

Angie’s sense of agency was also demonstrated in her decision to give back to society through volunteering. It indicated Angie’s ability to prioritise the areas of her life according
to their significance to her – not in terms of their utility in her survival, but in terms of how they value-add to her life in terms of meaningfulness. Despite facing financial constraints, Angie was willing to compromise her work to volunteer at her children’s schools. She did so not with the intention of “spy[ing]” on the children or to ingratiate herself with the teachers, but to “help, to lighten teachers’ burdens”, and “to give back” to “who[ever] help[ed]” them in the past, in contrast to work being “for the money”.

Through her sense of agency, Angie created further resources. Firstly, by demonstrating agency in her personal life and in caring for her children, Angie had created a family environment that demonstrated her love and support to her children, that could also exist despite being a single-parent family. The commitment that Angie gave to her family created strong family support for her, as evidenced by the interest and care her eldest son shows Angie. Secondly, although Angie did not intend for her acts of volunteering to be beneficial in a tangible way, it also provided her with assistance in maintaining involvement in her children’s lives. Thus, Angie’s sense of agency not only indicated a strong sense of the value, but also that this provided a resource she translated into clear and effective action.

When Angie was able to assert her sense of agency, she was also able to create other resources. However, when Angie was unable to assert this agency and act in accordance with her values – as when she interacted with the medical team, she experienced meaning distress, anger and anxiety which she interpreted as her being a “useless mother”. Thus, it appeared that agency was a key resource for Angie, and aided her in pursuing her core value of being a good mother.

8.1.2 C2 Openness – I Can Learn from Each Experience

Angie’s openness to experiences was another key resource in helping her manage the various difficulties in her life. It was also a quality that she passed on to her children. Angie’s
openness was associated with her sense of agency. It was manifested through her open attitude towards learning and searching for alternatives.

**Openness to Learning**

Taking on a learning attitude aided Angie in gaining resources as she gained new knowledge in managing difficulties, such as being more “settle[d] down, and [doing]…” things step by step”, thus reinforcing her sense of agency. Angie viewed mistakes as an opportunity to learn, and that it was possible to learn something from anyone. She viewed her relationship with her children as a mutually benefitting one, seeing it as “not only [them] learn[ing] things from [her], instead, [she is] also learning things from them”. It was this underlying attitude of learning, the willingness to absorb and integrate information, that drove Angie’s pursuit to gain as much knowledge of her son’s illness as possible and underpinned her frustration when not gaining it.

**Openness to Alternative Solutions**

Angie was also open to trying different methods to solve her problems, a salient example being in her seeking financial assistance from a Member of Parliament (MP) for her divorce proceedings, then deciding to try other methods instead of depending on the assistance even when she had obtained it. This behaviour not only demonstrated her sense of agency in solving her problems independently, but also indicated an inquisitive mind that was open to possibilities. With regard to caring for her children, Angie was flexible in refining her strategies in balancing care of her children with her work, finding ways to help her son to learn both at home and in school. Her openness in trying out alternative solutions reflects cognitive flexibility and a wide and adaptive coping repertoire, further underscoring the significance of her sense of agency.
8.1.2D Coping

Angie described using a variety of coping strategies to overcome her difficulties. In this section, we will first describe coping in the light of coping strategies that were beneficial to Angie, and second in terms of unhelpful coping strategies.

8.1.2D1 Helpful Coping Styles – I Need to Solve this to Prevent Future Problems

Active Coping

In line with Angie’s sense of agency and openness, and her value of being a committed mother, her approach to challenges was one of active coping. Angie often combined active coping strategies with her values and resources. These took the form of her being strategic in her planning, being assertive, and obtaining information.

Being Strategic. Being strategic about her time and plans enabled Angie to focus on the problems at hand, thus allowing her to maximise her resources and fulfil her value of being a committed mother. This was played out prominently at various points in Angie’s life.

Angie showed the ability to organise her time between work and her children. This was particularly notable when Angie was simultaneously paying off her husband’s gambling debts and providing for her family single-handedly. Angie strategised her time by arranging to distribute flyers between the times her children were at school or sleeping, while maximizing the amount of money she could earn from the job.

Angie also implemented strategies to ensure her children were able to keep up with their school work. Knowing that her youngest son’s learning ability was slower, Angie thought of methods to increase his ability to “absorb” knowledge through various methods such as: “past[ing]” information such as the differences between “B” and “D”; and briefing him repeatedly him about daily activities in school before the start of the year. Angie’s active implementation of strategies to ensure her children’s well-being highlights the interaction between values, resources and coping style. Her commitment to her children, combined with
her sense of agency and openness to alternatives, facilitated her ability to think out of the box to implement various methods to allow her to maintain an active presence in her children’s lives.

Angie’s actions firstly demonstrate that choice of coping strategies occurred with the facilitation of her inherent values and available resources, and secondly, indicate a high level of processing skills and effective emotion regulation, despite her facing difficulties on several fronts.

**Obtaining Information.** Obtaining information was a critical form of coping for Angie in her daily life and, to a large extent, in reducing her distress associated with her son’s illness. With regard to her son’s illness, obtaining information not only meant knowing the cause, prevention, and reduction of her son’s “suffer[ing]”, but also meant being included in any treatment decisions the doctors had made. In her daily life, obtaining information pertained more to her vocation of baking. However, the difference in Angie’s reaction to being denied access to the necessary information between her work and her son’s illness was stark. Angie described being “more confused” when insufficient information was given to her by instructors at work. In contrast, she expressed feeling “angry” and “anxious”, and viewing herself as “useless” when she was unable to help her son. Thus, obtaining information served the function of fulfilling Angie’s values of agency and being a committed mother; being blocked in that endeavour resulted in significant distress on Angie’s part. The discrepancy in Angie’s responses with regard to these two situations highlights that the resultant distress of not obtaining information was a manifestation of her value frustration more than distress related to the inability to cope.

8.1.2 D2 Unhelpful Coping Styles – He is Out to Get Me

Angie’s engagement in unhelpful coping styles was counter-productive in managing the challenges in her life. They took the form of passive-aggressive responses and
confrontations and tended to occur predominantly in her workplace context. The differential occurrence of these strategies in different contexts reflected important ways in which other situations meant to Angie as compared to her son’s illness.

**Passive-aggressive Responses**

Passive-aggressive responses manifested mostly in Angie’s interactions with her boss, which might have led to escalations in conflict between them. This involved her making comments in front of her boss about the quality of his personality as a “jinx” and how she and her colleagues should “beat paper effigies” of him⁵, and following his instructions in a manner that conveyed her displeasure towards him, such as “buy[ing] more [bottles of water] at one go… and [she] won’t have to leave [her] work halfway to buy for [him]”.

**Confrontational approaches**

Angie’s confrontational approach included her questioning her boss’ “attitude”, and making personal remarks about his personality as “cruel”. Angie’s confrontational approach towards her boss was, while effective in keeping her boss in his place, detrimental in her relationship with him and ultimately to her sense of belonging to her workplace. It was also interesting to note that Angie’s confrontational approach towards her boss was different from her assertive manner when it comes to matters related to her children.

Although Angie did not specifically report being confrontational with the medical team, her descriptions of her experience during the intervention sessions, and her reported feedback to certain doctors, suggested a degree of confrontation. Angie reported having to “fight” for her son several times to have certain medications prescribed to him, and also feeding back to particular attentive doctors about how other parents were “anxious or so disappointed, or have so many complaints” due to doctors who did not seem to give due attention to their patients or their caregivers. Thus, although Angie was not as directly confrontational towards

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⁵ “beating paper effigies” is a superstition among the traditional Singaporean Chinese that bad luck was caused by jinxes, and they needed to be ‘beaten’ to be taught a lesson
the medical team as she was towards her boss, the distress she faced as a result of her value frustration might have led to expressions of displeasure.

**8.1.3 Assessment**

Angie’s scores on the assessment battery (refer to Table 24) showed a downward trend in her distress on the DASS-21 and IES-R, and an upward trend on the SOC-13. The trend of Angie’s scores was in the predicted direction. Of note were her scores on the DASS-21 and the SOC-13 questionnaires. Angie’s scores on the DASS-21 subscales showed a large reduction in her levels of depressive, anxiety and stress symptoms. With regard to the SOC-13, Angie’s scores showed an increasing trend. Her Comprehensibility score increased from 14 during the pre-test to 17 and 31 in the post-test and follow-up respectively. The scores corresponded with her reflective behaviour during the sessions, and her subsequent willingness to accept suggestions of her strengths in Session 4. Angie’s Manageability score increased from 11 in the pre- and post-tests to 26 in the follow-up. Lastly, her Meaningfulness score showed a generally increasing trend, from 16 during the pre-test, to 23 and 20 in the post-test and follow-up respectively. The increasing trend of her Meaningfulness score also corresponded with her reported change in managing her child’s illness. From sharing that she was “all over the shop” when her son falls sick in Session 1, Angie said that she would now “calm down and not use crying to solve the problem” in Session 2. The change in Angie’s perspective persisted at follow-up, on the open-ended meaning questionnaire, where she responded that she would “try to relax” when faced with stressful situations.

In addition, it was noticed from Angie’s scores on the Brief COPE that there was a general downward trend in her use of unhelpful coping strategies such as Self-Blame and Denial, and a maintenance of scores for helpful coping strategies such as Active Coping and Positive Reframing.
Of mention as well is the change in Angie’s responses on the Open-Ended Meaning Questionnaire (Table 25). Across the questions, Angie expressed a predominantly approach coping style. Nonetheless, the general trend of her responses seemed to incline towards an outward perspective, rather than an inward, self-blaming perspective. This means that, for example, for the question that asked what sense Angie made of her son’s illness, Angie’s pre-test answer was focused on the stress she experiences, and her inner confusion and meaning rupture. However, her responses on the post-test and follow-up were focused on resolving her son’s illness and getting him well, rather than her own distress. Similarly, for the final question on what had been difficult about her son’s illness, Angie’s pre-test response suggested self-blame and a focus on her own distress where she could “only see him suffer”. Her post-test and follow-up responses, however, were focused on broader issues, such as communicating with her son, and a preparation for future times when her son falls sick. The use of emotive language such as “very difficult”, “worry”, “very stressful” were also absent.
### Table 24

**Angie’s Scores on Psychological Outcomes**

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotion and Help Thermometers</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distress</td>
<td>7</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Anxiety</td>
<td>8</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Depression</td>
<td>7</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Anger</td>
<td>6</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Crushed Universe</td>
<td>5</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Help</td>
<td>8</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td><strong>Depression, Anxiety and Stress Scale-21 (DASS-21)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td>22</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Anxiety</td>
<td>24</td>
<td>8</td>
<td>0</td>
</tr>
<tr>
<td>Stress</td>
<td>24</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td><strong>Impact of Events Scale-Revised (IES-R)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>56</td>
<td>17</td>
<td>12</td>
</tr>
<tr>
<td><strong>Sense of Coherence Scale-13 (SOC-13)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comprehensibility</td>
<td>14</td>
<td>17</td>
<td>31</td>
</tr>
<tr>
<td>Manageability</td>
<td>11</td>
<td>11</td>
<td>26</td>
</tr>
<tr>
<td>Meaningfulness</td>
<td>16</td>
<td>23</td>
<td>20</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
<td>51</td>
<td>77</td>
</tr>
<tr>
<td><strong>Brief COPE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Distraction</td>
<td>3</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Active Coping</td>
<td>8</td>
<td>5</td>
<td>8</td>
</tr>
</tbody>
</table>

(continued)
Table 24. Continued

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brief COPE</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td>5</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Substance Use</td>
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<td>2</td>
<td>2</td>
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<tr>
<td>Emotional Support</td>
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<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>6</td>
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<td>5</td>
</tr>
<tr>
<td>Behavioural Disengagement</td>
<td>3</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Venting</td>
<td>6</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Positive Reframing</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Planning</td>
<td>6</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Humour</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Acceptance</td>
<td>7</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Religion</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Self-blame</td>
<td>7</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>
Table 25

*Angie’s Responses on Open-Ended Meaning Questionnaire*

<table>
<thead>
<tr>
<th>Questions</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>“When a stressful event occurs, many people make sense of it in different ways. What sense do you make of your situation?”</td>
<td>“very stressful when my son is very ill. Cos don't know what happen to him, if he fever (sic) continue more than a week. And doctor cannot tell me what happen (sic). I will want to find out why, and what caused him to sick (sic). I will check with doctor”</td>
<td>“Talk things out.”</td>
<td>“Take a deep breath. Try to relax. Try to solve it slowly.”</td>
</tr>
<tr>
<td>“When a stressful event occurs, some people find that certain things change. What do you think has changed for the worse for you, if anything?”</td>
<td>“Worry, can’t sleep well”</td>
<td>“Never.”</td>
<td>“Solve the things step by step. If really cannot, then I will ask for help.”</td>
</tr>
</tbody>
</table>

(continued)
Table 25. Continued

<table>
<thead>
<tr>
<th></th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>When a stressful event occurs, some people find that certain things change. What do you think has changed for the better for you, if anything?&quot;</td>
<td>“None”</td>
<td>“More relieved.”</td>
<td>“None.”</td>
</tr>
<tr>
<td>“Has there been anything in particular that has been difficult for you to deal with since learning about your child’s problem?”</td>
<td>“Yes, very difficult, when he sick or restless, (she) cannot help him, only see him suffer”</td>
<td>“Hard to communicate with my little son, whom I find is still not mature.”</td>
<td>“The cause of the illness for my son is still unknown, doctors can’t tell me what is going on, only tell me they need to observe.”</td>
</tr>
</tbody>
</table>

8.1.4 Evaluation of Intervention with Angie

The current section describes the evaluation of the MFT in terms of its fit with participants’ contextual reality. To assess this, the evaluation was carried out from two perspectives: (a) Delivery of Intervention; and (b) Receipt of the Intervention.

8.1.4A Delivery of Intervention

In this section, the researcher’s adherence to the treatment protocol is evaluated, and in the events of deviations, whether the objectives of the intervention and/or the sessions were met.
The frequency of identification of values or meanings will be presented first, followed by the clarity of their presentation, and lastly, the alignment of session contents with the objectives and purpose of the intervention. The discussion of values and meanings within each of these sections will be presented separately.

8.1.4 A1 Facilitating Identification of Values

**Identification of Values**

Throughout the four sessions, values, or moments where Angie’s values could have been identified, occurred 68 times. Out of these, the researcher identified Angie’s values (i.e., “Yes”) 60% of the time. Angie’s values were “Somewhat” addressed 31% of the time. Her values were not identified the remaining 9% of the time.

Identifications of Angie’s values that met the “Yes” criteria took the form of the researcher naming the values or value clashes. Explicit identification of Angie’s values occurred in situations where there were repeated patterns of values expressions or when Angie appeared more emotional when discussing her experiences. The researcher identified Angie’s values in a variety of ways. One was to make comments explicitly referring to her values, such as “you value using your heart to do something”. Here, the researcher noted Angie’s frequent use of the word “heart” to describe putting in effort to complete tasks, to reflect the value in her own words. The second way was to reflect observations of Angie’s behaviour, such as “…you are also quite open-minded… you won’t base… your current experiences with your previous experiences”. The third way was to identify Angie’s value clashes particularly in the context of her son’s medical care. An example of this was, “it seems like when you don’t have those… knowledge, it will make you feel very anxious”.

Angie’s values were indirectly identified when the researcher sought to confirm her underlying motivations. The researcher tended to do this via tentative questioning or relating
Angie’s actions to the researcher’s observations or experience. For example, the researcher’s responses were expressed through reflections of her preference of action to “experience things first, before [she uses her] experience to teach [her] children”.

During the remaining 9% of the time, Angie’s values were not identified. This occurred largely in the second session, when the researcher asked questions that did not identify values. For example, the researcher tended to ask questions that attempted to relate Angie’s actions to her sense of self, by asking “What does this say about you as a person”. The researcher’s question was in response to Angie’s report of instances where she had exercised her agency in her personal life, or behaved consistently with her values. However, that it met with “I don’t know” on Angie’s part, suggested that this type of question might have been unsuitable for Angie, and possibly might have worked more efficiently with questions specifically pertaining to her actions.

**Clarity of Presentation of Values**

The clarity by which values were presented was rated 45 times. Out of these times when values were presented, 62% met the “Direct” criteria, 27% met the “Subtle” criteria, and 11% met the “Vague” criteria.

“Direct” presentations of values involved the researcher naming Angie’s values and explaining the impact of her behaving consistently with them. Discussions around the impact of Angie’s values usually occurred in the context of her relationship with her children, as well as on Angie’s emotional well-being. For example, the impact of Angie keeping to her commitment to be a good mother was presented in the form of psychoeducation, such as, “… the reason why [her youngest son] is willing to apologise to you is because he knows you will still accept him, you will still dote on him”. In addition, the researcher also noted to Angie that she “[feels] more relaxed” when she is able to “take control of [her] life”.

“Subtle” presentation of values took the form of reflections on the tension between Angie’s values, or queries of the impact of values cohesion for Angie. Subtle presentations tended to occur in the context of discussing Angie’s care for her youngest son, such as “trying to balance wanting to discipline [her youngest son] and yet wanting to be an… approachable mother”, and querying “what effect does [a caring doctor] have on [Angie].”

“Vague” presentations occurred in situations where the researcher summarised Angie’s words without relating them to Angie’s values or using tangential references to Angie’s values. An example was when the researcher reflected that “[a]t least [the doctor] put herself at the same level with you, try to understand you” when Angie was praising a doctor who attended to her needs. The researcher’s reflection did not attend to Angie’s values that in this particular instance, the medical system had lived up to her expectations and had helped her to feel reassured with regard to her son’s care.

**Alignment of Session Content with Purpose**

Values were identified and presented with the purpose of bringing them to Angie’s awareness, in order to explore using them to overcome future challenges, or to enhance her sense of meaning. It was observed that regardless of how the values were identified, Angie’s responses were often value-laden in content. For example, a reflection of Angie (rated “Somewhat”) making the choice to “take out time to attend” her children’s activities despite her being “already so busy” led to Angie’s expression of just how deeply committed she was to her children, and to put them as her “first choice” over working. As the conversation unfolded, Angie’s purpose in life to see her children “do the same thing, and… [hoping] that [volunteering to help other people] will go on, thus concurring with her commitment to being a good mother.
However, it was also noted that there were some points when the conversation did not develop further. In these cases, Angie’s responses ranged from an agreement of a single “Ah” to “I don’t know”, to staying around specific examples. For the latter example, it was noted that Angie’s responses tended to stay at the level of specific examples such as lengthy chronological accounts of her son’s behaviour on his first day at school, rather than general, overarching values similar to “I will stick to myself that as a mother, I don’t want my children to get hurt”. It appeared that these responses often occurred in response to the researcher’s delivery style. In these cases, the researcher was noted to have stayed within specific examples of “so it sounds like you have helped him to do all the homework first, then when you go back, you will prepare him for primary school” (rated “Vague”). Hence, although it seemed like Angie’s responses were largely values-laden despite the clarity of the questions, how closely the questions and reflections related to the issue of values influenced the depth of her responses.

8.1.4 A2 Facilitating Identification of Meaning

**Identification of Meanings**

Throughout the four sessions, meanings, or moments where Angie’s sense of meanings were identified, occurred 11 times. Out of these, the researcher identified Angie’s meanings (i.e., “Yes”) 55% of the time. Angie’s meaning was addressed indirectly (i.e., “Somewhat”) the remaining 45% of the time when the researcher sought to explore potential meanings Angie could have formed from particular experiences.

The researcher identified Angie’s meanings using a variety of methods, such as reflecting the significance of words such as “useless”, using the analogy of her as a “big, big tree (that) will flower and bear fruits… [passing her genes] all on to [her children]”, or remarking that “your children are the centre of your life”. These statements directly targeted
Angie’s overall interpretation of her life in relation to her children. Direct identifications of Angie’s values took place when Angie’s responses were explicitly expressed, such as “a sense of satisfaction” in the case of her workplace, or when she described herself as “useless” or as having “sinned” during a conversation about managing her daughter and youngest son’s illnesses.

Indirect identifications of Angie’s meanings took the form of invitations to Angie to “tell me more”, or directly querying “why”, and occurred mostly when Angie was particularly emotional as when she started tearing while talking about her youngest son, or when she expressed that volunteering at her children’s schools was more “meaningful” to her.

**Clarity of Presentation of Meanings**

Ratings of the clarity of the presentation of Angie’s meaning occurred eight times. Out of these times when values were discussed, 25% met the “Direct” criteria, 63% met the “Subtle” criteria, and 13% met the “Vague” criteria.

Presentations that met the “Direct” criteria involved the researcher explicitly expressing the significance of the event’s meaning to Angie, such as identifying that Angie’s “children are the centre of (her) life”, and that her workplace is “like [her] child”.

“Subtle” presentations of meanings were expressed through questions that sought Angie’s elaboration on what she had said, such as “What do you think?” and “How does it affect you?” These questions were asked following changes in Angie’s emotional tone or content of her words. For example, towards her commitment to her youngest son’s health, Angie had teared as she expressed, “Perhaps you have a link with him. After all, you gave birth to him, so you feel you will have a feel[ing]. You won’t watch him die in front of you, or be sick. So anything you will definitely you will do for him (sic)”. This was a meaningful moment for Angie, and the researcher’s response of “when I hear you saying that, my heart
squeezed a little. It is very touching. I was wondering if you could tell me more about this feeling?”, was able to draw out Angie’s elaboration of this sense of meaning towards her children.

**Alignment of Session Content with Purpose**

As discussed previously, the majority of discussions around meaning were delivered in an indirect manner. Discussions of Angie’s sense of meaning appeared to be more effective under two conditions: when indirect approaches were used, and when the researcher made queries that were related to her meanings.

Situations where indirect approaches were more effective than direct approaches were particularly notable during times when Angie had described her experiences with her children or with difficulties she had managing their illnesses at length. A particular exchange in Session 2 reflected the efficacy of using a subtle approach to assess Angie’s meaning rupture:

Researcher (R): Then when these things happen and you feel anxious, helpless, erm… what do you think of yourself? What kind of person do you think you are?


R: Ok, Ok, I see. Useless. That is a very serious word to use!

A: Yes. This mother is really very useless, the child is so seriously sick and she cannot do anything. So I find [that I am] very useless.

The above exchange demonstrated that a subtle approach of reflecting Angie’s view of herself gradually unfolded Angie’s personal meaning when she was unable to fulfil her commitment to her son. Furthermore, later in the session, an acknowledgement of Angie’s coping strategy of “self-blame” led to Angie’s self-exploration of meanings made after joining Club Rainbow Singapore. In that instance, Angie was able to look beyond her distress to acknowledge that “those mothers suffer more than me”. This change in Angie’s meaning
suggests that an indirect reference to Angie’s attempt to make sense of her children’s illnesses was sufficient to move towards making meaning of her experiences.

Angie’s responses appeared to be dependent on the type of questions asked; the more closely related they were to her values, the more articulate she was in expressing her meanings. The difference between Angie’s articulate reply as compared to her responses of “I don’t know” seemed to depend on the phrasing of the question. Combining values with queries of their personal relevance to Angie, such as “What if you didn’t use your heart? What would happen then?” resulted in a clearer articulation of her shattered meaning of being likened to “guinea pigs”. This was in contrast to global questions of “What does this say about you”, which resulted in responses of “I don’t know”, and limited the exploration within the session.

8.1.4B Receipt of Intervention

This section describes the extent to which the MFT was received and understood by Angie in a manner as intended by the intervention. Assessment of Angie’s receipt of the intervention was based on whether and how well she completed her experiential exercises (i.e., indicating she understood the instructions to the exercises) and her participation in discussions of her values and her meanings.

8.1.4 B1 Experiential Exercises

Experiential exercises were implemented to facilitate participants’ identification of their values and sense of meaning. Hence, an evaluation of the extent to which Angie had completed the exercises, and whether she had completed them correctly, would provide information about her receipt of the MFT.
8.1.4 B2 Completion of Exercises

Angie completed all three experiential exercises in Sessions 1-4. The experiential exercises were: (a) her thinking of a particularly meaningful moment in the course of her son’s illness (Sessions 1 and 3); (b) reflecting on the areas over which she had choice and control (Session 2), and (c) her strengths (Session 3). She was proactive in demonstrating that she had completed the exercises, and always had them ready for discussion. In Session 3, Angie also shared that she had sought her colleagues’ input regarding her strengths.

8.1.4 B3 Accuracy in Completing Experiential Exercises

Angie’s responses on most of the exercises corresponded with the intervention’s objectives of enhancing her awareness of her values and meanings. However, some exercises seemed confusing for her.

Angie’s response to Session 1’s experiential exercise indicated that she understood it clearly. This was evidenced through her prompt and resolute response about her “three children”. Angie’s continuation of the topic in Session 2 that she had learnt the importance of “forgiveness” and “how a parent [should] lead a life with their children” demonstrated that between sessions, she had reflected on her life with her children in relation to her past, and had realised values (i.e., “forgiveness”) and meanings (i.e., what kind of mother she wants to be) in the process. Angie’s response reflected her core values of being a committed mother and her sense of agency, further suggesting that she had understood the exercise and was engaged with it.

The experiential exercises on areas of choice and control, and Angie’s strengths, seemed more challenging for her, but were completed correctly after clarifications and discussions. Angie had originally misunderstood the instructions, and reported circumstances where she had been unable to fulfil her value of being a good mother, and was blocked from
her sense of agency. In the exercise regarding Angie’s strengths, Angie’s initial response was related to pragmatic day-to-day situations such as “enjoy[ing]… eating”. Angie’s responses took on a more values-based content after the researcher clarified the instructions and walked through the exercise with her. In particular, Angie raised strengths of “practis[ing] what she preach[es]”, “[doing her] best”, and her sense of responsibility – areas of value to her and which she reported wishing to pass down to her children. It was also interesting to note that in raising Angie’s awareness of her strengths, she also became aware that her children had emulated her spirit of doing her best. This was significant because in previous sessions, Angie had appeared hesitant when the possibility that her children had emulated her positive qualities was raised, thus suggesting that she had been reflecting on her role as a mother within the family.

8.1.4 B4 Observations

Another way of accessing how Angie received the intervention was through observations of her behaviour and discourse across the intervention sessions. The observations yielded two overall themes. They were: 1) the depth of Angie’s answers, and 2) her level of engagement in the intervention. Within these two themes were sub-themes, as will be further discussed below.

**Depth of Answering**

The depth of Angie’s answers was found to be a significant indicator of the extent to which Angie understood the concepts of values and sense of meaning. Depth of answering was measured based on the amount of detail in Angie’s replies. It was noted that the greater the depth of detail, the more significant the issue appeared to be to Angie. Angie’s pattern of understanding implied that she understood the concepts of values and meaning in the intervention.
Angie’s values of commitment to her children, sense of agency, and openness to her interaction with her world were demonstrated through the significant depth of detail she went into during the intervention. This was an indicator of their relevance to her sense of meaning, or obstacles to her following her values, suggesting that the intervention was relevant to the distress she was facing particularly with regard to medical personnel’s care of her son.

A broad question such as “What is it about your son’s illness that is stressful for you?” was able to bring the researcher into her world of caring for her son, and her meaning rupture surrounding the medical system revealed the unpredictability and uncertainty of her son’s illness, threat to her sense of meaning over how “the doctors also don’t seem to be able to help [her] understand what the problem is and what is going on with [her son]”, and also a step-by-step description of the progression of her son’s illness, the supply of medication he received, and how many times they entered the hospital. Angie’s response demonstrated her reflective nature, such that she was able to associate the question to various aspects of her experience with her son’s illness.

In contrast, Angie’s responses tended to lack in detail for questions in which she was uncertain or had not given much thought to. These pertained more to situations where she was asked to answer questions about herself in her own words. The analysis showed that it was easier for Angie to describe herself in others’ words, and to report her contributions in terms of the things that she did rather than her personal characteristics. It appeared difficult for her to take ownership of her strengths and contributions, as evidenced by her response of “I don’t know”. Thus, while Angie’s replies seem to indicate an understanding of her values and sense of meaning, a part of the intervention that was challenging for her was her acknowledging these qualities of herself.
Level of Engagement in Experiential Exercises

Angie completed every experiential exercise before each session. However, her level of engagement seemed to depend on the relevance of the exercises to her values.

Firstly, thinking of a meaningful encounter appeared to be an exercise that engaged Angie best due to its resonance with Angie’s values. She was resolute and prompt in her response that giving birth to her children had provided her with a sense of purpose in life and she attended Session 2 with a more reflective perspective on how her childhood influenced her perspective on parenthood:

“Grandfather would very seldom speak to me, then grandmother is more nagging. She’s not the kind you can have heart-to-heart talks with. Probably if there is something she would remind you, like “Don’t go astray, don’t etc. etc. etc.”. So when I myself got married and had children, I was… I started to be able to feel, “Ok, how a parents…, lead a life with their children, then until you can also feel your children… just gave birth to them, so they won’t go astray, nothing will happen…”

Angie also continued to reflect on the “pros and cons” of having her children and what she had learnt from them. The depth of reflection which Angie engaged in after the exercise suggested, firstly, that the idea of children as her sense of purpose resonated deeply within Angie such that it triggered further reflections of how and why they were the way they were; secondly, that the exercise had been relatable and relevant to Angie.

Secondly, inviting Angie to list areas in which she had choice and control, and her strengths, appeared to be more challenging for her as they required that Angie reflect on her personal qualities. However, upon clarification of the purpose of the exercises and explicit identification of Angie’s strengths, her subsequent responses were more reflective of her values, such as, “If I want I will do my best, even it’s something I don’t know how to do”,
and her “sense of responsibility”. Angie’s difficulty in completing the exercise on her strength was consistent with her difficulty in identifying her qualities in session as to the “type of person” she is, and suggested that the exercise may, firstly, not have fit her pace of recognising her strengths and qualities; secondly, not have been engaged in enough detail prior to her completing it; and lastly, require other ways of identifying her strengths.

8.2 Case 2

8.2.1 Case Description

8.2.1A Demographic Information

“Tina” was a 21-year-old married Malay lady, and a mother of one. Her one-year-old daughter was diagnosed with Acute Lymphoblastic Leukaemia (ALL) when she just turned one. Tina’s daughter had been given a good prognosis.

Tina was living in crowded conditions at the beginning of the intervention. She and her family resided in a three-bedroom apartment with her in-laws, together with her husband’s three younger siblings, a girlfriend, and a cat. As there was limited space in the apartment, Tina and her family stayed in the living room. These conditions were not conducive to the child undergoing chemotherapy. For example, the cat also stayed in the living room while Tina’s daughter was undergoing chemotherapy. Between Sessions 2 and 3, Tina and her family moved and rented a room from one of Tina’s friends, which Tina reported was “really good”, and helped her daughter to sleep earlier. Tina’s family had been unable to apply for government rental flats as her husband was still in the midst of finalising the sale of his previous apartment with his ex-wife before they could be eligible to purchase a government flat. Private rental flats were not possible as they were beyond the family’s budget, whereas government rental flats are heavily subsidised.
Tina also faced financial difficulties. Her husband had only just started his new permanent job after taking on a few freelance jobs for six months. Tina herself had not been working since the birth of her daughter. They were thus relying on monthly financial assistance offered by the CCF and her husband’s monthly salary.

8.2.1B Presentation

Tina participated actively in the intervention, but seemed to find it challenging to complete the experiential exercises and answer questions about her values and self. She explained that this was due to her not knowing what her identity was. However, Tina was forthcoming in describing her experiences.

8.2.1C Relevant History

This section describes aspects of Tina’s history considered relevant to providing understanding of her. These included ongoing stressors and lack of social support that predisposed her to her distress during the MFT.

Tina reported the situation when her parents found out about her pregnancy as “chaotic”. Tina’s daughter was conceived out of wedlock, and Tina was brought forcibly to the hospital for an abortion by her parents and aunt. This was despite Tina refusing to do so, and the doctor telling them that the pregnancy could not be terminated. Tina’s parents withdrew their insistence on an abortion when the doctor let them hear their grand-daughter’s heartbeat. Tina reported that since the birth of her daughter, her parents had been very supportive towards her. Nonetheless, Tina expressed anger towards them for changing their stance towards her daughter so suddenly, and towards her aunt for being a “busybody”. Tina also expressed shock and confusion at her mother’s and aunt’s reaction towards her pregnancy, and verbalised it as a ‘betrayal” as she had expected them to support her since
they were both mothers. She reported that she had been having flashbacks of her parents and aunt forcing her to undergo an abortion ever since.

Tina reported she lived in an open marriage with her husband, which later led to marital difficulties when Tina’s husband shared that he was falling in love with another woman he had met. This had several implications for Tina. Firstly, it impacted on Tina emotionally; she said she felt “crushed”, and reported having difficulty looking towards the future without him. Secondly, Tina’s husband stopped providing financial support to the family, only paying the rent for their room. This thus left Tina with having to cover the family’s expenses based on the limited financial assistance provided by the CCF.

Tina also had limited social and emotional support that decreased further over the course of the intervention. She reported an on-off relationship with her best friend. Later, with her husband when he spent more time with his girlfriend, Tina reported that there was less instrumental and emotional support at home in caring for her daughter. Tina did not mention support from her siblings or siblings-in-law. However, there was some support, albeit limited, from her mother who sometimes helped Tina to care for her daughter while she attended the intervention sessions. Nonetheless, this was only when the sessions coincided with her mother’s off-days from work. Although Tina mentioned other friends, she also reported that she met them only sporadically.

8.2.1D Pre-test Scores

This section presents a summary of Tina’s pre-test scores. The breakdown of her scores is presented together with the post-test and follow-up test scores in Tables 7 and 8, in the Assessment section.

On the pre-test, Tina scored in the high distress levels on all five of the emotion and help thermometers, based on the NCCN’s recommended cut-off of 4. In particular, Tina
reported the highest level of distress on the Help Thermometer (score of 10), followed by on
the Depression Thermometer and Anger Thermometer (score of 9), the Anxiety Thermometer
(score of 8), and finally the Distress Thermometer and Crushed Universe Thermometer (score
of 7).

The DASS-21 scores indicated depressive symptoms in the Moderate range, and
anxiety and stress symptoms in the Extremely Severe range. On the IES-R, Tina’s reported
overall post-traumatic stress symptoms on the IES-R Total score was in the High range. With
regard to Tina’s sense of coherence, mixed scores were seen on the three SOC-13 subscales
and SOC-13 Total subscale. Her reported level on the SOC-13 Total was in the Moderate
range, Comprehensibility was in the Low range, Manageability in the High range, and
Meaningfulness was in the Moderate range. For the SOC-13, higher scores indicate better
preparedness for life challenges, while lower scores indicate difficulties in preparedness.

Regarding Tina’s utilisation of coping strategies, measured by the Brief COPE, she
reported almost equal utilisation of different coping strategies. While she reported frequent
usage of Instrumental Support, Planning, Active Coping, Humour, and Religion, there was
also a corresponding frequent usage of Denial, and Behavioural Disengagement. Tina’s use
of Active Coping and Planning corresponded with her responses on the Open-ended Meaning
Questionnaire.

On the open-ended meaning questionnaire, themes emerged of not being able to make
sense of her situation, and a lack of support in her home environment. On the question of how
she made sense of her daughter’s illness, Tina’s response that she “[doesn’t] really
understand what is going on”, yet continuing to “use the information given and… adapt to it”,
suggested perseverance on Tina’s side, and making the best of her situation to care for her
daughter. Her response corresponded with her reported frequent utilisation of the Active
Coping and Planning strategies on the Brief COPE, and her High score on the SOC-13 Manageability subscale. In addition, Tina’s report of “no one really helps” or “cares” also reflected the lack of social and instrumental support reported above, yet was in contrast to her reported high utilisation of the Instrumental Support coping strategy. These were interesting findings that will be better explained through the qualitative analysis of the content of Tina’s sessions outlined below.

8.2.2 Findings of Thematic Analysis

This section presents the analysis of the contents of the sessions with regard to Tina’s experiences of her child’s illness and contextual difficulties. Themes of additional stressors, meaning ruptures around her commitment to motherhood and her marriage, values, and choice of coping strategies, emerged (Fig. 2). These themes also yielded sub-themes. In Tina’s case, the narrative of her experience was an important data source that enhances the reader’s understanding of her subsequent meaning ruptures and other core themes, and will therefore be discussed first.
Figure 2. Thematic map of Tina’s experience showing relationship between core themes and sub-themes.
8.2.2A Narrative of Tina’s Experiences

The narrative of Tina’s experiences provided a context for understanding her current distress and difficulties. Her experiences included her search for her identity, and the additional stressors that she faced.

8.2.2 A1 Search for Identity – Who Am I

“Because I don’t know who am I, so you know, it’s like I could live with it, know what I am, and do what I am… what I am supposed to do, you know. But now I’ll be like doing things, you know, ah just do, you know, and survive, just… wash, clean, cook, wash, clean, cook.”

Tina’s search for her identity emerged as a significant difficulty for her, yet also a source of energy when she engaged in behaviours in line with who she wanted to be. Throughout the intervention, Tina questioned “Who am I” multiple times. For her, knowing who she was meant that she had structure and direction in life, and there was meaning in the activities that she engaged in. Tina’s lack of sense of identity led to her being “not confident enough to be independent” or to question doctors about her daughter’s medical treatment. It possibly had an impact on her marriage. Tina reported being “afraid to handle” discussions with the doctors, and being “afraid [she would] give the wrong information about the medicine”. Her strategy of “ask[ing her husband] to take childcare leave” appeared to place additional stress on her husband, who eventually engaged in an extra-marital relationship as it helped him to “feel better outside” due to “[their daughter’s] condition, with the rental… stressing him out”.

Nonetheless, it was observed that when Tina behaved in accordance to who she believed she wanted to be – an “independent” and “confident” person – she reported feeling “stronger” and also felt “very excited”. Such instances occurred particularly at crisis points
for Tina, such as when she insisted on changing her replacement doctor due to concerns of her daughter’s care under this doctor, and during her marital crisis. In these two situations, Tina’s tone of voice changed when she described the events. She spoke in a decisive and firm tone when relaying that she “don't want [the replacement doctor]”, and when describing how she fought for her marriage. Tina also described her “stronger” self as “shining”. In accordance to that description, she was observed to sit straighter and speak with more energy when she related these incidents. Her demeanour also changed, particularly the incident with the doctor. She was observed to smile widely, and speak faster in her excitement.

8.2.2 Additional Stressors – Changes and Fighting for What She Wants

Additional stressors in Tina’s life and her adjustment to them emerged as themes. Stressors occurred on several fronts, both before and after her child’s diagnosis, namely financial, situational, and environment, as well as personal and relational stressors. These stretched Tina’s financial, physical and emotional resources, and had implications on her adjustment. This section presents Tina’s stressors and her adjustment to them.

As outlined above, Tina faced a variety of stressors. Since Tina’s delivery of her daughter, Tina’s husband had been the sole breadwinner of the family, earning a monthly gross income of SGD$2,100, of which 20% was placed in a compulsory comprehensive savings plan created by the Singapore government. After paying the monthly household expenditures (i.e., bills, rent, children’s insurance), the family was left with about SGD$500 each month, without the monthly subsidies from CCF. This created a “very big hole” in the family’s finances, which was a source of stress on Tina and her husband. Tina reported being the “financial assistant”, “every day… counting [the budget] inside [her head]”. With her husband’s cessation of financial support, Tina was under considerable financial pressure with the main income being the subsidies provided by the CCF.
Tina’s physical energy and emotional resources were also taxed by the various stressors, particularly the environmental stressors while living with her in-laws, and a lack of social support. Living in crowded conditions with a cat in the living room made it necessary for Tina to constantly clean the surroundings to make it physically safe for her daughter. She reported being “busy with this and that… washing clothes, taking care of everything” and, with no support to care for her daughter, “it takes [her] about 1 hour just to finish [all the housework]” for tasks that would usually take “about 15 minutes”. It thus appeared that the lack of social support combined with a challenging living environment, which also did not provide emotional refuge for Tina, was taxing on her. Tina’s frustration about the lack of social support was echoed in her responses on the open-ended meaning questionnaire (Table 8), regarding what has changed for the worse for her (Question 2), and what has been difficult for her to deal with since learning about her child’s problem (Question 4). She stated, “People surrounding – no one really helps” and “People at home. No one really cares”, respectively. Tina’s responses not only suggested a lack of support in the home environment, but also a perception that she was isolated.

Lastly, the various stressors that Tina faced, particularly her marital difficulties, were emotionally taxing for Tina. There was a sense of helplessness as she reported that the relationship difficulties were “draining [her] out [and she] couldn’t even do anything”. Tina reported a lack of confidence in moving forward as she perceived that she is “not strong enough”. Despite knowing that she “[needed] to do something”, “at the same time… [she] couldn’t do anything about it. [She] couldn’t stop thinking about it”. This suggested that Tina’s marriage difficulties posed a significant block to her acting on her values and finding purpose in life, which might have implications on her experience of meaning rupture (discussed in the meaning rupture section).
In sum, the contextual stressors Tina experienced appeared more distressing for her than her daughter’s illness. The contextual stressors placed her in a vulnerable position that threatened her sense of meaning around motherhood and marriage. However, despite Tina’s difficulties, themes relating to her core values and her coping strategies also indicated that she was living her life as best as she knew how.

8.2.2B Values

Analysis of Tina’s values revealed two overarching themes. They were: (a) Being committed to motherhood; and (b) being a good wife. These themes yielded sub-themes.

8.2.2 B1 Being Committed to Motherhood – Just Think About the Baby

A core theme which emerged from the data was Tina’s commitment towards motherhood. An example of a statement demonstrating this was:

“If anything happens to her, I blame myself, you know. And try to make it up to her, you know. It really makes me feel better to actually make options. Because before I got pregnant, you know, I don’t make any options. Then I just, ‘Whatever I want to do, I do’. You know? … But now is, ‘If I do that, I die. If I screw my future with (her daughter)’…”

Tina’s statement showed a deep commitment to her daughter that brought about a change in her behaviour. The change saw her placing her daughter’s well-being and their relationship above herself, electing to “tie [her] stomach” and eat instant noodles for the sake of being able to afford the instalment of an air-conditioner for her daughter’s comfort.

Tina’s value of being committed to motherhood was challenged when her husband engaged in an affair. It contributed significantly to her distress. Tina reported that her daughter would “lose [her] too” if she lost her husband to the affair. However, although Tina was distressed about losing her husband, part of her distress was also about “[not wanting her daughter] to know that she’s from a broken family.” It was also noted that Tina teared for the
first and only time when she said, “Even [her daughter] was the main and the top priority; now becomes… nothing to [her] already”. However, Tina also subsequently acknowledged that “no matter what, [she would] still be thinking about her [daughter]”, and that it was something she “need[ed]” to do. She lived out this value through continuing to bring her daughter for each appointment despite finding difficulty getting herself out of bed, and withholding from smoking in front of her daughter. Tina’s distress at her husband’s affair may therefore have been exacerbated by it unsettling her value base and thus threatening her commitment to motherhood.

In addition, while trying to repair her relationship with her husband, Tina was also cognizant of a father’s influence on the children, emphasising that “[her husband’s] priority is the children”, and placing her daughter and step-daughter’s time with her husband as a priority. Tina’s concerns were for both her daughter and step-daughter, indicating that her commitment to motherhood was an encompassing value.

8.2.2 B2 Being a good wife – Giving him a good life

The second core value that emerged for Tina was to be a good wife to her husband. Tina’s way of demonstrating her love for her husband was through actions, and this gave her a sense of purpose. Doing something for her husband was a “requirement” for her to “do the job of a wife”, for a few reasons. The first was to maintain her marriage, and the second was that Tina saw her role as a “very big responsibility to the family”. To Tina, this meant that “it’s important as a wife and as a mother to… to make the daughter and the husband feel at home, feel that someone [cares] for them.”

Tina’s value of being a good wife was simultaneously most evident and most challenged when her husband engaged in the extra-marital affair. It was most evident in the way she continued “doing the job of a wife. To help [her] husband” by “[fishing] him out of the water” and helping him to return to being “the father of the child, of the children... the
husband… the son of [her] mother-in-law”. On the other hand, Tina’s efforts to help her husband was rejected, as “he [did not] want [Tina] to help him. He… wants to do it his way”. Her husband’s rejection of her help was met with discouragement on Tina’s part, where she expressed a significant struggle in “[wanting] to leave him, but at the same time [she] couldn’t leave him because [she loves] him too much”. Tina’s struggle suggested a dilemma between being true to her value of being a good wife, and leaving her husband.

8.2.2 B3 Meaning-Focused Coping

As meaning-focused coping refers to the use of values and goals in managing stressful situations, it is discussed here.

Tina drew strength from her core values of being a committed mother and wife to “pull [her] through the life” she saw as “miserable”. Her values thus acted as resources that facilitated her coping with the additional stressors in her life.

Tina’s focus on her daughter’s well-being was one of her ways to cope with the difficulties in her life. Her conceptualisation of her pregnancy as “God [given]” gave Tina strength to persevere and keep her daughter despite pressures to abort. Furthermore, Tina described the birth of her daughter as a particularly meaningful event that suggested life was worth living. Her decision to look forward and to not let her surrounding stressors affect her was borne from her desire to encourage healthy emotional development in her daughter.

Tina’s love for her husband also provided her with the impetus for change. She spoke of his efforts to “make [her] happy” as her inspiration to “go on with life” and “be better”. To Tina, “[being] better” also meant being more giving towards others. Her husband’s efforts to “make [her] happy to feel better” made her decide to pass on “what is given [by her husband] … to give to another life inside of [her]”. She reported being more “appreciative to
other people”, which helped to “change the way [she] see things”, and had brought about closer relationships with her colleagues.

Tina’s commitment towards her daughter and husband also influenced her emotion regulation. She chose to engage in eating and video gaming to distract herself when her flashbacks occurred in order to avoid “venting [her] anger on [her daughter] or [her] husband”. This choice reflected her commitment towards wanting to bring up a happy child (as opposed to an “angry child”), as well as providing a loving home environment for her husband. Although such behaviours might be seen as a form of self-distraction, the function of Tina’s behaviour was to uphold her values to “protect” her family.

8.2.2C Meaning Rupture

There were two ruptures to Tina’s sense of meaning. The first was the obstacles that presented to Tina’s core value of her commitment to motherhood, and the second was when Tina encountered her husband’s extra-marital affair.

8.2.2 C1 Rupture to Commitment to Motherhood

Tina’s value of motherhood ruptured when she was pressured to abort her daughter. To Tina, having a child was not only “God [given]”, but also a mother’s responsibility to decide “what she wants to do with it”. That those around her “actually forced me [to abort]” without Tina’s consent, threatened her role as a mother to “plan the future for the baby”. Tina’s expectation that her mother and paternal aunt, as mothers, “should know how it feels to carry a baby inside” was not met. The extent of the affront to Tina’s value of motherhood corresponded with a serious meaning rupture related to that value. The severity of this impact was evident through her experiencing flashbacks related to her being forced to have the abortion.
8.2.2 C2 Rupture to Meaning of Marriage

Tina’s husband’s extra-marital affair ruptured her sense of meaning around marriage as an institution built on commitment and “love” between husband and wife, with both upholding their “promises” to each other, and putting in effort to make it work. Her descriptions of feelings of defeat, weariness, and anger with regard to marriage after the affair were in direct contrast to her descriptions of feeling “very safe” and “appreciative towards others” before the affair took place.

Tina described her husband’s affair as “crushing”, and the experience of salvaging the marriage as “draining [her] out”. The news of the extra-marital affair and her husband telling her that “whatever promises and whatever… proposal he said to [her]… is just… fading away” threatened her trust in him and the marriage’s stability “if it pulls through”. Tina’s distress was also reflected in her post-test scores on the Crushed Universe Thermometer and the open-ended meaning questionnaire. Specifically, Tina’s pre-test score of 7 on the Crushed Universe Thermometer had increased by the post-test and follow-up to the maximum level of distress of 10. Furthermore, on the question about what has changed for the worse for Tina as a result of her daughter’s illness, her response on her post-test and follow-up responses were that “the relationship [she] had with her husband drastically changed” and “intolerant”, respectively.

Tina’s description of being a “nobody” to her husband and not feeling “strong enough” to the point that her daughter might “lose [her] too”, suggested that the meaning rupture of her marriage was a blow to her self-efficacy. Her reports of a loss of social support and being drained of strength corroborated with her Manageability subscale score on the SOC-13, which saw a decrease to the Low range in her post-test and follow-up sessions. Furthermore, it was also noted that Tina’s reported use of Active Coping strategies had also decreased during her post-test and follow-up session, as compared with her pre-test scores.
8.2.2D Coping

Tina utilised a variety of coping skills that ranged from being helpful to less effective.

8.2.2 D1 Helpful Coping Strategies – Planning

Tina engaged in active coping strategies in the form of planning, thus demonstrating her ability to make decisions independently. Although it appeared that Tina tended to utilise these strategies in structured or pragmatic situations such as budgeting or seeking help, she was also behaving consistently with her values to provide the best environment for her daughter and family.

Planning was a theme that was predominantly present in the first three sessions of the intervention. Tina’s utilisation of these strategies was evident in managing her family’s financial limitations or seeking help to care for her daughter. Engaging strategies to address these challenges gave Tina a sense of self-efficacy, purpose and energy, which were manifested in her tone of voice and presentation in the sessions.

Tina called herself the “financial assistant at home”. She planned the household budget with her husband’s salary. Furthermore, in trying to provide a comfortable environment for her daughter, Tina also planned and modified the household expenditure according to her daughter’s needs. For example, in deciding to buy an air cooler or portable air conditioner for her daughter, Tina took the lead to solve the dilemma she and her husband shared, by keeping in mind the family’s financial limitations, possible factors contributing to their daughter’s discomfort, and searching for alternatives to provide the best option for their daughter. This demonstrated use of elaborate thought processes, suggesting that her commitment to her family as a wife and mother facilitated flexibility of thought and coping approaches. It was observed that when Tina shared her role in the family, her tone of voice was excited, more confident and authoritative. She also sat up straighter in her seat. These
observations of Tina suggested that having a role within the family energised her and gave her a sense of purpose.

8.2.2 D2 Less Effective Coping Strategies – Behavioural Disengagement

Behavioural disengagement from threatening situations emerged as a theme in contexts that pertained to Tina asserting herself. Tina’s utilisation of behavioural disengagement had implications for her engagement in experiential exercises and the way she referred to herself. These had links to her sense of identity.

According to Tina, her tendency to disengage from situations that required her to assert herself or be firm reflected at times opposite pathways. Her general tendency was to disengage or to not question or challenge. She reported being “afraid to handle” situations where she had to “be firm”, to the extent that she would “be sad, angry, and cry”. This led to Tina tending to give the doctors the benefit of the doubt because “[They] know better, [she] will listen to [them]” without questioning their procedures. Tina’s disengagement from making decisions thus required her husband to take over. While her behaviour reflected dependence on her husband, other perspectives should also be considered. Existential issues such as Tina’s lack of identity likely contributed to her apprehension in questioning the doctors or make decisions. Furthermore, given the lack of financial and social resources available to Tina, making treatment decisions or questioning treatment procedures may have been a big challenge that was beyond her ability to provide.

However, as described above, in situations where the consequences of a situation could be detrimental to her daughter, Tina tapped into her value of committed motherhood, which enabled her to engage in assertive action.

Similarly, with regard to challenging topics such as giving her opinion on herself, Tina reported that she “always side tracks to something else.” Tina described past
experiences of perceived rejection made her decide to “just keep quiet”, or “give up”. Within the intervention, Tina was reluctant to write down or draw out her responses to the experiential exercises because she “[did not] know if [she had done] it correct or not”. She also declined to write or draw in activities within sessions, stating that “mind map is really not my thing”, she was “bad in mind map”, and found difficulty in listing qualities of herself.

8.2.3 Assessment

Tina’s post-test and follow-up test scores and responses showed mixed outcomes of the intervention. The reader is referred to Tables 26 and 27 for a breakdown of her responses.

Tina’s scores on the assessment battery showed an increase in her distress on the DASS-21 and IES-R, and a generally stable trend on the SOC-13. The trend of Tina’s scores were opposite of the predicted direction, which could be due to the marital difficulties that had arisen at the end of the intervention and continued beyond. Of particularly note is the decrease in Tina’s score on the Manageability subscale of the SOC-13 between pre-test and follow-up. Tina’s pre-test Manageability subscale score of 21 had reduced to 11 and 14 on the post-test and follow-up assessments, respectively. This coincided with Tina’s reports of being “planless” and finding it “so hard” to “wake (her husband) up” from his extramarital relationship.

In addition, it was noticed from Tina’s scores on the Brief COPE that there was a general downward trend in her use of helpful coping strategies such as Active Coping, Instrumental Support, Planning, and Use of Humour. Instead, there was a general increase of unhelpful coping strategies such as Self-Blame, Venting and Self-Distraction. Tina’s scores on the Brief COPE corroborated with her SOC-13 Manageability scores as her tendency to cope actively and constructively with difficult situations decreased and she engaged in more avoidance coping strategies.
Tina’s responses on the Open-Ended Meaning Questionnaire suggested changes in Tina’s perspective of her stressors, which the standardised measures did not detect. Specifically, the depth and specificity of Tina’s answers seemed to have changed between the pre-test and follow-up stages. For example, in the question about what sense Tina makes of her situation, Tina’s pre-test response suggested confusion in “(not) really (understanding) what is going on”, and seemingly searching in the dark by “just (using) the information and… adapt to it”. Her post-test and follow-up answers suggested having made meaning, with her attributing the situation to “(happening) for a good reason”, or “a reason”, and that her strategy was to “adapt” to it. In another example, Tina’s responses on the pre-test were generally vague and broad, such as attributing her difficulties in managing her daughter’s illness to “people at home” in the pre-test, but her responses on the post-test and follow-up were more specific, which was her relationship with her husband, and that she was unable to receive “emotional support” from her husband. That Tina was able to set a scope for her difficulties suggested that the confusion she had been facing with her daughter’s illness initially had shifted to a more conceptualized and discrete difficulty she was facing, which made it possible for her to seek help from her best friend and her social worker.

Thus, the study of Tina’s response to the intervention suggested that although her assessment scores seemed to indicate limited efficacy, her actions and qualitative responses seemed to indicate otherwise. This might be due to Tina’s tendency to attend to immediate crises rather than prioritize difficulties, as well as her preference to act on her values rather than verbalising them, suggesting that the intervention might have been successful in certain areas in creating change in Tina. These will be discussed in the Discussion section.
Table 26

*Tina’s Scores on Psychological Outcomes*

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotion and Help Thermometers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Distress</td>
<td>7</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Anxiety</td>
<td>8</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Depression</td>
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<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Anger</td>
<td>9</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Crushed Universe</td>
<td>7</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Help</td>
<td>10</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Depression, Anxiety and Stress Scale-21 (DASS-21)</td>
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<td></td>
</tr>
<tr>
<td>Depression</td>
<td>14</td>
<td>34</td>
<td>32</td>
</tr>
<tr>
<td>Anxiety</td>
<td>26</td>
<td>32</td>
<td>30</td>
</tr>
<tr>
<td>Stress</td>
<td>38</td>
<td>34</td>
<td>36</td>
</tr>
<tr>
<td>Impact of Events Scale-Revised (IES-R)</td>
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</tr>
<tr>
<td>Total</td>
<td>71</td>
<td>74</td>
<td>67</td>
</tr>
<tr>
<td>Sense of Coherence Scale-13 (SOC-13)</td>
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<tr>
<td>Comprehensibility</td>
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<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Manageability</td>
<td>21</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Meaningfulness</td>
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<td>16</td>
</tr>
<tr>
<td>Total</td>
<td>49</td>
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<td>42</td>
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<tr>
<td>Brief COPE</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Self-Distraction</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Active Coping</td>
<td>6</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

(continued)
Table 26. Continued

<table>
<thead>
<tr>
<th>Measure</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
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</thead>
<tbody>
<tr>
<td>Brief COPE</td>
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</tr>
<tr>
<td>Denial</td>
<td>6</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>Substance Use</td>
<td>4</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Emotional Support</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Instrumental Support</td>
<td>8</td>
<td>5</td>
<td>4</td>
</tr>
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<td>Behavioural Disengagement</td>
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<td>6</td>
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</tr>
<tr>
<td>Venting</td>
<td>3</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Positive Reframing</td>
<td>5</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Planning</td>
<td>7</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Humour</td>
<td>6</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Acceptance</td>
<td>5</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Religion</td>
<td>6</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Self-blame</td>
<td>4</td>
<td>5</td>
<td>7</td>
</tr>
</tbody>
</table>
Table 27
*Tina’s Responses on Open-Ended Meaning Questionnaire*

<table>
<thead>
<tr>
<th>Questions</th>
<th>Pre-Test</th>
<th>Post-Test</th>
<th>Follow-up</th>
</tr>
</thead>
<tbody>
<tr>
<td>“When a stressful event occurs, many people make sense of it in different ways. What sense do you make of your situation?”</td>
<td>“Don’t really understand what is going on. I just use the information given and I adapt to it.”</td>
<td>“Situation happens for a good reason; try to adapt to the situation.”</td>
<td>“Happens for a reason.”</td>
</tr>
<tr>
<td>“When a stressful event occurs, some people find that certain things change. What do you think has changed for the worse for you, if anything?”</td>
<td>“People surrounding - no one really helps”</td>
<td>“The relationship I had with my husband drastically changed.”</td>
<td>“Intolerant.”</td>
</tr>
<tr>
<td>“When a stressful event occurs, some people find that certain things change. What do you think has changed for the better for you, if anything?”</td>
<td>“None”</td>
<td>“I am expressing my inner self.”</td>
<td>“Nothing.”</td>
</tr>
<tr>
<td>“Has there been anything in particular that has been difficult for you to deal with since learning about your child’s problem?”</td>
<td>“People at home. No one really cares”</td>
<td>“The relationship with my husband after 6 months of learning about her condition.”</td>
<td>“No emotional support from the father.”</td>
</tr>
</tbody>
</table>
8.2.4 Evaluation of Intervention with Tina

8.2.4A Delivery of Intervention

8.2.4 A1 Facilitating Identification of Values

**Identification of Values**

Throughout the four sessions, values, or moments where Tina’s values could have been identified, occurred 74 times. Out of these, the researcher identified Tina’s values explicitly (i.e., “Yes”) 66% of the time. Her values were addressed indirectly (i.e., “Somewhat”) 32% of the time. For the remaining 2% of the time, Tina’s values were not identified.

Explicit identifications of values took the form of stating them directly, such as “You take your responsibilities very seriously” and that “[her daughter] is the centre of [her] world”. The researcher identified Tina’s values explicitly mostly in Sessions 3 and 4, particularly Session 4. Upon closer investigation, 36% of Tina’s values were explicitly identified in Session 4 alone, with the purpose of reminding Tina that she had behaved in accordance with her values. These took the form of reminders that she “fought for [her] marriage”, identifying value clashes between Tina and her husband, and of instances where the “real [Tina came] through”. It was noted that the content of Session 4 did not align with the original purposes of the session due to its exclusive focus on managing Tina’s distress. Session 4’s original objectives were to consolidate the values and experiential techniques that Tina had engaged in, to make plans for the future. However, because Tina had been so distressed over her husband’s affair to the point of expressing that her “main priority is [her] marriage, not her [daughter] anymore”, and that her daughter would “lose” Tina too if she and her husband divorced, Session 4 focused on revising Tina’s values and bringing them back to her awareness. It was observed that when Tina was reminded through several examples that she was still “following [her] value… a good mother”, and that she had been engaging her
“independent self”, her presentation and the content of her words changed. Specifically, Tina started to smile and express that she is “actually still strong”, and declared that “[the real Tina] should come out. She should be shining now”. Furthermore, Tina also acknowledged that identifying these values “could help [her]… in handling this situation better”.

Tina’s values were indirectly addressed when the researcher sought to confirm her underlying motivations. Indirect identifications of her values occurred mostly in Session 1, and were exploratory in nature, taking the form of questions such as “why is it important to you to make breakfast for him”. Furthermore, as Tina tended to express her values in terms of action, the researcher also sometimes identified Tina’s values in the same way, such as reflecting that Tina is “trying to change [her daughter’s] future” to “not be so angry with herself”.

During the remaining 2% of the time, Tina’s values were not identified. This occurred when the researcher was too focused on particular issues, such as the nature of Tina’s flashbacks, that her value of protecting her family from her emotional dysregulation was not explored.

**Clarity of Presentation of Values**

The method of presentation of values (i.e., clarity) by which values were presented were rated 58 times. Out of these times when values were presented, 58% met the “Direct” criteria, 31% met the “Subtle” criteria, and 11% met the “Vague” criteria.

“Direct” presentations of values involved the researcher naming Tina’s values in several ways. One was through naming them as statements such as “you were… caring about [your daughter]”. Values were discussed in a direct fashion mostly in Session 4 for the purposes of reminding Tina of her core values of “being a good mother”, a “good wife”, and
how she had followed her value of being “independent” and “strong”, qualities that she had expressed wanting to possess from the earlier sessions.

Another way of directly naming Tina’s values was through identifying her value clashes that led to meaning rupture. The researcher juxtaposed Tina’s her commitment to motherhood against her forced abortion by noting, “…you see [your daughter] as a God-given to you. Secondly is you… you want to use your own rights, you want to exercise your own rights as a mother”.

A third way of directly presenting Tina’s values was through psychoeducation. It was used to explain the roles of values in her daily life. Tina was reminded of how her values “actually helped [her] to decide the person [she] wants to be” and how “[sticking] to [her values of] wanting to be a good mother” helped her to “[stick] through all that [difficulty]”.

Presentations of Tina’s values rated as “Subtle” were exploratory in nature and sought to get Tina to express her values herself. Subtle presentations were used when Tina had raised areas which were important to her, as suggested by the tone of her voice, the emotional and verbalised content of her words. An example was the researcher’s subtle statement of “no matter how hard things are, you guys will still continue on, just for the sake of [your daughter]” in response to Tina’s conviction that “as long as our daughter feel comfortable… then, ok”.

“Vague” presentations of Tina’s values occurred in situations where the researcher did not clearly indicate that values were being discussed, such as asking Tina “what kind of person do you think you are” and what Tina thought of certain situations. These occurred when Tina talked about things that she would like to do to fulfil her “job, as a wife, as a mother to (her) daughter”, but were not explicitly stated as values to her.
Alignment of Session Content with Purpose

Values were identified and discussed across all the sessions, and although the researcher and Tina engaged in these discussions, it was observed that the discussions often meandered into Tina’s flashbacks, existential crisis and current difficulties (e.g., housing issue, husband’s infidelity), more than her daughter’s illness, and her values were explored through these events. Although Tina often reported being unaware that she had been expressing her values, her behaviour between sessions seemed to suggest otherwise.

While towards the end of Session 1, Tina expressed that she “didn’t even know (she) had actually talked about values”, it was observed that throughout that session and in subsequent ones, she had voluntarily identified the areas that were important to her, such as preserving the marriage by “serving the husband by… doing the wife’s job” and being “a mother to (their) daughter”. Even with subtle prompts such as “What else is scaring you about (the divorce)”, Tina was able to gradually express her desire to provide a complete family for her daughter, suggesting that she was able to respond well to questions pertaining to her values.

Furthermore, in the situations where her values had been tested, such as the incident with the replacement doctor and keeping her marriage together, Tina behaved in accordance with her values. While Tina could have engaged in these behaviours independent of the MFT, the situations occurred while the MFT was ongoing, and especially when Tina’s values were identified and presented in very direct ways. Thus, there was a possibility that Tina had internalised some of the discussions during the sessions.

When Tina was reminded through several examples that she was still “following [her] value… a good mother”, and that she had been engaging her “independent self”, her presentation and content of her words changed. Specifically, Tina started to smile and express
that she is “actually still strong”, and declared that “[the real Tina] should come out. She should be shining now”. Furthermore, Tina also acknowledged that identifying these values “could help [her]… in handling this situation better”. The change in Tina’s presentation and content of her words suggested that re-connecting her to her values served as resources that gave strength to face her difficulties.

8.2.4 A2 Facilitating Identification of Meaning

Identification of Meaning

Throughout the four sessions, the identification of Tina’s meanings occurred 28 times. Out of these, the researcher identified 89% of Tina’s meanings explicitly (i.e., “Yes”). The remaining 11% of the times, Tina’s meanings were identified indirectly (i.e., “Somewhat”). Tina’s meanings were explicitly identified in the following areas: (a) her role as a mother or a wife; (b) her actions in preserving her marriage; and (c) her search for her identity. With regard to “Somewhat” identifying Tina’s meanings, these occurred around areas where Tina expressed a change in perspective or appraisal about her self-efficacy.

Tina’s meanings of being a mother were identified through the use of summarising statements and questions. Examples of these were “You want to be a part of [your daughter]’s life”, and “can you tell me more about why [her husband and daughter] are the important ones?”. These statements were reflected back to Tina’s actions of being a committed mother. In Session 4, Tina was also reminded of her commitment to motherhood through the researcher’s reflection that “[she is] keeping the family together, also for [her daughter]”. The purpose of such statements was to remind Tina that even though she was distressed over the potential dissolution of her marriage, a part of her distress was due to not being able to fulfil her duty to her daughter. Through associating Tina’s distress about the disruption to a larger
meaning – providing the best for her daughter – the objective of enhancing Tina’s awareness of meanings was met.

Tina’s meanings for persevering in the marriage were identified through reflective statements such as “the part of (her) that is fighting is… recognizing… what your husband is like, having faith that the person is still there… and believing in your marriage”. This was to remind Tina of her purpose, or the meaning she placed in her marriage as an institution bound by promises. Again, in Session 4, the pursuit of Tina’s meaning in caring for her daughter and persevering in her marriage, particularly the latter, did not align with the objectives of the session. It was compromised in favour of returning Tina to a less distressed state. Yet, in reducing Tina’s distress through re-connecting her to her values and meanings, as evidenced through her belief that she could use the renewed meanings to “stabilise the situation”, the researcher also kept to the overall principles of the intervention.

A prominent part of Tina’s distress was related to her search for identity. Explicit identification of Tina’s sense of self was through explorations of Tina’s encounter with the replacement doctor. The explorations took the form of “what difference does this have on [Tina]” and brought up Tina’s own acknowledgement of feeling “stronger” and “independent” after the incident.

With regard to “Somewhat” identifying Tina’s meaning, these situations occurred when Tina identified changes in her perspective, or when her relaying of experiences hinted at an existential crisis. When identifications took a tentative approach and used hypothetical questions such as “What happens if (Tina doesn’t) do this kind of thing” to highlight discrepancies in Tina’s appraisals, the ensuing discussion unveiled Tina’s fear of rejection and search for identity.
Clarity of Presentation of Meaning

The identification of Tina’s meanings led to a discussion of it 25 times. Out of these instances of discussions, 48% met the “Direct” criteria, and the remaining 52% met the “Subtle” criteria.

Statements that met the “Direct” criteria involved the researcher explicitly expressing the significance of the event’s meaning to Tina, such as identifying that “(Tina’s daughter) is the centre of (her) world”, or when the researcher was engaging in psychoeducation about the significance of meaningful moments, such as “if we have too many of these meaningful moments, then what’s the point?”. Direct statements tended to be used in situations where the researcher was summarising Tina’s experiences, or when Tina had already expressed her sense of meaning.

Subtle statements tended to be made when particularly meaningful moments were identified by the researcher but not yet recognised by Tina. These subtle statements sought to get Tina to reflect more on what she had said, such as “What effect did it have on you?” and exploring characteristics of distressing situations for Tina. The researcher phrased these as questions in order to obtain Tina’s perspectives.

Alignment of Session Content with Purpose

Meanings were identified and presented in a direct manner for the purposes of bringing Tina’s attention to meaningful areas of her life, notably caring for her daughter and her marriage. For example, in the identification that Tina “want[s] to be a part of [her daughter’s] life”, and “so that’s a different set [of relationships] you want to make to your relationship with your parents”, the researcher was enabling Tina to make sense of the purpose of her actions. Tina responded that “What my parents did to me, I will make a change to my relationship with my daughter… to be a goal”. Her iteration of her “goal” being
to build a close relationship with her daughter was an expression of the meaning her relationship with her daughter held for her. It also therefore suggested that the objective of aligning Tina to her sense of meaning had been achieved.

The purpose of presenting Tina’s meanings in a subtle manner was to encourage her own exploration. It had mixed results. Upon closer analysis, it was noted that the researcher’s choice of words made a difference towards Tina’s response. Words that were more concrete and action-based, such as “effect”, “difference”, and “signify” allowed for responses related to meaning. For example, in asking Tina “what difference does [focusing on her daughter] make to [Tina]”, her response of “To focus on something makes me a better person” was associated with positive changes she noticed about herself. In contrast, when the question was phrased as “what does this mean to you”, Tina’s responses tended to be “I don’t know”, or be rooted in descriptions of her actions. Such differences suggested that Tina might have been more responsive to concrete, action-based questions than abstract words.

8.2.4B Receipt of Intervention

Assessment of how well Tina received the intervention was based on whether and how well she completed her experiential exercises (i.e., indicating she understood the instructions to the exercises), and observations of instances where Tina reported encounters in between session that were consistent with her values and meanings, or related to the constructs of values and meanings during the intervention.

8.2.4 B1 Experiential Exercises

Experiential exercises were implemented to access participants’ values. Where the experiential exercises were not completed in session, Tina was asked to complete them as homework. To assess the extent to which Tina understood the exercises and the constructs inherent in them, two aspects were considered. The first was whether or not Tina completed
the exercises when she brought them home. The second was whether she had completed them correctly. Although subjective, these provided the best gauge of Tina’s engagement in the intervention, as well as whether she had understood what was discussed during the sessions.

**Completion of Exercises**

Tina engaged in three experiential exercises across Sessions 1 to 3. These were: (a) thinking of a particularly meaningful moment in the course of her daughter’s illness (Session 1); (b) reflecting on the areas she had choice and control (Session 2); and (c) her strengths (Session 3). Tina engaged in verbal discussions of the experiential exercises during the sessions, but reported difficulties in completing such tasks in writing or through drawing. As such, Tina did not complete the exercises at home, stating that she had tried, but had ended up “staring” at the paper.

Overall, however, Tina engaged in the experiential exercises through discussions, rather than writing or drawing. Tina expressed that she “really [doesn’t]… write much, because [she is] afraid that it will be wrong, and people won’t accept it”. She then related it to a “fear of rejection”. Nonetheless, guidance in the form of encouragement, prompts, and feedback facilitated her engagement with the exercises.

In Sessions 1 and 2, Tina expressed resistance in engaging with the exercise on brainstorming her personal qualities, stating that she “[did not] even know how to express [herself]” and was “bad in mind-map, everything”. She declined to write or draw, but was open to speaking about areas important to her, such as her husband, daughter, and respect.

In Session 3, Tina reported that she had tried to complete the exercise on Choice and Control, but had “stare[d] at that paper for one hour. But… didn’t write anything” as she did not understand what to write. She had also expressed concern about whether she “[did] it correct[ly] or not”, and that she “[did not] know if she could actually answer, because [she is]
really… not the person to think much.” However, it was noted that Tina actively participated in discussions about the exercise during the session.

**Accuracy of Experiential Exercises**

Given that Tina did not complete the exercises at home, there would not have been any measure of the quality of her responses. Nonetheless, during sessions, particularly in Session 3, time was used to complete the exercises.

It was observed that Tina’s self-appraisals tended to incline towards the negative, such as her “[liking] to spend money”, “to go out”, or not having any choice. Her self-appraisals suggested that she viewed herself as a passive participant in life. Nonetheless, with guidance, Tina’s responses were more in line with active coping, such as enlisting her mother’s help to care for her daughter, while she started working to ease the family’s financial burden. Such a response was contrary to Tina’s previous view of her “life as miserable” and that “nobody cares” about her; she was now thinking of alternative solutions to solve her issues.

Thus, it seems that discussing experiential exercises within sessions were more effective in engaging Tina and facilitating change than reinforcing them through homework.

**8.2.4 B2 Observations**

Observations of her behaviour across the intervention sessions were especially important in Tina’s case due to her tendency to express values in terms of action. In addition, it was also interesting to note that although Tina “didn’t actually see (she was acting in accordance to her values) until (the researcher) told (her)”, she had actually been doing so in situations where her values had been tested. Specific evidence that supported the intervention were when she insisted on changing her daughter’s replacement doctor, and her choice of coping strategy to cope with the distress of her husband’s extra-marital affair. What was
significant about Tina’s behaviours in these two situations was that, rather than the passive individual who “keep(s) quiet” and is “afraid to handle… situation(s)”, Tina stood up for her values and her needs.

Firstly, between Sessions 2 and 3, Tina insisted on changing her daughter’s replacement doctor as she felt that the doctor did not “show care and concern to (her) patient’s parent and… don’t have any emotional… support for the… patient’s emotion”. Tina stood up for herself and her daughter motivated by her value of being a good mother, and she was decisive in her choice. Her behaviour was a change from her usual stance of deferring to doctors’ decisions, and also unlike her usual indecisiveness. Tina’s shift in behaviour was noted to come after Session 2’s exclusive focus on Tina’s values of being a committed mother and wife, and areas of strength.

Secondly, Session 4 indicated a departure from Tina’s preferred coping strategy of avoidance and needing “someone to push the button” before she would talk. In that session, Tina acknowledged the “need to talk to someone” as she was “already thinking about suicidal”, despite knowing that she was “shaming [her] own marriage”. Furthermore, the researcher was notified by Tina’s CCF social worker after the intervention, that Tina had sought her help to be referred to a psychiatrist and other avenues of financial help. It was noted that Tina seeking help came after Session 3’s discussion of her asserting the “Real (Tina)” by “progressing for (herself), and of exploring her feeling “stronger” and “very excited” at “(making) that own choice by (herself)” instead of her husband. In addition, Tina’s independence in seeking help after Session 4 was also noted to coincide with more engagement in feedback and education with regard to Tina’s values and adherence to following the “Real (Tina)” within Session 4.
Thus, it appeared that Tina’s behaviours were a good indicator of possible changes resulting from the intervention, possibly due to her having a more concrete and pragmatic approach to managing difficulties. Evaluating her actions and indirect value expressions offered a different dimension to assess Tina’s changes throughout the intervention.
Chapter 9: Study 2 Discussion

The current study sought to answer the research question of whether a meaning-focused intervention (i.e., MFT) can reduce the distress of mothers of children with cancer or a chronic illness. This research question was answered through a three-pronged approach: (a) to map out the subjective experiences of parents of their child’s illnesses in their contextual reality; (b) to assess the efficacy of the MFT; and (c) to evaluate the fit of the MFT to the participants via its delivery by the researcher and its receipt by the participants. In the discussion, I will integrate the information presented in the findings, including descriptions of the participants and their test scores, as well as findings of the thematic analysis related to themes of meaning ruptures, values, narratives of their experiences, coping, and resources.

Next, the efficacy of the MFT will be discussed, followed by the findings from the evaluation of the MFT. The limitations and implications of this study will also be presented.

9.1 Contextual Influences on Parents’ Distress

The overall findings of the case studies suggested that the participants’ contextual experiences such as their relationship with the medical personnel, and marital issues had a bearing on their perceived distress, psychological symptoms, and how they coped, over and above their experiences of their child’s illness.

The study had a particular interest in the meaning distress experienced by parents. What was learnt from the findings was that participants’ meaning distress was not necessarily directly caused by their child’s illness, but rather, was a more complex picture of the interaction between contextual factors and the child’s illness.

The thematic analysis revealed three common core themes of meaning ruptures, values, and coping for both participants, in addition to the factor of additional stressors for
Meaning ruptures emerged as a core theme for both Angie and Tina. These meaning ruptures were not specific to their children’s illnesses, but to contextual issues concerning their well-being. Angie’s meaning rupture was associated with the failure of the medical system in including her as an active partner in caring for her son. The obstacle to actively caring for her son formed a threat to her sense of agency, that in turn prevented her from being aligned with her value of being a good mother. On the other hand, Tina’s meaning ruptures were firstly around being forced to do something against her values (i.e., abort her daughter) by people she trusted and thought would support her, and the collapse of her beliefs of marriage as an institution of trust. Her meaning ruptures and existing challenges associated with her daughter’s illness – medical costs, lack of a conducive accommodation, and, although not explicitly stated, her marital difficulties – heightened Tina’s distress. The current state of knowledge is that contextual stressors such as financial and marital difficulties, and relationships with medical personnel, predispose parents to greater distress when caring for their children (Alaee, Shahboulaghi, Khankeh, & Mohammad Khan Kermanshahi, 2014; Bayat, Erdem, & Gül Kuzucu, 2008). The finding that contextual stressors had a greater impact on Angie and Tina’s values and therefore posed ruptures to their meanings, rather than their children’s illness, extend the current knowledge on the impact of contextual stressors on parents’ caregiving stress, by first showing that parents’ core values may be threatened by events that are not directly related to their child’s illness, and second that prior meaning ruptures may create vulnerabilities in parents, thus predisposing them to higher distress when their child is diagnosed with a chronic and/or life-threatening illness.
In support of the impact of contextual stressors on heightening parents’ distress, George, Vickers, Wilkes and Barton (2006) found that poor relationships between parents and medical personnel, and insensitive remarks from surrounding others, exacerbated parents’ grief over their children’s chronic illnesses. Furthermore, prior meaning ruptures as predisposing parents to higher distress when their child is diagnosed with cancer or a chronic illness, is supported by Granek et al.’s (2014) study that prior unresolved, difficult life circumstances predisposed parents to higher levels of perceived stress.

It was further noted that both Angie and Tina reported marital difficulties. For Angie, they led to divorce, while for Tina, they were associated with high psychological distress. In Tina’s case, while it was not clear if her daughter’s illness was the cause of her marital problems, it was interesting to note that the marital difficulties co-occurred with her daughter’s illness. Angie’s case was similar. Although her marital difficulties could have been brought on by other issues, it was noted that she had two children with chronic illnesses. Research has often documented the impact of serious paediatric illnesses on the quality of marital relationships and marital satisfaction due to changes in intimacy and role strain (Quittner et al., 1998; Silva-Rodrigues, Pan, Pacciulio, de Andrade, & Nascimento, 2016), and on marital qualities predicting mothers’ psychological well-being (Benson & Kersh, 2011).

A common core theme for both Angie and Tina was their valued commitment to being a good mother. They expressed this value repeatedly in sessions – Angie was more reflective in her expressions, often relating her ideas of what a good parent should be and her desire for her children to be responsible citizens, while Tina used more concrete expressions, such as frequently talking about sacrificing her needs in favour of her daughter’s comfort. This difference between reflective and concrete expressions of values and meanings was reflected in their SOC-13 Comprehensibility and Manageability subscale scores. Specifically,
Angie’s Comprehensibility scores were higher than her Manageability scores, while Tina’s Manageability scores were higher than her Comprehensibility scores. The variability of their scores in correspondence to their expression of values implied a relationship between individuals’ expression of values with their outlook on life and management of resources. The pattern of Angie’s and Tina’s expression of values and meanings and their scores correspond with research on values suggesting that individuals’ expression of values can be both cognitive and behavioural (Hayes et al., 2013; Hitlin & Piliavin, 2004).

Angie and Tina’s deep commitment to motherhood could be understood from a cultural perspective. Singapore adopts a Confucian perspective that emphasises the family as a bedrock of a successful society (Hing, 2004). What happens to a single mother, or, more fundamentally, to traditional values in the face of globalisation?

For Angie, being a single mother in Singapore went against the implicit cultural norms that still views a dual-parent family as ideal. Angie’s behaviours in emphasising character building in her children, and placing them as a priority above her own needs, echo Wong’s (2004) finding that single parents in Singapore turn to redefining the concept of family “less in terms of its structural characteristics and more in terms of function as a space for love and care” (p. 48), which Wong suggested to be particular to Confucian societies in Singapore. Against Singapore culture’s frowning upon single parenthood, Angie’s commitment to motherhood becomes more remarkable, as it emphasises her desire to make up to her children for the loss of firstly, a second parental figure in the family, and, also, for the way society would view her children coming from a single-parent family.

On the other hand, for Tina, her oscillation between distress at losing her main form of support who is her husband, and desire to be independent to care for her family, reflects an ethnicity that is still caught between tradition and modernity. Tina’s behaviour reflects Hing’s
(1998) finding that while Malay/Muslim women continue to accept their traditional roles of dutiful wife and loving mother, at the same time, with globalisation, they also face possibilities of other roles they could assume outside of the family. Thus, while it could be seen that embracing motherhood was a core value for Tina, this value sometimes came under threat when other competing values, such as her marriage, or more pertinently, her seeking an identity (discussed later). The conflict between values also reinforce the possibility that distress in parents of ill children may also be due to a conflict in values within parents’ living contexts.

Angie and Tina’s common core value of committing to motherhood was also visible in their coping strategies. Even in their most challenging periods, their central concern was their children’s well-being. Their behaviours support caregiver research that has demonstrated that parents’ commitment to fulfilling roles as nurturing parents spurred them to pursue alternative courses of action that have led to reductions in distress (Maciver, Jones, & Nicol, 2010; M. Y. F. Wong & Chan, 2006), or persevering in providing the best care for their child (Maciver et al., 2010). Reduction in distress through alternative courses of action was seen in Angie’s case through her steadily declining reports of psychological distress. However, this was less visible in Tina’s case, who reported stable and high levels of psychological distress.

While Angie’s and Tina’s coping strategies reflected their value of motherhood, their choices of coping strategies differed. Angie coped predominantly with a problem-focused approach, although an interesting finding was her high ratings of self-blame on the Brief COPE. On the other hand, Tina coped with a mix of active coping, meaning-focused coping, and avoidance coping though substance use and behavioural disengagement. Angie and Tina’s choices of coping strategies corroborated with their reports on the Brief COPE and psychological distress on the outcome scales, as elaborated below. Their choices of coping
strategies also had implications for their resources, which will be discussed within the resource theme.

Angie’s active coping strategies remained stable throughout the intervention, while her reports of self-blame around being a “useless mother” decreased. Correspondingly, her distress levels on the DASS-21 and IES-R decreased, while her Comprehensibility and SOC-13 Total scores increased. Angie’s results thus suggest two points: firstly, distress brought about by meaning ruptures or threats to core values tax coping strategies aimed at resolving practical problems; and secondly, there needs to be a match between individuals’ choice of coping needs and the situation. These suggestions might be explained by the literature on coping flexibility, where coping strategies that fit the demands of the situation, or where the individual modifies his or her coping goals to adapt to stressful events, are associated with lower psychological distress (C. Cheng, Lau, & Chan, 2014). Indeed, while Angie’s active coping strategies were adaptive in managing the practical challenges associated with her child’s illness, they were not successful in her management of her relationship with the medical personnel.

Tina’s engagement in meaning-focused coping corresponded with her stable and moderate scores on the Meaningfulness subscale on the SOC-13. Consistent with these scores, Tina engaged in meaning-focused coping even in the most challenging periods of her life (i.e., the threatened abortion, her husband’s extra-marital affair), when she considered her daughter’s well-being in all her actions. Tina’s continued increase in distress and corresponding decrease in Manageability scores despite stable and moderate levels of Meaningfulness scores on the post-test and follow-up phases suggest that the meaning rupture surrounding her marriage had adversely impacted on her coping and managing her remaining resources. The pattern of Tina’s scores were similar to Breitbart and colleagues’ (2012; 2010;
findings that the MCP had limited effect on participants’ anxiety levels, but improved their sense of meaning and overall quality of life.

The presence or absence of resources for Angie and Tina influenced their choice of coping strategies. Their coping decisions supported two aspects of Hobfoll’s Conservation of Resources Theory (COR Theory; 1989). The first was that the possession of key resources can enhance coping to generate further resources, and the second was the effect of resource loss on an individual’s coping. Angie’s sense of agency created resources in the form of her family’s support and children’s teachers’ assistance allowing her to follow her value of being a good mother, and follow through with her divorce. In contrast, Tina’s coping behaviours reflected a combination of proactive and defensive coping in the face of resource loss. Echoing the findings by Ångström-Brännström et al. (2010), Tina engaged in proactive coping through increased seeking of emotional support from her best friend. Her defensive coping strategies reflected avoidance of the stressor and withdrawal of resources. They took the form of smoking, self-blame, and contemplations to stop caring for her daughter. The loss of, and constant threat on Tina’s resources influenced her perception of additional stressors and her search for identity.

Tina’s difficulties with the additional stressors in her life were exacerbated by her search for her identity. Studies on identity development found that a search for identity was associated with psychological symptoms and distress, thus suggesting that individuals with a lack of stable identity could create vulnerabilities within individuals, particularly if they were also facing other stressors in their lives (Schwartz et al., 2011; Wängqvist & Frisén, 2011). In Tina’s case, she had voiced concerns over not possessing a stable identity; the lack of which had likely contributed to her apprehension in asserting her opinions and questions during doctors’ appointments and participating in the experiential exercises at home, as well as her dependence on her husband to make decisions. In contrast, Angie’s dedicated pursuit of the
life she wants with her family, her reflectivity and insight into her values and sense of meaning are indicative of having established an identity. These indicators of Angie’s achievement of a stable identity are supported by research demonstrating an association of identity achievement with self-esteem, possessing meaning and purpose in life, and having a sense of agency (Eichas, Meca, Montgomery, & Kurtines, 2014).

In sum, contextual experiences appeared to play significant roles in participants’ distress, and also had an influence on their meaning ruptures, values, coping, and resources. The participants’ contexts exacerbated their distress associated with their children’s illnesses, resulting in heightened distress and predisposing them to further threats to their coping and resources.

9.2 Efficacy of MFT

The overall findings of Angie’s and Tina’s pre-, post- and follow-up test scores on the standardised outcome measures suggested mixed efficacy of the MFT. However, findings from the thematic analysis and evaluation of the MFT are consistent with efficacy of the MFT. The results are discussed in this section.

In terms of the standardised outcome measures, the MFT was effective in reducing Angie’s distress and, of particular mention, her meaning distress. However, the MFT was limited in reducing Tina’s distress. Angie’s scores showed a general decreasing trend in her distress scores on the Emotion and Help Thermometers, DASS-21, and IES-R, and an increasing trend in her SOC-13 scores. Angie’s reports on the standardised measures also corresponded with the content of her narratives during the sessions, expressing agency, confidence to cope, and a general lack of distress in her life. On the other hand, Tina reported generally high and stable trends of distress throughout the intervention, and low-moderate levels of a sense of coherence on the SOC-13 individual subscales and total scores. Tina’s
scores thus suggested that the MFT was neither helpful in reducing her psychological distress, nor in enhancing or rebuilding her sense of meaning in life.

However, when the findings from the thematic analysis and evaluation of the MFT were considered together, a different picture emerged for Tina. The content of Tina’s reports within the sessions, particularly Session 4, differed from her reports on the standardised measures. Specifically, when Tina was re-connected with her values of identity and her commitment to being a good mother, her expression of her perception of her marital crisis and daughter’s illness changed from one where she “can’t help [herself]”, to one where there was an opportunity for her to “shine”.

The mixed findings from standardised outcome measures and the qualitative analyses highlight the value of triangulation of approaches in a case study research method (Yin, 2003). The findings from the thematic analysis provided a qualitative account of Tina’s changes throughout the course of the intervention, which was not captured by the standardised outcome measures. This may have been due to the dependence of standardised outcome measures on generalised data scores in terms of established norms and cut-offs and also their limited application to cross-cultural variations (Flyvbjerg, 2006).

9.3 Is the MFT a Good Fit?

The findings from the evaluation of the MFT (including delivery and receipt of the intervention) suggested that it largely fitted with the participants’ contextual reality because their behaviour outside of sessions appeared to correspond with topics of discussion in sessions. There were two aspects of the findings that deserve discussion. These were Angie and Tina’s differential responses to the clarity by which the researcher presented values and meanings within the session, and the deviation in protocol in Tina’s case in Session 4.
Angie and Tina had differential responses to the style by which the researcher identified and presented values and meanings in session, and engaged with experiential exercises. Tina required more explicit and direct identifications and presentations of values and meanings than Angie, possibly due to differences in their style of expression. Angie was more reflective, while Tina was more concrete. This finding calls for a more flexible approach in the delivery of the intervention. For example, with regard to the presentation of values and meanings, Angie responded well to subtle prompts, while Tina responded better to explicit prompts, particularly when they were action-based. Furthermore, with regard to the experiential exercises, Tina’s non-completion of them might have been due more to other reasons such as her tendency to disengage, her fear of rejection, and having to care for her daughter alone, than non-engagement. This assertion is further supported by Tina’s engagement in discussions within the sessions. These findings implied that while the content of the intervention might remain the same, the researcher may need to alter their delivery depending on the patient’s presentation and style of expression. A flexible approach can cater to the needs of different participants, tailor interventions to individuals’ cognitive styles and intellectual abilities. This is supported by researchers in various fields in psychotherapy, such as treatment of complex and atypical presentations of PTSD (Markowitz, Kaplowitz, Suh, & Meehan, 2012), elderly persons with and without dementia (James, 2010), and engaging individuals with concrete cognitive styles (M. Donovan, 2015). Together, the current study’s and these researchers’ findings support calls for a flexible approach in treatment protocols for future studies on the MFT or other meaning-based interventions.

The next aspect of the discussion is the deviation in treatment protocol in Session 4. Pertinent to the discussion here is that although the content of Session 4 changed, the focus remained on the values and meanings that had been discussed with Tina in the previous three sessions. These were used to anchor Tina’s distress, and resulted in not only reducing her
distress, but also meeting the overall objectives of the MFT, which was to use participants’ enhanced or rebuilt values and meanings as resources to cope with their child’s illness. Tina’s re-connection with her values and sense of meaning not only gave her strength to continue caring for her daughter, but also to manage her distress over her marital issues. The decision to focus on Tina’s recent crisis yet pursue the overall principle of the intervention is echoed by the principles of Dialectical Behaviour Therapy (DBT) that incorporate crisis intervention for self-injurious and suicidal behaviours within its overall treatment approach (Hampton, 1997). In DBT, individuals are taught skills and strategies to manage the crises they face. When crises occur, patients and researchers return to the skills discussed, to minimise the impact of the crises (van Goetham, Mulders, de Jong, Arntz, & Egger, 2015). Similarly, re-discussing Tina’s values and meanings served the purposes of addressing a crisis and reducing elevated distress by utilising established values to change her perspective to her stating that it was time for her “independent” side to shine. This not only indicated that values and meaning play a role in ameliorating parents’ distress, but more importantly, that values and meaning serve important functions in providing directions to accessing resources (Antonovsky, 1987).

9.4 Limitations

The current study largely met its objectives. However, there were some shortcomings of the research that will now be discussed. These pertained to aspects such as the analysis of the data, delivery of the intervention, and its conceptualisation.

The analysis of the data depended largely on qualitative observations and a rating scale used on the part of the researcher. In particular, participants’ receipt of the MFT was rated on a 5-point Likert scale, against markers that assessed their engagement in the discussions, the accuracy of their completed experiential exercises, and understanding of the constructs and skills learnt in the MFT. However, while the assessment was based on
scrutinising the transcripts of the sessions, they can be considered as secondary impressions by the researcher, who was also the therapist. Future research can consider administering self-report questionnaires to the participants, to assess their perception or understanding of the constructs and skills learnt, in order to obtain a more accurate understanding of the fit of the intervention (Bellg et al., 2004; Gearing et al., 2011).

With regard to its delivery, the MFT was primarily cognitively focused in its approach. Discussions focused heavily on reflections of past experiences and how participants perceived their experiences or changes. The findings indicated better suitability for reflective individuals than those who were more concrete. While the MFT is backed by theoretical findings that meaning is primarily a cognitive construct (Janoff-Bulman, 1992; Park, 2010; Park & Folkman, 1997; M. F. Steger, Kashdan, Sullivan, & Lorentz, 2008), some of these researchers – Steger and colleagues, Breitbart and colleagues, Frankl, and Ehlers and Clarke, also emphasised a component of action in order to either reinforce or to build extended meaning. Indeed, in Breitbart et al.’s (2011; 2012; 2010) MCP, experiential exercises incorporating Frankl’s (1963) three sources of meaning were used to consolidate participants’ knowledge of abstract concepts of meaning to their daily lives. Similarly, Steger (2012) postulated that meaning in life consists of two dimensions – comprehension (i.e., making sense of life and one’s place in the world), and purpose (i.e., goals that motivate action towards fulfilling the self-concept), suggesting that action is required to affirm individuals’ sense of meaning. These studies thus support the suggestion that future research explore a meaning-focused intervention that included more behavioural-based components.

The third and fourth limitations were related to the conceptualisation of the MFT, such as its duration, and the length of time between sessions.
The duration of the intervention sessions was short, and more improvements might have been achieved with more sessions instead of four. This was particularly notable in Session 3, where both Angie and Tina expressed difficulty in completing the experiential exercise on Choice and Control, resulting in a significant amount of time spent on clarifying and engaging in the exercise within the session. If more time was allocated, the exercise could more fully explore participants’ contextual stressors, thus allowing for greater opportunities to apply their skills to outside of the intervention. However, while it is definitely recommended for future research to increase the number of sessions, it is also just as important to keep in mind the burden to parents to attend the sessions. A common reason for declining participation in paediatric illness research has been a lack of time due to other commitments, feeling overwhelmed, and wanting to focus on the ill child (Kazak et al., 2005; Landolt, Ystrom, Sennhauser, Gnehm, & Vollrath, 2012). Thus, if more sessions pose too heavy a commitment to parents, future researchers can consider other options such as two half-day sessions instead of four 1.5 hour sessions, or online interventions, to fit into parents’ multiple commitments.

Lastly, the sessions were held based on the participants’ schedules, which resulted in irregular time lapses between sessions. For example, the sessions had to be rescheduled a few times for Angie due to work commitments such as rushing deadlines to complete consignments, or family commitments such as parent-teacher meetings. For Tina, the sessions were spaced apart to fit in with her daughter’s medical appointments, and also with substitute caregivers’ schedules so that Tina could attend the sessions while someone looked after her daughter. The reasons for the irregular time lapses between sessions thus further demonstrate the influences of contextual events not only on parents’ distress, but also as hindrances for parents seeking support. Irregular sessions could mean that progress from the MFT might have been slower to surface.
9.5 Future Research

In light of the current study’s findings, there are some issues that future research investigating meaning-based approaches may wish to consider. Firstly, given the difference in Angie and Tina’s cognitive styles and expression of values and meanings, a flexible approach to identifying and presenting the skills and concepts should be considered. Secondly, future studies should also consider incorporating cognitive-behavioural approaches such as problem-solving strategies and cognitive-restructuring techniques to target depressive and anxiety symptoms. Lastly, future research should also consider the impact of parents’ contextual realities when investigating their distress and its sources.

9.6 Conclusions

Overall, the findings suggested that a meaning-based approach targeting parents’ meaning distress while considering their contextual reality was efficacious. The participants derived strength from their values to overcome their distress. The MFT thus merits further research and exploration. Lastly, the case study approach allowed for an in-depth investigation of two different cases in the context of their full contextual lives and the current study built on knowledge about the influence of contextual experiences on parents’ distress. It also demonstrated the shortcomings of solely using standardised objective measures in the capacity to detect changes in participants’ presentations during the sessions.
Chapter 10: General Discussion

Parents face a range of distress when their child is diagnosed with a chronic or life-threatening illness, and when caring for their child. Among the types of distress they face, meaning-related, or existential distress, has been described by researchers (Bjork et al., 2005; Whiting, 2013) but not exclusively studied. The aim of this thesis was to investigate the existential distress reported by parents of children with chronic and/or life-threatening illnesses. It sought to address two issues within the paediatric illness field – the validation of a short screening tool that detects meaning-related distress on top of psychological distress among parents (Study 1), and the applicability and efficacy of a meaning-focused intervention to enhance parents’ sense of meaning through increased awareness of their values (Study 2).

10.1 Pervasiveness of Meaning-Related Distress

The key findings of Study 1 included the overall diagnostic accuracy of the thermometers, the incremental predictive ability of the Crushed Universe Thermometer (CrushedUniT) beyond Mitchell et al.’s (2010) original set of Emotion and Help Thermometers (ET and HT) in predicting IES-R Total and SOC-13 Meaningfulness, and the optimal combination of thermometers to predict different forms of distress. The most noteworthy finding of Study 1 was that the CrushedUniT not only showed promising diagnostic accuracy but was the optimal thermometer for most forms of psychological distress and protective factors, with the exception of SOC-13 Manageability. What this finding suggested was that parents’ distress was underplayed at best by an element of a disrupted worldview or at worst, full meaning ruptures that manifested itself as more prominent forms of psychological distress such as depression, anxiety, or post-traumatic stress disorder (PTSD). This assertion on meaning loss underpinning distress is supported by
proponents of meaning research from the cognitive and existential perspectives. Cognitive theorists such as Park and colleagues (2010; 1997) view meaning as the overarching framework by which individuals organise their knowledge of the world and their place in it. Ehlers and Clark’s (2000) conceptualisation supplements Park’s (1997) and Janoff-Bulman’s (1992) view in that individuals’ prescribed meanings towards events can break or fit in with their overall understanding of the world, which can significantly influence psychological well-being. Similarly, existential theorists such as Frankl (1963), Yalom (1980) and P. T. P Wong (2016), view meaning as individuals’ basic motivation towards fulfilling their potentials in life, the lack of which can be associated with Frankl’s proposed ‘mass neurotic triad’ of depression, addiction, and aggression (Frankl, 1978).

Study 2 was an extension of Study 1 in its provision of a meaning-based intervention after a process of screening. Two key findings arose from the study. The first was that the meaning-focused therapy (MFT) was applicable and efficacious in increasing parents’ awareness of their values, thereby enabling them to confront their stressors. Although the MFT showed limited efficacy when assessed via standardised pre- and post-test measures, qualitative observations and reports by the participants, particularly Case 2 (Tina), suggested otherwise. Beyond the efficacy of the MFT, Study 2 also indicated the benefits of using a meaning-based approach, and of tailoring the intervention to the participants’ cognitive style. Currently, available intervention models for parents of ill children favour the cognitive-behavioural (CBT) approach, which is highly structured and has an emphasis on addressing parents’ unhelpful cognitions about their child’s illness (Sahler et al., 2005; Stehl et al., 2009). Study 2, however, offered a different treatment model in its emphasis on parents’ values and how to harness them to reinstate a sense of meaning and purpose. It also tailored the practitioner’s style of questions and reflections to participants in a manner that suited their style of thinking and communication.
A second key finding of Study 2 was that contextual stressors that threatened parents’ core values were the causes of meaning ruptures or meaning-related distress. This finding added another dimension to the findings in Study 1, in that parents’ reported meaning-related distress reported by parents in Study 1 might be due more to contextual stressors surrounding the child’s well-being than the his or her actual illness. Together, Studies 1 and 2 suggest that parents’ meaning-related distress is more complex than originally thought. Notably, participants in Study 2 reported past unresolved difficulties, difficulties with healthcare personnel, marital and financial difficulties that were linked to meaning ruptures and subsequent significant distress rather than the child’s illness.

The complementarity of Study 1 and 2’s findings have implications for furthering our understanding of the Sense of Coherence Theory (SOC; Antonovsky, 1979, 1987). Whether the SOC is a multifactorial or unitary construct remains unresolved (Eriksson & Lindström, 2005; Holmefur et al., 2015). The findings of this study provide some evidence for it being a multifactorial construct. Study 1 firstly found that different thermometers predicted different components of SOC (i.e., Comprehensibility, Manageability, and Meaningfulness), suggesting that challenges to each component manifests in different types of distress. Study 2 furthered Study 1’s findings by demonstrating the nuances of parents’ meaning-related distress, that it was the challenge to their values, resource loss, and the uncertainty of their situations – marital relationships, financial difficulty, etc. – in relation to their child’s well-being that triggered the distress. In contrast, if the SOC was taken as a unitary construct, a subset of types of distress such as anger and depression associated with difficulties in accessing resources would not have been detected, thus limiting our full appreciation of parents’ challenges. Thus, the results suggest that in an applied setting, a multifactorial view of the SOC construct affords medical personnel with relevant information, and hence allows for targeted help to be given to parents.
10.2 Limitations

The limitations of each study were discussed in their respective sections and will not be repeated here. This section instead seeks to address the overall limitations of the thesis in terms of addressing the questions that still remain in the paediatric illness research and within theoretical frameworks. These gaps include the investigation of and measurement of meaning-related distress among parents of ill children, the efficacy of structured versus process-oriented, or deficit- versus strengths-focused interventions for these parents, and the structure of the SOC construct.

The thesis indicated the pervasiveness of meaning-related distress in parents of ill children, and suggested that sources of distress were from contextual stressors pre-dating and surrounding the children’s well-being. However, these assertions require more rigorous validation, which could be achieved through two aspects. First, we suggest the use of specialised meaning questionnaires, preferably with established cut-off points, either alone or in conjunction with measures of other forms of psychological distress such as depression, anxiety, and PTSD. Melton and Schulenberg (2008) summarised a list of measures of meaning, and found that the measures had promising psychometric properties in measuring the presence of life meaning. Second, we recommend that a different step to validating the outcomes of this study is to replicate the research with a larger sample size and a more homogenous sample of parents of children with cancer and of children with chronic illness.

Secondly, a randomised controlled trial is required to explore the comparative efficacy of the MFT against more standardised, structured interventions based on the CBT model.
Thirdly, future research may consider comparing the incremental value of using a multifactorial approach against a unitary approach towards investigating the SOC construct in the context of parents’ distress.

10.3 Conclusions

The present research is the first of its kind to pay particular attention to screening for existential distress among parents of children with cancer or chronic illness, and to address this distress via a meaning-based therapy. Support was found for the use of short screening tools to assess various aspects of psychological distress faced by parents, and that the meaning-focused therapy (MFT) implemented was efficacious in subtle ways. The findings also furthered knowledge in understanding parents’ sources of distress and the relevance of adopting a multifactorial understanding of the SOC construct. Although the research faced several limitations, it nonetheless represents a good start to furthering our understanding of parents’ distress when caring for a child with cancer or chronic illness.
References


cultural study. *Journal of Pediatric Nursing, 14*(2), 130-140. doi:http://dx.doi.org/10.1016/S0882-5963(99)80051-7


Miedema, B., Hamilton, R., Fortin, P., Easley, J., & Matthews, M. (2010). "You can only take so much, and it took everything out of me": Coping strategies used by parents of children with cancer. *Palliative & Supportive Care, 8*(2), 197-206. doi:http://dx.doi.org/10.1017/S1478951510000015


doi:10.1200/JCO.2014.57.4020


Appendix A

Study 1: KKH PARTICIPANT INFORMATION SHEET

You are being invited to participate in a research study.

Before you take part in this research study, the study must be explained to you and you must be given the chance to ask questions. Please read carefully the information provided here. If you agree to participate, please sign the informed consent form. You will be given a copy of this document to take home with you.

STUDY INFORMATION

Protocol Title:
Assessment of Distress of Parents of Children with Cancer or Chronic Illnesses and Offering Meaning-Focused Therapy

Principal Investigator(s):
Dr Catherine Cox
Psychology Service
KK Women's and Children's Hospital
100 Bukit Timah Road
Singapore 229899
Tel: 6394 3097

PURPOSE OF THE RESEARCH STUDY

You are being invited to participate in a research study of parents’ distress when they receive their child’s diagnosis of cancer or a chronic illness, or that their child has had a relapse. We hope to learn if a simple screening tool can help us to identify and help parents who are very upset and stressed. You were selected as a possible subject in this study because your child has recently been diagnosed with cancer or a relapse.

This study will recruit 195 subjects from KKH, National University Hospital of Singapore (NUH) Children’s Cancer Foundation (CCF) and Club Rainbow over a period of 24 months. About 30 parents will be recruited each from KKH and NUH. Club Rainbow is a non-governmental, non-profit organization that provides help and support to children and youths diagnosed with chronic and potentially life-threatening illnesses, and their families. They usually receive referrals through doctors from the public hospitals in Singapore.

Please note that all your information is strictly confidential and will be stored under lock and key in KKH.
STUDY PROCEDURES AND VISIT SCHEDULE

If you agree to take part in this study, you will be asked to complete a set of six emotion thermometers, and then three questionnaires that measure depression, anxiety, post-traumatic stress symptoms, and sense of meaning in life. There will also be a few questions that ask you about yourself and your family. Your participation in the study will last 15 minutes.

YOUR RESPONSIBILITIES IN THIS STUDY

If you agree to participate in this study, you should:

Fill up the questionnaires in the order given to you.

Answer all the questions in the questionnaires, and as truthfully as you can. Please do not spend too much time on each question.

Inform the Principal Investigator as soon as possible about any side effects that you may have encountered.

WITHDRAWAL FROM STUDY

You are free to withdraw your consent and discontinue your participation at any time without prejudice to you or effect on your child’s medical care. If you decide to stop taking part in this study, you should tell the Principal Investigator.

Your doctor, and/or the Principal Investigator of this study may stop your participation in the study at any time for one or more of the following reasons:

The Principal Investigator decides that continuing your participation could be harmful.

You need treatment not allowed in the study.

The study is cancelled.

WHAT IS NOT STANDARD CARE OR EXPERIMENTAL IN THIS STUDY

The study is being conducted because the Emotion Thermometers are not yet proven to be a standard procedure in parents of children with cancer or a chronic illness. We hope that your participation will help us to determine whether the Emotion Thermometers are accurate enough to identify parents who are very upset or stressed about their child’s illness.

POSSIBLE RISKS, DISCOMFORTS AND INCONVENIENCES

Filling up the questionnaires may take up 15 minutes of your time.

Filling up the questionnaires may require you to recall experiences in the last four weeks, which may require some time.

This may generate negative emotions if you recall upsetting or unpleasant experiences while completing the questionnaires. If you continue to feel distressed after completing the
questionnaires, please do not hesitate to speak to your assigned social worker, your doctor, or the Principal Investigator.

POTENTIAL BENEFITS

There is no assurance you will benefit from this study. However, your participation may contribute to the wellbeing of other parents and the community through the use of the Emotion Thermometers. Parents who need help can receive it as soon as possible. Furthermore, because help can be given to parents quickly, they will be in a better position to take care of their children. In addition, because the Emotion Thermometers are very short, the hospital staff can not only help parents by directing them to receive help quickly, but also be able to concentrate on other important tasks such as the quality of care for the patients.

ALTERNATIVES

If you choose not to take part in this study, the alternative is to have what is considered standard care for your condition. In our institution this would be continued liaison with your assigned social worker from the Children’s Cancer Foundation. He/She will refer you to the relevant sources of support should you need it.

This procedure has the following potential benefits:

You may access support from your Social Worker when you require it;

Your social worker will direct you to the relevant avenues of support.

and the following potential risks:

Lengthier assessment process to ascertain the areas of support that you require;

Longer waiting time for referral to psychosocial support (e.g., counsellors, support groups, etc);

Possible emotional problems such as depression and anxiety may not be picked up as quickly, which may compromise your ability to comfort your child.

SUBJECT’S RIGHTS

Your participation in this study is entirely voluntary. Your questions will be answered clearly and to your satisfaction.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you or your legal representative will be informed in a timely manner by the Principal Investigator or his/her representative.

By signing and participating in the study, you do not waive any of your legal rights to revoke your consent and withdraw from the study at any time.

CONFIDENTIALITY OF STUDY AND MEDICAL RECORDS
Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Only your Investigator(s) will have access to the confidential information being collected.

However, Regulatory Agencies, Institution Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you or your legal representative is authorizing such access to your study and medical records.

By signing the Informed Consent Form attached, you or your legal representative are authorizing (i) collection, access to, use and storage of your “Personal Data, and (ii) disclosure to authorised service providers and relevant third parties.

“Personal Data” means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. This includes medical conditions, medications, investigations and treatment history.

Research arising in the future, based on this Personal Data, will be subject to review by the relevant institutional review board.

By participating in this research study, you are confirming that you have read, understood and consent to the SingHealth Data Protection Policy- the full version is available at www.singhealth.com.sg/pdpa. Hard copies are also available on request.

Data collected and entered into the data collection forms are the property of KK Women and Children’s Hospital. In the event of any publication regarding this study, your identity will remain confidential.

COSTS OF PARTICIPATION

If you take part in this study, the following will be performed at no charge to you:

Screening of emotional distress

Interpretation of scores on screening measure and questionnaires

There is no reimbursement for your time, inconvenience and transportation costs.

RESEARCH RELATED INJURY AND COMPENSATION

The Hospital does not make any provisions to compensate study subjects for research related injury. However, compensation may be considered on a case-by-case basis for unexpected injuries due to non-negligent causes.

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.
WHO TO CONTACT IF YOU HAVE QUESTIONS

If you have questions about this research study and your rights or in the case of any injuries during the course of this study, you may contact the Principal Investigator (Dr Catherine Cox, at 6394 3097).

If you have questions about the study or your rights as a participant, you can call the SingHealth Centralised Institutional Review Board, which is the committee that reviewed and approved this study, the telephone number is 6323 7515 during office hours (8:30 am to 5:30pm).

If you have any queries that need to be attended to urgently after hours, you can call the Co-Investigator (Ms Tay Yi Ling, at 91599515).
## CONSENT BY RESEARCH SUBJECT

### Details of Research Study

**Protocol Title:**
Assessment of Distress of Parents of Children with Cancer or Chronic Illnesses and Offering Meaning-Focused Therapy

**Principal Investigator:**
Dr Catherine Cox  
Psychology Service  
KK Women's and Children's Hospital  
100 Bukit Timah Road  
Singapore 229899  
Tel: 6394 3097

### Subject's Particulars

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<th>Name:</th>
<th>NRIC No.:</th>
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<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Sex: Female/Male</td>
<td>Date of birth dd/mm/yyyy</td>
</tr>
<tr>
<td>Race: Chinese/ Malay/ Indian / Others (please specify)</td>
<td></td>
</tr>
</tbody>
</table>
Part I

I, _____________________________________(NRIC/Passport No._______________________) (Name of participant)
agree to participate in the research study as described and on the terms set out in the Patient Information Sheet. The nature of my participation in the proposed research study has been explained to me in

___________________________________ by Dr/Mr/Ms ____________________________________
(Language / Dialect) (Name of healthcare worker)

I have fully discussed and understood the purpose and procedures of this study. I have been given the Participant Information Sheet and the opportunity to ask questions about this study and have received satisfactory answers and information.

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reasons and without my medical care being affected.

By participating in this research study, I confirm that I have read, understood and consent to the SingHealth Data Protection Policy. I also consent to the use of my Personal Data for the purposes of engaging in related research arising in the future.

[Signature/Thumbprint (Right / Left) of participant] __________________________ (Date of signing)
Translator Information, where applicable

The study has been explained to the participant/legal representative in

Language by Name of translator

Part II – to be filled witness, where applicable

An impartial witness should be present during the entire informed consent discussion if a subject or the subject’s legally acceptable representative is unable to read. After the written informed consent form and any written information to be provided to subjects, is read and explained to the subject or the subject's legally acceptable representative, and after the subject or the subject's legally representative has orally consented to the subject's participation in the study and, if capable of doing so, has signed and personally dated the consent form, the witness should sign and personally date the consent form.

Witnessed by:  
(Name of witness)  (Designation of witness)  

(Signature of witness)  (Date of signing)

Part III– Investigator's Statement

I, the undersigned, certify to the best of my knowledge that the patient/patient’s legally acceptable representative signing this informed consent form had the study fully explained and clearly understands the nature, risks and benefits of his/her / his ward’s / her ward’s participation in the study.

Name of Investigator  Signature  Date
Appendix B

Study 1: NUH PARTICIPANT INFORMATION SHEET

1. Study Information

Protocol Title:
Assessing the Psychosocial Functioning of Parents of Children Recently Diagnosed with Cancer or Chronic Illness and Offering Meaning-Focused Therapy

Principal Investigator & Contact Details:
A/Prof Wong Chee Meng, John
Department of Psychological Medicine
National University Hospital
Tel: 6772 2002

2. Purpose of the Research Study
You are invited to participate in a research study of parents’ distress when they receive their child’s diagnosis of cancer or a chronic illness. It is important to us that you first take time to read through and understand the information provided in this sheet. Nevertheless, before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are properly satisfied that you understand this study, and that you wish to take part in the study, you must sign this informed consent form. You will be given a copy of this consent form to take home with you.

You are invited because your child has recently been diagnosed with cancer or a relapse of cancer.

This study is carried out to find out if a simple screening tool can help us to identify and help parents who are very upset and stressed when they receive their child’s diagnosis of cancer.

This study will recruit 180 subjects from NUH, KKH, Children’s Cancer Foundation (CCF) and Club Rainbow over a period of 36 months. About 30 parents each will be recruited from the National University Hospital (NUH) and KKH.

3. What procedures will be followed in this study
If you agree to take part in this study, you will be asked to complete a set of six emotion thermometers, and then three questionnaires that measure depression, anxiety, post-traumatic stress symptoms, and sense of meaning in life. There will also be a few questions that ask you about yourself and your family. You may be invited to take part in Part 2 of the study if you report scores above 4 in the emotion thermometers. Your participation in the study will last 15 minutes.

4. Your Responsibilities in This Study
If you agree to participate in this study, you should:

▪ Fill up the questionnaires in the order given to you.
▪ Answer all the questions in the questionnaires, and as truthfully as you can. Please do
not spend too much time on each question.
Inform the Principal Investigator as soon as possible about any side effects that you may have encountered.

5. Withdrawal from Study

You are free to withdraw your consent and discontinue your participation at any time without prejudice to you or effect on your child’s medical care. If you decide to stop taking part in this study, you should tell the Principal Investigator.

Your doctor, and/or the Principal Investigator of this study may stop your participation in the study at any time for one or more of the following reasons:

- The Principal Investigator decides that continuing your participation could be harmful.
- You need treatment not allowed in the study.
- The study is cancelled.

6. What Is Not Standard Care or Experimental in This Study

The study is being conducted because the Emotion Thermometers are not yet proven to be a standard procedure in parents of children with cancer or a chronic illness. We hope that your participation will help us to determine whether the Emotion Thermometers are accurate enough to identify parents who are very upset or stressed about their child’s illness.

7. Possible Risks and Side Effects

- Filling up the questionnaires may take up 15 minutes of your time.
- Filling up the questionnaires may require you to recall experiences in the last four weeks, which may require some time.
- This may generate negative emotions if you recall upsetting or unpleasant experiences while completing the questionnaires. If you continue to feel distressed after completing the questionnaires, please do not hesitate to speak to your assigned social worker, your doctor, or the Principal Investigator.

8. Possible Benefits from Participating in the Study

There is no assurance you will benefit from this study. However, your participation may contribute to the wellbeing of other parents and the community through the use of the Emotion Thermometers. Parents who need help can receive it as soon as possible. Furthermore, because help can be given to parents quickly, they will be in a better position to take care of their children. In addition, because the Emotion Thermometers are very short, the hospital staff can not only help parents by directing them to receive help quickly, but also be able to concentrate on other important tasks such as the quality of care for the patients.

9. Alternatives to Participation

If you choose not to take part in this study, the alternative is to have what is considered standard care for your condition. In our institution this would be continued liaison with your assigned social worker from the Children’s Cancer Foundation. He/She will refer you to the relevant sources of support should you need it.

This procedure has the following potential benefits:

- You may access support from your Social Worker when you require it;
Your social worker will direct you to the relevant avenues of support.

And the following potential risks:

- Lengthier assessment process to ascertain the areas of support that you require;
- Longer waiting time for referral to psychosocial support (e.g., counsellors, support groups, etc);
- Possible emotional problems such as depression and anxiety may not be picked up as quickly, which may compromise your ability to comfort your child.

10. Costs & Payments if Participating in the Study

If you take part in this study, the following will be performed at no charge to you:

- Screening of emotional distress
- Interpretation of scores on screening measure and questionnaires

There is no reimbursement for your time, inconvenience and transportation costs.

11. Voluntary Participation

Your participation in this study is voluntary. You may stop participating in this study at any time. Your decision not to take part in this study or to stop your participation will not affect your child’s medical care or any benefits to which you and your child are entitled. If you decide to stop taking part in this study, you should tell the Principal Investigator.

Your doctor, the Investigator and/or the Sponsor of this study may stop your participation in the study at any time if they decide that it is in your best interests. They may also do this if you do not follow instructions required to complete the study adequately. If you have side effects or feel more distressed after completing the questionnaires, the doctor and/or nurse will decide if you may continue in the research study.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you will be informed in a timely manner by the Principal Investigator or his/her representative.

12. Compensation for Injury

If you follow the directions of the doctors in charge of this study and you are physically injured due to the trial procedure given under the plan for this study, NUH will pay the medical expenses for the treatment of that injury.

Payment for management of the normally expected consequences of your treatment will not be provided by NUH.

The National University Hospital (NUH) without legal commitment will compensate you for the injuries arising from your participation in the study without you having to prove NUH is at fault. There are however conditions and limitations to the extent of compensation provided. You may wish to discuss this with your Principal Investigator.

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

13. Confidentiality of Study and Medical Records
Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available.

However, the Regulatory Agencies, NHG Domain-Specific Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you are authorizing (i) collection, access to, use and storage of your “Personal Data, and (ii) disclosure to authorised service providers and relevant third parties.

“Personal Data” means data about you which makes you identifiable (i) from such data or (ii) from that data and other information which an organisation has or likely to have access. This includes medical conditions, medications, investigations and treatment history.

Research arising in the future, based on this Personal Data, will be subject to review by the relevant institutional review board.

By participating in this research study, you are confirming that you have read, understood and consent to the Personal Data Protection Notification available at http://www.nuhs.edu.sg/personal-data-protection/nuhsnuh-data-protection-policy.html.

Data collected and entered into the Case Report Forms are the property of the National University Hospital. In the event of any publication regarding this study, your identity will remain confidential.

14. Who To Contact if You Have Questions

If you have questions about this research study and your rights or in the case of any injuries during the course of this study, you may contact the Principal Investigator (A/Prof Wong Chee Meng, John, at 6772 2002).

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion of your rights as a research subject you may contact the NHG Domain Specific Review Board Secretariat at 6471-3266.

If you have any complaints about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

If you have any queries that need to be attended to urgently after hours you may contact the Co-Investigator (Ms Tay Yi Ling, at 9159 9515).
CONSENT FORM

Protocol Title:
Assessing the Psychosocial Functioning of Parents of Children Recently Diagnosed with Cancer or Chronic Illness and Offering Meaning-Focused Therapy

Principal Investigator & Contact Details:
A/Prof Wong Chee Meng, John
Department of Psychological Medicine
National University Hospital
Tel: 6772 2002

I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction.

By participating in this research study, I confirm that I have read, understood and consent to the National University Hospital’s Personal Data Protection Notification. I also consent to the use of my Personal Data for the purposes of engaging in related research arising in the future.

__________________               _____________________                   ____________
Name of Participant              Signature                      Date

Translator Information
The study has been explained to the participant / legally acceptable representative in Mandarin by Tay Yi Ling.

Witness Statement
I, the undersigned, certify to the best of my knowledge that the participant signing this informed consent form had the study fully explained in a language understood by him / her and clearly understands the nature, risks and benefits of his / her participation in the study.

__________________               _____________________                   ____________
Name of Witness              Signature                      Date

Investigator Statement
I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of her participation in the study.

__________________               _____________________                   ____________
Name of Investigator/Person administering consent  Signature                      Date
Appendix C

Study 1: CRS PARTICIPANT INFORMATION SHEET

HELP US TO SUPPORT PARENTS

Thank you for reading this Information Sheet. My name is Tay Yi Ling, and I am a Doctor of Clinical Psychology candidate at Murdoch University, Western Australia. This research is conducted under the supervision of Dr Angela Ebert and Dr Peter Drummond.

We are interested in the experience of parents whose children have been diagnosed with chronic illnesses. Many of these parents report loss of control over their lives, confusion and feeling overwhelmed. We want to support these parents. To enable us identify and support them, we invite you to help us develop a screening tool, which offers a simple way to assess distress. There are many benefits to this screening tool. Firstly, parents who need help can receive help as soon as possible. Secondly, because help can be given to parents quickly, it may be easier for them to take care of their children. Thirdly, because the screening procedure is very short, the case workers can not only help parents by directing them to receive help, but also be able to concentrate on other important tasks such as taking care of the children. What does this require from you?

You will first be asked to complete a set of six emotion thermometers, and then three questionnaires that measure your emotional well-being plus a few questions that ask you about yourself and your family. This will take about 15 minutes. Please note that as your responses would be helpful for your case worker to provide quality care for you, a brief summary of your results will be provided to him/her.

Should you feel uncomfortable with this, you may choose not to participate in the study. If you choose to participate in this study, your participation is strictly voluntary and you may withdraw from it at any time. Please also know that your decision to take part in this study has no impact on the quality of help you and your child receive at Club Rainbow. Your information is strictly confidential and will be stored under lock and key in Club Rainbow’s office.

Your participation can help us to understand how to best support parents in a very difficult situation. If you decide to participate in this research study, please read and sign the consent form provided.
This study has been approved by Murdoch University’s Human Research Committee (Approval 2012/08). If you have any reservation or complaint about the ethical conduct of this research, and wish to talk with an independent person, you may contact Murdoch University’s Research Ethics Office (Tel. +61 8 9360 6677 or e-mail ethics@murdoch.edu.au). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

Who to contact for more information about this study:

If you have any questions about this project please feel free to contact either myself, Tay Yi Ling on 9159 9515 (mobile) or my supervisor, Dr Angela Ebert, on +61 8 9360 1273 (office). My supervisor and I are happy to discuss with you any concerns you may have about this study.

THANK YOU FOR YOUR TIME
FORM OF CONSENT
(For Adult)

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I ................................................................................................................................. have read

Given Names                                                             Surname

the information explaining Study 1 of the study entitled Assessing Parents’ Level of Distress and Offering them Psychological Support.

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I understand that in participating in this study, my case worker will be given a brief summary of the results on the questionnaires.

I understand I may withdraw from the study at any stage and withdrawal will not interfere with routine care.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

I understand that all information provided by me is treated as confidential and will not be released by the researcher and case worker to a third party unless required to do so by law or if there is clear and imminent danger of harm to myself and/or others.

Dated ................................. day of ............................................................ 20 ..........

Signature ............................
..........................................................
I, ........................................................................... have explained the above to the
(Investigator’s full name)
signatory who stated that he/she understood the same.

Signature ........................................................................................................................................
## Appendix D

### Evaluation Checklist

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<td>1) Delivery</td>
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<tr>
<td>a. Were values identified?</td>
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<td>Yes</td>
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<td>b. How clear were values discussed?</td>
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<td>Direct</td>
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<td>Somewhat</td>
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<td>Vague</td>
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<td>c. Were meanings identified?</td>
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<td>Direct</td>
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<td>Subtle</td>
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<td>d. How clear were meanings discussed?</td>
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<td>Yes</td>
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<td>Somewhat</td>
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<td>No</td>
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<td>e. Focus of therapist on issues discussed</td>
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<tr>
<td>Direct</td>
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<td>Subtle</td>
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<td>Vague</td>
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<tr>
<td>f. Response of therapist to participant’s style of interaction (e.g., concrete style of thinking, reflective, pragmatic, etc)</td>
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<tr>
<td>Focused</td>
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<tr>
<td>Attended to immediate issues</td>
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<tr>
<td>Maintained usual style</td>
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2) Receipt of intervention

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<tr>
<th>Experiential exercises</th>
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<th>2</th>
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<th>4</th>
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<tr>
<td>a. Did the participant attend each session?</td>
<td>Yes</td>
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<td>b. Did the participant complete his/her homework/experiential exercise?</td>
<td>Yes</td>
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<td>c. Did the participant require prompting for the homework/experiential exercise?</td>
<td>Yes</td>
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<td>d. Did the participant require clarification for the homework/experiential exercise?</td>
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<td>e. Were the participant’s responses in line with the topic of the homework/experiential exercise?</td>
<td>Yes</td>
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<td>f. Length of participant’s discussion on values?</td>
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<tr>
<td>g. Depth of participant’s discussion on values?</td>
<td>Long/Thorough</td>
<td>3</td>
<td>Attended, no elaboration</td>
<td>4</td>
<td>5</td>
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<tr>
<td>h. Application of values outside of session?</td>
<td>Long/Thorough</td>
<td>3</td>
<td>Attended, no elaboration</td>
<td>4</td>
<td>5</td>
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<tr>
<td>i. Length of participant’s discussion on sense of meaning?</td>
<td>Discussed in detail</td>
<td>3</td>
<td>Mentioned, did not mention</td>
<td>4</td>
<td>5</td>
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<td>j. Depth of participant’s discussion on sense of meaning?</td>
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<td>k. Awareness of sense of meaning outside of session?</td>
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<td>j.</td>
<td>Long/Thorough</td>
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<td>k.</td>
<td>Short / Dismissive</td>
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Appendix E

Meaning-Focused Therapy Intervention Protocol

Session 1 – Introduction and Concepts of Meaning:

- Introduction (15 min)
  o Facilitator’s Name
    ▪ My credentials
  o Programme Overview: Brief explanation of the programme which includes:
    ▪ Number of sessions
    ▪ Length of sessions
    ▪ Structure of sessions
    ▪ Brief overview of the programme
      • E.g., This is undoubtedly a very difficult time for all of you. I am not exactly sure what is the most difficult part for each of you, but we know that with the diagnosis the child has been given, everyone’s life changes. There is no book that you can read to find out what is the best way through this difficult time. It can be a very lonely journey. Which is why we have this group. This group is set up to provide support and guidance for all of you so that this journey with your child’s illness is a little easier to navigate. To begin, perhaps we could start with you introducing yourselves”
  o Self-introduction (15 min)
    ▪ Name
    ▪ A few words about what has happened/what is now different in your life since the start of the diagnosis
    ▪ What has changed since your child’s illness?”
    ▪ “What do you find most difficult about your child’s illness?”
    ▪ “On a scale of 1-10, 1 being the least and 10 being the most, how would you rate the challenge you just spoke of?”
    ▪ “What do they mean to you?” or “Why are they so distressing/challenging?”
    ▪ “How have you managed to deal with these challenges?”
      • Validate feelings expressed
      • “Can you tell me what is going on inside you as you are sharing this with us?”
    ▪ Gather themes of discussion. Validation of experiences gone through (10 min)
  o Listen out for threats to parents’ meaning and common challenges, but don’t go into detail with them.
    o “What does it mean to you that your child has cancer/chronic illness?”
- Talking about emotions (15 min)
A lot of times, when we talk about our lives, especially difficult ones, we might find it difficult to express what we are feeling. It could be because of many reasons. One, because we have so many feelings inside that it’s difficult to describe. Two, it could be because we can’t find the words to describe it. For some of us, it might be because we feel we need to be strong in front of others, or we have no right to feel a particular feeling. But you know what? Human feelings are built into us with positive and negative emotions coming together to help us survive. If we block out our painful feelings, not only might we find that we can no longer experience other positive feelings such as love, compassion and happiness, we might also find ourselves feeling more and more lonely in our difficult situation. It is important to be aware of our feelings because it can help us to be clearer in our thinking, and also to communicate with others better.”

Give out facial expressions handout, ask participants which facial expression best represents how they are feeling right now, and also give a bit of background as to why they are feeling like that.

- “The facial expressions are just a guide to your emotions, but we would like to hear your inner experiences”
  - E.g., “Just now, we heard from you that many things can be happening inside you at the same time. I have printed out a sheet that shows facial expressions. I’m giving it to you as an aid, to see which one works for you. But it could be that none of these works for you, and it may just be a sensation in your body. So feel free to use any way to share with us what is happening inside you.”
  - Allow participants to describe how they want it. Including physiological descriptions (e.g., “knife in the heart”, “rock in the stomach”). Encourage any way participants feel fit to describe their inner experiences.
  - Explore participants’ experiences
    - “Have you experienced these before?”

Experiential exercise (40 min)

- “Has there been any time in caring for your child, when you have felt, ‘This is worth it, I know why I am here’?”
  - Explore the situations that provided meaning to participants, link them with values or areas important to them.
  - Explore how these experiences or moments were helpful to participants
  - Link back to their inner experiences earlier – in what way were those experiences different from these meaningful experiences?

Discussion of experience when receiving diagnosis

- What situations did they experience meaningfulness during their child’s diagnosis (or not)
- What made living with their child’s illness different from prior meaning in life?

  - Closure (5min)
    - Thanking them for their attendance
    - Reiterating the essential components of the programme and how it will be useful to them
    - Addressing any concerns

Session 2 – Values and Strengths:

- Review (10 min)
  - Of week
  - How are you today? Try to tie in conversations mentioned in the last session.
    - Not necessary to use facial expressions handout, if they prefer physiological descriptions, then encourage that
  - How they have been over the week.
  - What do they remember from the previous week

- Discussion of values, living a values-driven life. What is impeding leading this type of life? (35 min)
  - Confrontation with child’s cancer
    - “Last week, you shared your experiences of receiving your child’s diagnosis and caring for your child after that. We also talked about the areas that were particularly challenging for you and what it meant to you. Yet, despite all these challenges, you still continued on to look after your child as best as you can. what made you continue to take such good care of your child and your family?”
    - “What has been challenging in keeping you going?”
    - “What has kept you going?”
      - Gather strengths and values brought up through parents’ discussions. Link it to the previous session where parents discussed their challenges, to identify meanings/interpretations attached to their child’s illness or their reactions to it.
  - Experiential exercise (35 min):
    - List some important areas of your life where it feels you have some choice and control.
      - “What keeps you going when you meet with challenges in these areas?”
    - List some important areas in your life where it feels you have very little control.
      - “What did you do about these situations?”
  - Discussion of what their attitude is when they face challenges that are realistically beyond their control, and discussion of whether they would prefer to have a different attitude to these challenges.
“We have heard many stories of strengths and courage from you guys today. Most of them, as you might have realized, came from within yourself. In last week’s session and also just now, we also heard areas of challenges in your child’s illness which you felt you had little control over, and some of you expressed frustration about it. I wonder if we could also use the same strengths to try to face those uncontrollable situations?”

- Ask participants to hold these strengths in their minds as they think about the particular challenges they had faced while caring for their child.
- “On a scale of 1-10, 1 being the least and 10 being the most, how would you rate how challenging the situations are now?”

- Closure (10 min)
  - Thanking them for their attendance, summary of today’s session
  - Addressing any concerns

Session 3 – Experiential Sources of Meaning:

- Review (10 min)
  - Of week and tie in with conversations from last session.
  - What do they remember from the previous week
- “Last week, we discussed what keeps you going during tough times. We looked at things which helped to sustain you, we looked at values as a resource that helped you during difficult times.”
- “We can also be more active in life through our attitudes and being creative in managing our situation. Sometimes, even just observing things going on around us can be a source of meaning. These things can be love (e.g., enjoying the feeling of holding your child in your arms), beauty (e.g., your child’s smile), and humour (e.g., when your child does something funny) (50 min)”

  - Experiential exercise:
    - “In our first session, we talked about some of the challenges you face managing your child’s illness. During this time, I wonder if there were other times when things seemed better/more hopeful/brighter/you had felt like ‘This is worth it!’ or ‘This is possible’?”
      - “What happened at the time?”
      - “How was this different?”
      - “Now that you reflect on it, what did you make of that?” Help them make connections to meaning. Make use of all the material from the meetings with them.
      - “What difference did/does that make to you?”
      - “So how were you with your child at that time?”
        - That might have been a creative moment where parent may have behaved differently from usual.
• **“What is actually a creative moment? Can you see that as a creative moment?”**
• Begin a discussion about creativity.

- Homework: Think about moments of that kind, or think about another moment like that.
  - **“How was this different from the way you usually handle similar situations?”**
  - **“What do you think helped you handle the situation the way you did?”**
  - Try to look for similarities and differences between the way participants dealt with different situations. Even within the same participants, try to note if the way they dealt with challenges was the same or different.
    - If same, explore possible values that may have driven the actions
    - If different, explore difference between this situation and previous, as well as values that had driven the action.
      - Discuss flexibility in approach to problems as a form of creativity as well.

- Parents have now thought about the strengths they had used in the past to do things differently.
- Now think about how they can use these strengths to manage challenges in the here and now, or to live life they want to.
  - **“If you think about the everyday now, how do you think you could use what you have discovered, and how do you think you can use it from here on?”**
  - Note that some people may have been carrying on some of the strengths forward
    - “it strikes me that you have continued to use what you had discovered

- **Closure (10 min)**
  - Thanking them for their attendance
  - Addressing any concerns

**Session 4 – Creative Sources of Meaning and Conclusion:**

- **Review (10 min)**
  - Of week and tie in with conversations in the last session.
  - Bring out the facial expressions handout (or also Beanie Men), check in with how they feel at this moment.
  - What do they remember from the previous week
- **Creative means of managing child’s illness (30 min)**
“Last week, we talked about using the strengths you discovered to living life as fulfilling as we can while keeping in mind your child’s illness. Each of you also set up something to try out at home. How has that been?”
- Discuss any obstacles and/or successes
- Summary of activities done so far (20 min)
  - What are your hopes and plans forward?
- Closure (10 min)
  - Thanking them for their attendance
  - Addressing any concerns
- Reminder that they will be contacted in three months’ time for follow-up
Appendix F

Study 2: NUH INFORMED CONSENT FORM

1. Study Information

Protocol Title:
Assessing the Psychosocial Functioning of Parents of Children Recently Diagnosed with Cancer or Chronic Illness and Offering Meaning-Focused Therapy

Principal Investigator & Contact Details:
A/Prof Wong Chee Meng, John
Department of Psychological Medicine
National University Hospital
Tel: 6772 2002

2. Purpose of the Research Study

You are invited to participate in a research study of parents' distress when they receive their child's diagnosis of cancer or a chronic illness, or that their child has had a relapse. It is important to us that you first take time to read through and understand the information provided in this sheet. Nevertheless, before you take part in this research study, the study will be explained to you and you will be given the chance to ask questions. After you are properly satisfied that you understand this study, and that you wish to take part in the study, you must sign this informed consent form. You will be given a copy of this consent form to take home with you.

You are invited because you had indicated that you were upset or stressed by your child's diagnosis, or that you indicated that you would like some support.

This study is carried out to find out the benefits of two psychological therapies on reducing parents' distress and finding meaning in their new life situation.

This study will recruit 60 subjects from NUH, KK Women and Children's Hospital (KKH), Children's Cancer Foundation (CCF), and Club Rainbow over a period of 12 months. About 15 subjects will be recruited from NUH.

Please note that all your information is strictly confidential and will be stored under lock and key in NUH. Videos that are taken during the course of this study will be stored and analysed only for the purposes of this study for a period not exceeding six months, and will be destroyed after completion of the study. The video will be transcribed after each session for supervision and analysis purposes. There will be no identifying information within the transcript.

3. What procedures will be followed in this study

If you take part in this study, you will be randomly allocated to receive meaning-focused therapy, cognitive-behavioural treatment, or a treatment-as-usual group. Treatment-as-usual means that participants are offered the standard care offered by the hospital (explained
further in the section on alternative treatments). Both meaning-focused therapy and
cognitive-behavioural treatment will have four sessions each.

For participants who would like longer term support, there is a second option where they can
take part in the group that receives both forms of therapy. This means that they will attend
eight sessions of therapy.

Randomization means assigning you to one of three groups by chance, like tossing a coin or
rolling dice.

If you are allocated to the therapy group (cognitive-behavioural treatment or meaning-
focused therapy), you will be asked to attend a weekly therapy session, where you will
discuss your experience of your child’s illness and different ways of viewing your life, as well as
learn other coping skills that may be useful in your journey with your child.

Your participation in the study will last for four or eight weeks, depending on your choice. You
will attend a session each week for about four or eight weeks, each session lasting 1.5 hours. There will also be a follow-up in three months. For participants who were allocated to
the treatment-as-usual group, you will be contacted after the three months to receive either
meaning-focused therapy or cognitive-behavioural treatment.

Please note that for the purposes of supervision and analysis of the therapy outcomes, the
sessions will be video-recorded.

If you are allocated to the therapy group (cognitive-behavioural treatment or meaning-
focused therapy), the following will happen to you:

Visit 1: As soon as a group of four participants is found

Final Visit: (Week 4 or 8, depending on your choice of treatment): 4 visits in all if shorter
term of therapy is chosen; 8 visits in all if longer term of therapy is chosen. Each visit is made
weekly.

Follow-up: The follow-up part occurs 3 months after the end of the therapy, and consists of
a 15-minute session where you complete a set of questionnaires.

Participants allocated to the treatment-as-usual group will begin treatment (either meaning-
focused therapy or cognitive-behavioural treatment) after the follow-up.

In addition, you will be completing a set of questionnaires and a screening tool before and
after treatment. If you choose a shorter form of therapy (i.e., 4 weeks), you will complete the
questionnaires and screening tool 3 times. That is, you will complete the questionnaires and
screening tool at Visit 1, Visit 4, and 3 months after Visit 4. If you choose a longer form of
therapy (i.e., 8 weeks), you will complete the questionnaires and screening tool 4 times. That
is, you will complete the questionnaire and screening tool at Visit 1, Visit 4, Visit 8, and 3
months after Visit 8.

If you are willing, we would like to invite you to share your experience about being a
participant in this research study. This will be optional and will help us to understand which
components of the intervention were most useful to you. Please note that there is a separate
consent form if you would like to share your experiences with us.

4. Your Responsibilities in This Study

If you agree to participate in this study, you should:

- Participate in the group discussions and activities.
- Keep your study appointments. If it is necessary to miss an appointment, please contact
  the study staff to reschedule as soon as you know you will miss the appointment.
- Be prepared to visit the hospital four to eight times and undergo all the procedures that are outlined above.

5. Withdrawal from Study

You are free to withdraw your consent and discontinue your participation at any time without prejudice to you or effect on your child’s medical care. If you decide to stop taking part in this study, you should tell the Principal Investigator.

Your doctor, the Principal Investigator and/or the Sponsor of this study may stop your participation in the study at any time for one or more of the following reasons:

- Failure to follow the instructions of the Principal Investigator and/or study staff.
- The Principal Investigator decides that continuing your participation could be harmful.
- Failure to attend more than two sessions of the therapies.
- You need treatment not allowed in the study.
- The study is cancelled.

6. What Is Not Standard Care or Experimental in This Study

The study is being conducted because offering parents psychological support in the form of therapy is not yet proven to be a standard procedure for parents of children recently diagnosed with cancer. We hope that your participation will help us to determine whether it will be feasible and helpful to parents to participate in these therapy groups.

Use of randomization (study selection by chance) is only done for research studies. Although meaning-focused therapy and cognitive-behavioural therapy may be part of standard psychological treatments, in this study the combination of both these therapies are being performed for the purposes of the research.

7. Possible Risks and Side Effects

- Discussing your experience of caring for your child may be a stressful topic for you, and may arouse feelings of sadness, anger, or guilt. Please note that this is normal and part of the process of processing your difficulties.

- We understand that this is a very stressful period for you now. Some of the activities in the therapy sessions may need to be conducted at home, which may add to your commitments.

- As the therapy sessions are conducted in groups of 4, you may be asked to share your experiences during the session. This may bring about some discomfort for you. This is understandable and normal, because there are few chances in our surroundings where we share our personal experiences.

- Due to the group nature of the therapy sessions, there is a possibility that other group members will share the content of the therapy sessions with their family members. There may thus be a breach of privacy and confidentiality. Nonetheless, at the start of the session, we will encourage all participants to maintain the confidentiality of the group and to respect the privacy of the group members.

- Throughout the therapy sessions, unfamiliar and perhaps unpleasant feelings such as anger, guilt, and sadness may be persistent. This is understandable and normal, because you are going through a stressful period. These feelings may persist or increase in intensity.

8. Possible Benefits from Participating in the Study
If you participate in this study you may reasonably expect to benefit from the study intervention in the following way:

- It has been found that when people are able to find a different meaning in their life and learn to use suitable coping skills, they tend to feel less stressed and anxious.
- Feeling less stressed and anxious may enhance your ability to cope with more situations, and also help you to make use of your resources to look after your child and family.
- Learning to use suitable coping skills for different situations may enable you to adjust better in not only caring for your child, but for yourself and the other members of your family.

9. Alternatives to Participation

If you choose not to take part in this study, the alternative is to have what is considered standard care for your distress. In our institution this would be a referral to the Children’s Cancer Foundation (CCF).

This procedure has the following potential benefits:

- Your social worker will direct you to the relevant avenues of support.
- You will be provided with information and other resources on your child’s illness.

and the following potential risks:

- The emotions and thoughts that you may experience may not be processed completely, which may compromise your ability to comfort your child.

10. Costs & Payments if Participating in the Study

If you take part in this study, the following will be performed at no charge to you:

- Screening and assessment of your distress;
- Psychological intervention to reduce your distress.

There is no reimbursement for your time, inconvenience and transportation costs.

11. Voluntary Participation

Your participation in this study is entirely voluntary. Your questions will be answered clearly and to your satisfaction.

In the event of any new information becoming available that may be relevant to your willingness to continue in this study, you or your legal representative will be informed in a timely manner by the Principal Investigator or his/her representative.

By signing and participating in the study, you do not waive any of your legal rights to revoke your consent and withdraw from the study at any time.

12. Compensation for Injury

If you follow the directions of the doctors in charge of this study and you are physically injured due to the trial procedure given under the plan for this study, NUH will pay the medical expenses for the treatment of that injury.

Payment for the management of the normally expected consequences of your treatment will not be provided by NUH. By signing this consent form, you will not waive any of your legal
rights or release the parties involved in this study from liability for negligence.

NUH without legal commitment will compensate you for the injuries arising from your participation in the study without you having to prove NUH is at fault. There are however conditions and limitations to the extent of compensation provided. You may wish to discuss this with your Principal Investigator.

By signing this consent form, you will not waive any of your legal rights or release the parties involved in this study from liability for negligence.

13. Confidentiality of Study and Medical Records

Information collected for this study will be kept confidential. Your records, to the extent of the applicable laws and regulations, will not be made publicly available. Only your Investigator(s) will have access to the confidential information being collected.

However, the Regulatory Agencies, Institution Review Board and Ministry of Health will be granted direct access to your original medical records to check study procedures and data, without making any of your information public. By signing the Informed Consent Form attached, you or your legal representative is authorizing such access to your study and medical records.

Data collected and entered into the data analysis software are the property of NUH. In the event of any publication regarding this study, your identity will remain confidential.

14. Who To Contact if You Have Questions

If you have questions about this research study and your rights or in the case of any injuries during the course of this study, you may contact the Principal Investigator, A/Prof Wong Chee Meng, John, at 6772 2002.

The study has been reviewed by the NHG Domain Specific Review Board (the central ethics committee) for ethics approval.

If you want an independent opinion of your rights as a research subject you may contact the NHG Domain Specific Review Board Secretariat at 6471 3266.

If you have any complaints about this research study, you may contact the Principal Investigator or the NHG Domain Specific Review Board Secretariat.

If you have any questions about the study that need to be attended to urgently after hours you can call the Co-Investigator, Ms Tay Yi Ling, at 9159 9515.
CONSENT FORM

Protocol Title:
Assessing the Psychosocial Functioning of Parents of Children Recently Diagnosed with Cancer or Chronic Illness and Offering Meaning-Focused Therapy

Principal Investigator & Contact Details:
A/Prof Wong Chee Meng, John
Department of Psychological Medicine
National University Hospital
Tel: 6772 2002

I voluntarily consent to take part in this research study. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction.

__________________               _____________________               ____________
Name of Participant                  Signature                           Date

Witness Statement
I, the undersigned, certify to the best of my knowledge that the participant signing this informed consent form had the study fully explained in a language understood by him / her and clearly understands the nature, risks and benefits of his / her participation in the study.

__________________               _____________________                   ____________
Name of Witness                     Signature                           Date

Investigator Statement
I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of her participation in the study.

__________________                  _____________________                   ____________
Name of Investigator/Person administering consent  Signature                           Date
CONSENT FORM

Protocol Title:
Assessing the Psychosocial Functioning of Parents of Children Recently Diagnosed with Cancer or Chronic Illness and Offering Meaning-Focused Therapy

Principal Investigator & Contact Details:
A/Prof Wong Chee Meng, John
Department of Psychological Medicine
National University Hospital
Tel: 6772 2002

I voluntarily consent to take part in this research study to share my experience as a participant in the intervention. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction.

__________________               _____________________                   ____________
Name of Participant          Signature                          Date

Witness Statement
I, the undersigned, certify to the best of my knowledge that the participant signing this informed consent form had the study fully explained in a language understood by him / her and clearly understands the nature, risks and benefits of his / her participation in the study.

__________________               _____________________                   ____________
Name of Witness              Signature                          Date

Investigator Statement
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__________________               _____________________
Name of Investigator/Signature          Date
Person administering consent
CONSENT FORM

Protocol Title:
Assessing the Psychosocial Functioning of Parents of Children Recently Diagnosed with Cancer or Chronic Illness and Offering Meaning-Focused Therapy

Principal Investigator & Contact Details:
A/Prof Wong Chee Meng, John
Department of Psychological Medicine
National University Hospital
Tel: 6772 2002

I voluntarily give consent to the National University Hospital of Singapore ("Hospital") in my personal capacity to take videos of myself. I understand that and I do give my consent as aforesaid for the said videos to be used by Hospital authorities for record and academic purposes only. Further it is my understanding that the Hospital authorities shall use all reasonable endeavours to ensure that my identity and the identity of the ward will not be disclosed whenever such videos are reproduced or used in academic discussions/meetings and medical/scientific journals/publications. Pursuant thereto, I agree not to hold the Hospital authorities liable for any consequences that may follow such disclosures. I have fully discussed and understood the purpose and procedures of this study. This study has been explained to me in a language that I understand. I have been given enough time to ask any questions that I have about the study, and all my questions have been answered to my satisfaction.

__________________               _____________________                   ____________
Name of Participant                     Signature                          Date

Witness Statement

I, the undersigned, certify to the best of my knowledge that the participant signing this informed consent form had the study fully explained in a language understood by him / her and clearly understands the nature, risks and benefits of his / her participation in the study.

__________________               _____________________                   ____________
Name of Witness                     Signature                          Date

Investigator Statement

I, the undersigned, certify that I explained the study to the participant and to the best of my knowledge the participant signing this informed consent form clearly understands the nature, risks and benefits of her participation in the study.

__________________               _____________________                   ____________
Name of Investigator/             Signature                          Date
Person administering consent
Appendix G

Study 2: CRS PARTICIPANT INFORMATION SHEET

CAN WE HELP YOU?

Thank you for reading this Information Sheet. My name is Tay Yi Ling, and I am a Doctor of Clinical Psychology candidate at Murdoch University, Western Australia. This research is conducted under the supervision of Dr Angela Ebert and Dr Peter Drummond.

Adjusting to your child’s illness may be a very stressful time for you right now. You might be feeling that you need to be doing everything at the same time, and you have to continue to be strong because your family needs you. You might be experiencing feelings you might not be familiar with, or feel you should not feel emotions such as guilt, anger, or sadness. Your world may no longer be the same. Strategies that used to work for you may not work as well for you now as compared to the past. You might be interested in seeking extra support for yourself in managing all these challenges. All these are normal thoughts and feelings to have, and this study hopes to reduce your distress and help you to adjust better to your new life situation.

The purpose of this study is to compare two psychological therapies for reducing distress and finding meaning in this new life situation. One of the therapies aims to use the relationship between thoughts, emotions, and behaviour to manage difficult situations, as well as learn to use suitable coping skills. The other therapy aims to help parents find a different meaning in their life situation to enhance or find new coping strategies to manage the stress of taking care of their child. It is believed that when people are able to understand their situations better and are able to use suitable coping skills, they tend to feel less stressed and anxious, and may gain confidence to manage the current challenges as well as other stressful events in the future. In addition, the group format of the interventions may also help you realize that you are not the only one dealing with these challenges. Rather than choosing which therapy group to join, participants will be allocated to one of the two therapy groups. Each therapy comprises four sessions, each lasting 1.5 hours. In these sessions, participants will discuss their experience of their child’s illness and different ways of viewing life, as well as learn other coping skills that may be useful in the journey with your child.
Participants who would like longer term support may also like to consider taking part in the group that receives both forms of therapy. This means that they will attend eight sessions of therapy, each session lasting for 1.5 hours.

As this is a group intervention, we require a minimum of four participants to start each session. However, if we are unable to find sufficient participants within two weeks of your agreement to take part in Study 2, we will continue to go ahead.

We would also like to inform you that the sessions during the intervention will be video-recorded for supervision purposes and to make sure that the therapist keeps to the intervention guidelines. The videos will be transcribed and any identifying information will be destroyed before being sent for supervision. Please be assured that the recordings will be destroyed immediately after viewing. Please let us know if you would like to participate in the study but do not wish to be video-taped. Your decision will not affect the quality of care of your child. To measure the effectiveness of the therapies, you will be required to complete the emotion thermometers and questionnaires similar to that in the previous study. Please note that as your responses would be helpful for your case worker to provide quality care for you, a brief summary of your results will be provided to him/her.

Should you feel uncomfortable with this, you may choose not to participate in the study. If you choose to participate in this study, your participation is strictly voluntary and you may withdraw from it at any time. Please also know that your decision to take part in this study has no impact on the quality of help you and your child receive at Club Rainbow. Your information is strictly confidential and will be stored under lock and key in Club Rainbow’s office.

Your participation can help us to understand how to best support parents in a very difficult situation. If you decide to take part in this research study, please read and sign the consent form provided.

This study has been approved by Murdoch University’s Human Research Committee (Approval 2012/08). If you have any reservation or complaint about the ethical conduct of this research, and wish to talk with an independent person, you may contact Murdoch University’s Research Ethics Office (Tel. +61 8 9360 6677 or e-mail ethics@murdoch.edu.au). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.

**Who to contact for more information about this study:**

If you have any questions about this project please feel free to contact either myself, Tay Yi Ling on 9159 9515 (mobile) or my supervisor, Dr Angela Ebert, on +61 8 9360 1273 (office). My supervisor and I are happy to discuss with you any concerns you may have about this study.

**THANK YOU FOR YOUR TIME**
FORM OF CONSENT
(For Adult)

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I .......................................................................................................................................................................................... have read

Given Names                                                             Surname

the information explaining Study 2 of the study entitled Assessing Parents’ Level of Distress and Offering them Psychological Support.

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction.

I understand that in participating in this study, my case worker will be given a brief summary of the results on the questionnaires.

I understand I may withdraw from the study at any stage and withdrawal will not interfere with routine care.

I agree that research data gathered from the results of this study may be published, provided that names are not used.

I understand that all information provided by me is treated as confidential and will not be released by the researcher or case worker to a third party unless required to do so by law or if there is clear or imminent danger to myself and/or others.

Dated ........................................... day of ..................................................................................................... 20 ..........

Signature ............................................................................

I, ........................................................................................................... have explained the above to the

(Investigator’s full name)

signatory who stated that he/she understood the same.

Signature ..........................................................................................................................
FORM OF CONSENT
(For Adult)

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I .................................................................................................................................................. hereby give

Given Names .................................................. Surname

consent to Club Rainbow to take videos of myself. I understand that and I do give my consent as aforesaid for the said videos to be used for academic purposes only. Further it is my understanding that Club Rainbow shall use all reasonable endeavours to ensure that my identity and the identity of my child will not be disclosed whenever such videos are reproduced in academic discussions and medical/scientific journals/publicity/publications. Pursuant thereto, I agree not to hold Club Rainbow liable for any consequences that may follow any such disclosures.

Dated ........................................ day of ............................................................ 20 ..........

Signature ......................................................

I, ........................................................................................................................ have explained the above to the
(Investigator’s full name)

signatory who stated that he/she understood the same.

Signature ....................................................................................................................
In the first five columns, please mark the number (0-10) that best describes how much emotional upset you have been experiencing in the past week, including today. In the final column please indicate how much you need help for these concerns.

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