
Resilience in resource-poor settings

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Providing palliative care in resource-poor settings demands a considerable measure of resilience in healthcare professionals and volunteers involved in responding to the often formidable needs of vulnerable local communities. In this chapter we explore the ways providers of palliative care engage in the 'dynamic process' of resilience as defined by Egeland *et al.* (1993) and Luthar *et al.* (2000) using the 'protective attributes' of positive adaptation, functioning, and flexibility in the face of significant adversity. Such challenges can include the negative impact of globalization, political and military conflicts, or environmental hazards that leave vulnerable communities in the developing world struggling with social and economic inequalities. Using examples from our research undertaken as part of the global development programme with the International Observatory on End of Life Care (IOELC), Lancaster University (Clark *et al.* 2003), we examine the strategies and limits of individual and community responses in attempting to deliver palliative care when challenged by poor levels of education, long-term conflict, and chronically under-resourced healthcare systems.

Much of the key writing on the concept of resilience arises from research into developmental processes of children and adolescents who appear to survive and overcome severely adverse and deprived family or community situations (Rutter 1985, 1993; Garmezzy 1991; Cichetti *et al.* 1993; Bluglass 2003). However, discussing palliative care provision in terms of resilience we draw on literatures in community psychology (Sonn and Fisher 1998), which explore how communities find the capacity to maintain resourcefulness, identity and function in situations of chronic socio-economic disadvantage, cultural oppression (Elsass 1992; Hernandez 2002), political and military conflict (Kimhi and Shamai 2004), and environmental disaster (Wisner 2003). In the writings on resilience at the end of life and in old age we see descriptions of individual resilience dependent on a complex interrelation between individuals and their community (Byock 1997; Walter-Ginzburg *et al.* 2005). Key factors, many of which can translate across into palliative care provision in resource-poor

settings, include an individual's capacity to maintain or regain self-esteem, having a realistic outlook of abilities and needs, a strong sense of spiritual meaning in life and the need for self-fulfilment, and positive relations with others (Ramsey and Blieszner 1999; Nakashima and Canda 2005). In the context of palliative care provision in resource-poor settings, it is also possible to observe what we term 'professional resilience'. By this we mean that healthcare professionals demonstrate resilience through the ways they use their professional judgements and skills, including a capacity and vision to make use of, and create, educational and care provision opportunities with determination and patience, despite adverse opinions and opposition from other colleagues.

Resource-poor settings in context

The term 'resource-poor settings' refers to a wide range of situations from chronic underfunding of healthcare services in otherwise relatively stable developing countries to settings where there is extreme and continuing hardship involving a whole region or areas within countries. There may, as we note above, be a number of reasons for such inadequate resources and poverty. For example, complex and negative effects of globalization on vulnerable populations in developing countries can result in a decline in the capacity of communities to be socially and economically sustaining and supportive (Baumann 2000). In this context there are adverse effects for professionals attempting to support palliative care needs. Lee and Zwi (2003) make the point that the ability of individuals, societies and countries to adapt to the process of globalization is unequal, with those less able to adapt engaging in risk behaviours under conditions of poor access to healthcare, that have made them, for example, more susceptible to HIV infection.

We observe that in settings with fewer resources, particularly where social networks are threatened, palliative care need increases but is less likely to be met. Wright and Clark (2006) note in their study of service provision in 47 African countries that 21 countries in the continent have no reported hospice or palliative care provision. In such regions where social welfare and healthcare systems are in an extreme, fragile state palliative care providers, if they exist at all, have to be exceptionally resilient, able to champion and campaign for training and services. They may derive such resilience in part from their ability to utilize human and social capital, including seeking their own education, working sensitively with different cultural needs, capable of providing some basic palliative care training for healthcare colleagues and developing social networks from which to draw volunteers. In part this resilience is dependent on the individual's capacity to be flexible, adaptive, perceptive, and realistic. Stjernswärd and Clark (2003) suggest that: 'finding ways to empower families

and communities ... is an urgent priority and in this socio-economic and cultural solutions will be as important as medical ones if meaningful palliative care is to be achieved.' (p. 1202). From this perspective, healthcare professionals and volunteers are more likely to develop resilient systems of provision when they are able to engage with local knowledge and local cultural values and needs (Altman 2003).

Other more extreme examples of resource-poor settings include those struggling with military and political conflict and continuing hardship. These communities are often on the edge of potential collapse with subsequent failure of capacity to provide a modicum of adequate healthcare. Where a community is forced to employ multiple strategies to maintain their very existence palliative care needs may be quickly subsumed in the pressing need for basic survival. Hence an individual's dying process may not be considered a priority when the whole community is under threat. In this situation the focus is more likely to be on distribution of food and water, the urgency of feeding infants to prevent malnutrition and avert a threat to the survival of the next generation. Such are the situations faced by many healthcare professionals and volunteers in many regions of Africa and South America, parts of India, and certain regions of the Middle East.

In the following two sections of the chapter we reflect on the nature of individual, community, and professional resilience in three different resource-poor settings in India, the Occupied Palestinian Territory, and Turkey, where each region presents different obstacles and challenges. We explore the relationship between these different forms of resilience and the key factors that benefit the development of palliative care services. In this context we examine the interaction between resilient individuals, professional resilience, and how this builds and works with community resilience. Our observations in the following sections are drawn from research undertaken for the IOELC global development programme, which aims to map the development of hospice and palliative care services in regions around the world, focusing in particular on resource-poor and transition economies. A key aspect of the programme is the production of in-depth 'country reports' using a common template to map palliative care development, history, and current services. The reports are published freely on the IOELC website www.ioelc-observatory.net providing a resource for current and future policy, education and training, and service development. Reports are compiled using a multi-methodological approach of quantitative and qualitative analysis, including statistical information, ethnographic interviews and narrative accounts, referenced peer-reviewed and grey literature and photographs. Interviews are conducted wherever possible in each country with key healthcare professionals and others involved in service provision.

The research for the country report on India was undertaken between 2004 and 2006; research for reports on the Occupied Palestinian Territory and Turkey was conducted during 2005.

Resilience and palliative care in India

India is a challenging country for those involved in developing palliative care. In 2000, the World Bank Development report notes that India contains one-sixth of the world's population, of which 89% live on less than US\$2 a day and 53% on less than US\$1 a day (International Bank for Reconstruction and Development/World Bank 2000). The impact of globalization has generated substantial gains in economic investment and yield but India faces serious problems such as widespread poverty, enormous pressures of overpopulation, environmental degradation, and religious and ethnic conflict (The World Factbook <http://www.cia.gov/cia/publications/factbook/geos/in.html>).

In terms of palliative care needs an estimated 1 million new cases of cancer are diagnosed each year in India, with over 70–80% of patients presenting at stage III and IV and in need of supportive and palliative care (Kumar and Rajagopal 1996; Seamark *et al.* 2000). Palliative care provision in the country has grown over the last 20 years but progress has been slow and uneven. Our research identified hospice and palliative care services in only 16 of the total 35 Indian states and union territories (IOELC Country Report: India http://www.eolc-observatory.net/global_analysis/india.htm). Overall, coverage is poor and usually concentrated in large cities; opioid availability is limited and there is no national palliative care policy. Resilience at an individual and community level has proved to be crucial in order to successfully develop palliative and supportive care services at the end of life in communities around India. One element of this resilience appears to stem from the capacity of healthcare professionals and volunteers to adapt Western models of hospice and palliative care into the different cultural contexts of India. In his discussion about the challenges of providing palliative care in India, Dr M.R. Rajagopal, a founder of the Neighbourhood Network of Palliative Care (NNPC), Kerala, makes clear why this adaptation is critical to the successful delivery of services:

Our suffering people need a system of palliative care delivery that is suited to our social and cultural milieu. It has to be inexpensive; we cannot possibly have enough expensive inpatient facilities for a million people. We can learn from the hospice system of the West, without duplicating it in its entirety. We have a strong point in our favour and that is the family structure in India. People generally prefer to live and die at home. If we have a system of delivery of palliative care based on treatment at home, with the relatives being empowered in the care of the patient, it has a definite chance of succeeding.

Rajagopal (2001, p. 66)

Two examples of services which have shown exceptional resilience and positive adaptation in the face of immense difficulties are 'CanSupport', located in New Delhi, northern India, and the NNPC, in Kerala, south-west India. CanSupport is a palliative care home care service, set up through the efforts of a single woman, Harmala Gupta, as she recovered from cancer. This is an example of a resilient individual working to build community resilience. The NNPC has been highly successful at developing a community participatory model of palliative care. The NNPC story demonstrates how existing community strengths and resilience have been utilized and developed by individual volunteers and healthcare professionals.

CanSupport, Delhi

CanSupport, founded by Harmala Gupta in 1997, was the first palliative care home care support service in Delhi, northern India (CanSupport 2004). The organization provides free home-based palliative care, day care, and counselling services, including bereavement support for patients and their families. There are four home care teams of specialist trained doctors, nurses, and counsellors working from different centres in Delhi. Each team visits the homes of about 80–85 patients with advanced cancer every week (Hind 2004). Family members are trained in simple nursing tasks so they can keep the patient comfortable until the next home visit. The entire service is funded through donations and grants. Harmala Gupta speaks of the challenges for CanSupport:

... any area you touch there is a problem, which is why we have, as you suggest, gone beyond the traditional palliative care support and provided dry rations, dried food rations to people, sometimes help with transportation, we provide them with all kinds of medical aids. Really I think we also perform a much needed social function, because families tell us that even their relatives have stopped visiting them. We realise there is so much ignorance around cancer; a number of people believe it is contagious and they stop visiting.

Gupta (2004, pp. 32–38)

CanSupport was set up as a result of Harmala Gupta's own personal illness journey requiring her considerable determination and resilience. In 1986, she was diagnosed with non-Hodgkin's lymphoma while studying for a PhD in Canada. The experience of dedicated cancer patient support services in Canada was in stark contrast to the stigma Harmala encountered when she returned to India. This spurred her to instigate a cancer patient support service, which eventually led to collaboration with a hospital pain and palliative care clinic and the CanSupport homecare programme. Harmala's inner resources are central to her resilience as a cancer survivor and as a palliative care pioneer. In the extract below, her personal resolve is evident as she describes her motivations and early struggles:

I felt very strongly that it was important for me as a survivor to identify myself and to go out and let people know that you could still continue to live after cancer, and I approached the Indian Cancer Society in Delhi and was alarmed to realise that as a survivor I could not become a member ... I mean it was just crazy ... Well I joined the society nevertheless and I tried to persuade them that there was value in investing in patient support services, because there were people who recovered.

Gupta (2004, pp. 32–38)

Harmala Gupta has shown great tenacity in overcoming the difficult circumstances of her illness, which can be attributed in part to her ability to positively adapt to adversity. However, as Luthar *et al.* (2000) argue exposure to adversity is mediated by cultural and socio-economic factors as well as individual psychology. In the following extract we see the kind of difficult socio-cultural dynamics Harmala faced, given the paternalism of healthcare professionals she encountered during her treatment and the cultural perception of cancer as a stigma:

... there is a very patriarchal relationship between the doctor and the patient where the patient isn't really supposed to ask questions. They just obey orders; they are told what they are supposed to do. So given the situation a lot of people found themselves quite disempowered and had a sense of helplessness and hopelessness, and it was important to break through that and I really had to struggle with the doctors and tell them that there was value in having someone who had been through this experience to talk to people who were going through it ...

Gupta (2004, pp. 32–38)

Harmala Gupta has the advantage of being highly educated and of speaking fluent English. To some extent she feels able to 'struggle' with the medical profession because she enjoys a high social position, similar to medical professionals within Indian society. She has access to significant economic, social, and cultural resources in addition to her inner strength. She goes on to describe the gender-specific aspects of adversity that she discovered in the course of her experience as a woman faced with a cancer diagnosis, which demanded another level of resilience and determination to overcome:

I realised that people are not told their diagnosis. Especially for a woman, there is this belief somehow that women can't take bad news. And the doctors being predominantly male tend to ask the woman to leave and discuss the diagnosis with the husband or the male member if any male member has come. Of course there is a lot of suspicion because if you are asked to leave the room you realise immediately that it must be something quite serious. But when you ask questions you are immediately brushed aside and told no, no, no, there is nothing to worry about, everything's under control.

Gupta (2004, pp. 32–48)

The resilience required by Harmala Gupta to overcome and make good use of these challenges in order to set up a functioning palliative care home care

service may be due to a number of factors. As an individual Harmala Gupta demonstrates certain important 'protective attributes' identified as indicators of individual resilience, such as flexibility, self-awareness, a strong sense of social awareness and support (Nakashima and Canda 2005). She has drawn upon her high social status, educational advantages and inner resources. She has the capacity to inspire other committed individuals to join together to build new palliative care services. CanSupport services in turn help to develop community resilience. In the following account of palliative care service development in Kerala we describe an example of a community response to adversity that draws on existing community dynamics to build community resilience.

Neighbourhood Network in Palliative Care, Kerala

In the state of Kerala, south-west India, there are impressive innovations in palliative care that have been achieved against a background of extremely limited resources (Rajagopal and Palat 2002). The development of palliative care services in this state appears to be shaped by community resilience; defined by Sonn and Fisher (1998) as a community's capacity and resourcefulness to cope positively with adversity and therefore generate effective ways of coping with the challenges of living and, in this case, dying.

The NNPC is a network of 63 palliative care clinics across Kerala, providing care free of charge to patients in need. The NNPC is a joint venture with four other non-government organizations (NGOs) attempting to develop a sustainable 'community led' service capable of offering comprehensive long-term care and palliative care to those in need (Kumar 2004). Volunteers from the local community are trained to identify the problems of people in their area who are chronically ill or dying and to intervene effectively, with active support from a network of trained professionals. NNPC aims to empower local communities to look after chronically ill and dying patients within their community (NNPC 2005).

At the beginning of the 1990s, there was only one pain clinic in Kerala at the Regional Cancer Centre in Trivandrum in south Kerala (Bollini *et al.* 2004). Palliative care services were initially set up in 1993 by a small group of doctors and social activists. The idea was swiftly taken up by local communities, the project going beyond what the originators had anticipated. NNPC programmes appear to have been exceptionally successful wherever they have been launched in Kerala. The programme was first 'ground tested' in Malappuram, a poor district in Kerala with a population of 4 million. Within 2 years a rate of 70% coverage in provision of long-term care and palliative care was achieved. There is an NNPC clinic at roughly every 10 km, which means patients should not have to travel more than 5 km to their nearest clinic (NNPC 2005).

The success and growth of palliative care provision appears to be, in part, due to the capacity of local communities to adapt positively to difficult circumstances. There is also a cultural tradition in Kerala of community involvement. In January 2005, NNPC physician Dr Suresh Kumar reflects, in an interview, on 10 years of developments in palliative care in Kerala:

I think that the definite trend, as far as Northern Kerala is concerned, is palliative care moving out from the institution into the community, and this has been happening much faster than even some of us who are part of it expected. And from '93 when the first palliative care clinic was started in Calicut, it was a very much institution-based, doctor/patient model. We had a few volunteers but they were doing odd nursing jobs after training, and the whole team was centred around the doctor and there was some support from the community, financial, like some of the donations. Now we have reached the stage where most of the care is delivered in the community and the doctor in many palliative care units in northern Kerala is somebody who looks after or takes care of the physical problems, and most of the other issues like social support, the spiritual issues, other emotional problems are taken care of by the volunteers. Most of the units now are run by the local groups and they employ the doctor, that's against the earlier clinics initiated by doctors and the volunteers and other people acting under him.

IOELC interview (14 January 2005)

Community resilience can be thought about in terms of communities being capable of providing members with opportunities to be meaningfully engaged in activities and social relations. In other words, to feel a sense of belonging and identification that meets the psychological needs and material requirements of involved individuals (Sonn and Fisher 1998). In Kerala, this process can be seen in the ways different local communities have developed effective coping strategies to deal with the challenges of living and supporting those who are dying. Mr T.S. Babu, a NNPC volunteer, explains the role of volunteers in the organization:

They can console the family to boost their morale, this thing is more important because the patients which we go and see are very, very poor; the rate of survival is a problem. More than the medicine they need the moral support and the financial help; that is what they need—so I collect money also from others.

IOELC interview (19 January 2005)

As Dr M. Numpeli, programme executive of NNPC notes, the extent of this collectivization of palliative care can be illustrated through the voluntary nature of the service delivery and funding (IOELC interview: 12 January 2005). Dr Suresh Kumar gives examples of two highly successful fundraising ventures in Malappuram, through small community donations such as 'Palliative Care in Campus' where students contribute a rupee every month or in another example

the bus drivers entering Nilambur bus station each day contribute two rupees per bus (Presentation at Lancaster University, UK: 26 September 2005).

The success of NNPC relies upon existing community resilience, partially sustained by the state's investment in education and healthcare for local people. This investment provides the social context and resources that facilitate a community cohesion or social consciousness (Sanders and Chopra 2003). The way in which an effective palliative care service has been developed in Kerala is an example of resourceful, far-thinking individuals building on existing community resources in order to provide low-cost care end of life to large numbers of people.

Resilience and palliative care in two settings in the Middle East region

Providing support at the end of life in settings, for example where healthcare services are affected by political and military conflict or chronic poverty requires a particular flexibility and willingness in health workers to seek diverse strategies to effectively use local and community resources. In the following two examples we describe the resilience observed in healthcare professionals and volunteers providing care provision in very different situations: the West Bank and Gaza in the Occupied Palestinian Territory, and Turkey. Healthcare professionals in both regions, and for a range of different reasons, report problems in finding adequate resources with which they can provide effective palliative care services. Consequently, where services are provided, in however basic a form, we observe individuals and communities demonstrate certain resilient characteristics of resourcefulness, a positive sense of self and community values and identity, and the capacity to grasp opportunities and to make good use of social resources. These characteristics are well documented in other similar contexts (Sonn and Fisher 1998; Hernandez 2002; Wisner 2003). As we observed above, however, a key resilience characteristic in palliative care provision is the ability to 'champion the cause'.

Occupied Palestinian Territory

In the West Bank and Gaza ongoing and increasingly serious conflict has resulted in a crisis for all healthcare services (WHO 2006a,b). Healthcare professionals are unable to provide palliative care beyond the most basic pain relief and symptom management. Their efforts are further hampered by lack of available medication (IOELC Palestinian Authority country report http://www.eolc-observatory.net/global_analysis/palestinianauthority.htm). This situation forces providers of healthcare to test their resilience to the limits and

draw on a range of survival tactics, or risk facing the collapse of any effective health service.

From our work in the region mapping palliative care services we identified one key service, the Patient's Friends Society-Jerusalem (PFS). Situated in East Jerusalem PFS acts to 'champion' and actively promote a range of services such as breast cancer and osteoporosis screening and support services for patients with cancer, including where possible, patients at the end of life. Carol El Jabari, director of PFS, works with local women who have, or have survived, breast cancer. The women are almost all from the West Bank. Carol is a firm advocate of self-help and education; working with women in the West Bank to run self-help support groups and a telephone helpline. She also organizes study days for physicians and nurses. As Carol notes the first requirement for the success of self help groups is commitment: 'it was important to identify women that were as keen or as committed as me to make it a reality.' The second crucial element is flexibility:

For those women that can't get to us from the West Bank, we go to Ramallah, Jericho, Hebron and Bethlehem. My coordinator contacts women, or women contact us, and we try to gather a few to make a group session. We have a fixed meeting scheduled every month but often have other meetings as well depending on people's need. While not structured the meetings are conducted based on the women's interests ... Access is a major barrier for women from areas outside Jerusalem and dependant on the 'authorities' issuing, and honouring, a permit. If we want to go to the West Bank we never know if there will be restrictions or delays, and women don't always have the financial resources to get to meetings. So there are many difficulties. Despite the misery of living under occupation, we have a group of women living with cancer and other comorbidities that are committed to the 'group' and want to help others. That this has continued and grown is really great! It shows the women are committed, and they're so keen and it's changed their lives for some of them.

IOELC interview (10 March 2005)

In terms of palliative care, though, PFS can only help in indirect ways. Because there are no government resources to deliver formal palliative care services in the West Bank or Gaza families are called upon to care for their relatives. PFS volunteers will offer psychosocial support and help to get prescriptions, access medication, and make home visits where possible. How well these patients manage is uncertain. They are dependent on the resilience of family members having to deal with the cancer, which is still regarded as a stigma. One important factor lies in the strength of family networks, with family members willingly supporting their sick relatives despite difficulties accessing medical care, and often with their own health problems. Carol El Jabari outlines the situation:

Those that are terminal or a late stage of the disease are just on the margins and get pretty minimal care. This has been my experience. The families are not prepared; they don't have enough medical or financial support. It's really up to them to look after

their very ill or dying relatives. They don't have the skills or the knowledge. They do their best but there's no psychosocial support for them. Doctors and nurses are not specialized in palliative care so the quality of care varies. At present there are little if any resources and no mechanisms in place for change. Healthcare is under the Palestinian Authority and they're stretched just to look after diabetics and hypertensives. Cancer isn't high on the list.

IOELC interview (10 March 2005).

Her experienced is echoed by other healthcare professionals in the region, such as Dr Fouad Sabatin, a haematologist at the Augusta Victoria Hospital in East Jerusalem (IOELC interview: 2 May 2005).

Cancer appears, historically, in the West Bank and Gaza, to be a low priority in public health, with the more pressing needs of child and maternal health, problems of endemic infectious illness, sanitation, and nutrition taking precedence (Giacaman 1988). Over half of all deaths are due to cardiovascular disease, but cancer is one of the other major causes of deaths. With few resources for treatment, however, of either condition, palliative care need is high. As part of a strategy used over several decades by international NGOs and aid agencies to provide general healthcare across the West Bank and Gaza hundreds of small local clinics are found throughout the West Bank and parts of Gaza. Although fraught with supply problems the clinics do offer some mechanism for provision of medication and equipment. Unfortunately, without specific palliative care training clinic staff are unable to offer skilled support and patients have to attempt difficult journeys to get help as Dr Fouad Sabatin, oncologist at the Augusta Victoria Hospital, East Jerusalem explains:

People living in Ramallah [West Bank] are unlucky when it comes to having a diagnosis of cancer because there is no centre in Ramallah with the facility to treat these patients; and typically, these patients need to be referred to Beit Jala hospital or to Nablus, and all of them are far away, and there are several checkpoints in between. So getting to the hospital is really difficult, and usually it takes several days for these patients to be sent in the right direction ... And if you're asking about how these patients will do and their management, if they have a pain crisis or something like that, it's really very tough because, as I said, there is no place in Ramallah that's really able to treat these patients. They end up being treated by general practitioners at government hospitals until they can be referred to another place. It's a sad situation.

IOELC interview (2 May 2005).

The situation in Gaza presents an even greater challenge of human need; a densely populated area of 1.3 million people struggle to survive in a serious conflict with dwindling basic resources in a land area of less than 360 km². Oncologists there report that although there are three hospitals with oncology units, their efforts to support patients at the end of life are hampered by erratic supplies of opioid medication. Oncologists demonstrate professional resilience

in their flexibility within continually changing situations, for instance having to adjust prescribing according to available medication supplies.

An important development in improving palliative care skills in the region has been increased opportunities for education and training. As noted above PFS offers short study days in cancer and women's health, promoting self-help and support. The organization is committed to supporting research and training, and funds volunteers and professionals to attend international conferences. Since 2004, the Middle East Cancer Consortium (MECC)¹ has run two palliative care seminars open to oncologists, physicians, nurses, social workers, and academics in the region. Well-attended by healthcare professionals, the seminars have proved highly supportive, encouraging dissemination of skills and acting to develop resilience in those involved in providing palliative and supportive care. In these various ways PFS and MECC directly and indirectly help to build and nurture individual (volunteers and professional) resilience through education and training, and external support. This approach, it is hoped, will thereby benefit and in the longer term, build community resilience.

Turkey

Healthcare in Turkey is a complex system of provision by a government, military, and university facilities. This large country (land area 750 580 km²) has a population of about 73 million, and significant numbers live in resource-poor rural areas. The major centres of healthcare tend to be most advanced in the two largest cities Ankara and Istanbul. Palliative care is not well-developed in Turkey. Healthcare professionals and academics have a complex and difficult task ahead to educate and change professional and public attitudes. The nature of the challenge is less obvious in Turkey than in the previous examples of India and the Occupied Palestinian Territory; there are no unifying factors that demand survival tactics in the sense that communities are not engaged in active conflict or facing extreme poverty. However, the government as the largest health provider is proving slow to respond to palliative care needs. Consequently, the people are reliant on the health professionals to take the lead in providing support. There are no palliative care NGOs and virtually no known charitable organizations that are involved in care of the dying. The onus is on physicians, oncologists and specialist nurses, and social workers to

¹ The MECC was established in 1996 with the aim of setting up population-based cancer registries for member countries in order to monitor cancer incidence, mortality and epidemiology, promote preventative health policy, and encourage research and educational links. MECC members are Cyprus, Egypt, Israel, Jordan, Palestinian Authority, and Turkey. Since 2004 MECC has run two seminars on palliative care (Silbermann 2001).

find ways to provide palliative care within the context of general care and support at the end of life.

The most effective strategies appear to arise from professional resilience, in that healthcare professionals demonstrate their capacity and vision in order to grasp educational and clinical opportunities. Professionals wanting to develop services encounter a major problem of a lack of data. Professor Yasemin Oguz, a medical ethicist who has a particular interest in palliative care reported in 2003 that:

As the director of the needs assessment project for palliative care in Turkey I may say that our main problem is the lack of national data on the subject. Without essential data it is not possible to convince the Turkish Ministry of Health and National Health Insurance Organizations about the importance of the subject. Palliative care and end of life issues are a kind of no man's land in Turkey. Although many healthcare professionals encounter the problems and are aware of the need, they do not see the subject as their business. There are financial and legal restrictions. Our initial objective is to establish a continuous communication between interested professionals and patient advocacy groups.

IOELC questionnaire survey (2003)

Another major problem faced by Turkish physicians is lack of resources, as the government fails to provide adequate funding for specific end of life care. The other key issue is widespread fear of opioid prescribing. Against this background we observe positive changes emerging with oncologists in seven university hospital oncology units now actively developing palliative care skills. There are a few oncologists and physicians specializing in pain relief who are also 'champions' of palliative care. Almost all these physicians have gained skills by going overseas to complete specialist training and much of their resilience in practice is apparent through a combination of their professional and individual resilience, shown by a determination to gain skills and then to return to the country to train others and create local resources.

Pain specialist Professor Serdar Erdine aims to improve pain and symptom management (in the absence of active services in palliative care). As he says: 'pain is underestimated' in Turkey. He relates how the Ministry of Health (MoH) restricted his prescribing of opioids but when he told his patients that he was prevented from prescribing, they protested to the MoH, who gave permission for the drugs to be prescribed. Thus, with encouragement from committed healthcare professionals and public education, people can put pressure on government to improve services. Professor Erdine has focused on developing skills in pain relief and has been instrumental in the development of 'algology' or the study of specialist pain relief. With 25 years of experience and extensive knowledge of pain relief, he explains that through TV and articles in journals and newspapers he and other colleagues are trying to alleviate people's cancer fears by raising public awareness of the effectiveness of opioids

in relieving cancer pain. He is also organizing a campaign to educate physicians about the safety and efficacy of using opioids (IOELC interview: 11 July 2005).

Professor Erdine gives an example of his individual ability to grasp positive opportunities as they arise. Following the severe Turkish earthquake in August 1999, thousands of opioids were sent as medical aid by other countries. Turkish doctors, however, did not make use of this medication because of widespread opioid phobia and lack of awareness. As Professor Erdine observed, 'An estimated 100,000 people were suffering but physicians did not feel confident to give opioid pain relief'. After the emergency was over the authorities offered Professor Erdine some of these morphine stocks, which he accepted. He is still using the medication in his pain clinics. As he notes: 'Turkey is one of the biggest manufacturers of opioids in the world but uses less than some countries like the US.' (Presentation at Open Society Institute palliative care seminar, Budapest: 5–7 September 2005).

In another example of education supporting and building professional resilience Dr Deniz Yamaç, oncologist at Gazi University Hospital in Ankara, explains how she was introduced to the concepts of palliative care while completing training in oncology at Arkansas Cancer Institute, USA. Since 2000, she has been inspired to develop training in her oncology unit and has run short sessions and day workshops designed for other medical faculty members and resident physicians. There is a separate programme for medical students. She is especially interested in improving communication skills and sees this as an integral part of good palliative care training and practice. She also makes an important point about skills development helping to prevent 'burnout'. Healthcare professionals in palliative care can be particularly susceptible to burnout, a state that can seriously undermine even the most apparently resilient individual and reduce the effectiveness of organizations and communities. This is an example of 'professional resilience' supporting and building individual resilience:

I can see my way how to act, how to talk but I don't think that all Turkish doctors, especially concerned in cancer, do know this. So this is the thing we are trying to do: the workshop was about this ... You should tell it, they [the patient] *must* know, it's their life. I believe in that, so I try to tell it, not to break their heart maybe, without breaking their heart, but they must know their future, I think. So you *must* tell it but the way and the condition and the time is important. So I think I can manage it and I want to learn more or I want to teach people with that. It's something to prevent your burnout I think also.

IOELC interview (6 July 2005)

In 2005, Dr Yamaç set up workshops for nurses in the oncology unit and is also involved in a project—funded by private health insurance—to train nurses in home care for cancer patients. Part of her plan is also to encourage the

development of an inpatient unit. Physicians and other health professionals involved in the Turkish Oncology Group (TOG) are also committed to the development of palliative care skills, despite the ongoing problem of a slow uptake of ideas that presents less chance for effective change or support. TOG demonstrates a commitment towards building professional resilience by creating educational opportunities. The group has, to date, organized two conferences bringing interested Turkish healthcare professionals together with several key, international specialist palliative care professionals. As oncologist Dr Seref Komurçu explains, the hope is to encourage more professionals to take an interest in developing palliative care around the country (IOELC interview: 18 April 2005).

Conclusions

When reflecting on the phenomenon of resilience as a ‘dynamic process’ in the development and maintenance of palliative care services in resource-poor settings we are struck by the pattern of specific characteristics or requirements observed in individuals, in people’s professional practice, and in communities, that help to overcome, at times, formidable obstacles and challenges. Successful palliative care development requires the building of resilience at all levels, within the individual, professionally, and from within communities. Different situations and cultural contexts, however, demand strategies that may draw variously on the attributes of one individual, professional skill, or on existing community resources.

Of the three sources of resilience we would argue that the key is individual resilience, although there are resilience factors common to all three sources (see Figure 14.1).

Without some ‘one’ or some ‘small group’ inspired by one or two highly motivated individuals there can be no grasping at opportunities, no strategic moves to involve the community or educate and motivate colleagues, however active the professional and community spirit. Key ‘protective attributes’ include a certain element of charisma, meaning a person who is sociable, altruistic, has vision and intelligence, the courage to confront authority and be diplomatic, shrewd and far-thinking (Clark *et al.* 2005). The capacity to ‘champion’ seems to be mediated by gender to some extent—as yet under-researched—as a significant number of women are found in palliative care acting as ‘champions’, challenging oppressive regimes, poorly resourced healthcare, and adverse social or environmental conditions. Champions, whether men or women achieve change by clearly identifying end of life needs, encouraging social networking, and developing strategies to campaign at community and government level for new services or improvements to existing services. They successfully seek out other committed individuals and

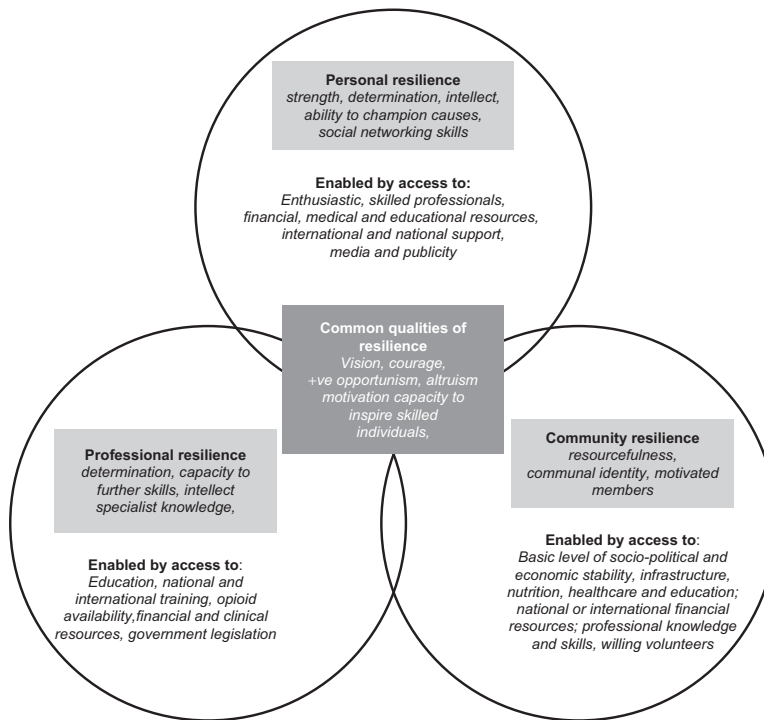


Figure 14.1. Interrelationship of personal, professional and community resilience in resource-poor settings.

have the ability to create palliative care support that utilizes local and community networks or existing healthcare services. The power of inspirational persuasion is a crucial factor in the development of successful organizations.

A second key pattern is that the individual has been ‘nourished’ from some outside source, by some inspiring educational experience or encounter. For example, many professionals and volunteers report that they were originally inspired by attending a lecture by Dame Cicely Saunders or by coming across her writings. This is often described as a life-changing experience and if coinciding with training or opportunities to work in a hospice has been the starting point for several ‘champions’ of palliative care, supporting and developing their inner resilience and resolve. The process of overseas training in building professional resilience has also proved to be a point of inspiration. However, we also observe examples, such as in the worse affected war zones in the Occupied Palestinian Territory, where educational opportunities alone will not necessarily build resilience or translate it into developing local services on return to the home

country, despite great personal courage in the face of daily active conflict and many obstacles and difficulties to overcome.

Thus we come to the third and pivotal element of building resilience and the effects of resilient individuals; the relationship between the individual with personal and professional resilience and their community. In India, for example, palliative care would not have developed without the persistence and determination of dedicated non-professional individuals and healthcare professionals throughout the country. In the cases of CanSupport and the NNPC, this resilience is evident through the work of individuals in relation to their communities and social systems. For example, Harmala Gupta's work in developing CanSupport, a homecare service, is an astonishing display of individual resilience, where she is able to draw upon her inner resources and her social and economic advantage of a reasonable privileged position within India's social hierarchy. However, her story clearly shows that for her individual resilience to translate into action beyond her own daily life, she had to have vision, altruism, flexibility, and sociability. She also had the opportunity to travel away from her home situation, experience a very difficult encounter with a life-threatening illness that provided great insights, which she was able to grasp and use by returning to her home country and 'championing' the cause.

In much the same way we observe Carol El Jabari, in her work with PFS, Jerusalem, bringing a combination of professional competence, vision, sociability, altruism, and flexibility into a very challenging situation, with a community whose members are frequently overwhelmed by despair. She saw ways she could utilize social resources within the community by working with existing family and social networks to encourage women with breast cancer to join the self-help group, which builds individual and community resilience by supporting women and training them to support others. Adapting to overcome adverse political situations that limit free access through the region, the group is set up to run as flexibly and self-sufficiently as possible. The PFS phone helpline is an important link for those women in Gaza who are unable to access any other psychosocial support.

The proliferation over a 10-year period of a community-led palliative care service in Kerala provides a different lens through which to consider resilience in palliative care development. In these circumstances, resourceful professionals have been able to work with existing social cohesion and awareness, encouraged by state welfare provision. Another aspect of NNPC's success is the professionals who have explored ways to effectively adapt Western concepts of hospice and palliative care to fit resource-poor settings. The role of resilience in a global context is complex, and specific to different countries, states, communities and individuals; influenced by ethnic, socio-cultural, and economic differences.

The success stories presented in this chapter demonstrate that nurturing individual, professional and community resilience, in all its complexity, is a crucial element in the development of palliative care provision in resource-poor settings.

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