



# The Social Pain of Cancer in East Africa: Understanding Need

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## A CARER'S STORY

We start this chapter with the story of a man we will call Mr. Maneno. Maneno's wife had been receiving treatment for breast cancer for 6 years by the time he was interviewed at a referral hospital in Kenya in 2019. Although some of the costs of care had been funded by the National Health Insurance Fund (NHIF), its coverage was only partial, and the current regimen of Herceptin, following multiple rounds of chemotherapy that had not prevented the cancer from metastasizing, was

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particularly expensive. Thus, Maneno and his wife had been obliged to “hustle for money” at points, holding a *harambee* (community fundraiser) to fund chemotherapy and accessing support from an NGO to pay for a mastectomy. Maneno explained that “...the big challenge with this thing is the finances”. He did his best not to allow his wife to be affected by the stress of finding money, meaning that as a caregiver “you have to carry that burden...you have to make sure she is psychologically well, and then you struggle looking for money”.

While facing the significant costs associated with treatment, household income had suffered after Maneno’s wife stopped work when he was concerned it was making her illness worse, and his caring responsibilities affected his capacity to run their business, which was now less successful than previously. In part this was due to the psychological difficulties he faced in coping with his wife’s illness, and he explained that for those caring for loved ones, “you cannot settle at work”. Caring for his wife was also time consuming for Maneno, as “you can’t leave her to come to the hospital alone, so it takes a lot of your time, such that it is hard to concentrate.... She can’t stay home without a help because she can’t do many things on her own”.

In addition to day-to-day challenges, the cost of care impacted the potential for Maneno, his wife, and their two children to imagine and realize future aspirations. Maneno had become used to “the stress” of managing ongoing essential expenditure on medicine, food and school fees, and no longer considered how they might invest in future plans. He noted, “you can’t, because when you think of investing, she relapses”, meaning further costs for hospitalization and medicine and more time spent away from the business.

Although the household had drawn on networks of friends and family to finance care, and for general social support, cancer had a difficult impact on these relationships. Maneno’s brothers had helped, but he acknowledged, “you know everyone has their own responsibilities... You can’t fully depend on them”. The high costs and multiple rounds of treatment involved in cancer care also meant that “sometimes it reaches a time they view you as a burden. When you call somebody they tell you that they will get back to you. It is difficult”. Friends too sometimes broke off relationships due to cancer. Maneno was grateful that his friends in the church had continued to be extremely supportive, “even when things are really bad”, and welcomed participation in a support group for those who had undergone cancer treatment and their carers. However, this was not

the case with his older friends and Maneno explained, “now you know you have to get new friends...the older ones feel that you have become a burden...those that we used to have a good time with ran away because there is a huge burden”.

Maneno described the stigma associated with a cancer diagnosis and recognized that his wife was fortunate to have been able to purchase a woven breast prosthesis, not available to many, for a relatively affordable price. This helped to “remove her stigma”, which was essential as from Maneno’s perspective, “it is the stigma that makes people sicker than the disease”. In discussing stigma, Maneno made clear the close relationship between limited awareness about cancer and cancer treatment and the unaffordable cost of care, which means patients forced to rely on friends and family risk undermining social relationships, saying:

Some people – when you mention cancer [they think of] the *harambees* that have been held... [when the patient] dies even before they treat the patient. Let us reduce the stigma. I actually was talking to someone else and I told him it is better to have AIDS, you know, because of that pain. Because, like for this chemo I have had to sell land too ... so the problem is that cost of medicine.

## UNDERSTANDING SOCIAL PAIN

The interrelated challenges associated with emotional distress, stigma, loss of social relationships, and the financial burden associated with accessing care described by Maneno echo those experienced by many cancer patients and their loved ones whom we interviewed in Kenya and Tanzania (see Chapter 1). That the suffering caused by cancer could not be understood only in physical and individualized terms was often recognized by healthcare workers, who referred to pain as “psychological”, “spiritual”, and, importantly, “social”. We thus argue for the importance of a holistic understanding of cancer pain, which acknowledges the impact of cancer beyond the individual patient, positioning them within wider social networks that are often essential to initiating and sustaining care.

The experiences and understandings of cancer and cancer care explored in this chapter illustrate the extent to which suffering is social (Kleinman, 1997). Existing literature exploring cancer care in Africa has considered the social construction of physical pain, which shapes how it is expressed and understood (Livingston, 2012). Here, we emphasize how cancer pain

is experienced socially, affecting valued relationships and undermining the agency and dignity of patients and caregivers, with implications for how they see themselves in society. Social pain is thus an experience arising from interpersonal rejection or loss, entailing relational devaluation or threats to social belongingness (Hudd & Moscovitch, 2021).

Maneno's story also illustrates the extent to which the pain he and others described is intimately connected to wider socioeconomic inequalities and structural vulnerability (Quesada, 2019). Thus, understanding the pain caused by cancer as social "points to structural configurations of power in the many institutional contexts people living with cancer move through" (Burke et al., 2019, p. 6) such as hospitals, insurance schemes and communities. At the same time, the challenges faced by cancer patients and their families have an important social impact, with "staggering" economic consequences for society as a whole (Ministry of Health, 2017, p. 8).

The next sections explore in more detail these aspects of the social and economic pain generated by cancer. At the end of the chapter, and in subsequent chapters, we consider some of the implications of this revisioning of cancer as a social and economic as well as an individual crisis.

## DESPAIR, FEAR AND HELPLESSNESS

Being diagnosed with cancer was often hugely challenging for patients, many of whom shared widespread understandings of cancer as an untreatable disease that would result in their death. In addition to fear of the disease itself, misconceptions about how cancer was treated and the anticipation of treatment in itself (considered harmful and even deadly) caused distress for some. Feelings of despair were compounded by helplessness arising from an inability to perform expected social roles, which affected patients' and caregivers' relationships with others, and their sense of agency.

Having seen others undergo treatment or die from cancer, patients sometimes found that it could feel futile to continue or simply too difficult to bear. One woman described her own thoughts of killing herself, saying:

But now, you have been told you have breast cancer. You are devastated. You feel lost. You don't want to fight anymore. You have seen, like me, I look at how my mum was languishing in pain and I thought, I will commit suicide. (survivor, Kenya)

A cancer diagnosis was also difficult for those patients who understood their illness as having a non-biomedical cause. Some patients and caregivers described their own prior assumption, and that of their neighbours and relatives, that cancer resulted from being cursed or being a victim of witchcraft. One man described his difficulty in reconciling himself with his own diagnosis, saying he went to his church:

...to tell them that I have cancer and the cancer is not mine. I gave myself courage, and people even wondered why does this person have cancer? I told them cancer is not mine, it is a disease of the evil. (survivor, Kenya)

Limited understanding of cancer as a disease that could be treated generated fear for many, such that “some even fear mentioning the word cancer” (survivor, Kenya). In addition to fear of the disease, a widespread belief that treatment for cancer itself resulted in death was reported in Kenya and Tanzania. In the words of one survivor, “there are many myths and misconceptions in the general public...chemo itself is associated with death” (survivor, Kenya). One former patient from a rural area of Kenya explained how such fears had contributed to their own reluctance to seek treatment, explaining:

The message in my home village was that if you have cancer, you are being treated in a coffin...I think that person got the message wrong because what he was telling you about as a coffin is what you lie on in an MRI or CT scan machine...so that was my biggest challenge. And believe me, I got myself stigma for six years. I just kept the symptoms to myself, I tried everything, how can you go to be treated in a coffin? (survivor, Kenya)

Radiotherapy was described as particularly frightening for many. One doctor in Tanzania noted that some patients prescribed radiotherapy decided it was “better to remain with the disease and wait for the mercy of God” (health worker, Tanzania).

### FAILURES OF INFORMATION AND ADVICE

Survivors described their despair as being compounded by the way they were treated by medical professionals, and particularly a sense they were not adequately informed about what their diagnosis meant and the likely implications, often relying instead on seeking guidance from friends and

family. One person who had been diagnosed with leukaemia recalled having received no further information at the time about what the disease was, prognosis, or possible treatment, instead being told by a family member that they had cancer of the blood and could not be healed. They explained:

So for me that is the time my world got shattered, but later after some time...when I went to this doctor, for him to tell me what I am supposed to do, he actually told me, 'we are looking at six months, there is nothing we can do.' So he didn't give me information, so he already killed me at that particular moment. So I think close to like nine months after, that is when I got someone to remove that stigma and tell me I can do treatment, even if I won't survive I can be managed for some —but it was not from him.

Indeed, incomplete or insufficient disclosure of the likely outcomes of treatment and of ways of mitigating them was a common complaint from those who had undergone treatment (see also Mulemi, 2010). One survivor described his shock upon having awoken from a colostomy, which had not been fully explained to him:

...I wake up from theatre and find my intestine hanging out, and I am like 'what! How can the doctor do this? An intestine is an organ that should be in the body. How come mine has been left out and I am already from theatre?' You know, it is so traumatizing. (survivor, Kenya)

Others outlined their uncertainty regarding sex and fertility following treatment for cervical cancer and the extent to which they felt they were not sufficiently prepared to experience side effects of chemotherapy, such as hair loss, and the lasting effects of their cancer, which included hearing loss for one participant. For many this marked a continuation of a pattern that had characterized their pathway to and through treatment. Health workers and survivors shared stories of patients who remained unaware of their diagnosis after having been referred for oncology, and even, in one case, having been treated for two years (health worker, Kenya; survivors, Kenya). Limited understanding of their condition and the treatment required was discussed as a source of anxiety for patients. In the words of one Kenyan survivor:

Sometimes [a] cancer patient doesn't die of the disease. They die of the lack of information, the stigma, the trauma that they are taken through. That is what is killing patients most of the times.

In addition to the individual psychological and emotional toll of cancer, being ill could generate a sense of helplessness, and of an inability to fulfil meaningful social roles. Some patients spoke of the impact of their illness and side effects of the medications on their ability to provide their spouse with their "conjugal rights" (patient, Kenya). As one woman being treated for cervical cancer explained, "I cannot do some wife duties because of pain. I have been forced to live with my husband just like a brother" (patient, Kenya).

### LOSS OF SOCIAL ROLES AND RELATIONSHIPS

Patients were also unable to undertake other important familial roles. One caregiver in Tanzania whose father was undergoing treatment shared:

My father is everything to our family. He is a mentor, provider and good advisor, so to be honest our family has been affected a lot - not only financially, but socially as well.

Like Maneno's wife, many patients were also forced to give up or reduce paid labour following their diagnosis, and the impact of resulting financial difficulties on the ability of these individuals and family members to maintain social relationships and pursue their aspirations is discussed further below.

Informal caregivers are usually regarded as fellow sufferers alongside the patients they are caring for. The unmet needs of patients can intensify the level of caregiver burden. Many caregivers put their own needs and feelings aside to focus on the person with cancer. This can be difficult to maintain for a long time and undermines caregivers' health as well as compromising patient care. Many informal caregivers, including those who do not regard caregiving as a burden, suffer from a wide range of problems, such as sleep disturbance, anxiety, depression and practical and financial difficulties (Wang et al., 2018).

As Maneno described, caregivers sometimes tried to protect patients from the challenges they faced in providing care, bearing a significant psychological burden themselves. One Kenyan caregiver explained:

I have no happiness at all, even if you were to give me anything, I would not be happy. If you go into that room you will feel a lot of pain, I always tell other women that it's better to be sick than to look after the sick. Because you don't know if they appreciate the work you are doing for them. So you stay with a lot of pain in the heart.

The financial sacrifices caregivers made and the impact of caring responsibilities on their ability to work are discussed further below. In other ways, caring for a cancer patient could affect social life quite fundamentally. As one man, who had moved his family in with his mother to provide care explained, "we are missing a sense of being a family, such as privacy and togetherness" (caregiver, Tanzania).

### STIGMA AND REJECTION

Maneno's account of the impact of his wife's cancer on their social relationships was echoed by many patients and caregivers, who described experiences of rejection by partners, friends, or relatives, as well as sometimes a more general sense of alienation within the wider community. This social exclusion was often very difficult for patients and carers, contributing to feelings of despair and generating practical challenges in accessing care, both within public sector facilities and in patients' daily lives.

Unlike Maneno's wife, not all patients could rely upon the support of partners and close family. Patients and survivors described examples of spousal abandonment. One survivor suggested this was not uncommon, noting "some leave immediately, some go [and] come back after chemo to see how your reaction is" (survivor, Kenya). Patients and caregivers also told of examples of limited support from adult children, who were "tired of [the patient's] phone calls" (patient, Kenya), and from siblings who were "showing signs of giving up" on them (patient, Kenya). Others, like Maneno, described losing friends, who "left because they felt I was a burden" (patient, Kenya).

A range of reasons were described as contributing to the severing of social relationships. The symptoms that can accompany cancer and cancer treatment, such as odour or visible wounds, were sometimes difficult for others to tolerate and led to avoidance and reluctance to provide support (caregivers, Tanzania). One patient reported that his wife had left him after he had undergone surgery in part "because of the disease and the



smell” (patient, Kenya). The side effects of treatment could also affect the willingness of others to spend time with the patient. One survivor who had had chemotherapy described visitors’ response to finding she had lost her hair, saying “they say this is AIDS definitely, so you are isolated” (survivor, Kenya). Indeed, (Mulemi, 2010, p. 148) also notes that the similarity between some symptoms associated with cancer and cancer treatment, such as hair and weight loss, and those of HIV and AIDS generated anxiety for Kenyan cancer patients, who feared the moral judgement of others.

Misunderstandings about how cancer was spread were also identified as leading to avoidance and isolation. One caregiver, for example, explained that a belief cancer was communicable by touch caused others to “stay away from patients as much as possible” (caregiver, Tanzania). The misconception that cancer was communicable could be particularly challenging for spousal relationships, attributed by one survivor to a mistaken conflation of cancer with HIV (survivor, Kenya). Another described her husband leaving when she started treatment as “he didn’t want to be infected”, only wanting to return now she had recovered (survivor, Kenya) (see also (Mulemi, 2010, p. 152).

### SOCIAL ISOLATION

Fear of the disease and how it was treated and the assumption that the patient would die also led others to socially and physically distance themselves from those with cancer. Stigma associated with a terminal prognosis is observed in other studies of cancer care in Africa (Livingston, 2012; Mulemi, 2010). In the words of one survivor, “once people know that cancer has no cure, even marriages break, men go underground. So the information in the community is that cancer has no cure, and then there is stigma” (survivor, Kenya).

A doctor compared cancer to HIV to illustrate the importance of the potential for effective treatment in reducing stigma, noting:

With HIV we see at least they say they have found treatment. That is why people say they are okay with it. But you know they are spreading the gospel that cancer there is no treatment, so somebody knows that now I am just going to die. (health care worker, Kenya)

This sentiment was echoed by one survivor, who outlined their belief that “when you take someone and ask them to choose between cancer and AIDS they will pick AIDS [rather] than cancer...people are fearful” (survivor, Kenya).

Such challenges could be compounded when patients underwent treatment for a long time without evident improvement, as “sometimes if relatives take care of the patient for a long time without any hope, they start to discriminate against them” (caregiver, Tanzania). Reluctance to support a patient deemed unlikely to recover was closely linked to the financial burden associated with cancer care, discussed further in the following section.

Lacking social support was very difficult for patients and their primary carers. Firstly, it could be challenging to manage day to day care without support. One female caregiver, for example, whose husband was bed ridden, resorted to asking passers by for help to take the patient out for air and back inside, “because the children were refusing [to provide support] so I would sit and wait for young men passing by the road and ask them to remove him from bed since he cannot step down, his legs shake” (caregiver, Kenya). Those patients who travelled for treatment alone were pitied by survivors, who recognized how challenging it would be to navigate treatment alone. One described having offered space in his home to a fellow patient, a young man whose family were not supporting him, saying “you know when you are ill, you don’t have the strength to stand in queues, if you have a partner or a relative [they can help you], but someone is sick and is queuing!” (survivor, Kenya).

Outside of health facilities, unsupported patients could face significant challenges in managing everyday life, particularly if they themselves had caring responsibilities. A survivor in Kenya told the following story about a woman with the same cancer for which she had been treated:

There was a husband who used to visit his wife at the hospital and has young children and he said “I cannot stay with a person who has cancer and is dying” ... so he ran away. So when we went to visit them, we found that mum was very sick, and her breast was cut and she could not cook, she doesn’t have food. And her first born is in form one [first year in high school] and the one who remains with her in the house is in standard four (junior primary school) and is nursing the mum. I cried because that is a kid who is in class four and is nursing the mother and bathes her and dresses her and you wonder, even the neighbours neglected her. So the

neighbours ran away because maybe they saw she is going to die. So we went all along from here and we bought food for them, and we found her and that is why we are telling you it makes people languish in poverty.

Social rejection was also very emotionally difficult for patients and their carers. Echoing Maneno's assertion that stigma made people sicker than cancer itself, one survivor, reflecting on her own difficult experiences, felt "sometimes [a] cancer patient doesn't die of the disease, they die of the lack of information, the stigma, the trauma that they are taken through. That is what is killing patients most of the times" (survivor, Kenya). As the accounts described above demonstrate, survivors particularly recognized support from loved ones as essential, and often did what they could to help others with whom they empathized, through providing informal counselling and advice about treatment expectations or symptoms management, or sometimes practical assistance with managing the disease and day to day needs and responsibilities. They placed significant value on peer support, in light of the misunderstanding or lack of respect they often encountered in the wider community and in their interactions with medical professionals.

### THE COST OF CANCER AS A SOURCE OF SOCIAL PAIN

Cancer can impose a significant financial burden on patients and their families and friends. The cost of care, and of travel and accommodation to access it, reduced opportunities to generate income. Illness, caring responsibilities, travel to access care, and sale of assets to fund care, all generated stress for participants in the research, and impacted their social relationships.

The cost of care as a contributing factor in generating social pain in African countries has been explored in relation to HIV. In his account of the HIV epidemic in Burkina Faso and Cote D'Ivoire in the 1990s, Nguyen (2010, p. 78) quotes a research participant who described diagnosis as "knowing you are condemned to a slow death and most probably to being abandoned by your family and friends - not because they don't love you anymore, but because they can't afford to look after you and won't be able to bear looking you in the eye because of that". Since the expansion in access to antiretroviral therapies (ARVs), the development of a large donor-funded NGO sector focused on HIV and AIDS

in Kenya and Tanzania, and provision of free treatment in both countries, such challenges are now less common for patients testing positive for HIV and indeed HIV-dedicated clinics can be relatively privileged spaces within public health facilities (Prince & Otieno, 2014; Sullivan, 2012). In contrast, cancer care, as described in greater detail in the following chapters, is often extremely expensive, even in Tanzania where many public sector treatment charges are waived after diagnosis with cancer. Indeed, survivors and health workers in Kenya, where there is no free treatment policy, sometimes explicitly compared cancer to HIV, calling for cancer to be declared a “national disaster”, as HIV was in 1999, and for provision of free treatment and counselling and support for peer support groups on the same scale.

In contrasting the experience of cancer patients and their families with those diagnosed with HIV, survivors and health workers illustrated the extent to which suffering resulting from cancer is not something that can be resolved only through interventions addressing the individual physical and psychological health, but will also require action to address the barriers to care explored further in Chapters 4 and 5, which mean that those with cancer must rely heavily on social relationships in order to fund and manage their care.

## FAMILIES’ ECONOMIC LOSSES

Families in Tanzania and Kenya had been obliged to sell a range of assets to meet the costs of treatment, costs of travelling with the patient, and to cover family expenses over sometimes very long periods of time. Some of the sacrifices made related to future aspirations and are thus difficult to quantify but were felt to be very significant by caregivers and survivors in explaining the impact of the disease on their family. One caregiver in Tanzania explained that his sister had been unable to study medicine as course fees were too high “because 70 percent of our income was used for [our father’s] treatment” (caregiver, Tanzania). Others had delayed or abandoned plans to invest in business opportunities or had been obliged to stop sending their children to school. The “psychological stress” (health worker, Kenya) associated with becoming “poor” due to paying for care was closely associated for some with the impact on family, as “if we sell our property, even our children will not have anything” (survivor, Kenya). A Kenyan health worker reflecting on the challenges facing patients noted that “the whole family gets drained and

when the family is drained, maybe the client was paying school fees. Children cannot go to school because the sickness eats up the whole family” (health worker, Kenya). Being seen to fail to provide for family could also expose patients to stigma. As one survivor described someone with cancer, “buys the drugs with school fees and they look for other ways to pay fees for their children, so that it does not look like this one has cancer” (survivor, Kenya).

The illness also had an impact on opportunities to generate income, for patients and caregivers. Like Maneno’s wife, the vast majority of patients interviewed (94% in Tanzania and 97% in Kenya) had experienced an impact on their working life following their diagnosis, either becoming unable to work or having to reduce their working hours and thus earning capacity. Close to half of those interviewed in both countries (48% in Tanzania and 53% in Kenya) reported having had to cease paid work entirely. The impact on household income could be very significant, to the extent that “you become very poor, even food at home becomes a challenge” (survivor, Kenya). In addition to this, patients could become vulnerable once they were no longer able to contribute to their households. Some female patients were sent away from their matrimonial homes after the condition made them poor. As one recounted: “I separated with my husband, I stopped being a bread winner, [I] drained family resources” (patient, Kenya).

Like those for whom they cared, many primary caregivers reported the impact supporting patients had on their ability to work and generate income due to time spent accompanying patients as they received treatment at distant hospitals. One woman, who had travelled approximately 600 kilometres to Ocean Road Cancer Institute in Dar es Salaam explained “everything I do for my personal living has stopped. Like last week my neighbour from the village called me to tell me all my paddy has been destroyed because there is nobody to harvest it” (caregiver, Tanzania). In addition to the impact on livelihoods, caregivers often described a less tangible impact on their potential to realise future aspirations, whether, for example, to own a milling machine or to attend medical school. As articulated by one woman supporting her mother, “whatever I had in my plan about my personal development was totally changed, because it’s better to forgo everything in order to keep your mother safe” (caregiver, Tanzania).

## FINANCIAL BURDEN AND SOCIAL STIGMA

Many in Kenya and Tanzania are obliged to seek financial support from friends and family in order to access cancer care. This could have a difficult impact on patients' and carers' social relationships. As one Tanzanian patient's daughter explained, "between us relatives we are sometimes not on good terms because not everyone is willing to help my mother" (caregiver, Tanzania). Several caregivers felt that this was particularly challenging because the treatment did not always seem to be helping, and many believed cancer was not curable. One recalled:

...a relative called my brother [the patient] on the phone and told him "you will not be healed as cancer is incurable." Unfortunately this relative then refused to give financial support for [my brother's] treatment. Others didn't answer the phone when we called to ask for support or hung up. (caregiver, Tanzania)

Sometimes even when people did contribute, it was evident to patients that they were doing so reluctantly and with little hope it would make a difference. One survivor in Kenya described his experience of being "discriminated" against by relatives, saying:

When you ask for 200 shillings, they will give you the money but [they] know that you will not last three days before you ask again. When I wanted to go to Nairobi for treatment I organized for a *harambee*, but it was painful. People contributed, but at the back of their minds they knew that I would not make it. Some called me to find out how I was doing and disclosed that their contribution was not going to help, that I was going to die. As we speak, I have never gone [since] to my home. People think I am dead.

The challenges associated with accessing support when an illness was assumed to be terminal are also documented by Benson Mulemi (2010) in his ethnography of the cancer ward at Kenya's Kenyatta National Hospital, which documents the extent to which cancer can undermine relations of mutual reciprocity. He observes that as a patient's illness progressed, relatives and friends "tended to reduce their support as they expected less in return from terminally ill patients" (Mulemi, 2010, p. 143).

Difficulty in accessing financial support could be compounded by comorbidity with HIV, which is common in the case of cervical cancer and other cancers including Kaposi's Sarcoma. One doctor at a regional hospital explained that HIV-positive people with suspected cervical cancer sometimes did not get diagnosed as their HIV status made family members less willing to contribute to support travel and treatment costs (health worker, Tanzania).

Inability to access financial support through social networks, could lead to feelings of isolation when family "run away" due to the financial burden (health worker, Kenya) and when contacting friends felt "like it is just disturbing them...Even if they know it is very difficult, the problem is yours and your family" (health worker, Kenya). One Kenyan survivor described having concealed her illness due to the anticipated cost of treatment, recalling:

I got sick and made a plan on how to lie to my mother because of the drugs. It was 22,000 [Shillings] and the drugs were not there, so I lied to my mum that I have been told not to take any medicine because I might die, and it is because I did not have money. (survivor, Kenya)

Caregivers too suffered when unable to afford to provide what they believed to be meaningful care for their loved ones, as described by Maneno. Beyond expensive hospital bills, patients often had other needs which were difficult to provide for. The cost of appropriate food in Nairobi, where Kenyan patients had to travel to receive radiotherapy as well as other treatments, was frequently raised by survivors. One caregiver explained they felt "psychologically tortured", because "the patient is not eating, and things like fruits and vegetables, [in] the dry season they are expensive and not available...so it is also challenging, both financially and psychologically" (caregiver, Kenya).

### THE SOCIAL PAIN OF SURVIVING CANCER

Those who had been successfully treated for cancer also described ongoing experiences of social pain. Their accounts of the difficulty they faced in living with dignity and affording continuing care needs have important implications for how high quality cancer care is conceptualized and provided.

Those who have been treated for cancer may experience subsequent disability that further affects social relationships and generates psychological distress. Mulemi (2010) discusses the trauma experienced by Kenyan cancer patients who had undergone amputations, mastectomy or skin grafts. Described by some as “being half-dead” (*ibid.*, 136), the after-effects of treatment compromised patients’ sense of personhood, making them “an incomplete physical and social being” (*ibid.*, 137).

Survivors described the difficulties they faced in mitigating such challenges and regaining full participation in social life. Rehabilitative commodities were often difficult to obtain due to availability and affordability constraints. In the case of some items, such as colostomy bags, this has a significant impact on a person’s ability to conduct daily activities and to interact with others. As one Kenyan who had been treated for bowel cancer explained, “you can’t live in dignity without a colostomy bag. I could not be seated here with you if I was not wearing one” (survivor, Kenya).

Cancer survivors may face many ongoing care needs that may not be well understood by others. As described by one Kenyan survivor: “they say, hasn’t she already healed?... when you are sick they can fundraise for you, they can take you to hospital, but the moment the disease is not there, you sort yourself”. For many, the costs associated with survivorship remain significant, and some described a difficulty in seeking help when they were considered to be recovered. One survivor who was part of a group of young cancer survivors, mostly in their early 20s, outlined the struggles they and their peers faced, having finished school but lacking employment:

...Your parents have let you go, because you are now a person. They paid school fees, they are done with you...You are sick... there are some bills. You have called home until now... You just have to take care of yourself...Every time [you have to go for a check-up in the clinic] you are calling home, ‘send me money for the clinic’. They reach a point they tell you they don’t have any either (survivor, Kenya)

## RECOGNITION OF SOCIAL PAIN IN THE HEALTH SYSTEM

Healthcare professionals working with cancer patients often recognized these complex psychosocial aspects of pain. Understandings of social pain reflected the entanglement of the financial burden of cancer care and its



impact on social relationships as well as the need for psychosocial support. One healthcare professional at the national specialist cancer hospital in Tanzania described the provision of palliative care at the facility as follows:

It depends...if it is social or physical pain. One pain can cause another pain. So we do a holistic assessment and integrate the findings into a plan. So for physical pain we use morphine. For social pain we coordinate with spiritual leaders and they conduct guidance sessions. In certain cases we coordinate with the social worker(s), whereby they then link with the finance department if the issue concerns money... for example if the patient is thinking about costs of tests. (health worker, Tanzania)

Thus, practical support to address financial issues was an important aspect of palliation, as well as counselling from spiritual leaders. As one health professional noted, “palliative care consists of many caregivers: nurses, psychologists, doctors, religious leaders, social workers and Sheikhs. After assessment you will know the area to focus the intervention on” (health worker, Tanzania).

Health workers in Kenya discussed the role of their own faith in the care they provided to cancer patients. One nurse described one of the first stages of her working day as entailing spiritual preparation, saying: “there are so many challenges which we usually meet, so first of all before you start working you have to prepare yourself spiritually, you tell God to guide you” (health worker, Kenya). Spiritual dimensions were evident in both the pain experienced by patients, who were “not only...sick physically; mentally, spiritually they are also sick” (health worker, Kenya), and in the kind of care they required. When asked about responsibilities for patient care, one nurse explained:

This cancer patient is like in the centre of [the] whole world where there are the health care providers, the relatives, the nutritionist, the spiritual worker. So because of the aspects that will make you to be what you are, they are diverse, ranging from spiritual, psychological, physical - you need to eat, you need love - so it is like everybody [who cares for the patient]. (health worker, Kenya)

The importance of faith in supporting provision of cancer care, for both patients and staff, has been observed in relation to palliation (Esmaili et al., 2018; Hartwig et al., 2014) and more generally (Mulemi, 2010, pp. 155–156) at health facilities in Kenya and Tanzania. However, health

workers also recognized the importance of connecting patients and their families to hospital social workers who could sometimes exempt them from treatment costs or support them to find ways to pay, and they were acutely aware of the impact of the financial burden of care on patients and their families. Thus, the extent to which sympathetic health workers can meaningfully relieve the suffering of cancer patients is constrained by the wider policy framework within which cancer care is provided, and the barriers to access it produces.

## CONCLUSION

This chapter has explored the value of understanding the pain that results from cancer as social, illustrating the importance of social relationships in financing and providing care, and the often-devastating impact of illness on the ability to maintain them. That suffering is not experienced only as physical and individual was recognized by many health workers, who used terms such as “social pain” to describe the experiences of cancer patients they cared for, and by patients and carers who emphasised the impact of stigma and rejection on their wellbeing, even in some cases describing this as worse than the disease itself.

Crucially, experiences of social pain are shaped by the wider socio-economic and institutional context in which patients and their loved ones seek care, and create further economic and social damage. Maneno’s story and the others explored here offer compelling insights into the consequences of barriers to accessing care explored in later chapters in this volume, illuminating the devastating everyday realities that the growing cancer burden in Tanzania, Kenya and other African countries often entail. Addressing these challenges may involve greater recognition of the emotional challenges associated with cancer, and greater attention to psychosocial support within cancer care. The scale of the misinformation about cancer documented here, and its association with stigma and despair, require to be tackled through a major public health information effort.

However, those who participated in the research also called for much broader and more fundamental changes, involving improving the affordability of care improving the ability of patients and their families to rely upon a safety net in times of crisis and enabling those who suffer, and those who survive cancer, to live with dignity. This chapter has documented the broad economic and social losses engendered by cancer,

including destruction of social relationships and loss of ability to work and support the family. This research project has thrown into sharp relief the need for much more attention to survivorship and has identified the social benefits that would result from support for carers' and survivors' ability to work and rebuild lives. Cancer patients, and their families and social networks, can as shown become trapped in a downward spiral of social isolation and economic and financial loss that damages whole families' futures. Cancer, in this sense, is a whole-society crisis and needs to be tackled as such.

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