Psychosocial Oncology & Palliative Care in Hong Kong

The First Decade

Edited by

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1 Psychosocial and Palliative Care in the Chinese Context: The Challenges Ahead

Cecilia Lai-wan Chan and Richard Fielding

INTRODUCTION

We learn about cancer, death and bereavement from our patients. Their stories of courage and perseverance have given us the energy to put this book together. Their experiences, time and, in some cases, even money to support research have been given with a generosity that is hard to match. We become knowledgeable about the cancer experience because patients and their family members so willingly share their stories, pain and joy with us. We have learnt about their strength in the face of adversity and of their sometimes amazing capacities to cope with what, to most of us, would be overwhelming demands in facing cancer, dying and bereavement. It is sometimes hard to imagine any benefit from these diseases, yet these stories are the 'gifts' that cancer can bring (LeShan, 1989).

This book brings together a mixed collection of care experience, practice wisdom and careful research. In many cases the authors have developed these approaches through direct daily work with cancer patients, survivors and their family members. These chapters reflect special efforts made to research and develop culturally relevant and gender-sensitive practices appropriate to the Chinese population in Hong Kong (Lee, 1978, 1984; Sheik and Sheik, 1989; Ho, 1991; Fielding et al., 1994; Tang, 1994; Fielding, Ko and Wong, 1995; Ma, 1995; Fielding and Hung, 1996; Tsang, 1996; Chan and Rhind, 1997; Chow, 1995; Fielding, Wong and Ko, 1998). We have deliberately tried to include as wide a range of material as possible to give some flavour of the kinds of work that has been done so far. All this work has one thing in common: it focuses on improving care practices for patients with cancer in Hong Kong.

CURRENT STATE OF THE ART

Many millions of people in the world today are surviving with a cancer and there are probably more than 200,000 of them in Hong Kong. A number of developments have taken place in Hong Kong during the past decade to support and facilitate people's journeys with cancer. These include self-help groups, voluntary organizations and charities, improved patient-centred hospital services, and more psychosocially aware staff trained in a wider range of techniques. These developments have been driven partly by research and partly by sheer determination, in some cases through the efforts of one or two individuals, to raise both the awareness of need and the funds to meet those needs. The development and implementation of these interventions has been disseminated to the local and international health care and scientific communities through a series of conferences, principally the Hong Kong International Cancer Congress (HKICC) and more recently the annual Hospital Authority Convention.

As a result people have begun to change their attitudes towards cancer and cancer care, and survivorship and dying within the community of Hong Kong. This is important because it reflects a growing attempt by people themselves to regain both their dignity and control over their lives when cancer emerges or re-emerges in their families. Survivors are forming self-help groups, via support networks based in major hospitals and community support centres such as CancerLink, the Stoma Association and the New Voice Club. The Stoma Association was founded twenty years ago (in 1979) and the New Voice Club for laryngectomees has existed for fifteen years (since 1984). There are now almost thirty community and hospital-based groups for different site-specific cancers in Hong Kong (Chan et al., 1996).

Many of these organizations, both the self-help and the hospital-based cancer centres, were originally funded by charitable groups including The Hong Kong Cancer Fund (HKCF), the Society for the Promotion of Hospice Care (SPHC) and the Children's Cancer Foundation. Other groups, including Wishing Well, PlayRight and Treat, have also worked very hard during the past decade to promote the total well-being and overall quality of life of young cancer patients. These groups have contributed resources, time and organizational acumen to help promote new ideas for care and attitude change among professionals and more tangible material support such as information on cancer to consumers. The HKCF and SPHC in particular sponsored parallel conferences at the HKICC meetings over the past five years, where innovative techniques for facilitating cancer care were shared. These techniques include music therapy, art therapy, psycho-educational groups, clinical communications, health information and screening, diet and alternative health care (Chan et al., 1996). The HKCF has published more

than forty information booklets on various aspects of different cancers both in Chinese and in English. Without these organizations, it is questionable that the improvements seen would have occurred anywhere near as rapidly, if at all.

Regional hospitals in Hong Kong have cancer patient resource centres. Queen Mary Hospital, Queen Elizabeth Hospital, Pamela Youde Nethersole Eastern Hospital, Tuen Mun Hospital and Kwong Wah Hospital provide psychosocial care and information support to cancer patients. Information booklets provide an anchor for patients during the most desperate period of diagnosis. In some cases, these hospitals have highly specialized units providing holistic care, such as the Kwong Wah Breast Centre. More than ten hospitals now have hospice beds or day chemotherapy clinics, and one dedicated hospice for cancer and a second for HIV/AIDS have opened. All these services started to mushroom in the 1990s.

Professionals are also realizing the value of being organized in order to provide the best possible care for patients. New professional organizations such as the Society for Palliative Medicine, a society for oncology nurses, and an informal group of oncology social workers have formed recently to promote and improve professional oncology care. However, psycho-oncology has remained underdeveloped and the number of psychologists working in oncology in Hong Kong remains lamentably small. In part, this has been due to the tendency of hospitals to employ social workers as generic psychological and social care specialists from a time when there was a lack of available psychologists. Now psychologists see the niches filled with social workers and this view is shared by the Hospital Chief Executives. Psychological services need to be further developed and included as a key component of a broad approach to oncology and palliative care. Psychiatric services are beginning to be provided for cancer patients at some Hong Kong hospitals.

Lastly, it is important to stay focused on the need to encourage high standards of evaluation and audit for established and new services, care and activities in the area of cancer support in Hong Kong. This has been helped, in part, by the Young Investigator Awards, given annually at HKICC, stimulating a number of local studies among front-line workers who might not otherwise have tried to evaluate their activities. These have contributed to improving our understanding of patients' needs, their quality of life and their response to innovative psychosocial care and palliative treatment. However, much more needs to be done, especially with culturally sensitive practices (Chan et al., 1998). Most of the services provided have never been carefully evaluated, and where attempts have been made, these have tended to lack methodological rigour. The challenge we now face is to improve the quality of research in clinical psychosocial oncology and other aspects of cancer care as much as is possible. We need to reach a position where we

know that what we are doing is beneficial to the recipients, and where we have good evidence that this is so. So long as evidence is lacking, we must be prepared to accept that we may not be doing as much good as we believe or hope, or that the good we think we are doing is, in fact, occurring as a result of other activities or reasons.

FUTURE DIRECTIONS

Evidence-based interventions

Psychosocial care will have to produce more evidence of effective and beneficial outcomes in order to establish credibility. Practitioners and researchers must assign time and effort to carefully document and evaluate interventions to provide good-quality evidence of the benefits of psychosocial care in quality of life, treatment outcomes, survival and quality of death. This should include economic evaluations to assess the costs and benefits of interventions (Doyle, Hanks and MacDonald, 1998). Nurses, radiographers, psychologists and social workers across Hong Kong are conducting clinical practice research to assess the effectiveness of interventions in information support and psychosocial care. Queen Mary Hospital is starting a roving hospice unit to provide pain and palliative consultation for all departments in the hospital. Other universities overseas have specialty teams or staff working for children and adults with particular cancers. We also need to research the differences in quality of life of dying patients receiving palliative or domiciliary care. Persistent hard work pays off, and, in oncology and hospice units, psychosocial and palliative care can soon become an integral part of oncology care if we provide the evidence of cost-effectiveness. Queen Mary Hospital has been experimenting with *qi gong* exercises since 1998. More can be done in the area of alternative services for cancer patients (Fink, 1988), but must be evaluated if they are to be accepted on a par with existing services.

Creative and innovative approaches in intervention

Instead of struggling and fighting against cancer, there is a tendency for Chinese patients to become submissive (Sheikh and Sheikh, 1989; People's Medical Publishing House, 1984). Cultural myths about grief and bereavement also compound the difficulties individuals face in adapting to

the changes brought to their lives by cancer, as well as through death (Chan et al., 1998; Gibbs and Achterberg-Lawlis, 1978). Local practitioners have tried innovative approaches, including art in counselling, group work in cancer and bereavement counselling. The creative therapeutic use of culturally relevant concepts and art media hold great promise of effectiveness in helping cancer patients to express their emotions and attain a more relaxed state of mind (Fromm, 1970; Rossi and Cheek, 1988). There is now a need to move beyond these first-generation approaches to evolve new strategies, which may be of a very different kind to those currently in existence.

Specialist training

The University of Hong Kong, the Institute of Advanced Nursing of the Hospital Authority, Kwong Wah Hospital and some other organizations have established postgraduate certificate or diploma programmes in oncology care and palliative care for nurses and health care professionals. With an increasing number of nurse specialists in oncology and hospice, there is a good chance that oncology and palliative nursing can develop rapidly. However, to reiterate, all new training developments should be evaluated before they are assumed to be justifiable by fundholders (Tam Wong et al., 1998).

There is still a strong demarcation between oncology care and palliative care in the minds of most health workers. Oncological treatment remains focused on curative outcomes, and only when oncological care has 'failed' is palliation seen as appropriate. Thus, palliation has not been considered 'real' (i.e., curative) medicine and, as a result, has a lower priority in service provision. If quality of living is important, then quality of dying becomes a key determinant of life quality in the patient's remaining life (Ho, 1991). Thus, an emphasis on developing appropriate attitudes conducive to palliative care as a normal and acceptable part of practice should be explicitly emphasized throughout both undergraduate and postgraduate professional curricula (Doyle, Hanks and MacDonald, 1998). We are still a long way from this becoming a reality, despite recent developments in professional curricula in Hong Kong.

Transformation from loss

The medical model of diagnosis-treatment-prognosis overemphasizes the prevention of loss of life relative to accepting that dying is as normal as birth and that, like birth, it is something we all must experience. In this regard, years of life lost are widely seen as the most important target of prevention.

Professionals are preoccupied with the various dimensions of loss of life in cancer and in grief; while the side-effects of treatment and the overall difficulties in coping are often disregarded or relegated to being unimportant (Ma, 1995). However, despite the more obvious losses patients and family members face, they often report important gains, as a consequence of their illness experiences. Personal experiences of transformation after the turmoil of cancer or bereavement are commonly heard. If we focus on the growth that can occur through pain and on their strength of coping, instead of the fear and suffering that is stereotypical of these diagnoses, the experience of cancer becomes far more rewarding (Chan, 1998a).

Bureaucratic and ethical-legal considerations

Almost all medical treatment of cancer remains fixated on improving survival rates much more than on quality of life, quality of death and cost-effectiveness, though these criteria are now being increasingly advocated and accepted. Very expensive and disruptive 'treatments' continue to be given to patients who benefit little or not at all in terms of symptom reduction or life expectancy but for whom doctors feel they 'must do something'. This is particularly common among younger patients, in marked contrast to some elderly patients who might benefit from certain treatments but who may not be offered the treatments because the patient's remaining life is seen as short and of less value. The need to keep doing something is tied inexorably to the attitudes and expectations instilled during undergraduate education and reinforced by the observations made by trainees of more experienced practitioners. This is amplified by the expectations from many family members who want the patient saved at all costs. Until attitudes change, these expectation-linked inappropriate treatments will persist. Inexpensive alternative methods are excluded from most clinical services, and will remain so until they are shown to be of benefit in carefully designed studies, just as new medical treatments are no longer adopted simply because they are different. Psychologists, social workers and nurses need to persuade physicians and surgeons to include in randomized controlled trials treatment arms involving alternative interventions, so that these can be evaluated under the same stringent criteria to which other treatments are subject (Fink, 1988; Tam Wong et al., 1998).

Until we can begin to present the newly diagnosed cancer patient and family with a better interface, these problems will remain. Some patients are put under long-term chemotherapy treatment protocols, which tie them down to hospital where they are condemned to spend their remaining days. There may not be time for individuals to venture into new experiences or to finish

tasks that they would like to complete before they die. As a result, patients very often die with regrets and unfinished business (Chan, 1998b).

A NEW INTERFACE?

What might a redesigned interface for the patient be like? The first foundation feature is a true multidisciplinary team. In addition to doctors and nurses, pain specialists, physiotherapists, social workers, psychologists, spiritual counsellors, and people who have themselves survived cancer and could now be employed as full team members need to be available. Families, most of all, need time and information and this should be given in an unhurried manner, in a comfortable home-like environment. Each family should have a contact whose job is to liaise with the family and clinic, maintain contact, provide additional information as and when needed, introduce alternative activities and request input from more specialist team members. This role could be most effectively fulfilled by the lay members of the team. Those with personal experience of cancer are extremely beneficial and would be backed up by professional training in counselling skills and direct support by professional care providers. Community-based activity centres could be made available, perhaps as camps or retreats where people undergo the equivalent of antenatal classes for surviving cancer and getting used to the idea that, while many do not survive, many others do. There, in support groups, patients can learn about different treatments, others' experiences and common problems that can be overcome. The family would be encouraged to be involved in the same way fathers are involved in antenatal classes. A principal aim is to move dying out of hospitals and back into the community once more where it originally belonged. Community care teams would provide support on an outreach basis with mobile teams travelling to the patient rather than the other way round. As we begin to evolve these kinds of services, we can move closer to providing a new cultural value for serious illness, dying and death as pinnacles of experience rather than as the depths of despair (Chan et al., 1998).

It is important to provide care and support to people with cancer long before they become terminally ill. Counselling services should be available well before terminally ill people's health has deteriorated to such an extent that they have no more energy left to do things that they would love to accomplish. Home care and provision to help patients die at home remain very much underdeveloped in Hong Kong. Everyone should have a choice of where to die. When given such a choice, few prefer an anonymous hospital to a caring home. Those who choose to die at home should be provided with

the necessary domiciliary support and provision of death certification. This would be more cost-effective for hospitals and more comforting for patients. Lastly, tighter regulations and controls over funeral service providers are needed to prevent vulnerable families being taken advantage of by profit-minded companies that use fear and guilt to fleece the unwary with grossly inflated funeral packages.

Preparation for death, living wills or no-resuscitation agreements (DNROs) should be adhered to and not be treated in isolation from other aspects of service delivery. Often, even when DNROs are attached to case notes, they are ignored by doctors or overridden by relatives demanding the doctor do everything to 'save' the patient. This is a consequence of poor communication. Sadly, despite years of advocacy in Hong Kong, the quality of communication with patients remains lamentably poor in many public sector care facilities. Health care professionals need help in the process of breaking bad news and dealing with the death of patients too. The major service provider in Hong Kong, the Hospital Authority, must recognize the major shortcomings that exist in communication and take more directive steps to provide competent and effective in-service training of communication skills for senior doctors, who should then be held accountable for the junior members of their teams in the same way they are for other aspects of clinical care. This step will have more impact than the present arrangements. It will not have as much impact however, as will a growing tendency to resort to legal means to redress perceived malpractice, but it will provide a better outcome than the proliferation of litigation. All that might be expected in the latter case would be a rapid move to more defensive medicine and unnecessary treatment.

Death should not be seen as reflecting a 'failure' of medical services. The death of a loved one can be a stimulus for growth among the remaining family members. However, doctors too have to break out of their stereotype of the good doctor as one who cures all the time. The good doctor is the one to whom patients turn when they are ill, incurably ill and dying.

The procedures for assisting family members when spending private time with patients before and after dying should be clearly stated in clinical practice guidelines and patient information manuals (Chow, 1995; Tsang, 1996). Time for the family to be with the dying should be the care priority close to death. This is particularly important for the death of a child. It is also critically important for subsequent adaptation of the living that allowance be made after death for close relatives to spend time with the deceased, again especially in the case of a child. Family members often need support after the death of a loved one, and emphasis must be placed on providing support during various activities in the post-death phase. This includes mortuary identification, guidelines on how to register a death, help with how to tell children and other

family members, contact numbers for undertakers known to be supportive rather than predatory, different organizations, including religious groups, and so on.

Patient advocacy

Chinese patients are generally quite modest and compliant (Chan and Rhind, 1997). Unlike the USA, where strong advocacy movements have created powerful pressure groups, these are not found in Hong Kong. That may not be a disadvantage however. In the USA, some pressure groups with strong political clout, such as the Breast Cancer Coalition, have forced through services, such as mammographic screening for women under thirty years old, that are probably detrimental to those women they intended to help. Lacking a powerful lobby for health policy and resource, Hong Kong instead has relied on informal negotiations and communication between patient groups and the Hospital Authority. This has limited impact compared to the breast cancer or prostate cancer movements in the United States, but may ultimately work to ensure the services received actually do provide some benefit to those receiving them. Linkage with survivors' groups on the Mainland may bring new insights on how health care systems can be changed through collective action.

CONCLUSION

This book attempts to bring together some experiences and early work done in Hong Kong in the area of psychosocial oncology. It marks another step in the process of building locally relevant practice information for the benefit of Chinese cancer patients in Hong Kong. The development of culturally sensitive practice is of importance in Hong Kong, as elsewhere. 'Rome wasn't built in a day', and no established service, no matter how flexible, can change overnight, without the will of its providers. With that will, however, great things can be accomplished. We hope this book prompts more readers to consider evaluating what they are doing, to include these dimensions in their studies, to begin a change in their attitude towards what good-quality care is. We hope that more patients and professionals will contribute to building an evidence-based psychosocial oncology tradition in our health care system.

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14 Conclusion: The Next Decade or a New Millenium?

Richard Fielding

Whatever one thinks within oneself,
That alone is experienced by him.
To a man in great pain, a night is an epoch;
And a night of revelry passes in a moment.

Vasishthaya, India, sixth century
(Trans. Venkatesanada, 1984)

INTRODUCTION

The contributors to this book have all been involved in some aspect of developing and researching care for people with cancer, some of whom may be at the end of life, and their family members and care-providers. One clear message emerging from these pages is that psychosocial care in life-threatening illness is a growing philosophy of care practice. It is a philosophy that can be, and is being, adapted to suit the particular Chinese cultural context in Hong Kong. It extends to fit the cultural values and practices of the people it seeks to serve.

THE FUTURE OF PALLIATIVE CARE

Palliative care used to be thought of as something provided as a final service

to patients with incurable cancer to maintain a symptom-free state that permits dying with dignity, when options for cure have been exhausted. It had been considered synonymous with hospice care. It was a practice left to specialists in special, usually out-of-the-way, places, but not something for the average doctor, nurse or social worker to concern themselves with. It was a service to the dying, somewhat tinged with religiosity and pity. This had been reflected in the almost complete absence of palliative care from undergraduate medical and nursing curricula. Thus, palliative care was so special, so specialized, that postgraduate training in special units was needed to practise this, and a certain heart-of-gold twinkle in the eye went a long way to helping with graduation.

Increasingly, there are challenges to these assumptions about palliative care. Why must it be delivered by specialists, and only for people with cancer? What about other diseases? What about heart disease and renal failure? What about pneumonia? The symptoms of these diseases require palliation also. Why must it be in a special place? General hospitals now have palliative care units, but why must there be units? Why is it that only some doctors and nurses understand the principals of symptom control? What is happening to professional training that medical and nursing graduates are not intimately familiar with application of the three-C pyramid: 'Cure when possible, Control when not, and Care always'? Why not have a roving team involving staff who, understanding these principles, can be brought in to each ward for every patient who needs such care? For that matter, why are we limiting this to hospitals? Why is it that we are not providing the medical, nursing and psychosocial support for all those people who need this kind of care so that they can remain in their family homes where they prefer to be? Economically, this makes much more sense than gathering people into highly complex and expensive hospital environments where they are often faced by overworked staff and decision-makers who are often nameless, faceless and, if truth be told, really could not care less.

The second principle of palliative care that is under attack is the limit of this care to the period of incurable decline. Hospice care was originally developed by Cecily Saunders as a means of combating the impersonal and degrading care that patients with cancer received in general hospitals. What happened? Saunders recognized that patients were being treated as biological units and not people. What is hospice care? It is caring for people as if they mattered, because they do. It is continuing to care even after the person dies, supporting the family that remains until they can support themselves. What is palliative care? It is recognizing that symptoms are part physical, and dealing with that part as effectively as possible with the tools that bioscience has produced. It is also recognizing that the other part of symptoms are the fears, attachments, identities and meanings that we embody, it is recognizing

that we are people always and respecting this. Palliative care and hospice care are embodiments of a set of attitudes: respect, interest, empathy, honour, justice and morality. What is happening in our health care systems and cultures that we have not yet managed to establish these values throughout all care settings?

The key concept of Chinese traditional medicine is balance. Balance in the different *yin* and *yang qi* energies and ensuring appropriate circulation of these energies underpins the whole therapeutic approach to health maintenance. Harmony of the inner with the outer and balance between Heaven, Humankind and Earth ensures peace, longevity and the prosperity of the people. Why have we adopted so quickly the *yang* of science into the home of our health care systems and left the *yin* of caring outside in the rain? The problem is one of attitude, that bioscience, the new hegemony, will provide all the answers. The hope? That the ultimate disease, death, will one day be cured (it will not be), and that ageing will be halted in our teens so we all remain eternally twenty-one-year-olds in body, if not in mind. The possibility that these nightmare developments might actually be achievable is sucking in huge amounts of funding that might otherwise be used to provide care. Nonetheless, care must be the cornerstone of good late-life service provision. The economics of supporting, but not dumping, people at home as much as possible are very favourable.

Balancing the curative approach to health care with improved care practices has to be a priority in the next decade in Hong Kong. But this should not be done on the backs of charity and the good offices of volunteers and dedicated fund-raisers as it has been since inception. The government needs to increase funding for the provision of community-based palliative services, and the Hospital Authority must fund developments in roving palliative care teams in all hospitals in Hong Kong. This should be until such time as we manage to get our professional training right.

LIVING WITH DYING

Dying, so it is still widely believed, is a necessary evil that, try as we may, we cannot escape. Threats from the afterlife have permeated both the Judeo-Christian and Buddhist spheres of cultural influence, where they have proved a very useful contribution to social control. However, all of our cultures, Chinese or otherwise, also hold the promise of something great, wonderful and final awaiting us. To reach it, however, we must pass through the Valley of the Shadow of Death, or hell, or demons, ghosts, ghoulies, or the myriad nameless things of our cultural mythologies that go 'bump' in the night. Are

these simply the persistent projections of our own childhood superstitions which, as we grow, grow with us in sophistication? Do they represent the terror of having to let go, to depart alone? For whatever reasons, most of us retain fears of dying. And yet, is it not the greatest adventure imaginable? The most interesting vacation possible? The best rest we can ever have?

Psychological research provides strong support for the notion, expressed by Roman philosopher Epictetus two thousand years ago, that humans are less affected by things, than the views they take of them. No doubt, other people in other places, probably many in Asian cultures, have been saying the same kinds of things for centuries before that. So how can we improve death education, demystifying and demythologizing death, so that people's views of dying will begin to change?

This will be difficult. We are faced with significant cultural ambivalence about death. The contributors in this book are working hard to make dying an acceptable part of living. At the same time, we read of the latest promises of cures for disease, of techniques to extend life for those with rare and complex disorders. Many of us worry about the increase in suicide rates, about the risks we take during our lives — smoking, drinking, promiscuity — and work just as hard trying to ensure people do not die prematurely. Thinking of death as a wonderful adventure is one way of trying to change people's attitude towards dying. But it will take the publicity surrounding just one person who commits suicide for this supreme adventure, to undo many years' work. Another approach is therefore needed. One way might be to extend bereavement services in the same way that palliative services might be extended. However, great care will be needed to avoid the perception of ghoulish social workers and others visiting, like Angels of Death, those helpless patients who are thereby cursed and doomed. Other ideas need to be explored as well.

Whatever policies, services or systems are put in place to cover the needs of people who face incurable illness and death over the next decade, they must be rigorously evaluated. The need for a solid evidence base is perhaps greater for psychosocial than for biomedically-based care at the end of life. Psychosocial care still faces the accusations that it is not 'scientific'. Similarly, traditional cultural practices, from whichever culture, also need to be demonstrably beneficial if they are to be components of funded services. This means that we must adopt greater methodological rigour to evaluate our interventions. To do so will require the use of both quantitative and qualitative methods. We need better training in the application of these methods, which should be mandatory if we are to make progress in what is becoming a more evidence-based environment.

Increasingly, we are dealing with issues that are cross-disciplinary, and we need to develop approaches to evaluating what we do which involve

comparisons of cutting-edge technology against standard approaches with and without psychosocial components of care added. Multi-disciplinary teams need to work to evaluate the multi-disciplinary interventions that have been developed.

FINAL THOUGHTS: RECONSTRUCTING DEATH

We should not forget that the subject of death was chosen by Ivan Illich (1976) to illustrate his thesis that cultural iatrogenesis has become a major product of the late twentieth-century health care industries. Illich argued that the removal of death from normal human experience resulted in the amplification of suffering and isolation for the incurably ill by stripping away the context surrounding suffering that gave it meaning and thus made it bearable. The processes leading to death, and death itself, need to become re-established in a culturally acceptable and accepted framework that considers it as a vital and vibrant part of life. It must give meaning back to the process that our science-dominated culture has stripped away. Perhaps the best way we can help achieve this is by each one of us living what we believe to be a better way of facing the great adventure of life. By our own example, we can all help others see alternative views that may be less obvious. However, we must also use the tools of science to demonstrate the greater benefit in this. The balance between these two holds the key to optimizing the end of life and the care services needed to achieve this.

REFERENCE

Illich, I. 1975. *Medical nemesis: the expropriation of health.* London: Calder & Boyars.

Index