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Abstract

In our study that explored the current end-of-life care provision for Chinese older people with advanced/terminal cancer, hope emerged as a significant aspect of coping with their condition. Drawing on data from in-depth interviews with a group of older people, their family carers and health professionals, this paper explores participants' constructions of hope in terms of what they were hoping for, how their hope helped them cope with their illness and what socio-cultural resources they drew on to build and sustain this hope. While acknowledging similarities to western studies of hope in terminal illness, the paper identifies significant divergences in terms of the impact of different socio-cultural values and their implications for clinical practice in light of an unfavourable health care environment for patients with advanced cancer and a social support system sustained mainly by Chinese families. It argues that hope represents an important resource for coping with terminal illness among these patients.

Keywords

Hope, advanced cancer, older people, China, qualitative

Background

Empirical studies in nursing, psychology, psychiatry and palliative medicine have found that hope plays a significant role in terminal illness (e.g. Dufault and Martocchio, 1985; Felder, 2004; Perakyla, 1991). In our study¹ that explored the current end-of-life care provision in mainland China for older people with advanced/terminal cancer, hope emerged as a significant aspect of living with the condition. For these older people, their hopes provided an important coping resource, reflecting key needs and concerns at the end of life. Drawing on data from interviews with both patients and carers, we illustrate how hopes were facilitated by ‘hope work’ carried out by carers (both formal and informal) as part of their care work. Further, these hopes reflected the broader sociocultural milieus wherein they lived, including predominant sociocultural norms and expectations surrounding end-of-life and terminal cancer.

Health care for cancer patients in China

China's population is ageing at one of the fastest rates ever recorded; correspondingly, cancer has become the main cause of death in China, representing 25 per cent of all

¹ Funded by the Open University.

deaths in urban areas and 21 per cent in rural areas (Minister of Health, 2008; Zhao et al., 2010). As such, cancer suffering is extensive in China.

The current health care system is market-oriented, relying heavily on private funding and charging excessive fees. Consequently, it is generally hard for Chinese people to access and afford health care (Theory Bureau of the Propaganda Department, 2010). For cancer patients, the excessive use of anticancer treatment (Western Medicine) is common (Li et al., 2011) and curative interventions are continued either until patients are no longer able to endure the side effects, or at the end of their disease trajectory. Further, when patients are close to death, resuscitative measures such as intracardiac injections and even cardio-pulmonary resuscitation at the moment of death are taken. However, despite advanced interventions close to and at the point of death, physicians fail to take advantage of the accessible analgesics to relieve patients' pain.

Traditional Chinese Medicine (TCM) provides a complementary approach to relieving cancer suffering (Ji et al., 2008; NG, 2006; Xu et al., 2006). It helps to enhance patients' overall physical and mental wellbeing, potentiate curative Western Medicine (WM) treatment and counteract its adverse effects, and mitigate symptoms of the disease. It has fewer side effects and is safer and cheaper than WM, as well as being more 'dialectic', 'holistic', and person-centred (Chen, 2012).

Palliative/end-of-life care has yet to establish its niche in China (except in Hong Kong) despite the increase in mortality from cancer and other long-term conditions (Bai et al., 2010; Li et al., 2005). The existing services appear insufficient in meeting patients and families' complex needs at the end of life (Chen, 2012). Not only were palliative services unavailable and inaccessible to most people, but also usually the last resort after mainstream curative treatments were exhausted. According to the Economist Intelligence Unit (2010), China was among the lowest-ranked countries in terms of 'basic end-of-life healthcare environment', 'availability of end-of-life care', 'cost of end-of-life care' and 'quality of end-of-life care'.

Social support for older people

China is facing severe problems arising from uneven economic, political and social development, particularly between rural and urban areas and east and west, or the 'One China, four worlds' phenomenon (Theory Bureau of the Propaganda Department, 2010: 5). In other words, the Chinese population is ageing rapidly while China is ill-prepared to provide for and support such a large older population.

Currently, family provide fundamental social support for Chinese older people (Zhang et al., 2009). For example, adult children provide financial support by giving their parents money, or paying for their medical expenses, in rural areas, this includes

material support such as food and clothing. Further, families provide personal care and assist in the activities of daily living, as well as nursing care at home when older people are ill. Families also provide psychological and emotional support, e.g. through listening, accompanying, sharing or helping out in difficult situations. In view of the traditional value of filial piety, the emotional and psychological satisfaction acquired in a harmonious and caring family cannot be replicated or replaced by any form of professional support or services. Indeed, as the moral foundation of the long-term care model for older people, filial piety is reinforced by Chinese laws, such as the Constitution of the People's Republic of China and 'Law of the People's Republic of China on the Protection of the Rights and Interests of Older People'.

However, informal care traditionally provided to older people at home by adult children will become increasingly unfeasible in the near future, when the parents of the first generation since the introduction of the One-Child policy start reaching old age and retirement. Rather these single children will face the need to care for two parents and often four grandparents without siblings with whom to share the responsibility, a problem sometimes referred to as the '4-2-1 problem'(Flaherty et al., 2007) . In light of this, a social service system for older people has taken initial shape, based on family care, supported by community services and supplemented by institutional services for

seniors. Nonetheless, despite significant improvement, these social services still fall short of public needs (Zhang et al., 2009).

Chinese views on death

Chinese culture is dynamic and diverse; the dynamism is 'produced by a formidable culture's interaction with both its own ancient, albeit never static, traditions and the flood of new global cultural influences' (Louie, 2008: 334). Confucianism, Taoism and Buddhism are the most dominant traditional religious/philosophical tenets in China. They influence more Chinese people as compatible philosophical traditions than as exclusive religions (Gall, 1997). Confucianism emphasizes life rather than death; Buddhism focuses on perusing a life after death through nirvana; Taoism emphasizes the importance of harmonizing with nature and death as a normal part of life, which should be accepted as a natural ordinance. Generally, greater importance has been attached to life in Chinese culture, and death is almost always perceived as a negative life event (Wang and Wang, 2011; Xu, 2007). For the Chinese, a life is lost forever when death occurs, and therefore heroic measures to sustain and prolong life should be implemented and sustained at all cost. This attitude is reflected in end-of-life care treatment. In a survey of Chinese oncologists' practices and attitudes toward end-of-life care, Wang et al. (2004) found that the majority (80%) would continue giving anti-cancer agents up to the end of life; and that a heavy demand for continued treatment by

patients and their families and reluctance by oncologists to give up on their patients were the top two reasons for not discontinuing chemotherapy.

Hope in terminal illness

Hope in the context of end-of-life, particularly in relation to terminal illness, has been extensively published in Western literature. Hope is defined as ‘a multidimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant’ (Dufault and Martocchio, 1985: 380); and which ‘has experiential, spiritual, rational, and relational attributes that energise and provide a sense of freedom and resilience’ (Felder, 2004: 321). Empirical evidence has highlighted the significant role hope plays in terminal illness. Particularly, hope has been found to facilitate effective coping (Felder, 2004) and holistic healing (Feudtner, 2005).

In terms of the source of hope, Perakyla (1991) found that patients’ hope was actively constructed through recurrent interactional patterns among caregivers, patients and family members, which either enhanced or diminished hope in the management of end-of-illness trajectories. He defined ‘hope work’ (Perakyla, 1991: 409) as a particular type of medical work that leads to either the establishment of a particular hope or its

dismantling in a clinical setting. He contended that it is usually implicit, but nevertheless essential and pervasive in hospital life.

Feudtner (2005) located the individual experience of hope in the socio-cultural environment. He demonstrated that a paediatric patient and his/her parents constituted the most intimate level of their social network, but their individual hope would be influenced substantially by the conduct of health care staff, social workers, pastoral care workers, other members of the family and community. He further argued that, via their social network, patients' and families' hopes were shaped by the broader sociocultural environment, encompassing the media, religious communities, economic realities, cultural values, social structures and the like. As such, 'this network of social influences on hope, concatenating outward from an intimate to a macro level, suggests that the individual experience of hope can be situated—and perhaps best understood—within an encompassing ecology of hope' (Feudtner, 2005: S26).

As hope is an experience tied to socially constructed meanings, the findings about western populations may not apply to Chinese communities. Mak (2007) and Mok et al. (2010) in examining the meaning of hope from the perspective of Chinese advanced cancer patients in Hong Kong, found similarities to those from the West in terms of hope for cure, functional independence, social support, personal control and reconciliation with life and death. While suggesting the universality of the experience

of hope at the end of life, they highlighted culturally specific meanings behind the universal experience of hope that have significant implications for clinical practice.

Although a few studies have been conducted among Hong Kong Chinese, their experience may not represent that of mainland Chinese, as Hong Kong was a British Colony until 1997 and the histories of the two societies are divergent. In mainland China, however, only a few quantitative studies have been conducted (e.g. Zhang et al., 2010), all of which focused on cancer patients' hope level – a measurable quantitative construct based on Herth Hope Index (Herth, 1992). The following qualitative study therefore addresses a significant gap in shedding light on socio-culturally specific meanings of hope in terminal illness in the Chinese (mainland) context.

Methods

In exploring a practically and ethically complex situation, we employed a 'multiple embedded-case study' design (Yin, 2002), which included three care organisations and individual patients (see Table 1). This design allowed us to study end-of-life care 'within its real-life context' (Yin, 2002: 13) and from both the providers' and the users' perspectives. Three organisations (the committee, the hospice and the ward) were selected to represent different patient groups and different types of care provision for people with advanced cancer (see Table 1). Hence, they presented the opportunity to

explore varied experiences of end-of-life care and hope among older patients, thus enabling data corroboration. Patient participants were selected on the basis that they were older people² with advanced cancer (see Table 2). Patients selected for interview should also be well enough to talk, able to speak Chinese (Mandarin or local dialects) and have consented to being interviewed.

We used multiple methods and sources of evidence with the aim of ensuring the comprehensiveness of findings as well as potentially strengthening their validity (Keen, 2006; Yin, 2002). The first author- HC (the main researcher) used qualitative interviewing and observation to collect data about the three organisations and the selected patients within them. Data were collected from patients, their families and health professionals caring for them. Using multiple methods and sources of evidence was also important for ethical reasons in that we wanted to include the experience of those patients who had rare and unpredictable moments of lucidity or were unable to talk (see Table 1). To explore patients' experiences of end-of-life care (as defined by them) and living with a terminal diagnosis, HC interviewed patients from the committee and the hospice, who were able to talk, and interviewed one family member and the doctor-in-charge of each selected patient in the ward. During observations in

² Aged over 55 in rural areas and over 60 in cities.

the three settings, her role was ‘the observer as participant’ (Gold, 1958), in which she had minimal involvement in the social setting being studied.

Table 1 should appear about here

Table 2 should appear about here

HC’s Chinese origin (born and brought up in China) placed her in a position to be able to offer new angles and a depth of understanding to which an outsider might not have had access. However, HC was less of an ‘indigenous insider’, and more of an ‘indigenous outsider’ (Banks, 1998), in the sense that she was assimilated into outside cultures, having worked, studied and travelled in some western and south Asian countries. More importantly, her scientific ‘conceptual framework’ related to the topic areas – theoretical, conceptual and methodological, was mostly ‘western’, acquired through her academic studies in the UK.

HC transcribed and translated all the interviews and field notes of observations. The process of translation was experienced as capturing and transforming a particular fragment of Chinese social reality into an English one. Therefore, it was another dimension of ‘data interpretation’, which was subject to her knowledge of both cultures, her proficiency in both languages as well as her autobiography (Birbili, 2000). The

process of transcription and translation allowed HC to become thoroughly ‘immersed’ in and therefore familiar with the range and diversity of the data. This process laid a solid foundation for further analysis using framework analysis (Ritchie and Spencer, 1994).

Ethical approval was gained from Human Participants and Materials Ethics Committee (HPMEC) of the Open University. In China, non-interventional, qualitative studies were not subject to ethical approval from the hospital’s ethics committee (Cao et al., 2004). Culturally and ethically appropriate and acceptable verbal consent (audio recorded before and after an interview) and proxy consent (for observation) were approved and applied in the field work. All participants were pseudo-anonymised to protect their identity.

Findings

We argue that, hope, as experienced by Chinese older people with advanced cancer, served as a coping mechanism, that is, they coped by ‘hoping for the best and preparing for the worst’. This hope was driven by and sustained in interpersonal connectedness through carers’ ‘hope work’. Furthermore, this hope and how it was socially constructed reflected the broader sociocultural milieus wherein they lived, particularly in terms of health care and social support.

'Hope for the best and prepare for the worst'

In patients' talk about how they had coped or how they were coping with their advanced cancer, a unifying hope emerged: summed up as 'hope for the best and prepare for the worst'. In this way patients ostensibly vacillated between two mental attitudes that seemed to be cognitively and emotionally dissonant. However, the fragile balance between the attitude of 'holding on to hope' and 'accepting the inevitable' enabled them to maintain control over things within their capabilities, but also to let go of the uncontrollable aspects of life.

All patients explicitly expressed their hope for cure or remission as 'the best' they hoped for. By hoping for cure or remission, they really hoped for a reprieve from a death otherwise prognosticated or felt, that is, they hoped to live longer. This hope was active and goal-oriented with the determination to struggle and strive to live on. Patients were motivated by the hope to act (psychologically, physically, socially and religiously) and directly effect the hoped-for outcome. And they were energised by the hope to take action directed towards attending to the daily demands of living, expanding or revitalising interests, extending themselves to others, caring for others and altering their personal outlook.

Without exception, patients made it explicit that 'the worst' that they were preparing for was death. This is mainly because the cancer diagnosis was invariably perceived as

‘a death penalty’ regardless of the stage. Mostly, patients focused on their mental and emotional preparations for death, while some also reported making practical preparations, such as preparing a will, planning the funeral and burial, putting their affairs in order and making other arrangements concerning families and friends. Mental preparation appeared to involve confronting and then reconciling the prospect of death, as conveyed by Ze and Gho:

Ze: It is the nature’s rule to control human population during its reproduction process, no one can defy it. If no one dies, no one gets ill, in the end, there will be no foothold on this earth. Since it is a rule, it is contradictory – life versus death; there must be something that causes death, it is a matter of what, cancer or something else. As it is a rule, no one can defy it, so you have to just accept it, and adapt to it... Yes, there was [high risk of me dying in the surgery], so I had imagined the worst scenario and arranged the things to do with my families. [He laughed] To be honest, since medical examination, then surgery till now, I have been always calm. One should be calm, that one gets ill and eventually dies, is a rule, which no one can defy; it is only a matter of when and how, which you don’t know; you should understand this.

Guo: At that time [when I just got to know my diagnosis], I just felt that nothing could be done about it. Here I have to talk about my personal views of the life and death issues. In the past, I went to Bai Ma temple to do what the Buddhism calls Zen, which is basically the same as Christianity. It was on the Qian Hu Mountain; the couplet said: “it is to return to be born – it is to die to be born”. In Christianity, it is like this as well, it says that it is like this to be born.

Thus, acceptance boiled down to their beliefs on ‘life and death’ issues, which appeared to be personal interpretations of the three traditional philosophical/religious tenets discussed earlier and other religious beliefs that coexisted in Chinese culture. For example, Ze’s view resonated with those of Taoism that the divine produces/governs all things and provides harmony and balance, and that people should not work against it because they can never win (Chen, 1961). Guo drew on both Buddhism and Christianity (which he was affiliated to) to make sense of life and death in his own way.

Ensuing from mental preparation for death, another important dimension of preparation was trying to ‘live one day at a time’ (live in the present) and to live each day happily and to the full. Reconciliation with death entailed an acceptance that life could be brought to an end at any time, despite all efforts to survive. This then prompted patients to cherish each moment and each remaining day in case ‘the worst’ were to happen. Moreover, living in the present- without thinking too much about the future, helped them to contain their anxiety about the future:

Ming: ... my biggest hope is to lead well and happily my life in the old age, after all I was sentenced to death already.

Guo: I don't think about tomorrow today. Today, I get up at dawn, I go somewhere to play for fun, and have some nice food; at night I go to bed. By the next morning, I say to myself: "don't think of tomorrow today".

In this way they did things that they enjoyed doing or found meaningful, that contributed to their wellbeing or at least temporarily diverted their attention away from pain or other problems. In other words, while 'hope for the best' was aimed at maximising the quantity of their life, in preparation for the inevitable death, they also made efforts to optimise the quality of their life; that is, 'When days cannot be added to life, add life to days (Chan and Chow, 2006: xv). As such, hope for the best (being optimistic) and prepare for the worst (being realistic) together gave their life meaning, direction and an optimistic focus and provided what was needed to stay engaged in living while shouldering the burden of an uncertain future.

'Hope for the best' and interpersonal connectedness

Participants' hope 'for the best' was often tied to and spurred by others; that is, they all had 'someone' to live for. Some hoped to live until an important future family life event had taken place. For example, Guo hoped to live longer to see his grandson go to middle school. Others hoped to live to until they fulfilled certain family responsibilities. A good example is Li who was diagnosed with advanced renal, pelvic and ureter cancer

and squamous cell cancer in 1992, and told that she would not live one year. At that time, her daughter was very young; and she hoped to survive as long as possible in order to rear her daughter. Her hope was so singular that it had sustained her for 19 years, during which time she tried her utmost to seek a cure and maintain health and dealt with ongoing financial crises while raising her daughter.

As such, patients like Li were not striving to prolong their physical existence alone, but also to continue their 'life' as a 'social experience', that is, to continue meaningful and valued social engagement with significant others, particularly their families. Therefore, interpersonal connectedness was driving 'hope for the best' in these patients.

This interpersonal connectedness was not only the drive for hope to live longer but also the resources to sustain it. Health professionals and families, as potential or actual care and support resources, contributed to what patients could hope for and how they might realise this hope. Hope was often influenced by patients' evaluation or perception of others' resources, capabilities, attitudes, actions or responses. For example, Rou had foregone her hope to go to a large hospital in Kunming to get potentially effective treatment for uterine cancer, which was suggested by the local doctor. This is because her two sons were working in Burma and nobody was at home to support her financially and practically. She was then suffering in isolation and in despair. But when she was introduced to the hospice which provided free home services, her hope was rekindled, she said:

Now the policies [of the hospice] are really good, so I also want to give it a go – try to treat my disease. If it works, I can live for two more years; if it doesn't work, there is nothing else to do.

Generally, the presence of caring and loving relationships with others was fundamental to sustaining hope for life in patients. Indeed, bonding with families enabled some patients to maintain the hope to survive in spite of experiencing extreme physical pain. Shui's physical suffering was the most extreme of all the participants, induced by tumours (advanced ovarian cancer and multiple metastasises) and related treatment (3 surgeries, 19 sessions of chemotherapy and frequent acute treatment to relieve severe symptoms). She told me:

Sometimes when I had such agonising pain that pain-relief drug would not help, I sat on the floor suffering [She laughed]. I cannot explain clearly, after all, people who have got this kind of disease suffer..... Now worrying that my blood vessels might be broken which might cause haemorrhage, I dare not go out to walk..... I cannot make it to just climb up the stairs; when I go upstairs, I feel out of breath, I just can not bear with it..... There is something breaking off which is frightening to me! Because it is cancer, the tumour inside rots and something breaks off and comes out. What breaks off and comes out is horrifying for me to see: blood, purulence, something rotten and the like; some comes out from my vagina, some from my anus ...

Nonetheless, Shui had endured this suffering for over six years; and conveyed how she still hoped to live because her children were very kind to her and they wanted her to live. As such, these Chinese patients struggled to stay alive for their significant others while they depended on them to survive. Hence, the interpersonal connectedness that drove and sustained hope for life involved a balance between living for and depending on others, between giving and taking, that is, mutually supportive relationships.

'Hope for the best' and hope work

As previously demonstrated, patients' hope for the best- for more life, was fostered in mutually supportive and caring relationships with significant others. This raises the question: how exactly did those who provided care and support contribute to such hope of patients' in everyday life? Perakyla (1991) found out in his study that patients' hope was actively worked up between patients and clinicians and 'hope work' was indeed an essential part of clinical care in the hospital setting. In our study, health professionals and families who directly provided care for patients also actively engaged in hope work, which was giving hope for life, although often implicitly and unknowingly. This hope work was a significant part of their care work, which permeated through their daily interactions with patients, influencing their hope.

The hope work was typically achieved through verbal communication between carers and the cared for. For example, Zhang (a ward hired nursing worker) told me:

Patients sometimes told me they hoped to die. I tried to counsel them. For example, one patient said she didn't want to be a burden, and she suffered so much, so she hoped to die. I said to her: "Don't think this way. To struggle to live on is still better than a good death. Other patients suffer more, but they still hold on. Your children are so nice to you; they come to feed you while they are busy with work. If you are alive, it is worthwhile for them because they have someone to call mum". Then the patient cried and said she wouldn't say that again.

Most obviously, by providing information about diagnosis, prognosis and treatment options and outcomes, health professionals and families contributed to patients' understanding of their situations. These contributions shed light not only upon what can be hoped for, but also upon how the hope might be realised. Jia is an extreme example, who had terminal cancer but told the hospice staff that she strongly hoped to continue with chemotherapies in order to recover. This is because although Jia's families informed her of her cancer and metastasis to her lung, they concealed the fact that metastasis had also reached her bones and was at such an advanced stage that chemotherapy would not help. What is more, Jia's doctor encouraged her hope for cure through chemotherapy by exaggerating the effectiveness of the therapy. Jia told me:

The doctor said it would be beyond redemption if cancer cells went into the brain; by then the chemotherapy wouldn't work, nothing would. But as long as cancer cells don't go into your brain, there can be a remedy.

Another example of the hope work is evident in Li's experience. Li told me:

I was most touched by a worker in my workshop, who lived across the street from the hospital... they had given me blood transfusion again [the third time]; but this time my situation did not improve at all. That was when I started to wonder if I was really doomed, and if so, what about my daughter. [That night] I felt really devastated... I was alone feeling really sad and thinking I must be doomed. At this moment, a child from the room opposite to mine came in with a bowl of soup in her hand. She asked me to drink the fish soup, saying that her mum [the worker in her workshop mentioned above] cooked it just for me. I did not know who her parents were at all. I was so touched! And she started to chat with me, which diverted my attention away. So the two hours before she came was the only time when I felt really in despair, then she came to chat; and after she left, two people from my factory came to chat till 11pm that night. Then I decided that as so many people cared about me, both acquaintances and strangers like the child and her parents, I must manage to live, even if it is just for these people who cared about me.

As shown in Li's account, both child and mum performed hope work through the tasks of caring. Indeed, when patients lost verbal ability, it was the behavioural interaction that comprised hope work. For example, serving food and drink appeared

to be very important in caring for patients among all families, even when artificial nutrition and hydration was prescribed by the health professionals and patients were in the last days or hours of life. The primacy of serving food and drink lies in that it also fulfilled hope work, in addition to providing sustenance for life. By taking food and drink, patients both communicated and realised their hope to stay alive, and by giving food and drink, families communicated, reinforced and facilitated the realisation of that hope. This is demonstrated in the following quote:

Deng (a senior doctor): some patients suffered from the most agonising pain but still hoped to live on. You could tell if someone hopes to live – if they try to eat even when suffering from eating – no appetite, vomiting, constipation etc. They keep eating because they hope to live on – that is basic desire for life.

What is more, according to Hochschild (1983), ‘emotional labour’ is an aspect of caring which can have profound implications for performers of caring roles. This labour requires one to induce or suppress feeling in order to sustain the outward countenance that produces the proper state of mind in others. In relation to nursing, it usually requires nurses to care for patients by calming them and appearing reassuring and positive, and to make patients feel cared for and safe (Smith, 1992). This is also true in terms of hope work: carers influenced patients’ hope through posing a positive

emotional being and radiating an aura of optimism when they were with patients. This is evident in Ze's account as follows:

Of course they [my families] must have felt upset. But in front of me he [my son] appeared to be very strong and did not show his anxiety or fear. When everyone in my family accompanied me to outings during the May-day holidays before the surgery, none of them showed their worries or fears about future, they all looked happy. But I knew that in their hearts, they must have felt sad. My family condition was very important to me, the way they affected me was important; I am only one of the factors. When knowing the truth, if I did not fall apart but they already did, it would be all over with me... later, when I met other patients' families in the hospital, I told them: "you must be strong! If you are in low spirits, you are killing him. At this time, your being strong is more important than him being strong".

Socio-cultural influences on 'hope for the best'

As a whole, Chinese patients' experience of living with hope indicated that both the hope ('hope for the best and prepare for the worst') and how it was constructed (hope work) in their particular social relationships (interpersonal connectedness) reflected the particular contemporary sociocultural fabric of Chinese society.

Noticeably, patients and their carers drew upon the dominant cultural understandings (often current in the media) of medical science to co-construct and sustain their hope 'for the best'. As Bennett (2011) contends, medicine is underpinned by a culture of

hope. In both research and clinical practice, medical science continues to subscribe to a narrative of progress, which sustains the hope that the treatment of disease and the alleviation of suffering become ever more effective. In China, this culture of hope in medicine extends to Traditional Chinese Medicine (TCM). The fundamental theoretical framework of TCM was established over 2000 years ago, so it is a long-standing, well-acknowledged, traditional approach to healing and health in China (NG, 2006). It has been an essential part of the mainstream health care in China (Xu et al., 2006); and the government has put it on their agenda to further develop TCM, foster a modern TCM industry and promote a culture of TCM (WHO, 2011). The media supported and promoted this culture; specific to cancer, they called it ‘a comprehensive approach to cancer care, combining western medicine (WM) with TCM’. So among these Chinese patients and their families, it was common that they built their hope not only upon WM but also upon TCM. Indeed, when WM failed to work, some of the patients from the committee resorted to and solely relied on TCM (e.g. herbal medicine and qigong³) to sustain their hope and their life.

Patients also drew on the assumption that the mind can influence the body, or positive thinking can facilitate recovery, which was enthusiastically promoted in the Chinese media regarding cancer rehabilitation. This discourse is identified by Delvecchio-Good

³ Qigōng (气功) is a TCM system of exercise and meditation that combines regulated breathing, slow movement and focused awareness (<http://www.zhongyibaike.com/wiki/%E6%B0%94%E5%8A%9F>).

et al. (1990) as a discourse of will, which incorporates western concepts of the individual as responsible for his or her own life and the relationship between psyche and soma. It sustained patients' hope in that they were persuaded to believe that through taking care of their own psychological, spiritual and emotional well-being, they could enhance and maintain their physical well-being, as many patients cited: 'the mind does 70 per cent of the curative work and treatment does 30 per cent of the work'. As such, in hoping for the best - to buy more time, the majority of patients made conscious efforts to maintain 'a good mental attitude', or 'a balanced mental attitude'. Ce concluded: 'as long as you have a good mental attitude and you are being careful in all respects, you can still fight it off; it is not uncommon that people with cancer survive'.

However, these patients had two troubling concerns that conflicted with their hope to live longer. First, their hope for living longer was conditional on their suffering (physical and psychological) being bearable. In some extreme cases, patients stated or implied that at times they also hoped to die - often when the magnitude of suffering countered their capability to endure it. Mei said: 'When it hurts so much that I cannot stand it, I hope to die. If it doesn't hurt, I hope to live on'. On the other hand, most patients directly expressed a hope for comfort, freedom from pain and that their symptoms would be well managed. Related to the hope for freedom from suffering and in response to flaws in the Chinese health care system and infrastructure, all patients hoped for improvement in health services, particularly in medical insurance coverage

and reimbursement; information about diagnosis, prognosis, alternatives of professional treatment and care and self-care; quality of care; and specialist services that aim to improve quality of life. Hence, their hopes were conditioned by and thus a reflection of an unfavourable health care environment for Chinese cancer patients at the time (Chen, 2012).

Second, the majority of patients were troubled by ambivalence about relying on families for care and support and expressed a strong hope that they would not be too much of a burden to their families. Although families were the reason that patients held on to life, as some of them related, at times, the burden of guilt eroded their will to fight cancer and live on. Driven by this hope not to be a burden, they did whatever they realistically could manage to minimise it, which could be material, financial, emotional and practical, as demonstrated in the quotes below:

Mei: I have to economise on food and clothes. I have to think of my children.

Lin: Sometimes, I had pain, but I didn't tell them – I didn't want them to know...I don't tell them for fear that they will be anxious.

Lu: How come they asked me to stay in the hospital but I was not willing to? It is because I had caused my children big financial burden; so I don't ask for anything.

This perceived burden of patients' reflected the real burden of day-to-day care that fell most heavily upon families, who provided personal care and other essential support: psychological, emotional, financial and practical on a daily basis, with little care and support from health and social care services as available in some western countries (Chen, 2012). Moreover, Western influence came to China and facilitated culture change at the turn of the 20th century, with the launch of economic reform and open-door policy (Lu and Chen, 2011). As a consequence, the value of 'filial piety' was challenged by the increasing sense of individualism and independence. Our findings reflected this tension in that although filial piety entails an entitlement to receive care in old age, all patients worried about being a burden to their families.

Discussion and conclusion

There are three main limitations worth noting. First, patients who agreed to participate in our study tended to be more hopeful, and it was hard to recruit those who were depressed and might have been feeling hopeless. Therefore, experiences of those who were depressed and without hope might not have been represented. Second, we focused exclusively on exploring how the external sources of hope could impact on patients' hope construction. Therefore, further research is needed to explore patients' active role in influencing their external environment in terms of hope and hence the two-way

interaction between patients' internal and external sources of hope. Third, the findings of our study are based on the experiences of older Chinese people of predominantly Han nationality, and therefore may not apply to younger generations and other nationalities in China, whose socio-cultural influences may be quite different.

Despite these limitations, our findings show the important role hope played in helping Chinese older patients cope with advanced cancer. These patients coped by hoping (fighting) for the best (more life) while preparing for (accepting) the worst (death). The balance between being optimistic and realistic, being in control and letting go, gave their life meaning, direction and provided what was needed to stay engaged in living while shouldering the burden of an uncertain future. Similarly, Back et al. (2003) found in their study that living with a terminal illness is often marked by profound ambivalence about the dying status, that is, patients vacillate between the state of continuing to live and plan and that of preparing for death. They suggest that the physician-patient communication strategies that are based on this approach of hope and preparation can effectively support patients in coping with living with dying. By acknowledging all possible outcomes, patients and their physicians can expand their medical focus to include disease modifying and symptomatic treatments and attend to underlying psychological, spiritual and existential issues.

In our study, patients' hope for the best in terms of living longer was tied to and driven by hope for interpersonal connectedness, which is consistent with findings from the

West (e.g. Benzein et al., 2001; Elliott and Olver, 2009). Moreover, interpersonal connectedness sustained hope in patients, their hope (for life) being co-constructed in mutually supportive relationships through ‘hope work’. Our findings support and extend Perakyla’s (1991) findings on ‘hope work’ being accomplished through conversation. We have demonstrated that for carers, an essential part of their work is indeed ‘hope work’, which is achieved not only through words but also concrete deeds and emotional work.

Although our findings are mostly in line with those from western societies, they highlight different socio-cultural resources, particularly in terms of social support and health care that Chinese patients and their carers (formal and informal) drew on in co-constructing and sustaining their hope. First, traditionally, the family occupies a central role in Chinese society, influenced by Confucians teachings (filial piety and reciprocal obligation) (Gao, 1996). Chinese people hold family bonds as sacred and honour them accordingly. Family members are mutually obligated to help one another. It is the parents’ responsibility to raise children and children’s responsibility to take care of parents in their old age. Being filial to parents is not only a matter of duty, but also a matter of virtue. Providing care for chronically ill family members is a life-long moral obligation. Fulfilling such family obligations remain central to family life despite the changes in family structure and government policies with respect to fertility, marriage and old age support, and western influences (Chen, 2012; Holroyd, 2003). But as China

continues on a course of rapidly aging family members and declining birth rates, family carers juggle competing demands with lack of support and resources both within the family and outside to sustain the level of care that they feel is right for their family member. Second, the Chinese health care system is unique due to the inclusion of Traditional Chinese Medicine, which promises additional hope for Chinese cancer patients. On the other hand, cancer care in China overly emphasises prolonging life using aggressive interventions while services aimed to improve quality of life, such as specialised palliative care services, are seriously lacking. In addition, it is generally hard for Chinese people to access and afford health care in the current health care system. As such, the overall health care environment is unfavourable to Chinese cancer patients. Our study suggests that fostering hope, as a resource, has significant implications for improving care and support for people at the end of life at multiple levels – personal, interpersonal, social and cultural.

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Appendices

Table 1. Embedded case study design

| | Urban setting (Kunming, Yunnan) | | Rural setting (Dehong Prefecture, Yunnan) |
|--|---|---|---|
| Embedded cases (care settings) | The committee: A self-help organisation run by and for cancer patients, which promotes 'comprehensive rehabilitation', survivorship and mutual support | The ward: An inpatient palliative care ward of a public general hospital, which serves those patients who can pay by medical insurance or pocket money | The hospice: A partnership between a public general hospital and a charity to provide free home-based palliative/end-of-life care for people with advanced cancer who are impoverished |

| | | | |
|--|--|--|--|
| Sub-units <i>(patient characteristics)</i> | 10 patients Mostly cancer survivors with a diagnosis of advanced cancer, pain and symptom controlled/free, living independently | 5 patients Mostly experiencing rare and unpredictable moments of lucidity or unable to talk | 10 patients Mostly poor rural residents, living in the geographically isolated and socioeconomically disadvantaged mountainous areas, suffering from severe pain and other symptoms, therefore bedbound/homebound |
| Interviewees | The director and 10 patients | 5 Family members, 3 senior doctors, 4 junior doctors, the head nurse, 4 nurses, 2 nursing workers (individual interviews), 5 nursing workers (a group interview), and a funeral service worker | 10 patients, 2 doctors (one was the director) and 2 nurses |
| Length and focus of observations | Patients' rehabilitative activities before or after interview in their community | Five-hour-per-day observation for a month Daily life of 5 patients; Roles and routines of families, 8 doctors, 9 nurses, 11 nursing workers, 2 funeral service workers; How death was managed | 25 home visits and Outpatient services Over a week |

Table 2. Demographic profile of the patients

| | % (n) |
|------------------|--------------|
| Age | |
| 55-59 | 12% (3) |
| 60-69 | 40% (10) |
| 70-79 | 40% (10) |
| 80-89 | 8% (2) |
| Sex | |
| Male | 44% (11) |
| Female | 56% (14) |
| Ethnicity | |
| Han | 92% (23) |
| Bai | 4% (1) |

| | |
|--|----------|
| Xi Bo | 4% (1) |
| Religion | |
| Non-religious | 88% (22) |
| Buddhism | 8% (2) |
| Christianity | 4% (1) |
| Marital Status | |
| Married | 72% (18) |
| Widowed | 24% (6) |
| Divorced | 4% (1) |
| Education | |
| Illiterate | 16% (4) |
| Primary school | 24% (6) |
| Middle school | 24% (6) |
| High school/secondary technical school | 20% (5) |
| Junior college | 8% (2) |
| Undergraduate | 8% (2) |
| Occupation | |
| Retired peasant | 24% (6) |
| Retired officer | 28% (7) |
| Retired teacher | 8% (2) |
| Retired doctor | 4% (1) |
| Retired worker | 28% (7) |
| Retired engineer | 8% (2) |
| Residency | |
| Urban | 60% (15) |
| Rural | 40% (10) |