

MELBOURNE COLLEGE OF DIVINITY

**Christian Faith: Help or Hindrance
for Chronically Ill Patients
in Their Experience of Suffering?**

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Abstract

This thesis will address some key questions and approaches to spirituality and health care in the Australian context from the perspective of chaplaincy. It will explore the specific Christian religious experience of ten patients who suffer chronic, life-threatening illness, and then relate their experience to some writings of allied health practitioners. These strains of thought will be explored for congruencies and incongruencies in their materials and their relevance to the patients' experience. The hypothesis for the research was that patients' belief in the human sufferings of Jesus and their Christian relationship with him would have some impact on their experience of illness. It is also hypothesised that the presence and support of church as expressed in the chaplain would have some significance for their experience of suffering. Finally the findings will be related to the current and future practice of chaplaincy in the healthcare setting and some reflections will be made in regard to current practice and recommendations made for both church and healthcare organisations for future directions.

Chapter One: Approaches to Spirituality

Introduction

The aim of this research thesis was to explore how Christian faith helped or hindered patients in their experience of illness. The motivation for doing this research came out of more than a decade of experience as a healthcare chaplain within a secular institution. It also came out of a perceived need for healthcare chaplains to better understand the declared Christian faith of some patients, a faith which may not always be expressed in traditional orthodox ways, and to explore the way these patients' Christian spirituality informed their experience of suffering.

In the first two chapters I will explore and reflect on some Allied Health literature about spirituality and suffering. It is important to understand this as background to the theological reflection which will follow. The medical experience of the patients and the context for their hospital in-patient experience cannot be separated from theological reflection. Therefore chapter one will explore some literature in the Allied Health field on spirituality, as this is now perceived as an area in which other disciplines besides chaplaincy may legitimately have input. I will also examine some of the writing about spirituality in allied health journals, overseas and in Australia, and then look at the place of spiritual assessment in healthcare, and at assessment tools which may be used. The second chapter will explore some Allied Health literature on suffering, as this gives the backdrop to how those who care for these patients may understand the patients' experience. I will also discuss definitions of suffering, elements of suffering, aspects of personhood related to the understanding of suffering, and some aspects of coping with suffering.

The third chapter will describe the research methodology, and the findings from the research. The discussion is divided into two chapters, namely that of the core findings, and then in a separate chapter a discussion of the theological themes flowing from these findings. The theological reflection is closely related to that of the patients themselves raised, rather than texts or positions that I might introduce as a chaplain.

First of all, I would like to explore the nature of spirituality before turning to healthcare literature. Many people are capable of merely existing in life, of just taking one day after another without any conscious engagement with the process of living. I believe that spirituality is the conscious engagement of a person with the process of living. This may be at a low or high level of consciousness, from wondering how one will cope with the complexities of the day to engaging with the meaning of existence. Even a low level of consciousness in this process is the beginning of a potential engagement with ultimate values and meaning and therefore an ultimate Being, however one understands the nature of that Being. To define spirituality as a conscious engagement with the process of living helps to begin to understand patients who express such a wide variety of awareness of spiritual matters, both with and without declared religious affiliations or belief systems.

Schneiders understands the spiritual life as “the vital, ongoing interaction between the human spirit and the Spirit of God with both poles receiving equal attention.”¹ Social Workers are trained in “person in environment” skills and work with patients in the areas which relate to their

¹ Sandra Schneiders, “A Hermeneutical Approach to the Study of Christian Spirituality” in *Christian Spirituality Bulletin*, Spring 1994, p. 10

families, friends and other significant people in their lives. From this perspective social workers are seen to be attending to the human spirit dimension. Chaplains, on the other hand are more focused on the “Spirit of God” pole of Schneiders’ definition, where the goal would be to facilitate a person’s own understanding of their strengths in the dimension of their being which relates to a Higher Power, however that is understood. Chaplains also aim to facilitate the patients’ concern to access the strengths within them which integrate their relating to both poles of their spiritual life. This might take the form of ritual, prayer or sacrament, or just sharing together about beliefs. However, the ideal in maximising overall care of the patient is to have skilled professionals from both disciplines working together with patients and families.

Spirituality in Healthcare Literature

In this section I will 1) examine three definitions of spirituality taken from healthcare journals and work towards a clear definition, 2) explore some healthcare journal articles and their lack of appreciation of the sacred within an understanding of spirituality, 3) explore some articles about spiritual assessments, and examine the place of these instruments, 4) look at some of the impact of spiritual care being offered across the allied health discipline, and 5) briefly look at how this might be addressed organisationally. Throughout this section I will emphasise how important I think it is to keep an equal balance of attention to both the human spirit and the Spirit of God (Schneiders), believing that the patient in crisis is not well served if attention is only given to the humanistic dimension.

Definitions of Spirituality – Countryman’s understanding of spirituality is straightforward and useful. He writes that: “...spirituality resides, decisively, in the individual person, where it forms an inner and consensual relationship with Ultimate Truth or Absolute Reality or God or whatever metaphor one uses to name that Mystery that lies at the foundation of all that is.” But for those who are working in the Allied Health context I believe the term needs more explanation. He leaves out any reference to the dimension of meaning making, which may be an implied sequela; however, it needs to be stated.

A more specific definition of spirituality in healthcare literature which, while more complex, seems helpful, is that of Rees:

Specifically spirituality refers to the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual. This relatedness may be experienced intrapersonally (as a connectedness within oneself), interpersonally (in the context of others and the natural environment), and transpersonally (referring to a sense of relatedness to the unseen, God, or a power greater than the self and ordinary source)²

This is a helpful definition because Rees refers to some areas which are important to an understanding of spirituality, namely meaning making and transcendence, which add value and empower people. He puts these in the context of relationships with self, others and the sacred or unseen power. This relational aspect of spirituality is important in healthcare settings where patients are often uprooted from their relationships with loved ones and where there may also be little opportunity for rituals which connect with the sacred.

² McSherry, Wilfred, & Cash, Keith, “The language of spirituality: an emerging taxonomy” in *International Journal of Nursing Studies*. 41, 2004, p.156

The following definition which is expressed in broader terms, adds another dimension to the understanding of spirituality which Rees puts forward. Stoll writes:

Spirituality is my being; my inner person. It is who I am – unique and alive. It is me expressed through my body, my thinking, my feelings, my judgements and my creativity. My spirituality motivates me to choose meaningful relationships and pursuits. Through my spirituality I give and receive love; I respond to appreciate God, other people, a sunset, a symphony and spring. I am driven forward, sometimes because of pain, sometimes in spite of pain. Spirituality allows me to reflect on myself. I am a person because of my spirituality – motivated and enabled to value, to worship, and to communicate with the holy, the transcendent.³

The important point in this definition is that it names spirituality as integral to one's being, and illustrates how this being is to be nurtured by reflection and communication with the sacred or transcendent. It is the whole of our being which responds to God, people, nature etc., and is the motivating force of a person's life. I agree with Stoll that one's spirituality is what gives one the energy for life and it is important that people do reflect on their life circumstances. Stoll's definition could fit with a religious or non-religious spirituality, and it is significant amongst definitions in healthcare literature because it acknowledges the place of the divine or transcendent dimension in life. However, it is not implied that this spirituality needs any active input, just that it is a given, and I would question whether any spirituality could be sustained without some way of a person being actively and consciously nurturing it and engaged with it.

These definitions are quite complex ways of referring to that which animates a person and gives meaning to their lives. I believe that Schneiders' definition of spiritual life is more holistic: "The experience of consciously trying to integrate one's life in terms, not of isolation and self-

absorption, but of self-transcendence.”⁴ This need not necessarily refer to a transcendent being, but Schneiders writes in an article elsewhere:

Spirituality is concerned with the *spiritual* life which is today understood as the vital, ongoing interaction between the human spirit and the spirit of God with both poles receiving equal attention and the focus being on the fact, the modality, the process, the effects, the finality of the interaction itself.⁵

What is important here is Schneiders’ emphasis on the fact that both the humanistic and sacred dimensions need to be equally addressed in any spiritual endeavour, and that one is fully engaged in that endeavour. The reference she makes to the sacred or transcendent is often missing in definitions given of spirituality in healthcare journals, especially in Australia. How a person understands the sacred aspect of these two poles will vary tremendously, even amongst those who call themselves Christian, let alone among those who have a more eclectic spirituality.

My own definition of spirituality would be an amalgam of these definitions, namely, Spirituality, one’s way of being, is a conscious integration of one’s life and meaning, being nourished by relating to and beyond oneself to others, and to the sacred. If a patient were to be asked about what has helped them to cope with their illness, they may give a clear picture of their spirituality without realising it. Similarly, to ask someone what it is that makes them get out of bed in the morning may be enlightening as to what is the animating force or spirit in their life. This may or may not refer to any element of sacred or transcendence, but there may be some transcendence of the self, maybe in their self-giving attitude to their families or loved ones.

⁴ This was taken from notes of a lecture by M.Confoy, and quoted from Sandra.Schneiders, *Beyond Patching*,73)

⁵ Sandra Schneiders, “A Hermeneutical Approach to the Study of Christian Spirituality”, in *Christian Spirituality Bulletin* Spring, 1994. 10

Spirituality and the Sacred in Healthcare Journals: The current writing about spirituality in healthcare journals comes mostly from the United States of America. While it is necessary for everyone who works in healthcare to be aware of what might nurture a person's being, there is very little clarity about the nature of spirituality in its duality of addressing both the human and sacred. Healthcare journals often refer to religious faith, but do not seem to allow for a faith in God which may be present but is not practised within a religious faith community.

Understanding that this core element of spirituality is important in the journey of healing is something which is lacking in the healthcare journals. Apart from reference to religious faith, healthcare literature seems to concentrate on the more humanistic aspect of spirituality, and while that is important it is not the totality. A concern for chaplains is that the sacred dimension is being forgotten, and omitted, and this may leave many patients without the support they need at a faith level.⁶

Some of this lack of clarity about spirituality may be due to the fact that this is an area which has only relatively recently come to the fore at the expense of belief in religion, which might preciously have been given attention in healthcare. What needs to be underscored in this transition time is that the sacred or transcendental element of spirituality not be lost. It is perhaps easy to understand how, in a setting of medical science, where the emphasis is primarily on the physical body and mind there is also an emphasis on the humanistic element of spirituality.⁷

⁶ This kind of thinking is reflected in conversations about essential criteria for chaplains, and whether being grounded in any faith tradition is an essential for the worker themselves. It is a concern for me that if we lose the transcendent and sacred dimension of what we offer, we will not serve our patients well who are looking for help in terms of their faith struggle or resourcing their faith as strength.

⁷ In this thesis it is an integrated understanding of the person that is used, rather than a divided one. In an essay on scriptural anthropology Wilken has written about the essential nature of humankind being understood by the church fathers as both body and soul, and that these cannot be separated. See Robert Louis Wilken "Biblical Humanism:

Attempts are sometimes made to explain spirituality exclusively in sociological or psychological terms. These terms may seem easier to explain and understand than the transcendent, which is the area of mystery.

In healthcare literature more and more references are being made to spirituality as a positive force for the patient to resource as part of their healing process. Spirituality is also named as an aspect to be taken into account in the holistic care of the sick, i.e. it is a recommended part of nursing assessments and care. Often the term spirituality is used in a very loose way, without any real understanding of what is being referred to. One example of this can be found in an article in the journal *Holistic Nursing Practice* in an article referring to an instrument for assessing patients' spiritual needs.⁸ In this example the authors look at seven major constructs for assessing spiritual needs, and these "constructs" are: belonging, meaning, hope, the sacred, morality, beauty, and acceptance of dying. While the authors state that their assessment tool is inclusive of traditional religion as well as "non-institutional spirituality" there is very little acknowledgement of or reference to the transcendent, or the divine in these "constructs". The "sacred" aspect may be behind all of these "constructs", but may not be perceived as such unless the person administering the assessment tool is personally attuned to such matters.

The concern for me, and drawing on some common examples from my own pastoral practice, is that most people are able to nourish a sense of spiritual well-being when things are going well in

The Patristic Convictions." *Personal Identity in Theological Perspective*. Ed. Richard Lints, Michael S. Horton, and Mark R. Talbot. William B. Eerdmans Publishing Company: Grand Rapids, Michigan, Cambridge, U.K., 2006. Pp.25-27

⁸ Kathleen Galek, Kevin Flannelly, Adam Vine, Rose Galek, "Assessing a patient's spiritual needs: A Comprehensive instrument", *Holistic Nursing Practice* 19 (2) (2005), 62 (I have only been able to reference the abstract for this article)

their lives by finding their meaning and motivation in their family or in nature. However this may not be enough to sustain them when they are pushed beyond their own resources by severe negative events in their lives. Family may offer something in the way of spiritual nurture if the patients are able to transcend themselves in a way that they can give their lives for their family or vice versa, but this may not be so if they are needing the family in a way the family is unable to respond to. To ignore the Spirit-of-God pole, to refer back to Schneiders, does not give a person anywhere to look for strength beyond themselves when in their weakness they are no longer able to transcend anything without the gift of grace.

An example of this inability to transcend circumstances was a patient, “Ian” who was suffering from renal failure, which was only going to get worse with time. His whole life and meaning revolved around his family and his personal role of being the carer and provider as husband and father. Unfortunately, as he became more and more unwell, he began to see himself as more of a burden on the family than a provider. With no other perspective, such as a divine “bigger picture”, he had no other way of re-framing his sense of meaning, and he was starting to think that the best way he could now help his family was to end his life and not be any further burden to them. His spiritual need was to find some meaning and worth in his inner being rather than just in what he did, or how he provided for his family.

Spiritual Assessment and its Place: It is very important for allied health workers, as well as chaplains, to be aware of the cultural dimension which may accompany a religious faith, and so it may be important for social workers to do a spiritual assessment for every patient. However I do not agree with Moore that they should also necessarily be working with negative spiritual issues such as spiritual oppression, or positive ideas or practices which the worker might then be

able to encourage the client to use to work through their current situation.⁹ While I believe that social workers should be very aware of cultural and religious issues, e.g. whether Moslem patients have the opportunities for their prayers or religious dietary requirements, I believe that issues of “spiritual oppression” and suchlike, are more complex than a social worker would ordinarily have the training to deal with, and therefore I believe that where there are negative spiritual issues referral should be made to chaplaincy. Other health care professionals may well be able to deal with spiritual issues, but complex spiritual and religious issues need to be referred to those who have specialised training in these complexities, namely chaplains.

An article in *Oncology Nursing Forum* gave recognition to the divine aspect of spirituality. They gave a definition of spiritual well-being as “the affirmation of life in a relationship with God, self, community, and environment that nurtures and celebrates wholeness”¹⁰ and this was seen as having two parts, namely the relationship of the person with God (religious well-being) and the person’s “satisfaction and purpose with life” (existential well-being).¹¹ This seems a more comprehensive understanding of spirituality. However it does presume that the patient will be practising some religious faith, and approximately fifty per cent of the patient population in the health care institution in which I work state that they have no “declared religious affiliation”. That does not necessarily mean that these patients do not have a faith in a higher power or in God, and chaplains must wait to hear what the beliefs and ultimate values are for each patient and family member. In this communal understanding of belief it is also important that social

⁹ Robert Moore, “Spiritual Assessment”, *Social Work*, Oct 48 (4) (2003), 558-565.

¹⁰ Cited from National Interfaith Coalition on Aging. In “Intrinsic and Extrinsic Religiosity, Spiritual Well-Being, and Attitudes towards Spiritual Care”, *Oncology Nursing Forum* Nov. 2004; 31 (6) p.1180.

¹¹ Catherine Musgrave, Elizabeth McFarlane, “Intrinsic and Extrinsic Religiosity, Spiritual Well-Being, and Attitudes Toward Spiritual Care: A Comparison of Israeli Jewish Oncology Nurses’ Scores”, *Oncology Nursing Forum*, 31 (6) (2004), pp. 1179-1183.

workers understand something of the patient's spirituality, as it is one aspect of their social networks and support system.

The Joint Commission on Accreditation of Healthcare organisations (the body which accredits hospitals in the USA) now recommends that spiritual assessments be the normal practice. There are a few practical reasons for doing this which enable better healthcare delivery. One example of this might be that knowledge that a patient is a practising Moslem, for example, would mean that it would be inappropriate to offer medication which has an alcohol base. Also, a preliminary assessment might indicate whether a more thorough assessment might be necessary. One reason for a more thorough assessment might be if spirituality/religion is central for a patient. This might indicate that it could be important for a devout Catholic to receive regular communion, or provision be made for a Moslem to be able to pray five times a day at the required times. These are important reasons which would seem to feed into a positive atmosphere for healing for these people.

There might also be a more negative reason for a thorough assessment, such as to ascertain whether a Pentecostal patient who might naturally describe hearing God speaking with him and telling him what to do, and who was also suffering from schizophrenia, was hearing voices as part of his illness or as a part of his religious practice.¹² It might also be important to refer to chaplaincy a Pentecostal Christian patient whose health was failing, as this might trigger a faith crisis.

¹² David Hodge, "Developing a spiritual Assessment Toolbox: A Discussion of the Strengths and Limitations of Five Different Assessment Methods, *Health and Social Work*, Nov 30 (4) (2005), pp. 314-323

I am not suggesting that spiritual assessments not be done by nurses and allied health workers, but I believe it is of paramount importance that we find a tool which will enable the exploration of the sacred pole as well as the human pole of spirituality. If such an instrument could be found, it might allow the other health workers to alert chaplains to patients who need religious or spiritual support as a part of their “treatment plan”. In Hodge’s review of spiritual assessment methodologies, he describes some common instruments. One of these is for the social worker to take a spiritual history, much like taking a family history. In this way they hope to discover the public and private beliefs and practices of the patient, and also the significance of those beliefs.¹³ Fitchett, a chaplain researcher in the United States, has devised a “7 x 7” model, which is a complete bio-psycho-social-spiritual assessment.¹⁴ These methods are very thorough, but they are time consuming, and therefore unlikely to be workable in a busy institution which stretches the resources of chaplaincy and social work.

The Association for Clinical Pastoral Education in the U.S.A. has developed a model they base on the acronym FACT. This explores the **F**act of their lives which is related to belief or spirituality; the **A**vailability or accessibility of this belief in terms of how they access what they need to apply this belief or spirituality; **C** is related to how their belief or spirituality helps them cope with their medical situation; and the **T**reatment plan is in relation to their beliefs and ways chaplaincy can support the patient. The most important aspect to taking this spiritual history, apart from respecting the patient’s beliefs, is not so much what it is they believe, but how it

¹³ David Hodge, “Spiritual Assessment: A review of major qualitative methods and a new framework for assessing spirituality” in *Social Work*, 46 (2001), pp.2-3.

¹⁴ George Fitchett, *Assessing Spiritual Needs*, Augsburg Press, 199, p. 3

impacts on the way they cope with their illness, and how much it is integrated into the whole of their life and not just to a practice which helps at times.¹⁵

The importance of understanding patients' spirituality, whether it is religious or humanist, is that it gives staff, and especially chaplaincy, the opportunity and insights to support the person at a depth which may also feed into other coping mechanisms if their belief and spirituality is integrated. This support may take the form of ritual, either church-based ritual or one which the chaplain crafts for the patient and situation. Ritual can speak deeper than words, and may have a great impact for the patient.

Impact of Spiritual Care Offered by All Allied Health Workers: Within the acute healthcare setting, it may well be appropriate for members of the staff other than chaplains to offer spiritual care. However, my concern is that a lot of the talk about spirituality within allied health journals leaves out the recognition of a power which is higher or more comprehensive than the self, and I believe this understanding has evolved as spiritual care has devolved to other allied health disciplines. This non-theistic spirituality is likely to fail when a patient is driven beyond their own resources or ability to cope. Patients will often describe, as one of the ways they use to cope in normal life, that they find release from stress and a new lease of life by walking in the bush, or getting in touch with nature, for example. That may serve them adequately when they are well enough to do that, and it is only the need to de-stress which is the issue. However, when that same person is confined to one room with limited visitors for six to eight weeks to receive a Bone Marrow Transplant, for example, there is no chance of walking anywhere near any nature

¹⁵ www.acpe.com. This is the website for the American Association for Clinical Pastoral Education and this assessment tool is recommended on this website. The Austin Hospital uses a slightly different version to assess all Liver Transplant patients before they go on the Transplant listing.

or even having flowers in the room for many weeks, and they may often have nothing else to draw on. It seems that at times like that, some people experience the need to have access to resources beyond themselves, to a higher power, so they can look beyond themselves for help and strength. In these kinds of more complex spiritual issues I believe it is necessary for allied health professionals to both recognise the complexity and then make a referral to chaplains.

As one approach to this devolution of pastoral care to other allied health professionals, The Alfred has moved away from calling Pastoral Care to relatives who are distressed at the death of a family member, and the call is now generally made to the departments of Social Work or Clinical Psychology, unless there is a very specific request for some religious rite or prayers. This 'pathologising' of natural grief has been something which has developed over the last ten years or so, and seems to fit in with a medical culture and mindset. While it is certainly true that grief work is something which many disciplines deal with across the hospital, and I don't claim that working with relatives at the time of death is necessarily specific to chaplaincy or pastoral care, it is interesting to note the shift in this approach, and in certain other aspects of coping with illness and death in the acute healthcare setting. If some sort of spiritual assessment had been done for these patients, it might mean that the allied health professional which was best suited to their spirituality might be called. This may in fact be a psychologist if the patient or family demonstrate that their belief system is more allied with science than any religious belief system. My argument is that the approach should be an informed response rather than based on an administrative procedure. The referral should be made by reference to the patient's expressed interests.

The understanding of a non-theistic spirituality raises a key question for chaplains, namely how to raise the possibility of spiritual help which acknowledges a transcendent being, in a way that patients may be able to access. Chaplains must at all times be respectful of the faith or spiritual understanding of the patient. Perhaps one way is to use an image from nature, if that is their love, and to explore with the patient whether there might be a life-force or higher power of nature behind the inherent strength of the tree. Otherwise chaplains might use the technique of explaining how they turn to God or prayer when they are in a difficult position, so that they are talking about themselves and not being critical of the patient's stance. The patient might also be asked if religious faith has any part in their life, and chaplains may suggest that for some people this gives them a higher power to turn to when they need it. It can be a fine balance between an acceptance of the other and their spiritual position while suggesting other possibilities which might be helpful.

It has become more popular in healthcare literature to address the issue of spirituality as something that might impact on a patient's experience of illness and what might be necessary for a patient in their recovery process. Ellison and Levin write that religion has been shown by epidemiologists to have some protective mechanism from illness, and that it may promote mental health.¹⁶ Humanist spirituality, theistic or eclectic spirituality and religious belief and practice all promote the exploration of ultimate value and meaning within life, and a sense of self-esteem which relates to a healthy way of coping with negative events, such as illness and accident.

“there is mounting evidence that religious cognitions and behaviours can offer effective

¹⁶ Ellison & Levin, “The Religion-Health Connection: Evidence, Theory and Future Directions” in *Health Education & Behaviour*. Vol 25 (6): Dec. 1998, p.701-2

resources for dealing with stressful events and conditions. Coping with stress, in turn, has been shown to be a powerful factor in both preventing disease and hastening recovery from illness.”¹⁷

In my practice as a healthcare chaplain I would generally agree with Ellison and Levin about the significance of religion, but I want to expand their concept to include people with a theistic spirituality, that is to say, a belief in a Being which is greater than them, a transcendent Being, however they understand that Being, and also to include those who believe in God but do not practice their faith in a religious setting. It is those patients who are unaware of any spiritual resources or who do not believe in a power greater than humanity, (for example those people who find their spirit revitalised by nature or for whom family is what gives their life its meaning,) who may find that their spirituality is not able to offer them any nurture or strength when they are stressed beyond their own resources to cope. The example written about earlier of the renal failure patient who felt that suicide was the only way he could help his family is an example of a person for whom the beliefs and values which had given him meaning were not adequate to support him at the time in his life when he most needed help to cope with his illness.

Nursing and other Allied Health journals are beginning to address patient care in a holistic way, and they now look at spiritual assessment as part of the complete assessment of a patient’s needs on admission to the ward. In an article entitled “Spiritual Care of Chronically Ill Patients” Narayanasamy writes that illness may leave a person in spiritual distress which is described as “an imbalance or disharmony of mind, body and spirit” and proceeds to list the features of spirituality associated with chronic illness, namely:

¹⁷ *ibid.*, 707.

1. “disorganisation and disruption” – this is related to the impact of the illness and the social isolation of hospitalisation;
2. the “search for meaning” – this may include both a search for some meaning within the illness itself, as well as an overall meaning for the person’s life and reason for being;
3. “spiritual encounter” – physical illness can become a spiritual encounter as the patient finds a way to cope with the illness;
4. “hope and strength” – a sense of hope, which encompasses ultimate values, will give a person strength to cope with the illness;
5. “love and harmonious relationships” – this is as important as the search for meaning, and a person who is suffering will need unconditional love. This may come from immediate family and close friends, but may also be offered by caring staff members;
6. “other spiritual resources” – strength may be drawn from spiritual practices such as meditation or receiving Holy Communion as well as emotional support from others.¹⁸

I would suggest that these spiritual issues are just as relevant to patients admitted to acute healthcare facilities, because they relate to the life transition the patient is making. This may be a temporary transition if the illness is able to be overcome, but it may also be a more permanent transition, as with the patients in this research. An outline such as this may be an excellent tool for training other health professionals to recognise spiritual issues so they can make referrals to chaplains when appropriate.

This aspect of general nursing care is a far cry from the traditional nursing practice in Australia, and the Australian nursing and other allied health journals suggest that at present this interest in spiritual care of patients is greater in the United States of America and Great Britain than it is in Australia. The culture within the healthcare institution in which I work has a general understanding of spirituality that does not seem to include the transcendent dimension, and this understanding is borne out in journal articles, or the lack of them that reflect on transcendent spirituality and its impact on the experience of illness in Australia. If the practitioner, be they

¹⁸ Narayanasamy, Aru, “Spiritual Care of Chronically Ill Patients” in *British Journal of Nursing*. Vol 5 (7) 1996. pp.412 - 413

nurse or social worker, is not open to the spiritual dimension themselves, it is unlikely that they will hear the sacred or transcendent dimension within the ordinary life of the patient. It is interesting to note that nurses who have a respect for religious faith are the ones who make referrals to Pastoral Care. This is a difficulty which overflows into spiritual care across the allied health spectrum where workers are not trained to hear nuances of spirituality or religious faith, nor are they trained to be attuned to them with patients. This may reflect a gap in nursing education as well as a lack of individual sensitivity. Ideally, chaplains might lead a seminar when health care trainees are doing their placements within the hospital. On such occasions the trainees would have some patient examples to reflect on with the chaplain.

When students come to the CPE Centre where I supervise to do Clinical Pastoral Education (CPE) it is interesting to see how initially, because they do not have a trained ear or the skills and confidence to explore faith issues, they can end up closing down the patient's conversation about faith more than helping them. By the end of the CPE Unit the students are just beginning to work well with patients and be of help to them in their spiritual and faith journey. If it takes people who are committed to the spiritual life three to four months to begin to learn these skills, how can we expect other health professionals to just have them? Therefore, while I am not against other professionals administering a spiritual assessment tool I believe it needs trained pastoral care workers and chaplains to work with the results.

Australian Writing on Spirituality in Healthcare Literature: I have left writing about Australian healthcare literature until last because spirituality has arisen primarily out of American and British thinking and practice. Australian thinking on the subject of spirituality within healthcare is at a very early stage, and is still finding its Australian expression.

One Australian who wrote about this is Professor Susan Ronaldson who has edited a book called *Spirituality the Heart of Nursing*. In this she writes of her own spiritual awakening as a nurse:

This spiritual awakening occurred as I was drying the feet of an elderly man residing in a large aged-care facility in north-east Victoria. ... For a brief moment in time I was struck by the translucency and radiance of the thin, pale, aged skin on this man's feet. This caring act represented to me the service role of nursing. I then understood at a very deep level that I was both immensely privileged and humbled to possess the skills to perform such a relatively simple, yet enormously important, act of caring. I was performing a most valuable human task – being at one with the needs of this undemanding and vulnerable elderly man. Much later I was to recognize this was an experience of 'vernacular spirituality', an appreciation of the sacred in the ordinary.¹⁹

I have quoted this at length because it demonstrates "sacred in the ordinary," which offers both a Christian and a transcendent spiritual perspective.

In the above example, I believe Ronaldson is talking about an experience which was emotionally powerful and motivating for her in her nursing practice. But I believe deep feeling is sometimes confused with spirituality, and expectation can be that what makes us "feel good" is therefore something spiritual. I believe the inclusive experience that is being described by Ronaldson could be described as a humanistic spirituality, in that she expresses the experience of self-transcendence and can be relating to a Higher Power in general or to the Divine as expressed religiously.

There is a danger in applying a twentieth century understanding of non-religious spirituality to past writings where the author was seen to be deeply religious. Fry, in her chapter in *Spirituality the Heart of Nursing* writes about the religious origins which gave birth to modern nursing, such

¹⁹ Ronaldson, Susan , Ed. *Spirituality The Heart of Nursing* Ausmed Publications: Melbourne, 1997. pp.1-2.

as the work of the medieval religious orders and of Florence Nightingale, who was a deeply religious Anglican woman. Fry writes that “Nightingale believed that spirituality is intrinsic to human nature and is our deepest and most potent resource for healing”.²⁰ That is a very twentieth century understanding of an eighteenth century religious mindset, which would not have seen spirituality as separate from belief in God and God’s healing power. She also quotes Nightingale as saying “Work your true work and you will find God within you” and describes this as a “spiritual approach to work”.²¹ It seems to me that it is a deeply religious approach to work, and not to be separated out from God, and Fry is attempting to offer an inclusively spiritual approach as well as a religious one.

This kind of interpretation raises questions about the transition in understanding from a religious spirituality (in Nightingale) to a generic spirituality. Fry writes that there is confusion in semantics in nursing literature which confuses religion and spirituality²², and it seems she is prone to a similar misunderstanding. It may be a contemporary issue as this generation struggles to find its own language about spirituality, and those working in healthcare need to find their own language rather than borrowing a religious language which does not connect with the patients they work with.

²⁰ Ibid., 8

²¹ Ibid., 14.

²² Ibid., 8

Another religious reference which leaves out the sacred dimension is Hall's chapter on "Nurses as Wounded Healers" where she refers to three great figures in history who were wounded healers, namely Aesclepius the Greek god of medicine, Christ and the Buddha.²³ She writes:

After the initial wounding each healer undertook a journey which involved trial and suffering. In the case of Christ, the journey also involved underworld time, a place which represents the soul. Eventually, through assistance from the higher self or spirit, the journey was completed and healing in the form of transformation to the highest state of being was experienced. From this basis, as divine or enlightened beings, they went on to heal many others.²⁴

While I am in agreement with Hall that by getting in touch with their own vulnerability, nurses will be able to stand alongside their patients with a greater sense of empathy and compassion, it is not clear that it is an easy transition.

I wonder whether spirituality is a term which has come to be applied to a mindset which tries to connect with the patient as a fellow human being rather than as a professional who is more distanced. The "beauty and strength of the human spirit" will come across in nursing care as a giving of the self, and a listening to the other's "situation and feelings inweakness". The carer who knows their own weakness rather than stands above it can lead to a deep human sharing which may be named as spirituality by some.²⁵

Nurturing this humanistic spirituality is then an area that chaplains also need to be attentive to. The social climate of some of our communities is also less likely to nourish spirituality in many instances. Whereas an older generation was more likely to have been exposed to a religious tradition as a child and maybe practiced their religion, many of the younger generation have had

²³ *ibid.*, 25

²⁴ *ibid.*, 26

²⁵ *ibid.*, 65

little or no exposure to religious faith and expression, and so they may have little to fall back on when they are in personal crisis. Many patients who are middle-aged or older have told me that they pray every night although they never go to church. However, they have some knowledge of a higher being to whom they can turn when their own resources are not sufficient.

Much of the late adulthood generation's faith or the young adult generation's exploration of spirituality is difficult to nurture, because there are not the opportunities for communal sharing of or connecting with religious wisdom and experience within our society. Currently, there is much writing in healthcare literature which almost sounds like a religious way of nurturing one's faith:

The spirituality of nurses and their work has a delicate balance. A high level of spirituality is realized not by the amount of work we accomplish but rather the purity of heart by which we seek and love the sacred/higher reality, however we define it. The development of spirituality is thus described as a maturation process which requires quality time for quiet reflection. Working to extremes retards spiritual development because quality time and quiet reflection tend to be undervalued and neglected. Work is not a substitute for spiritual development, even if we are particularly good at it. The notion of doing one's duty in productive work should not become excessive 'busyness' to the exclusion of balance in life.²⁶

This raises the question of what one is actually expected to reflect on. What is quality time in this context? Is it just to have periods where one's mind and body is relaxed, or is it important to spend this quality time on something which is important in one's life, for example, relationships or improving oneself intellectually? These are subjects which we as chaplains in healthcare address with staff as we go about our work, usually in an informal way, but sometimes also more formally when we talk at staff unit meetings or as part of a staff service in the Spirituality Centre.

²⁶ *ibid.*, 17

Summary

In this chapter I have explored some healthcare literature in the area of spirituality in order that it might inform chaplaincy to some extent about the patient responses to the research interviews, and also to understand the position of many of the healthcare professionals who care for these patients. Patients have not read theological or religious treatises any more than they have studied healthcare journals, but both areas of writing have something to offer in the exploration of the relationship of suffering and Christian faith in coping with that suffering.

There is a need to develop a spirituality which is clear and relevant for those who work in healthcare which will also shape the philosophy of our acute healthcare institutions. In this chapter, I have reviewed the current writing on spirituality in Australian healthcare, showing there is still a reliance on the language of Christian spirituality, while interpreting the language very differently. An Australian spirituality will also be different to an American or British spirituality, and may well contain elements of acceptance of adversity, toughing it out, giving everyone a fair go, and maybe the outback will give its expression a particular flavour.

Chapter Two: Suffering & Personhood

In this chapter I propose my understanding of suffering, and then I explore elements of suffering, some aspects of personhood related to understanding suffering, and then examine some aspects of the ways people cope with suffering in light of their faith or spirituality.

In order to explore the importance of Christian faith for patients who are suffering an experience of illness, it will be necessary to explore the nature of suffering. *The Concise Oxford Dictionary*²⁷ defines “suffer” as to “undergo pain, grief, damage etc. or to undergo, experience, or be subjected to (pain, loss, grief, defeat, change etc)”, and that its etiology is from the Latin root *suffere* meaning to bear. This is to define suffering more in terms of what happens to a person, rather than the ontological experience of suffering itself. The term needs further clarification in the healthcare context because for some people to undergo pain does not necessarily mean that they suffer, and conversely, someone who is in no physical pain may suffer acutely.

Another definition offered by Sparks takes well-being into account: “suffering may be defined as any experience that impinges on an individual’s or a community’s sense of well-being.”²⁸ This is a more ontological definition, but Cassell broadens the definition of suffering even further when he writes that it is “a state of severe distress associated with events that threaten the intactness of the person”.²⁹ This latter definition is the one I prefer to work with as healthcare chaplain

²⁷ R.E Allen, *The Concise Oxford Dictionary of Current English*. Clarendon Press: Oxford, 1990, eighth edition.

²⁸ R.Sparks, “Suffering”, *The New Dictionary of Catholic Spirituality* (1993), pp. 950-953.

²⁹ Cassell, Eric J, *The Nature of Suffering and the Goals of Medicine* Oxford University Press: New York, London, 1991. p.33

because it allows the exploration of all forms of suffering, psychological, spiritual, physical and existential, and also gives a position from which to explore why something may cause suffering to one person but not another. Cassell also writes that “suffering is experienced by persons, not the mind or spirit”,³⁰ which is why it is a better definition for use in this context, as it affirms that we are whole persons, not made up of parts which can be separated off or isolated from the whole self. If a person suffers it means that there is some aspect of who they are as a person which is under threat, and this is an existential suffering, which affects people at the very depth of their being.

Further, Cassell writes that many modern medical practitioners treat the disease rather than the person, and that this treatment can sometimes end up causing suffering whereas the original disease did not. An example of this from my own practice is that of a patient who was admitted to our healthcare facility with what was diagnosed as terminal cancer with metastases. The oncologists decided that palliative care was the most appropriate care for this woman who did not have long to live. The patient was accepting of her death, and seemed peaceful about that treatment regime. However, the oncologists then offered her an aggressive palliative care regime, including chemotherapy, surgery and radiotherapy to improve the quality of the life she still had. Consequently she became quite anxious and suffered terribly both psychologically and spiritually. She had come from the country where she lived a quiet tranquil life, and where death of livestock is a part of everyday life, and something she could accept, and she did not seem to have any spiritual or psychological resources within her to cope with the onslaught of aggressive treatment which appeared to leave her no “space” to come to terms with this invasive regime.

³⁰ Cassell, p.32

A chaplain was called to the ward several times to help her cope during panic attacks, and deep breathing and prayer was used to help her regain her sense of being able to cope. The pace and nature of the acute hospital seemed to threaten her sense of self as a tranquil, spiritual person, and the noise around her and the many people did not give her a place where she could re-connect with herself as she perceived herself to be, or with God, and so she could not regain her inner strength.

Elements of suffering

It is helpful to use Cassell's exploration of suffering in order to understand some of the elements which the research participants allude to. Suffering is such a personal thing and therefore can only really be understood by the person who experiences it, and it will be experienced differently by each person.³¹

- i) There are many elements which contribute to something being perceived as suffering, and it will depend on how it is seen by the person in terms of their being as a whole person e.g. sportsmen will normally suffer more from a leg amputation than scholars because it is part of their identity as a person.³²
- ii) Suffering is a very personal thing, and so can really only be appreciated and known by the person who is suffering. Therefore suffering can be a very isolating experience.³³

³¹ Cassell, 1991, p.35

³² Ibid., p.35

³³ Ibid., p.35. See also Elaine Scary, *The Body in Pain*, Oxford University Press: Oxford, 1985. Pp.3-59.

- iii) Pain may be one aspect but pain itself need not be a form of suffering. Pain can become suffering if the person believes that it is not going to be able to be relieved by drugs. Fear is an important dimension of pain which can mean it becomes suffering for the person.³⁴
- iv) If pain has an element which threatens to diminish a person's existence as they now know it, then usually there will be some degree of suffering. There is a temporal dimension of pain in that if a person perceives that pain will affect their future, or their perception of the future, this then becomes suffering. The element of fear is then focused on the patient's future.³⁵
- v) Suffering can become an additional element of pain or illness when a patient does not feel listened to by their physician.³⁶
- vi) If suffering seems to have no meaning or value but is experienced as totally random and useless, there will be an added dimension to the suffering.³⁷
- vii) In chronic illness, the threat to a person's integrity can be more difficult to identify. Their sense of diminishment as a person will invade all aspects of their life, including their family and social life, and there will be no end to it this side of death.³⁸ In chronic illness, people are not usually removed from their daily living routines, but they have the new element of not being able to do or be all that they once were able to. Because they are mixing with family and friends, they may still try to live up to the expectations of their life prior to illness, and so their life may now seem to be one of always letting themselves and others down.³⁹

³⁴ Ibid., p.36

³⁵ Ibid.

³⁶ Ibid.

³⁷ Ibid., p.37

³⁸ Ibid.

³⁹ Ibid., p.53

Christians believe that human beings are created to be relational (Gen.2: 18, 21-23) and therefore have a need to share their experiences in life. Isolation is seen as less than the ideal, and some would see it as a product of the Fall. In whatever way people understand the experience spiritually, isolation is a very real aspect of suffering, and therefore, for Christians, the importance of believing in God or Jesus as with them in their isolation can be extremely important. This understanding flows into an understanding of the way a chaplain, as a representative of God, can also accompany someone in their journey of suffering. This belief is related to my first research hypothesis, namely that the fact of Jesus' suffering would be important to Christian patients in their experience of suffering.

Often the chaplain can be safer to share pain with, because, unlike family members, there is no need to protect them as they do their loved ones. While chaplains cannot have a total understanding of the suffering involved for each particular person, they will be trained to listen with care and without judgement, in such a way that the patient can feel safe in their sharing. To feel heard, even if not totally understood, is of paramount importance to people, and can give a sense of validating patients' experience of suffering. However, in so many ways people who undergo chronic illness can feel that the medical "system" and professionals within it can be dismissive of what they are going through, and this can feel both diminishing and shaming, and may lead to a depressed feeling and sense of worthlessness.

My own experience has shown ways in which our basic human survival needs override religious faith many times, when patients are faced with the struggle for breath and life. I believe it is also one aspect of the grief that relatives feel when someone they love dies, as their emotions

temporarily override the Christian faith they have about death and resurrection. I do not believe this is a comment about a person's lack of faith so much as an example of our very human process of experiencing suffering. People with extraordinary faith can override their natural human instincts, but I do not believe that this is or should be the norm for all religious believers.

Aspects of Personhood: Cassell lists five elements of personhood,⁴⁰ namely personality, life story, past events, family and cultural background.⁴¹ It is unclear from the text what Cassell means by personality, but perhaps, as a medical practitioner, he is referring to our genetic makeup and disposition. These are all elements which make up our personhood. His understanding of the term seems to leave out the inner elements of meaning and story-making which people engage in for themselves to make sense of their own experiences. Such processes will usually turn out to be something unique to the individual, not just a product of their external environment. For this reason I add religion or spirituality to the understanding of personhood, as that element which gives the person meaning in their life. While religion may be seen as another external environment, personal spirituality and the meaning derived within that will be a unique dimension to the individual, which can never be replicated or fully understood by another. As a Christian I describe this as the divine Spirit, an aspect of being created in God's image.

(Gen.1:27RSV)

⁴⁰ Personhood can be understood in various ways, including legal, social, ethical and theological. In this context I am using a theological understanding of a person being created in God's image, and including all aspects of their being i.e. psychological, rational, physical and spiritual.

⁴¹ See 1991, 37. I believe these aspects of personhood are more a description of the components that go towards the formation of a person, rather than the essence of what a person is. Christian theology would see a person as reflective of God in that each person is created in God's image God. (See Gen.1: 27).

Relationships with others and the self are also important.⁴² It is obvious how the loss of a relationship can be perceived as a loss of a part of one's being. Divorcées and widows, as well as losing their partner, may also lose a perception of themselves as a partner, and part of the suffering is that loss of perception of self, as well as the grief and the work of learning to be a single person again.

The role we have in life is also important in self-perception. This loss of role is often a very real part of illness, for example, when a woman is no longer able to continue as the family nurturer, or a man in the role of provider and protector. To the extent that our role in life is seen as part of who we are as a person, it is part of the way we relate intrapersonally. Relationship with oneself is an element of personhood that is not always given much attention.⁴³

In illness, there are often expectations of how to cope, and if there is a perception of having let oneself down or that one's behaviour has changed, then there will be some suffering as a result because it may be perceived as failure.

Coping with Suffering: What is the hope for those who are suffering? Cassell quotes Alistair MacIntyre when he writes that "hope is ... a belief in a reality that transcends what is available as evidence."⁴⁴ There are two levels of hope, one which is about the immediate, such as hoping to get better, and the other is an eschatological hope, which is the kind MacIntyre is referring to in this definition. There has recently been some research done to explore what it is that might enable some patients to cope better than others, and the "Resilience Theory" which has come out of that study hints at an eschatological hope as the clue.

⁴² Role theory uses the 'social role' to help in the understanding of relationships and personality, and is one way of explaining ways of interacting with others. See Malcolm Payne, *Modern Social Work Theory*, second Edition, 1997.

⁴³ Cassell, 1991, 41

⁴⁴ Cassell, 1991, 43

Resilience Theory understands that the saying “suffering is good for us” can sometimes be true; negative assaults on our person can lead to growth as a person. There is now much work being done in the area of *Resilience Theory* as some social workers and psychologists realise that most of the time people do cope with amazing odds, and that their (i.e. the practitioners) energies had been unbalanced in studying those few whose suffering was more than they could have been expected to cope with and therefore were not coping well. Cassell explains resilience in terms of a person withdrawing an inner force from one manifestation of person and redirecting it towards another manifestation. Such a person rebuilds their life.⁴⁵ Participant Six demonstrated this very clearly when she found another way to be a mother. She also sought to find meaning in her random suffering, looking to Jesus who was also God as a fellow sufferer. Richardson writes about resilience:

There are three phases of resilient reintegration after a significant disruption or adverse life event; 1) the developmental building up of protective factors, 2) the process of reintegration after disruption, and 3) the force which drives a person to grow through adversity. It is this third phase which requires a great deal of energy to grow, “and the source of that energy, according to Resilience Theory, is a spiritual source or innate energy.”⁴⁶

This is important for chaplains and pastoral carers to bear in mind. Cassell’s comment about transcendence is that it is the most powerful way of overcoming suffering as it relates to the “bigger picture” of their lives and can be a way of becoming whole.⁴⁷ The question for those in chaplaincy is how to enable some growth towards this in patients and help them reach out

⁴⁵ Cassell, 1991, 44

⁴⁶ Richardson, Glenn E, “The Metatheory of Resilience and Resiliency” in *Journal of Clinical Psychiatry*. Vol 58 (3), 307-321 (2002).

⁴⁷ Cassell, 1991, 45

beyond themselves either to other people or to their God.⁴⁸ The word “wholeness” is one I use with patients regularly, because I believe that there can be a level of healing within their person which may or may not be expressed in physical healing. This is often seen in people who are dying.

The role of pastoral care and chaplaincy might also be to allow those who are suffering to gain strength from them until they regain their own strength again.⁴⁹ That is, if they can allow themselves to be “held” emotionally and spiritually while they feel fragmented, it can be a less stressful and anxious time. The chaplain can talk to them about holding them in prayer when they feel too tired and weak to pray for themselves. While they are allowed to express feelings at a deep level, it is also important to help the person feel that there is some containment, some safety, that they are being “held” within limits and that they will not be allowed to just “disintegrate” totally.

Spiritual Assessment and Strength: David Hodge, in writing about spiritual assessment tools for social workers, argues that clients’ spirituality can be an important strength in their overcoming of their present predicament. Assessment is critical to the incorporation of patients’ strengths into the therapeutic milieu. Hodge sees these strengths as related to;

a) a faith in a Higher Being which might give a sense of not being isolated, a sense of purpose in life, and giving a sense of personal worth or value;

b) rituals, which might alleviate anxiety, loneliness, and give a sense of security;

⁴⁸ Williams writes of this in terms of moving from victimhood to an understanding that one’s suffering is part of all human suffering, and therefore transcending one’s own sense of being “locked in” to particular suffering to recognising oneself as part of the whole human community.

⁴⁹ Cassell, 1991, p.45

c) participation in a faith-based community which can give a sense of belonging, being loveable and self-confidence;

d) the cognitive element of faith can help a person to feel loved unconditionally, and can give some framework to find meaning within suffering;

e) a faith framework generally gives a person a way to relieve a sense of guilt.⁵⁰

This framework for spirituality seems to be based on the premise of the first point, and is therefore almost a roadmap for chaplains rather than allied health practitioners to work with. However not every spiritual belief relates so strongly to such a sense of a higher being and the life that flows out from such a faith.

In addition to identification, spiritual strengths must be organised into a conceptual framework that suggests particular interventions. Gathering data is not an assessment in itself; the information must be interpreted, organised, integrated with theory, and made meaningful.

Accordingly, “assessment is defined as the process of gathering, analysing, and synthesizing salient data into a multidimensional formulation that provides the basis for action decisions.”⁵¹

Hodge relates this to resilience theory in that he is looking for the person’s strengths to work with, not propping up their weaknesses in a crisis.

The difficulty here is that unless we as practitioners are standing alongside our clients within the faith perspective, it can seem very intrusive and almost inappropriate. Most chaplains can do this sort of assessment in a less formal way as they talk with patients and families, who relate their

⁵⁰ *ibid.*, 208.

⁵¹ *ibid.*, 204

faith journey to strengths which they can call on. We can stand alongside the patients in offering rituals, or share an understanding of the other's faith and reliance on their God, and what this may mean in their experience of illness. Spirituality should be an integral part of holistic hospital experience and therefore, ideally, I would recommend that there be enough chaplains on staff within healthcare institutions,⁵² so that these kinds of assessments could be made on every patient admitted. It would then be possible to work with the patient and staff in providing an atmosphere where these spiritual/religious strengths could be nurtured and encouraged.

Relief of suffering: I will now explore some ways in which chaplains can assist in the relief of suffering. Cassell describes four strategies to relieve suffering:

- 1) to live in the present moment, because much of suffering is the fear of an anticipated future;
- 2) to learn to rise above what is happening as regards one's illness, in the way Eastern philosophies teach;
- 3) to deny the implications and impact of one's illness; and
- 4) to be flexible, that is, to replace in importance the aspect of oneself which is under threat.⁵³

Of these, I believe the first and last are particularly useful in a healthcare context, whereas the second and third would be beyond the ability of most people. Certainly if a patient's expectation, having been diagnosed with cancer, for example, is that they will face years of uncontrollable pain, then their mental suffering will be almost unbearable. If someone can sit with them, and help them to stay in the present when their pain is controlled and the doctors are listening to their

⁵² The Constitution of the World Health Organisation defines health as "...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity". *WHO Constitution*, 45th edition, 2006. Spiritual well-being is an aspect of "well-being" which I believe is also tacitly alluded to in the *WHO Ottawa Charter for Health*, 1986, in which it is written that health is "resource for everyday life, not the objective of living." In order for spirituality to be a part of a person's health resource, it needs to be able to be accessed and respected within the healthcare setting.

⁵³ Cassell, 1991, pp. 60-61

pain tolerance, then the rest of the illness will seem more able to be lived through. The last point is more difficult for people, but maybe it is possible with help from another to re-vision their image of themselves and to see another aspect of their being as more important. A person's belief system may be very important in this sort of re-visioning, perhaps seeing the inner life as becoming of prime importance rather than remaining locked into the physical aspect of their being. As an example, the chaplain may try to encourage the frail elderly to see how important their 'being' is as a person, especially if the person currently sees usefulness as their top priority or contribution to family or society.

I have learned anecdotally that many respiratory patients do very much live out of a philosophy of taking one day at a time. They seem to discover from the experience of their chronic illness that they will have both good days and bad days and these are unpredictable; but on the bad days they know that better ones will come again. Chaplains may have the opportunity to sit with patients and help them as they process the new experience of their illness, and help them connect with their own wisdom and affirm it.

I suspect that for people in this country who are of a Christian background, the second point of Cassell will be important but will be played out differently. Their spirituality may mean that they believe that God is giving them every help to bear their illness, and they consequently may have an acceptance of God's will, whatever suffering that may mean for them. Chaplains will be important to attend to such believers within the hospital context. In this sense Hodge is right to assess a patient's needs for these resources from chaplaincy.

There is much written in medical and nursing journals about suffering to either help patients in their illness or help staff cope with stress, but almost nothing about religious faith or spirituality in this context, hence the need for this current research. I believe that the Christian faith has much to offer Christians in terms of transcending and transforming the experience of suffering. Some of the ways this is experienced by patients will be observed and reflected on in the two chapters on the research and theological reflection.

Psychological Understanding of Suffering: My work with students in pastoral care as a Clinical Pastoral Education (CPE) supervisor illustrates that the students who are best able to sit with the suffering of others are those who have experienced some suffering in their own lives, and have processed it so that they can appreciate their strengths and the insights into people and benefits they have gained. They are not afraid of others' suffering, because they have suffered themselves, and know there can be hope of growth and new life in that place. They may be wounded people, but their wounds have healed enough so that they have some healthy "scar tissue" which has grown over their woundedness to protect them.

Pascal writes that psychological pain is a positive thing if only we can learn to interpret the signals and learn the meaning of that psychic pain.⁵⁴ He believes people suffer because they run away from pain rather than facing it and learning from it. This has been demonstrated many times by patients who only find peace when they can accept their illness. This can be true of CPE interns when they can accept aspects of their being which cause pain. They may need some support to enable growth both in their personal lives and in their ministry. These students also

⁵⁴ Pascal, *Jung*, p. 13

need to accept that patients' illness is a given and often cannot be changed or 'fixed', and that they need to meet the patient within the place of their illness.

This is relevant to all practitioners in the field of chaplaincy. For many patients their illness or accident is not an integrated part of their being. It is right, using a medical model, that illness is foreign to their sense of "wellness" and therefore it needs to be fought, and indeed military language of fighting is often used by medical staff. However, if the patient is to achieve "wholeness" a need to integrate their illness into their being can be experienced.

Chaplains work in a way that is counter-cultural to the medical scientific milieu of the modern hospital. In helping some patients to accept illness, this does not mean that they do not encourage them to try to overcome the illness and recover. However, even if patients fully recover from their medical event, the illness or accident is now a part of their life journey and needs to be integrated into the meaning of the whole life journey. Someone who fully recovers from cancer can hardly dismiss their brush with cancer and therefore, with the possibility of death. It needs to be faced, and the fact of recovery and a new chance to live also needs to be accepted.

Many people quote sayings about suffering making one stronger. "What doesn't kill you makes you stronger, right?" many patients say. Not necessarily! But it does offer an opportunity for reflection and growth. Perhaps this is one reason why people are open to chaplains working with them while they are ill in hospital. They are in pain at some level of their being, whereas when they are well they are often resistant to looking at their lives in any reflective and meaningful way. Patients' physical pain may lead to an awareness of a pain at the depth of their very being which almost demands to be addressed at such a time.

In many traditions (e.g. American Sioux Indians) suffering is deliberately sought to induce a higher level of consciousness and to facilitate a more intimate relationship with the spirits. However, in modern Western culture, pain is mostly avoided, and pain medication is taken for the slightest ache or pain. Many westerners believe that it is only a distorted understanding of the Christian tradition that uses suffering as a valuable means to an end, and there have been times in the history of the Church where suffering has been sought in an unhelpful way.⁵⁵ But the belief in the mystery of the life, death and resurrection of Jesus is at the heart of the Christian faith. This does not mean that suffering is sought, but it is necessary to understand that it can be integrated into Christian life.

The way religious faith and practice is used to transcend suffering can go some way to explain how some people cope with suffering, but this is not the case for every Christian or religious person. In prayer and ritual a person can become aware of their spiritual nature and closeness to God, and people may also be enabled to come to terms with their suffering by relating it to a redemptive purpose of God, or at least to find meaning and purpose to their suffering within their faith framework.

Summary

In this chapter I have explored the understanding of suffering as written about by a medical practitioner, a social worker and a psychologist. These medical understandings of suffering will

⁵⁵ Pascal quotes a story of the Buddha to demonstrate some wisdom related to suffering. A young woman who was overwhelmed with grief at the deaths of her husband and son was set a task by the Buddha to go and search for a family who had not experienced any grief or loss. This allowed her to see that suffering is the lot of every human person as she couldn't find anyone who had never suffered loss. She was able to move beyond her own suffering by understanding that everyone suffers in life. This can be important for patients to grasp so that they do not allow their own suffering to get bogged down in the smaller picture of their own existence alone, but can be seen as part of a bigger picture for humanity. Christians may have a more comprehensive understanding of the place of suffering which is related to that of Jesus' suffering, and the whole paschal mystery of death and new life.

be relevant to the ways patients describe their suffering and this will become more apparent when I describe the findings, especially the patients' answers to a question directly related to how they suffer.

Chapter Three: Research Methodology

Section 1 - Introduction

This study came out of life experience, both personal and professional. It was clear that the research question could not be related to personal experience, so it was necessary to clarify which aspect of the professional work of healthcare chaplaincy was to be explored in this research. The focus was to be on the experience of patients in their illness, or the way the intern chaplains who were trained in Clinical Pastoral Education at the hospital dealt with the suffering of those they ministered to. The former was a priority as it was hoped it would help those in healthcare chaplaincy to understand patients better and thus improve their efficacy in ministry. Formulation of the way to research the patients' experience of illness, and what that meant in the context of their Christian faith was the next step.

Section 2 – Hypotheses

Chaplains at the hospital are trained in theology and therefore have certain expectations about the ways in which Christian faith will help patients in their lived experience of illness. However, anecdotal evidence suggests that patients have their own understanding of their faith and what might be most helpful to them. Moreover, sometimes their Christian faith can be a risk factor and work in a negative way in their recovery process.

It is the intention of this preliminary exploration to help chaplains to have more understanding of patients and the ways their faith informs their experience of illness and suffering.

The hypotheses or questions which the researcher framed to explore patients' understanding of their faith in relation to their experience of illness were:

- that the belief in Jesus who suffered would be important in their experience of illness;
- that it would be important to the patient that the community of faith was with them in their illness, either through prayers, visits from their parish priest/minister or parishioners, or as represented by the presence of a chaplain;
- that some beliefs of participants might be unhelpful in their illness and impact on them in a negative way as they experienced their illness.

Section 3 - Method

There were three perspectives to understanding suffering in the context of healthcare chaplaincy. The first was to try to get a clear understanding from patients of their experience of illness and whether their Christian faith helped them or not. If it had helped, then in what ways was it helpful. The second was to use theological reflection to try to understand at a deeper level the place of suffering in the Christian tradition. Finally the investigation of allied health journals in relation to the spirituality and suffering was undertaken.

The discipline of clinical research is not one that is familiar to chaplains as it does not form part of the training. This project was therefore novel in the field of healthcare-based chaplaincy. There have been studies done in Australia which look at patient outcomes as a result of chaplaincy services to patients, but no studies have examined the impact of a patient's theological or spiritual understanding of their experience of being severely and chronically ill.⁵⁶

⁵⁶ E.g. Holmes & Carey, *Pastoral Care and Chaplaincy Provision within Metropolitan Health and Aged Care Services in the State of Victoria*, December, 2005.

Chaplaincy experience was used in the design of the research project. It was recognized that patients who experiencing illness which was acute and of sudden onset, would be in a certain amount of shock, and struggling to come to terms with the sudden change of events in their lives. In contrast, patients who have a chronic illness, and may have had several hospital admissions over a number of years, have had time to process their experience of illness and what it might mean in their lives, and the ways they are able to cope with it, and such patients would therefore be in a better position to answer research questions.

Ethics Applications were submitted for the hospital, as research was to be conducted with their patients, and also the Melbourne College of Divinity as part of this thesis research. Ethics approval from the hospital was for six months from November 2005 to May 2006. A total of ten patients were interviewed. All interviews were taped and later transcribed. During the interview with Participant Number Four, the tape recorder slipped off the bed and the patient grabbed it, inadvertently turning it off. This was not noticed until it came time to transcribe the tape. She has been kept in the statistics because she consented in good faith.

There were a total of six refusals, which is 37.5% of all patients who were asked, and all of these had initially told their chaplain they were willing to participate. However when the study was explained to three people, they immediately withdrew, giving no reason. Another woman talked about it with her husband overnight, and then stated that she didn't think she could do it because she wasn't very religious and it was her family who were important to her not her religion. Two other participants had faced life-threatening events recently, and while wanting to be helpful in

the research project, just found it would be too much. One young woman withdrew herself, and the researcher suggested to other that he withdraw and work with a chaplain.

The patients were approached as they were admitted to the clinical units which were included in the entry criteria, and so represent a sequential group of patients. The three denominations of Roman Catholic, Anglican (Church of England) and Uniting Church were chosen because they are representative of the Christian faith and it was important for research purposes to limit as many variables in the patient sample as possible. The hospital has chaplains from these three denominations and so the researcher was able to include these chaplains in the identification and initial request for approach to potential participants, and follow up care if that was required after the interview.

As part of the inclusion criteria patients needed to come from either the chronic heart failure or respiratory failure clinics, as symptomatology for these two conditions can be quite similar i.e. shortness of breath and fatigue, although the underlying aetiology is very different. This was also to limit variables in the patient sample as much as possible.

This therefore is an exploratory prospective study using sequential admissions of patients. As an employee of this healthcare facility meant that the researcher had access to information about patients, such as their clinic and stated religious affiliation. This question is generally asked on their admission to hospital. The researcher was able to identify potential participants, the respective denominational chaplain made a preliminary visit to explore the patients' interest, and if they were willing, the researcher explained the study and left a Plain Language Statement with

the patient. This was followed up the next day by written consent and the interview. The interview was taped and later transcribed.

Inclusion/exclusion criteria: Participants needed to be aged eighteen years or over, and mentally competent. Their English needed to be good enough to understand the interview questions. Participants were patients who identified themselves as being from specific Christian denominations (Catholic, Anglican (Church of England) and Uniting Church), and had chronic respiratory or cardiac illness. Patients from these medical units have been chosen because they have longer hospital stays and similar symptomatology. A convenience sample of 10 participants was selected from these particular religious and medical groups to minimize variation within the sample. Those who did not fit in to these categories were excluded so as to minimize variables and enhance commonality.

Data Analysis

The method of analysis which was chosen was thematically based on grounded theory. This was seen as the more appropriate method because an inductive approach could be used, and it was important in this research to learn from the patients, not to come with a deductive theory which would be made to fit the findings.⁵⁷

The interviews were taped and transcribed, and then analyzed on the first examination for common answers and expressions (open coding). The second stage of analysis was to look again at the data and group common answers more rigorously into themes which started to emerge

⁵⁷ P.Liamputtong and D.Ezzy, *Qualitative Research Methods*, Melbourne: Oxford University Press, 2005. p.265

(axial coding). The final stage of analysis (selective coding) was to look for a more general or “core theme” which unified or summarized all the themes.⁵⁸

Section 4 - Study Site and Patient Profile

The study site is the healthcare facility in which the researcher is employed as a chaplain. The Alfred is a major metropolitan tertiary hospital, and has the highest acuity and degree of specialization in the country. Most of the admissions are emergency rather than elective, and because it has the largest Trauma Centre in the country, many of those admissions are related to traumatic events.

Many of the patients with chronic heart and lung disease are referred to this hospital because of the Heart-Lung Transplant Unit, and some of the patients interviewed may in fact be offered transplant as a treatment option at some stage. This background is important in order to understand the nature of the patients who were eligible for the current study. They are a group of chronically ill but also extremely medically complex patients, who may have come to this facility because of the specialties and are therefore likely to be some distance from their families and support systems.

Within this healthcare facility there are chaplains who service the Anglican, Catholic and Uniting Church patients. This gave a secure back-up for follow-up care if any of the participants were to get distressed as a result of the interview, or if the interview caused them to think about their situation in a new way. The researcher did in fact refer one participant on to their denominational

⁵⁸ Liamputtong & Ezzy, *Research* pp. 268-9

chaplain following an interview, as the patient had identified a matter which it was felt needed following up.

Section 5: Findings

This section outlines the sub-themes which were identified in the process of thematic analysis of the patient interviews. Each question from the interview will be written about in a separate section, and then the overarching themes will be outlined in a final section.

Question One - Demographic Findings (n = 10)

The age range of participants was 33 years to 78 years, with the mean average age being 56.5 years of age. There were two participants in their thirties, four in their fifties, one in their sixties and two in their seventies. Five of the participants were female (50%) and five were male (50%). Eight of the participants (80%) were born in Australia; one (10%) was born in Ireland and one (10%) in England. Six of the participants (60%) were Roman Catholic and four (40%) were Church of England. There were no participants who identified themselves as Anglican or Uniting Church. Since the Church of England in Australia is known as the “Anglican” Church, I have included “Church of England” in this study. One (10%) participant had a tertiary degree, one (10%) had a TAFE qualification, three (30%) reached a matriculation standard i.e. Matriculation and Leaving, and the other five (50%) participants achieved secondary school level.

Question Two – Do you have a religious faith, and if so, what is it like? (n = 9)

There are four themes which emerge from these responses, namely 1) church attendance, 2) beliefs, 3) way of life arising from beliefs and also 4) a totally non-reflective response about faith.

Several of the responses were practical, such as “I don’t go to church” (P.1, 3, 4)⁵⁹ “I pray every night” (p.1, 3), “I disagreed with the priest on politics” (p.2), “living the way Jesus lived and being the best person you can” (p.3). Another approach to answering this question was to outline what the belief was e.g. “I believe in the Bible”(P.1), “I believe in Jesus and God”(P.3, 5), “I believe in a higher power as God”(P.6, 10), “I believe in a life hereafter”(P.9), “I believe in the ten commandments and ‘Do unto others’”(P.10) and two believed in the teaching of the Catholic Church (P.6, 7). One participant answered the question by talking about the impact of her faith on the way she lives her life and said she “believed in living the way Jesus lived and being the best person you can” and “in living with Jesus beside you”(P.3). Another participant said “my faith is strong” and another that “I don’t think about my faith, but its there” (P.5).

Question Three A – How often do you attend church i.e. monthly weekly or more often (n = 10)?

There were two themes discovered in the responses to this question, namely that going to church was either totally irrelevant or very important to the participants with the exception of two people, one of whom went when he felt like it and for whom it was enjoyable and meaningful when he did go (P.2), and the other who sometimes went with friends (P.8). Two (20%) participants said they did not go to church at all. Another three (30%) said they went to church infrequently e.g. “when I feel like it” (p.2), “on main days and a couple of others” (P.5) and “unless I go with someone” (P.8). One (10%) participant said he went to church monthly and some other times, and also “popped” into the church if he was passing by (P.9) The other two (20%) participants reported that they were prevented from going by their illness. One of these stated that she wants to get back to churchgoing with her children now they are at a church

⁵⁹ P = Participant number e.g. P1 is Participant No. 1

school (P.6), and the other (10%) has Communion brought to his home every Saturday night (p.7). The participant (10%) whose interview was only partially recorded reported that the priest often visited her at home, and this was important for her, although she did not mention sacramental ministry during those visits, and she also was too ill to go to Church (P.4).

Question Three B - How often do you pray i.e. weekly, daily or more often during the day (n = 9)?

Three (33%) participants stated that they prayed every night (P.1, 3, 5), two (22%) others “probably” every day (P.6, 9) and the other three (33%) whose responses are recorded said they prayed infrequently, “when they felt like it” (P.2) or “if they were at church” (P.8). One (11%) participant said she probably prayed weekly (P.10).

Question Four – How do you understand prayer? How do you pray? (n = 9)

There are five themes which come out of these responses, namely 1) prayer as communication, 2) prayer as a way of loving others, 3) prayer as the set prayers of the church, 4) prayer as asking for our needs, and 5) the ritual associated with prayer. Three participants (33%) stated that they used the prayers of the church e.g. the Our Father and Hail Mary (P.1, 7, 9). Another Participant (11%) said he “probably said the Hail Mary subconsciously because it was so ingrained” (P.2). Responses which were descriptive of how they understood prayer were that it is “talking to Jesus” (P.3, 5), “telling Jesus and thanking for what Jesus gives us”(P.3), that it is communication, “I say hello”(P.5), it is “worship”(P.5), and that it is about “loving others”(P.2) or “trying to help others”(P.2, 10). It is also described as “thoughts and messages, wishes and hopes, thank you’s (P.6) and it also “keeps you aware of God” (P.9). Responses which described

where they prayed described praying “when I lie in bed” (P.1, 5) and that one “can pray anywhere, doesn’t have to be in a church, can be on a tram, before a meal” (P.9).

Responses which described the way participants prayed included “sort of say it to myself” (P.1), and “make the sign of the cross and don’t look around at others” (P.9). The content of their prayer included “asking Jesus for what we need” (P.3), and “don’t pray much for myself, pretty happy with my life” (P.2). Two responses described what did or did not draw them to prayer, one response being “I pray when I feel like it so it means more” (P.2) and other being “don’t even pray if I’m in a tough spot” (P.8).

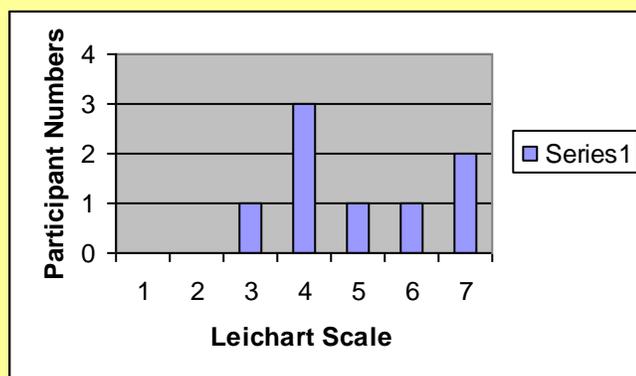
Question Five – In what ways do you experience suffering in your illness? (n=9)

The themes which emerge are 1) the disability from their illness and difficulty breathing, 2) isolation, 3) watching their families suffer, 4) fear and anxiety, 5) mental pain, and the loss of marriage. A common theme of the respondents (77%) to what was most difficult in their illness was that they could no longer do as much as they used to, or as one patient stated, “The loss of who I am as an active person”(P.6). Two (22%) participants reported that they could “not do much” (P.1, 7), and six (66.6%) reported that they could “not do as much as they’d like to” (P.2), or “not be able to do what they used to” (P.2, 3, 5, 6, 7, 8). One (11%) participant described himself as “incapacitated” (P.8). Related to this, three (33%) participants mentioned the struggle with not being able to breathe (P.2, 5, 7). The physically disabling effect of their illness was alluded to by almost all of the participants in various ways. One participant (P.3) mentioned the isolation, “not having anyone around to talk to”, and “no one understands how you feel”. Two responses mentioned family (P.3, 7) saying it was so hard watching your family suffer as they try

to help you, “Watching my son trying not to show his worry” and “mum because she tries to help” and “I can’t do it. I try and dry dishes for Mum but I’ve got to give up”. The concept of pain described varied, with two participants (P.6, 10) describing the pain being “not physical but mental and emotional” and one (P.5) describing the pain as “not mental pain, but physical”. “It’s different on different days” is another aspect of the pain I believe (p.3). Two participants (P.7, 10) described “fear” as one of the aspects of their suffering, and another (P.9) said “I get very anxious and have phobias when I try to sleep”. One participant (P.3) said “It’s just hard to get though the day sometimes” and one (P.2) said “it cost me my marriage...she didn’t know if she loved me because I was sick.”

Question Six – Do you feel that your religious background helped you to manage your suffering, rating that on a scale of 1 – 7, with 1 being “not at all” and 7 being “couldn’t have done without it”? (n = 8)

There were eight responses to this question, as one (12.5%) participant stated that he “wouldn’t know” (P.8).



Question Seven – Which particular aspect of your faith helped you? (n=9)

The themes which emerged from this question are 1) that faith does not really help a great deal, 2) that Jesus/"he" is there with them, 3) faith helps in meaning making, 4) Jesus has suffered and so understands our suffering, 5) a life hereafter to look forward to and 6) acceptance of what God sends. The participants had some difficulty answering this question, and the question itself may have been a difficult one and therefore a fault in methodology. Three participants (P.1, 2, 8) responded to the question of how their faith helped them, saying "not really", "none" and "don't know, I'm a bit of an agnostic". But of these one (P.2) said "sickness made me think more about my faith and the major religions". One participant (P.7) stated that church people are helpful, "the priest comes" and "the people in the church are my friends". Three participants (P.3, 5, 9) related a sense of Jesus or "he" being there, "knowing he's there and walking with me (5)", "The fact that Jesus will hear and help if you deserve it (P.3)" and also "prayer, because I know there is someone there who looks after me, I am not on my own (P.9)." One participant (P.6) stated that it was finding meaning within her faith which was the most help, "a belief that there is some reason behind my illness, that there are things to learn, it is not pointless", and "faith is something that makes suffering better, that good can come out of bad because we are taught something about strength or meaning in life". For one participant (P.3) it was the fact that "Jesus also suffered so he can feel for us, he knows what it is like" which is important, and also (P.3) "There is the next life to look forward to". Acceptance was important to one participant (P.5) "I have to accept what he gives me".

Question Eight – Does your Christian faith include the belief that God took on our humanity and, in Jesus, experienced suffering and death, and if so, does this seem important to you in your experience of illness? (n = 9)

The three emerging themes from this question are 1) yes, the incarnation is important, 2) no, it is not important or is irrelevant and 3) lateral responses to the question. Three (33.3%) participants (P.1, 3, 6) responded that the incarnation was important to them in their illness, “yes, it is” (P.1), “Jesus suffered, he really knows what we suffer” (P.3) and “it helps to believe God/Jesus knows how it feels to have something pointless happen to you...not someone remote who is removed from you...like the neighbour next door” (P.6). Four (44.4%) participants (P.2, 5, 7, 10) stated that they did not find the incarnation helpful in their experience of illness and responded “hard to say” (P.2), “how is that important to me” (P.5), “Long way away from me” (P.7), and “I don’t believe in that part” (P.10). There were three other responses to note, namely “I think outside the Christian faith” (P.2), “Yes, the old saying ‘God give me strength and he has’” (P.7), and “his role is to look after me and he has, and my role is to respect him...inter-relationship with God is important” (P.9).

Question Nine – Have there been particular aspects of your religious faith that have not been helpful? (n=9)

There are three themes which emerge from this question namely 1) disappointment with God, 2) disappointment with the church, either because the clergy haven’t visited or the church structure and doctrine has meant pastoral needs could not be met, and 3) there were no unhelpful aspects of faith. Five (55.5%) participants (P.1, 3, 5, 7, 8) said there was nothing which had not been helpful in their religious faith. One participant (P.2) said that “lack of contact with the church...the priest never visits” (P.2) Another participant (P.10) responded “Yes, felt let down, why me” and “No, the church is negative” (P9). There was one participant (P.6) who had struggled with a very negative aspect of her religious faith. Because of her heart condition she

was advised not to have children, because that would probably be fatal to her. This would mean a surgical sterilization to be quite safe, and being Catholic, she had hoped to have the procedure in a Catholic hospital. This was impossible unless she presented herself to the bench of bishops and argued her case, and she found that to be such a degrading thing to do that she went to another hospital. She was outraged because it was such a major loss for her to never have her own children, and she had not made the decision lightly. It was a costly decision, and she was unable to have the support of her church at the time when she needed it most. She has since adopted children and is still a staunch Catholic.

Question Ten – What else have you found that has helped you manage your suffering? (n=9)

The predominant theme in this question is 1) family and friends, especially children and spouses, and related to that 2) others' belief in them, 3) dogs, and 4) inner qualities such as strength and stubbornness. Seven (77.7%) of the participants named family as helping them to cope with their suffering, "my family makes me feel better" (P.1, 5, 10), "my family are ready to help" (P.3), "playing with grandchildren become one of them again" (P.5), "family, want to be part of their growing up and not isolated" (P.9), and also ""wife and family" (P.7, 10). Four (44.4%) participants (P.3, 5, 6, 7) also named friends as being important. One participant (P.10) named "dogs" along with family, and another participant (P.6) named "inner strength...other people's belief in me". Another participant (P.8) said "wouldn't have a clue...own stubbornness".

Question Eleven – Are there particular people in your church who have been helpful to you at this time and in what ways? (n=9)

There are three themes emerging from this question, 1) that there are no particular people from the church who have been helpful, 2) that church members have been helpful in some associated way, and 3) that many people have been helpful. Five (55.5%) participants (1, 2, 5, 8, and 10) answered in the negative to this question. One participant (P.3) answered that friends of her mother who helped her were mostly from the church. Another participant (P.6) stated that she was helped by prayer groups and the parish school community where her children went to school. One participant (P.7) stated that people from his church were long-term friends and often rang him. And one participant (P.9) stated ‘No, because he goes to the church to give help not receive it’.

Question Twelve – Do you have a sense of God being with you in your suffering, and if so, how do you understand this? (n=9)

There were three themes in the responses; 1) that the sense of God’s presence is very important, 2) an awareness of God’s presence upon reflection only, and 3) God’s presence is not a particularly helpful concept. Two (22.2%) participants (P.5, 9) responded affirmatively to this question, stating “with you all the way” (P.5) and “I don’t know how but he’s there” (P.9).

Four (44.4%) participants (P.2, 3, 6, 10) described a sense of being looked after, “feel protected and safe” (P.10), “find I get through and am coping, being carried” (P.6), “not in the suffering but helps me afterwards” (P.3) and “suppose so to a degree because I don’t feel any pain” (P.2).

One participant (P.1) answered “I’d say he would be...this aspect is not particularly helpful”.

One participant (P.3) stated that “it would be much harder if you didn’t have faith”.

Question Thirteen – Is there anything else we haven't talked about today that you would like to tell me or it is important for me to know in relation to this study? (n =9)

The themes raised here are diverse and individual, and there are no trends. One participant stated that he thought it was important to “respect others’ religious faith and expect respect” (P.2).

Another stated that “prayer always helps even if you don’t get the answer at the time” (P.3) and “you’ve got to keep praying and have faith” (P.3). Yet another stated that “believing that there is a reason for illness helps one to cope” (P.5) and that suffering is like “the obstacles God gives us are so we can learn” (p.5). One participant stated that it was important for chaplains to understand that “those without a great faith can believe in a higher power and purpose” (P.6) and also that “everyone needs others to carry them” (p.6). Participant 7 stated that “if you get strength to cope with pain and keep going, there must be a “big one”, and also that “it is important not to give up” (P.7) Participant 10 stated that she “believes you can pray anywhere, you don’t need to be in a church...is private” and one person had “Nothing to add” (P.8).

Emergent Themes and Issues

The researcher will now discuss the findings by writing about the themes which emerged from the data.

Discussion of demographic data.

Relating to the demographic information, it may at first sight seem surprising that the ages were so low for chronic illness. However, that reflects the kind of hospital in which this research took place; that is to say, it is because of the highly acute nature of the specialties which are a part of the hospital facilities that patients are referred for treatment. At least two of these nine people

would be eligible for transplant of either their heart or lung. The demographic statistics as regards gender are as expected with equal representation amongst the participants from each sex.

The author believes the statistics about the participants' country of origin reflects the normal demographics of our population, that is, Australian-born predominantly, with a smaller number of migrants. The fact that the two migrants in this sample were from the United Kingdom would reflect the church groups from which the patient sample was taken. The fact that 60% of the Participants were Roman Catholic reflected the patient demographics of the hospital in-patient profile. Most days the denominational lists reflects about 90-100 Roman Catholic patients, about 50-70 Anglican and Church of England patients, and only 6-8 Uniting Church patients out of about 320 inpatients. It is perhaps more interesting that there were no Anglican patients, but all were church of England amongst those who were eligible for the study and who took part.

The author was most surprised by the variance amongst the education levels and noted that of all the participants, the two who were able to be the most articulate were women, one of whom had a degree, and the other of whom had attained her Matriculation. Those who only went to lower high school levels would not have been taught the skills to think more critically and have their own arguments for or against a concept. This may have been a contributing factor to the many answers which were barely more than monosyllabic responses. It raises a question for further research, because without more reflective answers to the research questions, the research itself will not truly reflect what the researcher is hoping to find answers to. It will be a challenge to find a way to address this in further research work in the area of pastoral care and chaplaincy

which is qualitative rather than quantitative, and maybe the approach will need to be quantitative where all the questions are asked in the form of a questionnaire with yes/no answers.

Faith

Articulation – These responses were surprising to the researcher in that the participants were quite inarticulate about their faith and as the researcher pondered this it became quite apparent that it is an extremely difficult area for general discussion. “Professional” Christians, such as chaplains/pastoral care workers and clergy, who have to explain their faith regularly to others, may be able to do this more readily, simply because they have had many opportunities to think through their faith and articulate it. However, something about the participant’s faith was often revealed in their answers to other questions e.g. the personal way in which participants prayed. Only two participants could reflect in any depth on what their faith meant to them. This raises questions about what it might mean that 62.5% of the participants responded by talking about what they did rather than what they believed. It is certainly easier to talk about how one lives one’s faith than what that faith is. It is also important to note that for some people faith is just something that is a part of them, perhaps like breathing, which is accepted and taken for granted. Two patients commented that their faith was strong, and “just *is*”, and they were unable to say any more about it.

The nature of their faith: Five of the participants (55%) related their faith to whether or not they went to church. Even those who were very regular church goers were unable to be articulate about their faith, except to say they “accepted the teaching of the church unquestioningly”. (Three participants said that about their faith (33.3%) and these were all Roman Catholics.) The researcher is pondering what this church attendance might mean in terms of their faith, that is to

say, how it might relate to their belief in God, or to their understanding about the community of the faithful?

I suspect the fact that so few of the respondents attended church may have reflected some understanding that faith is a private and personal thing, and not any one else's business. This was in fact expressed by one respondent. That may partly reflect our society in that individuality is fostered rather than a sense of community, and so there will be no sense of needing to think about a faith community in which to share and help each other in the living out of faith. I think it also says something about their understanding of the nature of God, namely that God concentrates, as it were, on one aspect of life at a time rather than the global or cosmic picture of salvation and the coming of the Kingdom of God.

It also helps to make sense of why a chaplain would not often be asked for by patients, because if one's faith is so private and individual, then each person works out their faith in relation to their life on their own. It would not be a usual expectation that help from another would be asked for. It also means that if a person cannot make sense or find meaning in their current situation in terms of their faith, then they "sink or swim" on their own. This is unfortunate in many ways, not least is that often a person could find meaning with the help of another person of faith who understood the dilemma. Not to require others in our faith journey would also seem to imply that one would not pass on such a personal matter as faith to one's children or discuss it with friends.

The author notes that two of the three very devout Catholics in the study who regularly attended church accepted what the church taught them without question. That also meant they had given it

no further thought. The one exception (P.6) said that she did not accept all the doctrine, which indicates that she had been thoughtful about her faith. This same participant had also disagreed with the Church's stand on sterilization, and had gone ahead with that procedure for the sake of her health, but she was otherwise faithful to the Church, as much as her health would allow. The researcher has seen many examples in her practice of people who have left their church because of disagreements such as this, which have sometimes been so hurtful that there has been no way of reconciliation.

The two participants who accepted the church's teaching without question were older, and I wonder if this would be the case with many younger Catholics? However, it is worth noting that the Christian churches which are more literalist⁶⁰ are attracting many young people who are very happy to accept the teaching given them without question. It is worth noting that of the ten participants only two were regular church-goers, although a third would have been except for her illness. Another participant was a Christmas and Easter attendee. This raises a question as to why the other participants declare themselves as belonging to one of the institutional churches.

It is interesting to note that when questioned about whether there had been a time when their faith had not been helpful, three participants spoke about the church rather than their faith. Participant 10 was the only exception to this. She claimed that she had felt let down a few times by God when she had become very ill. She was a woman in her fifties who seemed to expect that the nature of God was such that she would be cared for and kept alive until she was considerably older. She could accept her illness and not feel let down by God because she was ill, but being close to death was not her expectation of God.

⁶⁰ I prefer this term to "fundamentalist"

Content of belief - The beliefs which the participants said that they held were the Bible, God, Jesus, Catholic faith and the life hereafter. Where these matters were further reflected on, it seems they were translated into areas of living out their faith rather than further reflecting on the nature of the faith itself. While the participants nearly all prayed, there was no indication that they studied or read their Bibles as a part of this belief or as part of their way of prayer. Therefore the researcher questions how these aspects of their faith were nourished, and suspects that it has not been nourished since they were children, with the exception of the church attendees.

This lack of ongoing resourcing of faith has implications for both the nature of their faith and its maturity. Without joining with other members of the faith, the Christian community of faith, there is no way for individuals to check their beliefs and values against that of others within the faith community. This would ordinarily lead to an individual understanding and expression of faith, which may or may not be consistent with orthodox theology. In fact this was demonstrated when more than one participant said they did not believe in the incarnation of Christ, a foundational Christian belief.

If faith is not nourished and growing, it is unlikely to be an entirely reliable resource in times of difficulty. The researcher has encountered this many times in her practice, when patients are facing life threatening events with the faith of a child. People with this form of childish faith often have no understanding of the place of suffering within God's economy, and their expectations of God can sometimes be likened to magic. If there is no relationship of love and

trust with God, there is very little room to accept negative events within life and trust that God is in those as well as the good things in life. It is an extremely difficult area within ministry. The lack of congruity between the beliefs of those whom I interviewed and traditional church teachings is apparent in the chapter on theological reflection.

The areas of belief named by the participants, namely Jesus, God, the Bible, and a life hereafter, meant that they expressed the need to “pray every night”, “live the way Jesus lived”, “live with Jesus beside you”, receive communion weekly, and “respect others”. These outcomes actually say something about the kind of God the participants believe in, although they showed minimal awareness of that. The researcher can see that they understand God as a relational God who wants them to be active in that relationship in their prayer and in the way they live. It also makes a statement about the quality of that relationship, namely, that it is one of mutual respect and modeling on the life of Jesus who revealed the nature of God. These participants appear to sense something of this core nature of God.

One participant said she believed in “a higher power as God” and felt it was also important that pastoral carers accept those whose faith was more basic and who maybe held only a belief in “something and that that’s helpful for them even if they don’t have faith.” The researcher also believes that it is part of our role to support these people in their time of illness. There is a great deal of anecdotal evidence from chaplains who hear patients talk about their “faith” in ways that are novel and probably unformed e.g. “I find God in the garden”. One wonders about who this “God” might be for them in their suffering. Other people may say they find God in nature, and

this may presume a far more robust kind of seasonal “God” who is prepared for loss of life, but who can be relied upon for the cyclic nature of winter (death) and spring (new life and hope).

One of the women in the study explained her faith in terms of the implications which it has for her life, namely that she must live her life the way Jesus lived, and be the best person she could, and it also meant “to live with Jesus beside you”. Another participant said that faith meant that “you did the right thing by people, and they respect you” in the sense of the Golden Rule. This is interesting in that these two participants understand faith in relational terms, which is the way they are to live with themselves, God, and each other. This is a very ethical understanding of faith, although it has a spirituality which informs the way it is lived out. It is also reminiscent of the Jewish understanding of living according to the *Torah*.

Another aspect of faith seemed to be that of caring for others and having respect for others. This meant respecting different faith traditions, as well as that prayer is predominantly offered for others as a way of caring. I found this attitude of care extraordinary given that these people were so ill themselves. It is often a phenomenon that the focus of the seriously ill person becomes very narrow to the point of being focused only on themselves. This is perfectly understandable as their bodies are often crying out for attention. It is impressive to realize that a depth of spirituality enables these participants to rise above their own illness to think of others and pray for them.

Those for whom their faith was negatively impacting on their experience of illness have probably self-selected out of the research, either by not declaring themselves as no longer having a religious affiliation and therefore being ineligible for this study, or by declining to participate.

Evidence from the researcher's practice suggests that some people stop practicing their faith out of anger at God because things have not gone as well as they wanted. Several patients to whom the researcher has ministered have told stories of how they have never gone back to church or had anything to do with religion since they became sick, or since a close relative died. They feel that God has let them down or doesn't care about them, and so they turn away. Their participation would have been a valuable addition to this study however.

Incarnation - Jesus as human: Fifty percent of the participants believed in the incarnation of Jesus and said that it was important to them. Two of these connected the significance for them of the incarnation to what they believed to be Jesus' understanding of suffering from experience, and that was very important to them. One woman said,

It helps to believe that God wanted him, his son and himself, to understand what it was like to feel that you had something pointless happening to you, and had no control over your life and things like that, so he could understand where we are coming from when we pray to him about those kinds of things...in the sense that it makes him seem like Joe Bloggs next door who also has whatever hardships he has and not someone far away in heaven who's got everything fantastic and goes 'Oh, poor you.' (P.6)

Participant three said "Jesus also suffered, and if there was just a God who had no idea of how we suffer how would he be able to feel for us like he does, if he hadn't had to suffer himself? He really suffered so he knows what everyone else suffers."

This aspect of the significance of Jesus being a fellow sufferer was one of the hypotheses put forward for this research. The surprise was that there were only two people who valued this aspect of the Christian faith when asked explicitly and who could articulate its importance to them. It was expected that to connect with Jesus in his suffering would have been the main point of connection, because the experience of suffering is common to humanity at various levels of

intensity, whereas other aspects of Jesus' life are less easy to relate to personally. It is even more surprising to the researcher that the practicing Catholic participants did not relate to this, given that they were older and probably attended Catholic schools in an era when the virtue of offering up one's suffering with Jesus on the cross was taught. Rowan Williams writes that the place of the Passion is where most of us meet the Christ and that many of us do not progress further to meet the risen Christ, which is after all the end point of our Christian faith in terms of the life of Jesus.⁶¹ Participant three did not find that the experience of suffering in the incarnation offered her a sense of God's presence with her at the time of her suffering, but afterwards. There were three other participants who said that the incarnation was important. One (P1) just stated the fact that it was important, but couldn't elaborate on that, and another said "Yes, God give me the strength." (P.7) while a third said "his role is looking after me and I give him respect." (P9). These responses are difficult to interpret.

There is an inconsistency in the participants' answers to this question which indicates some misunderstanding of the question, or of the importance to people in the twenty-first century of the historic person of Jesus in the first century CE. Because of the inconsistencies in the participants' responses, the researcher understands that there is no carryover into the patients' own lives of an idea of Jesus knowing what it is to suffer and the presence of God being with them in their experience of suffering. One participant responded when asked about the person of Jesus, "How is that important to me?" This seems to imply that there is some importance to the historical Jesus, albeit at a remote level from the participant, and therefore is not connected in his faith experience. This same participant reported that the sense of Jesus being with him was

⁶¹ Rowan Williams, *Resurrection*, Morehouse Publishing: Harrisburg, PA, 1982. pp.76 – 97.

important. Perhaps there is a dissociation for him between Jesus and God who somehow is present to him. There is no understanding of the Resurrection of Christ. It was interesting to note that one response gave a sense of the incarnation of Jesus being so remote from his own experience while in other responses it was the very fact that Jesus suffered in a seemingly pointless way that helped them to make sense of their own seemingly pointless suffering. One response to the question about the incarnation was that illness had prompted him to look to other major religions for support and answers which might make sense. This was not explored with him, as the researcher felt it went beyond the scope of this project.

Another response was to pray “God give me strength, and he has” which seems to indicate that the patient also needs to be given strength to bear his load in the same way that he believed that Jesus was given strength. This participant was Catholic and may well have seen his illness as a cross to bear and that like Jesus he would need a Simon of Cyrene to help him carry it to the end. He made the connection of needing to be given strength. The connection with Jesus’ suffering would be a natural one for him to make. It is important for chaplains to listen carefully to where the patient is at the moment, and relate the aspect of Scripture which best connects with the present experience of the patient, otherwise the patient will not be able to make their own connections.

Two participants declared that they didn’t really believe in the incarnation at all (P.2, 10).

Another man could not see how it was important to him (P.5). It is worth noting that of all these participants, who each aligned themselves with one of the three major Christian churches in this country one third did not believe in this central tenet of faith in the Christian religion.

This makes it very difficult for Christian chaplains to minister to these people, unless the chaplain has a way of exploring what the patient's understanding of faith is first. There is a gap if the chaplain presupposes a belief in the fact of God becoming man in the person of Jesus Christ and thus offers the patient some connection in their suffering. This would be doubly so, if the chaplain were to respond to the non-believing patient's experience of illness and suffering by prayer to Jesus as one who understands what it is to suffer.

This research highlights a possible weakness in the teaching and preaching within our churches. If the central belief in Jesus as God incarnate is not understood or believed, or connected in some way to people's lives, it might warrant some further research as to why this might be so. Also it might be important to explore why people who have been educated within a Christian milieu might reject Jesus as Christ but retain their belief in God, and ways in which this belief in God can help or hinder their understanding of suffering in their lives.

Prayer

It is worth noting that despite a relatively poor understanding of the Christian faith and little sense of a personal relationship with God that there was a high incidence of prayer among the participants. Fifty-five percent of the participants prayed daily. Of the themes relating to prayer, the strongest one which was mentioned in the responses was that prayer was a form of communication with God (55.5%), whether this was quite informal e.g. "I say Hello" or "thoughts and messages, wishes and hopes, thank-you's" and "talking to Jesus", or whether it was more formal using the set prayers of the church, for example the Our Father and Hail Mary. The informal communications seem to demonstrate a personal relationship with God, which was

unable to be articulated in the prior question about their faith. It seemed these participants live out their faith rather than think it through or talk about it, or that they are unaware of doctrines which are foundational to some of their beliefs. Pastoral care workers and chaplains may need to look at these issues and ponder the questions they raise.

Prayer as a way of loving others was a surprising finding to the researcher. However, like the previous sub-theme, it seems to say a great deal about how the nature of God or Jesus was understood, and the consequences that, namely living in the way Jesus would want them to. This latter point was mentioned by one participant who said that she believed it was “living the way Jesus lived.” The researcher was struck by the attitude of these participants, given how ill they themselves were. For the Christian it is a moving example of the scriptural text: “We love because he first loved us.” (1 Jn.4:19)

The three participants who responded that they prayed using the set prayers of the church are also making a statement about how they understand the nature of God and how God is to be approached. One participant, when asked a clarifying question about whether he used the “set prayers” responded that “I know no others.” It is interesting to reflect on how important church culture is in the way people pray, and how much people are immersed in that culture during childhood live within it to a certain extent for the rest of their lives. Another example was a Church of England woman who never goes to church now, but was taught in Sunday school, who now prays the Lord’s Prayer every night when she goes to bed. The three Catholics who identified that their faith was the teaching of the Catholic Church would have a strong understanding of the church as a mediator for approaching the majesty of God, and almost the

“right way” to do that. They were immersed in the prayer culture of the Catholic Church and lived according to that cultural way of being and doing.

Church

The responses to the question about church attendance brought two basic responses i.e. they either never went or going to church was very important to them. It is of interest to the researcher to think about the fact that all of the interviewees declared themselves as belonging to a religious tradition, and yet only three of them gave any evidence of really relating closely to that tradition. Perhaps church is related to a cultural background from childhood, or it might stand for some sort of position within society or an adherence to a particular moral code. They may also believe that they hold to the faith of their church but just do not practice that faith within the religious institutional context of the church. In the United Kingdom, where until fairly recently it was necessary to be a member of the Church of England to hold a government position, this might be more understandable in terms of social position, but not in Australia. It is therefore puzzling as to why people might claim a religious affiliation which is no longer a part of their lives.

The other aspect of those who claimed religious connectedness but did not in fact connect with a church is an aspect of a modern society which Shuman and Meador write about in *Heal Thyself*.⁶² They write about the phenomenon whereby Christians come to believe in their own eclectic version of the Christian faith rather than the traditional version as taught by their churches. By not being a part of any specific faith community, they remove themselves from the discipline of reviewing their own faith alongside that of their leader or other members of their faith

⁶² J.J.Shuman & K.G.Meador, *Heal Thyself: Spirituality, Medicine, and the Distortion of Christianity*. Oxford, University Press: Oxford, New York, 2003. See also Chapter One on “Suffering”.

community. This style of religious affiliation can be quite challenging for healthcare chaplains who themselves live and work within a traditional Christian framework. There cannot be any presumption that the chaplain knows the faith position of any patient until they have listened to the patient tell them how their faith operates for them, or about their beliefs and values. Hence there is a constant need for chaplains to be very careful listeners and discerners in their ministry.

Suffering

The researcher was not surprised that disability and difficulty breathing were mentioned frequently by participants. Tiring very easily and *dyspnoea* or shortness of breath are hallmark symptoms of heart and lung failure. Also it is widely described that patients never know whether they will be going to have a good day or a bad day, and so it is very difficult to plan their lives ahead. The researcher was struck by the effect this then has on their families and the suffering of the patients with these symptoms. Again, patients' awareness of and concern for the impact of these symptoms on their families or friends visiting them demonstrates how they are still able to reach out beyond their own illness.

The experience of isolation within suffering is well documented and the researcher was a little surprised that only one participant mentioned it.⁶³ The experience of illness and all that it entails is usually so unique and needs to be experienced to be understood, that words are rarely adequate to convey what it is like. This can also be reinforced when other people who mean well tell the patient that they understand or can imagine what it must be like for them. Oftentimes, it can be too difficult for family members or friends who are close to the patient to hear about the reality

⁶³ See my reference in chapter two.

of their experience of suffering, as it can be too painful to listen to when they are not be able to do anything about it. The role of the chaplain as the listening ear is very important in this context. The chaplain is not emotionally close to the patient, and will therefore be less distressed as they listen. Also, the chaplain will be trained to listen actively and encourage the patient to talk out whatever they wish to be heard.

The aspect of fear and anxiety expressed by two participants is also not surprising. Being acutely short of breath is a very frightening experience, and all of these patients will have experienced that symptom at some time. This experience then leaves an emotional memory which is also connected with dying, as patients know that death will be inevitable if they don't receive medical help in a timely way. This research did not explore the fear more closely, but anecdotally from my practice, patients have told me that it is not death *per se* that they fear, but the acute shortness of breath, and the fighting for every breath. Also this very often develops at night, and so the phobias of the participant at night can be very easily understood. It is also very distressing for family members to witness, as they are usually helpless to alleviate the attack apart from calling for medical help.

It is not clear from the responses given what the nature of the various mental sufferings of the patient might be, although it seems reasonable to assume that it would include the fear and anxiety mentioned above. The loss of a marriage is another very specific form of mental as well as emotional suffering. It reflects the amount of stress that any illness is likely to place on a relationship, especially one as intimate as a marriage.

Helpful Aspects of Faith

The fact that three participants felt that their faith was a help spoke about their awareness that Jesus was with them in some way is significant. They also felt that the fact that Jesus had suffered meant for them that their suffering was understood. One participant elaborated on this and said that because Jesus had suffered, it meant that God was more like a neighbour than someone far away, as they expressed it, God knows what it is like to live in their neighborhood of suffering. It is easy to imagine that to relate with God in this way would eliminate occasionally at least some sense of the isolation which illness naturally brings, as there is the knowledge that God in Jesus suffered and knows just what it is like.

The aspect of faith being a tool for meaning-making in their context of illness was very important to two participants. For one of them it was important to think about her illness in a way that offered her more than just seeing it as random and pointless, and the fact of Jesus' suffering was helpful here in making sense of his suffering as well. She also felt that there was learning which could come out of her experience of illness, particularly that she could learn to be strong in ways she would not otherwise have the chance to grow in. People need to find some meaning in their suffering to be able to cope with it. For many of our trauma patients this may be on the level of having a reasonable explanation for how and why an accident has happened. But for many others, the meaning of a chronic illness needs to be found on an existential level, in terms of where it fits in to the meaning for their whole life and *raison d'être*. That belief in the next life could be a helpful aspect of coping with illness is very understandable as it puts a limit to the experience of suffering in this life, i.e. it will not be like this in heaven, and it also gives

the patient something to look forward to as there is no hope of a better life, at least physically, in this life.

Acceptance was important to one participant. He saw illness as a part of the life which God has given him. Psychologically this mindset of acceptance can mean a certain calmness about the situation, which then translates into a better physical state.⁶⁴ The place of God's will within illness and suffering is not something that patients had an easy and straightforward answer to, but some did accept the illness as part of their life in the here and now and their trust in God gave them comfort.

The overwhelming response to the question about what else was helpful in participants' experience of suffering was that family and friends were important to them in coping with their illness. There was a real understanding from them that playing with young children or grandchildren made them feel better, and that they wanted to be a part of their families growing up and not isolated from them, or even absent from them in death. One participant said the fact that others have faith in her helps her to cope with her illness. And this same woman also said that inner strength, which she didn't know she had until she had to call on it, also helped.

It is understandable that family and friends are so important in the coping process. The need to know that they are loved and valued by others causes some patients to keep going and not give

⁶⁴ As a generalisation, from my work experience, I can say that compared with patients from the other Abrahamic faiths, Christians are generally less accepting of their illness. Perhaps this comes from the knowledge of the Gospels where Jesus is reported to have healed all who came to him, and so there is some expectation that this should also happen for them if they ask in prayer. Many muslims see illness as a test, and so they must live well and in an uncomplaining way during their illness to please Allah. Jews also will see their illness as being from God, and will accept it.

up even when their suffering seems unbearable. People fight to stay alive to be with loved ones in many ways. Leaving loved ones can often be the most difficult aspect of dying for the one who is dying.

While good friends were high in importance, one participant named her dogs as being most important to her. The wife of another patient had just bought him a puppy, believing this would help her husband, although at the time of the interview the puppy was rather too boisterous for the low energy levels of the participant. There is some evidence that people who have dogs live longer, and they can certainly have a calming effect on the sick.

These responses help to make sense of the response to the Leichart Scale indicating where on a scale of one to seven participants placed their religious faith in importance. Most of the responses were in the middle i.e. as 4/7. This indicates that while their faith is important, there are also other things that may be important. It seems that for most of the participants their families were amongst the most important aspects of support in their illness, with their faith having some importance. This is an aspect which healthcare professionals are appreciating more and more as they attend to the spiritual needs of patients, whether these have a religious dimension or not.

Unhelpful Aspects of Faith

For most of the participants there were no particular aspects of their faith which were negative. However one man felt the church had let him down because the priest didn't visit. Another woman felt that God had let her down at the times when her illness had been so severe that she

thought she would die. Her beliefs expressed seemed to indicate a faith in an interventionist God who controls life in a microscopic way.

It is interesting to note that God can often be blamed for ill health and death when this is something that comes to all human beings in time. This understanding of God allows very little room for human will or error. It also seems to indicate a belief in humanity's right to good health and a reasonably lengthy life, and that it is God's job, as it were, to provide those. The most distressingly negative aspect of faith was experienced by one of the 30-year-old women, who was a devout Catholic but needed to be sterilised for the sake of her health, and suffered from the ethical teachings and sanctions imposed on Catholics in regard to such treatments.

Church Support

Five of the participants answered in the negative to the question about the church members helping them. Two participants valued the contribution of church people who either helped them or prayed for them and helped their children within the church-school community. This is a secondary way of people from the church being important for their coping with illness. One participant said that the people from the church were his old friends and were often ringing him and visiting him. He was the only participant who seemed to have a real sense of his faith community offering him something at a personal level. Another church-goer denied that people from the church helped him because he couldn't see his faith community in that way, only as the recipient of his help.

The responses to this question demonstrated that one of the researcher's hypotheses, which was that the faith community, however that was expressed, whether it was by visiting the patient, prayer, or as represented by the chaplain, would be an important aspect of faith and that it might help in the experience of illness. This hypothesis was based on an assumption that most people who declared themselves as being aligned with a church would have been regular or semi-regular church attendees, and they would have built up some sort of friendship or bond with the people from their local church. The framing of the hypothesis came out of practical experience in healthcare chaplaincy, where many religious people have mentioned how important to them it is to know that others from their church are praying for them, and sometimes even that the prayer chain has been extended across the world. There have been other examples where people from the local church have visited patients or it has been important to them that the faith community is there with them in the person of the chaplain.

Presence of God

A response to this question about God being with them was important for two-thirds of the participants, although they expressed it in different ways. For some God was "with you all the way" and for others there was a sense of being looked after or carried somehow, and that without this it would be much harder. It was clear from the thoughtfulness needed to respond that this was not an aspect that they thought about necessarily, but when asked to reflect on it, they could see that it was important to them in some way. Perhaps it is akin to asking people to reflect on how they walk or breath, because there is a sense that God is somehow there whether you are aware of it or not.

Role of Chaplains

There were a variety of responses to this, but the overall theme or participant response to take back to chaplains was that they should respect others' faith stance whatever that might be. The researcher was encouraged to honour the patients who do not have a "great faith" but believe in a higher power, and there was mention of prayer being important to keep going, the importance of not giving up (perhaps intended to ask chaplains to be encouraging of patients not to give up), and to consider how people all need each other.

It is reasonable to assume from these responses that the role of chaplains was seen as one of encouraging patients, which is certainly one aspect. The researcher understands that there are other aspects which are of equal importance, such as supporting and being present to people when they are going through the depths of despair, or facing issues of mortality, as well as celebrating healing and other breakthroughs which are positive.

The point made about supporting patients who are not traditional in their faith is an important one. There are many patients and families, not to mention staff, who would say they had no faith, but who are deeply spiritual, and the challenge for the chaplains is to be able to nourish these people in their beliefs and values, and facilitate these people resourcing these spiritual strengths.

Summary

This chapter has outlined the findings of the research interviews and then discussed them in a preliminary way. I explored those aspects of Christian faith that helped patients, expecting that it might be that because Jesus had suffered, they would have a sense of Jesus' close presence and

understanding in their own situation. I also expected that the faith community might be important to them, even if that was only represented by the presence of a chaplain. There was some surprise that although all participants expressed a belief in God, by and large there was no sense of the close presence of God with them in their suffering. It seemed to be their family rather than God that supported them. This was communicated not so much by the words used, which were in answer to my questions, but by the way so many of them spoke with such warmth and feeling as they spoke about their families and what they meant to them.

This is congruent with my clinical practice in that I have not noticed that Christians cope with suffering better than others with no declared religion as a general rule, although there are exceptional people in both categories. It seems that the common human experience and need to have people close to them, in this case their close families, is a primal need for people. Religion or religious faith may be a secondary adjunct to that human need, if the person is religious. I will explore the implications for chaplains of these findings in my final chapter.

Chapter Four: Theological Reflection on Aspects of Patients' Responses to their Experience of Suffering

Introduction

In this chapter the interview responses of the patients will be the subject of reflection in relation to the significance of their religious faith in their experience of illness. Patients were selected because of their self-declared Christian faith and it is the intention of this research to explore the relevance of Christian faith in the experience of illness, rather than to examine generic spirituality and its impact on suffering. Two major themes related to the original research hypotheses will be explored, namely the patients' belief about the importance of Jesus as human in their experience of illness, and the place of the church as a support in this time of vulnerability. In the interviews there were questions directly related to these two issues, and the patients' responses to these questions will be discussed in this chapter.

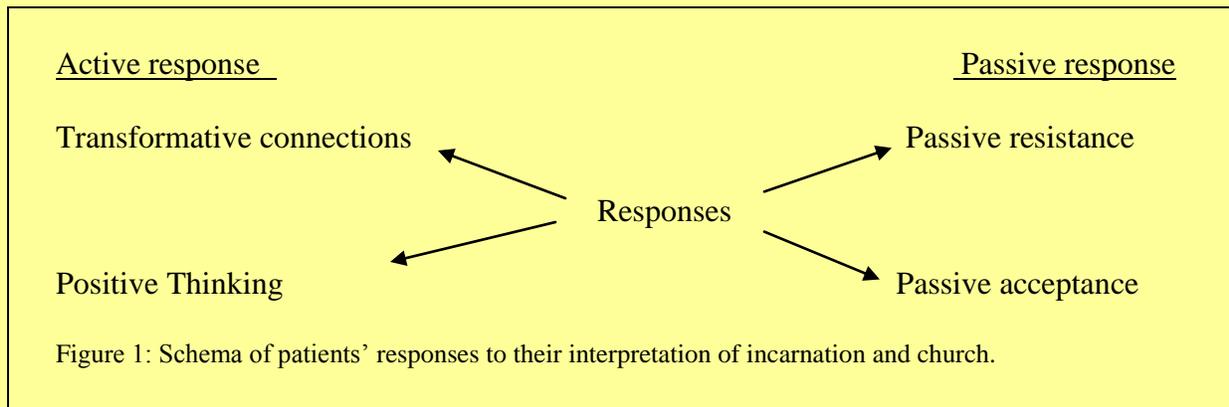
In this thesis I use the terms 'belief' and 'faith' as Wilfred Cantwell Smith defines them and Fowler uses them in *Stages of Faith*.⁶⁵ Here Fowler, relying on Smith, defines faith as "the person or group's way of responding to transcendent value and power as perceived and grasped through the forms of the cumulative tradition" or religion."⁶⁶ I understand this to be a collective response and set of beliefs, although the individual within this collective may have their own understandings and practices within the general collective tradition. Fowler, again relying on Smith, defines "belief" within the religious context, as "the holding of certain ideas'...out of the effort to translate experiences of and relation to transcendence into concepts...Belief may be one

⁶⁵ James W. Fowler, *Stages of Faith*, Harper One: New York, 1981.

⁶⁶ Ibid. p.8

of the ways faith expresses itself.”⁶⁷ These ideas will be formed by the individual, and may or may not be a personalised version of the traditional teachings of the Christian faith community.

The way patients interpret incarnation and church will be examined. I will also discuss their lives in terms of active or passive responses to their belief framework and illness.⁶⁸ By an active response to interpreting incarnation and church I mean either transformative or positive engagement with their belief, and by passive response I mean either a resistant, angry response or a passive, inactive response.



It is necessary to reflect theologically from within the Christian Tradition in order to discover the understanding of God that our patients are describing or are engaged with, and how their beliefs are or are not integrated with their suffering. The practise of theological reflection on the lived experience of these patients within the healthcare context of medical science is important for healthcare chaplaincy. It is also important as part of this theological reflection to be able to

⁶⁷ Fowler p.11

⁶⁸See Rowan Williams, *On Christian Theology*, Blackwell Publishing: Oxford, 2002. Pp. 162-3/ I have adapted the idea which Williams puts forth in his reflection on the tragic.

integrate the social and cultural issues related to health with the Christian tradition.⁶⁹ This needs to be done in an open way so that both the experience and the tradition are reflected upon and there is opportunity for exploration which may lead to a new pastoral understanding and action.

Killen and de Beer in *The Art of Theological Reflection*⁷⁰ describe the cost to theological reflection of being caught up in “Certitude” or “Self-Assurance”. The understanding of “certitude” about their faith tradition that Killen and de Beer propose, or of viewing experience from a faith stance, may lead to a denial of experience if their personal experience does not fit the patients’ understanding and interpretation of their faith. Consequently their response is seen as definitive and closed.

Alternatively, a stance of “self-assurance” is that by which they view their experience in such a way as to exclude their faith tradition. This stance may lead to a denial of the importance of tradition if their experience does not fit. In neither case is there room for “exploration” as Killen and de Beer describe, and the cost of not exploring personal experience is a lost opportunity to discover new insights about either their tradition or their personal experience.⁷¹

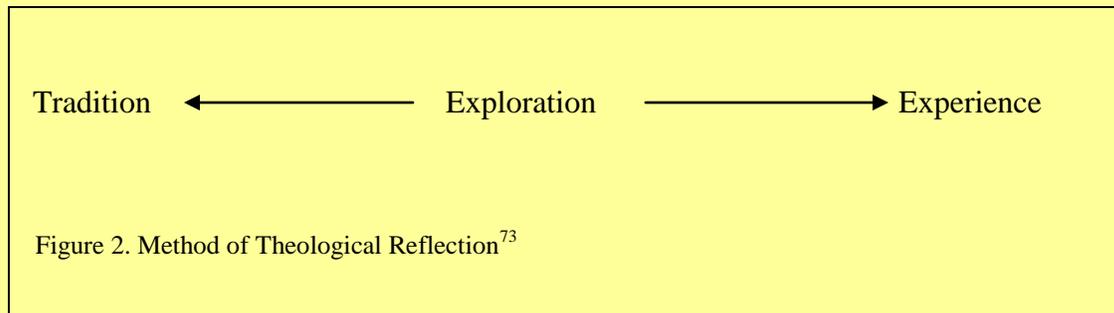
This thesis proposes that where an open exploration of their experience is undertaken by patients then both their own suffering and the Christian tradition are honoured and integration of faith and personal experience take place. Exploration of the impact of the social and cultural setting of

⁶⁹ See James D. Whitehead & Evelyn Eaton Whitehead, *Method in Ministry*, Sheed and Ward: Kansas City, Revised Edition 1995.

⁷⁰ Patricia O’Connell Killen & John de Beer, *The Art of Theological Reflection*, Crossroad: New York, reprinted 2006.

⁷¹ *Ibid.*, pp. 1-19.

their experience, namely their family and the acute healthcare facility will be woven into the theological reflection.⁷²



The purpose of engaging in this theological reflection, and indeed this whole research project, is to explore the implications of the responses of these Christian patients in order to minister more effectively as chaplains in the field of acute healthcare. A simple framework is proposed:

- a) observing two key responses of the patients to their interpretation of Christian faith, namely active and passive acceptance,
- b) identifying two main themes, namely Jesus as fellow traveller who helps give meaning to their own suffering, and the place of the church in their experience of illness, and,
- c) reflecting on the patients' interpretation of their beliefs and the Christian tradition and noting points of connectedness and disconnectedness.

⁷² James D Whitehead & Evelyn Eaton Whitehead, 1995, p.54 ff. The importance of cultural and social setting for the experience is also referred to in John Paver, *Theological Reflection and Education in Ministry*, Ashgate: Hampshire, England; Burlington, USA, 2006. p.43

⁷³ Adapted from Killen & de Beer .

The patient sample in this research all suffer from an illness that is experienced as tragic⁷⁴, mostly quite random in its attack, and life-threatening and debilitating in its chronic nature. The language of medical science often does not acknowledge the personally tragic aspect of chronic illness which has no cure. Science attempts to address illness and improve quality of life. The reality and enormity of the experience of suffering of these patients, and the tragedy of their situation, need to be a significant part of the conversation with chaplains who enable patients to give voice to their suffering.

Chaplains may also enable patients to attend to their faith responses and their significance for understanding their suffering. Such discussions also need to admit the limits of what can be changed in their illness, and accept the aspects of their illness and the experience of it that cannot be changed. Illness is a factor in their lives, and needs to be addressed authentically. Where some religious believers cannot face the mystery of suffering they sometimes try to cloak facts about suffering in pious or devotional language that is diminishing of a person's authentic experience. A religious evasion or minimising of the limits of illness and can often be destructive for all concerned. Their terminal and debilitating illnesses are "non-negotiable" realities. It is essential for patients, their carers and staff to see and admit the reality of illness and suffering and its consequences in human life⁷⁵.

⁷⁴ I use this term in the Greek tragedian sense in which the hero meets some downfall, usually as a result of his own pride, fate and the will of the gods, and because of human frailty or the gods or nature, the hero cannot rectify the downfall. While these patients have not all contributed to their illness by smoking, for example, they are all unable to turn around the effects of their illness in any significant way. www.en.wikipedia.org/wiki/Greek_tragedy

⁷⁵ Rowan Williams, *On Christian Theology*, Blackwell Publishing: Oxford, 2000. pp.162-3

Two approaches to Suffering: Active and Passive.

I will now explore active and passive responses by patients to their religious belief in terms of their illness. The first hypothesis of this research was that belief in Jesus who suffered humanly would be an important factor in patients' coping with their experience of illness. If 'important' is defined as 'of great effect or consequence'⁷⁶ then it will be advantageous to explore the consequence of faith in the humanity of Jesus for these participants. I will explore this consequence in terms of transformation and passivity. In the sense of living beyond the disabilities of their physical illness, I believe that each of the participants for whom the fact that Jesus was a fellow-traveller in their suffering was transformative at some level. It was transformative to the extent that they were able to see beyond their own personal suffering to that of another, in this case that of the Jesus, God become human. This means they did not describe themselves as victims of their illness; they could see beyond themselves to others, whereas those with a victim mind-set were not able to think beyond their own loss of function and place in life. In relation to this approach to suffering I have already referred to participant three who could see beyond her own plight to that of her son, and she tried not to let him see her suffering in order to spare him. Participant seven tried to help with domestic chores because he appreciated the burden he had become on his wife, but was distressed when he couldn't even dry the dishes. Another participant who lived alone saw prayer as a way of loving others, trying to help others, which is another way of seeing beyond one's own situation (participant two).⁷⁷

⁷⁶ R.E Allen (Ed), *The Concise Oxford Dictionary*, Clarendon Press: Oxford, 1991

⁷⁷ See Rowan Williams, *Resurrection*, Morehouse Publishing: Harrisburg, PA, 1982. Pp.10-27.

Active Response: For some patients, their faith enables them to be transformed⁷⁸ within or by the experience and often to sublimate their suffering. It is important to understand the meaning of transformation. *The Oxford Dictionary* defines ‘transform’ as “make a thorough or dramatic change in the form, outward appearance, character”, and ‘transformation’ is “the act or an instance of transforming”.⁷⁹ The same dictionary gives as one of the meanings for ‘transcendent’ “existing apart from, not subject to the limitations of, the material universe” and relates this especially to “the supreme being”.⁸⁰ This is the way I wish to understand transformation in relation to the patients, because they are unable to make any change in their “outward form” but have changed in the sense of their “character” being transformed or moving beyond the limitations of their physical abilities and external life.⁸¹ It is a more straightforward way to understand passivity, and the dictionary gives the meaning for passive as “suffering action, acted upon, abnormally unreactive”.⁸²

There are difficulties in understanding transformative potential in a chronically ill person. At one level this transformation changes nothing about their illness, and yet at another level it can change everything about the way they may live with and beyond the illness or disability.

⁷⁸ I believe there are both active and passive aspects to transformation. On the one hand the person needs to make changes or take some stance which enables change, and on the other hand, the transformation itself is from beyond their own person. In this thesis I am exploring the Christian faith of these patients. This makes transformation difficult to categorise as either active or passive, but I have included it under active response in Figure 1 because I believe that it always needs a stance of openness for real transformation to take place.

⁷⁹ *The Concise Oxford Dictionary*

⁸⁰ Ibid.

⁸¹ I understand this partly in terms of Erikson’s stages of human development. These chronically ill patients are not able to be fully creative as they once were in the age of ‘generativity’ and so need to find ways to transcend this so as not to stagnate. It seems they need to learn again a lesson from the age of forming their identity. They need to find a way to use “the accrued experience of the ego’s ability to integrate all identifications with the vicissitudes of the libido, with the aptitudes developed out of endowment, and with the opportunities offered in social roles.” In a way they are re-learning their identity in a new set of experiences. Erik H Erikson, *Childhood and Society*, W.W. Norton & Co: New York, London, 1985 edition. Pp.261-267.

⁸² *The Concise Oxford Dictionary*

Dorothee Sölle gives an example of such a transformation when she met an old Brazilian priest who was in overwhelming pain after rupturing a spinal disc. This man integrated his pain into his beliefs and values and transcended it by offering it up to Christ.⁸³ The devotional practice of the old priest certainly did nothing to relieve his physical pain, but it enabled him to actively sublimate it. He was able to transform it by adding his pain to the suffering of Christ to be used for the healing of the suffering of others, thus giving his suffering a wider horizon of meaning and purpose.

In this patient sample, participant three is an example of such an active transformative response in the way she rose above her own concerns out of love for her son. In her love for him as a mother, she found meaning in being able to nurture and protect her son. She had moved beyond herself and was open to the transforming work of her suffering by God.⁸⁴ This mother's love meant that she not only tried to shield him from seeing her suffering, but she also prayed for him and was connected with him in increasingly affirming ways for both herself and her son.

Another example of this sublimation can be seen in participant two who said that his prayer was not for himself because he was at peace with his life, but that his prayer was a way of loving others. There were several other participants in this study who transcended their own suffering in their outreach to their families, and had found personal transformation in and through their suffering. Perhaps the most notable of these was participant six for whom being a mother was so important, and yet she had been sterilised for her own safety. She had managed to rise above this

⁸³ Dorothee Sölle, "God's Pain and Our Pain" in Ellis & Maduro eds. *The Future of Liberation Theology*, Orbis: Maryknoll, NY, 1989. p.331.

⁸⁴ Sharon G Thornton, *Broken Yet Beloved – A Pastoral Theology of the Cross*. Chalice Press: St. Louis, Missouri, 2002. p.105

deprivation and adopt two children. Her current focus is very much on them and how she can get back to being a part of their school-faith community, although she is still very ill.

Accepting illness positively for Christian believers seems to be about accepting that one is powerless in many ways and that one can only rise above it through relating to a Higher Power. These patients were very open to possibilities of God's power, and they trusted in God's beneficent will for them. In this sense they could be said to be responding actively in their open stance to what medicine and life offered them parallel to their belief in a loving and saving God. This was also recognised in family members. An example of this was the wife of participant seven, mentioned earlier, who went to a great deal of trouble to get a puppy which she thought might entertain her husband, but which also added greatly to her workload. She was committed to the care of her husband, and despite the extra workload of caring for the puppy, she overcame concerns for herself in order to add quality to her husband's life with their family. There was another transformative element in the patient, who was able to experience his sense of worth within his family by being open to and grateful for what his wife was offering him.

There is another way in which an active response may bring about sublimation of the experience of illness. This is an ideological belief and relates more to the medical sciences and psychology. Patients are encouraged to 'think positively' about the outcomes of the treatment. There is some scientific evidence to support this way of thinking as it means the body's immune responses are more active when positive thoughts and resultant feelings are experienced. This mindset needs energy on the part of patients, and if they cannot achieve the result of changing the way of thinking about their illness, guilt can often result. This seems a subjective way of self-help, of

‘pulling oneself up by one’s own bootstraps’ as it were, and makes little allowance for any transcendent being beyond the self. While chaplains would not wish to destroy any positive thinking, they may strive to help the patient with religious beliefs to also look to a power beyond their own resources.

Participant five said he could override suffering because “I don’t fight it, I accept it”. This acceptance, while unrelated to faith, still enabled some form of transcendence of his physical pain and therefore some psychological respite as well. This is more like the working of positive thinking, in which patients themselves have the resources to overcome their physical disability. I have seen many patients employ this “positive thinking” and it is encouraged by the medical staff.⁸⁵ However I have also seen that it achieves relief only to a limited extent, and then it may become too much for the personal resources available to that person in their illness to stay positive. While it is not an automatic assumption that because a Christian has a faith they can access that faith to transcend their illness, at least it gives the chaplain a place to start working in terms of finding strength beyond the person when they need it.

I believe it is when the patient cannot see beyond their own plight that there is the risk of slipping into a victim mentality, and in the focus on the self there is no transcendence, no going out to the other, and therefore the victim becomes entrenched in their own position with little hope of transformation.

⁸⁵ I do not know whether this participant employed a particular technique. However in discussion with a Senior Clinical Psychologist on 8/5/08 at *The Alfred* I was told that medical staff use positive thinking in a general way rather than using a particular program. The psychologist expressed her difficulties with this approach when she saw patients who were using positive thinking to extremes. Her opinion is that it is better to be able to face the total reality of one’s condition, which will include possibilities of improvement and also possibilities of decline in health. She does use Cognitive Behavioural Techniques for patients who are depressed or overly anxious and who cannot see any positives in their condition.

Passive Response: I have given some examples from the research sample of patients with a transformative response to illness which is based on their beliefs, and now I will explore some passive responses from the same patient sample. Participant number eight seemed to lack any real religious faith, although he declared his religious affiliation to be Church of England. He was also unmarried and had no immediate family, although he referred to some friends. His manner of answering questions during the interview was quite abrupt, almost to the point of spitting out the responses. There seemed to be an underlying or passive anger in his acceptance of illness and his resulting incapacity. He claimed it was his stubbornness which got him through and which was the source of his inner strength. Anger can be an aspect of grieving for loss and this participant may have been expressing his grief at the loss of his future life in the way he had expected.⁸⁶ There was a passivity in his acceptance of his illness; it was not a peaceful acceptance, but rather a resistant attitude. He had to accept his illness because he had no choice. He thought chaplains were irrelevant and not helpful, and this was certainly the case for him.

Paradoxically this participant stated that he occasionally went to church with friends, and when asked if he ever prayed said “it’s probably when I’ve been to church with somebody, you know, and I’ve prayed with them”. He said he had never prayed for help, and that he didn’t think about his faith, but didn’t say he had no faith. He “didn’t worry about it”, but “just let it go on ... just like everybody else”. His disconnectedness from his religious affiliation was evident. Discussion with him led the researcher to the belief that his anger seemed directed more at himself for becoming incapacitated rather than at God, who wasn’t even worth turning to in trouble. God was irrelevant to this man. He did not have any experience of immediate family to support him,

⁸⁶ See Phil Barker, www.beyondintractability.org/essay/anger : Accessed October 5, 2008

and the one person he had relied on (himself) throughout his life, (he is now seventy-six), had let him down and become unreliable and incapacitated. This man was socially isolated in his experience of illness, with no intimates to support him on a daily basis. Often religious rhetoric or claiming of a denominational affiliation changes nothing and adds no real meaning to a person's life or experience. An ideological religious or clinical ideological stance may also support passive acceptance because such a stance offers a reasonable explanation for suffering.

Another form of passive acceptance can be seen in those patients who use their belief to passively receive treatment or care from medical staff, chaplains and family. While this belief was not evident in this patient sample, I have met patients in my practice who have accepted their suffering as the will of God and seen themselves as united with Jesus in his passion, and consequently they express no will to move beyond that connection. The medical staff find this attitude difficult to work with, because it does not bode well for any improvement in the patient's condition without some will to improve.⁸⁷ These patients are usually very polite in accepting any attention the staff offer, but they do not actively work with any advice, for example doing breathing exercises in-between physiotherapist visits, or planning how they will cope when discharged from hospital. They can become quite apathetic, and sometimes the medical team treat such people as being depressed. This can be an example of "self assurance" in which the patient is unable to explore their faith and the hope it can offer in terms of working with the medical team in dealing with their illness.

⁸⁷ Fitchett refers to patients who are at "spiritual risk" when their faith does not enable them to move in any way in their illness.

In this section I have analysed aspects of the participants' responses in terms of transformation and passive acceptance. I have explored transformation in terms of the way these participating patients overcame or transformed their experience of suffering by looking to the needs of their loved ones and thereby escaping becoming a victim of their illness. A quality of openness to life and meaning was observed in all the participants who were able to transform their experience in any way. These patients all interpreted their faith or religious ideology in a positive way and there were no examples of this being negatively interpreted in this patient sample.

The stance of passive aggression, which is more challenging to work with because most people are uncomfortable with anger, is a passive stance which turns patients' inability to accept their illness inwards. They may not be able or allowed to voice their pain, and so it festers inwardly in anger.⁸⁸ This stance can also be that of families, even when the patient is more accepting or in a place of transformation. Such passivity was observed only once in this research. One participant demonstrated a resistant kind of acceptance, filled with a passive resentment of his condition. All the other recipients seemed accepting of their plight in terms of being ill.

Two Key Themes in the Exploration of Suffering.

1) Jesus – Fellow-traveller and Meaning Maker

In this section I will explore the two themes which I identified as hypotheses in my research. One of the hypotheses for my research was the religious belief that God, having taken on our humanity in Jesus and suffered in a similar fashion, would be of comfort to these patients. In the

⁸⁸ Söelle, *Suffering*, Fortress Press: Philadelphia, 1975. p.76

research interviews a specific question was asked in relation to this, namely, “Does your Christian faith include the belief that God took on our humanity and, in Jesus, experienced suffering and death, and if so, does this seem important to you in your experience of illness?”

There was a diverse range of responses to this question. The responses ranged from: “We know he came down and made himself like us and was crucified – how could that be important to me in my illness?” (participant five), to “It helps to believe that God wanted him, his Son and himself, to understand what it was like to feel that you had something pointless happen to you, and have no control over your life and things like that, so that he could understand where we are coming from when we pray to him about those kinds of things. So it has helped to some extent” (participant six). This participant then went on to say, “It makes him seem like Joe Bloggs next door who also has whatever hardships he has and not someone far away in heaven who’s got everything fantastic and goes ‘Oh, poor you’.” Participant three said, “Jesus also suffered, and if there was just a God who had no idea of how we suffer how would he be able to feel for us like he does, if he hadn’t had to suffer himself? He really suffered so he knows what everyone else suffers.”

For another patient, a weekly communicant, the response was “it’s sort of a long way away from me” but later said, when asked if he had a sense of God being with him in his suffering, “I don’t understand it, but I know he’s there” (participant seven). There were also participants, who self-identified as Christian but who didn’t really believe in the humanity of Jesus and either stated that outright or skirted around the question. “I don’t really believe that part, I mean we were

taught it at school and I took it all in, but I don't really believe it now," (participant ten) was an example of these responses.

The aspect of their faith helping patients to find some meaning in their situation of illness was raised more obliquely by the interview questions. When participant six was asked whether there was any particular aspect of her faith which had helped her she said,

Probably very basically in the belief that there has to be a reason for everything, that horrible things like this don't have no purpose, at all, because there'd just be no point, and that while its not necessarily what God wanted, there are some lessons or things that I need to learn from my experience in order to make me a better and stronger person in the long run...and that there's something that makes that better, whereas if there wasn't something it would just be so pointless and horrible and never-ending in its sadness. Yes, that there's a point to it.

This is an example of belief that enables suffering to be transcended, and meaning to be found in suffering.

2) The Place of Church in Patients' Experience of Suffering

The other hypothesis in the research was that the awareness of a "community of faith" which would offer support to patients would be of importance in participants' experience of illness.

This community of faith might be visiting clergy or parishioners, or the chaplain as their representative in hospital. In the interview the participants were asked about their church attendance patterns in the demographic questions, and in another question "Are there particular people in your church who have been helpful to you at this time and in what ways?"

The response to being asked about people from the church helping them was interesting. Only one patient was an active member of a parish faith community and he said the visitors were his long-term friends. Five respondents said no one had been helpful, and three others received help second hand as it were, through the school community, friends of her mother who were from the church, or prayer groups. Another said he received no help because he “goes to church to give not receive from others.” (Participant nine)

Four of the participants said they didn’t go to church and another that he went rarely, only when he felt like it. One stated she couldn’t get there since her illness but wanted to get back to it, and another also could not go because of his illness but was brought communion each week. The other three had an idiosyncratic pattern of church-going, such as when they went with others, or were passing a church, or “monthly and some other times”.

For at least half of the participants, the church, although a part of their upbringing, was no longer relevant in their faith journey or support system, and so any benefits the church may have to offer were at best received passively. Perhaps the two participants who were prevented from attending church because they were too ill were more actively engaged with their faith community and there was a sense of transformation (Participants six and seven).

C) Analysis and Integration of Christian Themes.

In this section I will reflect theologically on the two research hypotheses discussed in Section B. I will explore the importance of Jesus as fellow-traveller in the experience of suffering, isolation,

and search for meaning. The further discussion of integration, in which I will explore the hospital and social context of the patient participants, is in the chapter on Allied Health.

The Importance of Faith in Jesus as Human

Theologically, Jesus was a perfect victim, who suffered sacrificially, because he alone did not deserve to suffer for any sinfulness.⁸⁹ But Jesus also chose to suffer on behalf of others in contrast to most sufferers who have no choice. These patients had no choice about their suffering, and while for some of them their illness may have been a consequence of their own behaviour, such as smoking, there is still a randomness about which smokers will become ill. Certainly for some patients, their resultant organ failure was because of a random viral attack on that organ. A characteristic of victim mentality in response to suffering is to try and find another person or event to blame. None of these participants expressed that. They were accepting of their illness, and were more intent on finding a way to live within it and beyond it. They connected with Jesus, who also did not blame the authorities who inflicted his suffering.

In the *Acts of the Apostles* Jesus identifies himself with those who are suffering when Paul asked who it was who was meeting him on the road. “I am Jesus, whom you are persecuting” (Ac.9:5). Participant Six certainly had some clear understanding of the fact of Jesus’ innocent suffering helping her to find some meaning in her own innocent suffering. She could feel carried at times by him, could feel he was alongside her as a next-door neighbour, and could then look for growth in herself as a result of her illness and coping with it.

⁸⁹ *The Oxford Dictionary* defines victim in three ways, one of which is “a living creature sacrificed to a deity or in a religious rite”. This is an intentional religious act, whereas one can be a victim by chance in another definition, “a person injured or killed as a result of an event or circumstance.” These patients were only victims in the latter sense, but did not express any sense of victimhood.

This thought leads naturally into a discussion about isolation as a result of suffering. The sense of isolation is a very real aspect of any form of suffering, for several reasons. One is that unless one has suffered it can be very difficult to truly understand the full impact of all that is involved in being alone, weak and ill. Also, the patients tend not to tell their loved ones about their suffering, the inner aspects of it, because they don't want to distress them any further. This is entirely understandable, and is probably the most powerful expression of selfless love they have left with their diminished energy levels.

Theologically speaking, in the Christian tradition, there is one person who has suffered and therefore understands, namely Jesus. The fact of Jesus being God en-fleshed and therefore more than just another person in history who suffered, means that their Christian tradition offers Christian believers an experience of suffering being transcended. There is the fact of being companioned by the God-man Jesus. They are able to trust that this person above all is truly able to understand their situation. It also gives their more mundane form of suffering a worth as it is connected to the redemptive suffering of Jesus the Christ. If the incarnational God in Jesus suffered then God will not be disinterested in those who suffer.

That Jesus also suffered can help people to find some meaning within suffering. The participants seemed to understand Jesus' suffering solely in terms of their own situation, which was in terms of what both Jesus and they had been allotted in life. Jesus also was a role model, in that he suffered well, praying for those who were executing him, and he did not succumb to bitterness of heart. With the exception of participant eight, these participants were not bitter about their illness

either, but seemed, like Jesus, to be accepting of their illness. That is not to say there was no sadness as they grieved for lost relationships and possibilities, and feared for loss of future time with the people they loved.

There was a common attitude in the way these patients, who were not able to transcend their illness were open to both their faith and to people. They were not feeling they were victims but were looking beyond themselves to their families and how they could express their love for them by protecting them from as much of their suffering as possible. They were able to receive the love and care of their families and friends in an open way, and were also open to God in Jesus, as someone who understood their situation, who was “with them all the way” or carrying them as in the “Footprints” prayer.⁹⁰ Because they were open to all possibilities, they were available to receive grace in the myriad ways that they believe God provides it. For some their experience could be connected to the attitude of acceptance of Mary at the Annunciation even though she did not know where this would lead. However, she was open to the will of God and God’s provision of new life. “Let it be with me according to your word.”⁹¹

These are examples of ways in which certain participants were transformed by their faith. Their approach was not one of acceptance in the defeatist sense.⁹² Christian faith can be used in this

⁹⁰ See appendix A

⁹¹ Luke 1: 35, 37.

⁹² For further development of such a defeatist stance see Rowan Williams, *On Christian Theology*, Blackwell Publishing: Oxford, 2000. p.162ff

way though, for example when patients identify with the passion of Christ without reference to the resurrection or afterlife which is a key element of the Christian tradition.⁹³

Church as Community of Support

I will now explore the importance of the church as it appeared in the lives of these patients. My second research hypothesis was that the church community would be important to Christian patients in their experience of illness. This hypothesis was not supported by the participants' responses, but rather they highlighted their family as being that supportive group. However, I will explore 1) aspects of receiving the supportive care of the church passively, 2) family as the supportive community, 3) the place of family in maintaining a sense of identity within illness, 4) the place of family in terms of self-image related to identity, and 5) the lack of personal benefit perceived by these patients in church community involvement.

Firstly, the participant responses showed a very low attendance or participation in religious practice rate for people who declare themselves as belonging to a church tradition. Of those who have some church involvement, it seems that they may be described as passive recipients of what the church has to offer in terms of prayer and sacrament, and works of mercy, such as social help and education. Even the participant who receives weekly communion said that he "accepted the teaching of the church unquestioningly" when asked about his faith (participant seven). He was unable to articulate his faith much beyond that except to say that he was given strength when he

⁹³ While patients were not able to put theological language around their transcending their condition, they exemplified what Harry Williams has written about in *True Resurrection*. Resurrection is something that relates to the present as well as the past or the life to come, and as a Christian chaplain, I believe these patients are experiencing a foretaste of the transformed self of the new Kingdom of God. (2 Tim. 1:1) H.A. Williams, *True Resurrection*, Mitchell Beazley: London, 1972. Pp.3-13

needed it and had a sense of God being with him, although he rarely prayed. It seems he is passive in terms of his belief in God in every aspect, including his belief and reception of grace.

While participant eight was resistant, the rest were all at ease in the presence of a chaplain interviewing them, and I believe would have been happy to have received a pastoral visit from chaplaincy. There was no sense in which they had need of this service, as for all of them their religious belief was a personal one; they had not actively engaged with their faith community in recent years. The possible exception to this might be participant seven who received weekly communion, and asked for that from the chaplain when in hospital, but since he talked of people in the parish as “long-term friends” I suspect they were more a social network than a community of faith in the sense of sharing of belief and values as well as support in suffering. I saw little evidence of any transformation in terms of faith community, either the faith community outside the hospital or that represented by the chaplain within the hospital.

In addressing my hypothesis about a supportive community, I believe that for all the participants, with the exception of participant eight, family was both the place of concern in relation to their suffering and their community of support. Family was mentioned by participants in response to the question about how they suffered e.g. “It cost me my marriage – she didn’t know if she loved me because I was sick” (participant two), “Watching the family suffer as they try to help you (participants three and seven), and “Watching my son trying not to show his worry” and “Mum because she tried to help” (participant three). Family were also named as being important in response to the interview question “What else have you found that has helped you manage your suffering?” Examples of responses were “My family, they make me feel better” (participants

one five, six and ten), “My family and friends are ready to help” (participants three and five), “Playing with grandchildren I become one of them again” (participant five), “Wife and family” (participants seven and ten), “The dog” (participant ten), and “Others’ belief in me” (participant six). One participant also named “inner strength” (six) and another “my own stubbornness” (eight) as internal qualities they had which were unrelated to other significant people in their lives.

It was not a surprise that those who are suffering expressed a need for a more tangible expression of care and connectedness alongside their faith. Chaplains might articulate this care as a way of caring for Jesus in the other, “I was sick and you took care of me” (Mt. 25:36), and in this way patients can experience grace from God as given and received in many instances and reflects the God who values our humanity so much that he took it upon himself in Jesus. The teaching of Jesus was that people should do more than just piously pray for those who are ill and suffering, but rather to actively do something in the way of caring for these people. “Truly I tell you, just as you did it to one of the least of these who are members of my family, you did it to me” (Mt. 25: 40). While it may be that Jesus’ teaching was that in serving others we serve him, this understanding by family members was not articulated in any of the patient interviews.

I believe that one aspect of the suffering of these participants is in their sense of identity, and families are an important aspect of their ability to retain some sense of identity. One participant said that she had lost a sense of “who I am as an active person” (participant six). I am sure that was one element of the patients’ need to participate as much as possible in the lives and activities of their families, so that they could continue to see themselves as still having their identity as a

parent or spouse. This was referred to in the interviews as being difficult to maintain e.g. participant seven who tried to help his wife with the dishes, or participant three who tried to spare her son from seeing her suffering. Self-perception and self-image are closely linked with one's sense of identity, and illness often impacts on this.⁹⁴

Loss of identity threatens a sense of personhood, a sense of who one is as a person. This is a very deep and personal type of suffering, difficult to articulate and share, and therefore an isolating aspect of suffering. This potential loss of identity is congruent with Cassell's definition of suffering, namely that it is a "state of severe distress associated with events that threaten the intactness of the person."⁹⁵ Paul is described as wrestling with some kind of weakness and he asked God to remove it three times (2 Cor.12:8). The social milieu for Paul was similar to modern Western culture, in which physical and mental prowess was highly valued and seen to be necessary to be a successful person. To lose one's physical strength and fitness can feel like a loss of a part of the self, and participant six expressed it as "the loss of who I was as an active person." People are holistic beings, and the impact of loss of physical wellbeing is felt in the spiritual, mental and emotional aspects of the person. The individual will ordinarily feel less of a person in the loss of physical ability. I believe that the love and care of families helped the patients in this research cohort to feel some self-integrity as to who they were. Even though they were feeling weak physically they were still valued as the member of the family, and in many ways were still given their place, such as mother, patriarch, daughter etc. They would have been able to claim something like Paul's "for whenever I am weak, then I am strong" (2 Cor.12:10), although they may not have always felt that way.

⁹⁴ Williams, *On Christian Theology*, p. 71

⁹⁵ Cassell, 1991. p.33

It would take a great deal of effort and energy for these people to go out from themselves and engage with a church faith community, and perhaps it can be extrapolated that the loss :: gain ratio would fall more heavily on the loss side by making that effort compared to what they might get out of going out to others. They have very limited energy, and need to husband it for their own perceived greatest benefit. For participant seven however, who has been engaged in a faith community for years, the members are now his friends and they come to visit him. It seems that these participants are now relating to a church community in terms of what benefits it might bring them. For participant six, it was of benefit to make the effort when she could in the future for the sake of her children, and so perhaps this is a sacrificial act of love for her family community which is so important to her. I did not detect from her responses that her own faith felt in need of support from a church-based faith community.

Connection and disconnection in terms of the two research hypotheses.

In this section I will reflect on the research hypotheses and the results coming from the patient responses in terms of connectedness and disconnectedness.

Relationship with Jesus: I believe I can demonstrate that the first hypothesis which was that their relationship with Jesus would be important in their suffering was correct. These participants connected with the fact of Jesus' life, death and resurrection as important in their experience of illness. However the second hypothesis about the church as an important supportive community is not correct and church is not important in their experience of illness, but rather the community of their family was of primary importance. The patients were generally disconnected from the church faith community.

My first hypothesis about the importance of Jesus' suffering was correct, although the participants articulated it differently. But it was important to them that God in Jesus understood what they were going through because he had also suffered as a human. Responses such as "he really suffered so he knows what everyone else suffers" sum up the general sense of being understood, and therefore they didn't have to explain or justify themselves to God. For them, it seemed that God already knew and accepted them as they were. There was a real connection for these patients.

There was also a sense that Jesus would know how they "felt" as well as understanding their situation, and this is another level of trust in God. They were able to be "at home" with God, because his Son had been a fellow-traveller with them. These people felt so "at home" with God that they were all able to pray, and indeed did so, with more or less regularity, whether or not they went to church. It was as if their journeying with Jesus the fellow-sufferer meant they could bypass the church, as if it were irrelevant to them. Their relationship with Jesus was important, but their relationship with the community of Jesus was either insignificant or did not exist at all in their reflections on spirituality. It was not that they did not need a loving community to support them, as I will discuss below, but they did not seem to need the institutional community of faith. There were two exceptions to this.

However their appreciation of Jesus' suffering, which they knew was played out on a bigger canvas than their own lives, also enabled them to rise above their own suffering and consider those around them whom they loved. They did find meaning, but not in a consciously articulated

way. These participants spoke about their efforts to either help their family members or prevent them seeing their suffering. They also spoke of their prayers, which were for others.

Participant two described prayer as “mainly loving others.” I found this to be an impressive level of sublimation of his personal situation. This was a man whose wife had left him when he got sick and who was now mostly housebound, and yet he could rise above or transcend his own state and think of others in his prayer. This was consistent with his whole attitude as a patient. There is surely a transformative process taking place here, which connects this patient with the salvific suffering of Jesus.

Jesus’ suffering was transformative for some participants in that it enabled them to make some sense out of a seemingly senseless and random suffering in their lives. As participant six said, “If there wasn’t something (. “lessons or things I need to learn”) it would just be so pointless and horrible and never-ending in its sadness.” What helped her make sense of her own suffering was both that she could grow and learn things as a person, and that Jesus, God’s Son, had also suffered in a similarly apparently purposeless way. She was an intelligent and reflective woman, who could see that she was growing in some inner way. Sometimes others could see this growth more clearly and reflect it back to her. She was also learning about the times that God had carried her, and she commented that there was “only one set of footprints” in her journey.⁹⁶ This woman was allowing herself to be transformed in her circumstance of severe, debilitating illness. She had experienced three losses, namely her health, her sense of “myself as an active person”, and her way of being woman and mother by undergoing sterilization. She was fully engaged and

⁹⁶ Participant six referred to the Footprints prayer as an illustration of how she felt God had supported her at difficult times.

open to her life and working within it as well as she was able until she received a transplant. I suspect the reflective process may have been more active at her times of hospitalisation, but she certainly was not shying away from that difficult integrative process. She was pursuing it as well as she was able. I believe there was a very real faith connection in her. This participant was very clear that her journey of suffering was teaching her in many ways, not least of which was a developing of her own inner strengths which others could also see in her.

I believe that for several of the participants⁹⁷ their sense of isolation was transcended by their belief in Jesus as a fellow-sufferer. Participant three said she lived “with Jesus beside her”. This was also stated as, “Jesus also suffered so God can feel for us – he knows” (participant three). However I noted that these responses were to a question about what it was about their faith that was helpful, but when asked about whether their belief in Jesus as human was important, they seemed thrown by the question. This suggests that these participants made a real connection with Jesus in their own way in their personal lives, and that the traditional way the churches articulate this relationship in terms of incarnate Godhead was neither helpful nor relevant.

They expressed the awareness, with the exception of participant eight, that they were in need of help from a transcendent being beyond their own strength and power, and they connected with this being. While, with the exception of participant eight, they were all positive and relatively cheerful, they were also very realistic about the circumstances of their illness. I believe they believed that the transformative power came from elsewhere, from a source beyond them, not simply from positive thinking.

⁹⁷ I believe this was evidenced by 60% of the participants from their responses.

There was a common theme in the responses of all the patients who had transcended their illness and found ways to rise above it. They were open people, open to the possibilities of medical treatments, even heart or lung transplants, and they were open to other avenues of help from family and friends, and were welcoming of me from pastoral care. They had taken an open stance to life even as their bodies were apparently closing down. I found this to be a much graced position to be in, and I believe the fact that these non-churchgoing participants turned to prayer was a sign that they recognised at some level the source of their strength.

There is also some maturity in their belief in God, in that they have remained in some level of relationship with God even though their lives, in terms of health, have not substantially changed for the better. Their expectation of God is that God will give them strength, as one participant said, “God give me strength, and he does” (participant seven). Another said his relationship with God was important and I understood that he meant the relationship must be a two-way intercourse (participant nine). Only one participant said she felt let down by God and that was at times when she nearly died. Otherwise she didn’t have an expectation that God would save her from exacerbations of her illness, but help her get through them (participant ten). These participants had seemed to accept that illness was their lot in life and they only asked for help to bear it. This was in contrast to some people I have ministered to as a chaplain who have totally rejected God following illness or the death of a family member. Williams writes about the importance of meeting or getting to know the risen Christ, because this is the Jesus who is beyond particular times and places⁹⁸. These participants were enlivened by their sense of Jesus’

⁹⁸ Williams, *Resurrection*, p.89

accompaniment on their journey of suffering. It was important to them that the man Jesus would understand, having suffered in a very real way himself.

In my clinical practice many patients refer to the “Footprints” prayer as matching their experience. While some patients, as part of a depressed state within their illness, describe a feeling of there being no sense of God or a sense of God not caring, they sometimes later on say that God was there all along, and was important in their recovery. While this was not reported by any of the research participants, perhaps it is an unreal spiritual expectation to assume that a conscious faith will always be a part of the journey of illness. This might explain why family is also very important to these people, as they carry their loved one through the acute phases when they have no reserves of energy to reflect on God or any aspect of their faith. In fact Participant Six gave voice to this when saying: “...my brother sent me a card the other day with “Footprints” in it, and when I think about that sort of thing, you know, when God carried you when you think he left you.”

Family and Church: My second research hypothesis was that the church as their faith community would be important for Christians in their suffering. This was not demonstrated by the participant responses. In fact, as mentioned above, there was generally a disconnection with their faith community, both as represented by clergy or lay involvement in visiting them or in their use of hospital chaplains as the representatives of faith communities.

Much of what Christian chaplains do in a healthcare facility is, I believe, sacramental, that is to say chaplains represent the presence of God in a tangible way, although that is more often than

not left un-named. Even when visiting those patients who have declared a religious affiliation, God may not be named or mentioned, but there can be a realisation on the patient's part of chaplains representing something greater than the role. This is demonstrated when chaplains have barely introduced themselves, and the patient will launch into talk about the critical nature of their illness, or the difficulties they are having sharing with their family, something which I believe shows they understand a deeper experience of connectedness in the conversation.

As a chaplain, I believe that when the patients in this questionnaire talked about their families in relation to their suffering and what helps them, they are talking about a deep spiritual issue. I believe that family can be understood as a sacramental representation of church. The community of faith believes that the body of Christ, as they meet in God's Name, make Christ present and alive, and that this is facilitated by the indwelling of the Holy Spirit⁹⁹. There are expectations of transformation and growth into the life of Christ, with fruits of this obvious in the life of its members. There is a faith and hope that these members will grow beyond themselves, transcend themselves and grow in their love for others. Mostly this will be lived out modestly in the way Christians behave and live with their families and those they work with.

Summary

In this research I have discovered these transformative fruits taking shape in the lives of the patients in the way they live beyond themselves for their family members, and believe that it is true to say that God's transformative Spirit indicates a presence of God in these families, although not necessarily articulated in those terms. It seems that for these patients, who have a

⁹⁹ Williams, *On Christian Theology* pp.188-9

belief in the Jesus who is with them in some way and knows about their suffering and can understand it, the faith community of God or Jesus, is represented in their families in a similar sacramental way as the church community of faith. It seems that these families incarnate God's love for these patients in the many ways they care for them, and they also love their families in a God-like sacrificial way of denying themselves the luxury of sharing their suffering and saddening their loved ones. They are also on a journey of being able to graciously receive that care, which can often be the most difficult aspect of being ill, namely being dependent on, or receiving from others.

Chapter Five: Research Recommendations and Conclusions

In this chapter I will bring together some final reflections on the results of the research in terms of my original hypotheses, and then discuss some recommendations for healthcare chaplains which can be drawn from the findings. The patients in this research sample interpreted their faith or religious belief system in a positive way with only one example of negative interpretation. Recommendations I will discuss will include 1) identity issues for patients, 2) working with esoteric or unexpected beliefs, 3) connection with Christian faith, 4) the place of the Church in healthcare chaplaincy, 5) organisational issues, and 6) finally chaplaincy training.

I will also reflect on the learning process which this research project has been for me. I believe I am the first to do qualitative research which has been wholly thematic in its approach and analysis in the field of chaplaincy and pastoral care. The findings have been deductive from the patient responses, and there are some implications for chaplaincy which were not expected by the researcher. Finally I will briefly reflect on possible future lines of enquiry which I believe this research has raised.

Learning from the Research and Thesis Project

I thought I knew something about research practice after being on The Alfred Human Research and Ethics Committee for nearly seven years, but there was a great deal of experiential learning for me in the actual carrying out of the research itself. I learned that a chaplain as/or researcher is not in control, because the patients come from their own understanding of faith, and it was from that understanding I needed to deductively engage in my theological reflection. Initially I had

planned to reflect on the patients' responses in light of the pastoral theology of Dr Rowan Williams, but it became clear that the patients' understanding was different and unique. To have used another theologian to analyse their responses would have meant not honouring their understandings and using inductive reflective discussion which I was unwilling to do. It seemed to me imperative to reflect deductively on the responses given. Hence the lack of control which I experienced as researcher, and my need to reshape the thesis in terms of the theology so that I could do justice to the participants.

I had also, in the very early stages of designing my thesis, not thought to include any reference to Allied Health understanding of spirituality and suffering. Again the patients set the agenda, as I realised that in order to truly theologically reflect on their suffering, I would need to take into account the medical setting and the medical understandings surrounding these patients.

While I am enormously grateful to both of my supervisors for their patient help and guidance in the process of research and thesis writing, the patients have been my teachers in terms of how they understand their Christian faith. This meant that I did not always recognise the importance of what they were telling me initially, but the more I reflected on their responses, the more I realised how much more of this sort of research needs to be done so they can be better understood in terms of their spirituality and faith and the ways it helps them in the place of suffering.

Conclusions from Research Responses for the Future of Chaplaincy

1) Identity Issues for the Patients.

The chaplain offers him or herself as the representative of Christ to be a fellow-traveller with the patient. The chaplain is called to be a symbol of hope, which while this may not be articulated, it will be lived out in the chaplain's faith and being. The Christian chaplain will also be someone who has meditated upon the life, death and resurrection of Jesus, and so will be present and listen to the patient with the heart and mind of Christ. Because the chaplain is not someone with close emotional ties he/she will often be seen as a safe person to voice suffering to, as a person to whom patients and family members can speak "the unspeakable" in terms of their inner suffering. In this act of listening deeply to the pain of the patient, the chaplain may facilitate the patient's finding of some personal acceptance of their situation, and also the terms of reference of that acceptance. That is to say, the patient may be able to discover where their illness fits within their life meaning and values, and hopefully where it all sits in terms of their faith in God. I mean by this both a positive and active acceptance of their illness, a coming to terms with its impact on their inner being and who they are. Out of that, the patient may find a way to live positively with the life and energy they have left. This is indeed a way of transcending their illness and seeming loss of identity.

The physical body is one aspect of our self-perception. The patients in this study had a holistic sense of themselves in that they gave no evidence of any unhealthy attitude that some Christians have of a dualism which elevated the importance of the soul or spirit over the body which was seen as something of a burden to be overcome. These patients seemed to perceive themselves as

wholly integrated selves.¹⁰⁰ Families can be a place where love is expressed in very physical and tangible ways, the whole person is related to in this context, and therefore a place is found for full identity as a person.

A sense of identity is an important aspect of a person's sense of self-worth, and is a core basic psychological need for everyone. This giving of oneself is always expressed with the whole of the person, which involves the physical as well as emotional, rational and psychological. In severe, chronic illness the energy and ability to self-express to the other is depleted, and hence this physical aspect of life was one which was named by nearly all the participants when asked about how they suffered from their illness. Sometimes the most they could contribute, which is in fact a great deal, was to protect their loved ones from seeing their suffering as much as they could.

Chaplains are in an excellent position to affirm and name the love and identity which is offered and found within family. From the patient's perspective acts of love, such as shielding loved ones from seeing their suffering, may seem trivial. The chaplain can then name it as a God-like, sacrificial love, in that it is self-sacrificing, at a time when the patient most needs the love and understanding of those who are close to them. It can be named as "God-like" to those who declare a belief in God, but may be named as sacrificial or ideal parenting or partnering as they put the needs of the other before self. The chaplain can be present to affirm patients for who they are as a person, regardless of their lack of physical strength and ability. The family can also be affirmed by the chaplain for their role not only in caring, but for their faithfulness in love to their

¹⁰⁰ The negative and dualistic spirit of Jansenism has lingered in the Christian churches well beyond the time of its active practice and belief, and there have been some quite unhealthy divisive attitudes to our physical being especially in the Christian life in the 18th and 19th centuries.

sick family member. This can be very difficult for adult sons and daughters who have been used to seeing a parent as the strong one, as they now take the place of carer. It is also difficult for spouses who are used to sharing and who feel they can no longer burden their sick spouse with worries over finances or other domestic matters. The chaplain can sometimes become almost an “honorary” family member during an acute hospital admission as different family members, including the patient, share some of the worries from their own perspective. This is a very privileged position of trust to be in.

Patients often struggle to maintain their sense of personal identity and autonomy within the hospital setting. They are expected to fit in with the hospital’s routine and conform to its culture, no matter how foreign it might be to the patient’s own way of living. While usually there is a rhetoric of patient autonomy, the reality is that patients pick up on the unspoken word of “if you want to get better you will do things our way.” Hospitals are large and can be frightening institutions, and so it is usually a very daunting thing for patients to assert any real autonomy about routine, or how they would like to be treated. Chaplains are in an excellent position as members of the health team who stand outside of their medical treatment, to act as patient advocates. This may mean encouraging patients to speak out for themselves, or speaking on their behalf and with their permission.

2) The Christian Chaplain’s Role with Diverse Religious Beliefs of Patients

Chaplains need to listen to the faith of the person very carefully, as even if patients have a declared religious affiliation, they may have a very esoteric version of that faith. The patients and their families are themselves caught up in their situation of suffering, and often do not have the

opportunity to engage in theological reflection on that situation. Therefore it is important that the chaplain be able to do this where it is appropriate. Whether or not their reflection is ever shared with patient or family members, the minister will have given some thought to the nature of God's presence and engagement in the situation of suffering that they recognise in the patients. The majority of patients in this small sample, while declaring themselves to be Christian, gave no evidence of being engaged in an ongoing process of exploring their Christian beliefs. Some of their understanding was eclectic and would not be recognised as orthodox by those churches they were affiliated with. The chaplain may be able to reflect with the patient on their faith, shedding some light or inviting further thought or highlighting other possibilities to think about. While families are caught up in their loved one's illness and consequent care, chaplains choose to minister to the sick out of a sense of vocation, and therefore can be more objective as they articulate and explore the relevance of belief to a situation.

Chaplains cannot take for granted that just because a patient has declared themselves to be of a specific denomination, the patient is necessarily practising that faith or is in line with that church's teaching. Apart from clerical error in the healthcare system which may have a Catholic nun as "Nil" religion or a faithful Anglican as "Unitarian", as I have experienced, there needs to be an alertness to what the denominational affiliation might mean for each patient. For some it may be making more of a statement about social placement and origins. An example of this is an Englishman who declared he was Church of England because of his link with his village church and all that meant in his early life in England, which is still so much a part of who he is, even in Australia many years later. Or it may be that a woman went to a Catholic school and she sees that childhood past as her faith affiliation, rather than reflecting on her present beliefs and

affiliations. Jewish people recognise this in a more realistic way and differentiate between religious and cultural Jews. For Jewish patients, a visit from a Jewish visiting chaplain is seen as a link with their community, but not necessarily a religious visit.

This connection with family origins and community is something that hospital chaplains have not been good at recognising and taking into account in the past. Chaplains have given notional recognition to the dis-connection that hospital admission might mean, but they have not necessarily thought through the implications of this in terms of a disruption to patients' identity and support system. Gibbons has written about this issue in terms of chaplains making pastoral diagnoses.¹⁰¹ This is an important consideration, as it will give chaplains indicators of what ministry needs the patient actually has.

The chaplain's role is that of Christ's outreach on behalf of the church, and not just as a generic spiritual representative. There is a move amongst some chaplains to recognise non-faith-based women and men as chaplains. However, I believe this study reveals that patients have both esoteric and subtle understandings of their Christian beliefs, and there needs to be some understanding of diverse forms of spirituality and of belief in the transcendent to be able to understand patients who may have moved to neo- or post-Christian beliefs in a transcendent Being, who they may name as God and Jesus. It is unclear to me how a person who has no faith in a transcendent dimension of personhood can walk alongside and explore this with patients. I hope that chaplains who have a belief system and practice in place can walk with those who give

¹⁰¹ Graeme D. Gibbons, "Spirituality and Health Care", in *Ministry Society and Theology*, Vol 2. No. 2, Nov. 1988. pp. 42-45.

no evidence of having a belief in the transcendent to support them in whatever spirituality enables the patients to find meaning in their suffering.

Chaplains, who have some training in theology, need to find ways of speaking about the Christian faith that are congruent with how theologically untrained or unsophisticated people make sense of their beliefs for themselves. We must also allow for some personal idiosyncrasies as people sift out what they will accept and not accept from orthodox or conventional Christian teaching of the mainstream churches. Chaplains are taught to let the patient direct the conversation but they can often facilitate a deeper treatment of the subject than the patient would have been able to engage in on their own. This can lead to a very deep sharing on the part of the patient, what I would describe as a deeply spiritual conversation, although neither the word “spirituality” nor “God” may be used.

Patient’s families may often have a different belief to the patient, and may try to impose their beliefs on the situation as the patient becomes less well. Chaplains will need to work with great sensitivity when they try to be the voice of the patient as they are rendered voiceless by the increasing severity of their illness, and at the same time hear the concerns of family for their loved one.

3) Patients’ Connection with Christian Faith

The patients in this research generally related closely to the suffering of Jesus, and it gave them a real sense of connectedness with God in their own sufferings. Through Jesus they knew that God understood their plight and walked closely with them in a supportive way. There was little sense

of self-pity in their attitude to life, but neither was there hope of a cure. They looked to the medical staff for relief of their current symptoms, and hoped to continue for as long as possible in this life so they could spend more time with their families. I could identify in several of these participants a triumph of spirit over their physical sufferings. In some cases this meant they could disregard their own sufferings sufficiently to care more about their loved ones, such as protecting a son from seeing how much his mother was indeed suffering.

As a Christian and as chaplain, theologically it seems unsatisfying to me that the participants for whom Jesus' suffering was important communicated no sense of resurrection for themselves or in their Christian beliefs. The Christian church has always celebrated Jesus' suffering and death in conjunction with the entire Paschal Mystery of the life, death and resurrection of Jesus, or new life, and yet these participants did not have any sense of this. Their experience is important and needs our attention in regard to Christian education and preaching.

4) The Place of Church in Healthcare Chaplaincy

Traditionally it has not been entirely comfortable for chaplains as they bridge their churches and the hospital ministry. This can be for several reasons. Sometimes it can be for such a simple reason as a lack of understanding by those in the Church who have never been immersed in a *milieu* of suffering and whose ministry is more one of comfort and cheer within the everyday aspects of life. Sunday services can sometimes seem a far cry from suffering as the focus is on trying to find a supportive place for parishioners to renew their spirit for the week's work. Priests and ministers may experience that there are more demanding commitments and difficulties they face rather than attending to calls to the healthcare institution in their areas. Hospital calls are

often in times of trauma, which may mean being called away from parishes at times of worship, or even when chaplains are expected to provide a worship service at the hospital on a Sunday, which can cause time pressures or may alienate the chaplain from service to their own parish community.

However, if the Church of the future is to be relevant in all situations, I believe chaplains have a responsibility to speak prophetically back to their churches from their experience in healthcare contexts. This may take the form of preachments which address issues of suffering and what the Christian faith offers at such times. Or it may take the form of research and study on healthcare chaplaincy, which can then be fed back into the Church. This thesis is intended as one way of exploration to do this and I will look for ways to feed the results back in to the Anglican Church in particular, and also to other Christian churches who provide chaplains.

Historically, chaplains have been focused on clinical work and not on writing or research. The Healthcare Chaplaincy Council of Victoria (HCCVI) is planning to change this by introducing a Diploma in Chaplaincy in which research will be addressed as one of the subjects. Research will not only give chaplains a tool for speaking with their churches, but also to the healthcare institutions. Research is language medical institutions understand, and data will be important to feed back to hospital management for future funding and planning.

Is God only present where God is named as being present? For example, in a church service God is named as being present, and there is also intention in that it is the people of God meeting to worship God; can we also say that God is not present if not named or there is no intention

regarding God? In the hospital setting the chaplain has some intention about their role as the “God-person” within the organisation, even if the patients and staff do not always see that as clearly. And this is very much the intention in visiting patients, that they are an outreaching of the incarnate love of God in the person of Jesus.

5) Organisational Issues re Spirituality.

Chaplains and Pastoral Care Workers seem to be silent in our healthcare institutions, and I suspect this is because of the need to be politically correct and / or to respect others’ beliefs or lack of beliefs. Chaplains in a secular institution have no right to start talking about the benefits of a belief in God unless the patient indicates that is what they would like. They can only reflect back the patients’ own realisations of their suffering experiences, or their lack of spiritual or other resources and need for meaning in their suffering. From this they might try to explore with patients where else they might expect to look for help, but always being guided by a sensitivity to the other person’s place. However, that need not stop chaplains from being articulate within the culture of the institution and amongst other interdisciplinary colleagues and expressing what they see as an area of needed support or difficulty for some patients in their healing process.

The very fact of chaplains being members of the employed staff of a secular healthcare institution is a witness in itself. The presence of a chapel or Spirituality Centre speaks of the recognition of a spiritual and transcendent dimension to health and life. Hospital-employed chaplains, who are ecumenical and multi-faith, usually find ways to be present across their healthcare organisation in a way that no other departmental member, except the CEO, either has

the authority or the ability to do. That presence also witnesses to a dimension of being within the organisation that transcends the ordinary management structure while also being subject to it.

I believe that there are many ways in which beliefs of patients are not heard, or even asked about. Patients who are listed as “No Religion” may in fact have a very strong belief in a higher power, and will often name that power as God, or in fact may not even have been asked about their religion on admission. The latter is often the case with emergency admissions to hospital. Other health workers within the organisation can then be puzzled about the necessity of chaplaincy in these instances. I believe that chaplaincy can be even more important in these cases than if the patient was engaged actively with a faith community. It may indicate isolation in their place of belief, and someone with whom to share and explore may be quite strengthening at a time of vulnerability.

Nursing and other Allied Health journals are beginning to address patient care in a holistic way, and now look at spiritual assessment as part of the complete assessment of a patient’s needs on admission to the ward. This aspect of general nursing care is a far cry from the traditional nursing practice in Australia, and the Australian nursing and other allied health journals suggest that this interest in spiritual care of patients is greater in the United States of America and Great Britain than it is in Australia. As a hospital chaplain I am concerned with talk about spirituality which leaves out the recognition of a power which is higher than the self, and I believe this understanding has evolved as spiritual care has often devolved to other allied health disciplines. It has become more popular in healthcare literature to address the issue of spirituality as something that might impact on a patient’s experience of illness and recovery process. The culture within the healthcare institution in which I work has a general understanding of

spirituality that does not seem to include the transcendent dimension. If practitioners, be they nurse or social worker, are not open to the spiritual dimension, it is unlikely that they will hear the sacred or deeper dimension or questions within the ordinary life of the patient. It is interesting to note that nurses who have a respect for religious faith are the ones who make referrals to Pastoral Care, not those who have no time for it themselves. This is a difficulty which overflows into spiritual care across the allied health spectrum. These workers are not trained to hear complexities or nuances of spirituality or religious faith, nor are they trained to explore them with patients.

The author of an article in *Holistic Nursing Practice*, a journal from the United States, presumes that nurses will offer prayer with patients, and the writer tries to educate readers about using a wider variety of prayer than just that which the nurse might be personally used to, encouraging the nurse to look at what the prayer practice of the patient might be.¹⁰² In Australia, and certainly in my own organisation, the practice of prayer by nurses would be seen as a crossing of boundaries into the realm of pastoral care and not encouraged! Without training, a nurse may only be aware of how prayer is offered within his or her own faith community, and it might be quite foreign to the patient e.g. a Catholic is generally more likely to be comfortable with the Hail Mary and Our Father, but a Pentecostal Christian patient would be quite uncomfortable with that, and would want something far more extemporary and “spirit-led”. Prayer is usually asked for in the context of a pastoral conversation and rarely does the request for prayer come “out of the blue”. Again, I would not advise healthcare professionals without appropriate training to

¹⁰² M. Durfee-Fowler, “Form Prayer and Nursing Care”, *Holistic Nursing Practice*, Sep/Oct 17 (5) (2003),pp. 239-241

engage in pastoral care, just as I, as chaplain, would not presume to engage in social work or nursing matters.

6) Chaplaincy training – Chaplaincy training will need to involve theological education and vocational formation as well as some education in the social or health sciences. Theological studies will include the study of theology of their own faith or denominational tradition as well as some knowledge of other Christian denominations and religious faiths. It also demands that chaplains be well formed in their spiritual life and religious practices in order to maintain their own spiritual well-being in the midst of suffering. The second aspect requires some education in social sciences, such as sociology and psychology, in order to work with patients in the healthcare context. Patients are always part of a family and social context as well as a religious/spiritual background, and chaplains need to be aware of this as they interact with patients and their families, or with the absence of family members.

At the time of writing, the requirements for a healthcare chaplaincy position are tertiary level theology or pastoral care studies and two or three units of Clinical Pastoral Education (CPE). If chaplains have been formed in a traditional theological stance, and are immersed in the life of their own faith community, they will usually have a different understanding of where patients who declare themselves religiously affiliated might be, especially if the patients in fact no longer attend a church, or are only nominally Christian in their beliefs. It will need a level of alertness and listening to ascertain the other's faith position rather than to assume they will conform to, or even be informed by their church's beliefs or teachings. Where the faith of the patient is idiosyncratic or ideological, it will be even more important that the chaplain listens carefully to

the nature of the other's beliefs and values in detail. How the patient may be helped to access their faith as a resource may be challenging at times, because it may be quite foreign to the chaplain or in fact not be helpful to the patient because of its unorthodox or limited understanding of God. Sometimes also, the patient's understanding of God may be too small, or be limiting of God. I believe this makes it of primary importance that there is a practical pastoral component in theological training for clergy and those in any sector ministry, so that they have the skills necessary to listen to where the other person is coming from and how they understand their faith. Patients are in a vulnerable place, and chaplains must always be careful not to take advantage of that vulnerability in any way.

Conclusion

This research highlights some significant and nuanced findings which are important to healthcare chaplaincy, as I have outlined in this final chapter. I also believe this thesis highlights the need for further research and exploration in healthcare chaplaincy and pastoral care. As I write I am aware of a research project being conducted at The Alfred which intends to map the spiritual journey of patients, their families and staff members. However, I am also aware of a need for further research to take into account the faith of people in parishes, as this is where their faith is formed and nurtured before Christians are exposed to a health crisis in which a mature faith could benefit them greatly.

Appendix A

“Footprints”

One night a man had a dream. He dreamed he was walking along the beach with the LORD.

Across the sky flashed scenes from his life. For each scene, he noticed two sets of footprints in the sand; one belonged to him and the other to the LORD.

When the last scene of his life flashed before him, he looked back at the footprints in the sand.

He noticed that many times along the path of his life there was only one set of footprints. He also noticed that it happened at the very lowest and saddest times in his life.

This really bothered him and he questioned the LORD about it. “LORD you said that once I decided to follow you, you’d walk with me all the way. But I have noticed that during the most troublesome times in my life, there is only one set of footprints. I don’t understand why when I needed you most you would leave me.”

The LORD replied, “My precious, precious child, I love you and would never leave you. During your times of trial and suffering, when you see only one set of footprints, it was then that I carried you.”

(This is a familiar reflection on cards and posters. One of the many web-sites which reproduces this prayer is: <http://faithweb2.tripod.com/id4.html> - Accessed October 28, 2008)

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