

“Current”, “heated rods” & “hot vapour”: Why patients refuse radiotherapy as a treatment modality for cancer in Northern Sri Lanka

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Abstract

Purpose: Significant proportions of patients either refuse or discontinue radiotherapy, even in the curative setting, leading to poor clinical outcomes. This study explores patient perceptions that underlie decisions to refuse/discontinue radiotherapy at a cancer care facility in northern Sri Lanka.

Methods: An exploratory descriptive qualitative study was carried out among 14 purposively-selected patients with cancer who refused/discontinued radiotherapy. In-depth semi-structured interviews were transcribed in Tamil, translated into English, coded, and thematically analyzed.

Results: All participants referred to radiotherapy as “current” with several understanding the procedure to involve electricity, heat, or hot vapour. Many pointed to gaps in information provided by healthcare providers, who were perceived to focus on side effects without explaining the procedure. In the absence of these crucial details, patients relied on family members and acquaintances to fill these information gaps, often based on second- or third-hand accounts of experiences with radiotherapy. Many felt pressured by family to refuse radiation, feared radiation, or felt ashamed to ask questions, while for others COVID-19 was an impediment. All but three participants regretted their decision, claiming they would recommend radiation to patients with cancer, especially when it is offered with curative intent.

Conclusion: Patients with cancer who refused/discontinued radiation therapy have significant information needs. While human resource deficits need to be addressed in low-resource settings like northern Sri Lanka, providing better supportive cancer care could improve clinical outcomes and save resources that would otherwise be wasted on patient preparation for radiotherapy.

Introduction

Radiotherapy is a curative treatment option for about forty percent of cancers either alone or in combination with other modalities.¹ Despite robust evidence that radiotherapy improves clinical outcomes, a subset of patients with strong clinical indications, whether in high- or low- and middle-income countries, refuse or discontinue radiotherapy, even in the curative setting.²⁻⁴

Poor survival outcomes are reported in patients who refuse or discontinue radiotherapy.⁴ Moreover, as the decision to reject/discontinue radiotherapy is often made late, substantial resources may be wasted on patient preparation and immobilization devices, constituting a burden on healthcare systems. The consequences of refusing or discontinuing radiotherapy are amplified in low- and middle-income settings where healthcare resources are scarce, supportive care is minimal, and cancer tends to be stigmatized.⁵

Sri Lanka, a lower-middle-income country in South Asia, offers non-fee levying cancer services, including radiotherapy, through the country’s public healthcare system. In the context of an economic crisis, healthcare resources are scarce. According to oncology experts, refusal or discontinuation of radiotherapy is not uncommon in the post-war North. The reasons for refusal remain unclear.

This qualitative study explores beliefs and perceptions that underlie decisions to refuse or discontinue radiotherapy among patients with cancer in northern Sri Lanka. For the purposes of this study, 'refusal' means radiotherapy was indicated, but the patient refused to undergo radiation. 'Discontinuation' conveys that the patient either did not return for treatment after completing the preparatory phase or refused to continue with the treatment after it commenced.

Methods

This exploratory descriptive qualitative study was conducted at the Tellippalai Trail Cancer Hospital, a state-run cancer center in the Northern Province.

Data were generated using semi-structured in-depth individual interviews by two physicists who had no direct contact with the participants prior to data collection. They were trained in qualitative interview techniques by two experienced qualitative researchers. Mock interviews were held with staff who served as simulated patients.

The list of patients who refused or discontinued radiotherapy was obtained from the patient registry. Fourteen patients, selected by purposive sampling to ensure wider representation by age, gender, and district of residence, were recruited for the study. The mean age of the sample was 55 years (median 55 years) with most in the 40-59 years age group and predominantly males. Several participants had never been to school or had only primary school education, reflecting the post-war setting of northern Sri Lanka (Table 1). They were all Tamil-speaking, representing all five districts of the Northern Province. The interviews were carried out on average 4.5 months after the diagnosis (range 1-7 months).

Data were collected from August 2019 to July 2021; the study period had to be extended by a year due to the COVID-19 pandemic. Interviews were conducted in clinic rooms in the out-patient department when clinics were not in session. Participants were compensated for travel to and from the hospital.

Both data collectors participated in all interviews, taking turns interviewing and note taking. All interviews were conducted in Tamil and digitally recorded. Data saturation was achieved by the fourteenth participant.

The interviews were transcribed verbatim in Tamil and translated into English by translators proficient in Tamil and English.

The interviews were thematically analyzed by two experienced qualitative researchers. They were first reviewed to obtain a "big picture" understanding of the data. A list of pre-defined and *in vivo* codes was developed, and the interviews were coded using QDA Miner Lite (v2.0.8) software. The codes were organized into themes. The two qualitative researchers reached consensus at each stage of the analysis.

Results

Several clinically relevant themes were drawn from the data: what radiotherapy means for patients, including information gaps; the critical role played by the family in decision-making; cancer-related stigma; and the reality of accessing cancer care in the face of competing priorities.

Current, heated rods and vapour

All participants referred to radiotherapy as “current” (the colloquial term for electricity) and many felt it was harmful to health. P01 with cervical cancer had consented to treatment and underwent treatment planning. While awaiting treatment, a friend convinced her to abandon treatment: *“[She] told me that they will insert a heated rod into my vagina and burn the cancer,”* she confided. Similarly, P013, with nasopharyngeal cancer recalled his understanding of radiotherapy: *“When they first recommended current, I thought they would place a heated iron rod over the tumour”*. Along the same lines, P04’s perception of radiotherapy was shaped by her son-in-law’s experience: *“He lost a lot of weight after the treatment and died. So, I thought current treatment affects the whole body, that it burns the body”*.

As the term “current” implies, some participants believed that electricity passes through the tumour during radiotherapy. *“I thought current treatment means burning [cancer] with current,”* P07 stated. Others understood radiotherapy to involve heat or hot vapour. P09 said, *“I thought they would use a hot tube emitting a vapour to treat my cancer,”* while P10 expected radiotherapy to involve heat being delivered to her mouth for short durations.

While the majority understood radiotherapy as a fearful form of treatment, some saw it differently. P011 was not afraid and understood its role in her treatment: *“I never thought it was going to be like the current we use at home or that the treatment will be painful...my understanding was that the cancer cells will be killed with the current without pain”*.

The varied understanding(s) of radiotherapy had emerged in the context of inadequate information on radiotherapy. Many pointed to gaps in the information provided by healthcare providers, who they perceived to focus on side effects without sufficient discussion of what radiotherapy entails. P01 believed what her friend said about radiotherapy because the information she received from her doctor was inadequate: *“The senior doctor (consultant) initially told me that I must undergo current treatment at Tellippalai (research setting) and Colombo (National Cancer Centre for brachytherapy). I didn’t understand what it meant. She did not explain the procedure...”*. P02 also felt that the information he received was inadequate: *“I did not know about current treatment. I did not ask anyone about this treatment. The doctors also did not say anything.”*

Perhaps owing to low levels of literacy, fuelled by a 30-year war that ravaged northern Sri Lanka, most participants did not seek knowledge from more reliable sources. P07 pointed out that she did not “waste time” watching educational programs on TV. Some were not even aware of web browsing as an information source; indeed, P07 and P09 did not even know what the internet was. Importantly, this lack of information resulted in misbeliefs, compromising cancer care. As P06 reflected: *“I thought I would be all right after some time, and that they may say that I don’t need this current treatment.”*

Tug of war

Even when patients understood the importance of radiotherapy, they had to contend with family members who had differing views. P02 was single, unemployed, and depended on his family: *“My sister told me that I won’t be able to eat after the current treatment...she did not want me to go through with it.”* He pleaded with his family to be taken for the treatment, to no avail. Although P010 had decided to accept radiotherapy based on his doctor’s advice, his son urged him to reject the treatment: *“At one point he said that I should undergo this treatment...later, he said not to go. He was also confused as he got different opinions from different sources...”*. P010’s son had been misled by false information *“Someone had mentioned to [my son] that I could live for 20 years without the current treatment”*.

When family members supported the decision to accept radiotherapy, opposing views came from other quarters. P01 opted to listen to her friend’s opinion over her family’s: *“My children and husband insisted on me going for current treatment, but I trusted my friend’s opinion and refused”*. Similarly, P06, a cobbler, was swayed by stories circulating in the village: *“The big madam (consultant) clearly explained everything, but I was not sure whether to believe her...my customers told me that, with this treatment, I will have hair loss, sores on my body, and my skin would change colour. They also mentioned that I may die earlier with this treatment”*. As P10 pointed out, *“The doctor explained... but we cannot ignore what others say, isn’t it?”*

Past experiences with loved ones who had undergone radiotherapy were a key deterrent. P04 recalled his son-in-law’s experience: *“Because he died after 12 current treatments, my family was against it... I also thought, it was due to current treatment and decided to discontinue.”* Similarly, P07 attributed his uncle’s death to radiotherapy: *“My uncle from Chankanai (a village) was getting current treatment for throat cancer and died shortly after....., he would have lived peacefully for some time if not for the current”*.

Yet, a few had received all the information they needed; they trusted their healthcare providers and did not seek alternative explanations. As P05 pointed out: *“The big madam (consultant) explained everything in detail, I didn’t bother to ask a lot of people; others cannot explain this better than the doctors, isn’t it?”* Even so, P05 discontinued her therapy after having misplaced her clinical registration card. Similarly, P012 was not interested in further explanations because the doctor had said radiotherapy would cure her. However, his wife feared “current” and did not allow him to proceed with the treatment.

Keeping a secret

Cancer-related stigma led to the cancer diagnosis being kept within the family, often compromising adherence to treatment. As P012 explained, *“My wife got scared ...she did not allow me to tell my children about this”*. Patients spoke of hiding their diagnosis from loved ones, even those who might understand and support them. *“My eldest daughter-in-law is a teacher. I could have gathered information from her. But I did not ask anything from them. I don’t think it’s nice to ask my daughters-in-law about this,”* P01 confided. Similarly, P011 did not discuss his penile cancer with his children because he was

embarrassed about its location: *“Only my wife is aware ... If I discuss this with others, they will want to know where the cancer is and how I got it... When my children and neighbours inquire, I bluff saying I’m going to the hospital for sugar and heart problems.”* P02’s family was distraught by the cancer diagnosis and did not even want him to visit the hospital: *“I did not have a mobile phone of my own...the appointment to commence current treatment was received by my brother who neither told me nor took me for treatment. My brother felt that it would be better for me to die...As I am dependent on my brother, I had to accept his decision”.*

Competing priorities

A multitude of health and social problems prevented many from visiting the hospital for radiotherapy. Side effects of radiotherapy were one such barrier. As P03 explained: *“I did not default treatment because of fear. But my general health did not permit it. I had many side effects due to chemoradiotherapy including mouth ulcers. I couldn’t even walk or talk when I was called for treatment”.* P013, who had nasopharyngeal cancer, felt too weak: *“I was struggling to eat. I was only able to take liquids like lime juice. I fainted as well. I couldn’t continue the rest of the treatment”.* P011 missed his radiotherapy appointment because he was rushed to the hospital with chest pain: *“I was prepared to come, but the day before the treatment, I had a heart attack ... There were no calls from Tellipalai Hospital thereafter, and I didn’t bother to follow it up.”*

Other family commitments were cited by some participants. As P07 explained: *“My wife and I look after our grandchildren. If I go for the current treatment and suffer, it’s a headache for my wife and children. I thought about it and decided to live like this without going ahead with the treatment”.* For P011, the long course of treatment would have affected his livelihood, making the hospital stay unfeasible: *“Even if you offer me food and lodging, I cannot stay here for 30 days...I can’t leave my home and cattle.”*

For others, getting to the hospital was just too complicated. P01 with cervical cancer had been to Colombo (400 km away) a couple of times to book her appointment for brachytherapy: *“they told me to complete current treatment at Tellipalai Hospital and then come back. I came here to find that the machine was not working, so I went home and never came back”.* For P08, the thought of traveling out of Jaffna was too daunting: *“After I finish a course here, I must go to Maharagama Hospital (in Colombo) for the rest, they said. But I have never traveled outside Jaffna. I don’t even go out of my home boundary...I can’t imagine going to Colombo and getting the treatment. It’s impossible... I’m ready to live like this and die”.*

The pandemic made the situation worse. P013’s radiotherapy was disrupted by the lockdowns: *“I went through 25 out of the recommended 33 fractions. I stayed at CANE [Cancer Aid North & East, transit home] during the weekdays and went home for the weekends, but the bus service was interrupted by corona after the 25th fraction.”.* During the lockdowns, patients had to arrange their own transport to the hospital with added expenses.

Repentance comes late

In the end, all but three patients claimed they would recommend radiation to patients with cancer, especially when offered with curative intent even as the remainder were non-committal or felt radiation involved unacceptable side effects and suffering. P05 said *“I regret not going through the current treatment,”* while P06 added, *“I feel that I should have gone for current treatment earlier. I would advise everyone to go for current treatment without delay.”*

Discussion

Radiotherapy has made immense technological advances toward accurate targeting and minimizing toxicity. However, fear and misbeliefs about radiotherapy prevail.⁶ Although ignorance and illiteracy have been identified to underlie misbeliefs, studies conducted in countries with higher literacy rates also reveal negative perceptions of radiotherapy.^{6,7} This study was conducted in a public non-fee levying healthcare setting where much of the clientele represents a lower socio-economic status. Hence, their understanding of the nuts and bolts of radiotherapy may be limited, reflected in the varied understandings of “current treatment” as involving the insertion of heated iron rods, passage of electricity or hot vapour to ultimately “burn” cancer.

The findings point to significant information gaps on radiotherapy with several participants expressing that information received from healthcare providers was inadequate. Side effects tended to be the focus of consultations, in neglect of how radiotherapy works and how the treatment is delivered. In the absence of this information that was felt to be crucial, they turned to friends and family for clarification, resulting in confusion and ultimate rejection of radiotherapy. Hence, addressing the patient’s fear and misconceptions is mandatory during the consultation⁸, both individually and in the presence of family members. Educating patients with lower health literacy and deeply ingrained misconceptions about radiotherapy can be demanding in a resource-limited setting. The lack of oncological supportive care in Sri Lanka⁹ adds to the workload of the radiation oncologist and may be an impossible task to handle during busy clinics.¹⁵ Involving radiation therapists in patient education may help to overcome these human resource deficits. Moreover, videos or graphical demonstrations prior to the formal consultation may be of help.^{10,11}

In the closely-knit predominantly Tamil culture in northern Sri Lanka, patients not only consulted their family members but also the community in decision-making. Torn between the scientific information bombarded by medical professionals and lay perspectives conveyed by family and friends, several participants spoke of abiding with a loved one’s decision on radiotherapy. Their beliefs and perceptions were laced with cancer-related stigma, rendering the diagnosis a closely guarded secret within families.⁹ Participants spoke of hiding their diagnosis, even from their own children to avoid judgment, especially when cancer involved the reproductive tract or genitals. In some instances, when the family was supportive, negative community perceptions weighed in on the decision, often based on prior experiences of patients.

Public awareness and perceptions of radiotherapy are reported to be significant predictors of treatment acceptance.³ Hence, educating not just patients but also the public through awareness campaigns, and mass and social media is mandatory. Designing educational tools that are culturally appropriate and targeted to a spectrum of educational levels is important.^{10, 11} Posting resources on social media and encouraging patients and their loved ones to gather information from such sources may help to counter community beliefs and perceptions. Steps taken by the Royal Australian and New Zealand College of Radiologists to counter public misconceptions by sharing patient stories about radiotherapy via electronic media may be a starting point in settings where health literacy is high.¹⁶ Despite internet searches and mass media being widely used by patients to gather information in other settings,⁶ however, participants in the present study were not internet savvy, posing further challenges to information access. Accessing radiotherapy in a low-resource setting is not easy. Long courses of treatment at healthcare facilities located in distant places combined with lacking transport—intensified by COVID-19 lockdowns—deterred patients in northern Sri Lanka from completing radiotherapy. Moreover, the general inconvenience of accessing care from multiple healthcare facilities, as required in Sri Lanka due to the unavailability of resource-intensive equipment at all cancer centres, has intensified the problem.

Modern radiotherapy is moving toward hypofractionation^{12, 13} which involves shorter courses of treatment in curative and palliative settings. Such treatment modalities could potentially alleviate interruptions to earning and family dynamics and reduce travel costs. Sadly, having access to these technologies close to home is unlikely to be realized in the near future in low-resource settings like Sri Lanka aggravated by the current economic crisis. Until such time, taking steps to streamline referrals, strengthen follow-up, and offer transport and short-stay lodging located close to cancer care centers may support patients continuing with cancer treatment¹⁷.

Cancer care constitutes a significant financial burden, aggravated by expenditures on transport, nutrition, etc., even though the treatment itself does not incur any cost within the non-fee levying public healthcare system.⁹ As a significant proportion in the present study hailed from lower socio-economic backgrounds, financial stressors led to discontinuing radiotherapy, especially among informal sector workers. Currently, the social service department offers a monthly allowance of Rs. 5000 (approx. USD 15) to cancer patients, which is grossly inadequate in the context of the ongoing economic crisis in Sri Lanka.

Ultimately, most participants regretted their decision to reject or discontinue radiotherapy. Many indicated that they would encourage others to follow their doctor's advice and proceed with treatment, replicating findings from other settings. For instance, a study among American women who underwent breast radiotherapy reported that the overwhelming majority believed patients would not refuse radiotherapy if they knew the "truth".¹⁴ The credibility of such information may be increased by sharing perspectives of patients who have experienced radiation.⁶ Together with our findings, this evidence suggests that creating peer support groups led by patients who have experienced radiotherapy may be helpful to counter the bad "public image" of radiotherapy.⁶

Conclusion

Patients in northern Sri Lanka perceive radiotherapy as a frightening mode of treatment with many refusing to take up or discontinuing treatment even in the curative setting. Patients and families need information in parallel with formal radiotherapy consultations to alleviate fear and misbeliefs for better decision-making. Educating the public through awareness campaigns and mass media is essential as community perceptions and cancer-related stigma contribute significantly to decision-making. Furthermore, patients must be supported to continue with treatment by streamlining cancer care, strengthening follow up services, offering transport and lodging, and providing financial assistance. Taken together, our findings throw light on the deeply contextual nature of decision-making related to cancer care and call for tailored interventions to increase the acceptance of radiotherapy in low-resource settings.

Declarations

Statement & Declaration

Conflict of interest: No actual or potential conflict of interest exists

Source(s) of support: The authors did not receive support from any organization for the submitted work.

Ethical approval: This study was performed in line with the principles of the Declaration of Helsinki. Approval was granted by the Ethics Review Committee of the Faculty of Medicine, University of Jaffna (Ref J/ERC/18/100/NDR/0201)

Informed consent: Informed consent was obtained from all participants

Consent for publication: Consent for publication was obtained from all participants.

Availability of data and material: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Author contribution: All authors have contributed significantly to this paper

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Tables

		n	%
Age group ^a	<40 years	1	7
	40-59 years	7	50
	≥60 years	6	43
Sex	Males	10	71
	Females	4	29
Education level	Never been to school	3	21
	Primary	5	36
	Secondary	6	43
	Tertiary	0	0
Total		14	100

Table 1. Participant characteristics