

**My Heart Sings:
learning about spirituality in
palliative care**

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SUMMARY

Holistic health care recognises that body, mind and spirit operate as an integrated whole yet spirituality remains a neglected element of total health care. A co-operative inquiry group, comprising staff from two cancer care centres, met for one year to explore spirituality. The aim of the inquiry was to explore participants' own spirituality with a view to how that affected their work. The eight health care professionals involved in the co-operative inquiry brought varied religious and non-religious perspectives as well as different professional roles. A church based journey into faith group also contributed to the research. A significant outcome of the co-operative inquiry group was the development of a continuing professional education module for health care staff about spiritual care.

Although spirituality is a word used increasingly today, there seems little clarity about the concept. Confusion between spirituality and religion aggravates this lack of clarity. Significant influences in the development of the post modern, western world have marginalised the spiritual to the extent that it can be argued that people have lost a cohesive voice with which to discuss spirituality. For those contributing to this research, the experience of talking about spirituality with others in a safe but challenging environment was both enlightening and encouraging. From this experience emerged a greater clarity about spirituality which influenced both personal and professional experience. Clearer understanding led to greater confidence, enabling individuals from different professions to become more effectively involved in spiritual assessment and spiritual care. Continuing professional education about spirituality, particularly involving reflection on experience, offers an opportunity to extend this work to others.

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PREFACE

In the wake of the terrorist attacks in America, gardening writer Monty Don described his sense that activities such as gardening, far from being trivial, had become doubly precious:

I have no embarrassment about elevating the goals and rewards of gardening to the spiritual. It seems self evident in the sheer power of the life force that fills every cell of the smallest backyard to the great estates. The trick is to pay attention to it, to notice things, to be fully alive yourself (2001: 74).

While carrying out the research on which this thesis is based, those involved have been paying deliberate attention to the spiritual in our everyday life and work. We have experienced together the feeling, expressed by no less a source than Pooh Bear, that ‘*a Thing which seemed very Thingish inside you is quite different when it gets out in the open and has other people looking at it*’ (Milne 1965:99). The outcome of our shared attention has been a clearer understanding but, perhaps even more importantly, a greater confidence when approaching the subject of spirituality. Such outcomes affect our own lives as well as our working practice. During the six years I have been preparing this thesis, spirituality has been referred to increasingly in many different settings. This attention seems unlikely to lessen in the near future but I long that people from all walks of life will attend to spirituality not only more frequently but also more deeply and with greater discernment. This research represents one attempt to facilitate the process of rediscovering a voice with which to speak of spirituality.

Notes:

Numbering of quotations from participants used in the text relies on the system developed by the NUD*IST data analysis programme. The first number indicates the document or co-operative inquiry group meeting and the second number indicates the text unit number within that document. For example: 1:3 indicates session one, text unit 3.

Pseudonyms are used throughout to preserve confidentiality.

INTRODUCTION AND CONTEXT

Chapter One: Theoretical And Personal Concerns

Spirituality is a word in increasing usage today, particularly in education, health care and the arts. Supporting this increasing interest in spirituality is the phenomenon often referred to as post modernism. The phrase is used here to distinguish the current era from the modern era of the early twentieth Century. Two themes often highlighted during discussions about post modernism are particularly pertinent to this thesis. One is a greater openness to other paradigms which can be understood as a reaction against the rational, analytical approach characteristic of modernism (Horseman 1996:3). The optimism of the modern era is harder to sustain as it becomes clear that science and technology alone are not able to solve complex problems such as poverty and environmental damage, and may even be contributing factors. A second related theme is the coexistence of diverse approaches and understandings rather than any single overarching framework (Horseman 1996:5). While discussion about spirituality may appear confused, or even contradictory, it forms a recurring theme in the post modern world. Growing out of my recent experience in palliative care, this research will consider human spirituality specifically within the two complementary subjects of health and adult education. Within health, I have been exploring the essential nature of human spirituality as an aspect of holistic care, including its influence on well being. Within adult education, I have been concerned to discover ways of facilitating greater understanding of spirituality, particularly among health care professionals. The process of exploring spirituality with colleagues led to the development of a series of opportunities for others to explore spirituality, which in turn influenced my own thinking, setting in motion a continuing cycle of reflection and action.

Personal and research interests

I am a white, middle-class British woman with enough income to survive and enough 'leisure' to research issues which are personally important to me. I am a Christian locating myself within a broad Anglican tradition and valuing the variety of ideas that coexist there, while at times frustrated by established church bureaucracy and dogma. My own spiritual journey has been towards a greater recognition of spirituality in the whole of life, towards a sense of integration rather than an isolated individualism. That understanding of spirituality has been profoundly affected by my work in palliative health care. Holism and holistic care, a concept which underpins palliative care but is more widely used, is considered to embrace the integrated care of the whole person,

body, mind and spirit. It seems self evident that human well being should be dependent on the nourishing and sustaining of that whole self. Despite the renewed interest in spirituality, a lack of clarity about the concept remains with only limited apparent opportunity to discuss spirituality openly. Even in holistic care, my own experience suggests that a lack of clarity about the concept of spirituality continues to limit the spiritual care available to clients and health care professionals. The rhetoric of spiritual care as an integral part of the holistic approach is not always recognisable in practice. Discussions with colleagues confirmed this sense that the provision of spiritual care, as opposed to religious care, falls well behind other aspects of the holistic approach. This lack of clarity about spirituality in health care to some extent simply reflects a more general picture. The current resurgence of interest in spirituality in western society follows a period of increasing alienation, outlined in chapter two, which has left a legacy of confusion and uncertainty. The gap between interest in spirituality and its actual development stems partly from the lack of an acceptable common framework within which to explore spirituality. In a modern pluralist society a specifically Christian, or even multi faith, framework is no longer acceptable to the majority, but a clear alternative has not yet emerged. I began this research in order to explore my own uneasy sense that every person has an in-built spiritual potential which is currently often misunderstood and neglected. Opportunities to explore this aspect of self are not widely available or easily recognisable. Palliative care claims to offer one such opportunity but it is not always clear how this occurs in reality.

The root of the word 'spirit' is common with that for breath (as in inspire) suggesting an aspect of life which is vital and yet mundane. A related understanding of spirituality is concerned with elements of life which transcend material and physical aspects of life, distinct yet inseparable from everyday reality. Hope, beauty, love, for example, all lie in this arena and may provide people with meaning and purpose, a key theme in the understanding of spirituality developed during this research. When viewed in this way, spiritual themes can be recognised as an integral part of many everyday life events. Relationships with others, experience of the natural world, art or music, as well as specifically religious or spiritual experiences, all impact on human spirituality. Certain periods of life, notably around times of transition such as birth and death, seem particularly likely to stimulate interest in spirituality. Facing death, as in palliative care, may lead both clients and health care professionals to articulate both metaphysical struggles and a greater appreciation of

life. This may lead to a greater awareness and appreciation of spirituality within everyday life but it may also provoke difficult, even painful, questions. Supporting a client who is struggling with ultimately unanswerable questions (such as ‘who am I?’ and ‘why is this happening?’) extends any encounter between health care professional and client. Similarly, sharing something of a client’s sense of the value of life, despite, or even because of, that life being threatened, enhances our own perception of life. The search for meaning has been a key element of our understanding of spirituality. As health care professionals we may find meanings very different from those of our clients in the experiences we share, indeed each individual may interpret their experiences differently. If, while claiming to offer holistic care, we fail to offer clients the opportunity to explore their own situation in this way, we are not fulfilling our mandate. Our role is not to offer answers but to facilitate the client’s own exploration. Staff need to be comfortable with the fact that they may not have an answer to give clients about spirituality. Offering their own answer may even be profoundly unhelpful. This difficulty touches on issues of human relationships within professional practice such as using intuition or maintaining safe boundaries in professional relationships, all of which can be explored in reflective educational groups. Such groups offer support when participants recognise their own vulnerability in the face of unanswerable questions which crack neat professional barriers, a process which may be highly uncomfortable. Spirituality itself highlights the fact that within our professional roles we remain human beings with our own needs for understanding, meaning and purpose. A frequently revisited metaphor in both our initial inquiry groups and in later continuing education groups was that of the journey. Spiritual exploration is not clearly mapped out and is without a visible end but this sense of discovery remains an important aspect of it. If such a sense of exploration is part of their own life, health care professionals will have greater confidence in recognising and responding to similar concerns in others. The effect of this process on participants’ awareness of spirituality will be discussed further in later chapters.

Mirroring my own experience, colleagues working in palliative care reported a new, or increased, interest in spirituality, which cut across both their personal and professional lives. Indeed, the intertwining of personal and professional, theoretical and practical was a recurring theme throughout this research. Despite the general recognition of spirituality as a core element of holistic care, there appeared to be a lack of opportunity to explore this topic even in the context of palliative care.

Indeed, such opportunities appeared rare in any setting except specifically religious or philosophical organisations. While reluctant to isolate spirituality from the wider context of an integrated approach to health care, my specific focus redresses this wider neglect. My main concern has been to explore spirituality within the context of adult learning, specifically within the safe but challenging environment of small educational groups. The focus of my research was, therefore, on opportunities which enabled groups of adults to reflect on their own spirituality in the setting of palliative health care. The main groups contributing to the research are outlined in figure 1:1.

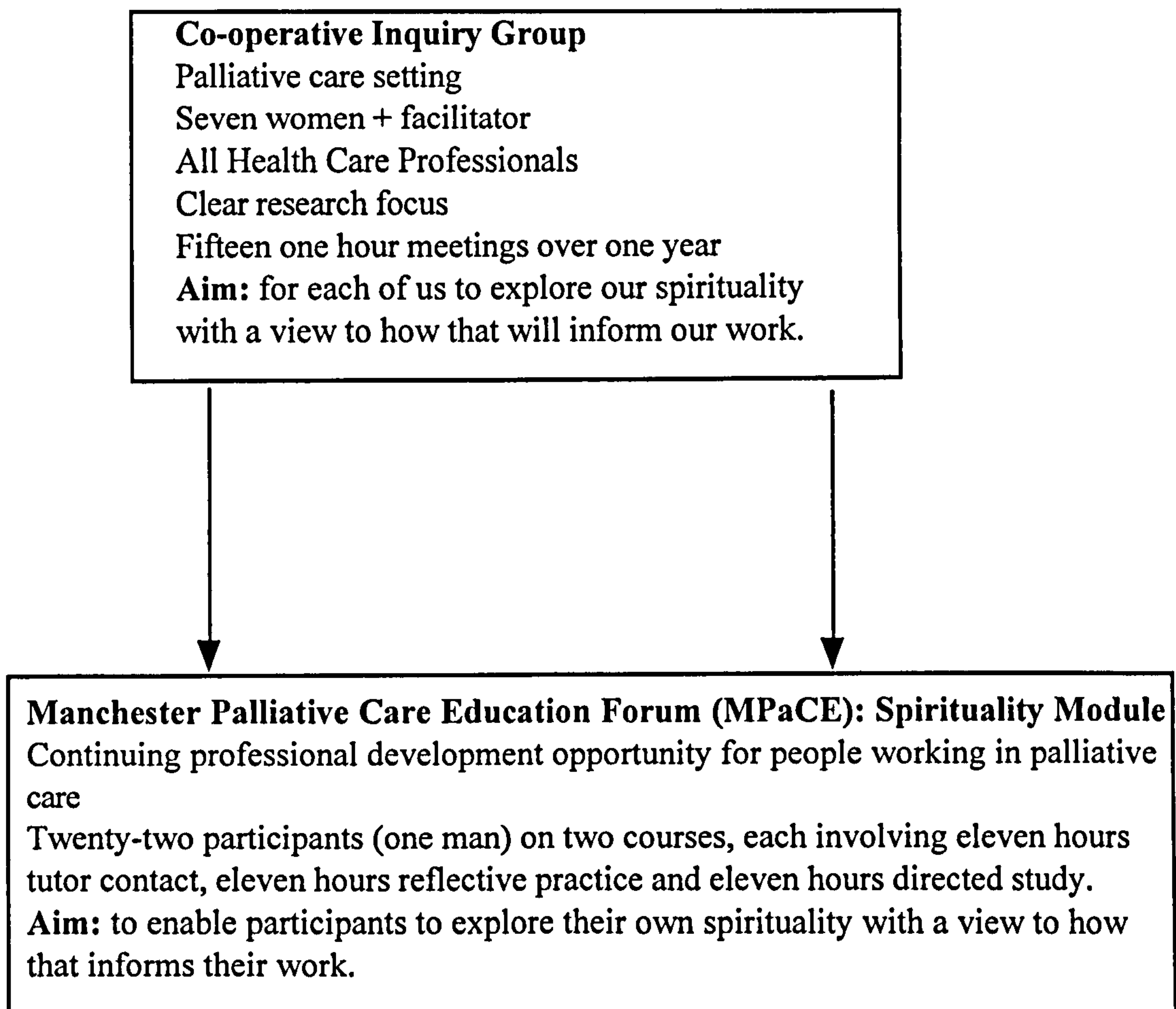


Figure 1:1: Groups Contributing to the Research

During the course of the research it became apparent that while individuals understood spirituality in different ways, certain themes recurred (such as the importance of meaning, hope and connection) whatever the context of the group. Although, initially, I wished to explore the nature and development of spirituality in a variety of contexts,

ultimately there were greater opportunities to develop this work and to affect policy in the arena of continuing professional development within my own work experience. Hence, a work based, palliative care setting provided the primary forum for the research.

As described earlier, the basic theoretical concerns underpinning this thesis are drawn from adult education and health. The research occurred at the intersection of these two areas and was supported by a qualitative research methodology using the framework of co-operative inquiry. The primary focus of the research is on spirituality in health care, particularly palliative health care, and how education can help adults working in this area to explore their own spirituality in the context of their work. A personal reflective diary charts the progress of all aspects of the research and insights from this material will be included in later chapters as appropriate. Co-operative inquiry methods resonate with the values that underpin both holistic care and adult education, including respect for individuals.

Educational concerns

Rather than looking primarily at the theoretical nature of spirituality or the practical provision of spiritual care, I have been concerned to identify and address the learning needs of palliative health care staff in relation to spirituality. While it may be possible to learn about spirituality in a purely theoretical way, I have not taken this approach for the reasons described earlier. Instead I have focused on the development of a more integrated understanding of spirituality and the application of this understanding to health care practice. Finding and utilising an educational approach, which would enable people to learn about spirituality in a way which embraces both personal and theoretical concerns, was a vitally important aspect of the research process. It seemed likely that learning about spirituality, a complex aspect of human personality, would need a predominantly experiential rather than cognitive or skills based approach. Research in both America and the United Kingdom suggests a significant practice-theory gap in this area, such that while the importance of spirituality is affirmed, in practice spiritual care is often limited (Taylor, Highfield and Amenta 1994, Waugh 1992:iii, Ross 1997a). Nursing staff may recognise spiritual concerns but feel unable to respond personally for a number of reasons ranging from practical issues, such as limited time and an unsuitable environment to lack of staff confidence and understanding (Ross 1997a, Taylor, Highfield and Amenta 1994, Narayanasamy 1993).

Other research has shown that health care professionals consistently use distancing techniques to block attempts by clients to disclose psychological concerns (Maguire 1985, Maguire et al 1996a). Personal awareness of the spiritual dimension, similar experiences and a perception of spiritual care as part of their role all facilitated a personal response to perceived spiritual need (Ross 1997a).

A multidisciplinary, team approach is central to palliative care provision. If, as described above, spirituality is such an integral part of holistic care, all team members need to be aware of the issues involved and comfortable enough with these issues to recognise and respond to clients' concerns. Continuing professional education activities in this research, therefore, concentrated on introducing spirituality and spiritual care to the wider palliative care team, rather than on educating a small number of specialists. Fundamental to this research has been enabling health care professionals to explore these intangible issues in a safe but challenging environment, thus building both awareness of the issues involved and confidence about their ability to respond. My hope is that this process of self exploration, especially taking an integrated approach, will support participants who encounter such issues with clients. Key educational approaches which have underpinned this work include the following concepts which are common in the practice of adult and continuing education.

Adult learning

The term 'andragogy' may be used to distinguish the art and science of helping adults learn (Knowles 1990:54-55). Too sharp a distinction between adult and child learning can be criticised (Tennant 1986) and Knowles himself avoids this extreme. Yet the adult nature of all those learning as part of this research should not be ignored. Knowles suggests that andragogy rests on four crucial features of growing maturity: that self concept moves from dependence towards self direction; the resource of increasing experience; readiness to learn is oriented towards social roles and the orientation of learning shifts towards immediate problem solving (Knowles 1990:55). Certainly all those taking part in this research brought a wealth of experience and knowledge about spirituality, learning was oriented towards their social roles and problem solving related to those roles can be clearly seen. Learning was largely self directed, in that there was no necessity for people to take part, although collective learning was a very important feature throughout. Indeed, a key feature of this research was to create continuing professional education opportunities which drew on personal

experience rather than giving information. Such opportunities provide a setting in which to consider theoretical ideas, old and new, in the light of personal experience. In this process of reflection, learners may recognise the relevance of spirituality to their work, for example, for the first time. Such learning also creates a space to recognise ideas which have previously been tacitly accepted ('taken as given'). For example, in spirituality this may include the assumption that spirituality is the same as religion or only the concern of religious people. When such assumptions are made overt they can be more easily challenged, reflection may then lead to change, or affirmation, so that their effect on practice becomes more transparent. This way of working with experience can be difficult for participants and tutors, involving as it does a degree of personal challenge and an equity which both may find uncomfortable. Individuals may not recognise such a process as learning because of previous education which emphasised knowledge in isolation from experience. However, using experience is an important motivating factor in learning, at least ensuring that educational opportunities are relevant and, at best, profoundly affecting the life and work of those concerned. A significant proportion of the people involved in this research described how personal experiences had motivated them to explore spiritual issues. Karpiak uses the term '*teachable moment*' (Havighurst, used by Karpiak 1992:53) to identify particular opportunities in professional development which provide a catalyst for learning. Working with people who are dying, whether in palliative care or not, may provide such a moment for spirituality.

Knowles (1990:56-57) suggests self direction is a key feature of adult learners, who prefer to learn what they understand as important rather than simply follow what is suggested to them. This may change as the pressure increases on qualified health care staff to complete further education and to maintain competence. However there is currently little pressure on general health care staff to explore personal spirituality as part of their continuing professional development. Any individual, health care professional, care assistant or volunteer, may wish to explore this area at particular points in their life, significant among which would be an encounter with dying people and their carers. As spirituality is explored and develops, working practice may be affected in return, engendering a sense of mutual benefit for individuals and their employers. Opportunities to learn about spirituality in this personal and experiential way should be available to all those involved in the wider multidisciplinary team. Participation in such educational opportunities about

spirituality, especially personal spirituality, must remain voluntary, so that a comprehensive approach remains difficult, an issue that will be returned to later.

Work in groups was another important aspect of this research, in both the initial co-operative inquiry phase of the research and the resulting development of continuing professional development opportunities concerned with spirituality. Small groups also provided an additional forum for non health aspects of the research. Groups of individuals have a synergy as they bring together a range of experience and ideas with which to build a wider and deeper picture of spirituality. Exploring such issues in the context of a group also demands, to a significant extent, that ideas and experiences are articulated by participants. Attempting to explain tacit beliefs and ideas to others, in a supportive environment, may actually help participants clarify and develop their own thinking, enabling them to encounter their own and other peoples' ideas in new ways. Basic principles of work with groups, such as respect and a concern for equity, lie at the very heart of adult education and have proved essential in facilitating discussions about spirituality. Such principles are vitally important in this sensitive area, where the material is essentially exploratory and participants are struggling to express complex ideas that are difficult to articulate. Establishing and maintaining a group dynamic that provides an environment in which participants feel safe both to explore and challenge has been a central aspect of the research. Due attention needs to be paid to this process and the time and effort it involves. An understanding of group dynamics and the role of the facilitator are important elements of the research which will be considered further in chapter three.

Continuing professional development

Commitment to continuing professional development is a basic requirement for most health care staff, important for maintaining competency to practice as well as for learning about new skills or techniques (Department of Health 1998:41-49). Also important for National Health Service employees is the growing emphasis on clinical outcomes and effective practice, mediated partly through continuing professional development (Department of Health 1998:33-38). Health care professionals working in palliative care are generally highly experienced with, or in the process of acquiring, specialist qualifications. There are many areas in which such staff could further their professional development but, as already indicated, working with people who are dying and their carers forms an important 'teachable moment' for spirituality. An

international work group on Death, Dying and Bereavement (1990, see appendix 8) noted that while the health care curricula should foster an awareness of the spiritual dimension in clinical settings, references to spiritual care are often lacking in contemporary education for health care professionals. Continuing professional education about spirituality may be particularly relevant for health care staff working in areas such as health care of the elderly, palliative care and midwifery. Experience during this research confirms my view that such education should attempt to integrate personal and professional aspects of spirituality. The place of continuing professional development about spirituality could, for example, be compared with education about sexuality, another area that can be hard for clients and staff to talk about comfortably but which should not be ignored because of its potentially far reaching effects on health and well being. Assumptions about sexuality, like spirituality, are often unspoken, relying on tacit knowledge in a way which hinders understanding. Continuing professional education about sexuality can help health care staff to recognise human sexuality as a continuum which clients may express in different ways. Such education may also provide an opportunity to consider their own sexuality and how that might affect their work with clients. In a similar way, spirituality could become an essential part of the health care curriculum alongside physical, psychological and other areas of health care, offering both a theoretical overview and opportunities for more personal development.

Although spiritual exploration remains primarily an individual concern, discussion with others could be of particular value for health care professionals whose work brings them into contact with people with widely differing beliefs and experiences. As described above, the very process of exploring spirituality in a safe but challenging environment may help develop an individual's understanding of spirituality. In a health care setting which endeavours to provide holistic care, it is essential that staff share a basic understanding of the concept of spirituality in order to ensure consistency. It is no longer adequate to assume that a single shared understanding of spirituality exists within a given team, yet without that foundation spiritual care cannot be provided effectively. Occurring within a small and clearly focused team, this research indicates that it is possible for team members to clarify their understanding of spirituality in a way which engenders a more collective approach to the subject. More broadly the research is intended as a contribution to health care

policy¹, emphasising the human skills and understanding required to complement the equally essential scientific basis of modern medicine.

Existing theories about spirituality appear to have had little effect on current holistic practice. My present research is not concerned to develop such theories; to do so would demand a quite different approach, rather this research is an exploration of the integration of existing theory into current practice. It is one thing to discuss spirituality in theoretical terms; quite another to explore in a more personally demanding way while still contributing to health care policy, as I have chosen in this thesis. The focus of the research has not been to promote any particular spiritual framework or to attempt to impose personal spiritual exploration. Rather I have been concerned to comprehend whether greater awareness and understanding of spirituality, both personal and professional, are of benefit to people working in palliative health care. Individuals with a clear grasp of their own spirituality (whatever that is) may find this as difficult as those with a less clearly committed viewpoint, while other staff may simply not see the relevance of this area of learning for their work at all. Such personal learning about spirituality also needs to be related to more formal continuing professional development requirements and frameworks. Personal development for the individual practitioner is important but harder to quantify than more professional concerns; it is also more difficult to justify the use of scarce institutional resources for such personal development. Conversely, as already indicated, staff who are aware of the spiritual dimension of their own lives may be more able to recognise and explore spiritual issues with clients (Ross 1997a). Continuing professional development provides a forum where professional staff can explore spirituality and spiritual care in the workplace setting which will ultimately support the provision of effective holistic care to the benefit of staff and clients. An experiential educational approach facilitates an exploration of spirituality and spiritual care which goes beyond simple awareness. The format of continuing professional development provides a useful springboard, although it may prove too restrictive for those wishing to explore spirituality in depth. Emphasising the integration of work and spirituality within such opportunities supports the needs of the organisation as well as personal development. These issues will be explored more in chapters six and seven.

Reflective practice

Recognising the importance of spirituality in theory does not necessarily affect actual

¹ See appendix one for contributions to professional journals and conferences

practice (Taylor, Highfield and Amenta 1994). Throughout this research I have been concerned to promote learning about spirituality that is integrated into practice rather than provoke an isolated theoretical debate. Reflective practice is used increasingly in the education of health professionals and offers a grounded process which values both human experience and theoretical concepts. Reflection in and on experience ensures that theoretical concepts are measured against actual practice, aiming to bridge the gap between theory and practice. Schon's metaphor of professional education strikes a cord with current health care practitioners:

In the varied topography of professional practice, there is a high, hard ground overlooking a swamp. On the high ground, manageable problems lend themselves to solution through the application of research based theory and technique. In the swampy lowlands, messy confusing problems defy technical solution. The irony of this situation is that the problems of the high ground tend to be relatively unimportant to individuals or society at large ... while in the swamp lie the problems of greatest human concern (Schon 1988:3).

The direct concerns and questions raised by the complex reality of working practice provide the starting point for learning, while ideas generated by the exploratory process can also be subjected to the spotlight of human experience.

A short lecture within a formal course may address the issues involved in the complex area of spirituality but will not easily offer a forum in which participants can begin to work out the implications of those issues for their life and work. A characteristic of this research has been the development of educational opportunities where individuals can explore spirituality in the light of their own experience in a way which is integrated with theoretical concerns. Such discussion draws on ideas from the media and arts, from religious and non religious groups and other areas of the participant's background, fuelling a broader discussion. Reflection needs to occur in an environment which will both challenge and support participants as they explore issues that are difficult to articulate and may be emotionally challenging. As participants consciously reflect on their experience, relating that to a growing body of literature, in turn measuring the literature against their own experience, their confidence and understanding of the topic grows. Such a rational process cannot comprise the whole of spiritual development but does provide a valuable, and often lacking, balance to other more creative and intuitive activity. The overall aim of all the

groups in this research has been to develop a grounded understanding of spirituality, drawing richly on many different sources, which will equip participants to support themselves and their clients more effectively in the face of spiritual questions. Greater awareness of spirituality, its nature and concerns, supports a more balanced holistic approach. Spiritual care is also necessary for practitioners, forming an important aspect of 'self care', particularly relevant for stressed health care practitioners who are struggling to help their clients, potentially at the cost of neglecting their own health (Wright and Sayre-Adams 2000).

Offering a group dimension for reflective practice generates a broader spectrum of ideas and opinions, more challenging but potentially also more supportive and fruitful (Bennett et al 1997). This was very much the format of the original co-operative inquiry group, described in chapter four, and in the parallel Journey into Faith group. It was also important in educational groups which developed from it, discussed in chapter seven, although a shorter time span and more defined content somewhat limited our freedom in this context. Ideas can be challenged within a supportive environment, although groups may struggle to cope with highly divergent ideas. Individuals may withdraw, physically or emotionally, if the group creates too great a personal challenge or fails to maintain ground rules such as mutual respect. Despite this, if people can successfully traverse the 'forming' and 'storming' stages of group life, relationships within the group will be greatly enhanced. Where whole teams of staff are learning together they may be able to develop a more consistent approach to spiritual care. Clear discussions about ground rules, particularly those ensuring respect for individual beliefs, are vitally important from the earliest stage. It is also important that ground rules are adhered to and the facilitator, as well as the group itself, plays a pivotal role in this. Participants who feel safe and supported grow more confident and therefore more able to express their ideas about spirituality, as well as something of the struggle involved. As participants are supported in finding a 'voice' in which they can talk comfortably about this issue, their own ideas develop and clarify.

Models of health care

The concept of health means different things to people, encompassing a wide range of ideas from general well being to the absence of disease (Black 1988:33). In my previous dissertation I identified three common models or approaches to health care (White 1994:15-33). In reality, the three approaches overlap and all have much to offer health

care practitioners and their clients. For simplicity, each will be explored briefly here but the primary setting of this research remains within the holistic model.

The medical model sees health as freedom from disease, so that health care is described as 'allopathic' or concerned with the '*cure of diseased action by inducing another of a different kind, not necessarily diseased*' (Little, Fowler and Coulson 1973:49). Strictly within this approach, all diseases of body and mind are understood to have an underlying cause: if only this can be found and treated, health will return (Kearney 1996:44). With its roots in Cartesian philosophy, the medical model takes a mechanistic view of the human body which has become a powerful strand in western medicine (Black 1988:33). There have been significant health improvements as a result of this approach, for example, tests which have enabled the early diagnosis of many diseases, the replacement of worn body parts and an ever increasing battery of curative medication. Despite these gains, there is a danger that the model becomes so dominated by technological developments that other aspects of health are excluded. Illich goes so far as to suggest that the medical establishment has itself become a threat to health (1976:3). At its most extreme, this approach reduces disease to the merely physical, isolating the body from the whole individual and their environment (McKee 1988:776). This risks dehumanising the very people medicine is designed to help, creating barriers between health care professionals and their clients. The medical model is particularly vulnerable when faced with death or the increasingly dominant diseases of middle and older age where cure is rarely possible.

A social model of health takes a wider view, emphasising the promotion of well being alongside the treatment of disease (Black 1988:34). Starting with the, rather idealistic, World Health Organisation definition of health as a 'state of complete physical, mental and social well being and not merely the absence of disease' (WHO Constitution 1948, quoted in Townsend, Davidson and Whitehead 1990:34), many factors are understood to affect health. Social models of health look beyond physical causes of ill health and its influence can be clearly seen in public health initiatives such as the provision of clean water, immunisation campaigns and better working conditions. This approach recognises the importance of a healthy society, looking for change at a political and social level rather than an individual response. Again there have been significant health improvements throughout the world because of this approach yet links between poverty and poor health, for example, continue even in the

developed world (Townsend, Davidson and Whitehead 1990, Atchison 1998). Knowledge alone is not sufficient to overcome barriers to health, particularly where individuals feel isolated and dis-empowered. Similarly, powerful groups within society, such as tobacco companies, have a vested interest in maintaining the 'status quo' despite the effect on health. A social approach concentrates on the prevention of disease by looking at its underlying social causes but may have little to offer individuals, especially those who are already ill.

In essence, the root of the word used for health is whole, incorporating soundness of body but also spiritual, moral or mental soundness (Little, Fowler and Coulson 1973:938). The holistic model both understands that health is more than the absence of disease and sees each individual as a unique whole, seeking an integrated approach to the whole person, body, mind and spirit. Although often associated with alternative health care providers, this model is also recognised more widely, at least in theory. The holistic approach promotes the body's own resources, as well as the best of external resources, to aid the healing process and promote health. Simplistically, the holistic approach can be contrasted with the other models by its emphasis on the whole person. Yet this important emphasis is potentially a weakness which may lead to an imbalance of individual and collective responsibility. Overemphasising individual responsibility for health and well being fails to challenge injustice and social deficiencies which also lead to poor health (McKee 1988:775). Holistic practitioners may, for example, reject effective methods of physical care, ignoring well proven and effective allopathic approaches in favour of unproven alternative methods. However there is an increasing emphasis on holistic care even in more traditional medical approaches where the deficiencies of a purely physical and technological approach are being recognised. A truly holistic approach should underpin all health care, drawing on the best features of the medical and social models. In this way holistic practitioners will recognise that each individual is both a unique whole and part of a particular community, deserving high quality evidence based health care which recognises the integrated totality of body, mind and spirit.

Within western health care, palliative care has championed the holistic approach, emphasising the need for high quality, person centred care where cure is not possible. Effective symptom control is valued alongside other aspects of care in a speciality which started with the modern hospice movement and is now moving into

mainstream medical care. Recognising the intimate connection between body, mind and spirit, prompts health care practitioners to look more widely than physical symptoms. Motivation, self esteem and personality affect health in addition to physical make up, lifestyle and environment. Contrary to media suggestions that '*psalms and sermons could help you*' (Illman 1998, Woodward 1996, Garner 1999), evidence of the link between religion and health remains weak and inconsistent (Sloan et al 1999). However, the growing interest in spirituality among health care practitioners serves as a reminder that both religion and spirituality are potent influences in the totality of people's lives. If holism is to truly underpin health care, the notion of 'spirit' needs to be more clearly understood and articulated as an integral part of that concept. A more complete understanding of spirituality would encompass spiritual well being as well as spiritual struggle. Nurturing the human spirit then becomes part of everyday life rather than primarily focused on ill health, even though this may be a catalyst for spiritual growth.

Spiritual care is frequently equated with religious care, encompassing all faith communities in a multicultural environment (NHS Management Executive 1992, National Association of Health Authorities and Trusts 1996, Lewis 1999). In today's western society, such an equation leaves significant numbers of people, with no particular religious affiliation, outside the boundaries of spiritual care. A broader understanding of spirituality ensures that spirituality is more easily recognised as part of health for all. Spiritual distress can also be recognised more accurately and responded to more effectively. Rather than a specifically religious drive, the human spirit can be understood as an integrating, or connecting, force within the body with the potential to play a significant role in health. While the spirit, the vital human spark, remains inseparable from the live physical body (Watts 1997), it transcends purely physical needs to speak about underlying values and beliefs. Benson stresses the importance, currently neglected, of 'self care' in health, involving not only exercise and nutrition but also beliefs that promote healing (Benson with Stark 1996:23). Recognising and valuing the spiritual dimension of life plays a part in developing such beliefs. Benson also describes the benefits of regular relaxation as part of self care, noting that relaxation is induced in meditation or prayer (Benson with Stark 1996:19, 131-133, 161-166). Stressful modern lifestyles often lack opportunities for relaxation and self care which may be particularly important for spiritual growth (Hay 1982:198). Hay also notes the link between spiritual experiences and psychological well being (Hay 1990:57). Palliative care clients, also facing a stressful situation, speak of the

benefits received from the deep relaxation induced by many complementary therapies. Spirituality itself emerged as a powerful force in the lives of breast cancer survivors (Fredette 1995:41). Underlying and unvoiced questions about metaphysical concerns may be a further source of stress, such that providing therapeutic opportunities to face these concerns becomes another aspect of self care. Experience in health, particularly palliative, care supports the importance of meaning and purpose in people's lives. Simsen (1986:42) compares the search for meaning to the 'border in a jigsaw puzzle', making this the encompassing theme in her study of patient spirituality. Connection is another key theme in discussions about spirituality, suggesting supportive and positive relationships which are also important for wholeness, for example, the benefits of support groups in women with breast cancer (Wood 1996:13-14). Recognisable underlying themes within the concept of spirituality will be discussed further in chapter five.

Even with a broader understanding of spirituality, concerns remain about the actual provision of spiritual care. Spiritual issues are hard to articulate, a trend exaggerated by fear of derision and social embarrassment (Hay 1982:159-160, Hay 1990:57-60). A more proactive approach to spiritual care, especially in key areas such as palliative care, ensures that clients have permission to explore such issues when they wish to do so. Clear, shared understandings of spirituality and spiritual care within health care teams are vitally important if this is to be attempted without becoming an opportunity for proselytising. Equally health care professionals themselves need to be comfortable talking about spirituality, particularly with a view of spirituality which raises unanswerable questions. Recognising and accepting this shared uncertainty in the face of spiritual questions breaks through professional boundaries in an area where the health care professional is not the knowledgeable expert but rather a fellow human being. This sense of common humanity renders staff and clients vulnerable in a way which may be difficult for both. The potential benefits of a therapeutic human relationship are identified in the Rogerian model of person centred counselling which emphasises the core conditions of congruence, unconditional positive regard and empathy (Mearns and Thorne 1999:14-16). Ersser also indicates the importance of presence or 'being with' in any nurse-patient interaction (Ersser 1991:78-81). Such relationships offer opportunities for personal growth for health care professional and client, including spiritual growth, within a safe and supportive environment. These concerns about spiritual care will be discussed in chapter six.

It is contradictory to isolate a single aspect of holistic care, yet the confusion surrounding spirituality calls for a temporary spotlight to be placed on this area. Research and education, in the context of this research, have provided that spotlight. Opportunities to explore spirituality in continuing professional development aim initially to make participants more conscious of spiritual aspects of their own work and lives, with the longer term aim of developing a more truly holistic and integrated approach to palliative care practice. The development and effectiveness of this approach will be discussed in chapters five, six and seven.

Qualitative methodology and co-operative inquiry

Modern research has grown up in a positivist milieu, dominated by physical science, which influences even approaches to social research. Recognising the danger of tacitly accepting positivist ideas, some researchers have called for new approaches to human research (Reason and Rowan 1981a:xii). The roots of this movement lie in 'alternative' activity in the traditional behavioural sciences, for example, in humanistic psychology, phenomenology and action research (Reason and Rowan 1981a:xvi). Practitioners build on the work of social philosophers such as Dewey and Deveraux (Reason and Rowan 1981a:xvi, Reason 1988:2) while their intellectual debt to reflective practitioners such as Dewey and C Wright Mills can also be recognised. Various called human inquiry, participative research or even new paradigm research, these approaches purport to represent a paradigm shift in research methodology (Reason 1988:9-14). A defining feature of human inquiry is the endeavour always to place human beings clearly at the centre of research, opposing anything that appears to dehumanise or trivialise people and situations (Reason and Rowan 1981a:xiv-xv). Participation in the research is a key concern: human inquiry is about '*research with people rather than research on people*' (Reason 1994:1). Disputing the possibility of pure objectivity, proponents propose a method that is '*objectively subjective*', drawing on both observation, or empirical, information and 'common sense thinking' to create a systematic, rigorous search for truth (Reason and Rowan 1981a:xiii). Rejecting the notion of the researcher as neutral observer, human inquiry research methods accept the reflections and experience of practitioners as an integral part of research. As in orthodox approaches, but perhaps even more important, there is an emphasis on the researcher recognising and acknowledging their intellectual debts and clearly searching the literature (Reason and Rowan 1981:xiii-xiv). Individual personal experience is then synthesised with theoretical concerns in order to reach a deeper understanding. Co-

operative inquiry, the method used in this research, offers a group of co-researchers the possibility of using repeating cycles of reflection and action to explore a shared aspect of their life or work as outlined in figure 1:2 below.

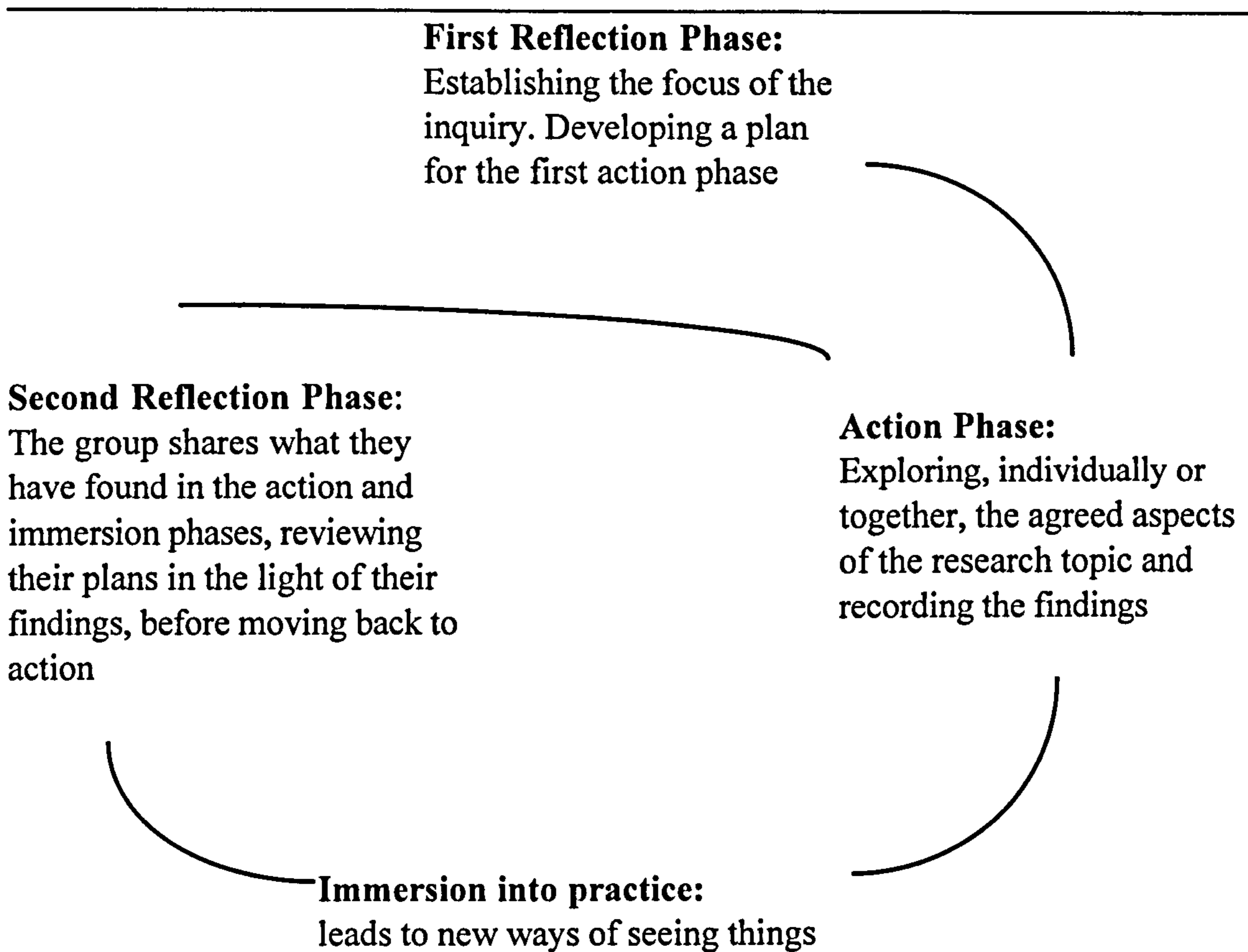


Figure 1:2: A Co-operative Inquiry Cycle, adapted from Heron 1996:49-50

Human inquiry researchers endeavour to recognise and make explicit ways in which their own concerns influence the research rather than endeavouring to ‘observe’ from outside the research. Thus, in human inquiry, my own commitment to a spiritual journey, occurring within the Christian tradition, plus my interest in holistic and palliative care become overtly part of the research. My growing awareness of personal spirituality ceases to be a disadvantage, offering instead an opportunity to integrate this subjective experience within the context of the research. My experience of the research is also open to exploration, in this case both as part of the co-operative enquiry group and through my reflective diary. There is a clear recognition that neutral objectivity is impossible, therefore my own assumptions and background need to be made visible in order to be challenged by my own thinking and by the group. Personal

exploration challenges and exposes tacit assumptions leading to new understandings and ideas. A detailed review of co-operative inquiry will form the basis of chapters three and four which explore the methodology adopted in general and specific terms.

Having outlined the primary concerns of my research, the following chapter begins a more detailed journey through that research by discussing the changing relationship between spirituality, religion and society over time. Tracing the roots of the current situation in this way establishes the context in which my own research about spirituality and health has developed.

Chapter Two: Finding A Voice For Spirituality

One area affected by the current spiritual crisis is health. As discussed in chapter one, the traditional medical model relies heavily on mechanistic images of the body but health is increasingly understood to be far more than just a physical condition. There is now a much greater recognition that health and well being is a complex mix of physical, social, emotional and spiritual factors (Neuberger 1999). Many factors play a part in this but my particular concern has been for the role of spirituality. Benson, a conventionally trained doctor based at the Harvard Medical School, describes his view that the current spiritual crisis profoundly affects health and well being (1996:108). Outlining his own dawning recognition of the importance of spirituality in medical practice, he stresses the role of 'remembered wellness' or belief as a vital part of health care, suggesting that this lies behind the placebo effect (Benson with Stark 1996:17-19). To me, his ideas emphasise the link between wholeness and health, with a sense that people (and health care practitioners) need to value and nurture the whole of themselves, including body, mind and spirit. A number of studies now link spirituality or religion with quality of life and health (Moberg and Brusek 1978, Levin et al 1997, Ziegler 1998, Garner 1999, Benson with Stark 1996:173-176). Other studies show positive links between health and religion in groups of black elders (Musick 1996). Although some of the positive links between religion and health can be explained by social benefits or lifestyle choices, such as reduced diet or alcohol intake, the overall relationship appears to be more complex (Epperley 1997:48-49, Ziegler 1998). Sloan, an American medical researcher working specifically in this area, notes that while the association between religion and health remains weak and inconsistent, a position somewhere between promoting religion as a medical treatment and avoiding the subject all together may be of benefit (Sloan et al 1999). Discussions such as this have contributed to the renewed interest in holistic approaches to health care, even within traditional medical practice (Fulder 1986). To some extent the renewed emphasis on the holistic approach and the place of spirituality particularly, has been led in the United Kingdom particularly, by the modern palliative care movement which provides the setting for this research.

Neglect of spirituality in health care cannot be divorced from the wider social context. Fluctuating levels of interest in spirituality are closely connected with changing ideas within Christianity, a theme which will be explored later in this chapter.

The current resurgence of interest in spirituality occurs in a post modern context which is characterised by the embracing of many divergent viewpoints and a deep distrust of meta-narratives and absolute truths. Paradoxically, as post modernism reacts against the rigid rationality of modernism, it both affirms spiritual values and rejects Christianity, previously Western Europe's predominant spiritual meta-narrative (Horseman 1996:4-5). This leaves a vacuum with little clarity about the key concepts underpinning spirituality and, therefore, some difficulty in exploring spirituality with other people. An emerging theme in this research has been that of finding a language, or voice, with which to speak of spirituality. Exploring the image of the spiritual voice, which has moved from a pivotal position, through relative neglect, to recent multifaceted rediscovery, provides the focus for this chapter. A brief summary of the key concepts within spirituality which underpin the thesis is followed by a review of the origins of our present spiritual crisis. This material is intended to establish the historical context in which the exploration of spirituality described in later chapters occurred.

Understanding the key concept

Spirituality is hard to articulate. The general difficulty of expressing any non-rational concept is aggravated by recent history's tendency to dismiss spiritual concerns. The word 'spirituality' has commonly been associated with religious belief or practice while related words, such as spiritualism, create an association with the supernatural or occult. 'Spiritual' or 'spirituality' are increasingly used more broadly by the media, although the concepts which underpin this usage are often unclear and inconsistent. My research experience suggests that there are benefits for groups of people who attempt to clarify the meaning of spirituality by the difficult process of articulating their ideas together. This shared journey of spiritual discovery, using personal reflection, discussion and debate, became the central element of my research. Exploration of metaphor was particularly illuminating as one of its primary uses is to '*express the inexpressible*', providing a powerful tool with which to discover and share meaning in everyday experience (Candy 1986:93-94). Pinning down this complex mixture of analysis and intuition is difficult, confirming the former Bishop of Durham's description of spirituality as a '*slippery word*' (Jenkins 1997). The co-operative inquiry group described here, meeting in 1997/8, was able to identify a number of shared themes in their understanding of the concept. However ultimately they found it undesirable, as well as impossible, to produce a clear cut definition of human spirituality. The themes

discussed by the co-operative inquiry group will be explored further in chapter five; they also provided the basis for exploring spirituality with later educational groups, explored in chapter seven. In view of the general confusion about spirituality, however, some initial clarification of the concept seems valid at this point.

Traditionally the word spirit or soul is linked to the breath or the animating principle of life, a link also seen in words such as inspire and inspiration. The Oxford English Dictionary defines 'spirit' in this sense as

The animating or vital principal in man and animals; that which gives life to the physical organism, in contrast to its purely material elements; the breath of life (Simpson and Weiner 1989:251).

Hence, spirituality can be understood as the essence of each human being, distinctive yet integral to the physical and intellectual. The Japanese poet, Basho, describes it rather more eloquently

In this poor body, composed of one hundred bones and nine openings, is something called spirit, a flimsy curtain swept this way and that by the slightest breeze (Basho 1985:10).

Other definitions add to this sense that the spiritual is both other worldly and essential. For example, 'spirit' can refer to supernatural, incorporeal beings (ghosts) and to distilled volatile liquid, including alcoholic liquid (Simpson and Weiner 1989:251). The French phrase for distilled spirit, 'l'eau d'vie' or water of life, highlights these resonances! Yet spirited can also imply 'lively', a more down to earth understanding which still implies an essentially human feature. The related adjective 'spiritual' is understood as '*concerning the ... higher moral qualities especially as regarded in a religious aspect*' (Simpson and Weiner 1989:257). This link between spirituality, religion and morals is common yet perhaps less accurate than in the past.

Definitions reflect something of the culture in which they have developed. One tendency attached to these particular definitions is that the spirit becomes essentially separated from the body and the mind, viewed as either irrelevant or superior. This is in contrast to an holistic understanding, described earlier, which emphasises the essential integration of body, mind and spirit in the whole being. McSherry writing about the scientific basis of an holistic approach to health notes the

traditional Jewish use of the word 'shalom' to denote wholeness and health (1983:217). Hebraic tradition, in common with Celtic and Aboriginal, recognises human beings as a 'gestalt', or whole, with all elements in a state of critical interdependence and centred on a metaphysical presence (McSherry 1983:217). In contrast, she suggests, the dominant picture of human beings in Western Christianity has been based on the platonic idea of three discrete though interrelated units (spirit, mind-emotions and body) in which the spirit is the chief governor (McSherry 1983:217). Returning for a moment to the related concept of breath provides a reminder that other distinctive human elements, such as the physical and mental, are never truly separated. Body and mind clearly operate in an integrated way even in such a physical act as breathing. Emotion, such as stress or relaxation, affects the breathing process, which affects the emotions in its turn. The sense of separation or disconnection often linked to definitions of spirituality reflects, therefore, our history rather than being integral to the concept. This history will be explored further in a later part of this chapter. Significantly, and in contrast, a key element of spirituality in this research has been a growing conviction that spirituality is best expressed in terms of human connection, connection with self, with other human beings, with the earth and with the transcendent (Renetzky 1979:215). This then is a key element of the ontology which underlies this thesis, that human beings are comprised of a connected whole which includes body, mind and spirit.

Although often linked with spirituality, religion is best understood as a particular system of faith and worship (Simpson and Weiner 1989:568-569). It is now more rare that religion is understood as *'action or conduct indicating a belief in, reverence for or desire to please a divine ruling power'* (Simpson and Weiner 1989:569). Members of specific faith communities are generally understood to have a range of overlapping beliefs and practices which centre around a common framework. This framework affects the life of the individual but also helps create a community with shared values and ways of viewing the world. This *'sacred canopy'*, described by Berger in his book of the same name (1969), binds communities together protecting and legitimising shared meanings in a wider frame of reference (Berger 1969:38). Like spirituality, religions are concerned with recurring human themes, such as creation, life and death, hope. Religious institutions tend to formalise belief and practice in a way that may restrict spiritual growth. Conversely, religious structures can foster spiritual growth, ensuring a communal rather than an individualistic framework. Hence although religion has links with spirituality, the two are not synonymous. Rather spirituality can

be understood as the broader concept, a potential within all human beings which is concerned with connection, with meaning, hope and other metaphysical concerns. Spirituality may be expressed and developed in creative activities, relationships and many other aspects of human life, all of which may be important to people who do not adhere to any particular religion as well as those who do. If this view of spirituality is accepted it follows that a range of appropriate opportunities to nurture spirituality should exist in our current multicultural, and largely secular, society. This research project suggests just one specific opportunity to do this that has been developed in a health care setting.

Spirituality loses its voice

The dawn of a new millennium, occurring midway through writing this thesis, highlighted the way in which the concept of spirituality has shifted from the very heart of life to an ambiguous position on life's margins. While it is no longer possible, or even desirable, to return to the unity and security of mediaeval belief, it remains a useful exercise to trace some of the key influences on British spirituality as a background to this study. Christianity has been the dominant religious influence in Britain, and in much of Western Europe, during the last thousand years and provides the main focus of this chapter. More recently, the establishment of other faith communities in Britain has led to the development of a more multicultural society. Christianity, previously the primary voice for expression of spirituality in Britain, has moved from being *the* religion to one religion among many or none. While belief in a divine being is still important to many people, particularly at moments of transition such as birth or death, daily life usually continues with little reference to metaphysical beliefs or religious life (Leech 1985:2). Spirituality has 'lost its voice' in the sense that its underpinning concepts can no longer be confidently articulated or recognised by the majority of people. Out of this loss comes a sense of uncertainty and, for some people, a restless searching for a more complete and integrated world view. This in itself may be a significant step towards finding a more appropriate voice, yet, so far, this does not seem to have occurred. Three significant influences in this journey of loss and rediscovery will now be explored.

Losing touch with the earth

An early and highly significant influence on Western Christianity was platonic dualism. Christianity became the 'state religion' in Western Europe with the establishment of the Holy Roman Empire by Constantine in 313 AD. However it was not until the

mediaeval period that Christian society became a dominant feature of life in Britain. More than a formal state religion, Christianity was woven through every aspect of life in a way that is almost impossible to imagine today. Cathedrals and churches, often built on previously pagan sites, acquired a central place in society, providing centres for worship but also for social activities and the arts as well as refuges from war or punishment. Similarly, traditional festivals were often Christianised, developing a system of 'holy' days throughout the year, so that the very calendar reminded people of the thread of spirituality running through their lives (Lacey and Danziger 1999:53,142-3). This blending of the sacred and profane was characteristic of the middle ages where religion was an integral part of everyday life (Comby 1985:148). Pagan customs like the yule log and midwinter festivals, were absorbed into Christianity, relics provided an opportunity for ordinary Christians to '*touch the sacred*' (Comby 1985:149). Similarly, Davies, describing the fifteenth century 'Play of the Shepherds' shows how naturally the medieval actors interwove their own experience with the Christian story (Davies 1999:88-89).

Celtic Christianity originated in Ireland and nurtured the Christian faith in Britain from the Roman withdrawal until Augustine's mission in 597 AD. Originally spread by monks in an essentially rural setting, it drew together the mixed Celtic tribes who lived in Britain, uniting them by a common culture shaped by their new faith (Edwards 1989:25-27). Early Irish Christians were willing to absorb and transform the marks of older religions rather than seeking to erase them, paving the way for the medieval way of life described above. The Christian gospel was seen as fulfilling older Celtic mythologies rather than in opposition to them, allowing many traditional ideas to remain, including the Celtic sense of intimate connection between the divine being and creation which probably originated from the druidic nature mysticism (Newell 1997:26-27). This strand of thought seems particularly relevant now in view of modern concerns about the environment. A sense of connection, with other people and with the earth, may also be important for health (Epperley 1997:49-51). Linked to this positive view of the earth was an equally positive view of human nature which was seen, like the rest of creation, as essentially good (Bradley 1993:59-60). The positive Celtic viewpoint is in stark contrast with the more negative view of humanity propounded by Augustine of Hippo, who saw both humanity and creation as inherently sinful (Newell 1997:14-15). The Augustinian view has been a dominant strand within western theology, as both the Catholic church, and later the protestant reformers, emphasised sin and wrong doing

(Bradley 1993:51); a position that continues to stimulate debate today (Fox 1983, 1991).

The European Church, led from Rome, was established in a more cosmopolitan, urban setting based on classical culture and came to be dominated by Augustinian theology. Early Christians considered that the birth of Christ occurred at a *'historical moment of conjunction between the Jewish religion, Greek philosophy and Roman Empire'* (Tarnas 1991:98). Early Christians recognised the benefit of integrating sophisticated Greek philosophy into their new religion, rather as Celtic thought had been absorbed in Britain, giving credence to Christianity but also corroborating and giving new meaning to platonic principles (Comby 1985:18, Tarnas 1991:101). This process continued with the development of a systematic theology fusing Judaeo-Christian theology with Greek metaphysics which was advanced by theologians such as Justin Martyr, Origen and, most notably, Augustine of Hippo (Tarnas 1991:102). Particularly pertinent to this thesis are the dualistic patterns of thought absorbed from Platonism which emphasise the essential divisions in human experience such as male and female, light and dark, heaven and earth. Most religions show some degree of dualism but also recognise an ultimate unity or resolution (Bowker 1997b:296). This view can be contrasted with the sense of connection described above as part of the Celtic world view, which is also important in other traditions, particularly eastern religions.

An over-emphasis on dualistic ideas may lead to the opposition of body and spirit, where the spiritual is seen as superior to the physical. Such dualism has contributed significantly to a disconnected view of spirituality that can be seen in Western Christianity. The Roman church, although influenced by classical ideas and philosophy, rejected many other aspects of pagan culture. One outcome of this was the development of a negative view of the physical aspects of life and anything or anyone seen as connected with them. This contributed, for example, to negative views of women which have existed in the church for much of its history (Maitland 1983:7, Ruether 1992:43). Greco-Roman culture was predominantly masculine (Comby 1985:27), both Plato and Aristotle stressed male superiority, with the male linked to the divine soul and the female to the imperfect body (Sampson 2000: 24). In contrast, Celtic tribal culture had more positive attitudes towards women and the Celtic church continued to hold women in high esteem (Bradley 1993:23, Newell 1997:13). Maitland

highlights the roots of the negative status traditionally accorded to women by the church:

In a society where men have already gained ascendancy in the intellectual, legal and social life, and where asceticism is felt to be the way in which the spiritual-human can overcome and dominate the material-human, it is all too easy to project the dark, bodily, dangerous and uncontrolled elements of life onto women. Women are therefore dangerous, alien, other; they are also not what God is: good, orderly, and in terms of imagery, therefore, male (Maitland 1983:7).

Negative attitudes to the body, and to women because of their link with it, has influenced health care. Achterberg suggests the struggle for women to be fully accepted in medicine, despite their traditional role as healers, is the direct result of such a link and the fear that accompanies it (1993:15,18). Such links may even lie behind the persecution of women for heresy and witchcraft (Achterberg 1993:15, Starhawk 1989:19-21).

A further, related, effect of dualism has been the breakdown of the connection between Christianity and the earth or created world. For the Celtic Christian, prayer and spirituality were integrated into every detail of their daily experience, clearly celebrating the goodness of creation. This can be seen in many traditional prayers, for example, the *Carmina Gadelica* (a collection of prayers from the Western Isles) includes prayers for the most ordinary activities of the day such as kindling the fire, milking the cow, greeting the sun and moon or weaving cloth (De Waal 1988). This spiritual thread formed a rhythmic accompaniment throughout each day, rather than playing a more limited role in church worship (Newell 1997:40). Such prayers were suppressed after the Scottish Reformation, a process enhanced by the highland clearances in the early nineteenth century which largely destroyed this communal residue of Celtic spirituality (Newell 1997:52-54). In what does remain is a sense of the spiritual intertwined with and through the physical; a tradition echoing the Hebrew psalms, of seeing *'our voices as joining the voice of the whole universe in giving praise to God'* (Newell 1997:46). This connection with, and respect for, the earth can be seen in other people living close to nature such as North American Indians and Australian Aborigines (Bradley 1993:53-54, Morgan 1995:15). Again, from centuries ago the Japanese poet Basho, although hardly primitive, identifies this link between nature and art *'all who achieve greatness in art...possess one thing in common:*

they are one with nature' (1985:10). The roots of the current ecological crisis must rest partly in the erosion of this sense of connection with the earth and the respect it engenders.

Mystical experience is beyond description but is generally considered to involve a direct experience of transcendent reality (theistic or non theistic) (Bowker 1997b:671). Mystical or spiritual experiences can be said to represent interior or personal aspects of spirituality, whereas religious tradition and practice represent the exterior or communal perspective. In reality, the two may be linked, personal spiritual experience influencing religious practice, which provides a framework for further spiritual experience. Yet Jung's dictum that *'religion is a substitute for religious experience'* highlights the long standing difficulty of finding a balance between the two (quoted in Fernandez-Armesto and Wilson 1996:49). Religious, or spiritual, experiences are probably more common than might be expected especially in a so called secular society (see appendix two for further discussion). Mysticism is a strand in all religions but in Western Europe it has generally been treated with some caution by the Christian Church. Mysticism flourished in the later middle ages reflecting the re-emergence of a more personal approach to religion (Dowley 1977:342). Maitland notes that the institutional church seems more willing to accept women as mystics, for example, Julian of Norwich, Teresa of Avila, Catherine of Sienna, than as theologians (1983:159-160). Mysticism was, of course, expressed through the dominant religious ideas of its time but can still be linked with more recent ideas about spirituality. Bancroft, writing about twentieth century women mystics from differing faith communities, suggests that they share this emphasis on integration or *'a relatedness to existence that embraced both the timeless and the immediate present'* which she suggests is more apparent in women (Bancroft 1989:viii). Rediscovering this emphasis on personal connectedness in spirituality offers an important focus for today's world which may be explored to advantage by both men and women.

Loss of connection with the earth, and of a sense of the sacredness of creation, seems a particular feature of the western, developed world. A greater integration of spirituality remains in other cultures. Nelson Mandela in his autobiography notes that traditional Xhosa religion is characterised by: *'a cosmic wholeness, so there is little distinction between the sacred and the secular, natural and supernatural'* (Mandela 1994:15). 'Afrocentricity' has been developed, largely in North

America, as an alternative philosophical model to the dominant Eurocentric viewpoint. Based on traditional African philosophical assumptions, it assumes that there are cultural differences between African and European people and a distinctively African viewpoint needs to be uncovered. A review of Afrocentricity notes that the Eurocentric view values the material needs of the individual over the collective well being of the group, placing a heavy emphasis on material and physical attributes rather than non-material or intangible qualities (Schiele 1994:154). Afrocentricity, in contrast, offers a more holistic conception, emphasising both the community perspective and spirituality, which is seen as essential to the human makeup, linked to morality and the concept of a supreme being, both of which are highly valued (Schiele 1994:155). Ani describes spirituality as:

The apprehension of cosmic interrelationship. The apperception of meaning in existence, and the degree to which one is motivated by such meaning. Spirituality is one's ability to relate to the metaphysical levels of experience. It unites thought and feeling and thereby allows for intuitive understanding (Ani 1994:xxviii).

Asante notes the importance of spirituality to African people, whether expressed in Christian or other terms, with key emphases on

A humantic stream running through the spirits of African people, a deep respect for the sacred, for harmony, for rhythm, for righteousness (Asante 1988:78).

This is reminiscent of the Celtic world view described above and resonates with the emphasis on connection and integration described in this research. A link can also be seen with increased interest in the spirituality of other cultures, for example, pagan (Vidal 1998, Hollinghurst 1996) and Native American traditions. Myths and stories from these traditions (for example, Cameron 1984, 1986) suggest ways of understanding the world as a connected, sacred reality (Furlong 1995: 2-3).

Leech argues that the erosion of our sense of the sacred has resulted in a fundamental lack of respect for both people and the environment (1985:4) which is an increasing concern. These concerns, at least partly, support the interest in forms of spirituality which recognise and value the human connection with the earth. The Sacred Land Project, sponsored by the World Wide Fund for Nature UK, aims to rediscover a sense of the sacred throughout Britain. This is a five year project which will be

completed in 2002. Working in partnership with all major faith groups and with conservation organisations, the project aims to recover lost, often ancient, sacred sites, to enhance environmentally those still in use and to create new sacred places, particularly in urban areas. Examples of their work include, re-establishing pilgrim routes and shrines, the development of urban spaces offering opportunities for quiet and reflection and creating wildflower sanctuaries or sacred gardens in church yards (Palmer and Palmer 1997:17-18). It is interesting that this modern project aims to reconnect spirituality with the environment, restoring a link destroyed by the legacy of dualism described above. Its overall aim is to re-establish the sense that land and surroundings have an emotional and spiritual significance thus fostering a deep seated change of attitude (rather than just pragmatic changes) to the environment, summed up in its basic message that *'this land is sacred and we should learn again to walk gently for we tread on holy ground'* (Palmer and Palmer 1997:16). Despite such movements, the situation in Britain remains a long way from the collective understanding of spirituality described in Afrocentricity. Much of the interest in spirituality in this country continues to be highly individualistic, reflecting other strands of our spiritual and social heritage.

Reformation: losing touch with society

The division of the western church at the Reformation provides a second highly significant influence on British spirituality. An increasingly individualistic and personal approach to spirituality, particularly in non-conformist denominations, has contributed to the withdrawal of church from community life. The Reformation, beginning as a demand within the church, eventually led to the break up of the church's unified voice within Western Europe (Comby with McCulloch 1989:8). While the mediaeval church had claimed ascendancy over the state, paradoxically it had grown increasingly powerful in the secular sphere. Secular rulers in the developing European nation states reacted against the increasing power of the church (Comby 1985:172). Between them, the Black Death and the Hundred Years War had laid waste large areas of the countryside and decimated the population (Comby 1985:181, Tarnas 1991:225). The Church itself appeared corrupt and devoid of spiritual integrity (Tarnas 1991:225, McNair 1977:346), for example, in the sale of indulgences (Comby with MacCulloch 1989:8). In the midst of this upheaval, the Renaissance acted as a powerful moderniser, ushering in a short lived but highly influential period of cultural and technical creativity. Seen as the rebirth of Western Civilisation, the Renaissance was stimulated by the rediscovery of

classical texts and culture during the Crusades (McNair 1977:348). The introduction of the printing press made such discoveries more accessible (Comby with MacCulloch 1989:3, McNair 1977:352), eroding the monopoly of the Church on learning as well as supporting a new emphasis on biblical texts which later played a significant part in the Reformation. At the very heart of this movement was a new confidence in human ability, seen especially in art, literature and science. A growing emphasis on the worth and capacity of the individual was reinforced by the humanist ideal of the free and multi-faceted, innovative man, typified by Michelangelo, da Vinci and Galileo:

The mediaeval Christian ideal in which personal identity was largely absorbed in the collective Christian body of souls faded in favour of the more pagan heroic mode - the individual man as adventurer, genius and rebel (Tarnas 1991:227).

Developments in mathematics and astronomy challenged the cohesion of the mediaeval world view, beginning a process which would eventually lead towards a profound division of sacred and secular. Such a cohesive viewpoint is unimaginable today and its loss was resisted; Galileo, for example, upheld the Church's Aristotelian picture of the world even while his own scientific discoveries contradicted it, dreading the drawing of battle lines between communities of faith and science (Sobel 1999:63, 264). Similarly, Montaigne, a prolific essayist writing just before Galileo, maintained 'a double truth' that kept faith and reason separate but valued both (Montaigne 1958:16 introduction). Tolerance of such a dichotomy began to end as the Church itself was threatened by protestant reformers and an increasingly powerful science (Tarnas 1991: 302).

These changes in outlook led to a greater emphasis on the independence of the state, the value of the secular life and the role of laity in the church (Tarnas 1991:227, Comby 1985:173-4). Tarnas suggests that the renaissance spirit was marked by:

Individualism, secularism, strength of will, multiplicity of interest and impulse, creative innovation and a willingness to defy traditional limitations' (Tarnas 1991:228).

This laid the foundations for the modern European character. The rediscovery of biblical texts combined with the personal experience of leading reformers led to a renewed emphasis on personal faith (or grace) rather than the Church and its traditions (Tarnas 1991:235-237). The Reformation played a significant part in shattering the

cohesive structure of the mediaeval world view. The church was no longer synonymous with the state and church-going came to be a voluntary activity (Walsh and Taylor 1993:6). People at all levels of society were forced to make decisions about their religious practice rather than simply accept the traditional teaching of the church. As religious expression diversified, faith became a private activity, a matter of individual choice rather than an integral part of community life. In time this would grow to include freedom to reject rather than choose a particular religion.

The paradox of the Reformation lay in combining '*a conservative religious reaction with a radically libertarian revolution*' (Tarnas 1991:237). The freedom that eventually followed the Reformation paved the way for new ideas, especially in the natural sciences, and an increasingly secular world view. It was not an aim of the Reformation to increase individual freedom yet by breaking the monolithic power of the church, it paved the way for greater freedom and choice (Elton 1963:280-281). The emphasis on personal faith acted out in the world, plus a sense of disillusionment with the church, brought greater tolerance and diversity:

When the passions had produced war and exhaustion, when most men had agreed to differ on the details of faith, it was seen that by breaking the authority of the church, by liberating the individual responsibility of men and by preserving so much of the intellectual achievement of humanism, the protestant Reformation had helped to give a new range and a new strength to the human mind and spirit (Elton 1963:323).

While the new religion did not view the world as good, it did regard it as a natural place in which to live out the Christian life (Elton 1963:277). Operating in the world rather than the cloister, protestant religion led to a greater acceptance of secular activities such as commerce. Max Weber, writing in 1904, suggested that in developing the concept of 'calling', Protestant Reformers enabled lay people to see their daily work as God-created, something to be actively and profitably pursued (Elton 1963:312). Tawney further developed these ideas in a series of lectures delivered in 1922, suggesting that by creating a more successful arena for economic growth, the Reformation, particularly Calvinism, paved the way for the growth of capitalism (Tawney 1926). These views are not uncontested. While not denying the influence of the Reformation, Samuelsson disputes the direct link implied by Tawney. He argued that Protestant Reformers were less interested in economic questions than in political and spiritual ones, although they did condemn activities such as speculation and exploitation (Samuelsson 1964: 27,31).

In essence, the Reformation was a spiritual movement breaking into a cohesive world, which affected many aspects of life. The protestant ethic produced a Europe that was varied and adaptable, perhaps therefore, more capable of exploiting the growth in population and the development of new markets that was occurring at the same period (Elton 1963: 319). Crucially, the Reformation made 'doing' more acceptable and overtook the previous emphasis which made 'being' or spiritual aspects of life superior (Chadwick 1975:8). Interestingly, in discussions during this research, a number of participants suggested the need for a shift back towards 'being' rather than 'doing', hinting at a continuing lack of balance between these two essential aspects of life.

Discussions about the meaning and value of work and their reflection in organisational structures continue to provide a link between spirituality and work (Ottaway 1994:3). The renewed interest in holism which is affecting health care can also be seen in discussions about organisational structures and management (Wheatley 1994). The Leeds Institute began to investigate links between spirituality and work following increased discussion about spirituality around the death and funeral of Princess Diana in September 1997 (Wilmer 1997). A pilot study was carried out in 1997, interviewing people who worked in a local museum (The Royal Armouries). Nine out of the ten people interviewed recognised a personal significance in the word spirituality. Meaning and purpose were common threads in participants' descriptions of spirituality, although this was particularly related to everyday concerns and questions (rather than ultimate significance and meaning). Most people felt spirituality was an important aspect of being human (*'the essence inside you'*) and that it needed input of some sort in order to develop appropriately (*'it's like a bank account, it needs topping up'*). Such 'topping up' could be from religious or non-religious sources but the environment and arts such as music or literature as well as human relationships were also important resources. This link with the arts, as well as the environment, is interesting in view of recent references to spirituality and religion in the arts generally. It also provides a further connection with total health, to which the arts may contribute (Neuberger 1999:22). Theatre critic Michael Billington suggests that the arts remind people of spiritual questions which are otherwise neglected:

Even a supposedly secular society retains its hunger for mystery, with art now fulfilling the function once exercised by divine service. It satisfies our need for the numinous ... Theatre, music and visual art are what really stir our spiritual longings (1999).

Most people in the Leeds pilot study did not have an active religious affiliation. Asked specifically about work, the majority felt that their work was an absolutely central part of their life. Others felt that work was largely separate from the important part of their life which was concerned with relationships, particularly with family and friends, although colleagues could also be important. Most gained an important sense of meaning from their work, particularly related to the connection with both national heritage and with life and death in the context of war. This pilot scheme was later extended to a wider range of local businesses but the results have not been reported publicly.

Rationalism: losing touch with metaphysics

A further paradox of the Reformation was the way in which a movement so essentially religious inadvertently opened the way for the growth of secular intellectualism (Tarnas 1991:240). From the seventeenth century onwards there was a shift which gradually replaced divine authority by experience, experiment and observation:

When one asks 'does it work?' or 'even does it pay?' instead of 'is it God's will?' one gets a new set of answers (Clark 1969:195).

This increasing emphasis on the induction of factual knowledge from experience, particularly in scientific experiments (Rowse 1974:323), led to a gradual separation of arts and sciences (Clark 1969:219). Vitally important for the solution of technical problems, this approach was less helpful when applied to more metaphysical concerns such as the search for meaning (Sacks 1991:33). The eighteenth century saw the development of the changes that became known as the industrial revolution, which accelerated rapidly in the 19th century. Interwoven with these developments was the period of the Enlightenment which upheld principles such as the existence of natural law, belief in justice and toleration and encouraged a more civilised and less cruel society (Clark 1969:245). The notion of natural law suggests an underlying eternal order of what is right and fitting to which human justice should conform (Foster 1942:228). This idea, apparent in Greek and Roman thought, was further developed in Christian doctrine, notably by Augustine and Aquinas. Reason, the conviction that there are natural and ordered principles behind the apparently chaotic functioning of the world, became an increasingly important way of understanding the world. This emphasis on reason brought a helpful detachment from the passions that appeared to have brought such harm to Europe in previous centuries (Clark 1969:245). Human rationality was

seen as distinctive, conferring fundamental rights such as freedom, equality and independence which could form the basis of a new and better society. A profoundly sceptical viewpoint prevailed, ensuring everything was subjected to the test of human reason and thought (Cragg 1970:234). Old forms and structures, traditional authorities including the church, were all challenged by an increasingly confident appeal to natural law and human reason. The intellectual challenge posed to religious ideas by the Enlightenment was particularly powerful, human reason and discovery gradually replaced divine revelation as a way of understanding the world (Cragg 1970:12-13). While the deism of philosophers such as Locke and scientists such as Newton emphasised the reasonableness of Christianity, this view presented a remote, detached God, very different, for example, from the immanent presence recognised by the Celtic church (Tarnas 1991:271).

Leech argues that the sense of spiritual impoverishment current in Britain arises partly from the dominance of this seventeenth century understanding of a divine power that was detached and remote (1985:1). The growing influence of rationalism, on the church as well as society, also contributes to the marginalisation of spiritual experience. Despite this, the Alastair Hardy Research Institute has shown the continuing importance of spiritual experiences (see appendix two). Hardy postulated that what he called 'religious awareness' must be an essential part of human nature to have been widely accepted for so long (1979:14, Hay 1990:22-23). This theme is picked up by Benson, in a medical context, who describes human beings as '*wired for God*', implying that spirituality is built into the human genetic code because of its importance for human survival (1996:196-7). Bowker, writing about world religions, also supports the idea that human beings are genetically disposed to religious belief (Bowker 1997c). By helping make sense of life, religious or spiritual awareness stimulates a positive immune response which promotes survival (Hay 1982:195, Benson 1996:155-6). Perhaps this is partly why religious belief, although its form continues to change, has not died out in the wake of the Enlightenment (Sacks 1990:3, Updike 2000, Tyler 1998).

It is too easy, on the basis of the foregoing discussion, to suggest a dualistic opposition of science and religion but this is an incomplete picture:

The contrast between objective, rational science and mysterious irrational

theology is no longer so clear as it once seemed ... it can no longer be said that science involves the expulsion of mystery (Leech 1985:9).

Increasingly modern science, particularly physical science, includes space for mystery and beauty seen, for example, in the discoveries of chaos theory. Some scientists are aware of the dangers of a mechanistic view of human nature and emphasise the need for openness and a sense of mystery in both science and religion (Leech 1985:9). Polanyi, a scientist writing on the philosophy of science, suggests that human beings '*can know more than they can tell*' (1983:4). He goes on to describe how even scientific discovery includes sudden leaps of intuitive understanding as well as more rational discovery (Polanyi 1983:21-24). A survey of one thousand randomly selected American scientists in 1996 suggests that 40% continue to believe in God, a figure remarkably similar to a similar survey in 1916 (Larsen and Withan 1997). In addition, belief in a divine being is not a prerequisite for recognising the importance of meaning, a key theme in the concept of spirituality discussed in this research. Psychologist Steven Pinker stated in a recent interview, that:

We have meaning and purpose here inside our heads, being the organisms we are. We have brains that make it impossible for us to live our lives except in terms of meaning and purpose. The fact that you can look at meaning and purpose in one way, as a neuro psychological phenomena, doesn't mean you can't look at it in another way, in terms of how we live our lives (Douglas 1999:6).

Both religion and science need to be recognised as human systems, albeit ones that have developed over many centuries; both can be challenged without threatening to shatter our whole world view. Recognising and allowing a place in this debate for all that lies outside the rational and explicable is a huge challenge but a vitally important one. Feminist theologians, such as Mary Grey and Rosemary Radford Reuther suggest that our current world view, including much Christian thought, is dominated by the rationalist, dualistic perspective which requires a counter emphasis on relationships, intuition and connection (Reuther 1990, 1992, Grey 1993). Grey outlines a parable with these two stereotypes as characters (Logos and Sophia) in opposition over the current ecological crisis, struggling to find a way forward (Grey 1993:7-9). Finding them all too often in simplistic opposition, she seeks to draw on the insights of both. It is this struggle to draw together different perspectives that lies at the heart of the holistic ideal which must surely value the insights of both thinking and feeling, of science and art. An exploratory and open attitude which nonetheless values non rational ideas and

beliefs, ensuring there is room for poetry and metaphor alongside experiment and rational argument, would be a good place to develop a spirituality for our own time.

Searching for an authentic voice for spirituality

While recent years have seen a resurgence of interest in spirituality, the majority of the twentieth century has been characterised by an apparent rejection of the spiritual dimension. Modernity reached out to the tangible and innovative, discarding intangible spiritual traditions. Instead, materialism and science have dominated the understanding and vision of the modern era. Marx and Freud, both highly influential in shaping this modern vision, were critical of the religion of their time (Hay 1990:86-87, Leech 1985:10-15). Much of their criticism was directed at formal religious dogma rather than inherently opposed to human spirituality but, as long as religion and spirituality were indistinguishable, this entailed a parallel rejection of the spiritual dimension. These critiques, plus the reactions of the institutional church to them, helped to create a polarised atmosphere surrounding religion and spirituality. In such an environment it becomes almost impossible to find opportunities to openly explore spirituality with other people. McIntyre, who has written from both Marxist and religious perspectives, describes the difficulty of discussing religion when there is so little agreement about the concepts it entails (McIntyre 1970:62-3). The same could be said of discussions about spirituality; with little or no shared framework of understanding attempts to explore spirituality with others seem doomed to failure. It is significant therefore that the creation of such opportunities played a key part in this research. Providing a safe space in which to tease out key concepts about spirituality, as we attempted to do in the co-operative inquiry group, generates a common foundation from which to explore further.

The latter part of the twentieth century has been characterised by the gradual rediscovery that religion may not be the same as spirituality and that previous ways of understanding religion itself may be inadequate. There has been a growing sense of disillusion with the modernist emphasis on the material and technological and a renewed appreciation that there may be more to life than a soulless materialism. The scientific-technical model, although a vital element of how we view the world today, has little to say about the meaning or purpose of life, being more concerned with questions about how the world works than why. Loss of the previous Christian framework, for all its flaws, as a place in which to explore and experience the inner spiritual dimension

has further contributed to this sense of emptiness leaving a potent void (Leech 1985:20). The developed world's greedy desire for material possessions has been linked with world wide environmental and social damage. Problems such as poverty and ill health are clearly too great to be solved by science and technology alone, although their contribution is important. Life appears increasingly fractured and disconnected despite a restless desire for greater wholeness and a dawning recognition that something is needed beyond the physical and intellectual. Instead, while superficially we live in a secular society, a powerful undercurrent of spirituality surfaces in an indeterminate mixture of astrology, feng sui, environmental concern and meditation (Greeley 1972:153,160).

Religion, in its traditional guise, no longer provides a convenient receptacle for spiritual aspects of life. Perhaps it never could, for this reinforces the impression that the spiritual is a discrete element rather than an integral part of life. Gradually a process of searching for other ways of expressing and exploring this spiritual dimension has developed with a new acceptance that for many spirituality will not be expressed through formal religion at all. Much of the public interest in spirituality has already been outside Western Christianity, linked, for example, to new age groups, alternative communities, the women's movement and environmental organisations. A review of spirituality and the secular quest showed many non-religious ways in which spirituality can be expressed, including sport, arts and social issues such as feminism, justice, health and ecology (Van Ness 1996). Even humanists now speak comfortably of the spiritual fulfilment to be found in art, music, nature or sport (Edwards 1989, Kennedy 1998, Tyler 1998). Spirituality provides a convenient, non religious way of reasserting the importance of the transcendent element of human nature, expressed, for example, in poetry, art and music (Tyler 1998).

The earlier part of this chapter has outlined briefly how the Christian framework, once the primary way in which spirituality was explored and experienced, has become misunderstood and alienated. Yet the current interest in spirituality, far from encouraging a positive variety of alternative spiritual expressions, risks simply being another short lived phase, a temporary 'buzz word'. Certainly the framework of the past is no longer appropriate but where old ideas about spirituality are no longer adequate, new ones need to be developed. The current uncertainty about spirituality can be seen in the way in which spirituality is used to sell material products such as

cars and fizzy drinks as well as the semi-religious significance sometimes given to group activities such as football and shopping! Alongside the growing interest in spirituality outside religion, there is a need to foster greater discrimination between the authentic and the 'phoney' in the spiritual dimension, something which has been largely forgotten during previous years of neglect (Leech 1985:23). A better understanding of spirituality would give people the tools to discriminate between a life enhancing spiritual connection and a marketing tool. This need to understand the concept of spirituality has been one of the issues grappled with by the groups in this research and will be explored in chapter five.

The crisis in spirituality described earlier affects health care at least as much as other areas of life. Spiritual and religious concerns often become more important to people during periods of crisis, including those of health (Ziegler 1998, Speck 1993: 517-8, Simsen 1985). When spirituality is understood as a broad human concern, as I have described it here, the link with health becomes even more apparent. Ill health may challenge an individual's sense of meaning and purpose, question their values and beliefs and threaten relationships. The current confusion about spirituality leaves both clients and health care staff ill equipped to respond appropriately to such an event. Benson compares health and well being to a three legged stool which struggles for balance if one leg is neglected or missing (Benson 1996:22-3). It seems obvious that where spirituality is neglected total health and well being will be reduced. Chapman, writing about health promotion, says:

It is rare to find a [health promotion] program that openly labels a specific activity or intervention as oriented to the enhancement of spiritual health. Yet any perspective that defines the human condition in a narrowly mechanistic or value free manner seems to be unnecessarily sterile and consequently incomplete. Our current collective approach to health promotion gingerly side steps this reality. We generally feel somewhat embarrassed to mention things like love, joy, peace, sense of purpose, connectedness, reverence for living or achieving one's full potential in the context of health promotion programs. Should we not strive to broaden our concept of health promotion to include these kinds of issues? After all what is life worth if there is no love in it? or joy? Are we only interested in prolonging life and unclogging arteries? I hope not (Chapman 1986:38).

The inter-relationship of spirit, mind and body can be illustrated by the response to stress (Labun 1988:315-316). Similarly, Benson notes how prayer, meditation and 'remembered wellness' provoke the relaxation response, which activates neurological

pathways to promote healing (Benson with Stark 1996:131-133). Again, bell hooks, in her self help book for black women, stresses the need to pay attention to spirituality, including time for solitude and contemplation, in order to prevent dissatisfaction (hooks 1993:183-5). Attention to intangibles, such as inner beliefs and personal meaning, are aspects of self care which tend to be under-developed in western health care, partly reflecting the current spiritual crisis. Reviewing the American literature about spirituality, Bensley notes the following recurring themes: fulfilment and relationships; values and beliefs; wholeness; well-being; a higher power and the human-spirit interaction (1991:287). The importance of personal aspects of faith, particularly beliefs and values, is also affirmed by Simsen's work with people in hospital (1985, 1986). Sachs suggests that ultimately such meanings belong not to individuals but to communities and traditions (1991:18). Grounding the search for meaning in shared values reduces the risk of developing a personal spirituality dependent on meanings that are harmful to an individual or their community (for example, racism or power). Forrest-Maher and Hunt challenge the 'helping arts' to incorporate spirituality, establishing first that practitioners must also recognise and explore their own spirituality (1993:26-27). Exploring personal beliefs, in a way comparable to the experience of the co-operative inquiry group described in chapter four, offers an important element of self care for health care professionals and their clients. Palliative care offers just one particular space in which to explore spirituality in ways which may be important for total health. A clearer understanding of spirituality equips health care workers to integrate spirituality into both health promotion and health care as appropriate to the needs of themselves and their clients.

In America, the National Institute for Health Care Research, a privately funded non-profit making advocacy organisation, has published extensive literature reviews suggesting that religious faith and practice can be positively linked to health status (Ziegler 1998, Levin 1997), although the value of some of this evidence is disputed (Sloan et al 2000). Discussions about spirituality are a recognised part of the curriculum in nearly thirty American Medical Schools (Levin et al 1997). While it is important to address the issue of spirituality in health care, too simplistic a consideration risks trivialising the complex issues involved (Sloan et al 2000). In Britain also there have been attempts to stimulate debate about spirituality in health care (Wright 1997, Salvage 1997, Neuberger 1999, Sloan 1999). The Anglican Church has also recently published a report about healing (Church of England 2000). Yet despite

the growing interest, there remains a yawning void between interest and actual provision of spiritual care. As part of a group of staff working in cancer care, all of whom were committed to the provision of holistic care, I was very conscious of the discrepancy between our talk of a holistic approach and the actual spiritual care offered. Far from being an integral element of our care, links between spirituality and health were often neglected and our understanding of spirituality, mimicking the rest of society, lacked clarity. Although recent publications encourage the provision of spiritual care, even they appear to confuse religion and spirituality (NHS Management Executive 1992, National Association of Health Authorities and Trusts 1996, Department of Health 2000a). Hospices, which have traditionally emphasised spiritual care, often have a religious foundation which is not always helpful (Walter 1997).

Without some shared understanding of the nature of spirituality it is hard to begin to provide a truly holistic service. Yet opportunities to explore spiritual ideas and concepts with colleagues are rare and often hampered by preconceptions and misunderstanding. In common with the world beyond health care, our group found we had no shared voice with which to articulate and respond to the spiritual issues which arose in our professional practice. The research outlined in this thesis originates from this basic inability and the struggles of myself and colleagues to find a new voice with which to speak about spirituality in the context of holistic care. Our experience suggests that continuing professional development, especially reflective and experiential education, has the potential to facilitate the required exploration of spirituality. If spirituality is innate, of course it cannot in itself be taught. However, as with characteristics such as intelligence, sporting or musical ability, education offers an opportunity to develop and nurture the innate potential. Some individuals may be more open to learn about spirituality than others but perhaps all need a basic awareness. Some understanding of the tools required to nurture spirituality in ourselves and others may be particularly useful for health care professionals. The provision of an open and reflective environment creates opportunities for such health care professionals to explore spirituality with other people in a way which is profoundly inclusive and enriching. That process creates a foundation on which to build, relating ideas about spirituality to the issues arising in personal life and professional practice.

Those involved in this research were uncomfortable with a purely religious understanding of spirituality, which seemed inappropriate for an open centre

where the staff themselves did not share a common faith, yet we had no alternative to offer. Walter suggests that an alternative view of spirituality as the search for meaning provides the best way forward in this situation (Walter 1997). Yet such an approach, and its implications, needs to be explored in some depth before it can be used effectively. Recognising spirituality as a shared search for meaning and purpose reinforces this as a common human task which transcends professional boundaries. While this may have benefits, such boundaries exist to protect both professional and client so that the cost of transgressing them when providing spiritual care needs to be weighed carefully. This issue will be considered further in chapter six.

Conclusion

Interest in spirituality is re-emerging after a period of relative neglect. Christianity, previously the primary voice with which spirituality was expressed in Britain, no longer fulfils this role. Yet no comparable framework in which to explore these concerns has yet developed. Indeed, there seems little clarity even about the nature of spirituality, so this emerging interest remains marginalised and unfocused. Moments of transition, in the case of this research facing illness and death, provide important openings for an exploration of spiritual ideas. Such an exploration is important for both health care workers and those for whom they care. This may be particularly important for a generation which has lived through a period where spirituality has been neglected or focused primarily on religious belief. Helping people to understand spirituality as a broader concept may provide an opportunity for people to begin discovering an authentic 'voice' with which to express their own spirituality. Exploration with others, encompassing both reflection on personal experience and on theoretical ideas, can balance the tendency of spiritual exploration to be inward looking and individualist. Such exploration helps develop a basic framework within which spirituality can be further explored on an individual or corporate level. There has been little specific research into how this can be done effectively, although work in related fields is available. The research outlined in this thesis is relevant, therefore, to both academic and wider professional concerns.

METHODOLOGY AND PRACTICE

Chapter Three: Co-operative Inquiry: a methodological approach

Recognising the shifting interest in spirituality highlighted in previous chapters was one thing; finding a way to research spirituality in the context of this thesis was quite another. The topic defies neat boundaries, straddling the fields of education and health; it encompasses adult education, continuing professional development, complementary and traditional health care, theology and philosophy. How could such a diverse area be researched effectively and what methodology would be appropriate? My decision to use human inquiry methodology reflects my personal experience, the character of the methodology and the nature of the topic. These three aspects will now be discussed and I will outline the general theoretical basis of human inquiry methodology, with particular reference to co-operative inquiry. Chapter four provides a more practical and detailed review of the specific co-operative inquiry which forms a central element of this research, including the organisation, process, outcomes and analysis of the research. Questions of validity, both general and specific, provide a recurring theme in both these chapters.

Selecting an appropriate methodology

Personal reasons

A basic positivist tenet that there is '*a single tangible reality out there*' (Lincoln and Guba 1985:37) still dominates much medical research. My own experience, and that of colleagues, suggests that such a reality is never quite discovered. Our understanding of life and practice appeared more in line with the naturalist view that reality is '*multiple, constructed and holistic*' (Lincoln and Guba 1985:37). Qualitative approaches to research are becoming more acceptable in health care (Boulton and Fitzpatrick 1994), yet the 'double blind clinical trial' remains the gold standard in medical research. Stereotyping quantitative research methodologies as 'bad' and qualitative methods as 'good' is simplistic, both are of value and can be done more or less well (Silverman 1997). However, I sensed that quantitative approaches, invaluable in some circumstances, would not be effective in this research, failing to recognise the complexities of people's lives so that the picture produced is incomplete, even unhelpful. The pre-eminence given to the scientific viewpoint in medicine partly reflects trends in western culture, discussed in chapter two, which have also contributed to the marginalisation of spirituality. Hence my concerns about medical research echo my concerns about a medical model of health care, failing to recognise

that health care is an art as well as a science. Research concerned with spirituality required a different approach to that of empirical science yet I wished to approach the issues with an equivalent rigour. Spirituality is quintessentially about an indefinable quality of the human spirit, the art of living and dying, of relationships and wholeness. It seemed of little value, even if it were possible, to neatly package such issues for a clinical trial! Any results obtained would surely tell us little of value about the nature of spirituality.

In the positivist paradigm an independent researcher stands outside the research process, neutrally observing the activity of others (Lincoln and Guba 1985:37). As a human being, researching an essentially human characteristic, it was difficult to imagine myself maintaining such a position. As a health care practitioner, I was part of the group of people being researched, while my own beliefs were inextricably linked to my choice of topic. Ignoring such a reality seemed to make the research process more liable to distortion rather than less. My own faith and understanding of spirituality needed to be openly declared and integrated into my research, ensuring that these could be challenged along with the understanding of other participants. Such concerns struck at the very heart of my previous understanding of research, demanding not just new techniques but a whole new approach. I wanted to find a methodology that recognised my involvement yet still enabled me to challenge and explore these internal meanings. Involvement in adult education, particularly reflective practice, encouraged me to look beyond health care for a different approach to research, recognising this may be neither acceptable or comprehensible to all my health care colleagues. Human inquiry, discussed briefly in chapter one, appeared to offer an alternative methodology which both endeavoured to make overt the conscious and unconscious assumptions and recognised a broader spectrum of knowledge than the purely scientific. I was conscious of my own inexperience with such an approach and of the difficulty of recognising my own tacit assumptions including the effect of my own medically based training. I remained concerned about validity, aware of the need to be 'objectively subjective' but wondering how possible that was to achieve.

Methodological reasons

As discussed in chapter two, the Enlightenment brought a profound shift of emphasis towards observation and empirical evidence as the foundation of knowledge. This, in a variety of forms, became the dominant paradigm for research, increasingly influencing

the social, as well as natural, sciences. However, observations, diaries, recordings and other 'remains' of human activity are of limited value in exploring human meanings, ideas and beliefs (Hughes 1990:97, 115). A determinist view of human activity underplays uniquely human factors such as values and meanings (Hughes 1990:19), yet spirituality is essentially about that which cannot be perceived with the senses. Researching it required a view of knowledge that recognises beliefs, values and stories as well as factual material. If this type of knowledge is dismissed as unimportant then questions about spirituality can also be brushed aside. A view of human life which reduces a complex individual or group to the merely physical and material is likely to deem questions about the human spirit irrelevant and evidence for such an entity non-existent. A different, more pluralistic understanding of knowledge is required and human inquiry purported to be a method which consciously engaged with these very themes.

Practitioners of human inquiry suggest that research with people can only be truly achieved if those people are engaged as persons, co-subjects and co-researchers, in any enquiry (Reason 1994b:10). Proponents criticise medical research for the exclusion of its subjects from the totality of the research process, particularly the powerful thinking and decision making (Heron and Reason 1984:86). Heron and Reason argue that the double blind clinical trial:

Is a quite invalid approach to the study of persons as wholes because it fails to take into account that persons are self directing and can become intentionally self healing (1984:87).

The necessarily random nature of such trials fails to respect human potential and seems particularly at odds with the holistic approach (Heron and Reason 1984:87). Hence an inclusive, participatory epistemology is foundational to human inquiry rather than optional and methodologies have been developed on this basis such as participatory research, co-operative inquiry and research partnerships (Reason 1994b:10). The emphasis on wholeness and holism in spirituality supports the need for a participatory approach, which takes seriously the knowledge of all participants. The more difficult task was rather to explore that knowledge and understanding, particularly when this often appeared tacit and unclear.

Engaging with experience is another essential aspect of human inquiry,

resonating with my concern to integrate spirituality rather than aggravate the fragmentation described in chapter two. Positivist methodology distinguishes between two orders of reality: identifiable acts, structures and institutions and subjective beliefs, values and attitudes (Hughes 1990:115). While it is possible to investigate human meanings by outside observation (Hughes 1990:97), of necessity this omits the internal human perspective. Returning to the idea of being objectively subjective, outlined in chapter one, this approach consciously brings together subjective thoughts and ideas with more theoretical viewpoints, transcending both to create a deeper understanding of the topic (Reason and Rowan 1981:xiii). Participants' lived experience, including the researcher's own, becomes central to the whole approach, rather than an unhelpful contaminant. Human inquiry endeavours to achieve a more complete knowledge, drawing on life experience, theoretical understandings, intuition and feelings. Rather than a single observable reality, human inquiry suggests that knowledge consists of a dense web of interdependent ideas and beliefs (Reason 1988a:11). Although this picture is more complex than a dualistic understanding of reality, it resonates with our experience, particularly in the co-operative inquiry group. Such holistic knowing requires participation and empathy to create knowledge which draws together theory and practice (Reason 1988a:10-11). Human inquiry provides a 'human' research methodology for a topic where a facet of 'being human' is a central concern. The tendency of orthodox research to dehumanise and trivialise people in its concern for empirical evidence is at odds with my understanding of spirituality which is profoundly 'person centred'. A research methodology which fails to take this into account could not grapple with the complex questions this research needed to address. Yet in order to be recognised by other health care practitioners, and therefore achieve my aim of contributing to health care policy, the research also had to make explicit the foundation on which its claim to validity was based. The failure of modern medicine to appreciate and value qualitative research, in comparison with quantitative approaches, makes this task a delicate one.

Traditional medical research implies that such a qualitative approach is easy, mere 'soft' research with little intellectual rigour (Boulton and Fitzpatrick 1994:19). The failure of some medical research to question its own underlying epistemology does not help here, ensuring that qualitative research is seen as merely an alternative technique rather than a different approach. In reality my own experience, and that of others, suggests that achieving truly rigorous, participative research is far

from easy (Reason 1994:3). Measures to ensure validity in human inquiry must be an integral element of the whole research process. Dewey describes reflective thought, an integral part of human inquiry, as:

Active, persistent and careful consideration of any belief or supposed form of knowledge in the light of the grounds that support it and the further conclusions to which it tends (Dewey 1910:6).

Not easily achieved, such thought requires a union of skilled method and appropriate attitudes (Van Manen 1995:34). Referring back to Dewey, Van Manen suggests that character traits such as *'open mindedness or sincerity, wholehearted or absorbed interests, responsibility as well as the need for a habit of thinking in a reflective way'* are required in reflective practice (quoted in Van Manen 1995:34). Such challenging and flexible habits of mind are not easily achieved or maintained by anyone. Genuine openness to the reflective process requires that researchers are willing to recognise and challenge their own established beliefs and customs as well as those of others. They must remain open to new ways of thinking and behaving whatever the constraints imposed upon them by the research. Genuine participation removes total control of the research process from the researcher, who is rendered vulnerable to challenge by all those involved. Procedures to ensure the validity of this particular research will be discussed in chapter four.

Topic reasons

An earlier study of spirituality and nursing practice had also chosen a qualitative methodology, based on grounded theory, to ascertain practitioners' ideas about spirituality, suggesting that a more personal approach is appropriate in this field (Harrison and Burnard 1993). From many possible qualitative research approaches, I made a conscious decision to use the human inquiry approach, and specifically to focus on co-operative inquiry. Initially, I was struck by the fact that Reason, describing the foundations of human inquiry, suggests themes which resonate remarkably with the issues highlighted in previous chapters, particularly his suggestion that the purpose of human inquiry is to heal (or make whole) the fragmentation and division that so characterises modern experience (Reason 1994:10-13). Interestingly, Reason links wholeness, in the sense of a more participatory approach, with holiness, suggesting that awareness of the world as 'sacred' is an essential part of the participatory approach (Reason 1994:10). Elsewhere he describes his own struggle to recognise and

integrate this sense of the sacred into research, describing how his essentially secular understanding of human inquiry had been challenged until he recognised that:

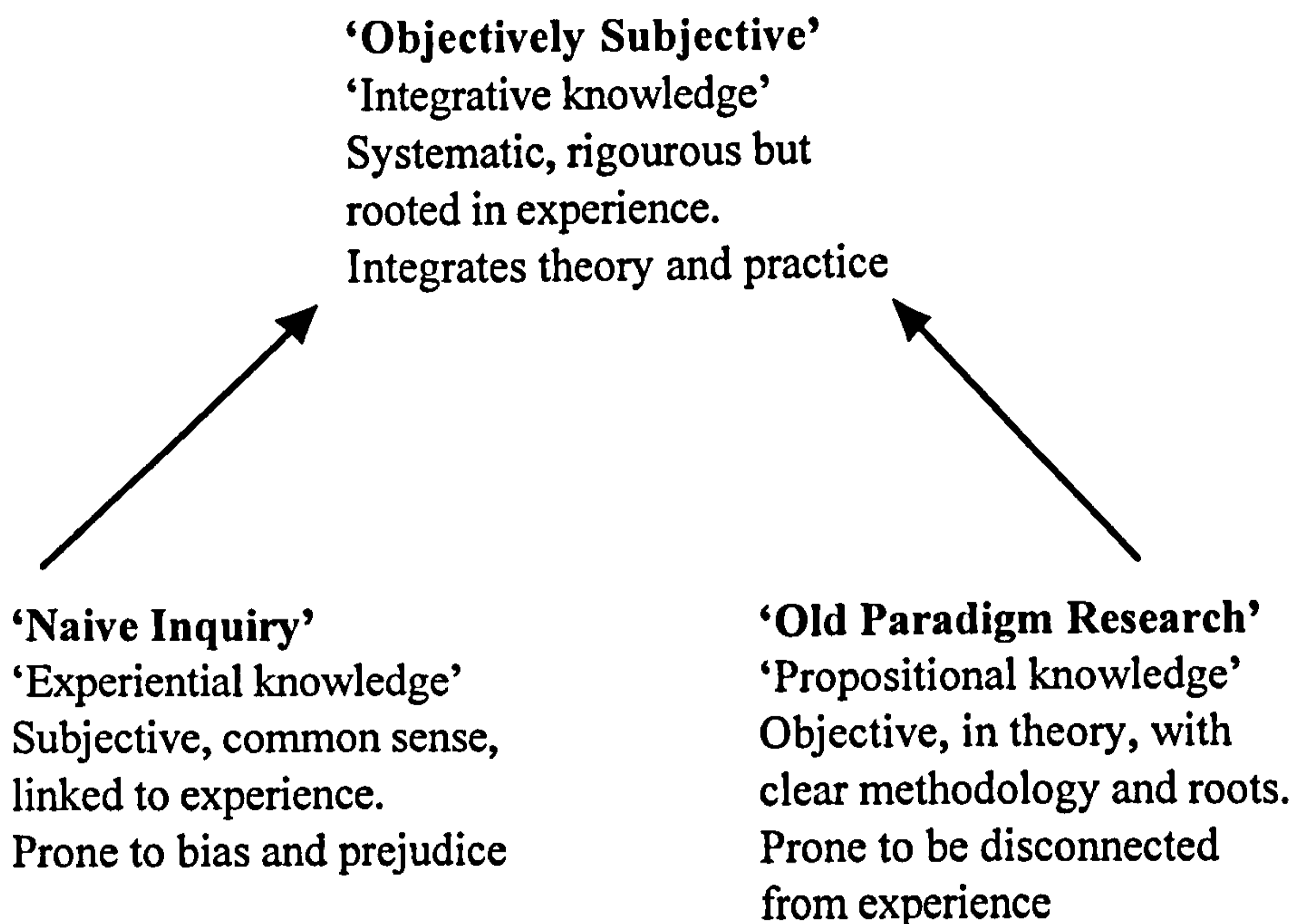
Human inquiry must be grounded in a sense of the sacred, and its purpose must be to nurture the growth of love, beauty, wisdom and compassionate action (Reason 1993).

As understood in this thesis spirituality lies at the very heart of what it is to be human. Human spirituality cannot be tied down to a physiological phenomenon, it transcends body and mind while remaining intimately linked to them. Metaphysical concerns about transcendent values and meanings, apparently of little concern in empirical research, are integral to spirituality. An alternative methodology, such as human inquiry, is required which recognises and values these concerns. Spirituality requires a different way of looking at things, a more intuitive, experiential knowledge which accepts that *'we know more than we can tell'* in Polanyi's classic phrase (1983:4). Polanyi suggests that such tacit knowledge forms an indispensable part of all knowledge, such that any attempt to achieve a detached perspective is doomed to failure (1983:20). Tacit knowing is accepted and valued in human inquiry in a way that would not be possible in more traditional methodologies. There is space here to retain a sense of wonder, to accept an element of mystery, both vital in any discussion of spirituality. There is also a respected place for intuition, metaphor and subjective ideas. Spirituality and human inquiry methodology both honour the variety of human experience, looking for coherent meanings within that variety, rather than attempting to impose one particular model. This honouring of variety adds depth to any investigation of spirituality particularly where there is greater awareness of the spiritual than in Western European culture. Discussion in chapter two, for example, suggests there is much to be rediscovered from traditions where spirituality continues to play a valued and integral role (such as Celtic or African). Heron also outlines his intellectual debts to mystics and modern thinkers ranging from Friere to Buber and Polanyi (Heron 1996:14). Such perspectives are also important in human inquiry, providing routes by which greater understanding can be achieved as traditional viewpoints are challenged (Reason 1994b:13). The sense that western civilisation stands at a significant turning point, proposed for example by Tarnas (1991:xi-xii), resonates with human inquiry practitioners (Reason 1994a:1). The metaphor of the journey is frequently used in spirituality and, for all my concerns about its adequacy, it remained an important theme throughout this research. The sense of openness to exploration and discovery

which journey implies is vital in both spirituality and in human inquiry.

Using the human inquiry research model

Such a brief review of my reasons for choosing human inquiry inevitably tends to simplify and polarise the complex spectrum of research methodology in actual use. Introducing their source book on human inquiry methodology, Reason and Rowan describe their own wariness of being merely opposed to traditional research methods (1981:xii). They propose drawing on the strengths of traditional research and naive inquiry to establish a method that is 'objectively subjective' (see figure 3:1):



**Figure 3:1: Objectively Subjective,
adapted from Reason and Rowan 1981a: xiii**

Naive enquiry, based on life experiences, provides a rich source of material for exploration but is easily dominated by prejudice and conformity. Conversely traditional scientific orthodoxy, in the exalted value it gives to objective and factual material, loses sight of significant aspects of human experience. Human inquiry looks for an alternative approach which is characterised by both objectivity and subjectivity, sometimes called critical subjectivity or objective subjectivity (Reason and Rowan 1981a:xiii, Reason 1988a:11-12). Reflective thinking provides a way of developing subjective experience, using the lens of rational consciousness, to create a more

integrated and creative understanding. Recognising and incorporating knowledge gained from the unconscious, rather than attempting to exclude it, is an important element of human inquiry (Reason and Rowan 1981a:xvi). Accepting insights from the imagination and intuition allows links to develop across the whole web of human experience creating knowledge which is more integrated or 'connected' to use the co-operative inquiry group's terminology. Rather than trying to be objective about reality, Reason and Rowan claim that the scientific method in research concocts a 'scientific fairy tale' which is divorced from the reality of how research is carried out as well as from life experience (1981a:xvi). Summarising this approach, Rowan and Reason suggest that:

A true human inquiry needs to be based firmly in the experience of those it purports to understand, to involve a collaboration between 'researcher' and subjects' so that they may work together as co-researchers, and to be intimately involved in the lives and praxis of these co-researchers. But in order to do human inquiry we need some changed way of looking at the world and interpreting it (1981:113).

The integration of research with the world as it is lived in reality is particularly important, helping to ensure the knowledge developed in research is integrated with experience (Hughes 1990:116).

Human inquiry methodology regards knowledge as multidimensional, involving three subtly interwoven strands of knowing (Reason 1988a:4, Heron 1981a:27-30): propositional knowledge (knowing about) involves ideas, theories and propositions; practical knowledge (knowing how to) involves skills and abilities; experiential knowledge (knowing by encounter) is tacit, intuitive and holistic. A fourth concept of presentational knowledge has also been suggested, involving the ordering and presentation of tacit ideas in a creative way (for example, as poetry, movement, art) which offers a potential bridge between experiential and propositional knowledge (Reason 1994c:42). Heron's pyramid model, shown in figure 3:2 below, illustrates how knowledge is based on a foundation of experience. Heron contrasts this view of knowledge with traditional university research, where propositional knowledge is regarded as pre-eminent and self-sufficient (1996:32-33). My developing awareness of spirituality, particularly related to experience in palliative care, is the primary reason for undertaking this research. While I undoubtedly do not recognise all the ways in which this experience has affected the research, I do acknowledge its profound influence. From my involvement with this process of research I have begun to

understand some of the effects of that influence. This opens up new possibilities for the research, even though it also to some degree clouds my vision.

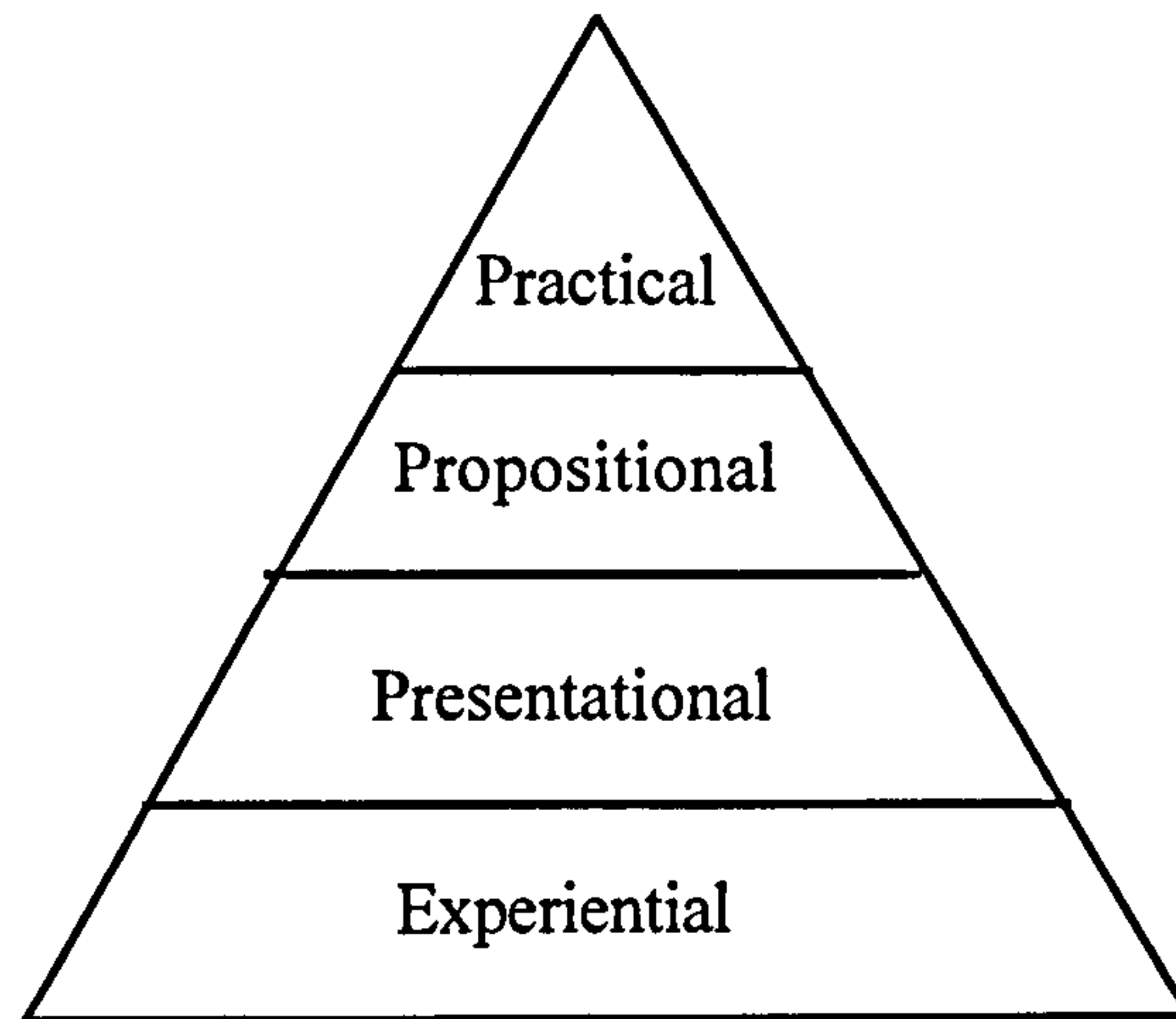


Figure 3:2: The Pyramid of Fourfold Knowing, from Heron 1996:53

Human inquiry methodology offers an opportunity to investigate my own developing spirituality, endeavouring to integrate and understand my subjective experiences and allow my reflections on them to be part of my research.

As I have described, human inquiry is a cyclical process, shown diagrammatically in figure 3:3 on the following page. The research process is seen as starting from a state of 'being', the situation in which the researcher, or group of researchers, is involved. Here a concern or problem is recognised and the researcher moves, through thinking about that particular concern in a systematic way, towards developing a specific project through which to investigate his or her concerns. As the project is carried out there is an encounter between ideas or theoretical reflections and reality which generates data. The researcher, or researchers, spend time trying to make sense of the data acquired before communicating their findings to others, finally returning to a state of 'being' once more (Reason 1988a:6-7, Rowan 1981a:97-106). This process, initially described by Rowan (1981a:97), is used by a number of researchers as the outline of their own research process, including Coleman (1991) and Rosen (1981). The diagram rather neatly describes a lengthy and complex research process, which in reality feels far from neat much of the time.

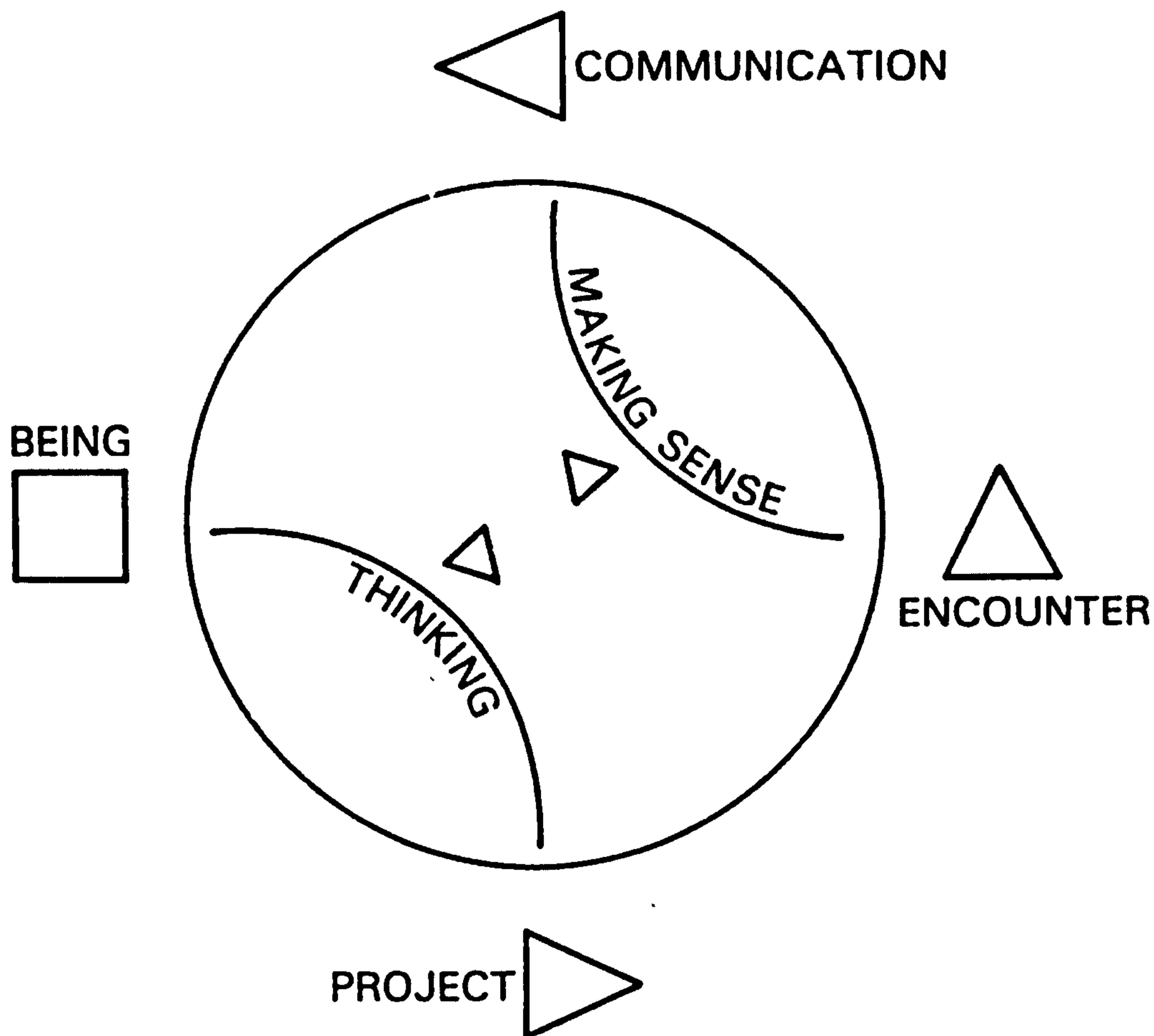


Figure 3:3: The Research Cycle Model, from Rowan 1981a:98

Co-operative Inquiry

Co-operative inquiry is the particular expression of human inquiry research which became a central stand of this research. Continuing professional education activities flowed from the co-operative inquiry group, described in chapter four, established to explore spirituality during 1997-8. Reason outlines how co-operative inquiry was first described by Heron in 1971 and has gradually developed since then (1994c:41). It is currently most fully described by Heron in his book of the same name (1996). Co-operative inquiry is a dynamic process, and Heron makes clear that his book represents his view of the method, not a final definition of the 'correct' way to do it (1996:49). The defining features of co-operative inquiry methodology are clear involvement of the subjects in all research decisions, intentional interplay between reflection and action, explicit attention to validity procedures and the skills needed for human research, an open unbounded awareness and approach where the full range of human sensibilities

are available to the inquiry (Heron 1996:36).

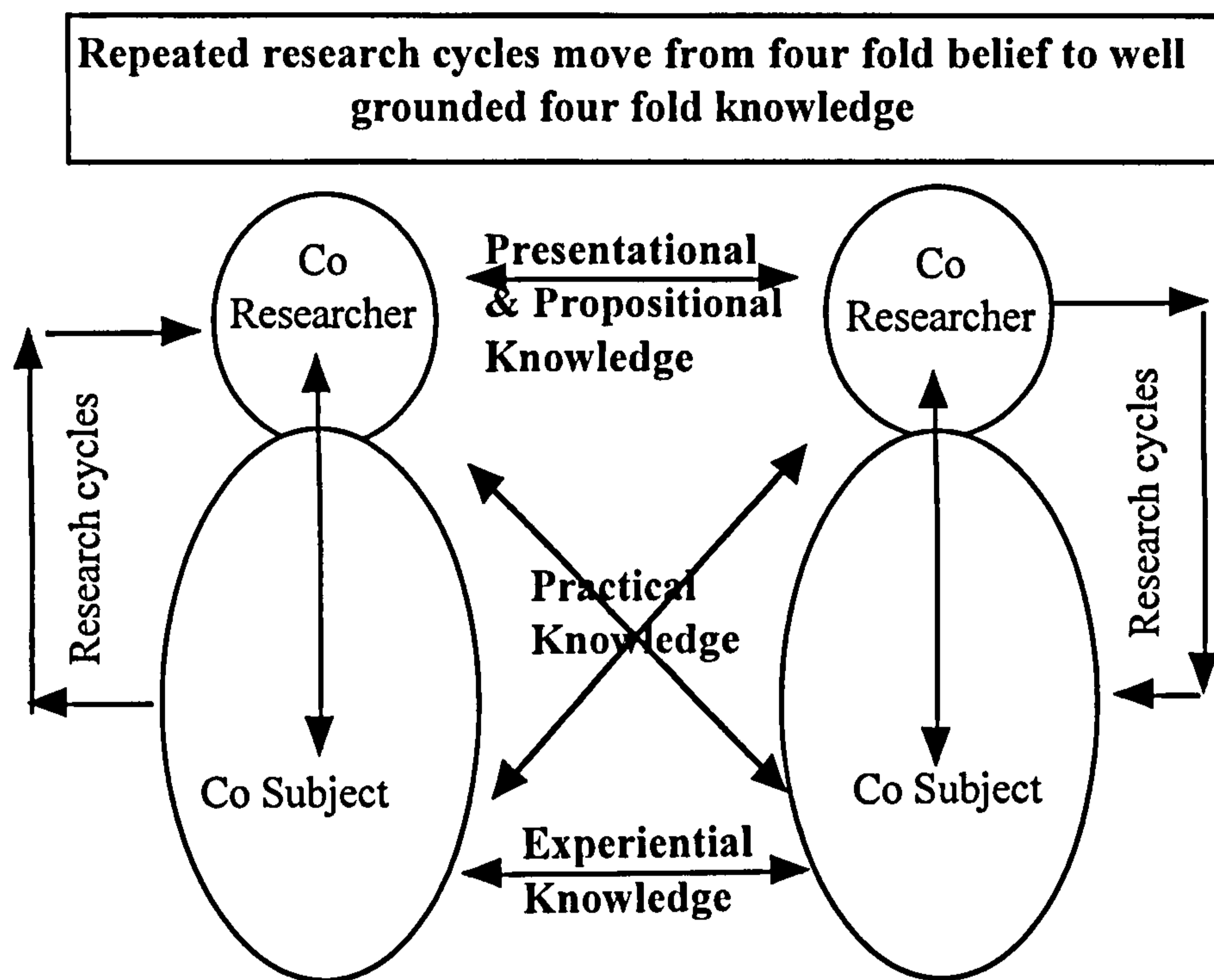
Co-operative inquiry is based, as a form of human inquiry, on the assumption that human beings are self determining, that each person is a

Fundamental spiritual entity, a distinct presence in the world, who has the potential to be the cause of his or her own actions (Reason 1994c:41).

This sense of each individual's unique spiritual potential provided another link between methodology and subject. Co-operative inquiry was particularly important as the first stage of the research, providing a foundation of inclusive shared knowledge which became a platform for other activities. The exploratory nature of co-operative inquiry methodology encouraged the development of knowledge which was grounded in our experience. Meanwhile, the acceptance of different forms of knowledge helped create a safe space in which to explore the subject widely and deeply. Increased knowledge, of all types, gained from the inquiry was both based on and integrated with practice. The co-operative nature of the inquiry was particularly important. As facilitator of the group, I was able to be part of the research process in a far greater way than with other qualitative methods; while for all participants, the group dynamic provided a forum in which to challenge as well as support each other.

In essence, co-operative inquiry involves a group of co-researchers meeting to inquire into some aspect of their life or work utilising a cyclical process of reflection and action. One of Heron's diagrammatic models of the process is shown in figure 3:4, indicating the different stages of the inquiry and showing how the differing types of knowledge, described earlier in this chapter, interact. Reason outlines the process of an inquiry in words (1988a:4-5), referring also to the model of the inquiry process shown in figure 3:3 (1988a:6-9). As the initial idea of the research is presented to an existing or potential group, facilitators and group members explore their ideas and feelings about the inquiry during this and the first reflective stage (presentational knowledge). Towards the end of the first reflective stage, the group clarifies the focus of their research proposal and how they aim to research it (propositional knowledge). In the next active stage, group members take the results of these discussions out into their life and work. This may involve self observation, use of journals or observation of other group members (practical knowledge). This active phase of the inquiry may become so integrated into their lives that they no longer feel that they are 'doing

research' (experiential knowledge). The inquiry then returns to a more reflective phase.



Two researchers/subjects are shown here but any number may be involved

Figure 3:4: The Interaction and Development of Knowledge in Co-operative Inquiry, adapted from Heron 1996:56

Group members present their findings to each other or to the wider world using a variety of approaches, moving on to attempt to make sense of these experiences, redefining models and theories in the light of their experience (Reason 1988a:4-5).

Heron identifies three primary strands to the work or life of a co-operative enquiry group, all of which need to be considered both in establishing the group and in looking at its findings (Heron 1996:65-71). The initiation of any co-operative inquiry group is an important phase in its development, establishing the setting in which the research will occur. The three primary elements of co-operative inquiry described below must be introduced to the group during its initiation then built into all the group's working practices. This process of initiation may be carried out by the facilitator or shared between group members but it is vitally important that all group members understand and own all three strands if the group is to function

effectively. The process of initiation in this specific inquiry will be described in chapter four.

The inquiry strand

There is obvious work to be carried out by the co-operative inquiry group in exploring concepts and ideas, including those which underpin the methodology. Concepts need to be made explicit and clarified, varied understandings within the group explored, ideas, old and new, challenged. The focus of the inquiry strand may either be to delve deeper into a common field of interest or to bring together a wider range of opinions and ideas. In any inquiry group, even one centred on a common interest, there will be different views, ideas and approaches. As these differences are recognised and explored there may be tension but there should also eventually be greater understanding and possibly new ideas. This is one of the advantages of working in a group, where it is possible to offer a broader awareness than can be achieved by a single individual. There are also greater resources in terms of knowledge and experience to share. In addition, a group can provide a safe space for critical feedback on ideas, although this is dependent on the development of trust. Heron suggests that an essential task of the inquiry strand is to develop a greater understanding of the research methods (1996:65). He points out that the inquiry aspect of the research may be approached in different ways, ranging from a rational, logical approach (apollonian) to a more intuitive, emotional approach (dionysian) (1996:45-46). Researchers should consider which of these approaches is more applicable to their group and its topic, aiming to achieve an appropriate balance of the two extremes. This decision will be reflected in the activities of the group, for example, a more apollonian group will tend to emphasise planning and structure while a dionysian group will emphasise an improvised and diffuse approach, using symbols and stories.

The emotional and interpersonal strand.

The emotional dimension is an element in any group's life. Ignoring this tends to be counter productive; the inquiry strand will be affected, for better or worse, by the emotional atmosphere of the group. Therefore, co-operative inquiry methodology makes overt the task of identifying and managing the emotional state of the group as well as more cognitive aspects of any inquiry. Work happens, or fails to happen, because of this emotional layer at least as much as any other aspect of the group's life. The description by Bennett et al of their experiences within a supervision group

describes this process well (1997). Reason (1988:27-28, quoted in Heron 1996:69) suggests three stages in the life of an effective co-operative inquiry group, each with a different emotional climate. First there is the stage of safety and inclusion where people in the group need to get to know each other and feel comfortable together as they clarify the nature of the group's task. The second stage is about difference and disagreement where very varied opinions are expressed and the group has to find ways of working with these diverse perspectives. Finally, the group moves towards authentic collaboration and mutual respect and the task of the group becomes more fully shared. This is very similar to the more general experience of group dynamics described in adult learning situations (see for example, Rogers 1990, Tuckman 1965) with the added tensions of the research process. Facilitation of the group becomes an important aspect of the research, requiring adult education teaching skills, such as an understanding of group dynamics, in order to develop an effective learning (and researching) environment (Reason 1988a:2).

The collaboration strand

Collaboration is a characteristic feature of co-operative inquiry and other forms of human inquiry research, applying particularly to periods of reflection (Heron 1996:67). Groups need to consciously recognise the importance of individual participants in the co-operative inquiry group, for example by making space for each other to contribute (Heron 1996:67). Each individual has a unique contribution to make, both in what they contribute and in their openness to listen and learn. It is therefore important that there is space for all group members to contribute and that there is a way of levelling out contributions, if necessary. Decision making can be a difficult issue in this aspect of the inquiry. There needs to be a balance between recognition of personal autonomy on the one hand, celebrating difference and variety, as well as collaboration on the other (Heron 1996:69). This is very different from traditional medical research which tends to demand clear outcomes and have a distinct hierarchy, again making this methodology more attractive as a way of researching spirituality. The role of the facilitator is vital in this strand, as it is in the other two. Boulton and Fitzpatrick note the importance of the facilitator in any qualitative research, particularly the need for skills in group working (1994:21). In co-operative inquiry, the facilitator plays an important role in ensuring the initiation and maintenance of the inquiry, although there is a degree of tension between this role and participation in the group. Facilitators may choose to retain key roles or share tasks among group members (Reason 1988c:30-32).

Co-operative inquiry methodology has been used in a number of studies which are comparable to my present research, three of which are particularly relevant. A co-operative inquiry study by Coleman (1991) looked at the role of women in management organisations. Using Heron's outline of the research cycle (figure 3:3) as the framework for her thesis, she analysed progress round each stage of the cycle in turn. Coleman raises important practical and personal concerns about maintaining a research group over time (1991:61-62) which were mirrored in my own research diary as I struggled with the long term maintenance of the co-operative inquiry group during a period of great change at the Cancer Care Centres where we worked. Reason and Heron describe a 'Whole Person Medical Practice' inquiry they facilitated in 1982/3 (Reason 1988b, Reason and Heron 1985). Sixteen doctors (mostly General Practitioners) volunteered to take part in the inquiry, meeting for six inquiry cycles to explore their understanding of holistic care. The full report describing the group's life suggests a larger scale project than mine yet there are distinct similarities, including somewhat similar peaks and troughs in the group's experience and a sense of chaos at times during the process, despite a more consciously 'apollonian' approach. Spirituality became a key strand in this group's exploration of holistic care and their exploration of this issue provides an interesting counterpoint to our own inquiry group's findings. The difficulties of utilising a radically different form of research in a health care setting are discussed (Reason and Heron 1985:5). Finally, Traylen writes about her experience of co-operative inquiry with a group of health visitors (Traylen 1994). I valued her observations on the personal nature of the inquiry, particularly with reference to her role as facilitator (1994:59-60). As a health visitor, Traylen was part of the professional group that her inquiry comprised rather than an outside facilitator, a position similar to mine. She raises similar concerns about her relative inexperience of the methodology and the complexity of much that has been written about it (Traylen 1994:61). Describing the inquiry, she also notes that it led to personal growth for those involved (Traylen 1994:79-81). I found, similarly, that this research highlighted the topic (spirituality) in an integrated way, touching feelings as well as thoughts, ensuring that my own understanding grew and developed alongside that of other group members. Perhaps this was not surprising in view of the topic but again it challenges the traditional view of the researcher as remaining aloof from the research process as well as the idea that research is concerned with academic (essentially propositional) knowledge only.

Questions of validity

Traditional research methods, including the medical research with which I was familiar, stress the inherent validity of research which includes accurate measurement and an experimental approach (Reason and Rowan 1981b:239-240). Still a vitally important concept in this new approach, validity is very differently founded. Human inquiry's claim to validity rests fundamentally on two key features, its emphasis on a personal encounter with experience and its participative nature (Reason and Rowan 1981b:242, Heron 1988:39-40). The relevance of the research is also important, particularly whether it adds practical and useful knowledge about the topic being considered. By grounding the research in experience and fully involving the subjects, knowledge gained can be richly meaningful as well as deeply practical. The intention during an inquiry is that the 'real world' is consciously encountered through the experience of participants who endeavour to make sense of these experiences as they reflect together (Heron 1988:41). Much presentational knowledge is tacit, certainly in spirituality, and part of the inquiry process is to bring into the open this tacit understanding, in a sense to make it more propositional. Heron describes another triangle, shown diagrammatically in figure 3:5, which demonstrates the dynamic interaction occurring in co-operative inquiry. There is a growing congruence as the three elements of the triangle interact and greater illumination develops.

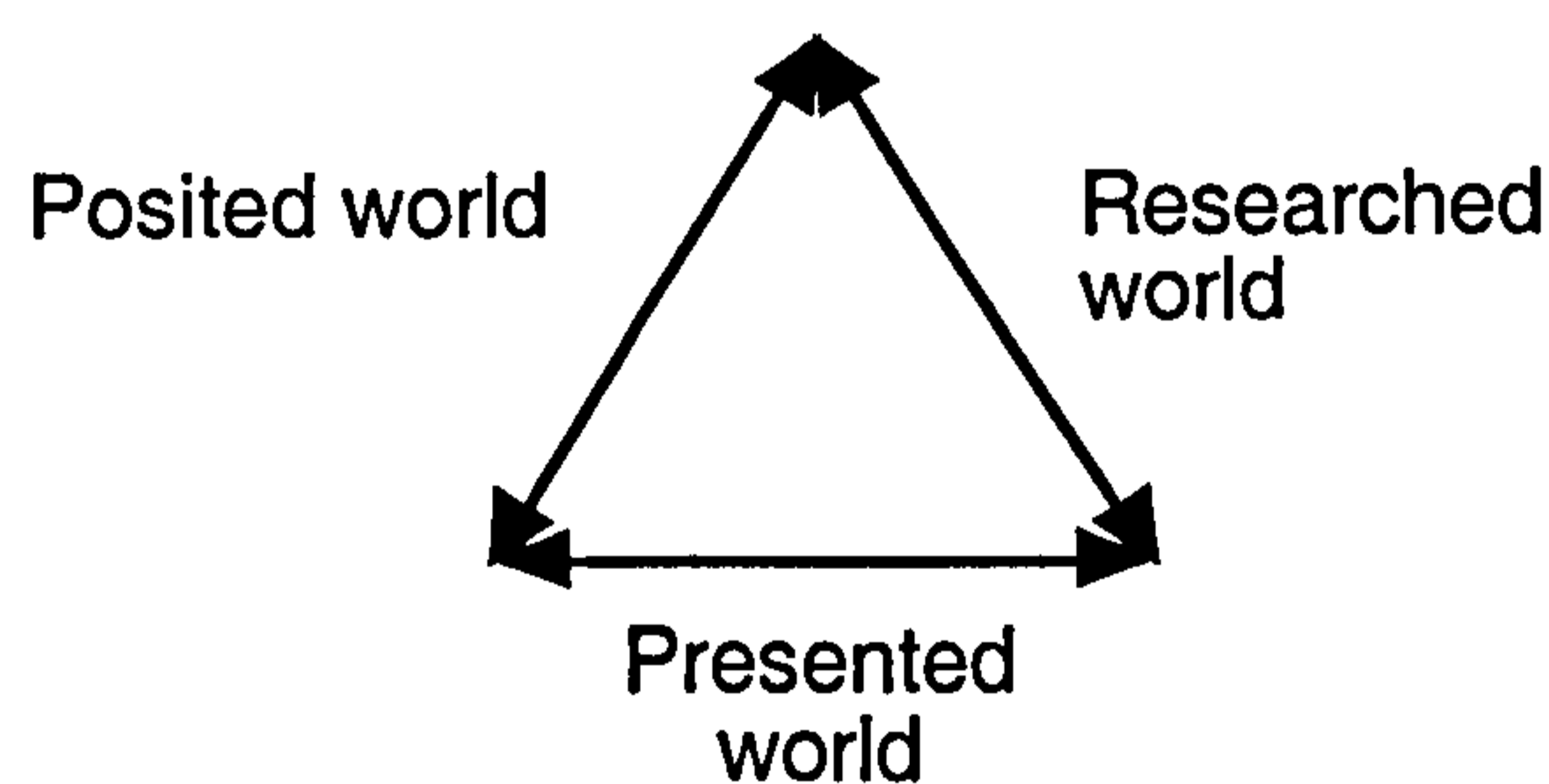


Figure 3:5: Validity in Co-operative Inquiry, from Heron 1988:43

An essential test of validity in human inquiry is that the ideas and insights it generates are coherent with life as experienced in reality (Reason and Rowan 1981b:241). Human inquiry should be a valid process, not just a valid measurement, an understanding that is growing and developing, in encounter with people and with experience. The personal skills and sensitivity of the researcher are an important part

this process: careful, accurate reflection and awareness are personally demanding, requiring researchers to recognise unconscious forces affecting themselves as well as others (Reason and Rowan 1981b:245-246). Such an approach is deeply challenging, requiring the systematic development of self knowledge. Reason and Rowan would also argue that valid human research should not be conducted by an individual alone (1981b:247). The involvement of co-researchers, as in co-operative inquiry, ensures the findings of the inquiry are examined in the light of a range of ideas and experiences. The differing perspectives within the group generates a multidimensional picture, the validity of which increases as participants challenge each other and the theory that is developing (Heron 1981:30). In other forms of human inquiry friends or peers are needed who can challenge and make plain unconscious assumptions (Reason and Rowan 1981b:247). The researcher can also consciously try to observe the research material from different perspectives, looking at evidence from different sources or talking to people known to have different views or deliberately taking a different or contradictory stance (Reason and Rowan 1981b:250). A further important element of building a valid process is the use of research cycling or feedback loops. In co-operative inquiry, as described earlier, repeating cycles of reflection and action are used to ensure research outcomes are well grounded and that propositions are examined in the light of actual experience (Heron 1996:131-134). Underpinning all these validity measures is the need for participants to remain committed to being objectively-subjective, the principle on which human inquiry is based. Heron outlines more clearly how practical validity procedures can be applied (1988:44-59, Heron 1996:133-177). Validity procedures used in this inquiry will be described in chapter four.

Conclusion

Human inquiry, and specifically co-operative inquiry, offers a methodology which is particularly appropriate for research into spirituality. In contrast to the medical and scientific research that I was familiar with, human inquiry provides a rigorous and valid methodology which does not fail to recognise the essentially human nature of this topic. The following chapter will show how the decision to work within this approach became a reality.

Chapter Four: Comfortable To Question: a co-operative inquiry into spirituality

This chapter will outline the actual organisation, process and outcomes of the co-operative inquiry group which forms the central strand of this research, explaining how the methodology described in chapter three has been used in a specific setting. Describing the research methodology in some detail, prior to reporting its findings, provides an opportunity to establish the validity of the inquiry. As described earlier, the strength of human inquiry rests on its emphasis on '*personal encounter with experience and encounter with persons*' as a source of knowledge (Reason and Rowan 1981b:242). The extent, therefore, to which this dual encounter is developed throughout the whole co-operative inquiry is an essential determinant of its validity. Specific measures to ensure validity are integrated throughout the research process and will be described later in this chapter. This emphasis on establishing a valid process throughout was also important in the other groups which form part of the overall research (outlined in figure 1:1). Similar themes were discussed in all these groups but, more importantly, the process involved was remarkably similar despite the different objectives and settings. All the groups involved shared this dual emphasis on personal encounter with experience and with people. Together the different groups provide an element of triangulation for the inquiry which also contributes to its overall validity.

The nature of the group

The co-operative inquiry group was developed with staff working for the Neil Cliffe Cancer Care Charity. This organisation, at the beginning of the inquiry, was responsible for community based health care services for people with cancer at two Centres in Manchester. Towards the end of the co-operative inquiry period the charity merged with another local organisation providing hospice services. The charity's work focuses on rehabilitation, aiming to support people with cancer as they adapt to changing circumstances caused by their disease. The stated aim of the charity is to

Enable individuals whose lives have been affected by cancer to adapt to their changing needs by providing a range of multidisciplinary, community based services including education and support for health care professionals and others (Leedham and Platt 1998:59).

Client involvement is most appropriate around the point of diagnosis, during treatment

and at possible recurrence. Services available include advice and support, information for clients and health care professionals, medical management of symptoms or side effects, complementary therapies such as aromatherapy, reflexology, acupuncture and 'divertional' therapies such as painting and gardening. The Centres are used by people with cancer and those caring for them, hence individuals using the Centres are referred to throughout this thesis as clients rather than patients. Spiritual needs are apparent in care givers, both personal and professional, and those receiving care (Carson 1997).

Heron suggests three ways in which co-operative inquiry groups may begin: those initiated by experienced facilitators; existing groups that request a facilitator; and so called 'bootstrap groups' where both the group and the facilitator are new to co-operative inquiry and aim to learn the methodology together (1996:38-40). The co-operative inquiry group described here appears to fall into the category of 'bootstrap' group, a feeling confirmed by John Heron (see appendix six). Interest in spirituality was high among staff in both the Cancer Care Centres. My own interest in this topic had been stimulated by my work at the Centres and had become the broad focus of my doctoral research into adult learning. The more precise focus and the methodology of this research was discussed initially with my supervisor as well as with colleagues at the Centres. Co-operative inquiry, indeed any form of human inquiry methodology, was unfamiliar to the staff at the Centres, most of whom had a medical background akin to my own. However, there was considerable interest in the possibilities this approach offered, both for researching this subject and for the future. The Centres' involvement with both education and complementary medicine ensured that potential group members were open to qualitative approaches and already had some of the reflective and other skills that would help them participate effectively. Despite this background we recognised the difficulties of starting such a group with our very limited experience of the methodology. Heron suggests that this very lack of experience may help promote a greater equality in the group as regards methodology (Heron 1996:40) but it was with some apprehension that I began the process of initiating the group. I was particularly conscious of my dependence on the group for my own research, which increased as the inquiry group became such a central element of that research. All group sessions apart from the introductory meeting were taped, with the participants' permission, and the transcripts have been used for analysis. Pseudonyms, chosen by participants, have been used throughout so that they can be quoted directly and confidentially. The system of identifying the quotes is outlined in

the preface on page vii.

With the support of the Centre Manager, I briefly explained the idea of the research at a team meeting and distributed a flier asking for volunteers to the wider staff team (about twenty people, including some providing only sessional work or on the fringes of the organisation). A copy of this initial flier can be seen in appendix five. Ten people attended an introductory meeting which provided an opportunity to outline the nature of the research process as well as to introduce the topic. Heron stresses the importance of this initial meeting as a way of inducting and selecting group members and of developing a contract about the research process (1996:39). Reason also notes the importance of this early contracting process (1988c:23) which provides an opportunity to explore the commitment required. Tension at this early stage can arise from conflict between the group's need to be involved in decision making about the research focus and the facilitator's need to identify that focus so that the group are clear about what is involved in the research (Reason 1988c:25).

- ◇ Introductions and expectations
- ◇ Brainstorm ideas about spirituality and religion
- ◇ General discussion about spirituality
- ◇ Outline of the method
- ◇ Discussion of what is involved
- ◇ Options for the future

Figure 4:1: Outline of the Introductory Meeting

Notes from our initial session suggest that the first meeting gave people time to test out the boundaries of the research topic (discussed further below). There was some helpful discussion about practical aspects of the group, particularly the venue and time commitment involved. Although group members expressed interest as I outlined the research methodology, I wonder how much they really absorbed about it at this stage. Later sessions provided an opportunity to explore the methodology further but I felt throughout that the clarity and degree of understanding of the methodology by the whole group hampered our experience. The methodology was discussed in some detail both at this initial meeting and in subsequent sessions, particularly in the first reflective phase (see figure 4:2) and a research paper about human inquiry and holistic care (Heron and Reason 1984) was distributed to participants. This method of research,

although not easy, should be accessible to ordinary groups of people wanting to research an aspect of their lives and practice (Heron 1996:65). However, like Traylen (1994:61), I found much of the literature about co-operative inquiry impenetrable, often using dense, technical language. Other participants expressed similar feelings and had less motivation to understand the approach in detail. My own limited experience of the methodology made me reluctant to press for a deep understanding of the methodology on group members. This ensured that all group members remained involved in the exploration but perhaps prevented the group using the methodology to its optimum effect.

The boundaries of group membership were also clarified at this initial meeting. It had been decided (by the Centre Manager and myself) that the group would be restricted to staff and this was made clear at the initial meeting. There were no other selection criteria, apart from the need for commitment to the co-operative inquiry process. The restriction to staff was imposed because we felt that, apart from the ethical difficulties of including seriously ill people in such personal research, the presence of clients might inhibit the staff involved. The failure to involve clients in the group raises questions about the extent of our discussion of spiritual care. The inquiry group were only able to explore this area from their perspective as health care providers rather than offering a true clients' perspective in this area. Excluding clients limited the scope of our inquiry, yet including them suggested an inappropriate breaking down of boundaries. This issue of personal and professional boundaries, transcended by spirituality yet a necessary part of our working experience, was significant in later discussions and is referred to in chapter six. Ruth described wanting to provide similar opportunities for clients, feeling this had the potential to be helpful to them as it had been to her:

I'm getting more used to Mondays and that opportunity to talk about [spirituality]. I'm sort of noticing new questions popping up, things that are going on in my daily life are starting to pop into my head more than they were before ... indicating that maybe a space for doing it does create something. I suddenly see what we're doing here in this context as a way of exploring that ... and is that something we would want other people to have the opportunity to do? (4:165-167).

The opportunity to develop a form of inquiry for clients was considered as a possible outcome of the group. A number of the people who inquired about the group, including

several who did become part of the inquiry, expressed concern that they might not be the 'right sort of person' for this process. Further discussion suggested that these concerns reflected their ideas about spirituality as much as their concerns about co-operative research. For example, people were concerned about their religious background, or lack of it, as well as a sense that their ideas about spirituality were not clear enough to be researched. Many of these concerns, particularly the link between religion and spirituality, were discussed extensively as part of the co-operative inquiry process.

Eight people, including myself, agreed to become part of the co-operative inquiry group which started meeting that Autumn. The overall pattern of the inquiry is outlined in figure 4:2 on page 71. The group included representatives of most of the professions working at the Centres: allied healthcare professionals (occupational therapists, dietitian); nursing; administrative; complementary therapist and chaplain. Individuals were of varying ages, although most had significant experience of working in palliative care, as expected at a specialist centre. The spiritual and religious background of participants also varied, with individuals professing a variety of Christian beliefs as well as Jewish (non practising), humanist, atheist and agnostic ones. The varied background and experience of the group was valued by participants even though it contributed to some of the tensions we experienced. Jane reflects in the penultimate session:

It hasn't been without its frustrations and its challenges certainly but undoubtedly its been a richer experience for that. I don't know how it would have been if everybody had of been of the same ilk, whether it would have still worked or not (14:138).

All the group were women, perhaps not surprising in a predominantly female work force. One of only two men working in the Centres expressed interest in the group but was unable to become involved for family reasons. The female nature of the group does raise questions about women being more interested, or perhaps more willing to articulate and explore their interest, in personal experience of spirituality. This approach, of exploring ideas about spirituality in a group setting, may be particularly appropriate for female groups where other approaches would be better suited to mixed or predominantly male groups. Although important, gender was not discussed extensively by the co-operative inquiry group and remains marginal in this thesis.

Inevitably the group comprised those who were interested in this topic. It felt unethical, and unrealistic, to attempt to impose either the human inquiry approach or personal spiritual exploration on anyone else. Although the group included a wide range of views, the primary context was of people who were exploring spirituality rather than those who had found answers. This openness to explore and question was felt by the group to be an essential element of any spiritual exploration yet some participants were more comfortable with the idea of spirituality being a continuing exploration than others. Summarising for the group, it was suggested that:

Perhaps the journey is the thing we all have in common, that we are all, not just us but all people, potentially on a journey, whether they have elected to start travelling or not.... and there's something about how we journey alongside other people (Margaret 8:124).

Journey was the metaphor most frequently related to spirituality during the group's discussions, as Ruth says:

I'm just so fixed on the journey that to me the questions are what interests me. As soon as someone says they've [arrived] I feel they've found something that's 'there' and I can never be 'there' because for me it's the journey and it will always be the journey and that's where my spirituality lies (7:176).

While there was a general acceptance by the group of the need for continuing exploration in spirituality, some participants appeared defensive about their own position particularly in the initial reflective periods as the group was becoming established. Indeed this contrast between exploration (or journey) and arrival was a key element of the group's discussion and provided a recurring point of tension and challenge even within this essentially exploratory setting.

Heron outlines a number of variables which affect the development and outcome of the group, groups select differing positions within these areas, depending on the nature of the inquiry and the group. These include initiating the inquiry, the level of co-operation, the nature of the topic, roles of group members, the boundaries of the group, the approach taken by the group and the aim of the inquiry (Heron 1996:40-49). Key variables are described here in the context of this particular inquiry.

The initiation and form of the group

Our group was internally initiated, indicating that I was a full member of the group

from the beginning rather than an outsider. All the group members worked in the Centres, although some were more involved than others (some were part-time, myself included). Equally group members shared in each aspect of the research which helped ensure that each person in the group was both a full researcher and full subject (see figure 3:4). However I have referred already to the way in which the added pressure of my thesis influenced my motivation to be actively involved in maintaining the group and a desire to ensure its 'success'. Although participants in the inquiry represented different professions or roles, the organisation was actively encouraging a more generic approach so there was considerable overlap between the work of different health care professionals. Spirituality was an area that concerned us all and the inquiry was therefore established on a 'same role' basis in which all participants could be viewed as peers. All these factors added to the group's sense of involvement with the inquiry. The initiation of the group, as an important element of the inquiry, is described in more detail later in this chapter.

The focus of the inquiry

The inquiry was clearly focused on the external issue of spirituality and its effect on our lives and those of our clients, rather than primarily on an aspect of the group's own life. Spirituality by its very nature tends to break through clear distinctions between personal and professional, internal and external. Throughout the inquiry there was considerable, and not unexpected, overlap between personal spiritual exploration and professional concerns. There appeared to be a greater initial emphasis on personal issues with a clear shift of focus towards professional concerns from the second reflective period onwards. Although personal exploration was important throughout the inquiry, the group were clear that context of the inquiry was their work and that this had a very definite effect on the nature and outcomes of the inquiry.

The boundaries of the group

Once established the group was effectively closed, although there was some discussion at the end of the second reflective phase about inviting additional people to become involved. A decision was taken by the group in the first reflective phase to concentrate on our own ideas and experiences, rather than draw in visiting luminaries as in the whole person medicine inquiry (Reason and Heron 1985). The decision not to involve outside experts may have limited the breadth of the group's explorations. This was partly practical, as a small group with no financial resources it was difficult to request

expert support, especially as we were not aware of any locally. We were also conscious of the tension between safety and challenge as we began to discuss a sensitive and complex subject in a highly personal way. Our external input came primarily from reading and discussions with other people (in the active phase or between reflective meetings). Elizabeth describes the importance of this material:

All that reading and everything ... it brings you in touch (or aware of your lack of touch) with your own spirituality or how important that is to you. Then you can be aware of other people's spirituality (10:203).

Material being read by the group included references and research articles but also biographies, novels and other material. Members of the group who attended conferences or other outside events also reported back on these where appropriate.

The aim of the inquiry

Heron sees the primary aim of co-operative inquiry groups as either informative or transformative, that is they set out either to describe an area or to change it (1996:48-49). In practice, we found it less easy to differentiate between the two. The aim agreed by the inquiry group was *'for each of us to explore our own spirituality with a view to how that informs our work'*. This aim was both informative and transformative, intending to develop greater understanding about spirituality for ourselves and others but also to transform our practice, perhaps even our lives. The first part of the inquiry, up to the end of the second reflective period focused primarily on understanding the concept of spirituality. Returning to the group for the second reflective period, a number of group members spoke of personal transformation having occurred by the end of this period. The second period focused more on spiritual care practice but again was both informative (for example, finding out about practice in other areas) and transformative (for example, trying new ways of working with clients about spirituality).

The culture of the inquiry

Heron suggests two complementary cultures that may be present in inquiry groups: 'apollonian' and 'dionysian' (1996:45-47), described on page 57. A creative blend of the two cultures (rational and creative) is a key part of any effective inquiry. Although an apollonian approach can be seen in this inquiry, with a rational pattern of regular meetings, written reports, planned reflection and action, a subject such as spirituality also encourages the more dionysian approach, with space for intuitive and imaginative

approaches.

The organisation and process of the group

The group met fifteen times during 1997/98, most meetings lasting just over an hour with a longer review meeting at the end of the inquiry (see figure 4:2). During the period of the inquiry there were a number of changes of staff (two members of the group moved out of the area, one changed her role in the Centres and was no longer free to attend) and the Centre itself went through a financial crisis resulting in a merger with the local hospice. Despite these pressures, the group remained remarkably stable and committed to the inquiry, possibly finding a beneficial source of support in both the group and the subject. Discussion after the second, shorter, reflective phase suggested that the pattern of a six week block of meetings with a longer action phase was preferred by the group. Participants commented:

I've found the block of six [meetings] together more motivating than I think I would find even more frequent twos together (Jane 8:11).

I agree. I've found when [the group has] been there I've been more focused on it ... I feel like a block is better than odd ones because it takes us a while to get back into it really (Ruth 8:15).

My research journal describes my continuing anxiety that the group would cease to meet or that people would lose interest in the topic but this never happened. Although some meetings had a small attendance, at least half the group were always present and people generally had good reasons for not attending.

Co-operative inquiry, as described in chapter three, involves cycles of reflection and action. The pattern of research cycles for the spirituality inquiry is outlined in figure 4:2 on the following page. Meetings in the reflective phases were grouped in blocks for practical reasons but this affected the dynamic of the research. With hindsight, it feels as though there were three full cycles of research plus fifteen mini research cycles occurring between individual meetings. Participants were conscious of moving between reflection and immersion each week, as well as during the longer action phases (see figure 4:2).

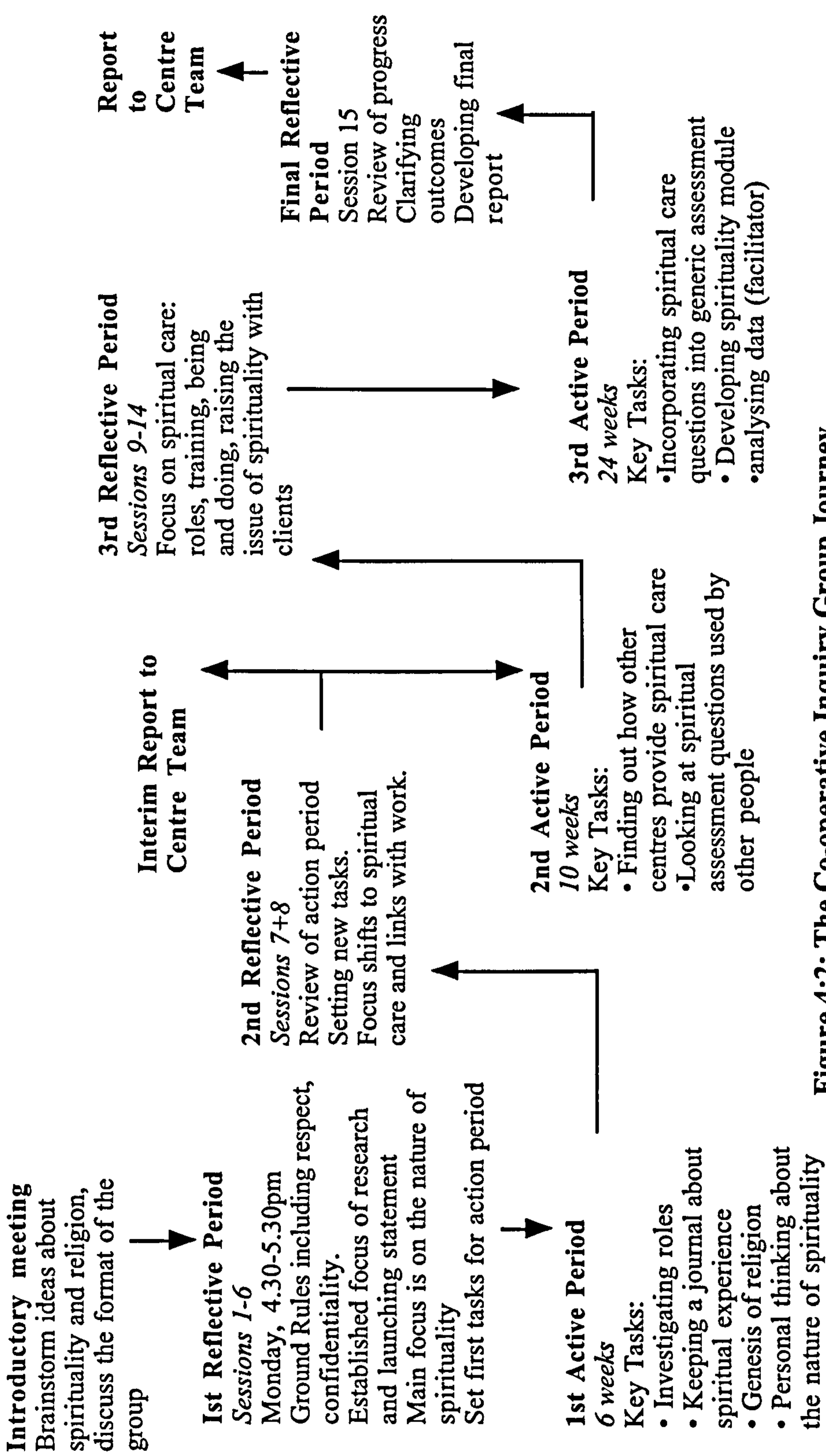


Figure 4:2: The Co-operative Inquiry Group Journey

Heron stresses the importance of the immersion phase, suggesting that it is a state of mind and being that lies at the heart of the action phase:

A full engagement with the relevant experience or practice, a great openness of encounter with the chosen domain (1996:84-86).

This deep immersion is a vital opportunity for the inquiry, the point where transformation may occur as group members create new ideas and proposals. Alternately, this may be the stage at which group members '*fall asleep*' forgetting that they belong to the inquiry group and returning to conventional ideas and practice (Heron 1996:84). Group members certainly found that meeting regularly as part of the inquiry group helped them build on their own individual thinking between sessions. Realistically, few had much additional time to spend on the project outside meeting times, although most spoke of raised awareness of spirituality in their working and personal experience. Notes were given out after each session in an attempt to summarise the content for members who were not able to attend specific meetings as well as to remind people about specific tasks.

Again, although Heron describes co-operative inquiry methodology clearly, he notes that these are his personal reflections rather than a strict protocol (1996:36). Constant attention to the defining principles of human inquiry, encountering experience and persons, remained our watchwords throughout the process of the inquiry. Our lack of experience with the methodology meant, though, that we lacked confidence that we were 'doing it right'. We were encouraged therefore by a supportive and positive response from John Heron to whom we had sent a paper about the group (see appendix six).

Initiating the co-operative inquiry

Initiating the inquiry is an important first step in any research process. In co-operative inquiry it is important to ensure that this initiation encompasses all three strands of the research process, that is the inquiry itself, the emotional and interpersonal aspects and collaboration (described in more detail in chapter three). It was important for group members to recognise the equality of all three strands from the outset. The nature and importance of all three strands within the methodology was discussed at the introductory meeting and returned to repeatedly during each reflective stage. Other group members were experienced facilitators and quickly recognised the importance of

balance between these three strands. This can be seen in the ground rules that were established by the group during the first and second meetings. Specifically these included the recognition that the group should be a comfortable place to question ideas, both our own and each other's, the importance of everyone's contribution and the need to be open about tensions and differences in the group without taking these back to the workplace. Other ground rules focused on mutual respect and a general recognition of the sensitive and personal nature of spirituality and religion (see also figure 7:3 which compares the ground rules agreed by the co-operative inquiry with those for the continuing professional education groups).

Initiating the inquiry strand

Heron suggests that the inquiry strand is primarily about enabling the group to understand the methodology and approach (1996:65-67). Having explained the basic process of co-operative inquiry at the introductory meeting, I was able to explain it several times during the first research cycle, highlighting where we were in the process and prompting participants about the focus of the different stages. A paper (Heron and Reason 1984) describing the co-operative inquiry into holistic medicine, referred to in chapter three, was also circulated to participants. Linking co-operative inquiry with holistic care, this stimulated discussion about the methodology both in the group and between sessions. It became clear in our discussions that some people in the group found the methodology difficult to grasp. Although the basic theory appears straightforward, explanations of the methodology can be difficult to penetrate, prone to rely on 'technical language' which was unfamiliar to us. The different founding of human inquiry also necessitated re-thinking previous understandings of research, as I had also found when first exploring this approach. I was aware of an internal tension between my desire to use the method correctly and my reluctance to impose too great a burden on people. Traylen also expresses concern about her role within the group and of needing to accept a degree of leadership in the early stages of the inquiry, when participants were not confident with the approach (1994:65). Setting tasks for the first action phase was a time of particular tension about the methodology as my research diary illustrates (White 2000b). There was a sense of the group trying to work out what counted as a 'valid task' which became much less marked as the inquiry proceeded. The tasks of the first action stage remained very broad but later phases became, appropriately, more clearly focused. Members of the group did not specifically share the tasks of initiating the different strands but all group members

participated in each of the three strands, often taking the initiative to start the discussion. Almost certainly, I was seen as having the greatest responsibility for assuring we used the methodology appropriately, perhaps because people felt that I understood it better, although I was sometimes unsure about that!

Initiating the collaborative strand

As ground rules were discussed in the first full meeting of the inquiry, participants recognised the tension between a desire for everyone to be equally involved in the inquiry and the need to avoid forcing people to contribute. As facilitator I started off the discussion for the first few meetings, usually bringing ideas or papers to discuss, and group members reported that they had found this valuable. After the first four meetings I rarely initiated the group's discussions, beyond welcoming people and switching on the tape, allowing others to raise ideas and themes they had been reflecting on between sessions. The importance of each person's contribution was a key ground rule established from the first meeting and helped create an atmosphere where everyone involved in the group was able to contribute. Inevitably some people spoke more than others at particular times but everyone did take part. 'Rounds' were used on some occasions, especially at the beginning of the inquiry, to ensure everyone spoke on a particular topic and again this was felt to be valuable by participants. Brainstorming was also useful in the beginning, as were periods of silence which often preceded the introduction of a new direction or topic. The idea of storytelling was introduced in terms of 'telling our own story' and the group consciously used metaphors as a way of exploring our own intuitive ideas about spirituality. Setting tasks for each action phase was strongly influenced by the time people had available outside the group as well as their personal interests. The first action phase was very diverse, most people choosing to follow up their own ideas rather than working collaboratively in this phase. Not all the tasks chosen for this first action phase developed fully (for example, the genesis of religion) but this was an important 'trying out' phase for the group as individuals grappled to understand both the methodology and the issues more fully. In the second and third action phases there was more agreement about tasks and some collaborative working, for example on the development of the educational groups.

Initiating the emotional and interpersonal strand

Reason identifies three emotional stages in an inquiry, described on page 58, and these

provide a basic framework in which to consider the spirituality inquiry. Although everyone in the group worked at the Centres, some people worked together much more closely than others. Participants were concerned about the emotional strand of the group from the beginning, recognising that spirituality involves deeply held values and any challenges to these may be distressing to individuals, affecting both the life of the group and relationships within the Centres. Ground rules encouraged people to bring such concerns to the group rather than let them affect working relationships outside the group. As facilitator I was keen in the early stages to help people feel comfortable enough to voice their ideas, hence the inclusion of focused brainstorming and rounds, trying to enable each person to articulate their ideas. People were initially diffident about sharing personal experience but gradually offered more personal links, both to their work and their life outside work. This may reflect some of our own struggle, as health care professionals, to recognise that personal experience can be part of research as well as the need to develop an atmosphere where such disclosure was possible. The second reflective phase brought a more assertive mood, with group members challenging each other more clearly. At times exchanges within the group were quite sharp, as can be seen in chapters five and six, highlighting the necessity for robust ground rules in order to maintain a safe but challenging environment. Although the second reflective phase included periods of tension and disagreement it helped to clarify areas of difference and similarities which the group needed to respond to. Tension often focused around issues of exploration and certainty, particularly where individual group members held strong viewpoints. Discussion about the metaphor of the journey as a strand in our understanding of spirituality, explored in chapter five, typifies this debate. Other group members noted tension around individuals needing to 'make a stand', the sense that each person wanted to say where they belonged. There were also tensions related to the material and topic concerning issues such as individual roles in spiritual care and the nature of spirituality. Where people held strong, and very different, views they sometimes appeared to have difficulty 'hearing' other people's perspective. These particular struggles were noted and discussed in the meetings. We were not always able to resolve the issues being discussed but we did appear to move on to a final stage which encompassed a deeply committed mutual respect. Individual group members still disagreed but there was a much greater sense of accepting and listening to each others' views.

Other group members were particularly involved in managing the

emotional strand in the group. This was an area where I felt less confident, aware that group members with counselling experience and qualifications had more skills than I and conscious, again, of a temptation to avoid conflict in order to maintain the group. I was aware of the way in which emotional tensions built up in the group, particularly in the second reflective phase. This was also a period of significant tension for the Centres where we worked, a tension which occasionally seemed to spill over into the inquiry. This never become overwhelming and different group members stimulated an exploration of the emotional state of the group. The group discussed personal changes, particularly increased awareness and greater clarity about their own spirituality but our inquiry was focused primarily on our working experience. Perhaps people did not choose to reveal themselves as deeply as they might have done but in the end they needed the freedom to choose what to discuss and how much to reveal to other people.

The role of the facilitator

It is important that the whole group, rather than just the facilitator, becomes familiar with the methodology of co-operative inquiry. Indeed in our so called 'bootstrap' group, the facilitator was never far ahead of other group members! I had been a member of the team at the Centres almost from its first opening in 1992 but only spent three half day sessions there each week, so my normal role fell between that of core team member and visitor. My research was a powerful motivating force in beginning the group but that was only possible because there was already significant interest in the topic. This interest needed a framework, suggested by my research, within which to develop. The Centres experienced significant amounts of change during the period of the research and it is possible that the inquiry may have floundered without a keen facilitator to keep things on target. I was conscious of the tension between the need to work collaboratively and my own need to get the work done. As already described my role was greater in the beginning; my research journal shows that I took the lead in proposing the research to the centre manager and other staff, in advertising the inquiry and calling the initial meeting. I also played a greater role in the group's initial sessions; although I feel very much a novice in co-operative inquiry methodology, my knowledge of it was greater than that of any other member of the group, so I was required to take a lead particularly at the beginning. In addition, having been reading about this topic for over a year, I was able to bring a greater variety of theoretical material about spirituality to be shared by the group. At times, I felt more of an observer within the group, although still very much involved in the topic. I wonder if my role within the

Centres (as a specialist dietitian rather than a more general key worker) helped ensure I was seen as somewhat neutral:

I actually think it's incredibly useful you're a dietitian because it's completely separate and divorced from [spirituality] and I never get confused with what your agenda might be.... certainly not from a professional perspective (Jane 14:159-163).

This seems odd when my own faith background, which was known to all the group members, could have ensured a very different image. Perhaps it also highlights how difficult it is to see spirituality as integral to everyone's role, even a dietitian! Typing up the tape transcripts helped me get an overview of the process of the group and also of the discussion. My smaller and more focused role at the Centres meant I had less contact with clients than other group members but I did have experience with other groups away from the Centres. These things helped ensure that my attention was on the group as much as on the topic. I felt a great sense of responsibility for the group, as can be seen in my journal, partly because of the pressure of my research of which the inquiry became a central part but also as the main initiator of the group.

Analysis of the research material

My desire to capture something of our discussions in a more tangible form led to the sessions being taped and this has proved a very useful tool for my research. Once the group finished I became the keeper of the transcript material with the group's permission to use this material for my research. In theory, transcripts were available to all group members but in reality were not accessed directly by anyone other than myself. Each tape has been labelled and details about the session recorded, such as those attending, the date and venue. I had listened to the tapes many times in the course of typing up the material, a time consuming process which I aimed to complete before the next session, mostly within a week. This helped me become familiar with the material, including the atmosphere of the sessions, notes of which were added to the transcripts. Impressions of the sessions were fed back to the group through the notes of each session, as well as referred to in future discussions, particularly in session fifteen. Although this was not the same as every member of the group hearing again the detail of their discussions, it was perhaps a realistic compromise. The typed material produced was very dense and at times difficult to read, spoken English being very different to written English. There are many different ways of ordering and

presenting experiential knowledge that can be used within co-operative inquiry, including reports, diagrams, movement, story and drama (Reason 1994:42). Similarly, Miles and Huberman (1994:11) emphasise the importance of presenting the data in qualitative research. With hindsight, it may have been useful to look for ways of presenting this data to the group, for example, at the end of each reflective block, to enable the whole group to be more involved in the analysis of the material. In practice I was too busy struggling to keep on top of the typing process to think about doing anything more. For the final reflective session I presented a summary of key themes in the inquiry, based on the analysis I had been doing using the NUD*IST (non-numerical unstructured data indexing searching and theorising) programme, and including relevant quotations from the material. This direct confrontation with our earlier reflections helped individuals see how their thinking had developed. For example, participants were able to review and refine the metaphors they had chosen in the first reflective phase, they were also able to see how important a metaphor 'the journey' had been throughout the inquiry and discuss why this might be so. It was clear from our discussions that there was greater awareness and clarity about the concept of spirituality by session fifteen:

I've had lots of interesting questions with patients and carers about their different perceptions of health professional and ways of being or ways of relating, which has all been around like 'spirit to spirit' and 'spirituality' but not in so many words (Elizabeth 15:65).

although group members still resisted defining the concept. Presentation of the inquiry group findings beyond the confines of the group is discussed later in the outcomes of the inquiry.

The process of analysing the data

Confronting the data was a daunting task that I began as I typed up the material but entered a new phase as I looked more closely at the material as a whole. Riley provided excellent, practical advice about the organisation and processing of research data, particularly allowing the data to speak more clearly such as summarising, examining the data 'in role', looking specifically for surprises (Riley 1990). After the third reflective period I began a more systematic process of analysing the data, using the NUD*IST programme (see below). The initial results of this analysis were fed back to the inquiry group in session fifteen, the final reflective period. Analysis of transcripts is not just about presenting quotes or material but rather about finding themes, trying to see what

the material itself is saying (Boulton and Fitzpatrick 1994:23-24). Transcripts lack the fresh immediacy of group discussion, or even tapes of that discussion, but do allow time to reflect on the content. I read through the transcript material a number of times, making notes of themes that were arising and seeing where ideas recurred. A key task of analysis is to allow the unexpected to emerge from the material. I expected certain general themes to arise in our discussion: for example, ideas about the nature of spirituality and key themes usually identified with it, such as meaning and purpose and connection. Indeed, these issues had been specifically raised in the inquiry to encourage participants to reflect on recurring themes in the literature in the light of their own experience. A second group of themes arose unexpectedly in the group's discussions but could be clearly identified as issues to which the group returned repeatedly: for example, the importance of language and the issue of 'nostalgia'. Finally the process of analysis led to a third group of themes becoming clearer: for example, the process of the group and links between the various themes.

Once a theme had been suggested, NUD*IST was used to search for further references where possible. If a theme appeared to be important, a definition was agreed and additional coding was carried out by a combination of reading the transcripts and adding coding to the NUD*IST material. A list of definitions acted as a check list to increase consistency in coding. The overall themes and their definitions were discussed with both the inquiry group and my supervisor. As I began the final stage of analysis, I listened to each of the tapes again, reading through my notes as I listened, adjusting the NUD*IST coding as necessary and making further annotations on the transcripts. This helped familiarise myself with the material again as well as refine my results.

Use of computer analysis

I chose to use a computer analysis programme in order to make good use of my limited time, selecting NUD*IST as an accessible and relatively inexpensive option. Computer assistance can reduce the time needed for analysis, speeding up some of the more mundane tasks required (Weitzman and Miles 1995:4). The computer does not replace the necessary work of interaction with the data, but provides a method of handling that data. Although this is an advantage, Webb suggests that the computer can alienate the researcher from the data (particularly if it is only seen through the computer), thus losing the intuitive grasp of the data which is required in qualitative research

(1999:325). Repeatedly reading through the whole transcripts, and listening to the tapes, as I checked and re-checked the NUD*IST codes, was helpful in retaining awareness of the context in which things were being said. NUD*IST certainly made it easy to search for key words or phrases and this was particularly helpful in the early stages of analysis. Searches for cognates (for example, connection, connect, connected) also provided a superficial guide to how much these ideas had been discussed in the inquiry. However, care had to be taken that the resultant findings were not taken out of context (for example where words have more than one meaning) and that the finer detail of our discussions was not missed (for example, using other words to express the idea of connection). NUD*IST automatically produced a diagrammatic 'tree' showing how the coding nodes interact, summarised in figure 4:3 below.

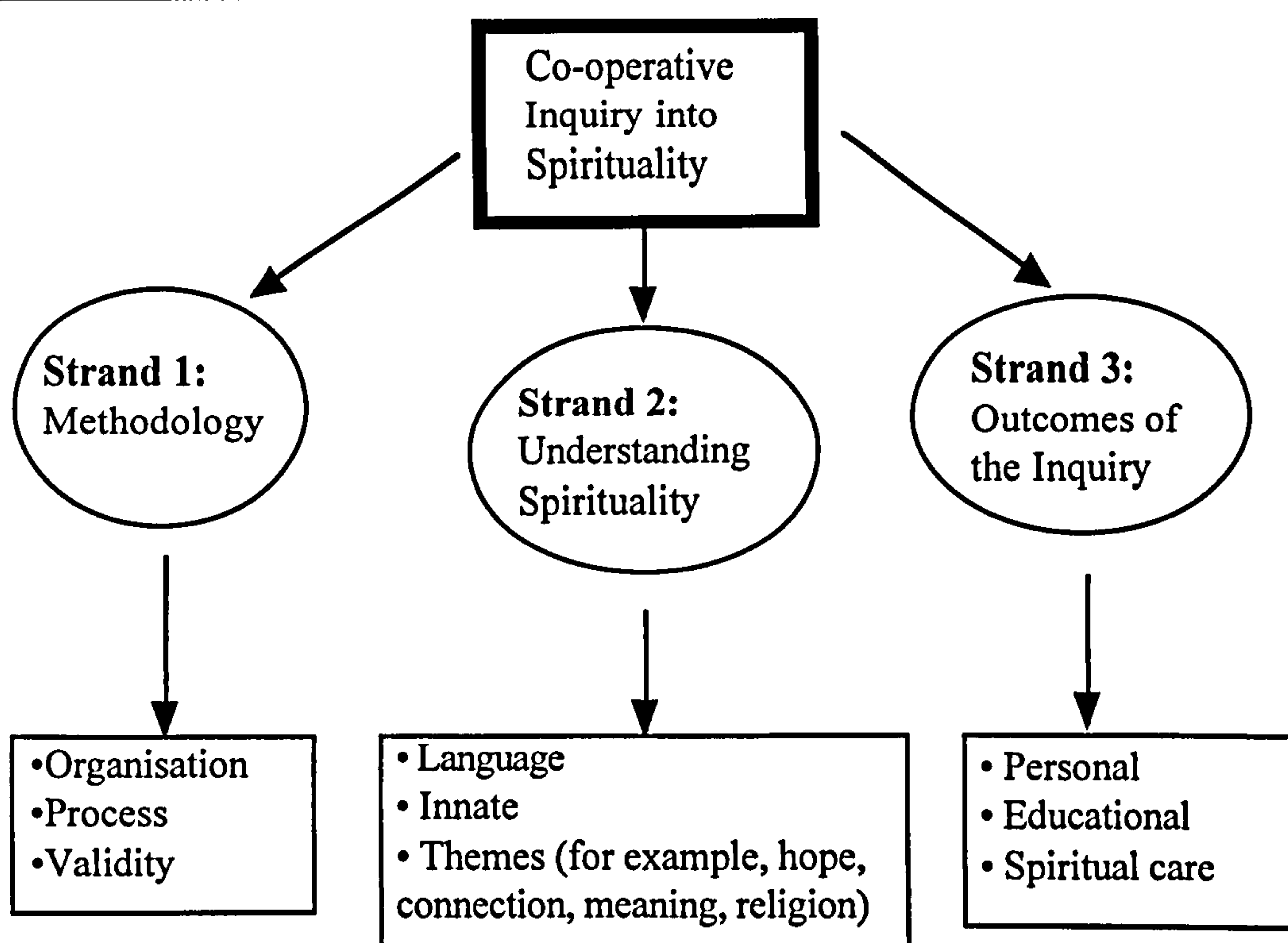


Figure 4:3: Emerging Themes

This summarised the analysis and was constantly adapted as the themes within the research became clearer. A matrix outlining how often each theme was referred to, using data obtained from NUD*IST, was also developed and is included in appendix three. New nodes or concepts could be added as a possible theme became clearer and in addition nodes could be moved around as the overall plan of the material developed. Indeed, nodes could be moved on an experimental basis as the material was viewed from different perspectives. The programme automatically kept a history of each node

which enabled me to see both how themes had developed and to back track if necessary. NUD*IST supports the production of many reports about the data, ranging from simple lists of codes through detailed lists of the content of each node to coding stripes which show how nodes interact. I certainly recognised the danger that such large quantities of data could become overwhelming, particularly after a period away from the material. However this was outweighed by the relative ease of coding the material and the convenience of printing out reports. More detail about use of the NUD*IST programme is given in appendix three.

Use of a research journal

Burgess suggests that a research diary should be substantive, methodological and analytical (1984:199-200). Usually the journal is written as events occur but the themes and patterns developed within it can be explored by subsequent analysis and interpretation, so that it acts as both a factual record and an opportunity to reflect. Starting in September 1996, my journal was hand written until November 1997 when I began to keep it on the computer. At this point the journal changes considerably, moving from a rough log full of diagrams and scribbled but irregular entries to a more consistent record of my thoughts, feelings and actions. Entries become more frequent and regular (writing up the journal was usually my first action on sitting down to work on the computer). Although I missed some of the freedom of working with pen and paper, writing in itself, with pen or keyboard, did clarify my thoughts and generate new ideas. Indeed the need to type my ideas may have pushed me to formalise ideas that were unclear more than hand writing would have done. I also carried a rough notebook round with me to make more active notes but it has always been difficult to 'catch the moment' in which to write in this. This notebook was especially useful at specific times such as during the MPaCE courses or the analysis of typed material. I kept a separate journal, also on the computer, about the Journey into Faith group which ran from August 1997 to October 1998, generally writing up my thoughts before and after each monthly meeting. Reflective journals were used by several members of the co-operative inquiry group and by participants on the continuing professional development modules. These remained private and personal but some individuals chose to share material from them during discussions. Any journal provides powerful tool for professional development as it *'taps the unconscious, it can make the implicit explicit and therefore open to inquiry'* (Holly 1989b:71), a task which is very much a part of the human inquiry approach. This resonated with my own experience of journal

keeping, including the tension between the creative and more routine elements (for example, record keeping). I was particularly interested in Holly's suggestion of returning to review the journal for analysis, looking for connections and themes, a process similar to that of analysing the transcripts (1989a:165-171). Reading back through the journal enabled me to draw together different perspectives, akin to the desire to be 'objectively subjective' so vital in human inquiry. It also offered an opportunity to do the scribbling and annotating that I had missed when using the computer. Ideas generated in this process have been referred to throughout the thesis. The journal became a receptacle for my emotions, including anxieties about progress, so that I have learnt much about myself from it. Concerns about work or my personal life that appeared unrelated to the inquiry also crept into the journal, usually because they were affecting my ability to concentrate or to spend time on the research, but sometimes these led to further insights into spirituality. Two personal bereavements during this period threw the discussions in the co-operative inquiry group into sharp relief as I reflected on these experiences.

Developing validity in the co-operative inquiry

As previously outlined in chapter three, validity in human inquiry is concerned with a process of being 'well founded', that is, based on the principles of encounter with experience and with others (Heron 1988:39-40, Reason and Rowan 1981b:242). The spirituality inquiry was founded on these principles, and in a sense these basic validity criteria have been referred to constantly during this chapter, an indication of the way in which the whole process was aiming to be valid. I have also indicated my concerns about the extent to which the founding principles were applied, particularly the degree of co-operation. Three main validity procedures were used in this inquiry, namely research cycling, convergence and divergence and a balance of reflection and action.

'Research cycling' was an integral element in ensuring the validity of this inquiry, with three full research cycles and fifteen mini cycles (see figure 4:2). The inquiry group discovered that this cyclical process gradually refined their findings, feedback from other participants pruned irrelevant material and amplified developing ideas (Heron 1996:60). A combination of individual and collective cycles were used, with individual research cycles occurring mainly in the initial active periods and a more combined approach developing as the inquiry continued. Research cycling establishes

positive and negative feedback loops between action and reflection: engagement between propositional and experiential knowing prunes ideas which can be seen as irrelevant or ungrounded, while positive feedback applies or deepens the ideas generated (Heron 1996:131-132).

The second main validity procedure involves balancing divergence and convergence within the inquiry. In a totally divergent inquiry each participant does something different in every action phase, so that there is no repetition. In a totally convergent process each participant does the same thing in every action phase, so that a few features are explored repeatedly throughout the different phases (Heron 1996:134-140). A combination of these approaches generally leads to a more rounded outcome. The early stages of this inquiry were predominantly divergent, allowing each group member to engage with the topic in their own way, exploring their own ideas or interests. As the inquiry developed it converged around the group's shared concern with spiritual care. Heron notes that while divergence and convergence are mainly elements of the action phases, they also apply to the reflection phase where sharing and feedback about both divergent and convergent material clarifies and expands the group's findings (Heron 1996:140). The variety of ideas and experience within the group was valued by participants; Carole says

It's been good to have such a mix [of people] because often one tends to talk to like minded people about your views in this area which doesn't give you the same challenge (6:288).

Differing views led to tension but also developed a much more robust understanding of self and others as participants struggled to understand each other's viewpoint.

Thirdly, the balance of reflection and action is an important element of validity. Too much reflection without action results in a loss of contact with experience but too much action without reflection devalues that active experience (Heron 1996:140-142). Generally this co-operative inquiry kept a balance of action and reflection, although the final action phase was prolonged because of holidays and management change. Different types of reflection can be related to different types of knowledge (Heron 1996:142-15). Presentational knowledge was particularly important in this inquiry, with informal presentation of group members' findings after each of the active phases. Presentations were primarily descriptive but subsequent discussion built

on this process by exploring and evaluating what had been discovered. Sometimes presentations sparked new ideas in other group members (for example, ideas about nostalgia); at other times the act of presenting, and the discussion which followed, helped the presenters themselves clarify or deepen their ideas. Heron also suggests that the degree of chaos experienced during a co-operative inquiry is an indication of validity (Heron 1996:148-149). This is in contrast to the order I had assumed to be required for research. At times our group certainly felt chaotic, as any new thought or practice can feel chaotic. As facilitator I initially found the chaos worrying, part of my concern that the inquiry was going nowhere or not doing things right, but new and valuable ideas gradually emerged from this chaos.

Maintaining collaboration throughout the whole process is the area I have found most difficult, particularly after the inquiry itself had finished. All group members were involved in the process of the group and its initiation, despite our inexperience with the methodology. Including data from others outside the group, as we did with other people at the Centres, allowed limited inclusion of the direct experience of people not able to take part in the inquiry. Writing up the findings of the inquiry for different audiences and examining it more closely, as I am doing for this thesis, is understandably more than most participants were able to undertake. As described earlier, chapters four, five and six were sent to participants for comment prior to completion of the thesis. Chapter seven was also sent to the colleague who acted as co-facilitator on both the MPaCE courses. I was conscious of Heron's warning that additional validity checks may be illusory, even undermining the shared nature of the inquiry (1996:160-161) but remained concerned that I should represent the views of the group adequately. This provided a realistic opportunity for participants in the research to share in one if its final outcomes and to check that I had correctly represented the truly shared findings of the inquiry. The overall validity of the project was further enhanced by a degree of triangulation between the different elements of my wider research (see figure 1:1) (Heron 1996:156). As an additional validity measure, two individuals with experience of hospital chaplaincy acted as critical friends reading through the whole thesis in its draft form. They added useful reflections on the overall process and content in the light of their own experience, as well as commenting on issues of clarity and readability.

The continuing endeavour to be 'objectively subjective' is an essential

aspect of validity in co-operative inquiry. Both challenging others and being challenged personally about this spirituality, where beliefs are often deeply held, was difficult. Familiar ideas become comfortable, so that it is difficult to retain, or rediscover, an awareness of their shortcomings or to see other ways of doing things. This process was compounded by the complexity of expressing ideas about spirituality, which necessitated that we listen carefully to each other, trying to hear beyond the superficial and sometimes inadequate words that people were using. The group worked hard to identify and challenge 'taken for granted' ideas both in themselves and each other but a key concern, as in later educational groups within the research, was to ensure the development of a safe space in which to achieve such a challenging exploration and this appeared to have been generally achieved. For example, Jane states:

I've used it very much in that way, thinking about myself, I haven't thought about anyone else ... the facilitation of it is what's enabled me to use it in that way. Its felt very safe, very respectful and I think that for me that's been its success (6:269).

Creating this space, with its growing atmosphere of supportive challenge, facilitates the process of co-operative inquiry. Ruth, during the first reflective period, described how her thinking was refined by the group:

My thinking has been refined by being able to talk about it academically and not just what my emotions are. The experience of hearing what other people say has formulated my own thoughts in a more structured way than I could have ever have done [alone] (6:136).

Respect and willingness to listen to each other grew through the challenges and difficulties of earlier meetings. Jane affirmed this as the inquiry drew to a close:

For me [testing and feeling out ideas with other people] has been a crucial part of the process. I don't think that reading and thinking and doing on my own would have been enough because I would only have seen it from my own perspective and that perspective wouldn't have been challenged such a lot, as it has been (14:25-28).

Significant challenges occurred as the group became established, particularly during the second reflective phase. It was also clear that the group was learning to listen carefully to each other, becoming more skilful at hearing the meaning behind people's words.

Research conclusions should be *'coherent, consistent with each other,*

interdependent and mutually illuminating' as well as agreed by all participants (Heron 1988:43). This does not necessarily result in unanimity but rather a greater understanding or illumination which is developed by the sense of *'unity-in-variety'* (Heron 1988:44). This was very much the experience of the spirituality inquiry. After a lengthy discussion within the group about the extent to which consensus about the nature of spirituality was possible or even desirable, Martha says:

To me the good thing about this is actually exploring [spirituality] in its wider sense and finding areas of meeting or questions or even differences. That it is all right to be different and still approach spiritual care. Its not having one answer or one way (Martha 8:61).

At the end of the third reflective period, Jane and Joyce recognised how much progress they have made in understanding each other's very different perspectives:

I know that's what you see and feel and believe. Its not what I see, feel and believe but I do think there is a middle ground of things that we would agree on (Jane 14:110).

Yes, that we do agree on, definitely (Joyce 14:111).

Outcomes of the co-operative inquiry

Heron suggests that four main types of outcome are possible for co-operative inquiries, corresponding to the four types of knowledge discussed in chapter three: experiential knowledge stimulates personal transformation as inquiry members engage with the focus of the inquiry, propositional knowledge generates reports outlining the group's thinking; presentational insights may be expressed creatively as art or drama and practical knowledge leads to the development of new skills (Heron 1996:36-37). The main outcomes of this inquiry were transformative, propositional and practical.

Transformative outcomes

The process of exploring spirituality with others was unexpectedly transformative for individual participants, both personally and professionally. Indeed inquiry group members described a clear link between the two as early as their third meeting. For example, Elizabeth says:

You can learn particular skills, which will be effective to a limited degree, but it's very much the self work and from that realising how valuable this might be to you (3:99).

Specifically the group noted how time spent exploring the concept of spirituality with other people had increased their understanding of this complex topic (described further in chapter five). For example, Carole says:

Being able to reflect with people who are safe and comfortable to talk to and add bits like 'well, I don't believe that, oh, I don't believe that' well, that's something isn't it? I now know I don't believe that, that is incredibly powerful isn't it? (4:168-170).

Some individuals described how this had encouraged them to explore their personal spirituality in new ways. Ruth describes how the group had enabled her to explore a topic she would have avoided in other contexts:

I've felt much more sparked as I've come away from it, I feel like I've got more energy and I know that I've been sort of talking about it and thinking things though more out side if it. I know its sort of made an impact. I'm slightly sceptical about myself about how long I sustain that. I think a weekly meeting's a good reminder each time. Every time I sort of come back into the room, I think, 'what are you talking about?' and then it sort of all gets in and I'm really enthused again. But I think its been a really valuable experience and I suppose the sentiment of saying that I think other people should have the opportunity to do it does reflect that how valuable I've found it and would never, never have, unless it was in this setting, have approached it (6:277).

An increased clarity about the concept of spirituality enabled group members to be more aware when these issues were raised by clients and gave them greater confidence, or comfort, to explore the topic with others. This transformative process affected the practice of individuals in different ways. For example, Martha describes how the inquiry had affected her practice when we reviewed the process of the inquiry in session fourteen:

Instead of seeing so many people, it's made me make choices about the way I operate and I think that's linked with what's gone on as we've been talking about this. It's less having to cover everybody but more having to spend quality time with some people (14:29).

Similarly, Elizabeth describes how the group had provided a sounding board:

It feels good to have somewhere to bring it back, to bring those issues back and explore that within the group and that increases my confidence to go out and tackle those issues again (8:31).

Finally the process of exploring spirituality had affected working relationships in the group. Carole says:

I now understand a bit more about how other people in the team tick ... it puts a different dimension on the working relationship. It's obviously a big part of peoples' belief and value system but you don't always talk about it. It is quite useful to have that connection (8:82-84).

There was some concern that this might be to the detriment of those who had not been part of the group.

Propositional outcomes

As already described, a verbal report about the progress of the group was presented to the wider multidisciplinary team after the second reflective period and a final written report was agreed and presented at the end of the inquiry period. A poster display outlining the inquiry was made available to all those using the Centres. The content of the inquiry has been presented to a wider public in a variety of ways (see appendix one). All these reports focused on the nature of the inquiry and its outcomes, particularly regarding our exploration of spirituality and spiritual care. Participants were consulted about the content of papers and posters produced about the co-operative inquiry group in 1998 (while I was still working at the Centres), although none were able to act as co-authors. As already described, a draft copy of the sections of this thesis concerned the co-operative inquiry group was circulated to participants for comment in August 2001. Participants felt that the material was representative of their experience in the inquiry group and their responses have been used to form the final document.

Practical outcomes

The organisation of a continuing professional development module for other staff and the specific inclusion of spirituality into the generic assessment process used at the Centres were the main practical outcomes of the inquiry. Several members of the inquiry group were involved in these outcomes which were supported by the whole inquiry group. Tension about time commitments was an important limiting factor in the collaborative nature of these outcomes. Group members were very interested in what had been achieved and clearly saw the need to take it further and to present the outcomes to others. However, some group members had moved out of the area or to other work by the end of the inquiry. Even participants who were still available had

limited time and these more public outcomes required greater commitment than some were able to give.

Conclusion

All the outcomes of the inquiry will be described more fully in subsequent chapters which concern both the inquiry group (chapters five and six) and the continuing professional development module (chapter seven).

Chapter Five: Understanding Spirituality

This chapter will describe and amplify the understanding of spirituality developed by the co-operative inquiry group described in chapter four. An exploration of the nature of spirituality must underpin the development of spiritual care and related continuing professional education. Yet, as earlier chapters have suggested, '*spirituality is a vague and elusive notion*' (Cornette 1997:6). Even where the spiritual dimension is considered a key element of total health, it remains hard to define, yet without such a definition it is difficult to fully integrate the spiritual dimension into health care practise (Bensley 1991:287). Attempting to define spirituality for nurses, Burnard shows how differently this concept may be understood (1990:38-39). Oldnall suggests that the absence of spirituality in modern nursing models and theories is due, at least in part, to the impossibility of quantifying it (Oldnall 1995:417). Similarly, Banks, working in health education rather than health care, indicates that the spiritual dimension of health is one of the least obvious and measurable components of health (1980:202), a particular concern in these days of evidence based practice. Again, Goodloe and Arreola suggest that accepting and developing this neglected dimension of health is linked to the ability to define the spiritual as a distinct entity (1992:221). Perhaps then, it should not be surprising that the co-operative inquiry group spent so long exploring ways of understanding the concept of spirituality. In the language of reflective practice, we were struggling to find definitions and descriptions that worked in the '*swampy lowlands*' of professional practice (Schon 1988:3). Clearer understanding and increased acceptance of spirituality was the first outcome of the co-operative inquiry group, underpinning other outcomes in continuing professional development and spiritual care. Throughout the whole co-operative inquiry discussion about the nature of spirituality was interwoven with discussion about other outcomes of the group. Analysis of the tape transcripts confirms the way in which developing individual and corporate understanding of spirituality supported other outcomes, for example, growing confidence and increased awareness. For this reason the concept of spirituality will be explored in this thesis in some depth prior to discussing other outcomes of the inquiry group. Rather than merely clearing the way for more important issues, this exploration of the understanding of spirituality developed by the group is vitally important in itself, underpinning all subsequent discussion. Other outcomes of the inquiry, particularly in spiritual care and continuing professional development, will be discussed in chapters six and seven.

While it can be argued that spirituality should not be seen as an optional extra at any point in life, it must be acknowledged that for many people the imminence of death raises questions about the meaning of life (Speck 1993:517). For this reason people working in palliative care, whatever their role, have a particular need to be comfortable with the issues involved in spirituality and spiritual care. Members of the co-operative inquiry group recognised that their own work in palliative care had been important in developing their own interest in spirituality. Cecily Saunders, the founder of the modern hospice movement in the United Kingdom, comments that *'the community needs the dying to make it think about eternal issues and to make it listen and give to others'* (quoted in Clark 1997:51). Palliative care guidelines developed by the World Health Organisation recognise the importance of such spiritual concerns for both clients and staff (World Health Organisation Expert Committee 1990:50-52). Continuing professional development, particularly with a reflective and experiential approach, offers an important space for health care professionals to explore these concerns in an integrated manner. The co-operative inquiry group played an important role in participants' own continuing personal and professional development in the area of spirituality. The experience of learning together, particularly where that involved struggling to understand different ideas and experiences, was an important feature of this process. Participants who felt that their ideas about spirituality were confused gained understanding. Perhaps even more importantly, they recognised that no one had all the answers in this complex and intangible area. Ruth notes her uncertainties in the first session:

I kind of think that unless I'm sure about my own spirituality it's much harder for me to feel I can communicate about it. I would probably defer to someone who thought, well, they really kind of knew where they were coming from to be able to assist, because I don't feel as confident because I'm not sure where I'm coming from ... There's information and techniques and strategies I could have and knowledge around cancer that I can have expertise in but in spirituality? I guess I could assist somebody, I would feel confident in assisting somebody who had a confused spirituality (1:105-107).

Later, Elizabeth comments:

For me one of the big things about this group is the fact that you always are aware of how big [spirituality] is and how few answers there are but I think the more you explore the more you realise how immensely different it is for people and how answers is probably the very wrong end of the spectrum to come from. So it's supporting each other to become more [confident] without the answers.

Sometimes, it's when you haven't got answers, that's the time when you do block ... or you aren't actively, you know, seeking to discuss it because what we like to do, I think, as nurses quite often is we like to have answers to problems. So that's the good thing to bring it back into a forum from which we can explore our exploration as it is (8:64).

Even individuals within the group who felt they had a clear understanding of their own spirituality gained from the experience of hearing other, often very different, perspectives. The co-operative inquiry group's experience clearly supported this link between the personal and professional, personal exploration occurring in parallel with professional development. Such an integrated exploration of the nature of spirituality lies at the very heart of this research.

An agreed core understanding .

A key issue for the inquiry group was the development of a core understanding of spirituality which could be agreed by the whole group. The outcomes of human inquiry should be coherent rather than necessarily unanimous, illuminating the area of research by overlapping individual perspectives (Heron 1988:43-44). A significant amount of the group's time was spent considering the nature of spirituality, especially in the first two reflective periods (see figure 4:2). I sense that this was partly because we ourselves were trying to formulate our ideas about spirituality, testing our own assumptions and preconceptions with new information gleaned both from texts and each other. The group needed time to listen to each other, reflecting individually and corporately on our developing ideas about spirituality in the light of our experience. We also needed time to discern what we held in common, a task made more complex by the difficulty of expressing spirituality in words. There was a sense of moving on and exploring during the first complete cycle of the co-operative inquiry group, with group members returning after the reflective period having developed or clarified their personal ideas about spirituality. Jane notes:

I've come quite a long way because at the end, when we'd finished meeting last time, I had a sense of wanting something to belong to but not being quite sure what that was. So the work that I've done has been about me and I suppose I haven't really been concentrating on looking for evidence or other people's spirituality ... I have some forms to fill in to join the Humanist Association and I feel really pleased about it. I'm not sure that I'm ever going to go on any of the special holidays or go to any of the meetings but I feel I've got something to back up kind of what my belief is, in a wider organisation (7:15-18).

Similarly Elizabeth felt that reflection had helped her clarify a previous tacit position:

Well, I suppose in terms of me, I suppose in terms of exploring my spirituality in relation to Christianity, I've tended to come from this angle that I was very much a failed Christian, very doubting and I'm more doubting the more I explore Christianity ... but actually I've come to a point where I'm actually feeling much more OK with that, that it's actually OK to be very doubting, that it's very wise to be very doubting, well for me, and that there are positive benefits. Rather than it being a place that you can't reach, because the doubts are very integral to being a Christian for me, so, therefore it's a good place to be. I'm not actually on the outside of Christianity anymore, I'm within it but because of the nature of my mind I'll always be very questioning but I'm actually seeing myself, my spirituality, as having a very strong Christian element and the doubts are OK to have. So, that's quite a movement for me actually and feels a bit like you (Jane) that I have roots and a place to start from which is quite comforting really (7:21).

Within the group's struggle to understand spirituality, we recognised the danger of making any definition either too narrow or too broad:

What I find uncomfortable myself is the idea that somebody can understand this very personal thing that can happen to me and apply it to their framework or how they understand it and I almost balk at any idea of any of us coming up with a shared definition, because it's so personal to me that if anyone dared try and tell me how it was with an explanation, it takes it away and I just want to grab it back and say 'no, that's mine' (Ruth 2:146).

I'm not sure that bringing that into a huge umbrella called spirituality helps us to really understand what it's about and know how to develop skills to help people (Carole 1:71).

While keen to promote spirituality as an element of nursing care, Wright also notes this need to balance freedom with discipline, suggesting that an unsupported spiritual journey may generate an unfocused 'pick and mix' approach (1998:188). The need for shared understanding became particularly important when the co-operative inquiry group began to discuss the work of the Centres; for example, there had to be some consistency in order to assess spiritual needs. Keighley writes about the difficulties of developing a way of understanding spirituality that works in an organisational context:

Definitions [of spirituality] exist but these may not suit all conditions. The difficulty reflects the struggle - personal and organisational - to encapsulate an intangible essence, which for many people gives the truest meaning of them and their lives (1997:47).

Initially the group were unsure whether a shared understanding of spirituality could be achieved yet certain shared themes did emerge from the group's discussions. These shared understandings resolved into a number of central elements plus descriptive themes which provided useful ways of exploring spirituality, all of which will be explored below. That spirituality was essentially unique and individual became one of these shared elements.

Central elements of spirituality

Spirituality as an innate potential

It is recognised that health encompasses far more than physical well being. Indeed, the World Health Organisation idealistically defined health as '*a state of complete physical, mental and social well-being and not merely the absence of infirmity*' at the end of the second world war (WHO 1948, quoted in Black 1990:34). Palliative care particularly looks for good quality of life including social, psychological and spiritual aspects (World Health Organisation Expert Committee 1990). The National Association of Health Authorities and Trusts guidelines on spiritual care make their starting point the need to adopt a holistic approach, with spirituality as an essential element:

It seems reasonable to argue that there is, in the widest sense of the word, a potentially spiritual dimension for everyone. This will manifest itself in different ways (1996:6).

These guidelines state clearly that spiritual care is not equivalent to religious care, although both are important (National Association of Health Authorities and Trusts 1996:6). Spiritual needs, then, are clearly not restricted to people with religious beliefs and even among those with such beliefs, there will be varying practices. This understanding equates to the earlier discussion, on page 3, which links the human spirit to breath or essence, an integrated strand of our essential humanness. A multidisciplinary group (named LUCAS) in Belgium which comprised nurses, physicians, psychologists, pastors and theologians, surveyed 841 palliative care health workers for their ideas about spirituality, spiritual care and religious needs (Cornette 1997). Their, rather abstract, definition of spirituality, approved by 90.2% of their respondents, was that the spiritual is

concerning that dynamic within each human being to situate oneself in a horizon that gives meaning to different life experiences (Cornette 1997:7).

The word 'horizon' was chosen specifically as suggesting something that is always receding, with the aim of avoiding a static view of spirituality. Other writers support the view that spirituality is innate. For example, a number of surveys carried out among health education workers confirm that most, though not all, respondents accept the spiritual as a reality, a dimension of well being and, therefore, a contributor to total health (summarised in Banks et al 1984:19). Similarly, a qualitative study involving nurses identified a general acceptance of the spiritual as a recognisable dimension of an individual (Harrison and Burnard 1993:67-8).

For the co-operative inquiry group, a single understanding of spirituality could not be simply accepted but rather needed to be understood and adopted by the group for themselves. In co-operative inquiry terminology, this propositional knowledge (theory) needed to be held up and examined in the light of personal and practical experience (Heron 1996:52-54). The whole person medicine group, referred to earlier, described a similar need to accept that the spiritual is an integral element of personhood before going on to consider how it can be understood today (Reason and Heron 1985:52). Recognising a spiritual potential within every person meant accepting that spirituality was relevant to all staff and clients, although not all would wish to explore this area. Indeed, National Association of Health Authorities and Trusts guidelines specifically state that the basis of spiritual care is respect for the individual, seen in acceptance and sensitivity to individual beliefs (1996:5). Accepting this idea had important implications for our work in the Centres and these too needed to be considered if they were to be integrated into the practice of the multidisciplinary team. Continuing professional development would be an important way of enabling this to happen. A key moment for the group occurred in session five when it was generally agreed that spirituality is an innate potential in each human being which can be developed in many different ways. Ruth summed up this experience for the group:

So if we agree that everybody like has a spirit, to me the fundamental question is like how do you potentiate people, enable people to potentiate that spirit within? (5:109).

From this point, discussion turned more towards ways in which the human spirit could be nurtured. Individuals within the group discussed ways in which their own spirit had been nurtured plus ways in which the Centres could facilitate this process.

Spirituality as essence or core

Stating that the human spirit is innate still says little about what it actually is. One theme in the group's discussions was that the spirit is the essence or core of each individual. Martha notes:

We're all born into the spirit, I mean, whether we like it or not. I mean the spirit is part of all of us. It's nothing to do with religion in a way but for some of us it is expressed in religion because of birth, because of something we've hooked onto. But the spirit is of the essence of being human as well but time has pushed it into this other thing [religion] which in a way has narrowed it too much, I think really, and put it into a box that's aligned it too much with religion and I think that as long as we go on those lines we're still confining spirit and therefore spiritual, which isn't necessarily religion you know, but it could, it can be for some people (5:98).

This essence exists independently of any roles that individuals adopt or acquire (for example, patient, child, teacher, health care professional), as Elizabeth describes:

Through all the things you gain and lose throughout this journey, this period, there is a 'thing' that is with you and that is the essence of you and although that might change, you can't really lose that, it stays with you. So although you lose lots of things and gain lots of things, that's a continuum in fact. There's a part of that child still within your spirituality which you possibly tapped into at that point. There's still that little girl, within me at any rate, there is within me, I don't know about you, but I am still that little girl (7:207-209).

Narayanasamy also uses the idea of the spirit as 'the inner self', suggesting that it can be a source of strength and hope which helps to develop a harmonious interconnectedness (1991:4). Connection was an important theme in the group's understanding of spirituality which will be explored later in this chapter. This essence, (the 'real me') may be neglected if spirituality is undervalued:

To unlearn all the things that have put (the real you) down, that have stopped it being what it really is, that have stopped you feeling confidence in being real. All your defences and the vulnerability, that's what you have to strip away. But the core of you, everybody has an essence and a very valuable essence, it's all the things that have, maybe, put it away or have put it down or have given people less confidence to just feel that, that we have to unlearn rather than learning to be real (Elizabeth 3:174-176).

Overemphasising the spirit as 'essence' risks re-creating the dualism that sees the spirit as superior to the body, as discussed on pages 27-28. Rather than separating the

spiritual, the co-operative inquiry group were keen to see it as an integrated and integrating element within human beings. The human spirit can also be viewed as the animating principle (the breath of life) in each person (Walter 1997:25), while Ross suggests that the spiritual dimension can be regarded as:

A central artery, which permeates, energises and enlivens the other dimensions of humankind ... around which all values, thoughts, decisions, behaviours, experiences and other concerns revolve (1997a:38).

Advocates of this model, including the influential Cicely Saunders, draw on the work of psychiatrist Viktor Frankl and his 'therapy of meaning' (Walter 1997:25). Frankl, in his semi-autobiographical book exploring his experiences in the concentration camps of the second World War, reflects that even in such horrific circumstances people seek and find meaning which supports their will to survive (1964:35). This resonates with Benson's idea of 'remembered wellness' discussed on page 21. Spirituality, when linked to a sense of meaning and purpose, can motivate and inspire individuals and communities. This may be important in changing behaviour or promoting health, hinting at the broad relevance of spirituality as a motivating factor (Narayanasamy 1991:4, Oldnall 1996:139). Looking back on essential or continuing elements of life became an important reference point for the co-operative inquiry group, something we experienced ourselves and with our clients:

That nostalgia taps into spirituality in a way because we've got different hair cuts and different clothes and we look different. Only when I look at things that I wrote when I was five, I can't obviously remember, but that was me. A sense of me as that little girl and looking back on a journey and thinking about where I am now and thinking about the future. When I've been in situations when people have been given bad news then those moments must flash behind and before them and it's somehow the closest I've got to being in a room with people who are experiencing [this], to a much greater degree to what I was, of nostalgia hooking to that. But it's those moments when you can almost see it in their faces when you tell them, yes, there's the fear and there's confusion and lack of knowledge and all those things but also in that flash of being told [bad news] something happens and they see their lives behind them and think of their lives in front of them in a spiritual sense (Carole 7:186-189).

The word 'nostalgia' was used by the group to summarise the idea of life continuing, creating a role for the human spirit in linking past, present and future. According to the dictionary, nostalgia means:

A form of melancholia caused by prolonged absence from one's country or home; severe homesickness; regret or sorrowful longing for the conditions of a past age, regretful or wistful memory or recall of an earlier time (Simpson and Weiner 1989:535).

This certainly implies looking back, but with a greater sense of regret than was necessarily intended by the co-operative inquiry group. Kearney describes how one of his patients also used nostalgia to describe her feelings as death approached, expressing both her sense of missing her own home but also a '*yearning for more of what she was already beginning to experience and of what she sensed lay ahead*' (1996:110).

The human spirit may be viewed as immortal, continuing after death in a different realm. Individuals who do not accept this understanding of immortality may still recognise, and value, the notion that someone who has died lives on in people's memories or life choices, much as the human genome continues through the physical world. The idea of the spiritual continuing beyond death was important to people in the group, who recognised the ways in which their own lives had been influenced by contact with other people, particularly clients:

My sense of trust or awe or wonderment in this kind of setting is via the potential of each of our spirits and the ability to connect with somebody else ... Something very similar to what you've described has happened to me just once and from that meeting, because this man touched me at that particular level, I have used him in the work that I've done with students, in teaching and, you know, in talking, in education and talking to people in this kind of centre. And it's a real motivation, it's a real drive and I imagine that you've used your experiences in that sort of way as well but, for me, that's not from an external source, that's kind of like how we all work and connect and how we connect on a spiritual level. Because I can see when I talk about this man and explain what happened and what happened to me, I can see it connecting with other people and they will remember it ... and that's how I see continuing life or everlasting life or whatever. [It] is that connection with that person and that connection with that person is a way of making us all connected ... So I don't see that it's like, we live, we die, that's the end of it. We live, we connect, we die. Bits of us, bits of our memories, I live in somebody else, they don't believe it's us living on but they affect or contribute to society's development in that way and I think that's fantastic (Jane 9:76+79).

Co-operative inquiry participants also saw how facing death, as client, carer or health care professional, could prompt people to consider these ideas for the first time or in a more profound way.

Remembering *and* reflecting provide important opportunities for people to review their history, or story, a process which may help people to identify elements that give their life meaning or a sense of worth. Participants recognised that this was a potentially important opportunity in their work with clients, linked to the ideas about nostalgia described earlier. Cawley notes that spirituality is likely to be personally defined by individuals, based on a number of factors including their culture, background, upbringing and social context (1997:36). Burton also suggests that each person's personal narrative is an amalgam of their own life cycle events, their family or personal structures and their cultural history, all of which affect how they cope with their experience of illness and suffering (1998:123,125). Co-operative inquiry group members described the effect of these elements on their own spirituality, including struggles against, for example, childhood understandings. Ruth was keen to assert this balancing effect of culture and upbringing beside our emphasis on individual understanding of spirituality:

I think that there's also a great influence from how we understand those feelings, the words we put in, the constructs in which we place them, which is beyond our own individual interpretation. I guess, the way that we understand those moments are a lot to do with our larger frame of reference, which come from our family, culture and a whole host of different things. I mean, I guess there must be an individual pathway through it but it's not this free individual. That's how I see it. I see it very much as being informed or defined by our frames of reference (2:109).

Martsof suggests that spirituality comprises the five attributes of meaning, value, transcendence, connecting and becoming, noting the importance of cultural background in developing these attributes (1997:232). The co-operative inquiry group hoped to look beyond cultural differences to find out what, if anything, we held in common.

I would say we've agreed that [spirituality] is part of everyone but that everybody has a different interpretation about what it is for them and for everybody else (Carole 6:6-8).

The uniqueness of the human spirit did compound the difficulties of definition:

Perhaps because it is so intuitive and so unique and personal and nebulous that it isn't, you know, yours is different to mine and mine's different to Carole's and perhaps we could talk about it till the cows come home and we'll never know (Jane 1:93).

I can only know my own, well, only attempt to get to know my own sense of spirituality, in that nobody will ever agree with that and it will never fit entirely with anybody else's model. In the same way that nobody else's model will seem right to me (Jane 6: 10).

Participants found accepting that each person's spirit is unique profoundly liberating:

If you think of the other levels, like intellectual, physical, emotional, nobody else's is really like yours. At the physical level of you, there's nobody else like yours, and the emotional level of you, so it's all right, I think, if the spiritual level is very individual (Martha 6:14).

Recognising this, we could better resist having to fit in with other people's ideas and affirm our own perspective and experience:

To pin down what I've learnt, and what makes sense from doing the course, is just that ... If someone talks to me about spirituality and what it is, it's always seemed to me that it's got rules and it's got parameters and this is how it is - 'oh well you're not very spiritual then'. So I really like that idea. Why should it be the same for anyone else? Why can't it be as unique as everything else about us that's unique? and it doesn't mean you haven't got it (Ruth 6:18).

The gradual acceptance by the inquiry group that the human spirit was innate was accompanied by a complementary emphasis on human uniqueness. Each person's understanding of spirituality was understood to be unique, in a similar way to other aspects of humanness, but the inquiry also recognised that there is also much that is shared by all. One outcome of this was the recognition that each person's spirit needed the freedom to develop in different ways, so that spiritual nurture, for health care professionals or clients, needed to come in many different guises as will be discussed in chapter six.

An integrated and integrating whole

In a holistic approach, body, mind and spirit are viewed as distinctive but not separate aspects of each human being. Although, in the past, attempts have been made to identify a specific site for soul (Greenfield 1998:4-5,76), this approach is irrelevant if the spirit is essentially concerned with meaning, purpose and connection. Spiritual concerns can only be expressed and experienced through physical and mental processes (Watts 1997). Mind, body and spirit are irrevocably intertwined, responding to each situation as a totality (Labun 1988:314). This integration suggests a creative, moving force rather than something static, one which draws differing aspects together in a

persistent movement towards wholeness. Van Kahn sees the human spirit as:

The dynamic force that keeps a person growing and changing, continuously involved in a process of emerging, becoming and transcending self; it is through this gestalt process that life is imbued with meaning and a sense of purpose for existence (quoted in Goddard 1995:809).

Goddard, attempting to define spirituality as integrative energy, also notes the importance of moving towards greater internal harmony in spirituality (1995:813). This connected idea of the spirit as woven through the whole person, rather than a separate element, was important to the co-operative inquiry group.

That all those things looking back, our history, our culture, our relationships, how we were when we were children, are all there and there's something about spirituality integrating those things. Perhaps we learn to integrate them more (Margaret 7:204).

This was reiterated in discussions about the nature of spirituality and can be clearly seen in the metaphors chosen by several members of the group to express their ideas about spirituality, as discussed in more detail on pages 109-110. Although often associated with larger concerns about the meaning of life, the group were keen to assert that spirituality also plays a part in everyday experience. As Elizabeth notes, questions about our identity affect even something as mundane as ironing:

People were very much making a big sort of distinction between the two and very much equating spirituality to the real deeper, big things and psychological to the everyday things. Whereas I think there's more of a continuum than that. And that was colouring the way people approached it because it was like 'what is your spiritual concern today?' whereas they were talking about women who wanted to talk about being about to do the ironing and [be] with the children. That it was very important to be the Mummy and I felt that there was an element of spirituality within that, you know, although it wasn't the whole picture (1: 65).

It's not that being able to do the ironing, it's [who] they are, their role and their understanding of their role and purpose (1: 67).

While we retained our concerns about spirituality becoming too broad, even to consider such a possibility demonstrates the essential integration of spirituality into the whole of life.

Transcendence

A common theme in writing about spirituality is that the spiritual is essentially transcendent, reaching out beyond the self, to others, to God or a divine power, or to absolute values such as beauty or love, or to others. A report by the World Health Organisation Expert Committee on Palliative Care states that the spiritual refers to those aspects of human life which transcend sensory phenomena (1990:50-51). A number of authors also highlight transcendence as an element in spirituality. Martsolf (1997:232) identifies transcendence as a key feature of spirituality, as does Highfield, who describes the spiritual dimension as the human capacity to transcend self, which is reflected in three basic needs, for self acceptance, for relationship and for hope (1992:2). Over-emphasising transcendence risks creating a dualism which isolates the spiritual rather than the integrated approach we were suggesting yet an emphasis on reaching beyond the self helps avoid spirituality becoming self absorbed and isolated. A more helpful image may be that spirituality integrates two planes or dimensions, the horizontal (connecting with other people and with the world around us) and the vertical (reaching outwards to a higher power or transcendent values) (Giske 1995:5, Ross 1997a:38). In the co-operative inquiry group's own discussions, spirituality was understood to involve reaching both inwards (personal exploration, integration and uniqueness) and outwards (relationships, transcendence, divine power). A related point of ongoing tension for the co-operative inquiry group concerned the origin of the human spirit:

What you were saying earlier on rather seemed to hinge round whether this spirituality is something that we nurture in ourselves and its ours, or whether in fact it's, you know, from an outside being or power. Because if it's coming from an outside being or power, but also in us and can be grown in us and can become larger in us as we know more of that outside spiritual being or power, then wherever we're coming from it doesn't matter because we're going to the same place (Joyce 5:57).

Burnard notes the Quaker tradition which identifies the spirit as '*that of God within every person*' (1990:38). For some co-operative inquiry group members, the human spirit was understood to originate in the divine; for others, the human spirit was originally and fully human. However, all participants recognised a general human desire to reach beyond themselves, whether that be towards other people, towards greater human potential or towards a transcendent power.

Nurturing spirituality

For the co-operative inquiry group, accepting the human spirit as innate was inextricably linked to discussions about the nurture of spirituality. As with body and mind, there was an expectation that the spirit would develop throughout life, a process helped or hindered by environment, culture and other factors. The inquiry group emphasised that each person's unique spirit, and spiritual journey, should be valued but were concerned that spirituality was neglected or ignored. The confusion about spirituality discussed earlier makes spiritual nurture problematic, even within a specifically religious environment. Involvement in health care, particularly where a holistic approach is taken, might be expected to stimulate thinking about spirituality. Yet participants were aware that actual attention to spirituality and spiritual development was limited. Harrison and Burnard, talking to nurses about spirituality, also received the impression that spirituality was a new concept to the majority of those interviewed (1993:70). Hay's work on spiritual experiences, described more fully in appendix two, also supports the view that spirituality is neglected in post modern society (1990:59-62). Even where people are interested in the spiritual, they may struggle to develop this aspect of themselves for the reasons outlined in chapter two. Elizabeth notes:

People try to find a concrete thing which gives them spiritual satisfaction ... like when you look at like money and consumerism or shopping, as if there's something external that's going to give people that, and also how they're failing because they're kind of looking in the wrong place, you know, [for] a sense of being or fulfilment and it does feel a bit like that when I see lots of people trying to find it in something else rather than trying to find it in themselves. It's quite sad, really, because it's a bit like seeing people whizzing around trying to find something that they're never going to get, from the wrong place. I've become much more aware of that really that somehow people have lost an awareness that their spiritual strength is gained from within and have become wrongly aware of that and more aware that somehow it's going to come from outside, and it's not going to (15:18).

Facing death or serious illness, or working with people who are doing so, can focus attention on spirituality in a way which demands attention as already described. Yet such a demand does not necessarily suggest how to proceed any further. Participants described their own experience of this uncertainty and how they saw it affecting clients:

I think that's the sad thing for me, because I feel that because of a framework that I was brought up with, which I then reacted against, that I then lost it. You know I had no framework and I believe lots of people are like that that, you know ... it's too difficult, it's too confusing. 'Well, that didn't fit right, so goodness knows what else will fit. I've no idea to know where to start, I've read a book on Buddhism and one thing and another and that's it' ... So you close the door and then you get, sort of bringing it back to our context, you get a life threatening illness and you think, gosh, you know, my life's gone or going, it's threatened and I never really spent the time thinking about it or working anything out and there's huge regrets then (Carole 4:204).

Being part of the inquiry group had made participants very aware of the confusion about the nature of spirituality and hence, how vital it was to recognise when clients expressed similar confusion as they struggled in this area.

Fowler identifies faith, or religious, development as a gradual process of making meaning, which moves from early intuitive faith to a final stage of selfless or universalising faith (Astley 1991:19-35, Brewer 1979:100-101). This work has been extended and criticised (for example, Astley 1991:44, 46); certainly individuals within the inquiry group felt that such a smooth progression was far from their own experience. However participants did recognise the importance of different life stages in spiritual development. The particular relevance of spirituality in serious illness and death was an essential part of our inquiry. Birth and ageing, however, were also seen as important. Participants reflected that their own childhood spirituality seemed more intuitive and accepting, comparable with Fowler's idea of intuitive childhood faith:

What I was thinking was when we started talking about it being innate and I was thinking back to as a child ... I went to a Jewish primary school, we used to have on the Friday afternoon we used to finish early and we used to have like a family meal and there was like an air of excitement about sabbath is coming and the sabbath queen is coming. We're doing a different thing and that was normal ... because that was my primary school and that was what I expected. And then looking back as an adult I interpret that now, and I'm thinking 'Oh, I'd get it' I never knew that was spiritual at the time. We just finished at quarter past two but now I get a feeling of that being exciting, you could say it was quite spiritual, there was an atmosphere there at the time but ... it was only, I had to be an adult and be outside of it to look on it in that way. I don't think that spirituality was innate in that I grew up with it and that it was there. I really feel, I was trying to remember when it was that I looked back on it and thought 'Oh that was quite spiritual' but it did feel like something that I grew up with as growing knowledge (Ruth 2:111).

Hay with Nye's exploration of non religious spirituality in children, suggests certain categories which can be identified as elements of spirituality (outlined in figure 5:1).

- ◇ *Awareness Sensing*: here and now, tuning, flow, focussing
- ◇ *Mystery Sensing*: awe and wonder, imagination
- ◇ *Value Sensing*: delight and despair, ultimate goodness/meaning.

Figure 5:1: Categories of Spiritual Sensitivity, from Hay with Nye 1998:59

The inquiry group also identified these categories as important within their own spiritual experiences, both as adults and children. Adulthood brought a greater desire for rationality and understanding which could lead to a rejection of religion, yet ultimately to spiritual growth:

I was very heavily into christian religion when I was in my teens and then suddenly woke up one day and thought 'what on earth is all this about? I don't really feel it, I don't really believe it'. It all seems very strange because as I became an adult, and I'm not saying it's a childhood thing, it was sort of as I started thinking for myself and trying to think it through. I felt like I'd sort of gone through the system to be approved of, rather than it being something that was [sort of] for myself (Carole 4:193).

Brewer's suggestion that social, cultural, physical and psychical aspects of life interact in flowing patterns, rather than rigid quadrants or straight lines, was more applicable to the inquiry groups' growing perception of spiritual development (Brewer 1979:106).

As described earlier, life experiences of many different kinds influence spirituality. Spiritual growth, as an integrated part of human growth, may be occurring when people are largely unaware of spiritual concerns or perhaps unable to articulate them. Our work with clients at the Centres aimed to establish a safe space in which those who wished to could reflect openly on spiritual concerns. The process of reflection provides individuals with an opportunity to look backwards and forwards at their lives, so that they need not say '*we had the experience but missed the meaning*' (Eliot 1959:39). A similar space for staff was provided initially by the co-operative inquiry, and more widely by the continuing professional development opportunities that arose from it. The individuality of this process was important to participants although exploring with others was both unusual and highly significant:

I guess what we might have in common is a feeling of our own individual spiritual search, whatever that might be. I'm just wondering whether fifty years ago whether people had that dilemma or whether they could fit more easily into larger institutions because they didn't have such a high concept of the intrinsic nature of the individual (Ruth 5:8).

Our experience with clients, and the profound effect described by some participants, suggests that opportunities to explore spirituality are not widely available in other contexts.

A key and recurring theme in discussions about spiritual growth was the metaphor of the search or journey. The journey is a traditional metaphor for spirituality which is still widely used in both religious and non religious writing. Modern writer Jennifer Lash describes the instinct to travel, both outwardly and inwardly, that she felt following her own experience of cancer:

[Cancer] may be sharp and full of pain, but it may also be a guide, a useful companion on a dark night. There is a hidden current within every individual. It seeks and stirs, hides and yearns. Sometimes it is bewildered, a mixture of anger, pain and certainty. It may recede, but it never escapes. In moments of crisis, it is often full of voice. Make a Pilgrimage. Go to ancient places. Go wherever there are contemporary seekers. Go in whatever way it works out. Just go! (1998:xi).

Initially I was concerned that journey was too linear an image, suggesting a clear goal towards which people travelled, something far from my experience of spirituality. However, the group returned repeatedly to this metaphor with its implication of movement and exploration. Searching, for meaning, hope, connection or understanding, was viewed by the group as a key part of spiritual nurture, supporting the view that 'the perpetual search for meaning in life' is the cornerstone of all spiritual existence (Cornette 1997:7). Spirituality was seen as developing in encounters with life events, both positive and negative, rather than being separated from those events. There was also a clear sense that spirituality flourished when there was freedom to explore:

And [spiritual growth] probably comes about by experience, don't you think? You know, it's experiences ... that make us think about it and grow and ... being open and being in an environment, maybe, where it's okay to explore that. And [a] more judgmental kind of, confrontational ... environment might suppress that or it might become something which is more secretive, covert. It's developing the freedom to ... develop [spirituality] in a more overt way (Elizabeth 2:48-50).

One thing we seem to be saying is that spirituality doesn't thrive under imposition or control and yet that's exactly the way many religious institutions have evolved (Elizabeth 4:231).

Ultimately each individual makes their own spiritual journey and our experience with clients suggested that struggle was often a part of this journey. As health care professionals we recognised both our own struggles for meaning and our role in walking alongside clients who were searching for meaning. Both these experiences support the need for reflection and an experiential approach to spiritual development opportunities. Discussions within the group clearly challenged participants about recognising and accepting the validity of each person's individual spiritual journey. Individuals may walk alongside each other but did not need to visit the same places:

We're all on a sort of journey of understanding more about life and what it's all about. Someone else is on a journey but in a different part of the continuum. It's the recognition of that that's really important. It's knowing that you're on a journey and knowing where you are on that journey spiritually yourself but recognising that other people are on their own journey and may never get to where you are on their journey but that it's still valid where they are. They don't have to get to where you are to have a meaningful journey (Carole 1: 117).

As described on page 67, a point of tension within the group which relates to use of the journey metaphor concerned the distinction between arrival and travelling, pointing to a wider tension around the need for comforting certainty and final answers (Stoter 1995:51). The poet RS Thomas echoes this sense of exploration and reflection:

*'As has been said,
the point of travelling is not
to arrive, but to return home
laden with pollen you shall work up
into honey the mind feeds on' (1995:293, quoted in Stoter 1995:13).*

Our task, personally and professionally, as individuals and as a group, was to facilitate this process of making honey from life experience. While we could not make honey for others, only for ourselves, we could encourage the process. This thesis, represents a small part of the honey we ourselves were making from our own spiritual journey.

Finding our own voice .

Language presented a recurring difficulty throughout the co-operative inquiry process. The whole person medicine inquiry also noted this difficulty over words:

How can one person know what another person means by the word [spirit]? With people with different cultures, classes and religious affiliations there are bound to be markedly different interpretations attached to the word, leading to misunderstanding and confusion. The Tower of Babel. Many people have thought so little about the subject and only have a rather diffuse idea as to what they mean themselves when they use the word, let alone what you mean when they hear you use the word (Reason and Heron 1985:52).

The multidisciplinary LUCAS group, referred to on page 94, also spent significant time examining the nature of spirituality before agreeing an understanding (Cornette 1997:6). Although the definition agreed upon by the LUCAS group was well accepted by other palliative health care staff, it continued to raise questions, particularly concerning distinctions between religious and spiritual, and between spiritual and material or physical (Cornette 1997:7).

Chapman dismisses the suggestion that simply substituting a different word would solve this problem (1986:38-39). Indeed, an earlier attempt to substitute spiritual for religious does not appear to have brought any greater clarity (Lewis 1999:337)¹. Goddard's suggestion that spirituality be redefined as 'integrative energy' (1995) can be viewed as restrictive rather than liberating: '*stripping away meaning in the name of a spurious scientism*' (Dawson 1997:289). The problems attached to spirituality are due not to the word itself but rather to the inherent difficulty of attempting to '*fathom the unfathomable*' (Halstead and Mickley 1997), compounded by the complexity of articulating the unfathomable in words at all. Exploring together helped clarify individual's own ideas about spirituality as well as beginning to develop a shared understanding. Participants experienced for themselves how difficult it could be to talk about spirituality, both before joining the co-operative inquiry and in its initial meetings. This was all complicated by our fear of being misunderstood, of not having the answers and of being wrong! Exploring together in a safe space on a regular basis had helped us to overcome these fears, initially with each other but later with clients as well. Once that initial barrier was overcome, participants described their fascination with the topic and their delight in being able to talk to others about it.

I think we talked about how little spirituality is discussed, even though, even though, we feel it's a massively important area of every human being's life and

¹ Lewis suggests that William Temple, then Archbishop of Canterbury, substituted the word spiritual for religious in the 1944 Education Act to avoid controversy and ease the Bill's passage through Parliament. The 1988 Education Act, while insisting on the provision of specifically Christian worship, also includes responsibility for the spiritual welfare of children and education faces similar difficulties to health in understanding what this means and how to achieve it (Hay with Nye 1998:37-38).

yet it's actually something that isn't discussed openly very often. People have certain discomfort often in talking about it (Carole 6:91).

Reminiscence and life review, akin to ideas about nostalgia discussed on page 97-98, can be used therapeutically, particularly with people who are elderly or dying (Taylor 1997:252). Listening to stories in this way may also provide a useful opening to discuss spirituality with clients for whom this concept appears alien or incomprehensible (Burton 1998:123-126).

Despite recognising the limitations of words as a vehicle for spiritual exploration, the group also saw the importance of trying to use this basic human communication tool. Spirituality *is* hard to put into words, as we have seen already in this chapter, but the process of trying to do so remained helpful. Tomlinson contrasts scientific and poetic approaches to language about religion; both offer ways of understanding reality, both offer helpful insights but neither has the complete picture (1995:88-89). Health care practitioners need also to retain the sense that spirituality is often too 'deep' for words. Hay suggests that aspects of human behaviour which are preoccupied with profound questions of existence, such as spirituality and religion, occupy '*transitional space*', described by psychologists as existing between fantasy and reality. Hence, although the roots of spirituality lie in the physical world, its articulation necessarily draws on the creative imagination (Hay with Nye 1998:46, 51-52). The importance of the creative arts, particularly drama and music, in spirituality was discussed briefly on page 34. There is a growing recognition in healthcare of the potential therapeutic benefit of the creative arts, for example, Bailey notes the basic human need to be creative, and how the arts can help regenerate body, mind and spirit (1997:243). She also describes how making objects for other people provides a way of being remembered, a further link to the idea of nostalgia, as described on page 97-98.

Concerned about the difficulty of describing spirituality, the group consciously explored the metaphors they would use for spirituality in sessions four and five (see figure 5:2). The primary use of metaphors is to '*express the inexpressible*' which makes them powerful tools with which to discover and share meaning in everyday experience (Candy 1986:93-94). Metaphorical language illuminated and expanded our ideas about spirituality, tending to stress themes of growth, variety, energy, warmth, interweaving, light, beauty and depth. The journey remained a recurring metaphor throughout the inquiry, although it was not specifically chosen by

any individual when metaphors for spirituality were selected.

Celtic knot designs
Plasma ball
Abstract interweaving, luminescent threads delving down into darkness
Hands welcoming
A well
A cottage garden
Light in the darkness
'Spaces' in a weaving or tapestry

Figure 5:2: Metaphors for Spirituality Used by the Co-operative Inquiry Group

Participants were interested to note the distinctiveness of their individual metaphors for spirituality and how strongly they felt about them.

I can't think of any other thing when you would try and say 'oh it's like that' and somebody might say 'no, it's not' and it might feel really quite offensive (Ruth 4:24).

Metaphors can be used to illuminate the reality of spirituality, enabling people to use pictures, even jokes or throwaway lines, rather than talk directly about difficult issues (Stanworth 1997a:19). The Greek root of the word symbol is to connect (Stanworth 1997a:22), a common theme in spirituality discussed at length by the co-operative inquiry group. The inquiry group itself needed to develop a safe space before talking openly about spirituality. We realised that this was also true for people using the Centres; as a staff team we needed to recognise and respond appropriately to indirect clues, such as metaphors, about spirituality.

Cox suggests that all human beings have an innate need to tell and hear stories and to have a story to live by (Cox 1974:9). Stories enable people to organise and shape their experiences, so that their 'personal narrative' can become an important coping strategy in illness (Burton 1998:123). As clients told us their stories, sharing something uniquely of themselves, they made a connection with us, affecting us as individuals and as health care practitioners and, again, leaving their mark on our lives (Taylor 1997:252). This sense of 'telling our own story' was also important during the co-operative inquiry:

It's been good for me, personally, to think things through, you know, to bounce the ideas and I think it's been very interesting to hear about what other people do ... I think there's also been an interesting element, and I think we've all done this, [we've] had a certain agenda that they were wanting to share with other people ... Yes, we've been able to discuss things on a superficial level and then, every now and again, you can feel someone wanting to share something about themselves. And given we all work closely together and probably don't know what makes us all tick, I've found that quite fascinating (Carole 6:263).

Individual participants also described incidents in their childhood or more recently which seemed significant in their spiritual journey. These tales were created and told in the midst of life, tales of continuing discovery and exploration not reports from an ultimate destination. Using an experiential methodology has allowed our research into spirituality to remain immersed in life, contextual and holistic rather than become linear and fragmented (Hall 1997:88). Participants in later education groups were offered a specific opportunity to talk about something they perceived as important in their spiritual history (discussed on page 170). This experience, which occurred as an unexpected element in the co-operative inquiry group, resonates with the findings of Stanworth, a nurse researcher based at St Christopher's Hospice, who has carried out an exploratory research project focusing on the spiritual needs of non religious patients (Stanworth 1997b). She analysed interviews with twenty-five hospice patients who had been given the opportunity to 'tell their story'. Metaphorical language was especially important, as discussed earlier, but symbolic expression in art, gesture and behaviour were also significant ways of articulating clients' deepest concerns, suggesting that communication needs to be understood in terms of depth as well as extension (Stanworth 1997b). For participants in the co-operative inquiry, and later education groups, this resonated with a growing understanding that spirituality, our own as well as our clients', could be expressed in many different ways. Recognising and nurturing spirituality involved a degree of 'tuning in' to questions and desires which lie beneath the surface of our life and experience as well as that of our clients. Reflecting on past experiences, being nostalgic (to use the terminology of the inquiry group), offered an opportunity to look again at the continuing meanings of our lives. MacIntyre uses the idea of 'narrative unity' (1985:217) to convey each person's need to develop a history, or story, which spans their whole life. This research, has offered those involved an opportunity to develop such a history with spirituality at its heart, rather than absent or marginalised. Such an exploration helped participants understand and facilitate a similar process with clients.

Spirituality and health care

The above discussion encapsulates the core elements of the co-operative inquiry group's understanding of spirituality. Within this basic framework, agreed by all participants, four particular themes recurred: meaning, purpose and fulfilment; connection; hope and religion. Rather than describing the precise nature of spirituality, these were foci around which ideas about spirituality congregated. These recurring themes find support in Renetzky, who defines spirituality, the fourth dimension, as:

The power within a person's life that gives meaning, purpose and fulfilment; the will to live; the belief or faith that person has in self, in others and in a power beyond self (1979:215).

The co-operative inquiry group were particularly interested to consider these as potential entry points when talking about spirituality, both as a group and with clients.

The World Health Organisation stresses the importance of the search for meaning and purpose in spirituality. This search becomes more pressing as death approaches, and can be seen in the desire for forgiveness, reconciliation and affirmation (World Health Organisation Expert Committee 1990:51). Certainly this was an important and recurring theme in the group's discussions, raised both by our own struggles and our contact with clients. Cecily Saunders, the pioneer of the modern hospice movement, has been influential in promoting a concept of spirituality which is strongly identified with the search for meaning (Walter 1997:25). Meaning or purpose may be found in religious belief but also much more broadly, for example in love, beauty, creativity or relationships. Kearney suggests that the soul brings '*a living connection between the surface and the unfathomable and meaning-rich depths of who we are*' (1996:59). Previous discussions about the need for reflection and exploration, which seems so much a part of spiritual growth, are linked to this life long process of finding meaning and purpose. Tom Gordon, chaplain to the Marie Curie Hospice in Edinburgh, recounts the following encounter as a way of explaining how exploring meaning may actually be a way of exploring spirituality:

I was at the sharp end of spiritual care, because a craggy, old, atheistic miner was asking a spiritual question - of someone with whom he would never agree in religious terms, but whom for his own reasons he trusted with this sixty-four thousand dollar question in the face of death ... Bobbie was on a spiritual journey, sorting things out before he died, finishing the business, concluding a

search for meaning, purpose, fulfilment, seeking an affirmation of the worth of his life (Gordon in Burgess and Galloway 2000:97-8).

Participants in the inquiry group described similar experiences of walking alongside individuals who, faced with the reality of death, were struggling to understand their life experiences.

There are times when you find a lost soul, and I don't mean that in a religious sense or anything, but someone who, you know, is really angst, who hasn't come to terms with their dying or with life, you know, who hasn't come to terms with life or death, has loads and loads of baggage that probably needs sorting out and things ... They haven't had the time or the energy to think about the meaning of life for them and suddenly they're ... faced with a life threatening disease, they're thrown into the crisis of what life is all about. Now, I think parts of that could be dealt with by your average counsellor because parts of it are bound to be wrapped up in relationship problems or issues that could be put through the psychological process to advantage but I think there would be chunks of it, they would need a facilitator ... for whom the outcome was that that person was calmer, more peaceful ... had come to some of their own conclusions about what life and living was all about and, therefore, could face their death in a different way (Carole 4:158).

Simsen suggests that meaning, in large and small ways, is vitally important to people during illness (1986:42) and the group's experience with clients supported this idea that a sense of purpose or meaning helped individuals cope with facing death or loss:

Loss must be very sort of devastating if you just feel that it's been a waste. A totally meaningless, pain ridden experience which has had nothing that's impacted on their life. It's more beneficial. Even like that girl today when we saw through the grief there were still all these things that she felt she was left with, there were good memories, there was lots that was important (Elizabeth 10:110).

Again referring to Frankl's work on the search for meaning, Hockley suggests a link between having hope and finding meaning (1993:183). Hope may be linked with the individuals' will to live but also with sources of hope such as relationships (Dyson et al 1997:1186). Shelly and Fish see hope as giving 'a glimmer of something better' (1988:44), suggesting a link with transcendence. Hope may be understood in different ways but is identified as a key component of spirituality (Dyson et al 1997:1186). Maintaining hope is a complex issue in palliative care, where health care professionals and their clients walk a tightrope between giving up and having unreal expectations. Talking about clients' hopes was an occasion when spiritual issues may be raised:

I feel like [hope] might open a few more doors when you start talking about hope, because you then have an automatic lead into talking about loss and, you know, and hope and realistic hope or loss of hope. So that word, I don't probably use the word enough (Elizabeth 11:24).

Post-White et al, working with people with cancer, equates hope with the sense of coherence, suggesting that both concepts incorporate the need to make sense of events, to find meaning, identify resources to assist in coping and set realistic goals (Post-White et al 1996:1572). Flemming suggests similar links with spirituality in her phenomenological study about what hope means to patients with cancer, identifying hopes for the maintenance of physical function, the positive presence of nursing and medical staff, the perceived existence of a positive future of the patient and their family (1997:14-18).

Labun suggests that a sense of connectedness, including self, others and a 'higher power', is an essential element of spirituality (Labun 1988:315). Goldberg identifies connection as a more helpful concept in practical, everyday health care than abstract ideas about spirituality (1998:836). Certainly, connection was used extensively by the co-operative inquiry group, particularly associated with their understanding of the human spirit as integrative. Such understanding draws on the idea that spirituality involves both horizontal and vertical planes, as discussed on page 102. Grey suggests three areas of connectedness which have been lost in Western spirituality, with the earth, with the past, and with the community (Grey 1993:65), which resonate with the ideas discussed in chapter two. Within the co-operative inquiry group, connection was the most frequently discussed theme, sometimes appearing to act as a summary for ideas about the nature of spirituality. Specific feelings of connection with clients was also discussed:

I can think of one man really in Asia ... he wasn't a Christian in that sense but it was what happened, in a searching for meaning. But for me it was also an experience of spirit and of wavering and for him it certainly was, you know, it was and quite a lot of time. If you came in from outside you wouldn't necessarily know but you just knew it was two spirits meeting and searching and the thing is without answers and not having to give answers and a lot of quiet and a lot of just being (Martha 1:176).

While we recognised the impossibility of experiencing such a close connection with every client, these moments remained important for individual participants.

Reviewing the nursing literature in 1978, Kreidler found that in most cases the word spirituality was equated with religion (quoted in Labun 1988:314). While there is now a greater recognition that religion and spirituality are not synonymous, some confusion remains. More recent writers also note that spirituality is still commonly linked with religion (for example, Highfield and Casson 1983:189, Ross 1994:442, Burnard 1990:38). Religion, particularly its concrete outcomes, can be easier to describe and quantify. For example, National Association of Health Authorities and Trusts guidelines about spiritual care (1996) recognise that spirituality and religion are different yet consistently link the two. Concrete outcomes of religious belief, for example dress or behaviour, provide opportunities to see how spirituality can affect the lives of individuals but should be recognised as the tip of an iceberg. The deeper effects of spirituality, while less obvious, may be more wide ranging. The co-operative inquiry group, which included people who both did and did not adhere to religious belief systems, increasingly felt that spirituality was relevant to all. The group recognised the need to respond appropriately to people with or without a religious belief system who were actively exploring spiritual issues.

Most religions provide shared ‘myths’ or ways of explaining the world which help create a sense of meaning and harmony, a state which is generally desired. Locating society in a wider frame of reference, religion can provide a connection with a fundamental order which lies beyond the physical world (Berger 1969:42). The co-operative inquiry group noted that while religion provided an important framework within which to explore and nurture spirituality, it could also be a block to spiritual growth. Religion, being more concrete and easier to measure than spirituality, is more often used in surveys of health (Ziegler 1998:1256). National Health Service guidelines, which emphasise multi-faith approaches, are also beginning to include individuals without religious beliefs at all. Yet an overemphasis on understanding different religions can become a barrier to meeting spiritual needs:

Sometimes I find that with someone who really is a scholar in terms of religion they're so into the detail and trying to get, I don't know whether you can get empirical but you know the sort of scientific stuff and knowing and being right, that you know, you've lost it again. You know too much (Elizabeth 13:170).

Meeting religious needs (for example, for sacraments or particular food) was considered relatively easy compared with the complexity of recognising and responding to

spiritual needs for identity, meaning, purpose and hope.

Religious needs can be very easily met without people wanting, quite often, to address other needs. Whereas, I think, I'm aware of meeting people more at another level of something else needing to be addressed. To me it links up with, you know, Kearney's thing quite often with the baggage they're bringing with them. And as spirit meeting spirit and so choosing really, in a way, to see that that's the pain that needs addressing and that, though it sounds terrible, religious things can be addressed, in one sense quite easily in a box. I'm sure there would be many a priest that might clout me for that but I think that emerges more and more. It's the spiritual, which might go with the religious for some people but for some, it doesn't always (Martha 14:31).

Conclusion

Although spirituality remained ultimately undefinable for the co-operative inquiry group, it had been an exciting and important process to reach towards greater shared understanding. Participants stressed that understanding spirituality should remain individual and exploratory, a feeling confirmed by one of the participants who commented on the final draft of this thesis. The group was able to agree certain core elements in their understanding of spirituality. Themes of meaning and purpose, hope, connection and religion, offered potential opportunities for use in assessment. Our individual and corporate exploration, had clarified and enhanced our ideas about spirituality but it had also confirmed our sense that this was a continuing, life long search or journey. Increased awareness of spirituality created a space in which this often neglected human element could be nurtured. Providing such a space for clients became a key element of our understanding of spiritual care and will be discussed in chapter six. Some awareness of spirituality is important for health care professionals, particularly those working in palliative care. Continuing professional development opportunities, explored in chapter seven, enabled other health care professionals to explore these issues. Personal and professional are intertwined in spirituality: experiential and reflective approaches to learning enable individuals to explore this issue in a way which integrates personal and professional experience. Co-operative inquiry participants were very aware that we could only develop our own spirituality, yet by accepting that spirituality exists and by creating a safe, open space in which it can be explored, we felt it may be possible to support this exploratory process in other people.

**CONTINUING PROFESSIONAL
DEVELOPMENT FOR SPIRITUAL
CARE**

Chapter Six: Spiritual Care: themes for continuing professional education

The relevance of spirituality to health care, and particularly to palliative care, has already been discussed. Spirituality is an integral element of the holistic approach and as such a central tenet of the palliative care ethos. Much has been written about the importance of spirituality in the hospice movement, particularly in the United Kingdom, but a lack of research about spirituality remains, so that it has been dubbed the '*ignored dimension*' (McGrath 1997:2-3). An international report on the principles and assumptions of spiritual care also notes this need for both research and education about spirituality in health care (Spiritual Care Work Group 1990, see also appendix 8). The difficulty of defining and articulating ideas about spirituality combined with the emphasis on measurement and objectivity in most medical research, ensures that spirituality continues to be largely omitted from the research agenda (McGrath 1997:3). The growing emphasis on 'evidence based' medicine makes spiritual care vulnerable unless such a research base is developed. Local standards about spirituality exist in some areas, for example, Catterall et al 1998:166, NHS (E) Northern and Yorkshire Chaplains and Pastoral Care Committee, 1995:13-14. Audit of spiritual care exists but is focused on measurable activities such as documentation and assessment (Catterall et al 1998) whereas the essence of spiritual care is often intangible and outcomes are unknown. Existing research about spirituality has been referred to already in this thesis, notably in Britain the work of Waugh (1992, also Ross {formerly Waugh} 1997b) and of Simson (1985) but more is needed. A review of research into spiritual care within American hospices suggests this is a growing area of interest (Millison 1995:3-4). Methodologies such as co-operative inquiry or narrative research provide alternative avenues through which to explore spirituality and spiritual care, as discussed in chapter three.

The co-operative inquiry group described in this thesis enabled spirituality to be explored in a way which integrated personal and professional experience, a theme which underpins all aspects of the research. As a shared understanding of spirituality developed, participants were able to discuss constructively the practical provision of spiritual care. Reframing the provision of spiritual care at the Centres where the research was based forms one important outcome of the inquiry. This was supported by the other main outcome of the inquiry,

which was to develop continuing professional education opportunities about spirituality and spiritual care. In this way, other staff could be drawn into a shared understanding of spirituality, stimulating greater understanding and confidence about spiritual care throughout the staff team. Reiterated in much of the writing about spiritual care, and echoed in our own experience, is the impression that such care is rarely provided without personal understanding and experience of spirituality. The co-operative inquiry group demonstrated the inevitability of linking personal and professional in an exploration of spirituality. Reflecting on our own experience and struggling together to a better understanding of spirituality had been central to the inquiry group's learning. This emphasis on personal and corporate reflection on spirituality and spiritual care became, therefore, an essential element of continuing professional education for other staff.

The continuing education module, while considering different ideas about spirituality, focused on spiritual care provision. Therefore, the themes explored within this chapter concerning the nature of spiritual care, became essentially the themes of the educational module which will be discussed in chapter seven. Spiritual care's relationship to spirituality is such that the co-operative inquiry group's understanding of the nature of spirituality, described in chapter five, underpins much of this chapter. Spiritual care may be needed uniquely during illness or loss, both of which are important in palliative health care. This chapter will, therefore, explore the co-operative inquiry group's understanding of spiritual care, including the specific themes of assessment and roles in the multidisciplinary team.

The nature and provision of spiritual care

Understanding something of the nature of spiritual care is a vital prerequisite to its provision. For the co-operative inquiry group, clarification about spiritual care followed naturally from discussions about the nature of spirituality. Similarly, an exploration of spiritual care, the primary focus of the continuing education module, flowed from initial discussion about the nature of spirituality. While spirituality is relevant during the whole span of human experience, our particular concern was spirituality in illness. National Health Service Guidelines indicate that:

The NHS should, where necessary, make every effort to provide for the spiritual needs of patients and staff. As far as reasonably possible, this provision should

*recognise the welfare needs of both Christians and non Christians
(NHS Management Executive 1992:1).*

Provision includes employment of suitably qualified staff and facilities for worship or other forms of religious observance (National Health Service 1992 (annex):1-2). Focussing predominantly on religious needs and experiences, such provision is limited. In contrast, World Health Organisation guidelines about palliative care suggest a broader requirement that was closer to the co-operative inquiry group's understanding of spirituality:

'Spiritual' refers to those aspects of human life relating to experiences that transcend sensory phenomena. This is not the same as 'religious', though for many people the spiritual dimension of their lives includes a religious component (WHO Expert Committee 1990:50-51).

Similarly, the National Association of Health Authorities and Trusts encourages providers to recognise that *'spiritual does not necessarily mean religious'* (1996:5). An international work group on death, dying and bereavement also takes a broad view of spiritual care, suggesting overarching assumptions and principles which resonate with the co-operative inquiry group's findings (Spiritual Care Work Group 1990, see appendix eight).

Even where a broad view of spirituality is recognised and accepted, it is not easily integrated into practice, as a member of the inquiry group describes:

I'm going to this multi faith joint consultation next week about the NHS and spirituality and the Minister of Health's coming and Chief Executives, so it's an area that's around and people do want to address. They're trying to get us to not only talk within our own little religious confines but it will be interesting to see if there's anybody who doesn't fit into any religious box and how they address that, or don't address it (Martha 6:141).

When spirituality is understood as a potential within each human being, as in the co-operative inquiry group, spiritual care becomes a more diffuse yet equally, perhaps even more, important element of total health care.

In addition to religious activities, meditation, outdoor pursuits, expressive and creative arts all provide potential avenues through which individuals may express or explore their spirituality. The Centres at which the co-operative

inquiry was based already provided a number of such activities, including gardening, art, music and creative writing as well as complementary therapies. Superficially, expanding the range of these opportunities, for example, by including reminiscence work to encompass our ideas about nostalgia, appeared to be the best way of providing spiritual care. However, the inquiry group retained a clear sense that all these activities, valuable as they might be, were not in themselves the essence of spiritual care. Reviewing a paper about spiritual care, Ruth says:

The thing is ... they were sort of talking about creativity being a spiritual thing. They were talking about divertional activities. I think there's much more [to it] than that and I just got a bit irritated. I felt what they were doing was to kind of highlight the idea of what is spiritual and then look round to see 'ah yes, well what have we got? oh yes, that's quite spiritual (3:71a).

Specific activities, such as those described above, may nurture certain aspects of spirituality but none of these activities embody the whole of spiritual care. The group recognised that such concrete, visible activities, could become a substitute for a deeper and more challenging approach to spiritual care:

Well, there might be a particular spiritual need or a spiritual question about 'where am I? who am I in the universe?' but actually spirituality might not have to be a need to put right or a need to fix. And it was very much about 'how do we identify this need?' which was just so concrete. ... It was really paying lip service to spirituality to enable a person or a team to say 'this is part of the task that we do' rather than the much deeper concept of how people relate to people and what's going on for that individual and being able to be available to that person if an experience is particularly touching for that person or relevant at that time, being able to go with it with them and just be with them and being able to explore that, which wasn't tasky at all then ... it's as if they were trying to put a label on it and pin it down but [spirituality] is so abstract that putting a label on it took the essence of what it was and its importance actually away from it, menialised it in some way (Elizabeth 3:71b).

Struggling to see beyond a task oriented approach, the co-operative inquiry group questioned whether spiritual care could be provided at all as well as by whom and in what way. Some of these questions were resolved as our understanding of the spiritual itself became clearer but this remains a complex and demanding element of holistic care.

Complicating matters further, spiritual health is not contiguous with physical or mental health, merely intimately connected to them. Chapman restates the

importance of spirituality within total health:

Optimal spiritual health may be considered as the ability to develop our spiritual nature to its fullest potential. This would include our ability to discover and articulate our own basic purpose in life, learn how to experience love, joy, peace and fulfilment and how to help ourselves and others achieve their fullest potential (1986:41).

Illness, even life threatening illness, is not necessarily associated with spiritual *dis-ease*. Spirituality may be a source of immense strength and comfort in the face of disease as can be seen in a number of studies: for example, spirituality (identified as prayer, meditation, religious practices or belief in God) emerged as a powerful coping force in the lives of breast cancer survivors (Fredette 1995:41); Reed linked awareness of spirituality with well-being in a survey of terminally ill, hospitalised adults (1987:341-342); Catterall et al reported their surprise that almost all the patients in their sample found the spiritual side of their life of great benefit (1998:165). Such a potentially positive force deserves recognition by health care professionals while not forgetting that serious illness may still precipitates a spiritual crisis, particularly when sources of purpose and worth are affected. An American descriptive survey which reported generally low levels of spiritual distress among people with lung cancer, noted that greater distress was experienced by young people and by those who felt less physically well (Highfield 1992:7). This resonates with Burnard's suggestion that spiritual distress is more likely where a client's sense of meaning is severely dislocated (1987:380).

Spiritual distress is not then an automatic outcome of illness, even severe and life threatening illness, but it may be more prevalent in certain circumstances. Labun has identified potential causes of spiritual distress, outlined in figure 6:1, which may indicate clients who are at risk (1988:317). Health care professionals who are involved with clients experiencing spiritual distress may find it helpful to delineate more clearly the roots of that pain. However, each client remains a unique individual and, again, health care professionals should be aware of the risks of analysing this human element of care too rigidly. Highfield (1997:237) describes a well mapped cancer journey through diagnosis, treatment, remission, maintenance, recurrence and survival or death. The physical journey through disease, which is often marked by rough and difficult terrain, stimulates in some people a parallel inner journey of discovery about themselves, as described on page 106-7.

Spiritual pain	Discomfort related to human or transcendent relationships, values and beliefs
Spiritual alienation	Loneliness not filled by other human relationships
Spiritual anxiety	Fear of unknown or impending doom for self or loved ones
Spiritual guilt	Concern about lifestyle and the values and beliefs it has expressed
Spiritual anger	Sense of injustice, blaming an undefinable or transcendent source
Spiritual loss	Feeling of having lost hold of aspects of life that give ultimate and transcendent meaning or purpose
Spiritual despair	Loss of hope in ultimate values, beliefs and transcendent experiences which were previously meaningful

Figure 6:1: Sources of Spiritual Distress, adapted from Labun 1988

Indeed, Kearney suggests that any spiritual crisis is provoked by the need to explore the depths of one's being, particularly in relation to death, and may be important in personal growth (1996:60). This inward journey should not be denied or avoided, even though it may be traumatic and difficult for all those involved:

A dying person will often make an inward journey, questioning the meanings of life, death and human existence; long held belief systems will be put to the test (Elsdon 1995:641).

While such an inward process may be virtually invisible, it can aggravate the client's physical and mental condition (Kearney 1990:51). Recognising something of the totality of the journey in which clients are involved is important for health care professionals. Attending to the whole person, including the spiritual dimension, has the potential to facilitate a deeper and more complete healing than physical care in isolation.

Spiritual care seeks to nurture the inner self, and the framework of meanings and values through which it is expressed. It also aims to sustain people through the shadow side of their personality, the alien within, that emerges during periods of great stress and grief (Amenta 1997:4).

Recognising and responding to the needs of individual clients, walking beside them on their journey, is a significant challenge for busy health care professionals. Spiritual care has the potential to play a profound role with clients entangled in such a process, offering support and companionship where it is desired. The intrinsic link between personal and professional in spirituality suggests that more than just professional practice will be affected for health care professionals who accept this challenge.

Religious and psychological care

The links, and the confusion, between spirituality and religion have already been discussed. For some clients, religion and spirituality are closely intertwined:

She always has her religion but it was a very ... spiritual belief. Times when she's very low and she's had her chemo, she said, 'I know that he's carrying me' and she said 'I say to my friend' who's the nun, you know, 'he's carrying me this week, I'm on his back but next week I'll be OK and I'll walk alongside him'. That felt really sort of meaningful and she wasn't frightened of death because there was meaning in life and there was more on the other side, her beliefs, her religion sort of, and I know that you can't always link the two, but it felt right. She felt very together because of her religious beliefs and I felt quite happy and comfy with her because she said she'd got that although she was possibly terminally ill. And I think that's where religion and spirituality do intertwine (Alice 3:139).

For others, previously dormant religious beliefs become more important in illness, particularly life threatening illness (Bradshaw 1997:55). Studies show that religion is important to significant numbers of patients in hospital, suggesting that religious needs, for example for prayer, worship, particular food or privacy, should not be discounted (Ross 1997b:713, Simson 1986:42). This also highlights wider requirements for privacy, quiet and respect. Religious practice retains greater cultural significance for older people and those with a non-european background (Royal College of Nursing Resource Guide 1998:8). There is a clear role for chaplaincy services in recognising and responding effectively to religious needs. However, non-religious clients will be excluded by such an approach, while the broader spiritual needs of all clients may remain unrecognised. Attending to the needs of individuals from differing faith communities also requires sensitivity:

Even if you knew the religion, you're not to know what would be important to them within it. ... I find that, you know, sometimes there's a push, you know, to be a bit of a scholar in terms of religion. The more you do it, the more clogged

you get with all sorts of external opinions and all the sort of history of the patriarchal, sort of, controlling system and so on. I mean, it's a bit like you could do with not knowing too much about anything really. So you don't get too clogged with it all. Sometimes I find that with someone who really is a scholar in terms of religion, they're so into the, again, the detail ... you know, the sort of scientific stuff and knowing and being right, that, you know, you've lost it again. You know too much. ... In fact it might be a nice thing for [clients] to share with us, that we don't know and they're sharing (Elizabeth 13:170).

Clarifying the relationship between religion and spirituality was a continuing element of the co-operative inquiry group's discussions and became important in continuing professional development groups. Greater clarity supported better assessment and provision, enabling the whole health care team to provide both spiritual and religious care effectively.

The co-operative inquiry group was also clear that psychological and spiritual care are different, although they acknowledged that the two are related and can be difficult to differentiate. Other writers also acknowledge this difficulty, for example, Harrison and Burnard 1993:68, Highfield and Casson 1983:190-191. Counselling training may help health care professionals recognise and respond to spiritual concerns. For example, breast care nurses who had completed counselling training were more willing to discuss spirituality and spiritual beliefs (Tait 1994:10). Two members of the co-operative inquiry group who were trained in counselling were clear that while similar tools, such as listening, may be used in counselling and spiritual care:

[Counselling's] categorically not the same thing as actually connecting with somebody's emotional experience of [exploring meaning]. To me, being able to have that spiritual awareness may mean you're more likely to be able to be more vulnerable or more open to connecting with another person (Jane 14:78).

As with other activities, discussed on page 121, counselling supports the provision of spiritual care rather than encompassing the whole of it.

A recent report, based on research by the National Schizophrenia Fellowship, has proposed a positive role for faith communities in promoting mental health, particularly through social support and links with a wider community (Health Education Authority 1999:10-11). The report suggests that spiritual and religious beliefs may be overlooked by mental health services despite their importance to some service users, although this is changing (Health Education Authority 1999:9, Reed-

Payne et al 1992:172, Thorne 1990:225). Indeed, Suyemoto and Macdonald show how religious practice may have a role in maintaining mental health (1996). If the holistic approach is adopted, then religious, or spiritual, psychological and physical well being are all intertwined. A spiritual or a psychological crisis may prompt an exploration of spirituality in a similar way to a physical crisis, as members of the inquiry group highlighted:

I feel that [spirituality] doesn't always have to be a positive thing really. You could still get a feeling of that great emptiness, couldn't you? Which could be very deep and profound and touch your spiritual self and I've not had that but I would say the spiritual experiences that I've had have touched on a deep longing and a feeling of emptiness (Elizabeth 6:152).

I think it's, perhaps for me, too simplistic to say that when a clinical depression is present that spirituality isn't. Because a lot of, well, it's exactly as Elizabeth said really, a lot of the crises, a lot of the work, a lot of the angst, is about there being no point to life, and to me that, that is a very spiritual time (Jane 6:153).

As described above, suffering and struggle may be important elements of a person's spiritual journey. Simply relieving pain and distress, as would be natural with physical pain, is not necessarily the answer in spiritual care. This point was made by Carole, a member of the co-operative inquiry group, in the quotation on page 113. Rather, as Applebaum suggests:

[The spiritual dimension] encompasses the psychic drive for integration, wholeness, balance, creative purpose in life, joy, episodes or a general state of expanded consciousness, a deep ethical sense and genuine conscience and a capacity for unity and integration between oneself and the many relationships and commitments in one's life (1985:152).

This drive for balance within an ever changing world necessitates the development of a sense of meaning which can cope with difficulty and pain as well as joy and ease. Georgeson and Dungan also suggest that the overall movement in spiritual care is towards integration, or wholeness (1996:377). This link between spirituality and wholeness highlights again the way in which spiritual growth may occur independently of physical health. Practical activities, counselling, reflection all offer opportunities for this process to continue despite failing health. Creative activities, including music, art and writing, provide opportunities to express emotional and spiritual needs without words, as well as to discover new abilities and enjoyment (Bailey 1997). Again, these activities are supportive rather than encompassing the whole of spiritual care.

'Meaning' was considered by the inquiry group during discussions of both spirituality and spiritual care, as outlined particularly on page 112-114. Bowers discusses the importance of belonging, transcendence, creativity, meaning and purpose as part of the rehabilitation process (1987:91). Simsen also stresses the importance of meaning in illness and hospitalisation, suggesting that spiritual well being results from satisfactory meaning being both found and integrated (1985:361). This need to identify and integrate meaning, which may change during illness, provides an interesting link with the co-operative inquiry group's emphasis on the importance of exploring or searching in spirituality, both personally and with clients. Meaning may encompass a deep sense of an overarching or ultimate purpose in life but the inquiry group were more aware of the everyday sense of meaning or purpose found in relationships or tasks. Frankl, stressing a universal need for meaning as described on page 97, suggests many different sources of meaning, including pleasure, creativity, relationships, even suffering (1964:67,79). The client's ideas about meaning and purpose may be an important element of spiritual care which should be explored sensitively, with the client's agenda remaining paramount. While health care professionals should not attempt to create meaning for their clients, they may be able to support them in exploring the significance of past and current experiences. Connection, with others, the past, the environment, was another important theme in the inquiry group's discussion about spirituality, as discussed on page 114, particularly linked with the need for integration. This sense of connection, or belonging, may be contribute to the overall sense of meaning.

Palliative care

Cecily Saunders suggested, as long ago as 1965, that spiritual care should not be considered an optional extra in palliative care (quoted in Cornette 1997:6). Smith points to a survey of hospice directors which indicates strong agreement about the need for attention to 'spiritual-religious matters', a need which is immensely heightened as death becomes imminent (Smith 1993:71). He suggests that in this context:

Religious and spiritual issues are designed for the explorations of the living who know that they are also among the dying (Smith 1993:72).

Such an exploration may occur at any time but facing life threatening illness, as patient, carer or health care professional, adds urgency. Reed's survey of terminally ill

hospitalised adults certainly suggested an increased spiritual perspective as part of the dying process (Reed 1987:341) and this was supported by the co-operative inquiry group's own experience. Spirituality is a vital part of the quest '*to find out what it means to be a person and what it means to have been born*' (Hall 1997:84). This search becomes urgent for many clients (patients and carers) facing death but is also important for the individuals supporting them. Kearney writes of his unease that palliative care practitioners should become merely experts in symptom control as they endeavour to '*solve the problem of suffering and death*' (1992:41). Palliative care workers must face honestly the reality of death, and the unanswerable questions that entails, if they are to support their clients effectively.

With the strong emphasis on spirituality promoted by Cecily Saunders, hospice care is rightly understood to be at the forefront of spiritual care. However, there has not always been a clear distinction between spiritual and religious care, as Carole points out:

I think that the hospice movement would say that from the 60s that they were at the forefront in providing spiritual care but I think if we were to look back on that now and analyse it, it would be spiritual/religious. Whereas I think perhaps now, with palliative care principles moving beyond the hospice, then that has brought in this other angle, that maybe it isn't all about religion (6:95).

A general perplexity about spirituality may leave people poorly equipped when questions of meaning, hope or identity are raised, perhaps for the first time, by contact with a life threatening disease. Modern attitudes towards death, which is often hidden or ignored, make it probable that clients will be in very unfamiliar territory. Previous exploration of spirituality may help when faced by a personal or professional crisis:

We spend so little time even throwing ideas out, you know, 'that truth's not for me and that truth's not for me'. Yes, we can say 'I'm a moral person' and 'I love my neighbour and I get on with my life' but we don't really spend a lot of time, as people, talking about [spirituality]. Not necessarily to seek anything or to come up with any answers but at least spend time exploring it. I think so many people go through their life and never do and I think that's a shame. Not that I have any agenda, that I want them to get to a certain place but, you know, I want that. They have nothing now and they haven't explored anything and there's an empty hole there (Carole 5:104-108).

Working in palliative care makes spirituality a more prominent concern, a finding

confirmed by the LUCAS survey of palliative care workers (Cornette 1997:12-13) as well as the co-operative inquiry group's experience. Health care professionals who have explored such concerns themselves are better equipped to support clients; that is not to assume they have answers but rather that they are less disturbed by the questions!

Barriers to spiritual care

Chapter two summarises some of the ways in which spirituality has been sidelined in modern culture. Even in palliative care, open and exploratory discussions about spirituality are rare for staff and clients. Participants in the co-operative inquiry, recognising their own struggle to articulate ideas about spirituality, did not expect clients to find this an easy process. Opportunities to explore emerging ideas in a space which was relaxed and non confrontational, were understood to be an important aspect of spiritual care. Research has shown that clients fail to disclose important concerns and feelings because of the behaviour of health care professionals (Maguire 1995, Maguire et al 1996a and b). Leading questions, over-emphasis on clarifying physical concerns, moving into advice and reassurance, all inhibited client disclosure (Maguire 1995:60). Wilkinson suggests that while there is a poor level of facilitative communication among nurses working with people with cancer overall, the level of communication is dependent primarily on the ward environment, the nurse's religious beliefs and the attitude to death (1991:677). Ross's study of nurses also suggests that while most are able to identify spiritual needs, many feel unable to respond for a variety of personal and professional reasons, as outlined in figure 6:2 (1997a:40-41). Again, Wilkinson found that communication is more likely to be blocked where the staff involved have high levels of anxiety regarding their own death (1991:686).

The difficulty of responding to spiritual concerns demonstrates how personal and professional exploration of spirituality overlap. 'Taking into account' spiritual or religious concerns within healthcare is different to making them a specific object of intervention (Sloan et al 1999). While a personal exploration was welcomed by the group, it was challenging in a way that not all staff or clients would find acceptable. The failure to incorporate spirituality into health care practice discussed already must bear some responsibility for the limitations of spiritual care. Oldnall, reviewing the nursing theories which underpin current practice (1996:142), suggests two main factors which prevent a response to spiritual need, that is a perception that

spiritual care is the realm of the hospital chaplain and a failure of nurse education to equip people for this task, a suggestion supported by Bradshaw (1994: x-xi).

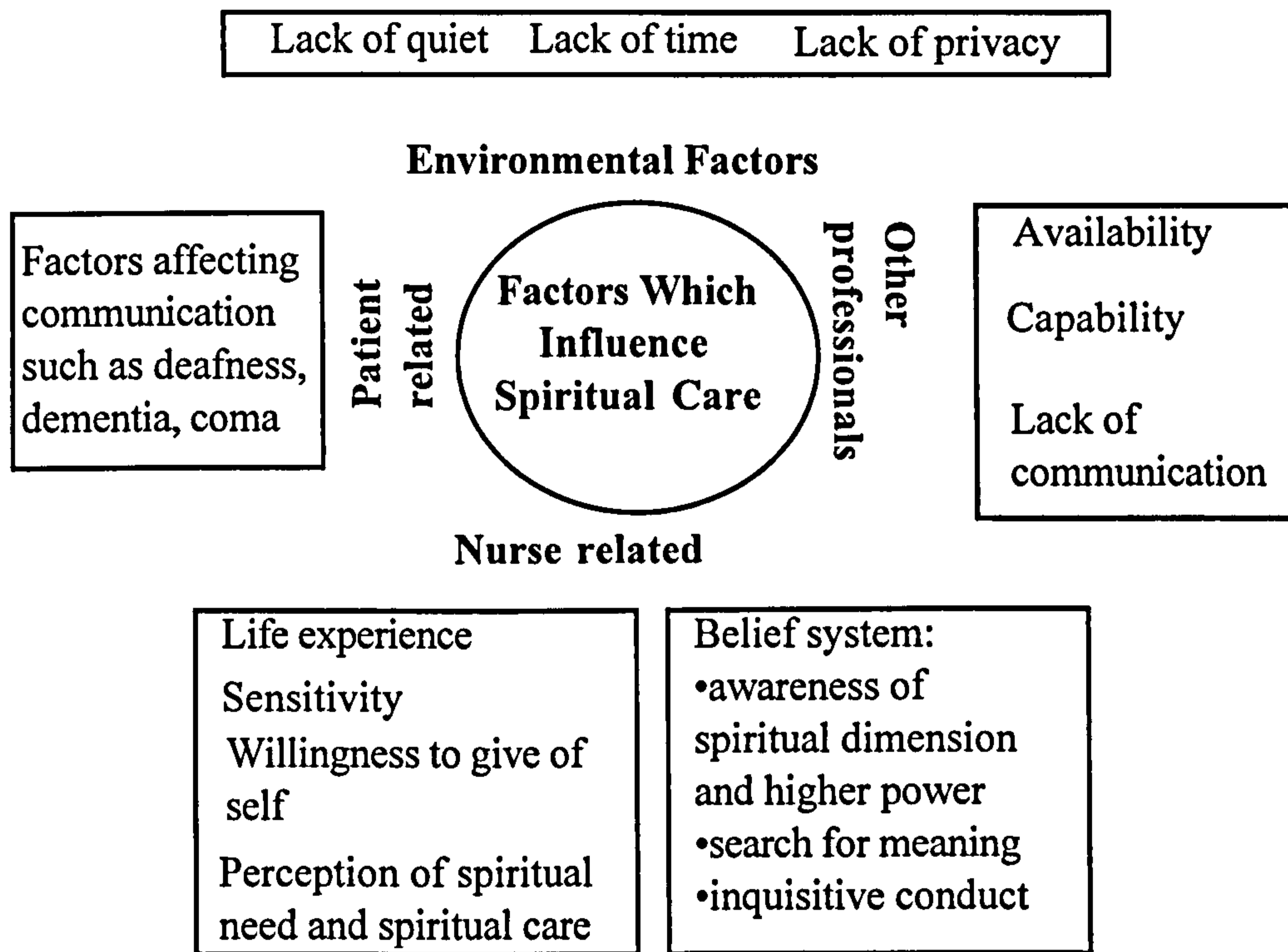


Figure 6:2: Factors Affecting Spiritual Care, adapted from Ross 1997a:40

Such findings support the co-operative inquiry group's understanding that spiritual care needs to be recognised as the task of the whole multidisciplinary team but also of the need for effective continuing professional education to support this process.

The therapeutic relationship

Many themes concerned with spirituality in the nursing literature are the products of a relationship and, therefore, can be identified with connection. Goldberg writing about spirituality as connection (1998:836), highlights presence, empathy, compassion, giving hope, touch and healing, as providing spiritual care. With hindsight, I felt the co-operative inquiry group used the term connection in two different ways, not always distinguishing between them. Connection in spiritual care was seen as both a particular feeling of closeness with specific clients and also a more general concept that formed part of our understanding of the nature of spirituality, outlined on page 114. The group recognised that spiritual care extended beyond the few individuals where we felt a specific sense of connection to the wider community of our clients but these few more

focused experiences of connection were often highly significant.

McMahon, writing about therapeutic nursing, stresses the importance of building positive relationships with clients based on partnership, reciprocity and intimacy (1991:5). Such therapeutic relationships are a vital part of total health care (Smucker 1996:97) rather than an irrelevant extra. Client centred counselling, based on the model developed by Rogers, similarly aims to develop a therapeutic relationship, founded on three core conditions of genuineness, acceptance and empathy (Mearns and Thorne 1999:16, 22). The co-operative inquiry group suggested that therapeutic relationships between health care professional and client provide an appropriate context for spiritual care, emphasising both the centrality of the client and the supportive role of the health care professional: *'What patients need from us is not psychology or theology but caring and presence while they seek answers'* (Hall 1997:93, my emphasis). A member of the co-operative inquiry group described it as:

I think, really, the person in the helper relationship is not the guide but is a person who is the accompanier, if that other person wants them to be the accompanier, or is the reflector or the mirror. But the person who is the guide is the person who is wanting to explore a particular experience at a particular time. So, maybe they go away and they come back the next week and there's been something particularly meaningful or a question that's particularly been percolating or whatever for them. The guide is that person, they will ... maybe want to explore that in a verbal sense and the person with them, if they feel comfortable and valued and able to do that, will be the mirror and reflector and not the guide. So, I see it very much the other way. I would never go in, in terms of, as I say, tasky or worky or even guiding, but it would be very much the essence of the relationship between two people. And it would be the relationship which would allow that person to talk about it or reflect on it or to explore a particular experience for themselves (Elizabeth 3:122).

The journey re-emerges as a theme in spiritual care, offering an image of the health care professional journeying alongside their clients for a time (Stoter 1995a:12, Maher and Hunt 1993:26). Again discussions in the co-operative inquiry group reflected this:

It was making me think that there's a sense that this picture of the journey again is the thing, in a way, that we have in common, that we are all, not just us, but all people perhaps are potentially on a journey. Whether they are electing to start travelling or not, whether they've stopped or they're keeping going. And there's something about exploring how we journey alongside people (Margaret 8:125).

It's that sense again, going back to our picture, of being fellow travellers rather than one person having arrived and trying to drag the other person to where they've got to (Margaret 15:250).

Rather than take clients to a particular goal Jean Vanier, founder of the L'Arche communities, suggests that the task is to learn their language:

*Learning a language
is learning what people are really saying.
The non verbal as well as the verbal language...
You must go deeper ...
and discover what it means
to listen deeply to another...
in order to understand people both in their pain and in their grief, to understand
what they are really asking so that you can hold their wound,
their pain and all that flows from it...
You must go deeper to and discover what it really means to see another-
To see the light shining in the darkness -
To give another hope and trust.
(Jean Vanier, quoted in Stoter 1995:27).*

As discussed above, the core conditions of the therapeutic relationship provide an environment where spiritual concerns can be probed in safety by clients. Georgeson and Dungan note the importance of a therapeutic relationship in fostering personal integration or wholeness (1996:377). As palliative care becomes a recognised medical speciality, practitioners must hold onto the centrality of this relationship to avoid slipping into an essentially technical approach to care. Providing appropriate medication and ensuring comfort are important but, like other tasks, they are inadequate alone (Kearney 1992:41). The underlying core conditions of the therapeutic relationship affect all aspects of our approach to clients. Providing spiritual care is not just about recognising and responding to spiritual questions but also about respect for the human spirit and its potential. Spiritual care is intrinsically human to human care, based on a partnership which recognises the essential humanity shared by clients and health care professionals alike. Such a partnership affects all aspects of their care, ensuring that clients are no longer *just* patients as Carole reflects:

I think a lot of cancer care, and any other kind of care, is human to humanness or touching spirits or however we might describe it and I think the fact that you bring a human dimension to any relationship you have with somebody with cancer is really hugely significant ... and the fact that you recognise them as a human being (Carole 1:109-111).

This human dimension is the essence of spiritual care and should infuse all elements of health care activity.

The co-operative inquiry group members recognised the common ground they shared with clients: we too struggled to find meaning in life; to explore unanswerable metaphysical questions; to connect with other people and to reach out to transcendent values. This is not to discount our professional skills, simply to recognise their limitations; we have no cure to offer for spiritual distress, we can only offer ourselves and we may not always be able to offer that. In this way, spiritual care requires a level of openness and vulnerability, a recognition of our own needs as well as our clients', challenging professional expertise and bringing a certain humility:

It's interesting because, it's that type of person that's really struggling, that really strips away all of my defences and I have no mechanical behaviour with that type of person ... I mean, it hasn't happened with that sort of person many times but it feels like there's no time or room for pretence, any sort of pretence (Jane 3:143-149).

That taps into our own vulnerability, doesn't it? I think, when those people are so vulnerable and feeling so insecure, it almost taps into where you're at as well (Alice 3:150).

A 'human to human' relationship challenges care givers as well as clients, such that the co-operative inquiry group questioned the actual reality, even the honesty, of aiming for such an equal relationship:

But do we change out of role? From, you know, from someone relating to us as the expert to saying 'no, now we're meeting as equals'. I thought it would be easier for someone with more power in the health professional role to say 'now, come on, I'm just Ruth, we're equals.' I've always thought that's a bit of a privilege to be able to say 'now, you know, now forget all the hierarchy, we're just equals.' It's much harder for someone who's come for help to be able to say we're equals (Ruth 1:113).

Participants in the co-operative inquiry group, and subsequent educational groups, recognised instances where they had received more in terms of spirituality from clients than they had been able to give, the physically diseased offering their spiritual strength to support the physically well. This reversal may save health care professionals from the tyranny of a heroic medical model which must '*make it all better*' (Kearney 1996:21, 44-45) but it also reminds us that the balance of power in professional

relationships may become distorted with the needs of the client no longer paramount (Norman 2000).

The boundaries within which health care professionals operate help to protect both the health care professional and their clients from the tensions referred to above, as discussed in recent guidelines for nursing staff about practitioner-client relationships (Norman 2000:30, UKCC 1999). Vulnerable clients must be protected from mental, emotional or physical abuse; vulnerable health care professionals must be protected from 'burn out' as the demands upon them become too great. Spiritual care, particularly at the end of life, appears to require that professional boundaries are sometimes transcended yet such a transgression is not without cost and this must also be taken into account. The overwhelming benefits of providing spiritual care effectively form a central theme throughout this thesis. Increased understanding of the nature of spirituality and spiritual care ensures that clients and health care professionals are recognised and treated as unique whole human beings, an enriching process for both. The concerns about meaning and values which lie at the heart of spirituality and spiritual care cannot easily be understood without the recognition that health care professionals and their clients share a common humanity. Yet this understanding needs to remain within professional boundaries, despite the tensions this engenders, in order to avoid harm (Post et al 2000). The cost of providing spiritual care may be physical, including adequate space, time and energy for both provision and training (Stoter 1995b:165-166). Perhaps even more important is the emotional cost, discussed on page 133 and 139, which includes the recognition of personal limitations (McSherry 2000:132, Cornette 1997:10-11). Engagement in this area of care may have a spiritual cost in the challenge it poses to the professionals own values or beliefs, perhaps ultimately enriching but also disturbing (Stoter 1995:27-28). Organisational costs, in addition to the resource implications outlined above, may also be linked to professional roles, such as the effect on health care chaplains as referred to on page 140 (Orchard 2000:146). The metaphor of the balance sheet is used in the above discussion but here there is no 'bottom line'; the costs cannot easily be subtracted from the benefits in order to weigh the value of spiritual care. There are clear benefits to using an holistic approach in healthcare, as discussed extensively in this thesis, and if this is to be a reality it must include the spiritual dimension. That spiritual care has a potential cost is clear but this should encourage attention to the avoidance and reduction of these costs rather than a withdrawal from the holistic approach. This research suggests a practical

way of responding to this tension. The opportunity to explore spirituality, both personal and professional, in a safe but challenging group gave participants greater confidence about the provision of spiritual care, reducing stress and encouraging 'self care'. Such an enhanced personal awareness of spirituality may help health care professionals recognise, and limit or avoid, some of the costs outlined above (McSherry 2000:1-8).

Haggart, while valuing the growing interest in complementary therapies also sees the danger of such therapies, like other aspects of medical care, becoming simply another task, rather than an integral part of a more holistic approach (1996:19). A key theme of the inquiry was that spiritual care was more about 'being than doing'; about who we are rather than what we do:

If I were to... shout out to a nurse or a doctor, you know, 'don't just stand there, do something' but in fact what's crying out in many people is, you know, 'don't do something, just stand there' you know ... and there aren't any rule books for that ... Well, the strategy is to be human isn't it? (Joyce 3:157-161).

The way in which health care professionals carry out necessary tasks is important but participants recognised that the time and attention given to clients was equally important. This need to spend time with clients was often difficult in an atmosphere of activity and busyness. The perception that staff are busy is thought to be one reason why clients do not disclose their concerns (Stoter 1995a:46, Maguire 1985). Co-operative inquiry group participants were privileged to some extent by our status as a palliative care centre with fewer physical tasks to perform and where the value of spending time with clients is accepted. We also recognised that it was sometimes easier to 'do something' than to accept our own helplessness in the face of a client's struggle. Health care professionals, used to a helping role, may struggle with the sense of helplessness this engenders. This illustrates again the linking between the personal and professional, 'caring for the spirit implies, primarily, caring for oneself' (Cornette 1997:13). Indeed, Kearney suggests that the only qualification for being with another person in their spiritual distress is:

my commitment to my own inner journey - the fact that I am myself crossing thresholds in my own experience, the fact that I am prepared, however falteringly, to entrust myself to the wisdom of my own deep unknowing. It is the belief that in this area it is not so much about the skills I have but the self who I am (1990:53).

Spiritual questions are raised for staff as well as clients by contact with death; ignoring these questions will affect professional activity rather than being a purely personal matter. Coping with the impending death of a client is one of the difficult points in palliative care. The LUCAS study suggests that staff coping strategies gradually move from emotional withdrawal to an attitude of compassion, the latter enabling professional carers to disclose their own internal questions (Cornette 1997:12). This intertwining of personal and professional is also raised by Keighley:

A carer who realises the importance of addressing 'spiritual needs' and feels afraid or concerned about the challenge, is also opening up a chapter in his/her own lives (1997:47).

Again, such personal questions offer a potentially massive challenge to busy health care professionals who may be reluctant to explore their own spirituality.

The co-operative inquiry group expressed concern that the Cancer Care Centres should not be viewed as an exclusive provider of spiritual care. Participants were keen to acknowledge a range of sources of spiritual care, including friends, family or religious groups. However, experience suggested that clients who raised concerns about spiritual issues appeared to either lack or under use other spiritual resources, as this exchange within the group suggests:

I get a slight feeling of arrogance here because we're all people and we must all get our spiritual care, whatever it's called, from somewhere and I don't know for how many of us it is from a place or organisations other than this one (Jane 1:160).

But do we? I mean, you're making an assumption, when there are unhappy and mixed up people about. ... I suspect that a lot of people [we see] are in some sort of spiritual wilderness (Carole 1:161-3).

Especially in the context of which we work. It may be a point at which they are challenged by these thoughts and these concerns and may have never explored it or had the opportunity to talk about it anyway (Elizabeth 1:164).

I agree that that the diagnosis of cancer obviously can be a catalyst for these things and ... I support the idea that we should be accommodating to that but I don't like the idea of us being exclusively accommodating (Jane 1:165).

We build up relationships that might lead to people being involved in very personal things that are going on for people and they have the time and the

privacy, the opportunity to do those things and it would feel comfortable that a number of people working with me in that situation might want to go on to explore this other aspect of their whole being. We're kind of setting up that situation really in a way, aren't we? We're opening that and kind of like have a responsibility to [be] open (Elizabeth 1:175).

A general lack of clarity about the nature of spirituality, plus the difficulties already described of raising the topic, may mean that other available sources of spiritual support are not used to their full capacity. Palliative care provides a particular setting in which these barriers may be overcome. Co-operative inquiry group participants increasingly saw their role, as health care practitioners working in palliative care, in ensuring that clients are offered opportunities to talk about spiritual issues. Spiritual care may then be provided from a variety of sources, including the Centres, if it is required. Clients may not wish to explore spiritual concerns and must retain their right to reject spiritual care as well as to choose the most appropriate ways of receiving it (Ross 1997a:38). Developing a clear understanding of spiritual care and recognising the importance of the therapeutic relationship are key factors in ensuring that spiritual care is integrated into health care. In the understanding of spirituality developed by the co-operative inquiry group, spiritual care involves creating a safe and hospitable space in which clients can attend to their spirit in the ways that are important to them, recognising that these will be many and varied. In such an environment, clients are enabled to reflect on the spiritual questions their experience raises, both positive and negative. Health care professionals will be better equipped to support them in this process if they have explored their own spirituality. They may also be able to point clients towards other sources of spiritual support.

The multidisciplinary team

If a broad understanding of spirituality is accepted, then spirituality becomes a potential concern for each and every client and, therefore, cannot be dealt with adequately by a single individual. Apart from the practical difficulties of such limited provision, the involvement of a wider team offers greater resources, for example in terms of understanding, approach and experience (Stoter 1995:47). However, this requires that the whole team is able at least to recognise spiritual issues and respond appropriately, accepting that this response may include involving other people. A shared understanding of the core elements of spirituality, as developed by the co-operative inquiry, enables a more integrated approach by the team. This understanding

should, ideally, involve personal as well as professional exploration of the topic, although this may limit those willing to be involved. A team approach to spiritual care offers greater potential for mutual support, with opportunities to share the load that spiritual care can impose. The experience of the co-operative inquiry group suggests that considering spirituality together strengthens bonds between team members, hopefully facilitating future working and support in this area. The inclusion of the wider team in considering spirituality brought a richer mix of understandings and ideas. One member of the inquiry made the point that every member of the team, including chaplains who may be marginalised within health care services, brings their own individual attributes:

I sometimes think the chaplain is perceived to have answers about these things but they actually haven't. Somehow or the other, the fact that there's something common there but it's not a religious commonness but it's a searching for the ways and meaning or whatever. There are also some links in with religion, because sometimes I think there can be a bypass of that but there are some links in with it as well, but it means something different when you're actually working then with patients or working with the group somehow, that you don't feel as though you're the one that's coming from out here and everyone else is getting on as a nurse or occupational therapist or whatever and hasn't got a whole background that they're bringing with it ... And so to me the good thing about this, is actually exploring [spirituality] in its wider sense and finding areas of meeting or questions or even differences. That it's all right to be different and still approach spiritual care. It's not having one answer or one way (Martha 8:62).

Nursing staff often have the most sustained contact with clients and are particularly well placed to recognise spiritual needs (Ross 1997a:39). Nursing has a specific tradition of holistic care yet modern nursing models have been criticised for neglecting spirituality (Oldnall 1995:417, 1996:143). Bradshaw even suggests that Florence Nightingale's 'lamp' tradition, which integrates the art and science of nursing thus providing an ideal framework for spiritual care, has been broken by secular nursing models (Bradshaw 1994:272). These views are supported by the fact that spiritual needs are not always correctly recognised or interpreted by nursing staff as has already been discussed (Highfield 1992:7, Oldnall 1996:142, Ross 1997a:39-40).

Other members of the multidisciplinary team also have a potential role to play in spiritual care. There is some recognition among occupational therapists that spirituality is an important element of patient rehabilitation, although most felt that

their ability to address such needs was limited due to lack of training (Engquist et al 1997:173). It has even been suggested, perhaps rather 'tongue in cheek', that physicians should prescribe religious activities because of their health benefits (Sloan et al 2000). Whether this is appropriate or not, medical staff are not necessarily better equipped than other health care professionals to discuss spiritual concerns with clients. Any health care professional with a focused role may struggle to recognise how they can be involved in spiritual care even before they struggle to provide it:

There were two occasions, that almost caught me by surprise, when people did start talking about things to do with meaning and purpose and connection. Which was interesting because I wasn't looking for them particularly and ... I found that I wasn't quite sure how to move on from them and that, in a way, surprised me because I'm usually fairly comfortable talking about ... spiritual things, being open to people talking about spiritual things and I certainly am open with people doing things like that in other places. I think that's partly because I see my role here as quite focused ... so it was so, 'well, I'm not sure if I should be doing this sort of thing here'. So it was, that was interesting to me to see myself doing that when we are trying to be holistic and yet we also have realistic boundaries on the time we have available to spend with people (Margaret 7:211).

This limited view of individual roles within the team is beginning to change, particularly in areas such as palliative care where a multidisciplinary team approach is stronger.

Involvement of the whole multidisciplinary team in spiritual care raises questions about how far the team extends, particularly concerning the role of volunteers and support staff who are often not involved in training and case discussions. Cornette (1997:10) reported high levels of spiritual distress among volunteers involved in pastoral care in palliative care units, with only moderate inclination to discuss these concerns within the multidisciplinary team. This may be related to the limited involvement of volunteers in team meetings. Perhaps it is pertinent to raise again the co-operative inquiry group's conviction that spiritual care is not about having answers but rather about supporting individual clients in their own spiritual journey, wherever that might take them. This understanding still requires support for those providing the spiritual care.

The specialist co-ordinator

The provision of hospital based chaplaincy services has expanded considerably during

the past decade. The Patient's Charter (Department of Health 1991) viewed respect for religious belief as a fundamental right, contiguous with the right to privacy and dignity (Keighley 1997:48). This, plus the National Health Service Guidelines on Spirituality which followed (NHS Management Executive 1992), stimulated a review of the nature and delivery of the expanding chaplaincy services. Health care chaplaincy standards identify a role with both patients and staff, encouraging the integration of chaplaincy services into the wider organisation (Keighley 1997:50). A recent report on hospital chaplaincy indicates that staff training and support is now a significant element of the chaplain's role but highlights the continuing marginalisation of chaplaincy services, for example, by failing to involve them in business planning or normal service monitoring (Orchard 2000b). The co-operative inquiry group agreed that the whole multidisciplinary team should be involved in spiritual care and that appropriate training is needed to enable this to happen. There was, though, considerable debate about the need for a specialist co-ordinator:

I do think there might be, and I'm not decided on this yet, I feel that the jury's out in my head on this one, but I do think there might be a role for people who feel more comfortable, whose function it is to discuss spiritual matters with people and I do think that all health professionals to a certain extent ought to know how to do that but they will know better by having an expert in their team who helps them help other people (Carole 4:143).

For me, there is a role in empowering and enabling and educating and pushing forward, yes, there's a role for that. What I don't feel there's a role for is for us to absolve ourselves of responsibility and that could be, I mean, we [appoint a co-ordinator] and say 'well, we have that particular person you have to go and see for that'. That we all have a role to be developing our relationship ... I think it's great because you do need someone who is comfortable and aware of the issues and moving the service forwards, moving awareness forward, but also that doesn't absolve us of any kind of responsibility for the work that we have to do in ourselves (Elizabeth 4:144).

I have a very strong feeling that, maybe, it would be good to have somebody who supported [us] to feel empowered and confident and educated and was very focused on spirituality but I just, I feel that it's not [just] something that we all should be doing but that it's integral to our relationship with that person. And that they may choose to explore those issues with you and it would be for somebody to help you feel confident to move forward on that, rather than another person that somebody would go to (Elizabeth 4:163).

Although the involvement of the whole team was seen as paramount, the inquiry group

finally recognised the value of having one individual with a co-ordinating role. The group also acknowledged that clients may prefer to talk about spiritual concerns to someone who was not providing everyday physical or emotional care. Furthermore, unless one individual had the specific role of co-ordinating spiritual care, including training, this area could easily be neglected. This co-ordinator would not have to be a chaplain, who might be seen as too partisan, but participants struggled to identify who else should take on this role. When spirituality was understood as the essence of being human, a professional spiritual care giver was almost a contradiction in terms, like being a professional human being! Our difficulty in isolating the precise skills needed by a specialist spiritual care giver illustrates the difficulty of separating spirituality from total care. Spiritual care should be understood as an integral element of all care, skills such as facilitation, listening, caring are essential but not enough on their own. A more co-ordinated approach, including chaplains as part of the multidisciplinary team appeared the best approach at present.

Self care

The personal, human resources of individual team members are an important element in the provision of spiritual care (Stoter 1995:46). A recent survey of social work students shows a significant positive relationship between spirituality and well being or hardiness (Kamya 2000). Similarly, as discussed in chapter two, there may be positive health benefits related to spirituality. Self care can be understood as ensuring that health care professionals respond to their own personal needs, as well as those of their clients, thus enabling them to carry out their professional role effectively:

It's who you are, who is relating to the people and responding and sort of them relating to you. It's that human to humanness that we talked about. So being more conscious of who I am enables me to do that better with other people because I'm more conscious about who I am being with them. It doesn't mean I know perfectly who I am but I'm more aware of who I am and of exploring rather than, maybe it's something about being aware of it being free and exploratory rather than thinking I know (Margaret 13:20).

Again, the LUCAS survey suggests that significant numbers of people working in palliative care experience spiritual distress (Cornette 1997:8-10, 13). Recognising and responding to this distress is part of supporting and enabling practitioners in their role. Some writers have stressed the need for spirituality to be part of health promotion activities, for example, Chapman as quoted on page 40. While ill health precipitates an

interest in spirituality for some clients, attention to the spirit may also be important as a way of maintaining good health among staff. Hall, a nurse working with people living with HIV, suggests that this process is part of *'learning to be ourselves - authentically and with confidence'* (1997:90). bell hooks emphasises a holistic and connected approach to life with solitude, contemplation, inspirational reading and listening to an inner voice being important in maintaining spirituality (1993:185). Among participants in the co-operative inquiry group, there was a recognition that personal exploration of spirituality may have benefits not only for clients but for our own health and sanity. The co-operative inquiry group's experience suggests that a non-personal exploration of spirituality has limited value; rather, personal and professional exploration intertwined and overlapped over the course of the inquiry period. Cornette's study of palliative health care workers also perceived beneficial spiritual growth while working in palliative care, including living more intensely and being able to enjoy the here and now (1997:12). The holistic approach reached beyond the working environment, challenging participants to ensure their own spirituality was not neglected.

Spiritual assessment

World Health Organisation guidelines for palliative care suggest that spiritual care should include assessment and provision of appropriate spiritual help and support, underpinned by attentive listening and respect for individual beliefs (World Health Organisation Expert Committee 1990:51-52). If spirituality is a central part of health care, as has been suggested, then assessment of spiritual needs is vitally important, otherwise spirituality is easily ignored or sidelined. Yet there is evidence that spiritual assessment is undertaken poorly even in palliative care units (Grey 1994:217, Catterall et al 1998:162). Even where spiritual concerns are recognised staff may not respond appropriately, as already discussed on pages 129-130. Spiritual assessment should not be carried out in isolation but integrated into the whole health care approach. A more proactive assessment model, linked to education for health care professionals about the nature of spirituality and spiritual care, would support more effective practice. Education should encompass cognitive, affective and practical domains, aiming to give those involved the knowledge, skills and confidence to recognise a broad range of spiritual needs and to react appropriately during the assessment process. Spirituality is an intangible and elusive concept; it is important that all those involved in spiritual care understand that this is a central element of health care where no easy answers or neat

care plans will suffice.

A shared, multidisciplinary assessment tool, in use at the Centres during the co-operative inquiry group, enabled staff from all disciplines to complete an initial assessment for new clients. Following this generic assessment, a member of the team was appointed 'key worker' for each client, co-ordinating care during their contact with the Centres (Leedham and Platt 1998:60). Any member of the health care team could add to the initial assessment documentation during subsequent contacts. Before the co-operative inquiry began, spirituality was not specifically mentioned at any stage of the assessment, although it could be raised in the section entitled 'other concerns'. Conscious of the difficulty of talking about spirituality, co-operative inquiry group participants felt it was appropriate to be more proactive about spirituality and planned to incorporate it as a specific theme in future generic assessment. However, finding the best way to incorporate spirituality was not an easy task. Engquist et al's study, with responses from 270 occupational therapists in America, showed a similar disparity: 48.5% of respondents agreed that their programmes should incorporate more activities allowing clients to express their spiritual needs yet 84% were unsure or did not wish to devote more attention to spirituality in terms of formal evaluation and treatment (1997:177). The authors suggest that respondents may be interested in more informal assessment and activity but the discrepancy remains, perhaps reflecting again the complexity of providing spiritual care (Engquist et al 1997:177). Stoter offers an assessment framework (see figure 6:3) which adapts well to the pattern of generic

Observations to include and record:

- the person's concept or view of themselves
- their perceptions of what is happening to them
- their hopes, fears and natural support mechanisms
- the strength and nature of support from family and friends
- the nature of relationships within the family
- their own views and beliefs and relation to their situation
- their stated religion and commitment to religious practice
- their cultural background
- their life experience, assessment of natural defence and coping mechanisms
- their openness and receptivity to help
- assessment of their general state of health
- assessment of mental and emotional well being

Figure 6:3: Framework for Assessment of Spiritual Need, from Stoter 1995:43

assessment, building an overall picture of the client and their needs which incorporates spiritual needs with physical and emotional needs (1995:43). Such an approach demonstrates the essential integration of spiritual into total care and is most appropriate within the context of a developing therapeutic relationship. Health care professionals expect to work with clients who have different views and understandings from their own and often need to ask about sensitive areas, such as sexuality or physical care. At the Centres, many of Stoter's topics were already included in the generic assessment and something more specific to spirituality was felt to be required. Despite their recognition of the importance of assessment, co-operative inquiry group participants remained concerned about how to raise the topic of spirituality, particularly when assessment occurs at an early stage in a client's involvement with the Centres:

This is not meant to be a knock on organised religion but I do think that what put a lot of people off was that. Certainly in nursing, you go round ... and people will have put things in notes or left things on patient's beds or one thing or another. And it got a poor press for raising [spirituality] as a 'is there anything you want to explore about the meaning of your life?' to 'oh, goodness, you must have an agenda for wanting to press on me some sort of religion'. And I think that, well, looking back over my career and thinking about the lectures we had in the early days and that, that that's what happened, that ... you became too worried to mention it to patients (Carole 5:135).

Assessment of spiritual needs could be carried out later, when a relationship has been established with a key worker, but this risks spirituality being forgotten. We were seeking a way for health care professionals to give permission to clients who wished to talk about spiritual concerns, as we now understood them. Having explored such issues they may put them aside again but from choice rather than lack of opportunity.

Terminology was a further concern; as has been discussed already, spirituality is not a word easily or commonly understood and the group was concerned to find reliable and clear ways of introducing the issue. Jane described an experience during the inquiry period:

What I don't normally get involved in is discussions about religion, you know, as a separate thing. Which is, you know, probably indicative of something and I saw a girl last week ... for whom religion had previously been a coping strategy and very helpful one for her. And so it was like, I wanted to kind of explore this but I couldn't think of the words. I couldn't, I didn't know how to phrase the

question to ask about it. So, 'you find that your religion, church, spirituality, (you know, what word?) is a comfort, do you?' You know, are they the right words? and I came up with a real sort of grammatical problem because it was very, very unfamiliar to me ... It was a funny experience because I couldn't gauge it, I didn't know whether I was trivialising it or offending her, hitting it right or ... it was like talking in a different language really (Jane 11:29-35).

The inquiry group had worked for over a year to acquire a shared understanding of spirituality; continuing professional development opportunities enabled other staff to share this understanding. This degree of shared understanding needed to underpin our attempts to find a form of spiritual assessment that made sense to clients. The co-operative inquiry group tried a number of spiritual assessment questions, given in appendix seven, during the third reflective period. The broad areas identified for exploration by the co-operative inquiry group were security and hope, meaning and purpose and dignity and identity, originally identified by Giske (1993). An assessment tool devised by Stoll (outlined in figure 6:4) is commonly referred to in the literature.

Concept of God or deity

- ◇ Is religion or God significant to you? If yes, can you describe how?
- ◇ Is prayer helpful to you? What happens when you pray?
- ◇ Does a God or deity function in your personal life? If yes, can you describe how?
- ◇ How would you describe your God or what you worship?

Sources of hope and strength

- ◇ Who is the most important person to you?
- ◇ To whom do you turn when you need help? Are they available?
- ◇ In what ways do they help?
- ◇ What is your source of strength and hope?
- ◇ What helps you the most when you feel afraid or need special help?

Religious practices

- ◇ Do you feel your faith (or religion) is helpful to you? If yes, would you tell me how?
- ◇ Are there any religious practices that are important to you?
- ◇ Has being sick made any difference in your practice of praying or your religious practices?
- ◇ What religious books or symbols are helpful to you?

Relationship between spiritual beliefs and health

- ◇ What has bothered you most about being sick or in what is happening to you?
- ◇ What do you think is going to happen to you?
- ◇ Has being sick made any difference to your feelings about God or the practice of your faith?
- ◇ Is there anything especially frightening or meaningful to you now?

Figure 6:4: Guidelines for Spiritual Assessment, taken from Stoll 1979

Stoll, an American Nurse and Chaplain, identifies four key areas which can be used to elicit a client's spiritual history in a way that goes beyond religious affiliation (Stoll 1997:1574). The group tried Stoll's questions in three areas but remained unhappy with the questions assessing the relationship between spiritual beliefs and health, despite recognising the importance of this area. Stoll herself notes the need for sensitivity, suggesting it is better to explore spiritual concerns once a relationship has been established and to explain why such questions are being asked (Stoll 1979: 1577). Rather than using one specific assessment tool, Carole described how she envisaged using these, and other, questions with our clients:

I could sort of imagine starting off talking with something like 'is it important for you to have a sense of hope?' 'what inner resources do you draw on for hope?' So using one or two [questions] out of these and then I think to say, I could go as far as to say 'do you pray?' because, I think, that is a very generic term. Which perhaps would then say to people, you know, 'so, what sort of things do you find helpful about that?' if they say 'yes, they do.' And, I don't mean that then I'd necessarily explore their religious beliefs, but to say that would be [asking] what they are doing that might be facilitated by the health professional being able to talk to them about whether at the moment they were in touch with that side of themselves or not. Because that would be the reason for my question, not to find out whether they wanted to see the vicar, you know, but more to do with ... that might happen from it but it would be, it doesn't want to be automatic. This is the message I'm giving that says 'do you want to talk to me about that inner self that you might be turning to?' ... I think that question would bring that response. And I think then the thing is 'would it help you to talk ... about the fact that you might not be able to draw on that at the moment' or 'that it might help you to draw on that more?' and 'what's sort of blocking you from being able to do that?' And I think that would be really helpful and, given that what we're trying to do is really help people express their concerns, not necessarily be able to put the plaster on [them], I think that that would be the right opening for me. It would get where I wanted to be with somebody (11:67-74).

When spirituality became a theme in the generic assessment, it offered an opportunity to explore sources of meaning or inner resources, using words recognisable to the client, in this way. Remembering the importance of the journey in the inquiry group's discussions, it was interesting to note that Smith (1993:75) suggests using the 'journey' as a way of asking people to talk about their spirituality over their life cycle and that a journal or exploration of stories and images may also be helpful. Other members of the inquiry who were key workers at the Centres, and therefore more involved than I was in assessment, elected to take forward this outcome.

Conclusion

Underlying our discussions about spiritual care was a serious question about whether it was possible to provide such care. Spirituality was understood as quintessentially individual, so that spiritual growth could not be provided in the same way as food or medication. The possibility that we might be able to support such a growth process flickered tantalisingly in front of us. Yet we remained very aware of the dangers of 'doing' spirituality to people and of the potential 'cost' of such work. There is some evidence that staff who are more aware of their own spirituality are better able to recognise and respond to spiritual concerns in others (Waugh 1992:227, Ross (previously Waugh) 1997:41, Wilkinson 1991:687). We hoped that by being more spiritually aware ourselves, we would at least avoid accidentally crushing and, at best, support others as they explored spirituality for themselves. Simply accepting the spiritual dimension as normal is a part of this, allowing clients and carers the space to nurture spirituality themselves, if they wish to do so. Cornette's survey of palliative care workers identified the need to be a good listener, to empathise and to be available, as of primary importance in spiritual care (1997:11). The co-operative inquiry group also suggested that a primary factor in the nurture of spirituality was the encouragement and freedom to explore spiritual questions. The recurring image of the human journey, or quest, and the emphasis on the search for meaning and purpose reinforced this view. This need to explore was particularly apparent in the context of the Centres where the inquiry was based. As cancer and palliative care centres, rather than hospices, illness provided an important catalyst for spiritual exploration yet clients were generally still physically well enough to explore these concerns. At the very end of life, spiritual needs may change, particularly where the client is slipping into unconsciousness. Support for spiritual exploration is underpinned always by respect for human life and dignity. A broader understanding of spirituality, as described previously, is linked to a wider provision of spiritual support, enabling individuals to search in different places or ways. An essential part of our role in this process was to provide a safe space (physical, emotional and mental) where clients can be sure that the spiritual dimension will be recognised and valued. Spirituality can then be discussed openly, whether tentatively or more definitely, by those clients who wish to explore this area, knowing that their views will be heard and respected. For the co-operative inquiry group, the experience of developing a space in which to explore spirituality freely, while retaining both the challenge and support of other people, had

been a key element in nurturing spirituality. This suggested the possibility of offering a similar collective experience to groups of colleagues. The support of others, including but not exclusively the health care team, could ensure that individuals were not left isolated but rather retained their sense of connection to a wider community. Educational opportunities which offered a safe space to reflect on spirituality, integrating the personal and professional domains, very much as the original inquiry group had been able to do, offered an important opportunity to extend what had been learned during this inquiry. The educational module, described in the following chapter, was based on the experience of the co-operative inquiry group and its structure largely follows the themes of this and the preceding chapter.

Chapter Seven: A Continuing Professional Education Module: development and provision

Continuing professional development is increasingly important for all health care professionals (Department of Health 1998, Department of Health 2000b). Continuing professional development encompasses a wide range of issues, including the maintenance of professional competency and regular updates in technical or scientific aspects of health care. Education about spirituality, particularly when related to personal as well as professional life, pertains to the art of health care practice, supporting and complementing technical and scientific concerns. While some would dispute the relevance of such a subject in health care education, there appears to be a growing recognition of its place in the health care curriculum. This may be particularly true in continuing professional development where experienced health care professionals recognise that they face complex issues which exceed purely technical skills. Karpiak suggests that such periods of professional struggle may provide particularly powerful stimuli to learning (1992:53). Caring for people who are dying, as discussed earlier, may create such a moment for some health care professionals, who become more open to learn about spirituality. Birth is another occasion where spirituality may come sharply into focus for midwives and their clients (Hall 2000:82). The co-operative inquiry group, discussed in previous chapters, provided a forum in which participants could explore spirituality in ways which integrated their personal and professional concerns (see figure 7:1).

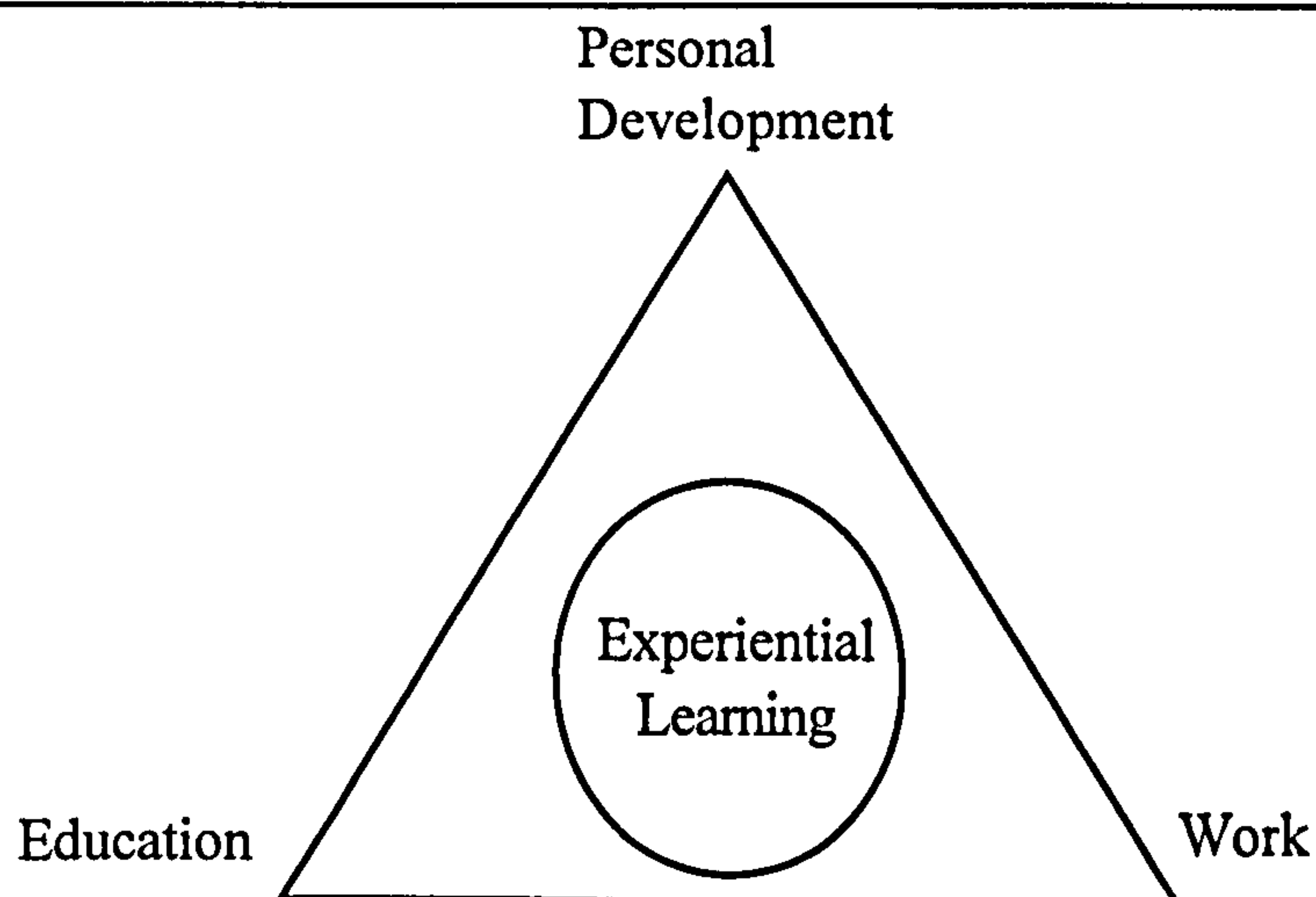


Figure 7:1: Experiential Learning as an Integrated Process, from Kolb 1984:4

The beneficial effect of this experience prompted co-operative inquiry group participants to seek out ways of providing similar opportunities for others. The development of a continuing professional education module on spirituality in the context of palliative care was a significant outcome of the inquiry and will be examined in this chapter.

Spirituality as an element of continuing professional education

Questions about how and why we should teach spirituality parallel concerns about how and why we should provide spiritual care, an issue which was discussed in chapter six. Spirituality stands somewhat apart from current preoccupations within health care. A predominantly scientific methodology, increasing technicality and the sheer workload of modern health care can lead to a neglect of spiritual concerns. There is a suggestion that spirituality lies at the heart of effective holistic care, yet it remains hard to define and lacks a strong research base. In such an atmosphere, it is important that health care practitioners consider all aspects of their practice; the art of health care in parallel with scientific concerns. As a member of the co-operative inquiry group states:

It made it much more clear to me about how we try to align ourselves always with the scientific ... and how really we spend very little time valuing or extolling or looking at how we kind of highlight the art of what we do, which is the sort of skill of 'being' in which spirituality is a big part. ... We've been so busy trying to align ourselves with science that we're asking [doctors] with a scientific positivist sort of approach to wake up to something that we've kind of not woken up to either. ... It's like a vehicle for something that we so unreadily identify, something which is important in our craft really (Elizabeth 15:110 + 116).

This integrated approach should be emphasised in education as well as in clinical practice. The wider context, discussed in chapter two, implies that health care practitioners no longer bring a considered view of spirituality to their work. Indeed, it may be advantageous, even for individuals with such a considered view, to explore spirituality specifically within the context of work in health care.

The philosophy of holistic care is deemed an appropriate area for study within pre- and post registration training for health care professionals. Yet spirituality, a key part of the holistic approach, remains a somewhat neglected area of the

curriculum (Oldnall 1996:141-142, Groer et al 1996:375). Several writers support this need for education about spirituality (for example, Piles 1990:37, Oldnall 1996:143, Groer et al 1996:376-377, Highfield and Casson 1983:191, Narayanasamy 1993:197,200). A number of spiritual education opportunities have been developed, which emphasise personal exploration as well as theoretical concerns (Narayanasamy 1991, Groer et al 1996, Harrison and Burnard 1993:99-125, Shelley and Fish 1988). Such opportunities are primarily aimed at nursing staff, although some courses are open to other disciplines. Certainly, the experience of the multidisciplinary co-operative inquiry group suggests that other health care professions are no more advanced than nurses in this field. Where the holistic approach is strongly promoted, as in palliative care, it could be argued that health care education has a particular duty to enable students to learn about spirituality and spiritual care, yet even here the actual emphasis is often on physical and psychological elements of holistic care. Guidelines about education in palliative care note the importance of spiritual and religious issues but recognise that such issues are often lacking in actual palliative care education, a trend which could increase as attitudes to religion change (National Council for Hospices and Specialist Palliative Care Services 1996:13). Perhaps then it is not surprising that health care professionals struggle to recognise or respond to spiritual needs (Simsen 1985, Ross 1994, Ross 1997a).

There are a number of possible reasons why spirituality and spiritual care, even where they are understood to be an important aspect of health care, do not play a significant role in the curriculum. Spirituality may be considered too personal and individual to be studied in this context. The experience of the co-operative inquiry group suggested that, while spirituality is indeed highly personal and individual, there are benefits to exploring these issues openly with others, recognising, of course, that this must be done sensitively. This process may indeed lead to personal change in individuals but such personal change is not unusual in health care and is certainly not confined to spirituality:

Nurses do not don their roles at work and act as if isolated from the essence of themselves as persons. That which affects and informs us as nurses spills over into our thinking and behaviour in the wider world and vice versa (Wright 1998:185).

Spiritual beliefs, even where tacit and unvoiced, almost inevitably affect professional

practice which involves people; spirituality is both intrapersonal (within) and interpersonal (among) (Groer et al 1996:375). Participation in the co-operative inquiry group suggests that making such beliefs more explicit may have benefits for health care professionals and their clients.

A further concern is the difficulty of articulating ideas about spirituality, discussed in chapters five and six, which is often linked with the personal and individual nature of spirituality. Finding ways of talking about spirituality with others provoked much discussion in the co-operative inquiry group, yet did not prove to be a bar to spiritual exploration. Indeed, the process of trying, sometimes struggling, to articulate ideas in a constructive and supportive setting was profoundly helpful for many of those involved, both personally and in later contact with clients. It may also be argued that the study of spirituality is inappropriate for health care professionals, being rather the province of theology and philosophy. This view may be more common where spirituality is equated with religion, a frequent misunderstanding which in itself is one of the arguments for taking time to explore the nature of spirituality. Exploring spirituality soon demonstrates its relevance to important questions in health care, suggesting that this area is too important to be left exclusively to people with limited practical experience of health care. Health care is, after all, primarily concerned with human beings and how to enable them to live well in their world. Recognising that human beings encompass more than physical and mental processes reinforces an understanding of health and health care which is about far more than just a matter of correct technical care. Questions about who a person is and what is important to them may be neglected in a techno-rational approach yet profoundly affect actual provision and practice. For example, recognition of the therapeutic relationship suggests how services could be provided, respect for the human spirit influences ethical decisions, acceptance of spirituality and religion affects both assessment and provision in health care.

The holistic approach emphasises the integration of body, mind and spirit and it could reasonably be argued that health education should model this ideal by integrating discussion about spiritual questions with other areas of the health care curriculum. However, such an approach needs to build on a basic shared understanding of the nature of spirituality, something rarely available in modern health care. In reality, as the co-operative inquiry group described, there are few opportunities to explore

spirituality in a deep or personal way in health care education:

It's something to do as well with this essence of teaching spiritually to nurses. Setting up courses. And the more we've done this, the more I see that unless we can actually get people to break down into groups and have time to explore then you can't and you don't ... It's only when you own something yourself that you can actually move into something like [spirituality]. I think that's become clearer and clearer. Now exactly how one does it I'm not sure but it's become, you know, much clearer in this sense and I think that this group has shown us all that none of us has got the answers and none of us exactly has a definition (Martha 13:20).

While spirituality may, perhaps should, be discussed in the context of practical issues such as feeding or health promotion, it also warrants, and needs, dedicated attention. Adequate time and an appropriate environment is needed to explore the complex underlying nature of spirituality before it becomes possible to truly consider its place in more practical aspects of health care. This dedicated time and space was a significant attribute of the co-operative inquiry groups that we wished to retain in the subsequent continuing education opportunities. There may be advantages to exploring spirituality within the context of continuing professional development where spiritual issues have been raised by practical experience. Spiritual questions, including their application to practical concerns, do not have easy answers. Although a crisis may prompt such questions, they are probably better explored gradually within an open and supportive environment where different views can be considered. Education about spirituality, as envisaged here, offers an opportunity to explore such issues with others, rather than imposing a particular viewpoint or doctrine. Although not uncritical, such education should be concerned to enable people to search, individually and together, for greater understanding of these issues, something which surely is appropriate in health care education.

Spirituality is qualitatively different from the technical skills taught in other areas of the health care curriculum. As one member of the group described:

Spirituality isn't like anything else because it isn't a technique you can learn, it isn't a theory you can learn, it isn't a psychological approach, it isn't, you know, an analytical approach. It is in fact about sharing something of you, which, although at the best anybody that is helping anybody should be sharing something of themselves, but this is a much more vulnerable, open uncharted area, isn't it? (Joyce 13:20a).

The co-operative inquiry group viewed education about spiritual care not as teaching people how to provide spiritual care per se. Rather its purpose is to open participant's eyes to what spirituality and spiritual care are, offering a space in which to explore their application to health care practice. As implied here, and discussed in more detail in chapter six, human relationships are integral to spiritual care. Such relationships cannot be taught but education may play an important role in developing the skills needed to foster them. Similarly spirituality is a human characteristic which cannot be taught in a purely factual or technical way, rather education may support individuals in exploring their own spirituality. As Joyce continues:

So, therefore, it is essential that the person themselves, even if they feel that they aren't standing anywhere, is at least aware that they are standing nowhere before they can embark on [exploring spirituality] with somebody. Perhaps more than anything else you have to have thought where you, at this time, are standing yourself on this issue (13:20b).

The educational approach taken should reflect this need for personal discovery, emphasising experiential and reflective approaches which support the integration of personal and professional aspects of spirituality.

Hall (1997:90-91) stresses the importance of recognising one's own needs (self care) in education about spirituality. Burnard notes how spiritual awareness begins with self awareness:

There is no single route to increased awareness in [spirituality]. All that seems to be true is that at some point all of us need to clarify our own spiritual position - whether that turns out to involve a belief in God or not. Once we are clearer about our own beliefs, we may be more help to others ... If we are to help our patients we must first help ourselves (1990:39).

As Burnard implies, the process of clarifying personal beliefs is facilitated by many things but, for the co-operative inquiry group, the opportunity to explore these issues with others in parallel with personal reflection played a key role in this process. Greater awareness of their own spiritual needs may help health care professionals avoid unknowingly projecting those needs onto their clients. Yet Cornette's study of palliative care workers indicated that personal needs are not generally communicated well with colleagues (1997:13). Specific opportunities to reflect on personal and professional spirituality, in ways comparable with the co-operative inquiry group,

should be a prerequisite for all those involved in spiritual care. In contrast to this view, Bradshaw suggests that such exploratory education about spirituality is unnecessary, even unhelpful, and that spiritual care is better learned by example and experience (1997:57). Writing from within the Judaeo-Christian tradition, she suggests that the neglect of spirituality in modern nursing, and hence in nurse education, arises from an over reliance on secular nursing models which she contrasts with Nightingale's original religious model (Bradshaw 1994:171,274). A different view of nursing education is required if spirituality (or this particular understanding of spirituality) is to be revived, one which emphasises the maintenance of traditional values and personal formation, as well as knowledge and skills (1997:56). Bradshaw's understanding of spiritual care as treating the person as a whole, embodying values such as 'agape' or charity (compassion) (1997:56), equates well with the co-operative inquiry group's understanding that spiritual care is concerned chiefly with a human relationship, discussed in more detail on pages 131-133. Compassion was also seen as a highly significant aspect of spiritual care in Cornette's study of palliative care staff (1997:12). However, I remain uncomfortable with Bradshaw's apparent assumption that spiritual care must involve a return to traditional religious (specifically Judaeo-Christian) values with the nurse's role as primarily concerned with care and compassion while the chaplain provides religious aspects of spiritual care (1997:56).

The maintenance of this therapeutic relationship by health care professionals is not an easy task nor is it easily taught. Again, Bradshaw's assertion that spiritual care is traditionally 'caught' rather than 'taught' seems too simplistic, precluding the need to learn from any experience (1997:56-7). It is also possible that less desirable aspects of care, such as blocking, avoidance or even coercion, may also be caught! Reflection on experience, individually and with others, offers an invaluable educational tool for health care practitioners wishing to learn more about spiritual care. Reflection is also important as a way of moving from theoretical education about spirituality to integration with practice. Participants need to be able to implement their knowledge about spirituality rather than just to increase it (Cornette 1997:13). Exploring spirituality with others provides an important opportunity for individuals to try out theoretical ideas, applying them to other people's views and experiences, as well as their own. Such an experiential, reflective approach is also important in ensuring that spiritual care does not simply become another health care task for overburdened team members while undermining an essentially integrated approach:

I think the modules would be so good. Because you give people ideas about what they should be doing and how they should be doing it or whatever and that increases their expectations of themselves and patient expectations but the culture still is that they have more and more tasks to carry. It's integrating all these things around the tasks. We still have this ethos that it's a separate thing, that you can't address spirituality while you're doing something ... It has to be like a conscious effort because there are no skills and there's no support to help people just feel confident with it. So it's like when we're breaking bad news, you know, it's such hard work and it's just so frightening and yet with the right support we can be using those techniques all the time, in everything, in all sorts of communications and then we'll feel really confident when it's the difficult questions. But we have no such support systems out there to do that, you know, to just help people gain their confidence and do their 'tasks' as well (Elizabeth 10:220).

The provision of spiritual care does not have to be separated from everyday work and activity, rather it adds a therapeutic dimension to the most mundane task. Specific clearly focused education about spirituality would enable this integrated approach to develop effectively in the current context.

The co-operative inquiry group decided that the development of a continuing professional education opportunity about spirituality should be a key outcome of the inquiry process. As far as we were aware at the time (members of the group were very involved in local palliative care education) no similar opportunity was available in our area. Inquiry group members recognised the limited nature of the input about spirituality currently provided to local palliative care courses by themselves or their colleagues. Based on the experience of the inquiry group, we wanted to develop a new opportunity, specifically focused on spirituality, that was both multidisciplinary and reflective, involving personal exploration as well as theoretical knowledge.

The Manchester Palliative Care Education Forum (MPaCE) Framework

The spirituality module has been provided within a framework of training established by Manchester Palliative Care Education Forum (MPaCE). This new body, formed by ten palliative care providers in Greater Manchester, arose out of a concern to bridge the perceived gap between theory and practice in local palliative care education. Most local training in palliative care is university based, providing a route for practitioners, primarily medical and nursing staff, to acquire formal, post registration qualifications. Such training is lengthy and expensive, limiting access for many staff. Courses draw on

the expertise of local practitioners for occasional input, but course content and organisation remains firmly in the hands of the university and validating bodies. While recognising the value of this formal training, local service managers had expressed concerns about the lack of effect on actual practice (Cawthorne and Lawther 1998). At the same time, in response to demands from colleagues, local practitioners were running occasional non validated courses on clinical aspects of palliative care such as pain management. Without central co-ordination educational provision could become unbalanced, with several providers offering some subjects while other topics were neglected.

The modular course developed by MPaCE aims to offer *'multi professional, skills based courses which will enhance the delivery of palliative care whatever the setting'* (Cawthorne and Lawther 1998). MPaCE offers a flexible approach with access to a range of clinically relevant modules, in a variety of settings, plus a recognised route into a diploma or degree programme. The course remains workplace based and practitioner led but is centrally co-ordinated with support and accreditation by a local university. Different palliative care providers have worked together to produce a comprehensive yet integrated range of continuing professional development opportunities from which many different practitioners can benefit. Modules are provided by experienced clinical practitioners and have a strong emphasis on clinical relevance. Hence, experienced practitioners who lack formal educational skills receive help with developing and evaluating modules; students gain a comprehensive, standardised pathway through which to develop their clinical skills plus credit for their learning; and the validating university gains a novel but comprehensive educational pathway. Ultimately the wider palliative care community gains practitioners with improved clinical competence in addition to recognised qualifications.

The overall MPaCE course revolves around a core module concerned with the therapeutic relationship, which all participants are encouraged to attend (this is essential for those applying for accreditation). Eighteen additional modules, on topics ranging from 'Coping with breathlessness' to 'Communication skills' (see appendix nine) are also available. Each module uses a basic framework of eleven hours teacher contact, eleven hours reflective practice and eleven hours directed study. The MPaCE course is open to any individual, including volunteers, who is active in

palliative care, although some modules have specific entry requirements. Every module includes an assessment of the skills gained by each participant and support has been provided by the validating university to help tutors identify and assess these key skills. The emphasis on clinical expertise, or clinical skills, is matched by an emphasis on multidisciplinary working, with tutors from different organisations and professional groups working together in many modules. The course thus provides both an opportunity for health care professionals to learn together and a model for the multi professional palliative care team. Participants can gain accreditation for their work through a number of routes depending on their requirements (see appendix nine). The course can also be used as evidence of continuing professional development as required by professional bodies.

The spirituality module

A regional survey of health professionals working in palliative care suggested there was considerable multidisciplinary demand for education about spiritual issues (Multiprofessional Education Group 1998). The MPaCE course offered a structure within which such education could be offered, while the experience of the co-operative inquiry group suggested how to approach this subject. Six out of the eight members of the co-operative inquiry group were involved in the development of other MPaCE modules, including myself, and were therefore familiar with its structure and requirements. MPaCE offered support both for planning of the module and for its administration, including advertising and recruitment. Local university based palliative care courses, mainly for nurses, included a single session (1-1.5 hours) on spirituality but the demands of the curriculum left little time for a personal exploration of spirituality. Co-operative inquiry group members, conscious of the benefits accrued by their own more prolonged exploration of this subject, supported the creation of a learning space where spirituality could be explored in a way which integrated personal and professional concerns. The MPaCE structure, particularly its emphasis on practical experience and multidisciplinary working, seemed to offer such an opportunity. The aim of the spirituality module was not to teach people a method of providing spiritual care but rather to increase awareness, by reflection on personal and professional experience, of what spirituality might be and how it might affect health care practice:

I think we intrinsically, we all have an inherent quality within us which we can hone, we can fine tune, we can learn skills to focus in on. Certain people will be able to work with other people or will connect with other people for whatever reason but I don't think you can learn to be real, I think you can unlearn all the things that stop you being real (Elizabeth 3:166).

It was initially more difficult to see the relevance of MPaCE's focus on skills in an exploration of spirituality. Something so individual and hard to define seemed at odds with the concept of developing practical skills. Despite this concern, we recognised that personal skills, such as listening, reflection and self awareness, could benefit the process of spiritual exploration. It was important that those preparing, facilitating and participating in education about spiritual care recognised the balance between being and doing, between personal development and skill development.

During the final active period of the co-operative inquiry group (see figure 4:2), I began to explore the development of a module on spirituality within the MPaCE framework. Other co-operative inquiry group members contributed to this process and to the planning of the module, although none were available to act as co-facilitators. It was agreed by the inquiry group that the development of an MPaCE module on spirituality should be a key outcome of the inquiry and I was appointed to continue this work after the completion of the inquiry. A co-facilitator, who had not been working at the Centres during the co-operative inquiry period but had an interest in spirituality, agreed to become involved in the development of the module. My co-facilitator has commented on this chapter in draft form. Two other co-operative inquiry group participants were involved in planning and facilitating the therapeutic core module (see appendix nine) which had clear links with spirituality. I also completed this core module, as a student, in order to understand the content better and clarify the links between the two. The co-operative inquiry group had already demonstrated the importance of personal exploration occurring in parallel with an exploration of relevant literature. Echoing the aim of the original co-operative inquiry group, it was agreed that the spirituality module should aim to enable participants '*to explore their own spirituality with a view to how that informs their work*'.

The co-operative inquiry group had helped participants become more aware of spirituality, both their own and clients', and more confident about recognising and responding when spiritual concerns were raised. Time to explore these issues with

other people in a safe but challenging environment had been a key factor in this process. We hoped that if other staff were given such opportunities they too would become more able to recognise, and even encourage, exploration of spirituality by their clients. For this reason, the first three sessions of the module focused on an exploration of the nature of spirituality. There were opportunities to brainstorm participants' ideas together with input from tutors summarising key themes, suggested reading and time for plenty of discussion. In the two final sessions, the emphasis of the module shifted from exploration of the underlying concept to the assessment and provision of spiritual care. More details about the module content are given in appendix nine.

The ethos of the module

The essence of the spirituality module, as previously indicated, is to provide an environment in which participants can explore their own spirituality in an integrated way. Reflection is a key element in competent professional practice and provides a common thread throughout all modules of the MPaCE course. Reflection offers an opportunity to develop knowledge that connects with the real issues of professional practice, trying to work out what new understandings mean in the confines of work and organisation, an important overall emphasis of the practice based MPaCE approach. A large body of literature now exists about the use of reflection, particularly in continuing professional development¹. Reflection challenges participants to examine ideas that may be taken for granted, both their own and other people's. Group reflection adds another dimension, the benefits of which could be seen in the co-operative inquiry group where it offered an opportunity to explore each other's varied experience and ideas, vital in a subject as personal and individual as spirituality.

I feel after doing [the co-operative inquiry group] that probably the best training is to have really reflected upon it and really have talked about it and really have spent some time highlighting it as a part of your life. ... So the best way is to explore it and your own awareness and your own journey and your own spirituality and through finding that I think you value what an important part of life it may be to you and to other people. Then you have the confidence to go with it and to hear it when it happens within the words or within the time that you spend with people and often that's a time where you're not actually looking for it, you're just, you know, you'll just become aware that what's happening or the discussion you're doing is a meeting of spirits or a spiritual experience and

¹ Schon (1983, 1989) is generally considered a seminal text in this area but much other literature exists. Miller and Jones' collection of papers delivered at the 1993 SCUTREA conference, which focused on reflection in continuing professional development, is particularly noteworthy, as is Stuart's (1997) paper on the use of reflection in health care.

what someone's reflecting on is the essence of being for them and the essence of comfort for them and they're just talking about their own spirituality (Elizabeth 15:266).

During the co-operative inquiry group, a shared understanding was reached that spirituality exists as a potential within each human being. Participants also recognised, not least because they saw it within themselves, that spirituality can grow and develop given the appropriate support and environment.

Creating a safe space for personal exploration was a vital part of the spirituality module, based on the experience of the co-operative inquiry group. During the course of this research, the module was provided on two separate occasions by the same facilitators with differing participants and practical arrangements (see figure 7:2).

Course One	Course Two
March-April 1999 4.45pm-7pm (after work) Five sessions over six weeks Eight participants 97.5% attendance Hospice, Cancer Care Centres, Community	June 1999 1.15pm-4.30pm (work time) Three sessions over four weeks Nine participants 100% attendance Hospice, Cancer Care Centres

Figure 7:2: Summary of MPaCE Courses

Attendance was high on both courses, only one person (who rang to apologise that a family crisis was going to prevent her attending) missed a session in either module, suggesting this opportunity was highly valued by those attending. Physical space was provided in a comfortable room at one of the Cancer Care Centres. Although within the working environment, this is not a room in everyday use, cultivating a sense of detachment and ensuring that sessions are not overheard or easily disturbed by other people. For practical reasons, the first course was offered at the end of the working day, a time where this Centre is relatively quiet and less prone to interruptions. Participants do need to use their own time to attend and I was concerned this would affect attendance. Fifteen minutes at the beginning of each session was kept free, with drinks and biscuits available, to create a space between work and study, enabling participants to greet each other and to help ensure that each session started in a relaxed

way. The second course was provided in the afternoons (in work time) with a similar break part way through. Course one included five sessions spread over six weeks, course two had three longer sessions spread over four weeks due to time constraints. The evaluation of the two courses does not suggest major differences between these two patterns, although it may be reflected in comments from participants in course two who felt they needed more time to apply the course material. The module content is ideally spread over at least five sessions, enabling participants to relate what they are learning more directly to their actual work as they reflect between sessions. Spreading the module over several weeks (rather than a day course as used in some modules) also allowed time for groups to become established and for trust to develop between group members and with the tutors. The MPaCE module offers more time to explore spirituality than other local palliative care training, but still only eleven hours group contact (over a maximum of six weeks) compared with approximately sixteen hours spread over more than a year of exploration in the co-operative inquiry group.

Within the physical parameters of time and place, tutors aspired to establish an environment where participants felt able to explore their own concerns about spirituality, questioning previously taken for granted ideas where appropriate. Much health professional training emphasises cognitive and technical aspects of learning, although this is changing with increasing interest in reflective practice. Despite this growing emphasis, in the busy atmosphere of health care provision it is not always easy to discuss personal experience, particularly where that involves painful emotions. Spirituality is a profoundly personal concept which is difficult to articulate and not widely discussed in society at large. With this in mind, the first session of the module includes time for group members to set their own ground rules and for discussions about confidentiality and mutual respect, key elements of the ground rules developed in all three groups (see figure 7:3 below). Tutors facilitated this section by writing down participants' ideas but the ground rules were chosen by the group. (Apart from acceptance of 'creative spelling' which was requested as a ground rule by the tutors and reflects our difficulty in spelling correctly when writing on flip charts!) The ground rules chosen reflect a general desire to combine the freedom to explore spirituality and learn together with a lack of pressure. It is interesting to note some differences between the ground rules developed by the co-operative inquiry (research) group which placed a much greater emphasis on the need for everyone to participate.

<p>Co-operative Inquiry Group</p> <ul style="list-style-type: none"> •Confidentiality within the group •Respect •Each participant has a responsibility to contribute or share their experiences in the group •Hear and be heard •Comfortable to question •Don't carry over disagreements into work 	<p>MPaCE Course One</p> <ul style="list-style-type: none"> •Confidentiality •Mutual respect •No pressure to share anything •Be open to gain knowledge from one another's experience •Creative thinking •Creative spelling •Only one person talks at a time •Losing your train of thought is acceptable •Challenge statements not people •Own what we say (I think...) 	<p>MPaCE Course Two</p> <ul style="list-style-type: none"> •Confidentiality •Mutual respect •Non judgmental •Creative spelling •Support + sensitivity •Respect other people's survival strategies •Challenge statements not people •Keep to times, finish on time
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Figure 7:3: Ground Rules

Participants chose to join the co-operative inquiry group with the recognised intention of exploring spirituality in some depth and in a research context, and this is clear from the ground rules they chose. This clear focus and challenging approach equates well with the ideal of co-operative inquiry as outlined in chapters three and four. Ground rules in the MPaCE modules appear more concerned to create an environment where participants are able to contribute without feeling pressurised to do so, as is appropriate in an adult education context. Ground rules for course two, occurring in work time, note the importance of finishing on time, unlike course one, which occurred in peoples' own time. This may also reflect the difficulty of having fewer but longer sessions. The ground rules for all the groups recognise the potentially explosive nature of the topic, emphasising the need for respect, confidentiality, listening and sensitivity.

Content of the module

The overall emphasis during both the co-operative inquiry group and the MPaCE module was that spiritual care is an integral part of total health care. Conversely, during the module, as during the initial inquiry, there was a recognised need to focus specifically on spirituality, in a sense to put it under the spotlight, in order to

understand it more clearly. Education about spiritual care was seen to occur on two levels. At one level there was the introduction of the concept of spirituality and spiritual care developed by the co-operative inquiry group to other staff, increasing their awareness and confidence when working with clients in this area. The outcomes and core content of the module emphasise this level of involvement (see figures 7:4 and 7:5). A basic understanding of spirituality was important for all staff but in a sense this

Aim: to enable students to explore their own spirituality with a view to understanding how that informs their work.

Outcomes: students will.....

- ◇ assess the place of spirituality in holistic care
- ◇ analyse the links and differences between spirituality and religion
- ◇ evaluate key themes within current understandings of spirituality
- ◇ discuss the links between spirituality and health
- ◇ recognise spiritual issues that people may wish to explore and be able to respond appropriately
- ◇ explore how spirituality may be nurtured within palliative care

Figure 7:4: Aim and Objectives of the MPaCE Module

was just the beginning. Beyond this basic level of learning about spirituality was a further, more personal, exploration which is hinted at in the overall aim of the module (see figure 7:4). The integration of these two levels, the personal and professional, had been a characteristic part of the co-operative inquiry group and became a distinctive element of the MPaCE module.

One of the important lessons of the co-operative inquiry group had been the benefits of developing this more personal understanding of spirituality within the context of a shared exploratory process:

Being able to explore spirituality as human beings with other human beings or with our patients. We can all see the benefits we have [had] of understanding and try, you know, looking at where people are coming from. That deepens our understanding, maybe, of their needs or their concerns or what's important to them.... In the wider terms it reflects on me, that if we have that, [if] we can develop that within a relationship with people who want it, how also it would deepen our ability to reflect their needs and offer support for those needs. And also, you know, a number of times it has been very good to share our own

personal values and thoughts on things and, you know, people have been listening and non judgmental and reflective. Again in the wider sense, for me, if we somehow can look at a way we can move that out into what we do, the good that can come out of what we've learnt ourselves in the group maybe can actually start to percolate though to our work with other members of the team and also our work with people that we support (Elizabeth 8:100-103).

While personal exploration was offered as an explicit element of the module, individual participants were free to choose the extent of this essentially voluntary process. It may be possible, although not necessarily appropriate, to impose some basic learning about the concepts of spirituality but it is difficult to imagine more personal elements of learning being imposed successfully.

Although largely implicit in the overall approach and ethos of the module, recognising personal aspects of spirituality is also a specific element in the course content (see figure 7:5). Tutors attempted to demonstrate the importance of

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- ◇ What is 'spirituality' all about? exploring the concepts involved
 - ◇ Finding a language to talk about spirituality
 - ◇ Recognising our own spirituality, its formation and development
 - ◇ Assessment of spiritual need
 - ◇ Nurturing spirituality as individuals and as an organisation
 - ◇ Whose job is it? The role of the multidisciplinary team in spiritual care

Figure 7:5: Summary of the Module Content

personal involvement by talking about their own experience of spirituality as well as more theoretical concerns. Individual participants chose how much they wished to discuss their personal concerns within the group, but retained the option of exploring them more privately in their reflective diaries. Tutors also recognised publicly that participants were free to put aside concerns that they felt were too painful to explore.

Throughout the module, tutors endeavoured to make clear that, although they had useful knowledge to share, they did not have all the answers. Indeed, the inquiry group's original understanding was that there may not be answers to spiritual questions. The co-operative inquiry group had been concerned that the module time spent considering theoretical understandings of spirituality should not 'squeeze out' the time needed to discuss issues arising directly from personal experience. All the

participants on the module were encouraged to keep a reflective journal which remained their own personal property. The first session of the module included an opportunity for participants to begin writing in their journal, helping to overcome what can be a difficult first step. All subsequent sessions began with a time of open discussion when participants could raise concerns, questions or comments about spirituality, drawing on their reflective journal if they wished to do so. A bulletin board was also provided where participants could share relevant articles, press cuttings or other materials. A number of participants used this facility to display poems or articles from magazines. The final session included an opportunity for group members to reflect together on the process of the module, concluding the group process with an opportunity to reflect in the group on an artefact which spoke to them about their own spirituality (see appendix nine).

An educational opportunity that is encouraging participants to articulate ideas and feelings about spirituality could, perhaps should, include an exploration of creativity, symbol, story, metaphor and ritual. Participants in the MPaCE module were encouraged to explore the use of poetry, pictures and symbols to make spiritual connections in their personal reflection and in group discussions. During the final session of the module there was a specific opportunity for each participant to tell something of their own story, an important part of spiritual exploration. Individuals who take time to explore their own life experiences within the framework of spirituality, are in the process of rediscovering their own spiritual voice, so often lost as described in chapter two. The module aimed to facilitate this process by offering ideas and understandings of spirituality, both theoretical and experiential, which may be new to participants. It also provides a space in which to explore these, as well as previous ideas and understandings, with a particular emphasis on professional as well as personal experience. It would be a mistake to think that one short module can do all of this, for some participants it was a new and important step on the way but remains part of a continuing process. For other participants the module offered an opportunity to relate well developed spiritual understandings to professional experience, their own and other peoples', in a new way. There is always a dilemma, when dealing with issues such as spirituality, about how much of their own beliefs and understandings tutors should offer in the group. Education about spirituality, as about any other contentious issue, cannot realistically be value free. Tutors do not leave their own personal understanding behind when they develop and

facilitate such a module, any more than they would expect participants to do so. Bradshaw notes the danger that a tutor's personal beliefs will influence learning in a covert way (1997:54-55). Part of the tutor's work is to recognise their own 'agenda', as much as possible, so that this can be explored openly alongside that of other participants. This was something we attempted to do throughout the MPaCE module. Both tutors spoke openly about significant influences on their own spiritual development, including the role of the co-operative inquiry group on my ideas about spirituality. Working with a co-facilitator who had not been part of the original co-operative inquiry group was helpful in further challenging the ideas that had been developed there. The two people facilitating the MPaCE module met to reflect before and after each course, in addition to shorter planning meetings throughout each course. This provided recurring opportunities to reflect on each course, including our own response to the group and the ideas raised there as well as more practical issues.

Assessment of skills

As discussed earlier the acquisition and assessment of skills is an important element of all MPaCE modules. A key theme in the inquiry group's discussion had been that providing spiritual care is more to do with *being* than with *doing*, with human relationships rather than with any particular task or skill, as discussed on page 135. This fitted well with the concepts explored in the core module about the therapeutic relationship but was harder to define in terms of specific skills. Anything which appeared to make spiritual care into a task risked distracting from this basic understanding:

I think, if you say, I know how to do this, you're probably least able to know how to do this... because one thing I've learnt about it is that ... it's not a doing thing quite often. It's not an area where you can do something to somebody else really, people 'do' for themselves and we, as I say, we walk alongside or with them and support that process and that ... maybe all we can do (Elizabeth 8:126).

Module tutors were concerned that participants should not feel, on completing the module, that they would then be fully equipped to 'do' spiritual care as though it were simply another task! If spirituality is about who we are rather than what we do, then tutors and module participants, health care professionals and their clients, become fellow travellers, exploring issues of spirituality together, hence the skills required are those which facilitate this process. Participants in the module should gain a sense that

spiritual exploration is part of being human, a life long process in which all are involved. The module aims to demonstrate this underlying sense of equity by valuing each person's contribution and encouraging a sense of mutual learning and support. As with all MPaCE modules, tutors are fellow health care professionals, well able to understand the pressure participants face at work; yet boundaries do exist between tutors and participants, particularly over the marking of assignments. This echoes concerns about the boundaries between health care professional and client discussed in chapter six.

During the planning of the module it became clear that skills such as reflection and assessment can be an invaluable part, although not the whole, of spiritual care. It was agreed, in discussion with other co-operative inquiry group members and with the MPaCE co-ordinators, that the following skills would be assessed as part of the spirituality module. The first skill, focused in the first part of the module, requires participants to reflect on a key journal article in the light of personal and professional experience. The second skill, focused in the second part of the module, requires participants to complete a simple assessment of spirituality with a trusted colleague or client. The ability to reflect on personal experience and to recognise spiritual concerns are certainly important but I remain uncertain whether these are the most important skills required or that they will be adequately assessed by this process. Other attributes, such as growing confidence and awareness, are perhaps more important but less measurable, even if they are recognised as skills. Spirituality seems too subtle to be pinned down and tested in this way, dangerously close to becoming a task after all. Even within these two simple assessments it will be hard to evaluate what participants produce. Inevitably, what is learned rests on participants' subjective understanding. For tutors to say whether this is correct or not is contrary to our ideas of learning together and valuing each person's experience. In the end, we have decided simply to confirm that participants have submitted each piece of work, a position which appears to have been accepted by the validating university. Questions about whether such self assessment is valid remain and should be explored further as the module continues to develop.

Spiritual education and the multidisciplinary team

A key element of the MPaCE approach is to work with the multidisciplinary team. Again this resonated with the co-operative inquiry group's experience which had a

strong multidisciplinary element and clearly saw spirituality as the role of the whole team. The lack of clarity about spirituality makes it difficult for employers to recognise the need for education about spiritual care, particularly where it is not generally recognised as someone's role. Participants need to be able to show their employers that individual MPaCE modules are relevant to their work. Even where it is recognised that the wider multidisciplinary team plays a role in spiritual care, it is by no means certain that this will guarantee funding or support for training. MPaCE modules cost money and funding by employers may be limited despite accreditation, although one (self funding) participant recognised that the module was good value, stating in the final evaluation that the module was:

Excellent value for money, thank you (Course one).

Although ultimately spiritual exploration may benefit institutions as well as individuals, it may not be seen as a priority amidst other pressures on funding. The MPaCE module's emphasis on personal exploration of spirituality may increase this tendency to marginalisation by employers.

The variety of personal and professional experience of participants had been an important element of the co-operative inquiry group. Discussing spirituality with people with very different ideas was challenging but offered the opportunity to explore the subject more broadly. MPaCE modules are open to anyone working in palliative care (including volunteers) and our aim would be to have participants from a variety of backgrounds. The tutors modelled this multidisciplinary approach: one was a nurse, the other (myself) a dietitian; one worked in a hospice and the other in the community and at the Cancer Care Centre. Interestingly neither tutor was a chaplain, the people usually seen as the professional providers of spiritual and religious care, although both have additional experience in pastoral and spiritual care. This raises questions about whether health care professionals without such additional experience would be able to facilitate learning about spirituality and spiritual care. As with the provision of spiritual care, additional skills are required which include reflection on personal spirituality and its role in professional practice. This multidisciplinary approach brings a variety of personal and professional experience to the tutor's input and demonstrates our conviction that spirituality is the concern of the whole multidisciplinary team. Course one included participants from the specialist oncology

and palliative care centres plus individuals working in the community. Most were health professionals (one doctor, three hospice nurses, one nurse/midwife working in a nursing home and one district nurse), although there was also a volunteer and a member of the volunteer support team. Course two was run specifically as an 'in house' option for staff at the Cancer Care Centres and the local Hospice (by then part of the same organisation). All the participants were health care professionals (six nurses, two allied health care professionals and one student allied health care professional). There was a concern among staff that completing the module would create a sense of exclusivity among those who had taken part. Talking about spirituality certainly appeared to generate a sense of closeness as individual participants shared personal thoughts and experiences, described on page 88 in the context of the co-operative inquiry group. Participants with strongly held and very different views about spirituality could create barriers which continued beyond the course if the ground rules were not clear (and maintained). Such differences had been clearly seen in earlier sessions of the co-operative inquiry group but the greater time span ensured that these were largely overcome. Neither of the above problems appeared to arise in the two MPaCE spirituality courses. Perhaps in reality the level of involvement, although significant, was more superficial than in the co-operative inquiry group. Groups such as this, where discussion has included personal as well as professional matters, need time to 'close down'. The final activity of the MPaCE module, facilitated by the tutors, provides the basis for such closure; however the group's interest in further meetings suggest that this may not be enough. The lack of other opportunities to discuss spirituality openly and comfortably aggravates the difficulty of closing the group.

Evaluation of the module

A summary of the formal post course evaluation for both courses is included in appendix nine with other information about the module. Slightly different evaluation forms were used for each version of the module: course one used the general MPaCE evaluation form with an additional taped discussion looking at the key themes of awareness, confidence and practice; course two (an in house course) used a specially devised evaluation form focused again on these key themes.

Evaluation of course one suggested that participants considered overwhelmingly that their clinical needs had been met by the course. Tutors concerns about ensuring adequate time for personal reflection and the assessment of specific

skills were addressed by participants in the evaluation. Participants in course one recognised and valued the sense of space for discussion and reflection available within the course. They also recognised, as did tutors, that the topic warranted further exploration, and that the module could only ever be a partial response to this need. Participants recognised that the two key skills selected for assessment, assessment and personal reflection, were taught within the module. Additional skills taught within the course were considered to be the holistic approach, the breadth of spirituality as a topic, the non judgmental approach, communication skills and multidisciplinary working, all of which were important themes in the development of the module, although not necessarily viewed as skills by the tutors. Overall the restrictions imposed by working within the MPaCE framework does not appear to have prevented significant learning by the group.

As with the co-operative inquiry group, participants described an increase in confidence about spirituality after the course which affected their clinical practice. Greater knowledge and a broader understanding of spirituality were seen as possible reasons for this increase in confidence. The main effect on practice was expected in assessment and increased awareness. The emphasis on personal reflection and the interaction with others were valued by participants on both courses, despite the tutors' concerns about intrusiveness. One participant, noting her enjoyment of the course, explained that it was not what she had expected initially:

I enjoyed the course - it wasn't what I was expecting and at first I was disappointed that it wasn't more structured and directed. However, I have learnt a great deal from the other participants and felt really peaceful after each session (Course two).

Perhaps this comment reflects conventional expectations of both spirituality as a topic and methods of learning. Similarly another participant commented that the integration of personal aspects of spirituality had been the most important part of the course for her:

I've thoroughly enjoyed [the course]. It's confirmed some of my thinking about spirituality and it's helped me to clarify some distinctions but without doubt the biggest help that it's been is about making me go and look at things on a personal level (Course one).

In general, the module appeared to have met its aim of supporting participants in

exploring both their personal and professional experience of spirituality. Indeed this integration of personal and professional was a valuable part of the process. Interestingly, several participants noted an increased awareness of their own spirituality and spiritual needs as an outcome of the course.

Participants did not appear to regard themselves as experts in the task of spiritual care following the module (another concern of those planning it). While valuing the focused input of the module, responses in the evaluation clearly demonstrate that participants understood that this was only part of a continuing process of exploration:

The course encouraged me to think much more deeply about the real concerns of people in a practical way (Course one).

It's about creating opportunities to address spiritual needs and being aware not to close down dialogue through our own fears or lack of understanding (Course two).

Certainly, as with the co-operative inquiry group, there was a recognition that there were no easy answers and that spiritual exploration would continue:

There are no compact definitions or answers, that it is an ongoing process and very different things for each of us, as unique as each individual (Course one).

A chance to focus and reflect, a starting point for growth in this area for me personally and also professionally (Course two).

Other elements participants would have liked to see included in the module were more practical opportunities to access spirituality, dealing with spiritual distress and further time on the application to patients' needs and assessment. Tutors felt that these need to be built on a foundation of understanding about personal and professional spirituality which was the main emphasis of the module. These comments may suggest there is scope for a more advanced module or some other form of follow up.

As facilitator of both modules, and of the original co-operative inquiry group, it has been interesting to reflect on all three opportunities. I have been excited to see, in all these groups, how the topic of spirituality appears to provide an important focus for discussion, at least for those individuals who elected to be involved. However spirituality is understood, an opportunity to discuss such metaphysical concerns

appears to be meeting a need among health care professionals which is not generally met elsewhere. Integrating personal and professional aspects of this topic was a distinguishing and valued feature of all the opportunities involved in this research. There were distinct differences between the groups, particularly between the co-operative inquiry group with its more conscious research focus and longer time span, and the continuing professional education modules. Notably discussion ranged more freely in the co-operative group and there were greater opportunities to relate discussion to practice and indeed, to review theoretical ideas discussed in the group against actual practice during the active periods. Discussion was sometimes more robust in the co-operative inquiry group, particularly as the group became established and individual participants felt more able to contradict each other or challenge ideas that they felt could not be reconciled with their experience or understanding. The MPaCE groups gained from the experiences of the co-operative inquiry group in receiving a framework about spirituality and spiritual care as a starting point but this did not replace the need to reflect on how this could be applied to participants' personal experience. All the groups contained both people who worked together regularly and people with no connections at all. Again I was interested to see how discussion about this personal and very human topic appeared to create a common bond, even among those with opposing view points. I cannot imagine that this would always be true; perhaps it reflects the fact that individuals within these particular groups were genuinely open to develop their own spirituality and willing to listen to each other as part of that process. Facilitating the parallel 'Journey into Faith' group (see figure 1:1) provided an additional, non health, perspective which suggests that concerns about spirituality are not unique to health care. The church setting of this group might suggest this is rather obvious but those participating in the group found the opportunity to explore human spirituality strikingly different from their normal experience. A specifically religious setting may suggest a more narrow focus for exploring spirituality, rather than the broad and open understanding used here. Further work is needed to see if there is interest in this subject in wider settings, particularly non health or church settings. A recent contact, responding to an article about the co-operative inquiry group (White 1998), is exploring spirituality in police education.

Further developments of the module

One of the participants in course one raised the possibility of a follow up session after the course or at least some continuing contact with other participants through a mailing

list. Other writers also stress the importance of continuing supervision and support for people involved in the demanding work of spiritual care (Cornette 1997:13, Stoter 1995:145-151). Organisation of a joint follow up session for participants in both the modules was well received, suggesting a need for continuing support in order to foster the growing local interest in spirituality. The session was attended by five participants (with one apology) plus the two facilitators. Most of these were from course one, perhaps because a greater time had elapsed between this course and the follow up session. This may also reflect the fact that participants in this more mixed group had fewer opportunities to meet outside the course. The follow up session essentially provided an open forum to discuss, both on a personal and professional level, how participants' ideas about spirituality had developed since the course had ended (see plan in appendix nine). Discussion focused particularly on the difficulty of getting recognition, even within palliative care, for this aspect of health care in the current climate of the National Health Service.

Unfortunately after this follow up session I moved out of the area and have not been able to continue my involvement in the course. The other MPaCE facilitator, plus a colleague who attended one of the MPaCE modules plan to provide further courses. However, changes in staffing, plus the long term illness of the MPaCE co-ordinator, have hindered the continuation of the whole MPaCE programme. I have also had a number of requests for information about the module following the publication of an article about it (White 2000a) and am discussing possible use of the module in Derby. As intimated by the request for follow up, the development of the MPaCE module marks only another step in the process of developing spiritual care provision in the Centres.

Conclusion

Providing space for the spirit appears to be an invaluable element of palliative care, for both clients and staff, which is currently often neglected. The skills of adult education, particularly reflective and experiential methodologies, have the potential to create an environment where spirituality can be explored with both discernment and support. As interested individuals reflect together, they venture into their soul or essence, the '*interior castle*' (Theresa of Avilla, quoted in Delfanne 1994:57) that few people explore. One health care professional completing the MPaCE spirituality module

described her sense that the course had helped her rediscover something important:

I'm towards the end of my career now and I've almost forgotten why I went into [health care]. This course has reminded me and brought it all back because so much has happened, the bureaucracy and politics over the years, and things have been changed so much that you could be side tracked and get worn down by all the rubbish that there is. So this has brought it all back - that the heart of medicine is about people and the essence of medicine is its spirituality (Course one).

For me, this comment encapsulates why spirituality raises such important questions for health care today. However valuable the technical developments in modern medicine, these are of limited merit if its essential humanity is forgotten. Whatever words are used to describe human spirituality, it is an essential part of the human relationship which connects health care professionals and their clients. The therapeutic effects of this relationship are incalculable and questions about spirituality lie at its very heart.

CONCLUSION

Chapter Eight: Returning Home

The initial concerns of this research, outlined in chapter one, were focused around education and health care and supported by an interest in human inquiry methodology. The research has focused on how health care professionals can better understand and provide spiritual care within an overall holistic approach. Continuing professional development has played a key role in enabling this to occur. Drawing conclusions from a research project which produces little empirical data is difficult but human inquiry accepts that deepening personal understanding has its own validity. Intuitive leaps and the unravelling of tacit knowledge complement deliberate data collection. The fresh insights of this research, relevant to both health care and education, have emerged from the experience of a co-operative inquiry group, discussed in earlier chapters and from the continuing education outcomes of that group, discussed in chapter seven. Limited triangulation of this data has been obtained using the experiences of a church based spiritual development group. The final chapter provides an opportunity to review the initial concerns in the light of my findings. While these findings cannot be generalised, certain themes have remained paramount and have particular relevance for all health care practitioners, especially those working in palliative care. The structure of this chapter will reprise these themes as developed throughout the thesis.

The context of the research

Interest in the concept of spirituality has moved, over several centuries, from the centre of life to its margins and now appears to be moving to a more ambiguous position. Active consideration of human spirituality is now largely focused round a limited conception as a specifically religious activity. Yet, conversely, the word spirit is being used with increasing frequency in advertising, the arts and elsewhere. Spirit portrays an unworldly feeling, associated with transcendent ideas and feelings that people may struggle to express. A legacy of misunderstanding and neglect around human spirituality, the roots of which are described in chapter two, leaves people today ill equipped to explore the concept of spirituality in a meaningful way. Health care and education have a particular interest in understanding spirituality better although, as this thesis has tried to portray, human spirituality can be understood as a vital consideration within almost any activity that involves people. The arts and leisure industries, for example, could benefit from a clearer and deeper understanding of

spirituality as a motivating human force. Whatever it is called, and it could be something other than spirituality, this innate human potential warrants a reassessment as an element which remains quintessentially human yet transcends the physical and intellectual. This thesis has provided an opportunity to examine this *'slippery word'* (Jenkins 1997) in the particular context of palliative health care. My own initial exploration led to a number of differing opportunities to explore spirituality with other people. Reflecting on the process of my research as I write this thesis offers yet another occasion to learn about a subject which affects me both personally and professionally. Although primarily focused in the fields of education and health, the thesis touches on philosophy, theology and history in order to better understand the context in which the research is situated.

Holistic health care

The benefits of the holistic approach are increasingly recognised in health care. Theoretically, holistic care recognises the spirit as an integral part of the whole person: body, mind and spirit. Earlier chapters have demonstrated the general recognition of the importance of spirituality in holistic and palliative care. Yet the experience of the author, and those involved in this research, is that this understanding is not always reflected in actual practice. Experience, supported by other literature, suggests that the spirit is neglected or isolated for a variety of reasons, some of which are outlined in earlier chapters. This research has chosen to focus, therefore, on the understanding and practice of spiritual care, particularly within a palliative care setting. Even where spirituality is recognised and valued and where health care professionals are attempting to provide holistic care, practical difficulties (such as time and environment) and, even more importantly, a lack of confidence about spirituality, ensure that spiritual care remains absent. Spirituality should ideally be understood as an integral element of holistic care. A specific focus on spirituality and spiritual care has been seen to build confidence about this complex facet of total care. This emphasis on the benefits of a holistic approach is especially important in view of the increasing emphasis on measurable aspects of health care (for example, in audit and clinical governance). Important as these are, they remain inadequate without the underpinning of an appropriate attitude of respect for each person. A key element of this attitude is the recognition that each unique human being encompasses more than a body and mind. Health care practitioners and planners need to remember these deeper questions to

ensure that they are doing the right things in addition to making sure that they are doing things right technically!

Overall agreement about a definition of spirituality appears to be an impossible task. Certainly the groups in this research were unable to adopt a single clear definition. However, time spent exploring the concept of spirituality has been an essential element of preparing for the research and important in all the groups which became part of it. This entailed a slowly developing process of exploration and adoption rather than a quick and easily accepted explanation. Perhaps such a slow process is more necessary in Western society today, where spirituality is often misunderstood and marginalised. Spirituality is about an indefinable quality of human life which may be given new, or more pressing, meaning by the closeness of death. Key issues about understanding spirituality raised in this research concern the use of language and the need for a flexible understanding based on recurring themes rather than the search for a tight definition. Clearer understanding, including the recognition that questions about spirituality continue, brought participants greater confidence in their ability to explore this element of their lives with clients.

Talking about spirituality

Spirituality as an abstract concept is elusive and hard to define; hampered by the recognition that to speak openly about it is difficult. Words, particularly rational words, are recognisably a limited tool with which to articulate such a complex phenomenon. Perhaps this was always true but the Western legacy, described in chapter two, is a compounding factor. Hay's suggestion (1990:58-59) that people are embarrassed to talk about religious and spiritual experiences could be extended to this more general difficulty in talking about spirituality. Concepts of spirituality are no longer clearly understood or shared within a given community while a pervasive pseudo-scientism undermines such abstract concepts. Spirituality is still most commonly associated with religious belief and practice. Outside this setting, little shared vocabulary appears to exist in which to discuss the spiritual, although this may be changing. An individualised approach to life, including spirituality, combined with limited opportunities to talk openly and discerningly about spirituality raises the idea, discussed in chapter two, that Western society has 'lost its voice' when it comes to speaking about spirituality.

Certainly participants in all the different groups involved in this research struggled to articulate their ideas about spirituality, a struggle that was sometimes mirrored in encounters with clients. However, the research also showed that, despite these difficulties, there were benefits in exploring spirituality with other people. As a group we learned to hear more than the words people were using, and gradually we began to share certain key elements of understanding spirituality. We also recognised, and generally accepted, areas where we differed in our understanding. Even struggling to find words together was an important and beneficial part of this process. The resulting growth in confidence about the topic of spirituality was particularly apparent in the two longer running research groups (see figure 1:1), although it was also present in the continuing professional development groups described in chapter seven. Such concerns about finding a language with which to speak comfortably about spirituality are also highly relevant to work with clients whose struggles to express their feelings and ideas about spirituality may be compounded by the health care professionals' difficulty hearing and understanding. Health care professionals who have shared in a similar struggle may be better equipped to understand their concerns and to support such individuals.

Developing a shared understanding

Gradually emerging from the exploration carried out in the first part of the research, was a shared understanding of the concept of spirituality. This shared understanding provided a loose framework within which it was easier to talk about spirituality together. Most immediate was an understanding that spirituality or the human spirit is innate and unique. More than any particular expression of spirituality, including religious expressions, spirituality concerns that part of every human being which seems to reach out to find meaning in life, to make connections with other people and with the environment; all those things which somehow weave through but transcend everyday mundane aspects of human life. The innate nature of spirituality ensures that any understanding of this concept needed to work in a post modern world which no longer shares one world view or faith. If spirituality is innate, then health care professionals need to recognise that it is potentially relevant to all clients, although not necessarily pertinent all the time. This also brought a sense that the human spirit could be expected to grow and develop, and we recognised that the end of life may be a time of particular spiritual growth for some people. All of this implied that spirituality was not just for religious patients, or just the work of the chaplains, but rather an integrated

concern within all our work with clients and the work of the whole multidisciplinary team. Equally, if spirituality is unique then people grow in different ways and express things differently; there is no right way to be spiritual but rather a recognition that spirituality is explored or grows in different ways.

The idea of spirituality as a continuing link between past, present and future became an increasingly important element in the co-operative inquiry group's understanding. Dubbed 'nostalgia', this idea was described by one participant in the following way:

Through all the things you gain and lose throughout this journey, this period, there is a thing that is with you and that is the essence of you and although that might change, you can't really lose that, it stays with you. So, although you lose lots of things and gain lots of things, that's a continuum in fact (Elizabeth 7:207).

In this way, the human spirit was seen as an element of human life which continues from birth to death and perhaps beyond, described on pages 97-98. A particular focus on spirituality, as in this research, provides a space within which to reflect on this unique human essence that continues despite disease and death, the 'me' that is more than any role or material possession. Exactly how the spirit continues is less clear; our group contained a range of ideas from the possibility of eternal life to the recognition that individuals live on in people's memories or in artefacts such as photographs, writing and crafts. Although our interest in the continuing spirit was undoubtedly influenced by our base in palliative care, interestingly, a character in a popular novel by journalist Tony Parsons describes a remarkably similar desire for people to continue:

I think the spirit lives on ... I don't know if it's in heaven or if it's someplace else, some other place that I don't know anything about. But it doesn't just die. It lives on. Even if it's only in the hearts of the people we love (1999:298-299).

Making such connections between our work and our own ideas and understandings is a theme which has resonated throughout the research. Spirituality can be understood as the integrating facet of human beings. Hence a clear element of learning about spirituality is to draw together the inner and outer life, endeavouring to make sense of life experience in the light of changing viewpoints. This integration continues as a clearer understanding of spirituality affects all aspects of life and work. This perpetual search for meaning in life can be understood as the cornerstone of

spiritual existence (Cornette 1997:7). Meaning may be found in both large and small things, including relationships, ideas, beliefs and tasks. Such meaning is not discovered once and for all but rather shifts and changes as the terrain through which we travel offers different perspectives. Again, this understanding reflects the ideas of exploration and discovery which have been so central to this research.

Influencing spiritual care

Setting key elements of the research in two Cancer Care Centres gave it a particular focus. Facing death, as patient, carer or health care worker, may provide a significant catalyst for spiritual development which affects all aspects of a person's life. Although it is invidious to separate personal and professional aspects of spirituality, as will be discussed later, the groups involved in this research were primarily interested in spirituality within the context of their working base in health care. A clearer understanding of spirituality, as it affected our own lives as well as those of our clients, was an invaluable preparation to explore the ways in which the Centres could provide spiritual care.

The growing understanding of the co-operative inquiry group was that spiritual care was not provided by any specific activity offered within health care but rather it was about who we are as health care professionals. Divertional therapies, complementary therapies, religious and psychological support, all have the potential to nurture the human spirit. However, the group were keen to emphasise that these were inadequate on their own, needing to be underpinned by a human relationship which recognised and valued the unique human spirit. This innate element of each person provides the basis for a 'human to human' connection between health care professionals and their clients. Faced with 'spiritual questions' about human identity, meaning and purpose, health care professionals are no longer experts with all the answers but fellow human beings, struggling beside their clients. Indeed, health care professionals may receive from their clients rather than always being the ones who give. Recognition of this essential human vulnerability in the face of life and death, brought a greater sense of equity to our relationship with clients. Of course, health care professionals still have particular skills to offer but we recognised that finally, in these matters, we could only offer ourselves. Indeed, Kearney suggests that the only qualification for being with another person in their spiritual distress is:

My commitment to my own inner journey - the fact that I am myself crossing thresholds in my own experience, the fact that I am prepared, however falteringly, to entrust myself to the wisdom of my own deep unknowing. It is the belief that in this area it is not so much about the skills I have but the self who I am (1990:53).

Practically, this means health care professionals considering the nurture and support of their own spirit as well as that of their clients. Self care for staff needs to be recognised as part of overall spiritual care provision.

Rather than a time consuming extra task, spiritual care can be understood as an essential attitude which pervades all elements of care. Greater recognition of spirituality in health care should ensure an environment in which common human concerns can be explored, whether that be through discussion, creative activity such as music and gardening, or in other ways. Yet the spiritual is so elusive, how could it be quantified or neatly defined? The co-operative inquiry group recognised that without some form of assessment, spiritual care could become inconsistent or even marginalised once more. We tried various spiritual assessment questions, finding some more helpful than others. Raising the subject became a key part of the process of assessment, often difficult for both clients and health care professionals. Again, language was important: finding the right words in which to raise the subject of spirituality in an acceptable and recognisable way was essential. While different members of the team would do this in different ways, feeling comfortable with different phrases and ideas, an overall shared framework was vital. Clients were also likely to understand spirituality in different ways. As in our own early discussions within the co-operative inquiry group, clients appeared to struggle to articulate the concept of spirituality, most commonly relating it to religion. Asking about meaning, connection or other related concepts in our understanding of spirituality provoked a wider discussion of ideas pertaining to spirituality. Staff who felt more confident about spirituality themselves were better able to raise the issue with clients or to recognise when clients themselves were raising it in an oblique way. Training provided for all staff working at the Centres, described in chapter seven, offered an opportunity to develop greater clarity about the overall concept of spirituality to be used at the Centres. This exploratory process facilitated both increased awareness and greater confidence for those staff involved in the provision of spiritual care. Spirituality was included as a separate broad concept within the generic

assessment process already in use at the Centres, aiming to ensure a more proactive approach to spiritual care provision without being intrusive in what is a very personal aspect of people's lives.

Continuing professional development

Continuing professional development has been a central concern throughout this research. The co-operative inquiry group and MPaCE education module both provide an opportunity for continuing professional development concerned with spirituality. These opportunities place a spotlight on spirituality while still retaining a specifically work related context. The development of continuing professional development modules about spirituality become one of the main outcomes of the co-operative inquiry group. Continuing professional development about spirituality offered the potential to enable busy and experienced health care professionals to learn about spirituality, both their own and that of their clients, in ways which would facilitate practical provision of spiritual care in health care settings. Reflective educational methods offered a particularly important way of supporting this process. Reflection on actual experience, both personal and with clients, offered a way of ensuring that theoretical learning was integrated with, even tested against, actual practice.

Personal and professional

Throughout this research, linked to both the methodology and the topic, is a sense that spirituality undermines the boundaries we erect between the personal and the professional. Human beings, health care professionals, clients or other people, all have a human spirit and are on a journey of discovery about that spirit. As discussed earlier, spiritual care is essentially human to human care, the therapeutic relationship that respects and heals all those involved. Therefore, in order to provide spiritual care for others we need both to be aware of and exploring our own spirituality. This awareness need not involve anything remarkable but rather a general recognition of our own need for a sense of meaning, for connections with others and a desire to reach out beyond the everyday and mundane aspects of life. This exploration could occur in many different ways but discovering the concept of spirituality together provided a particular opportunity which did not appear to be easily available elsewhere. While reflective practice is increasingly popular among health care professionals, the opportunity to reflect more broadly in ways which encompass our personal and professional lives remains rare. Health care professionals attempting to support clients

in their journey through cancer may be challenged, as I was, hearing more clearly their own deeper questions about life and death. Lifelong learning cannot simply be a prolonged process of gaining visible skills or qualifications, important as these may be. Such a process must in some way touch on the parallel, but more hidden, need for self discovery. Learning new skills, challenging old ideas, prompts a parallel exploration of who I am (or am becoming), affecting far more than just my professional role. Health care offers a similar opportunity for clients to pursue explicitly their inner journey in parallel with continuing everyday events. When the outward learning focuses on spirituality, as in the co-operative inquiry and continuing professional development groups in my research, both inner and outer journey are recognised and affirmed. Kearney, a palliative care consultant, talks of a journey into the meaning rich depths of ourselves which becomes more important as life approaches its end:

This task requires a lifetime of commitment and effort with many false starts and disappointments along the way. What could possibly motivate us to persist with what can seem such a fruitless task? It is the sense of knowing, silent as the ground we walk on, that this is the way to the heart of life itself. Whatever our life's work may be in a material sense, this journey into depth, this relationship with soul, will be our lifetime's inner task (1996:143).

Methodology

From my initial thought about this topic, I was concerned to find a research methodology which was appropriate to this quintessentially human subject. My particular concern was to understand how health care professionals viewed human spirituality in the context of their work and, if appropriate, how they could learn more about spirituality and spiritual care. Although more familiar with quantitative medical research, I sensed that such an approach would be neither fruitful or appropriate in this area. Yet considering other approaches, such as human inquiry methodology, was daunting as well as liberating. The traditional scientific view of the researcher as an onlooker seemed inappropriate for a subject in which I was so personally involved. Human inquiry methodology and spirituality share an emphasis on the value of personal experience. In human inquiry, I need no longer try, and fail, to stand outside a subject which is so much a part of who I am; yet somehow I needed to bring an equivalent rigour to the process of the research. Another important theme shared by human inquiry methods and my growing understanding of spirituality was a concern for integration, rather than a reductionist, disconnected, approach. Human inquiry

methodology offers a number of practical approaches to research, including co-operative inquiry which I eventually used (Reason and Rowan 1981a, Reason 1988a, Reason 1994a, Heron 1996). I have not regretted choosing this reflective, meaning seeking approach even though it has taken me along a very different path from traditional medical research.

The importance of human experience

Co-operative inquiry became a central strand in this research as described in chapters three and four. In co-operative inquiry a group of individuals reflect together about a chosen subject. The process of testing against experience is a significant validating feature of human inquiry research. Working collectively offers an additional validating feature as ideas are tested out against differing experiences of the group. The personal and individual nature of human spirituality has been both a problem and an opportunity throughout this research. Spirituality is difficult if not impossible to understand fully. Hardly able to understand our own spirituality fully, it appeared impossible that we should ever come to understand other people's, whether they be colleagues or clients. The varied experience of those involved in the research did provide a rich resource within which to explore ideas about spirituality and spiritual care. Yet these very differences in experience and belief also challenged ideas and attitudes that individual participants had previously simply taken for granted. The methodology, with agreed ground rules and clear attention to the collective process, provided a safe space in which to reflect on these potentially explosive personal issues. Gradually in all the research groups a level of trust developed which made it possible to talk openly and comfortably about spirituality even where we differed significantly. This in turn created an opportunity to learn more about ourselves and each other. In all elements of the research (co-operative inquiry group and MPaCE module, as outlined in figure 1:1) the aim of the group was clearly established from the beginning. While personal exploration was clearly accepted as a valid part of the research, the overall emphasis was not on personal development in isolation. Rather in these work based opportunities, personal exploration was seen primarily as intended to inform our working practice.

The role of facilitator

In co-operative inquiry the facilitator needs to find the appropriate balance between being a member of the research group and playing the facilitator role. In this particular

research group inquiry, I was clearly an ordinary member of the group by the nature of my role within the cancer care organisation where I was a fellow health care professional. Yet I had different pressures as a researcher, for example, I needed tasks to be completed, the process to work, which set me somewhat apart from the group. My involvement in the research extended beyond the inquiry both in preparing for the whole research project and in writing up the research after the co-operative inquiry had ended. Working with others as co-researchers, I nevertheless had to produce an acceptable thesis at the end of the process. This added agenda clearly influenced my involvement and activity. Participants expected me to understand both the process and the subject yet the whole underpinning idea of co-operative inquiry is that it is co-operative, not dominated by one person. My own involvement with the subject was another concern. How much should I contribute to the discussion? Where did the roles of facilitator and group member begin and end? I learned a great deal from all the groups with which I was involved and my ideas about spirituality changed significantly during the process of the research, as I will describe later. People in the group knew me both as a dietitian and as a Christian actively involved in a local church; they had expectations about my ideas (not always correct ones) which were also open to exploration. Facilitating any group of people is a complex process; negotiating a group around a topic such as spirituality which has all sorts of underlying currents and potential difficulties could have become the stuff of nightmares. That it did not says much for the methodology and the members of the group. Difficulties were undoubtedly encountered yet by listening and endeavouring to understand each other's perspective, and sometimes agreeing to differ, much was learned.

Further developments

One short qualitative research study cannot resolve all the concerns about spirituality, health and holistic care; it merely contributes to the debate. This debate is continuing in other areas, particularly in education and the arts, reflecting wider concerns about how people live in today's world. Without such a debate, in view of the historical perspective outlined in chapter two, people will be less able to apply a helpful discernment to somewhat overused term 'spirituality'. This work has focused particularly on health and palliative care. Further research is needed to explore the benefits of similar opportunities in other areas of work, including education, management, leisure, indeed any person-centred occupation. Such a debate is already

underway in schools which may help ensure that future generations are more aware of spirituality and have a broader understanding of what it entails (Hammond et al 1990, Hay 1998b, Hay with Nye 1999). The specific role of adult education in spiritual exploration could also be usefully examined further. Spirituality remains a highly personal concern which needs to be approached with great sensitivity and respect for individuals. Our findings suggest that adult education, particularly reflective and experiential education, has much to offer in providing a safe but challenging space in which spirituality may be explored. The majority of those involved in the research were motivated by their experiences at work but there remains a suggestion, reinforced by discussions outside the research groups, that more general opportunities to discuss spirituality may be welcomed.

Faith communities may also find it beneficial to consider the implications of changing ideas about spirituality. Individuals who adhere to a particular faith need to consider the ways in which they express (and nurture) their spirituality. However, the debate about spirituality and religion also raises broader issues for faith communities about their freedom to engage in an open debate about spirituality. This has particular implications for chaplains working in a variety of contexts, including health care, schools and prisons. In health care, for example, chaplains may play an important role in generating a debate about the nature of spirituality, yet they also have a clear role in maintaining particular faith traditions. Clarifying the relationship between spirituality and religion remains a key strand in any debate about spirituality. Representatives of all faith communities can play an important, but not exclusive, part in this debate without neglecting their specifically religious duties.

Health care policy makers should consider further the outcomes of the co-operative inquiry group. Of particular interest is the continuing development of the MPaCE module which could be expanded for use in other areas. Following an article in the nursing press (White 2000a), there has been significant interest in its use elsewhere, particularly by other multidisciplinary, palliative care teams. The opportunity to develop the module for continuing professional development in other areas of health care, such as midwifery or general medical care, is also important. If such a development occurred, certain key characteristics of the module should be retained, including its exploratory nature, its multidisciplinary and work based setting, and the reliance on adult education principles. Further work on assessment in spiritual care is

also important, although this was not the main focus of my work.

The overwhelming majority of the participants in this research were women; only one man took part as a participant in the first MPaCE course. This imbalance probably reflects the greater numbers of women working in health care, particularly among nurses and allied health professionals. Yet questions about gender and spirituality remain. A seminal research study of '*women's ways of knowing*' suggests that ways of knowing cultivated and valued by women, while powerful, are neglected or denigrated (Belenky et al 1986:preface). This research highlights five major epistemological categories of knowledge: silence, received knowledge, subjective knowledge, procedural knowledge and constructed knowledge (Belenky et al 1986:15). The researchers quote Sampson, who suggests that the:

commonly accepted stereotype of women's thinking as emotional, intuitive and personalised has contributed to the devaluation of women's minds and contributions, particularly in Western technologically oriented cultures which value rationalism and objectivity (1978, quoted in Belenky et al 1986:6).

It is not difficult to see possible links with the neglect of spirituality, also traditionally undervalued by rationalism, as described in chapter two. Yet to assume that '*women's ways of knowing*' are automatically more spiritual seems too simplistic. Conn, writing about women's spirituality, suggests there may be an over-emphasis on autonomy and independence as the goal of spiritual development which is at odds with the importance of relationship and belonging experienced by many women (1986:3). This returns to the importance of developing an underpinning discussion about the nature of spirituality. Connection developed as an important theme within this thesis, as outlined in chapter five, and appears to resonate with Belenky et al's recognition of the importance of connected knowledge to women (1986:100-130). Burkhardt also stresses the importance of connection (and of becoming) in her survey of twelve adult women's ideas about spirituality (1994:18-20). Metaphors of silence and voice, used throughout the study by Belenky et al, are contrasted with visual metaphors in their implications of dialogue and interaction rather than of separation (Belenky et al 1986:18). The way in which the groups in my research developed, particularly in their emphasis on connection, on integrated understanding and on learning together, may partly reflect their gender makeup. The experience of both the co-operative inquiry group and the MPaCE groups suggests that integrated personal reflection, both individually and

collectively, can be of benefit when exploring spirituality. Further work is required to see whether this approach would be equally effective in mixed or predominantly male groups and, if not, what alternatives are available.

The stimulus for my research journey was the challenge of working with people with cancer. The experience of working with people who were facing death challenged the understanding of health and spirituality developed during my own professional education as well as my Christian faith. The growing recognition that concepts I had previously taken for granted, particularly the holistic, patient centred approach to health care and a faith centred view of spirituality, were either ineffective or inadequate, prompted a far reaching review. Theoretically, spirituality was a key part of the holistic approach I espoused. Yet five years of working as a dietitian in oncology and palliative care had made me increasingly aware of the gap between this theory and my practice. My Christian faith made me value spirituality all the more but provided little clarity about how to actually work holistically with a broad spectrum of clients and colleagues in a multi faith setting. This research has provided an opportunity to explore spirituality in a way which draws together insights from the experience, both personal and professional, of myself and my colleagues. My understanding of spirituality, humanness, faith and health have all changed over the course of the research in ways which affect more than just my working practice. I now understand more clearly that spirituality is an integral part of every person. I recognise that my own spirituality, as well as other people's, has the potential to influence the whole of life and relates to far more than my faith. The experience of thinking about spirituality with other people has increased my awareness of the difficulties of talking about this complex area of human life. Yet far from putting me off, this research has made me even more eager to encourage opportunities for people, clients, colleagues and friends, to talk about spirituality. Rather than sterile confrontation, I have seen the benefits of an environment where such people can listen and learn together, where no one has all the answers and everyone has much to learn.

Health care, in parallel with other areas of society has been undergoing a review of its fundamental values and ideas. Concerns about an over emphasis on science and technology in health care should not be brushed aside in the debate about clinical excellence. Doing things right is not always the same as doing the right things and both are necessary. Health care desperately needs to remember its humanity

alongside its clinical excellence. Technical expertise, supported by audit, clinical governance and research, is vitally important but does not automatically ensure actual care. The impossibility of cure in palliative care highlights a distinction that is equally true in other areas but perhaps more easily overlooked. The increasingly technical skills needed for health care need to be supported by a foundation of shared human values. Remembering the centrality of the human journey of personal discovery ensures that practitioners remember that who they are is as important as what they do. Spirituality, by its very nature, highlights some of the key issues in this debate. Spirituality is elusive, highly personal and not at all technical yet, as the research draws to an end, I feel even more certain that it is vitally important in health care. Discussing these issues with other people has helped me to recognise that even more clearly. While some individual participants in the research felt they began with a clear view of their own spirituality, all recognised their engagement in a continuing process of discovery. The difficulties of the struggle to understand spirituality did not detract from the importance of trying to do so. Our health care practices, as well as our own lives, are richer and more effective because of this journey together. There will, I hope, be a number of practical outcomes to this research but equally important will be the profound way in which it has affected my understanding of who I am. This understanding is not static but part of a continuing process which will continue long after my research is completed. One outcome of the research which is already apparent to me is the greater recognition of my own spirituality and spiritual needs. How I and other participants meet such needs in the future remains an open question.

Conclusion

Twenty-first century human beings appear torn between the material and the metaphysical. Western society has become disenchanted with the empirical, reductionist viewpoint which has been such a pervasive influence. Holistic approaches are in vogue and we crave reassurance that there is more to life than the obvious elements that we see and feel and touch. Emerging from a period where such ideas were taboo, it is once more becoming accepted that there is more to life than the visible, utilitarian recognition of pain and pleasure:

It is it better to be a human being dissatisfied than a pig satisfied; better to be Socrates dissatisfied than a fool satisfied (Mill 1974:260).

Life is understood to be more complex than the material and physical, yet our history has left many people without the tools that would help them navigate in more complex waters. Experience with clients at the end of their life suggests that, even in illness and pain, people reach out towards meaning and hope, endeavouring to transcend the ordinary, yet struggling to know how. Friends, family, health care professionals, may all play a part in supporting this often difficult journey which assumes greater importance as death approaches. Although some questions will always be unanswerable, others have simply not yet been answered. Life remains a mystery, much of which we will never comprehend, yet that does not negate the struggle to find meaning. Such human questions are important and their exploration leads to new insights even as we recognise how much more remains to be understood. TS Elliot provides a fitting reminder that:

*We shall not cease from exploration
and the end of all our exploring
will be to arrive where we started
and know the place for the first time (1959:59).*

Six years and many thousands of words later, I am returning to the concerns that first prompted my research journey. While I am not sure that I now *'know the place'*, the experience of this journey means that it does not look the same. The submission of my doctoral thesis will certainly find me older and greyer but paradoxically convinced that there is yet more to discover. As the thesis draws to its close, I find myself no less fascinated by a subject which weaves like a gold thread through the many strands of my life. My lifelong learning journey is still far from over!

APPENDICES

Appendix 1: PUBLICATIONS AND PRESENTATIONS ARISING FROM THE THESIS

PUBLICATIONS

White G (1998), *Spirituality*, Hospice News, Stockport

G White (1998), Learning together about spirituality: a co-operative inquiry group, in Benn R, Editor, *Research, Teaching and Learning: Making connections in the education of adults*, Proceedings of the 28th Annual Conference of The Standing Conference on University Teaching and Research in the Education of Adults, University of Exeter

Winner of the Michael D Stephens Prize

G White (1999), Finding space for the spirit: helping others learn about spirituality, in Merrill B, Editor, *The Final Frontier: exploring spaces in the education of adults*, Proceedings of the 29th Annual Conference of The Standing Conference on University Teaching and Research in the Education of Adults, University of Warwick

G White (2000), Soul Inclusion: researching spirituality and adult learning, in Jackson A and Jones D, Editors, *Researching 'Inclusion'*, Proceedings of the 30th Annual Conference of The Standing Conference on University Teaching and Research in the Education of Adults, University of Nottingham

Winner of the Michael D Stephens Prize

White G (2000), *An Inquiry into the Concepts of Spirituality and Spiritual Care*, International Journal Of Palliative Nursing, 6 (10): 479-484

White G (2001), Hooked on the Journey: spirituality and the search for meaning, in West L, Miller N, O'Reilly and Allen R, Editors, *Travellers Tales: from adult education to life long learning and beyond*, Proceedings of the 31st Annual Conference of The Standing Conference on University Teaching and Research in the Education of Adults, University of East London

PRESENTATIONS

Church of England Readers Conference (Northern Province), Chester
Spirituality and Survival

Afternoon workshop and plenary, June 1998

Aromatherapy Group, Manchester

What is spirituality?

Afternoon workshop, January 1999

Manchester Dietitians Update Session: Research Methods, *Qualitative Research Methods*

Afternoon workshop, February 1999

Local Deanery Anglican Readers Group, Stockport
Spirituality and Survival

Evening workshop, February 1999

Cancer Care Conference 1999, Chester
Spirituality at the cutting edge

Poster presentation, February 1999

Rehabilitation Research Day, Nottingham
Soul Medicine: spirituality and health

Poster presentation, November 2000

OTHER CONFERENCES ATTENDED

Palliative Care + Spirituality

Marie Curie Cancer Care, 12th February 1996, Manchester

Spirituality and Health

30th September - 2nd October 1997, Durham

'Leave my Soul Alone!'

Dr Kenneth Boyd, June 1997, Weston Park Hospital, Sheffield

Part of a series of lectures organised by Trent Palliative Care

Engaging with adult spirituality

Adult Network, July 1997, Leicester

Spirituality

Short Course organised by Derbyshire Christians Learning Together,
Tuesday Evenings, 7.30pm-9.30pm, October 31st -December 12th 2000,
Morley, Derbyshire

Body and Soul

4th NHS National Conference on Spiritual Care, 24th May 2001

Stanford Hall, Leicester

Appendix 2: SPIRITUAL EXPERIENCES

Spiritual, or religious, experiences (also known as hierophany) have been described as

a manifestation of the sacred reality that underlies physical experience, a point of contact between heaven and earth, natural and supernatural, which demonstrates a reality at the very heart of life (Eliade 1969:11).

While such experiences are a recognisable element within religious practice, they are also more widely accepted. Attempts to delineate numinous, mystical experiences have traditionally been made by Otto (1936) and James (1985). Recent interest in these phenomena in Britain has focused particularly on the work of biologist Sir Alister Hardy, described in *Religious Experience Today* (Hay 1990). Hardy was instrumental in establishing the Religious Experience Research Unit, based at Manchester College Oxford in 1966 (now known as the Alister Hardy Research Centre). An early task of the unit was to collect accounts of religious experience. Describing three examples, Hardy invited individuals who *'have been conscious of, and perhaps influenced by, some such power, whether they call it God or not, to write a simple and brief account of these feelings and their effects'* (Hardy 1979:18). Initial adverts were placed in the religious press but, when the response was small, Hardy re-advertised in the secular press where there was a much greater response. The Unit had recorded approximately 4000 accounts of such experiences by 1980. Fuller details of these rich and varied accounts, plus attempts at classification, are given in Hardy's book *The Spiritual Nature of Man* (1979). David Hay, a former director of the research centre, suggests that the following major categories can be seen within the experiences described: synchronicity or patterning of events, the presence of God, answered prayer, a presence not called God, the dead, a sacred presence in nature, evil, experiencing that all things are one (Hay 1990: 41-51).

Hardy's initial research was taken further by Hay as part of a National Opinion Poll survey, which asked the question, *'Have you ever been aware of or influenced by a presence or power, whether you call it God or not, which is different from your everyday self?* plus some additional questions about the nature of the experience and the respondent. The results of this work are summarised in the book *Exploring Inner Space* (Hay 1982) from which the following material is taken. This again showed that such experiences are relatively common, experienced by

approximately 36% of respondents. Positive responses were more frequently made by women, older people, higher social classes (especially middle class) and those with a higher education. There were also geographical differences, with spiritual experiences most common in Wales and least common in Yorkshire and Humberside. Positive responses were most common among people whose religious affiliation was 'other non Christian' (a small group mainly from Asian religions) and least common from Anglicans, although significant positive responses were also received from atheists and agnostics. Those who responded positively were more likely to attend church (or other place of worship) occasionally, leaving a significant number of church goers who have never had a spiritual experience and an equally significant number of non church goers who had. Experiences were often very fleeting, and were more likely to occur when people were alone, distressed or in contact with nature (Hay 1982:144). Similar results had been seen in America (35% response rate) where religious groups were thought to be stronger (Hay 1982:115). Subsequently, Hay and his colleagues interviewed a random sample of 100 adults in Nottingham (fifty women and fifty men), where over 60% claimed that they had had an experience of this kind, suggesting that people are more likely to talk about intimate experiences in an in-depth interview (Hay 1990:57-58).

Spiritual experiences remain common even in today's supposedly secular world. While the existence of spiritual experiences does not answer questions about the existence of God, it does suggest that spirituality is a resilient element of human nature. A convinced Darwinian, Hardy believed that such '*religious awareness*' is widespread because it plays a role in human survival (Hay 1990:23). Hay suggests that greater awareness and acceptance of spirituality experiences is important for those outside religious institutions, particularly for health care and for education (Hay 1990:104-109).

Appendix 3: USING NUD*IST

The NUD*IST (Non-Numerical Unstructured Data: indexing, searching and theorising) computer programme was used to analyse the data from the co-operative inquiry group. The following is a summary of how I used the programme for this research. The tutorial which accompanies the programme gives further information about its use.

Stage one: Making a document system: typed transcripts from the co-operative inquiry group were imported into the NUD*IST system as plain text and labelled according to the number of the session (session one equals document one). NUD*IST automatically divides each document into 'text units' (TUs), with the boundary of each text unit identified by a carriage return. In my documents, each saying by an individual participant became a text unit (except in a few cases where a carriage return had accidentally been omitted). Each text unit was labelled in this way and this code has been used to identify the sources of quotations used in the thesis (for example, 1:33 denotes the thirty-third text unit in document one). Comments relating to each text unit were added, for example, I added annotations which were apparent from listening to the tapes but were not part of the text, such as laughter or anger. Other information was attached to each document as a memo, for example, I added details of who attended, the date and time of the session and, eventually, a summary of the discussion in that session.

Stage two: Making an index system: (NB stages 2 + 3 occurred simultaneously). NUD*IST has two sections, the documents explorer (where the documents entered in stage one are stored) and the index system (which contains a structure for the storage of nodes or 'containers for ideas'). Each node created in the index system has a title and an address which indicates its type and place in the system. Initially, I created two main types of nodes:

Index nodes: a few major themes that I expected to emerge from the data, such as meaning, connection.

Free nodes: themes that were emerging from the data as I began to code it

Each node was labelled with a name and definition as it was created and these were added to as required. As my ideas about the data became clearer a hierarchical index tree

was built up, showing how individual nodes related to each other. This index system was reshaped many times to develop the current tree (see page 204-5). Nodes were moved around the tree to reflect (or stimulate) my thinking about this structure. Wherever possible, free nodes were merged into the index system. Nodes were combined where appropriate, for example, text searches were combined with free nodes which described the same theme without using specific words such as connection. A 'history' of the changes to each node is automatically recorded by NUD*IST for future reference. A significant benefit of NUD*IST for me was that it was easy to identify how many times each theme (node) was referred to and at what points. Browsing the content of each node (in addition to the individual documents) during coding made it easier to review references to each theme, checking for links and discrepancies. Finally, reports could be made on each node at any time. A range of material could be included in each report, but I mostly looked at lists of text units included in each node, sometimes printing out the actual text, sometimes just the text unit numbers. This enabled me to check the material in each node against the definition, as well as look for patterns in the data across all the documents. Reports were made at various points in the data analysis; for example, in preparing feedback for the final meeting of the group and when I began writing chapters 3-7. Additional reports were made showing 'coding stripes' for each document (representing a single co-operative inquiry group meeting). Many text units had multiple coding and these reports enabled me to see how the main themes were interwoven in each meeting as well as to compare meetings. Only a limited number of coding stripes could be shown on each document, so just the main themes were used.

Stage three: Searches: NUD*IST was used to carry out 'string searches' (ie every occurrence of a string of characters). Related words can be combined in the same search, for example, free, freedom, freely, freeing. String searches were especially useful initially in helping to clarify themes that seemed to be emerging from the text. The results of these very basic searches needed to be reviewed carefully because of multiple meanings of the same word or part word (for example, a search for 'air' could also highlight hair, stair, although I later realised that searches could be limited to whole words). It was also important to remember that string searches were incomplete, failing to identify text that referred to a topic without using a specific word. For example in this material there were many references to a theme such as meaning, purpose and fulfilment where none of these words were used. This may be especially important in a topic such as spirituality where participants struggle to express their ideas, often using

complex language such as metaphors or anecdotes. NUD*IST will produce a report from each search that identifies all occurrences picked up by the search. Reading through these reports enabled me to refine the material by removing irrelevant references. The results of such searches can be combined with other material such as more general coding for meaning and purpose.

Description of a search: The word 'journey' was used a number of times in some of the early sessions. Having noted this, I searched all the documents for references to journey and related words. After looking at each text unit identified by this search (and excluding some which were irrelevant), it was apparent that references to 'journey' occurred throughout the inquiry although not in every session. A free node was created entitled 'journey' into which were placed the results of the refined string search. As I continued to read through the data, other references to journey or related ideas (such as pilgrimage or travel) were placed in this node. Eventually the node for journey was moved to a place in the index tree as it became clearer how it fitted in with other themes. A number of reports were created about the node which made it possible to see where, and how frequently, references to journey occurred in the data.

Stage four: Index searches: these allow patterns of coding to be noted and developed, for example, intersections of different nodes. I built up a matrix manually using the reports NUD*IST created. This matrix, the final version of which is shown on page 207, gives an indication of the number of references to that theme in each meeting. This is given by identifying the number of text units with that coding as a percentage of the total number of text units in that node. It also shows the number of references to that node in all the documents and shows how many sessions contained references to that node. This gives a limited impression of the relative importance of each node, both in each meeting and in the whole inquiry. Text units were not of a set duration and this numerical analysis gives little indication of the relative importance of each text unit in terms of content but does contribute to the overall analysis.

Summary: I read through the data and listened to the tapes from the inquiry many times, carrying out searches for ideas and themes using the index system that was developing. I later checked the coding attached to each text unit against the definition I had agreed. These tasks were not replaced by NUD*IST but the basic clerical activity of coding was made quick and simple. The ability to move and reshape nodes was especially useful and the formation of the node tree helped clarify and refine my ideas.

Definitions of Nodes:

SPIRITUALITY GROUP (1): a co-operative inquiry group aiming to explore spirituality in the context of life and work

Methodology (1:1): references to co-operative inquiry methodology as used in this group

Process (1:1:1): the process of the co-operative inquiry group

Organisation (1:1:2): the organisation of the co-operative inquiry group

Validity (1: 1: 3): references to validity, including examples of challenge and questioning

Understanding (1:2): exploration of the concept of spirituality

Language (1:2:1): issues of language in understanding and talking about spirituality

Metaphors (1:2:1:1): metaphors used to describe spirituality

Journey (1:2:1:1:1): journey as a metaphor for spirituality

Difficult (1:2:1:2): spirituality is hard to articulate

Innate potential (1:2:2): spirituality as innate, a potential that can be developed

Culture (1:2:2:1): the influence of culture on spirituality

Unique (1:2:2:2): spirituality as unique to each individual

Nurture (1:2:2:3): general discussion about the development or nurture of spirituality, including what acts as a catalyst

Death (1:2:2:3:1): death as a catalyst for spirituality, link with palliative care

Search (1:2:2:3:2): exploring, searching, struggling as part of the spiritual journey

Essence (1:2:2:4): spirituality as the essence of a person

Everyday (1:2:2:5): spirituality as part of everyday experiences, not just the 'big questions'

Spiritual experiences (1:2:2:6): spiritual experiences described or referred to, for example, becoming aware of a greater reality

Age (1:2:1:7): spirituality at different ages

Gender (1:2:1:8): links between gender and spirituality

Themes (1:2:3): underpinning themes in understanding spirituality

MPF (1:2:3:1): meaning, purpose and fulfilment

Hope (1:2:3:2): hope

Connection (1:2:3:3): connection with self, others, God or higher power

Religion (1:2:3:4): links and distinctions between spirituality and religion

external spirit (1:2:3:4:1): is there an external source of spirituality

Integrating (1:2:3:5): spirituality as an integrating element of the human personality, also the holistic approach

Indefinable (1:2:3:6): cannot pin down spirituality, themes not definitions

Freedom (1:2:3:7): freedom as a necessary aspect of spirituality

Outcomes (1:3): outcomes of the co-operative inquiry group

Personal (1:3:1): personal outcomes of the co-operative inquiry group

Ideas (1:3:1:1): descriptions of personal changes of ideas or views about spirituality

Awareness (1:3:1:2): heightened awareness of spirituality at work or personally as an outcome of the co-operative inquiry

Confidence (1:3:1:3): increased confidence about providing spiritual care

Educational (1:3:2): developing opportunities to learn about spirituality

HCP training (1:3:2:1): present health care professional training as a way of equipping (or not) health care professionals for the provision of spiritual care

CPD (1:3:2:2): developing a continuing professional development module on spirituality

Self care (1:3:2:3): exploration or nurture of spirituality as part of self care for health care professionals

Spiritual care (1:3:3): the provision of spiritual care

Being and doing (1:3:3:1): spiritual care is about being with more than doing to, not just a task

Assessment tools (1:3:3:2): how to assess spirituality. Is it possible? use of assessment tools

Environment (1:3:3:3): the role of the environment in spiritual care

Arts (1:3:3:3:1): spirituality and art/arts

Psychology (1:3:3:4): links between spiritual care and psychological care

Roles (1:3:3:5): whose job is spirituality, should there be a specialist?

Palliative care (1:3:3:6): specific concerns about spirituality in palliative care

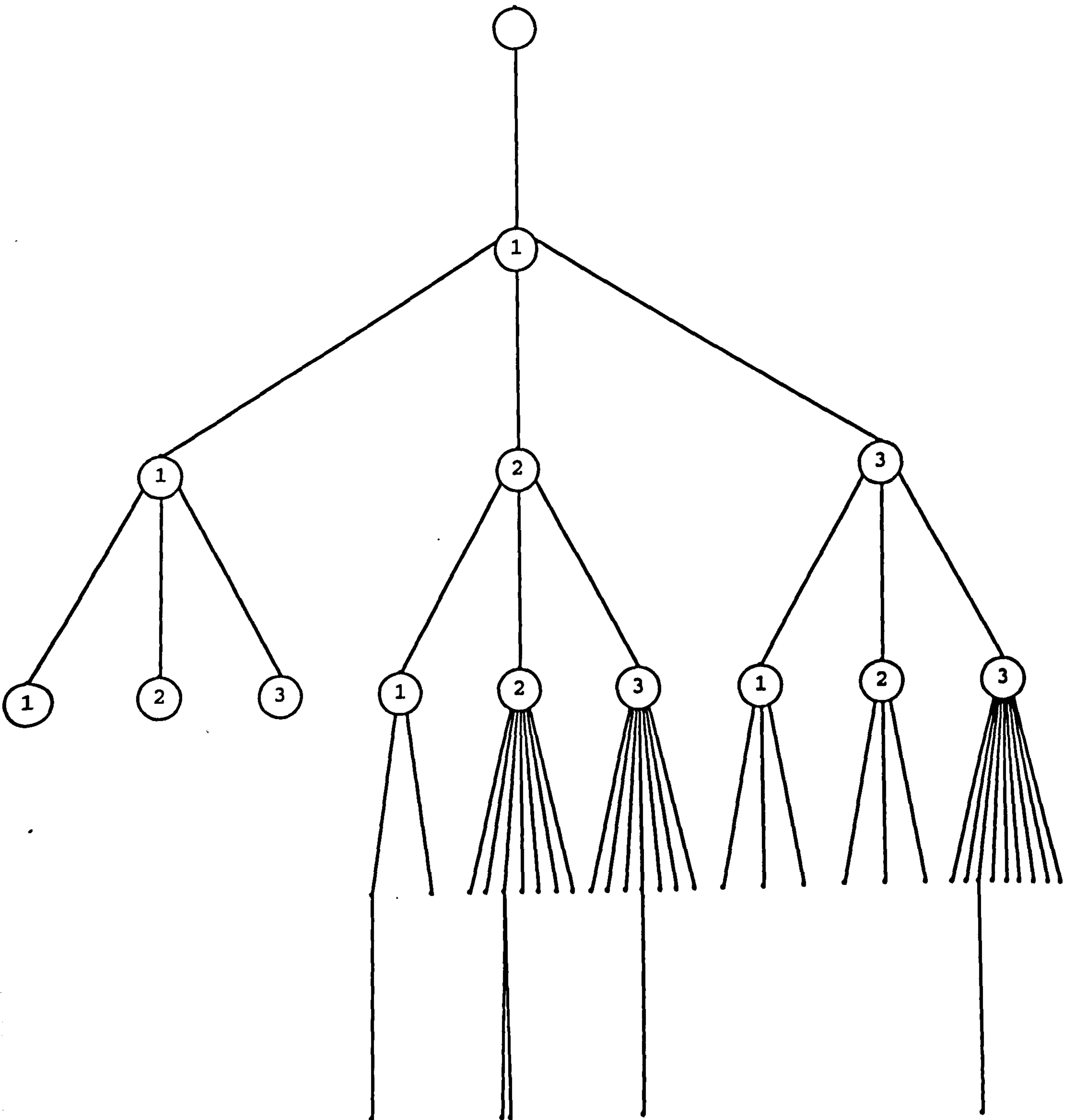
Therapeutic relationship (1:3:3:7): the therapeutic relationship as the setting to provide spiritual care

Therapies (1:3:3:8): complementary therapies in spiritual care

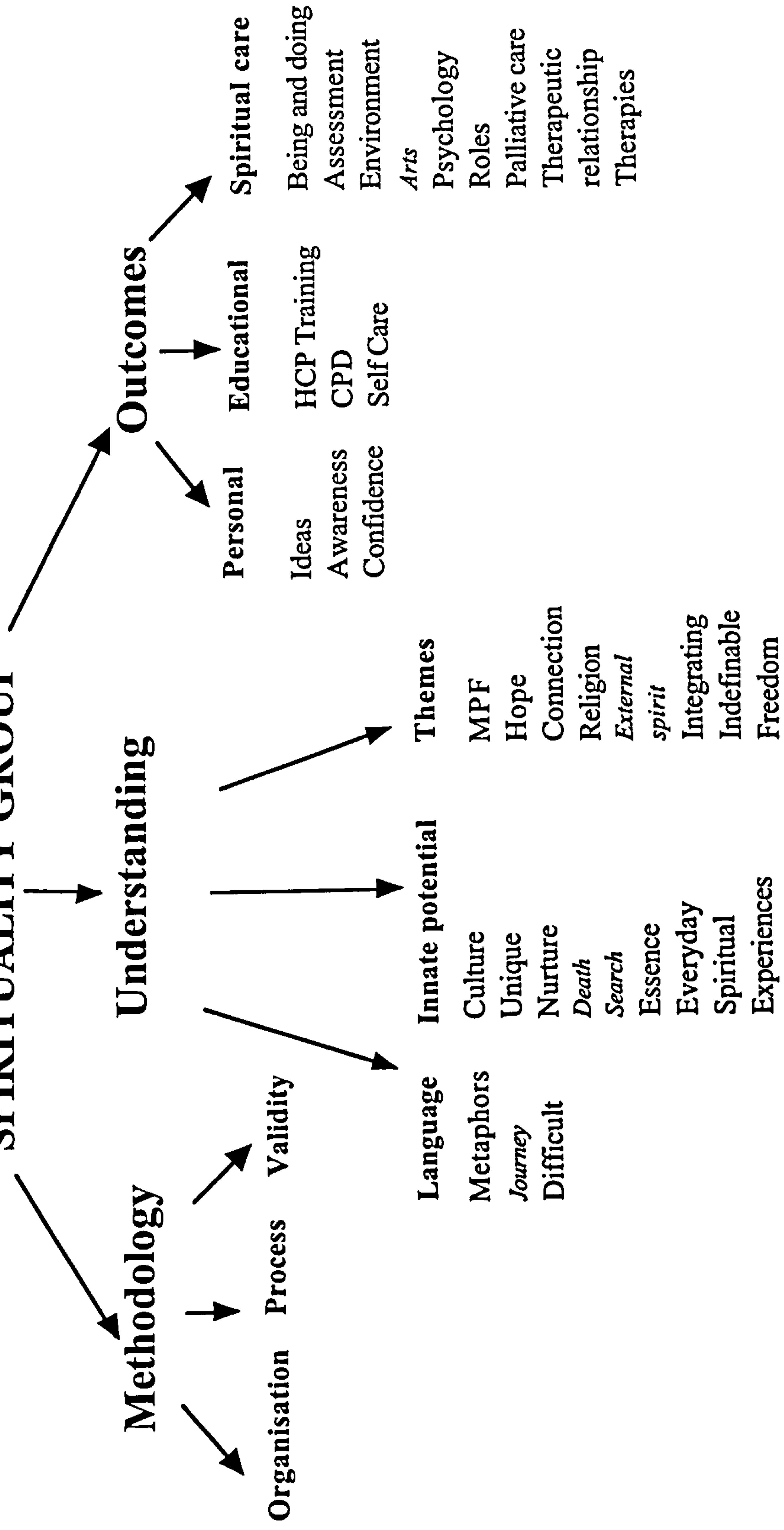
Remaining free nodes: nostalgia, external spirit, self work, intuitive

Summary Index Tree Created By NUD*IST

(NB see annotated copy on following page)



SPIRITUALITY GROUP



Personal
 Ideas
 Awareness
 Confidence

Educational
 HCP Training
 CPD
 Self Care

Spiritual care
 Being and doing
 Assessment
 Environment
Arts
 Psychology
 Roles
 Palliative care
 Therapeutic relationship
 Therapies

Language
 Metaphors
Journey
 Difficult

Innate potential
 Culture
 Unique
 Nurture
Death
Search
 Essence
 Everyday
 Spiritual
 Experiences
 Age
 Gender

Themes
 MPF
 Hope
 Connection
 Religion
External
spirit
 Integrating
 Indefinable
 Freedom

Notes:
 MPF = Meaning, purpose and fulfilment

Information from the Matrix (see page 208)

All three major themes were referred to in every session of the group, although there were peaks and troughs. Sub themes may only have occurred in some of the sessions.

Methodology: Not surprisingly sessions at the beginning or end of reflection periods have more references to the methodology. For example, session one involved a review of the methodology, establishing the aim of the group and setting ground rules; session eight included ending the second group of meetings, setting tasks for the next active period and planning the group of sessions.

Understanding: The first reflective period (sessions one-six) focused on exploring our own and other people's understanding of spirituality and were especially rich in this theme. However there were many references to it in later sessions, especially session nine and thirteen, indicating the importance of understanding as an underpinning issue throughout the inquiry.

Outcomes: This theme was more representative of the later part of the inquiry (particularly sessions nine-fourteen). Some sub themes within the area had particular peaks such as assessment, which was important in sessions ten-fourteen, but referred to relatively little in early sessions.

Matrix of Co-operative Inquiry

SESSION	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	1	2	3
Number TU	218	259	181	261	153	292	259	202	88	312	453	268	172	210	299			
METHODOLOGY	18	2.3	5	23	12	22	27	43	16	5.4	0.66	1.1	2.9	27	7 15/15	13	13	
Organisation	4.1	0.39	0	1.9	7.2	6.2	2.7	34	16	0.96	0.22	0.75	1.2	13	6.7 14/15	5.5	5.2	
Process	1.4	1.5	3.9	15	0.65	16	25	25	8	3.5	0.22	1.1	9.9	18	0.33 15/15	8.1	8.1	
Validity	0	0	0	2.3	8.5	0	0	0.5	0	0	0	0	1.2	0.48	0 5/15	2.3	0.63	
UNDERSTANDING	34	22	38	39	50	38	38	11	51	24	20	16	40	13	39 15/15	30	30	
Language	7.3	2.7	22	14	13	3.1	18	2.5	12	6.1	8.6	2.6	8.1	3.3	13 15/15	8.7	8.7	
Metaphors	0.92	0.39	13	3.8	2	0.34	2.3	0.5	2.3	0.32	0.44	0.37	0.58	0.95	2 15/15	1.7	1.7	
journey	1.8	0	0.55	0.38	2	0	2.3	0.5	0	0.32	0	0.37	0.58	0.48	3.7 11/15	1.2	0.85	
Difficult	0.46	1.5	0.55	7.3	5.9	1.6	0.77	0.5	8	2.9	1.3	0.37	0	0.48	4.3 14/15	2.3	2.2	
Innate Potential	15	19	13	20	40	31	16	7.9	43	12	7.1	2.2	28	10	27 15/15	17	17	
Culture	0	2.7	2.2	0.77	9.2	1.4	1.2	0	1.1	0.96	0.66	0	0	0	5 10/15	2.2	1.5	
Unique	2.8	2.3	2.8	4.2	7.2	5.8	2.7	0.5	3.4	1.3	1.8	0	1.2	0	1 13/15	2.7	2.3	
Nurture	0.46	6.6	2.2	8.8	33	14	5.4	3.5	24	5.8	2.2	1.1	11	1.9	16 15/15	7.8	7.8	
death	0	1.2	0.55	0.77	7.8	0.68	1.2	0.5	10	0.32	0	1.1	1.2	1.4	3.3 13/15	1.8	1.4	
search	1.8	0.39	3.3	4.6	12	2.7	1.9	3.5	12	0.96	0.22	0	6.4	0.95	9 14/15	3.5	3.2	
Essence	0	0	2.2	2.3	2	2.4	6.9	2.5	5.7	4.2	0.88	0.75	3.5	1.4	3.7 13/15	2.8	2.4	
Everyday	7.3	0.39	1.7	0.38	0	0.68	0.77	0	0	0	0.44	0	0.58	0	1 9/15	1.3	0.85	
Spiritual Exp	0.92	12	2.2	2.7	0.65	2.1	1.5	0.5	28	0	1.3	0	0	3.8	4.3 12/15	3.8	3	
Age	0	1.5	2.2	0.38	4.6	5.5	3.5	0	0	0.32	0	0	0	0.48	2.7 9/15	2.3	1.4	
Gender	0	0	0.55	0	2	1.7	1.5	0	1.1	0	0	0	0	0	0.33 6/15	1.2	0.41	
Themes	9.2	5	17	17	28	15	18	5.9	30	12	8.2	12	20	5.2	17 15/15	13	13	
MPF	2.8	0	0.55	0.38	0	3.1	2.7	0.99	0	1.9	0.22	4.1	0.58	1.4	1 12/15	1.6	1.4	
Hope	0	0.39	0	0.77	0	0	0	0	1.1	0.64	3.3	0.75	3.5	0.95	1.3 9/15	1.5	0.96	
Connection	6	4.2	0.55	0.38	1.3	4.8	1.5	0.99	10	0.64	2	7.5	2.9	2.4	2 15/15	2.9	2.9	
Religion	2.8	1.2	15	14	26	7.5	11	3.5	20	6.4	3.3	1.5	9.3	1.9	10 15/15	7.7	7.7	
external spirit	0.46	1.5	0	0.38	2	0.68	1.5	0	1.1	0.32	0	0	5.8	1.9	0.68 11/15	1.3	0.91	
Integrating	10	0	0	1.9	5.9	1.4	3.9	0.5	0	2.9	0	0	1.2	0	2 8/15	2.4	1.3	
Indefinable	0	0	0	2.7	0	1	0.39	0.99	2.3	0	0.44	0.37	1.7	0	4.3 9/15	1.5	0.94	
Freedom	0	0	0	0	2.6	0.68	0	0	2.3	1.9	0	0	2.9	0.48	1.3 7/15	1.6	0.66	
OUTCOMES	44	1.9	37	31	12	20	32	36	36	50	34	46	52	25	29 15/15	32	32	
Personal	4.6	2.3	0	3.4	6.5	6.5	13	20	9.1	3.2	1.1	0.37	7.6	12	3.7 14/15	5.9	5.6	
Ideas	0	0	0	0.38	0	4.1	11	3	3.4	1.6	1.1	0.37	5.8	9	2.7 11/15	3.5	2.7	
Awareness	2.3	0	0	1.5	0	1.7	0.39	0.5	0	0.64	0	0	2.9	2.9	1.3 9/15	1.5	0.91	
Confidence	3.2	0	0	0	0	0	0	1.5	1.1	1.6	0	0	5.2	0.95	1.3 7/15	2.1	0.85	
Education	4.6	0	14	1.9	0	0.68	0	2.5	0	6.7	1.5	3.4	16	4.3	5.7 11/15	4.8	3.8	
HCP Training	3.2	0	7.7	0	0	0	0	0	0	1.3	0	0	6.4	0	1 5/15	3.3	1.1	
CPD	2.3	0	4.4	0.38	0	0.68	0	2	0	3.2	1.5	1.1	9.9	4.3	3.3 11/15	2.6	2.1	
Self care	0	0	0	0	0	0	0	0	0	2.6	0	2.2	0	0	0 2/15	2.4	0.39	
Spiritual Care	34	1.2	31	29	6.5	14	20	28	35	50	33	46	47	14	24 15/15	28	28	
Being and Doing	4.1	0.77	11	8.4	0	0	0	2.5	3.4	2.6	1.1	2.6	6.4	0.95	8.7 12/15	4.1	3.3	
Assessment	0	0	3.9	0.77	0	0	0	1.5	0	3.2	2.3	2.2	1.6	2.9	4.3 9/15	1.2	7.5	
Environment	0	0	0	0	0	0	0	3	1.1	0.32	6.4	0	2.3	0	1.3 6/15	2.9	1.2	
arts	0	0	0	0	0	0	0	0	0	0.32	1.3	0	0	0	1 3/15	0.94	0.28	
Psychology	3.7	0	0	6.5	0	0	0	0	1.1	0.64	0.44	0	2.3	3.8	1 8/15	2.2	1.2	
Roles	13	0	2.2	15	0	3.4	0.77	3.5	0	6.7	0	20	14	1.4	2.7 11/15	7.5	5.5	
Palliative care	0.46	0.39	1.7	1.9	0	3.8	12	0.99	20	7.4	0.44	20	4.1	0.95	2.7 14/15	4.8	4.6	
Therapeutic R'ship	8.3	0.39	13	2.3	0	0.34	0	9.9	18	8.3	1.3	24	10	1.4	6.4 13/15	6.9	6.1	
Therapies	0	0.39	2.8	0	0	0.34	8.1	0.99	0	0.32	0.44	0	0	0	4.3 8/15	2	1.3	

Notes:

- 1: Proportion of sessions in which this theme was referred to
- 2: Percentage of references to this theme, excluding sessions where it was not referred to
- 3: Percentage of references to this theme, based on all sessions

Appendix 4: ADDITIONAL SOURCE MATERIAL

Co-operative Inquiry Group

Tapes and transcripts of all co-operative inquiry group meetings, except the initial exploratory meeting.

Copies of brainstorming sessions.

Notes from co-operative inquiry group sessions.

NUD*IST Reports.

Journey into Faith Group

Tapes of sessions 2 + 3.

My own Journey into Faith Diary.

Manchester Palliative Care Education Forum (Spirituality Module)

Handouts and course information.

Notes from brainstorming sessions on all courses plus follow up session.

Summary notes from tutors meetings.

Evaluation notes plus tape of group evaluation in final session of course one.

Evaluation notes for course two.

Appendix 5: INITIAL FLIER

This flier was distributed to all staff working at the Neil Cliffe and Amber Centres, including some individuals based at a local hospital.

What do we mean by spirituality?

Is it relevant to the work at the Cancer Care Centre?

Should it concern us all or is it a job for a 'specialist'?

What is the difference between spirituality and religion?

Does spirituality develop and if so how?

How do we develop our spirituality?

I am interested in setting up a cooperative inquiry group of 4-6 people to explore the whole area of spirituality. I am interested in doing this as part of my work towards a PhD and would be able to feed in other relevant research etc. I hope it would also be useful to the centre and the people involved in the group. (It might be fun too!)

Possible spin offs would be co-authored articles or presentations or a study day or training course. The group would be open to members of the staff team at the NCCC and would probably run for about a year. Times and frequency of meetings would be arranged to suit group members.

Let me know if you might be interested in joining the group. If possible, I would like to meet once before the summer holidays then start properly in the autumn.

Gillian White

Community Dietitian

Neil Cliffe Cancer Care Centre

June 1997

Appendix 6: LETTER OF SUPPORT

Heron refers to self initiating 'boot strap' co-operative inquiry groups developing as the methodology becomes better known, saying *'I don't know of any examples of a boot strap group but I hope and expect there may be many in the future and I look forward to hearing news of them'* (1997:40). Feeling we were an example of this type of group, a copy of the SCUTREA conference paper outlining the group (White 1998) was sent to John Heron. His e mail reply is reproduced, with permission, below.

Date: Sat, 19 Sep 1998 13:06:18 +0200

Dear Gillian

Your letter of 26 August and co-operative inquiry paper finally reached me here in Italy from Sage a few days ago.

I am very pleased to see the paper and appreciate your sending it to me.

Your research is an excellent piece of pioneer bootstrap co-operative inquiry, in the challenging field of spirituality, and I get the impression from your report that you and the group really have got hold of the method and made it your own. I am delighted to think that my book has made some contribution to your initiative.

I gather the first reflection phase extended over six weekly meetings of an hour each, then you had a six week first action phase exploring personal spiritual experience, followed by a second reflection phase of meetings over two weeks, then a second action phase of ten weeks looking at spiritual assessment and support of spirituality on the job, then a third reflection phase covering meetings over a six week period, and now you are in (or have just finished) the third action phase, although I am not quite sure what the focus of this is, except that two people are developing a training module of some kind. And presumably there will be a closing reflection phase.

It seems to me very important that the group has been able to nurture each person's spirituality apart from any traditional, doctrinal creeds and practices, and is looking at ways of exploring providing a similar opportunity for other staff. The finding that an increased sensitivity to a sense of connectedness is central to an increased awareness of spirituality I also find basic and valuable. And I am engaged by your finding that

'spiritual connectedness' and 'two spirits meeting' and 'just being' is more what it is all about on the job than the use of a spiritual assessment tool. This sounds as though people got to the heart of the matter.

I think your report reads well and does give the flavour and feel of what you were doing and how you were being. In terms of presentation, I see how you have used the four stages in four subheadings. Actually in my book, pp 49-50, these four stages were simply outlined as stages of the first full cycle from initial reflection to first action to second reflection phase. It might have been a little clearer simply to give an account of the actual chronological sequence of reflection and action phases, one after the other, as in my para 4 above (any issues to do with full immersion could be mentioned in passing in accounts of the action phases). However, I did tease the overall structure out fairly quickly.

As you say, the repeat cycling itself helps the validity of the inquiry, and I see you had mutual challenging going on in the second reflection phase. I found myself wondering whether there was any need to do any kind of emotional processing about anxiety and distress provoked in any way by the topic and process of the inquiry (pp 149-152 in CI).

It does seem to have been a remarkably successful and effective first go, and I wish you well with its concluding phases. Do keep me posted about future developments stemming from it.

With warm regards

John

Appendix 7: SPIRITUAL ASSESSMENT

Giske (1993) identifies three fundamental human concerns which underpin spiritual need:

- ◇ Security and hope
- ◇ Meaning and purpose
- ◇ Dignity and identity

Spiritual assessment questions, from a number of sources which are listed below, were discussed by the co-operative inquiry group in the group's third reflective period. The themes identified above were used roughly group a number of questions as indicated below. The following summary shows questions that co-operative inquiry group members felt they were most likely to use in italics. Group members tried using these questions during their assessments both between sessions in the third reflective period and in the final active period. The questions were also used in the MPaCE module.

Security and Hope (where am I going?):

- *Do you believe in any kind of existence after this life?*
- Has the recurrence or presence of pain changed any attitudes you had regarding your future?
- *What is your source of strength and hope?*
- What does having a sense of hope mean to you?
- What things do you do personally that give you hope?
- *What inner resources do you draw upon?*
- Who do you turn to when you need help? are they always available? In what ways do they help?
- What are your three greatest sources of strength?
- When you want to feel comforted, where do you go or who do you see?
- Who/what do you depend on when things go wrong?
- *How can I assist you in maintaining spiritual strength?*

Meaning and purpose (why am I here?):

- How would you describe the main purpose of your life?
- What goal do you have that is most important to you right now?
- What has bothered you most about being ill?

- How would you respond to someone who said 'are you ready for your life to come to an end' ?
- Is there anything that's especially frightening or meaningful to you at the moment?

Dignity and identity (who am I?):

- Do you feel that your faith or religion is helpful to you?
- Has being ill changed your feelings about this?
- *Do you pray?*
- Is prayer helpful to you? if so, how?
- Is God or any other power important to you?
- Has your illness affected your faith/belief system?
- Do you feel worried or concerned about anything in your life?
- Are there religious rituals that are important to you now?
- *Is religion or God significant to you?*
- How would you describe the God that you worship?

SOURCES OF SPIRITUAL ASSESSMENT QUESTIONS:

Elsdon (1995) Spiritual Pain in Dying People: the nurses role
Professional Nurse 10 (10): 641-643

Giske (1995) Spiritual Care in Nursing Practice
Christian Nurse International 11 (4):4-8

Georgesesen and Dungan (1996) Managing Spiritual Distress in Patients with Advanced Cancer Pain
Cancer Nursing 19 (5): 376-383

Labrun (1988) Spiritual Care: an element in nursing care planning
Journal of Advanced Nursing 13:314-320

Post White et al (1996) Hope, Spirituality, Sense of Coherence and Quality of Life in Patients with Cancer
Oncology Nursing Forum 23 (10):1571-1579

Smith (1993) Exploring the Religious and Spiritual Needs of the Dying
Counselling and Values 37:71-77

Stoll (1979) Guidelines for Spiritual Assessment
American Journal of Nursing September 1979:1574-1577

Appendix 8: ASSUMPTIONS AND PRINCIPLES OF SPIRITUAL CARE

Developed by the Spiritual Care Work Group of the International Work Group on Death, Dying and Bereavement. Published in *Death Studies* (1990) 14:75-81

General

1: Assumption: Each person has a spiritual dimension.

Principle: In the total care of a person, his or her spiritual nature must be considered along with the mental, emotional and physical dimensions.

2: Assumption: Spiritual orientation influences mental, emotional and physical responses to dying and bereavement.

Principle: Caregivers working with dying and bereaved persons should be sensitive to this interrelationship.

3: Assumption: Although difficult, facing terminal illness death and bereavement can be a stimulus for spiritual growth.

Principle: Persons involved in these circumstances may wish to give spiritual questions time and attention.

4: Assumption: In a multicultural society, a person's spiritual nature is expressed in religious and philosophical beliefs and practices which differ widely depending on one race, sex, class, religion, ethnic heritage and experience.

Principle: No single approach to spiritual care is satisfactory for all in a multicultural society, many kinds of resources are needed.

5: Assumption: Spirituality has many facets. It is expressed and enhanced in a variety of ways both formal and informal, religious and secular, including, but not limited to, symbols, rituals, practices, patterns, and gestures, art forms, prayers and meditation.

Principle: A broad range of opportunities for expressing and enhancing one's spirituality should be available and accessible.

6: Assumption: The environment shapes and can enhance or diminish one's spirituality.

Principle: Care should be taken to offer settings which will accommodate individual preference as well as communal experience.

7: Assumption: Spiritual concerns often have a low priority in health care systems.

Principle: Health care systems presuming to offer total care should plan for and include spiritual care as reflected in a written statement of philosophy and resources of time and money and staff.

8: Assumption: Spiritual needs can arise at any time of day or night and any day of the week.

Principle: A caring environment should be in place to enhance and promote spiritual work at any time not just at designated times.

9: Assumption: Joy is part of the human spirit. Humour is a leaven needed even, or especially, in times of adversity or despair.

Principle: Care givers, patients and family members should feel free to express humour and to laugh.

Individual and Family (Natural and Acquired)

10: Assumption: Human beings have diverse beliefs, understandings and levels of development in spiritual matters.

Principle: Care givers should be encouraged to understand various belief systems and their symbols; as well as to seek to understand an individual's particular interpretation of them.

11: Assumption: Individuals and their families may have differences in spiritual insights and beliefs. They may not be aware of these differences.

Principle: Care givers should be aware of differences in spirituality within a family or close relationship and be alert to any difficulties which might ensue.

12: Assumption: The degree to which the patient and family wish to examine and share spiritual matters is hugely individual.

Principle: Caregivers must be non intrusive and sensitive to individual desires.

13: Assumption: Health care institutions and professionals may presume they understand or may ignore the spiritual needs of dying persons.

Principle: Spiritual needs can only be determined through a thoughtful review of the spiritual assumptions, beliefs, practices, experiences, goals and perceived needs with the patient or family and friends.

14: Assumption: People are not always aware of, nor able, nor wish to articulate spiritual issues.

Principle (1): Care givers should be aware of individual desires and sensitive to unexpressed spiritual issues.

Principle (2): Individuals need access to resources and to people who are committed to deepened exploration of and communication about spiritual issues.

15: Assumption: Much healing and spiritual growth can occur in an individual without assistance. Many people do not desire or need professional assistance in their spiritual

development.

Principle: Acknowledgement and support, listening to and affirming an individual's beliefs or spiritual concerns should be offered and may be all that is needed.

16: Assumption: Patients may have already provided for their spiritual needs in a manner satisfactory for themselves.

Principle: The patient's chosen way of meeting spiritual needs should be honoured by the caregivers.

17: Assumption: The spiritual needs of dying persons and their families may vary during the course of illness and fluctuate with changes in physical symptoms.

Principle: Caregivers need to be alert to the varying spiritual concerns that may be expressed directly or indirectly during different phases of illness.

18: Assumption: Patients and their families are particularly vulnerable at the time of impending death.

Principle: Caregivers should guard against proselytising for particular types of beliefs and practices.

19: Assumption: As death approaches, spiritual concerns may arise which may be new or still unresolved.

Principle (1): Caregivers should be prepared to work with new concerns and insights as well as those which are long standing.

Principle (2): Caregivers must recognise that not all spiritual problems can be resolved.

20: Assumption: The spiritual care of the family may affect the dying person.

Principle: Spiritual care of family and friends is an essential component of total care for the dying.

21: Assumption: The family's need for spiritual care does not end with the death of the patient.

Principle: Spiritual care may include involvement by caregivers in the funeral and should be available throughout the bereavement period.

Caregivers

22: Assumption: Caregivers, like patients, may have or represent different beliefs as well as different spiritual or religious backgrounds and insights.

Principle: Caregivers have the right to expect respect for their belief systems

23: Assumption: Many health care workers may be unprepared or have limited personal development in spiritual matters

Principle (1): Staff members should be offered skilfully designed opportunities for

exploration of values and attitudes about life and death, their meaning and purpose.

Principle (2): Caregivers need to recognise their limitations and make appropriate referrals when the demands for spiritual care exceed their abilities or resources.

24: Assumption: The clergy is usually seen as having primary responsibility for the spiritual care of the dying.

Principle: Caregivers should be aware that they each have the potential for providing spiritual care, as do all human beings, and should be encouraged to offer spiritual care to dying patients and their families.

25: Assumption: Caregivers may set goals for the patient, the family, and themselves which are inflexible and unrealistic. This may inhibit spontaneity and impede the development of a sensitive spiritual relationship.

Principle: Care givers and health care institutions should temper spiritual goals with realism.

26: Assumption: Ongoing involvement with dying and bereaved persons may cause a severe drain of energy and uncover old and new spiritual issues for the caregiver.

Principle: Ongoing spiritual education, growth and renewal should be part of the staff program as well as a personal priority for each caregiver.

Community Co-ordination

27: Assumption: Spiritual resources are available within the community and can make a valuable contribution to the care of the dying patient.

Principle: Spiritual counsellors from the community should be integral members of the caregiving team.

28: Assumption: No one caregiver can be expected to understand or address all the spiritual concerns of patients and families.

Principle: Staff members addressing the needs of patients and families should utilise spiritual resources and caregivers available in the community.

Education and Research

29: Assumption: Contemporary education for health care professionals often lacks reference to the spiritual dimension of care.

Principle: Health care curricula should foster an awareness of the spiritual dimension in the clinical setting.

30: Assumption: Education in spiritual care is impeded by a lack of fundamental research.

Principle: Research about spiritual care is needed to create a foundation of knowledge which will enhance education and increase the spiritual aspect of the provision of health care.

31: Assumption: Freedom from bias is a problem in the conduct of research into spiritual care.

Principle: Research should be carried out into the development and application of valid and reliable measures of evaluation.

Glossary¹

Assumption: The act of taking for granted.

Principle: A general or fundamental truth, a governing law of conduct.

Acquired Family: Friends who have a special relationship, share the same household but are not related by blood or marriage.²

Bereavement: Loss of loved one by death.

Care: To provide for or attend to needs.

Caregiver: One that gives care.

Clergy: A body of religious officials or functionaries prepared and authorised to conduct religious services and attend to other religious duties.

Existential: Based on the experience of existence: empirical as contrasted with theoretical.

Grief: Emotional suffering as caused by bereavement.

Integrity: The quality or state of being complete or undivided: material, spiritual or aesthetic wholeness.

Need: A want of something requisite, desirable or useful.

Proselytise: To (wittingly³) convert from one belief attitude or party to another.

Religion: The personal commitment to and serving of God or a god (transcendental power⁴). The worshipful devotion, conduct in accord with divine commands especially as found in accepted sacred writings or declared by authoritative teachers.

Spiritual: Relating to the nature of the spirit rather than the material.

Spiritual dimension: Sensitivity or attachment to religious values and things of the spirit rather than material or worldly interests.

¹ It was recommended that an international dictionary be utilised to define the terms contained in the glossary of a document propounded by an international body of scholars and clinicians, Sources Websters Third New International Dictionary of the English Language, 1981, Unabridged, Springfield MA: G & C Mirriam C.

² Definition developed by Work Group Members.

³ Modified to incorporate noun of intentionality.

⁴ Modified to amplify concept of deity.

APPENDIX 9: OUTLINE OF THE MPaCE SPIRITUALITY MODULE

As described in chapter seven, Manchester Palliative Care Education Forum (MPaCE) is a palliative care education initiative based in Manchester. MPaCE provided the framework in which to develop a continuing education module about spirituality which was one of the outcomes of the co-operative inquiry.

Appendix 9 includes the following:

9a: Overview of all the modules available within the MPaCE Framework

9b: Routes of access available within MPaCE

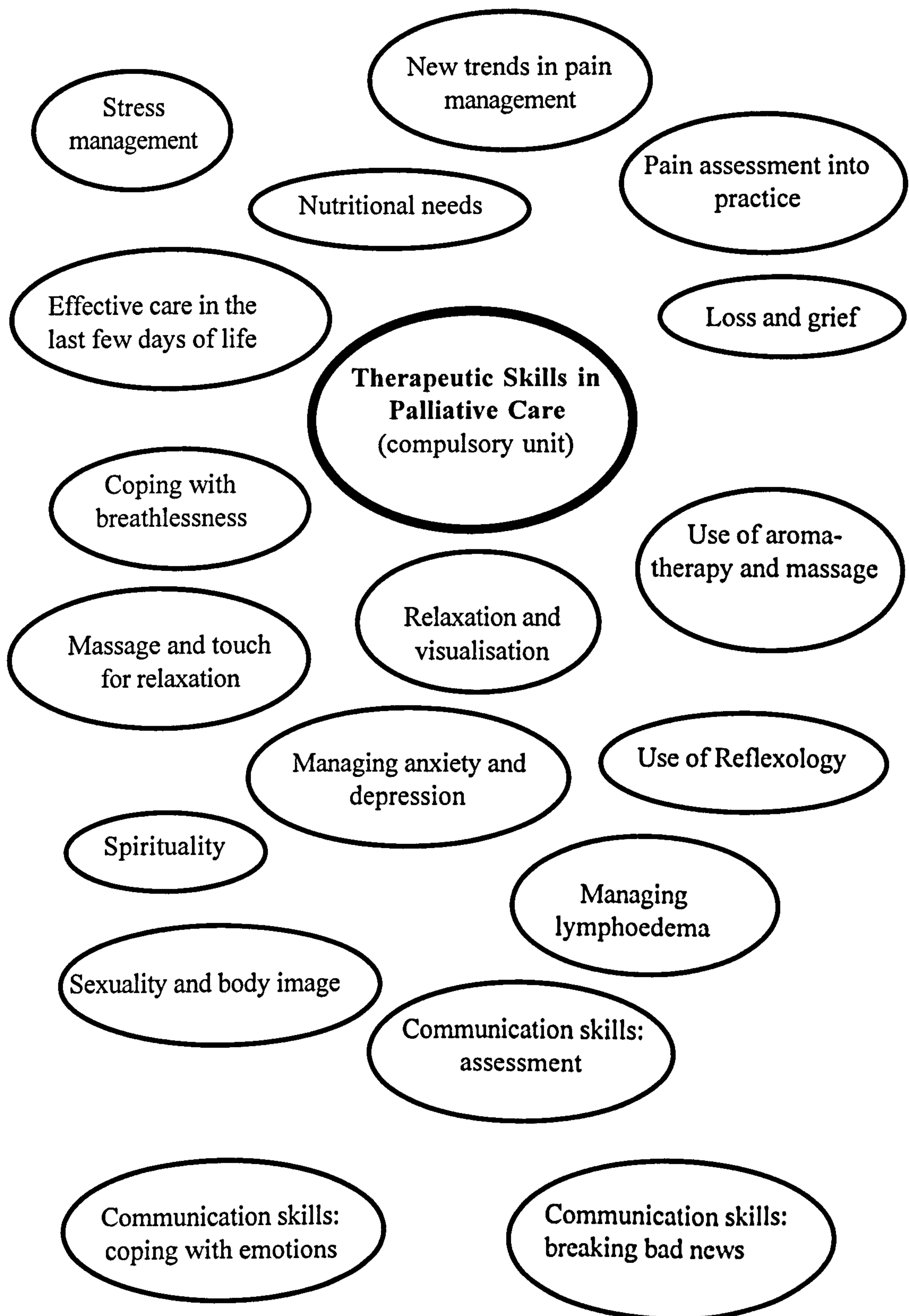
9c: Initial information about the MPaCE Spirituality Module

9d: Session notes for MPaCE Spirituality Module (course one, five sessions) + follow up meeting

9e: Session notes for MPaCE Spirituality Module (course two, three sessions)

9f: Evaluation notes for MPaCE Spirituality Module (course one and two)

Appendix 9a: Modules available within the MPaCE framework



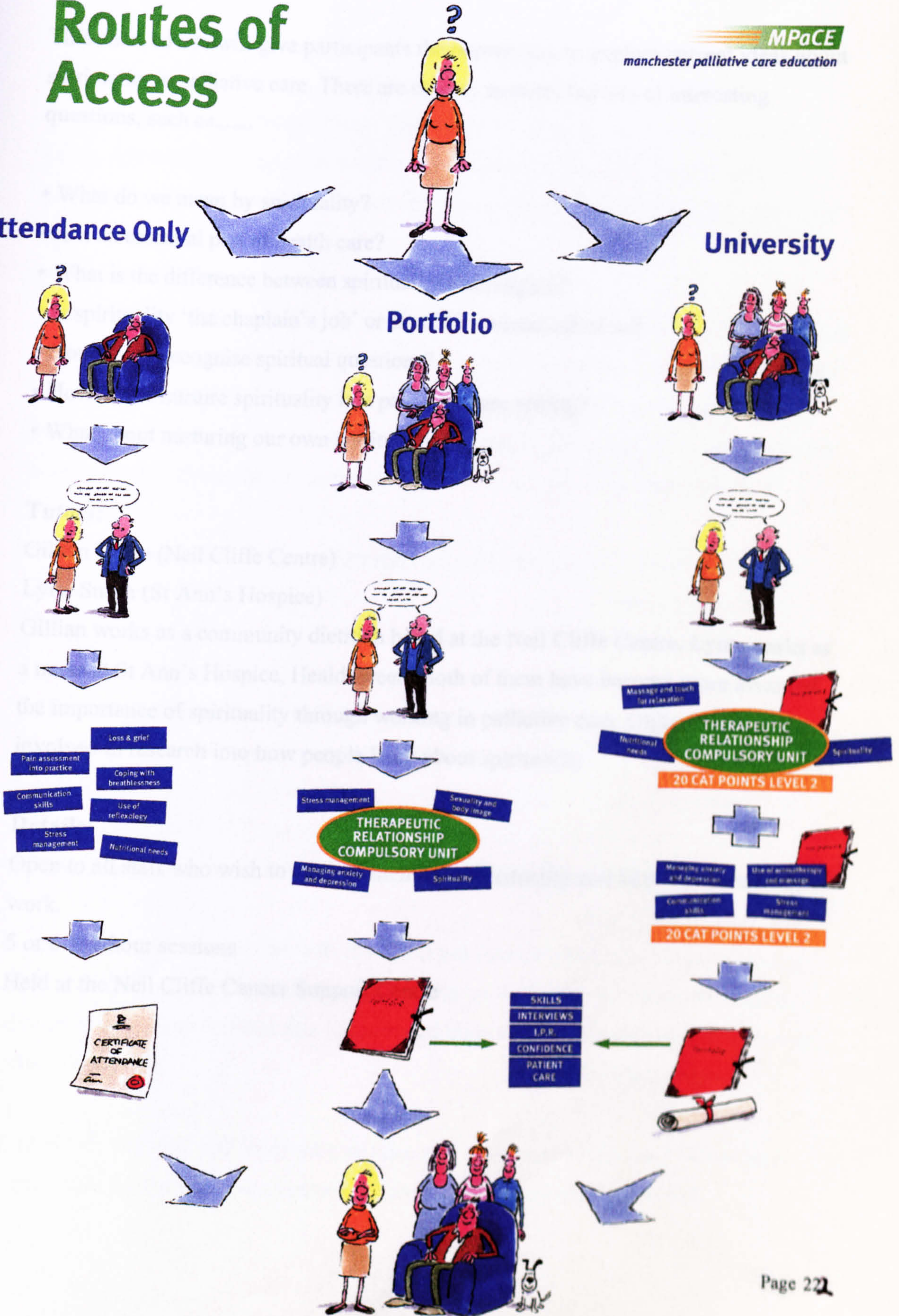
MPaCE Therapeutic Skills in Palliative Care

Routes of Access

Attendance Only

University

Portfolio



Appendix 9c: Initial Information about the MPaCE spirituality module

Spirituality in Palliative Care: luxury or necessity??

This short course will give participants the opportunity to explore current ideas about spirituality in palliative care. There are no easy answers but lots of interesting questions, such as.....

- What do we mean by spirituality?
- Is it an essential part of health care?
- What is the difference between spirituality and religion?
- Is spirituality 'the chaplain's job' or should it concern all of us?
- How do we recognise spiritual questions?
- How do we nurture spirituality in a palliative care setting?
- What about nurturing our own spirituality?

Tutors:

Gillian White (Neil Cliffe Centre)

Lynn Smith (St Ann's Hospice)

Gillian works as a community dietitian based at the Neil Cliffe Centre, Lynn works as a nurse at St Ann's Hospice, Heald Green. Both of them have become more aware of the importance of spirituality through working in palliative care. Gillian is currently involved in research into how people learn about spirituality.

Details:

Open to all staff who wish to explore their own spirituality and how it relates to their work.

5 or 6 X 2 hour sessions

Held at the Neil Cliffe Cancer Support Centre

Appendix 9d: Sessions notes for MPaCE spirituality module (course 1, 5 sessions)

Session One:

5.00pm: Tea/Coffee, register

5.15pm: **Welcome, introductions:** The impact of spirituality on health and well being, spirituality as part of an holistic approach to health. Why is spirituality particularly relevant in palliative care? any other areas or times of life? (Experience of leaders)

5.30pm: **Ethos of the module:** no easy answers, emphasis on exploring the issues and learning together. Every ones contribution is important. Should be enjoyable. Plan for the course (handout). Learning/exploring about own spirituality rather than learning just 'the theory'. Fellow travellers. Establishing ground rules to create a safe place for students to talk about their own experience. *Flip chart, handout*

6.00pm: **Brainstorm:** Religion/ Spirituality/God (New methods in RE teaching, Hammond et al 1990: 6-9). *3 sheets of flip chart, Blu tack, pens, paper*

6.15pm: **Defining spirituality** Brief presentation of definitions taken from the literature plus peoples reactions to them (Dictionary of Christian Spirituality, Leeds Institute, Renetzky). *Flip charts*

6.25pm: **Rose window activity** (cf Hammond et al 1990:99)

6.50pm: **Introduction of the reflective journal** (starter sheet plus Hammond et al 1990:29). Time to start the process of reflecting by writing about either the recent discussions or a key incident that has affected their thinking about spirituality or rose window activity. *Handout, paper*

Link Work: Students will be given a number of key articles to read and reflect on in preparation for the next two sessions. Explain assessment. Bulletin board

Session Two:

4.45pm: Tea/Coffee available

Bulletin board

5.00pm: **Register**

5.10pm: **Reflection Time:** feedback from reflective journals or the week

5.30pm: **Reviewing key themes:** Tutors to introduce each theme and lead onto group discussion based on reading and personal experience.

Block One:

- spiritual experiences including culture
- religion and spirituality

Summary: spirituality as an innate potential which can grow *OHP acetate*

Block Two:

- connection
- meaning, purpose and fulfilment
- hope

Summary: spirituality as an integrating force

OHP acetate

6.50pm: Reminder about presentations, additional articles to review if needed. Summarise what the article says and give personal reflection on it (what did you think?)

Articles

Introduce Link Work: Students continue to reflect on their spiritual experience and journey and prepare for presentation. Give out 'hope wheel' to reflect on for next time.

Session Three:

4.45pm: Coffee/tea available

Bulletin board

5.10pm: **Group Reflection:** any reflections from the week that has gone, hope wheel

5.30pm: **Short presentations by participants** based on their reflections on one of the articles plus discussion. *(NB Check who is covering which article and group feedback, ask for a volunteer to start.)*

Ideas that could come up in discussions:

- ❑ Everyday meaning and ultimate meaning.
- ❑ What gives life meaning for us and our clients?
- ❑ Frankl: coping better if have a meaning, suffering ... what destroys is not suffering but suffering without meaning.
- ❑ Finding a language for spirituality.
- ❑ Use of metaphor in spirituality.
- ❑ Images/pictures we use and clients use.
- ❑ Recognising when people want to talk about spirituality.

Introduce Link Work: Reflect on experience of spirituality in health care. How do they recognise spiritual questions? any questions about spirituality in assessment information? how do we get beyond our own spirituality?

Articles

Session Four:

4.45pm: Coffee/tea available

Bulletin Board

5.10pm: **Reflection Time**

Awareness exercise (Hammond et al 1990:55)

5.30pm: **Roles:**

- Spirituality and the multidisciplinary team
- Brainstorm: Who provides spiritual care and how? *Handout*

(NB Refer to therapeutic core if appropriate.... facilitating rather than telling, being with rather than doing to)

6.00pm: **Assessment:** Spirituality often neglected or not recognised (Ross, Simson, Highfield and Casson). Why might this be? Discuss participants experience. SWOT analysis of using a spiritual assessment (in two groups plus feedback depending on group). *Flip chart*

Summary of spiritual assessment tools/questions. *Handout*

Introduce modified spiritual assessment tool for use with a trusted colleague or other group member. *Assessment tool*

6.40pm: **Provision:** How are spiritual needs met?

Use of spiritual care plans, balance of task and attitude, safety.

NB Look out for ideas of space, retreat, others, telling stories, ritual, intuition

Emphasise individuality but may include creativity, music, listening, religious needs.

Need for humour and sensitivity.

Link Work: Use modified spiritual assessment tool.

For next week: Telling Our Own Story (an activity to end the course)... bring in something that speaks about their own spirituality that they are happy to share with each other (e.g. photograph of themselves at a stage that is important to them or book, artefact)

Session Five:

4.45pm: Coffee/ tea available

Bulletin board

5.10pm: **Reflection Time:** Feedback about using the assessment tool.

5.30pm: **Nurturing spirituality as an institution.** What is done? What could be done? (Be realistic.) *Brainstorm to flip chart*

Prompts if needed: Professional roles and boundaries, team work, the role of volunteers, chaplains, creativity, space, openness, spirituality as integral.

6.00pm: **Evaluation:** Examining the process of the group and its impact on our spirituality. Confidence, awareness, practice. *Tape + evaluation form*

MPaCE evaluation forms to complete, time to sign certificates and forms for portfolio.

Give back skills assessments

6.30pm: **Telling our own stories...** photograph or artefact!

- What nurtures spirituality for us?
- How do we 'feed' ourselves?
- What support systems are available that might help?

Drawing the threads together. Where do we go next?

Optional Reunion:

4.45pm: Tea or coffee and cakes available

5.15pm: Reflection Time:

- How have things been since the course?

- How has the course affected them? initially and on going?

Case stories of people we have been involved with since the course who seem to have particular links to spirituality (Facilitators to start)

Effect on knowledge and awareness, practice

List of contacts

Expanded book list

Appendix 9e: Session notes for MPaCE Spirituality Module (course 2, 3 sessions)

Session one:

1.30pm: Welcome, Introductions

The impact of spirituality on health and well being, spirituality as part of an holistic approach to health. Why is spirituality particularly relevant in palliative care? any other areas/ times of life? (Experience of leaders)

1.45pm: Ethos of the module: no easy answers, emphasis on exploring the issues and learning together. Every ones contribution is important. Should be enjoyable. Plan for the course (handout). Learning/exploring about own spirituality rather than learning just 'the theory'. Fellow travellers. Establishing ground rules to create a safe place for students to talk about their own experience. *Flip chart, handout*

2.05pm: Brainstorm: Religion/ Spirituality/God (New methods in RE teaching, Hammond et al 1990: 6-9). *Blu tack, pens, flip chart paper*

2.20pm: Defining Spirituality: Brief presentation of some definitions from the literature plus peoples reactions to them (Dictionary of Christian Spirituality, Leeds Institute, Renetzky).

2.30pm: Rose window activity (cf Hammond et al 1990:99)

2.45pm: Break for tea/coffee and biscuits

3.00pm: Reviewing key themes: *Block One:*

- spiritual experiences including culture
- religion and spirituality (?brain storm spiritual needs, religious needs)

Summary: spirituality as an innate potential which can grow

3.30pm: *Block Two:*

- connection
- meaning, purpose and fulfilment
- hope (give out hope wheel to reflect on for next time)

Summary: spirituality as an integrating force (warp & weft of personality).

4.00pm: *Link Work:* participants will be given a number of key articles to read and reflect on in preparation for the next session. Each person should prepare a written review of one of these articles (or a different one by agreement with tutors). Summarise what the article says and give personal reflection on it (what did you think?)

Articles, Pin board for notes, clippings or articles

4.15pm: *Introduction of the reflective journal* (starter sheet plus Hammond et al 1990:29). Time to start the process of reflecting by writing about either the recent discussions or a key incident that has affected their thinking about spirituality or rose window activity.

Hope wheel/ Handout/paper

Session 2:

1.30pm: Reflection Time: Any reflections from the week that has gone? hope wheel

1.50pm: Short presentations by participants based on their reflections on one of the articles plus discussion. (NB Check who is covering which article and group feedback, ask for a volunteer to start, break in the middle somewhere for a drink).

Ideas to highlight in discussions:

- **everyday meaning and ultimate meaning.** What gives life meaning for us and our clients? Frankl talks of coping better if have a meaning, suffering ... 'what destroys is not suffering but suffering without meaning'.
- **finding a language for spirituality.** Use of metaphor in spirituality. Images/pictures we use and clients use. Dandelions, journey
- **recognising when people want to talk about spirituality.**

4.10pm: Introduce Link Work: Reflect on experience of spirituality in health care. How do they recognise spiritual questions? any questions about spirituality in assessment information? how do we get beyond our own spirituality? *articles*

For next week: Bring in a photograph or something of themselves at a stage or event that is significant to their spirituality or to who they are. Something they are prepared to share with others.

Session 3:

1.30pm: Reflection time. Awareness exercise (Hammond et al 1990:55) if time

1.50pm: Whose role is spirituality in health care/palliative care?

Who provides spiritual care and how?

Brainstorm with summary on acetate and as handout. Refer to therapeutic core if appropriate.... ie facilitating rather than telling, being with rather than doing to.

2.15pm: Assessment: Spirituality often neglected or not recognised (Ross, Simson, Highfield and Casson). Why might this be?

Discuss their experience with assessment.

Formal spiritual assessment: Is it included? how? SWOT analysis of using a spiritual assessment (? in two groups).

flip chart

Written summary of spiritual assessment tools/questions plus modified spiritual assessment tool which could be tried or use questions in generic assessment

handout notes, assessment tool

2.45pm: Break for a drink:

3.00pm: Provision of spiritual care: How are spiritual needs met? who helps? where do you turn? regular and emergency? (highlight space, retreat, others, telling stories, ritual, intuition)

Discuss use of spiritual care plans, balance of task and attitude, safety. Emphasise individuality but may include creativity, music, listening, religious needs. Need for humour and sensitivity.

Winnie the Pooh acetate

3.30pm: Nurturing spirituality as an institution. What is done? What could be done? Being realistic.

Brainstorm to flip chart

Prompts if needed: Professional roles and boundaries, importance of team work, the role of volunteers, chaplains, creativity, space, openness, spirituality as integral

3.45pm: **Evaluation:** Examining the process of the group and its impact on our spirituality. Confidence, awareness, practice. *Evaluation form*

4.00pm: **Final activity** *Telling our own stories...* photograph or artefact!

What nurtures spirituality for us? How do we 'feed' ourselves? What support systems are available that might help?

Drawing the threads together. Where do we go next? ? reunion, ? contact list

**Appendix 9f: End of Course Evaluation notes for MPaCE Spirituality Module
(Course One, mixed course, written and verbal evaluation):**

Did the course meet your clinical needs?

7/8 participants felt the course met or enhanced their clinical needs, the exception was a volunteer who felt their needs were not clinical but it did meet other needs.

Was sufficient time given to each skill?

Generally participants felt that the course did include adequate time with a sense of space to discuss issues. One participant commented that they would miss the course. Another participant felt the topic warranted longer overall, although the time for discussion in each session was good. A request was made for follow up or continued contact with course participants.

Skills Taught within the course

Assessment (4)

Reflection and self awareness (4)

Communication skills

Holistic approach

Multidisciplinary working

Non judgmental

The width of the topic

How do you envisage using what you have learnt in your clinical practice?

Assessment skills used with patients (3)

More confident generally (3)

More confident about integrating spiritual care in a holistic framework

More comfortable working with clients, helping them to look at their spiritual needs

More aware of spirituality in others (3)

More sensitive to spiritual needs in others and more able to respond appropriately

Sharing the ideas gained with colleagues and addressing the issues at work

Encouraging other staff to do the course

More aware of my own spirituality and spiritual needs (3)

More able to separate my spiritual needs from client's needs

Additional Material From Taped Discussion:

Outcomes:

More sensitive and aware

More able to assess

Able to see things differently

Clarified thinking

Making me look at it on a personal level

More confident and comfortable

Especially important aspects of the module:

The variety of opinions and ideas, relevant to everyone whatever their grade and background

Talking about our own experience

Literature and references

The supportive environment

Other people (fellow health care professionals) understanding what its like

I've come feeling tired but have got new strength from each meeting

The integration of spirituality into professional care

Seeing beyond the disease to the person (patients and carers), what is important to them, what gives their lives meaning

Coping with practical aspects of care as well as providing spiritual care

This has reminded me why I went into medicine!

**Appendix 9e: End of Course Evaluation notes for MPaCE Spirituality Module
(Course two, internal course, written evaluation):**

Has the module affected your awareness of spirituality:

Yes (4)

Clearer concept but still many questions (2)

More depth and more aware of the variety within spirituality

More aware of the importance of spirituality and how we often skim the surface

Has the module affected your confidence:

Less frightened of discussing spirituality

More able to explore issues with patients, and to meet others where they are

Reassured that I don't need to have all the answers

More confident about including spirituality in assessment

Greater knowledge of the subject which naturally brings confidence

More aware how others see the subject

More aware of my own spirituality and of the essence of spirituality

Will the module affect your practice:

Will use it in assessments (3)

Need to review current documentation for assessment to include spirituality

More confident about addressing spiritual needs as well as religious needs

What is the most important thing you have gained from the module:

Chance to focus and reflect, supportive literature was helpful

A starting point for growth in this area, personally and professionally (2)

I will think about taking care of myself spirituality

Interaction with others, sharing experiences and thoughts, concepts

More awareness of spirituality and how it can be for others

Got to know colleagues better and how they tick

Anything else that could have been included:

Want to focus on applying it to patients more

Need to gain confidence in dealing with spiritual distress

More on assessment and planning

Would a mixed gender group have made any difference?

More about the research that has been done

Time to make a collage!

More about practical ways of accessing spiritual meaning for people

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