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RESEARCH ARTICLE

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Perceptions and Experiences of Informal Caregivers of Breast Cancer Patients in South India: A Qualitative Study

Shradha S. Parsekar¹, Louise Meijering², Ajay Bailey^{3,4}, Suma Nair^{1,5,6*}

Abstract

Background: This study was conducted to explore the prevailing perceptions and experiences of caregiving burden among informal caregivers of women living with breast cancer in South India. **Methods:** In-depth interviews were conducted among breast cancer care-receivers (n=35) and their informal caregivers (n=39) and a thematic analysis was used to analyze the data. Informal caregiver in the context of this study was defined as one who takes up the responsibility of an informal caregiving role, and were either self-identified or acknowledged by the care-receivers. **Results:** Four main inductive themes in the domains of: emotional culpability, financial and workplace liability, psychosocial affliction, physical strain and health system demand were identified, that were associated with caregiver burden. **Conclusion:** Informal caregivers form an integral part of the cancer care continuum in India. It is recommended to factor in the identified themes while developing a caregiver needs assessment model in the context of caring for breast cancer patients in the Indian setting.

Keywords: Breast cancer- burden of care- caregiving- In-depth interviews- India- qualitative study

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Introduction

Breast cancer is the most common cancer among women in India (Bray et al., 2018). Indian women are diagnosed with the disease a decade earlier than their counterparts in other parts of the world and most often at a late-stage, resulting in a high mortality to incidence ratio (Alexander et al., 2019). As with most cancers, breast cancer can have devastating effect on the physical and mental health of not only the patients but also their caregivers making them co-sufferers (Benyo et al., 2022; del-Pino-Casado et al., 2021; Kusi et al., 2020; Mbozi et al., 2020; Segrin et al., 2018). Caregiving is, therefore, a key element in cancer care and survivorship experience (Denlinger et al., 2014).

Advances in cancer treatment, has shifted the focus from short-term institutional care to long-term informal caregiving at home, wherein caregivers have a larger role to play (Bradley, 2019; Junkins et al., 2020; Kusi et al., 2020). Breast cancer, like other cancers, could result in a sudden deterioration of health or acute sufferings as a consequence of the treatment itself, giving rise to intense and time-consuming caregiving (Benyo et al., 2022; Bhattacharya & Chatterjee, 2020; Frambes et al., 2018;

Maree et al., 2018). Additionally, in low resource-settings, with poor healthcare infrastructure, the chance of out-of-pocket expenditure is high and this coupled with factors such as stigma and a concern of increased mortality gives rise to a fear of the disease further burdening the caregiver (Alexander et al., 2019; Kusi et al., 2020; Nyblade et al., 2017).

Caregiving in breast cancer is perceived differently by the survivors and their caregivers and understanding these nuances can help identify specific challenges, thereby facilitating customized interventions (Adelman et al., 2014). Indian studies on breast cancer caregiving burden have limited themselves to standalone factors such as stigma or financial burden (Nyblade et al., 2017; Alexander et al., 2019) and not explored the complexity of the concept. Most of the qualitative studies addressing this theme are restricted to formal caregiver experiences (Daniel et al., 2022; Fereydooni et al., 2022). A more recent systematic review on the subject has underscored the paucity of qualitative studies in low- and middle-income countries exploring breast cancer caregiving experiences (Kusi et al., 2020). Therefore, this qualitative study (with a phenomenological approach) was undertaken to explore the perception and experiences of caregiving

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burden among informal caregivers of women with breast cancer in South India.

Materials and Methods

Participants, setting and study tool

The study was carried out in a coastal district of South India. Care-receivers at various stages of the disease and their informal caregivers were subjected to in-depth interviews (IDIs) by the first author using an interview guide developed by the investigators, and pilot-tested prior to implementation. In an open-ended questioning format avoiding any leading questions, caregivers were asked to describe the changes and impacts of being a caregiver on their lives. The criteria for participant inclusion are listed in Table 1.

Research team

The research team including the first author, has extensive experience in the conduct and design of qualitative studies. The first author (SP) – a woman – holds a post-graduate degree in public health and is pursuing a PhD at the time of this study. SP, who is professionally trained in IDI methodology, visited the tertiary care hospital wards and out-patient departments, to interact with women diagnosed with breast cancer. SP contacted the participants with the help of medical social workers (MSW), receptionists or nurses and conducted the interviews. MSW (a woman) helped in rapport building, acted as a note keeper, and observer. The research team had no previous relationship with the study participants. Interviewer with no prior experience in caregiving could listen to participants' detailed information from an outsider's perspective.

Recruitment and data collection

Applying eligibility criteria, participants were purposively selected. Information about the study was provided to participants in a subject information sheet. After developing rapport with the participants, interviews were held in a private room of the hospital or at the participant's residence based on their convenience. Participants were interviewed separately; however, three interviews were held as a dyad (women and husband). Interviews were held in English, Konkani, Hindi, Tulu, Marathi and Kannada. It took between 20 and 90 minutes to conduct an interview and were carried out from August 2016 to July 2017. One repeat interview of caregiver participant was held. Two participants refused to take part in the study citing paucity of time. Interview notes were shared with some of the participants at the end of interviews to receive feedbacks, however, interview transcripts and study findings were not shared.

Interviews helped some of the participants vent their experiences, as they felt that someone could listen to their stories. Considering the sensitive nature of the issue, some participants broke down emotionally, at which point the interviewer showed empathy, offered water, and asked if they wanted to continue. As a result of participants' inability to control their tears, two interviews were terminated prematurely.

Data management and analysis

Interviews were continued till the point of saturation. Interviews were audio-recorded, transcribed verbatim and translated to English. Data were managed and analyzed in accordance with the principles of thematic analysis, with the help of Atlas.ti version 8 software. The interview transcripts were read multiple times by SP and a code tree was deduced. Thereafter, similar and co-occurring codes were grouped together to form a code family that translated to themes. Authors (LM, SN) reviewed these codes, code families and the emerging themes, refining it further till it was finalized.

Results

Socio-demographic characteristics

A total of 35 care-receivers and 39 caregivers participated in the in-depth interviews. Socio-demographic details of the participants are illustrated in Table 2. Additional details are provided as supplementary information.

Caregiving burden

Inductive themes that emerged from the data were categorized into five domains (see Table 3). Description of these themes are as given below.

a. Emotional culpability

Most of the care-receivers who were interviewed revealed that they hesitated to seek help when they first experienced signs of breast abnormalities. They reported to being shy or denied the problem, emphasized that it was painless, or did not prioritize their own health. Some women refused treatment dreading the cost, and side-effects of the treatment, while others presumed it to be incurable. One of the participants had lost a close family member to cancer despite long drawn treatment and this influenced her decision to not seek immediate care following diagnosis. Her 44-year-old husband revealed:

"Doctor mentioned that radiation should have been started as cancer is in second stage. But, she (wife) did not agree to go to hospital. She said, only her dead body will go. I could finally get her to the hospital only in the last stage (stage four). She is outraged and scolds, "why did you bring me here? I would prefer dying at home. They (doctors) will kill me in the hospital."

While some women did not want to seek care at all, some preferred to go for alternative system of medicine (e.g., Ayurveda) as it was perceived to be minimally invasive, have less side-effects and comparatively inexpensive. However, most often this resulted in treatment failures and seeking care at an advanced stage of the disease further escalating cost of treatment. Caregivers expressed guilt and regret when there was a delay in diagnosis and treatment as they felt responsible for this.

Some of the caregivers expressed distress and melancholy and this they felt hampered their caregiving activities. A 28-year-old son explained:

"I am tensed (...) Her cancer is in an advanced stage and it is spread all over. She is neither eating nor keeping well. I don't know what will happen. My sister is also eight

Table 1. Inclusion and Exclusion Criteria

Participants	Eligibility criteria
Caregivers	<p>Inclusion criteria:</p> <p>Informal caregiver in the context of this study was defined as one who takes up the responsibility of an informal caregiving role, and were either self-identified or acknowledged by the care-receivers.</p> <p>Informal caregivers who were > 10 years of age, willing to participate and actively involved in providing care to women diagnosed with breast cancer were recruited into the study. They ranged from spouses, offspring and siblings to parents, distant relatives, and friends or neighbors. There was no restriction on the number of caregivers recruited per care-recipient or the caregiving tasks they performed.</p> <p>To have a wider understanding of the nuances of caregiving and for better generalizability, efforts were taken to recruit participants whose characteristics spanned across age, gender, marital status, relationship with the care recipient, family type, religion care-recipients' clinical stage of cancer (localized vs metastatic), and stage of treatment.</p> <p>Exclusion criteria:</p> <p>Care providers such as home nurses, volunteers affiliated to non-governmental organizations or healthcare professionals were not included.</p>
Care-recipients	<p>Inclusion criteria:</p> <p>Care-recipients in the context of this study were identified as women of any age diagnosed with breast cancer between July 2015 and June 2016, residing in Udupi district during the study period and willing to participate.</p> <p>Exclusion criteria:</p> <p>Care-recipients, who were not aware of the cancer diagnosis, those with brain metastasis or existing mental health issues or on life support and unable to participate in the deliberations were excluded; however, their caregivers were eligible to participate.</p>

months pregnant. She has to come home for childbirth. I don't know how to manage everything."

This particular caregiver expressed concern in managing his mother's advanced disease in addition to accommodating a pregnant sister who needed to be cared for. This situation is quite unique to India where families believe in carrying out social and cultural obligations in the face of adversities. This often resulted in additional stress for the caregivers and one of them vented out saying "I am feeling bejaar (helpless)". Caregivers often hide this from the family as they feel that it would have an effect on the psychological health of the care-receiver.

The question 'why my loved one' was a common sentiment among the caregivers. They were concerned that the care-receiver despite having no risk behaviors, had got the disease. To quote a 44-year-old caregiver, daughter:

"My daddy got it (throat cancer), my mummy also (breast cancer). Why? I am thinking only this (...) I just thought, we were good, but this happened. How it happened? It happened by eating what? I am constantly preoccupied (ulazna) with these thoughts."

It was evident that not having a definite answer to the

Table 2. Participant Details

Characteristics	Caregiver (n = 39)	Care-receiver (n = 35)
Stage of breast cancer		
Stage I & II	-	18
Stage III & IV		17
Age (in years)		
<20	02	0
20- 49	26	20
50 and above	11	15
Education		
Illiterate and < 5 years of schooling	9	14
5-10 years of schooling	08	07
> 10 years of schooling	22	14
Employment status		
Homemaker	08	21
Student	02	0
Unemployed or retired	4	0
Employed and working	25	14
Marital status		
Unmarried	10	01
Married	27	29
Widowed	02	05
Gender		
Male	20	0
Female	19	35
Relationship of caregiver with care-recipient		
Spouse		
Offspring	12	-
First degree family members	14	
Other family members	03	
Family type		
Joint	20	19
Nuclear	19	16

cause of the disease remained a source of stress to the caregivers. Furthermore, a distinctive sense of alarm was evident among young female caregivers who were aware that the disease could have a genetic predisposition. To quote a 37 years old married daughter:

"My aunt (mother's sister) had cancer four years back. Soon she died. It was late stage. (Crying)... Now mother got it and doctors are saying that we (her daughters) are also at risk of getting the cancer (crying)."

Karma and God willing are some of the clichéd terms prevalent in the Indian context and this was observed among the participants of our study as well. This belief in Karma has a bearing on the patient's long-term outcome as they believe that having faith in God will make everything alright. Some of the caregivers visited their spiritual leaders or seers to receive blessings. Caregivers disclosed that the blessings included receiving sacred ash, sandalwood paste and other related customs that they

Table 3. Themes within Caregiving Burden

Inductive themes		Explanatory sub-themes
Emotional culpability	‘I am tensed- ‘bejaar’	Danger alarm: a hereditary disease
	‘It is a CANCER’	Hide emotions and be a counsellor
	‘I convinced her so much’	Future outlook
	Regret-delay in diagnosis	Feeling of being lucky that patient is in early stage
	Unresolved or complicated grief	Karma and God willing
	Preoccupied with the reason for breast cancer	Confidence from seers and oracles
Health system demands	Language and confusing arrangements of the hospital	Privacy and cleanliness
	Long waiting hours	Travel difficulties
	Hospitalization	Forced to find female bystanders
Financial and workplace liability	Inadequate or no health insurance	Treatment decisional conflict
	Difficulties faced to avail the health insurance	Monetary help from trusts
	Monetary help from extended family	Unorganized loans
		Loss of job / wages
Physical strain	Caregiving demands	Indirect expenses
	Role overload	Agriculture and livestock management
	Managing house and dependent family members	Changes in family structure
Psychosocial affliction	Effect on other family members	Uncertainty about the future of children
	Children / caregiver’s education	

felt had the healing power. Likewise, another caregiver admitted to having visited the oracle (‘daiva’), who assured that his wife (the care-receiver) would get better and this hope considerably comforted him. He confessed to having great belief in ‘daiva’, who according to him knows everything. These are some of the prevalent socio-cultural practices in the region that help caregivers cope in times of adversity. Some of the caregivers confessed to finding solace by reaching out to known cancer survivors and treating physicians.

b. Health system demands

Caregivers expressed their distress of hospital visits and considered various hospital formalities tiresome, challenging and time consuming. This was especially with reference to large tertiary care hospitals that provide cancer care. Despite appointments there were times when the participants had to wait for long, sometimes an entire day to consult doctor or get diagnostic tests done. Some of them expressed being intimidated by hospitals and called out to friends or family for help. In the likely absence of any support, caregivers felt burdened, especially if the hospital visits were too frequent. A 17-year-old son, a caregiver shared:

“I don’t mind coming here (hospital) with her (mother), but when it gets late, I have a problem. I have to go home and study. We have to wait here for long to meet the doctor, and therefore, my father cannot come every time”.

Participants living in remote areas stated travel related difficulties, as they were forced to travel long distances to avail treatment. This was specially the case when the insurance schemes did not enable availing essential treatment services at nearby hospitals. Also, specialized

cancer care services were available only at tertiary care hospitals, some of which were situated more than 60 km from their places of residence. A caregiver, sister-in-law, shared:

“We are from village, so we don’t know much about hospital. We have to travel far and at night if anything happens, then we have to hire a vehicle to reach here so it is difficult for us. Also, roads are not good.”

Families who did not own vehicles, were compelled to request neighbors and distant relatives for help or hire a vehicle as travelling by public transport was cumbersome and was particularly not available at night.

Hospitals in India mandate a bystander for the hospitalized patient and in the case of female patients, it has to be a female attendant. This is specially a problem to those from nuclear families and male caregivers are obliged to request female relatives to stay with the care-receiver. In the words of a 48-year-old husband, a caregiver:

“I find it okay to be in the female ward to take care of my wife. But, other female patients around me are not comfortable. That is why I had to request my wife’s cousins to come and stay in the ward. I sit in the lobby at night. Each of them takes turns and stay for 2-3 days. They also cannot stay for long”.

c. Financial and workplace liability

Cancer care in India is expensive and there is no cancer specific universal insurance scheme in the country. One of the caregiver participants mentioned discontinuation of a private health insurance scheme as a result of inability to pay the premium instalments. Those having insurance cover had to undertake cumbersome procedures that further burdened the caregivers. As narrated by a 42-year-

old care-receiver:

"First, come here (hospital), then go to ESI (Employee State Insurance office), then come back and get admitted and next day again go to ESI in town to submit it. Every week this has to be done (...) She (sister) also has to come with me, for her also it is a burden. Very tiring for both of us. I could have taken the injection and gone home same day but then I cannot claim ESI."

As the disease progresses and treatment costs escalate, it takes a toll on the financial situation of the family. This leads to high out-of-pocket expenditure, which was one of the highest stressors perceived by all caregivers irrespective of economic strata. Some caregivers reported digging into savings or forced to sell livestock and land to bear the treatment expenses and some resorted to borrowing from money lenders. Three of the participants discontinued chemotherapy due to mounting expenses and predictably their health deteriorated.

Some of the participants stated that they had approached elected representatives, religious organizations, health insurance schemes and so on for financial help. Those who received support felt comforted, however, not all schemes were accessible to everyone and some covered only partial costs, or could be availed only in select hospitals.

Caregivers who were working in an unorganized sector often faced loss of wages, when they had to accompany the patient for hospital visits or for other caregiving activities. Some caregivers had to quit their jobs to devote time for caregiving. Financial burden was also brought on by the fact that caregivers felt compelled to buy exotic fruits and vegetables, that claimed to have cancer fighting properties. Other expenses included wigs or padded brassiere in addition to travel and hospital catering charges.

Those who did not have an extended family system, were the ones who felt burdened the most as in many instances the extended family was a source of financial and other caregiving help.

d. Physical strain

Some of the male members and minor or unmarried children, who had taken on the role of the caregiver stated to being overwhelmed by the quantum of multitasking expected of them from housekeeping to taking care of livestock and other family members. Men, in particular, felt weighed down with the household work, as they were not accustomed to this. On the other hand, married women who took on the role of the caregiver were compelled to manage two houses that of hers and the patients. A 50-year-old sister, a caregiver, shared:

"It is difficult to manage house work, but what can be done? Can we leave her (patient) like this? My children go to school. I have to prepare tiffin for them. My husband does not help with cooking or house work and that makes it more difficult!"

Some caregivers reported being burdened by the care-receiver's demand for warm home cooked meal at all times and special diet for comorbidities. This work overload was a source of additional stress for the caregiver compelling some of them to relocate to their ancestral homes to receive help from extended family members.

Caregiving could take a toll especially when the main

household member is taken ill and appeared to have an indirect effect on agriculture and livestock. As narrated by a 38-year-old son:

"Our main concern is that there is no one to look after our cow. My mother (the patient) used to work before. Now, when my father and I am back from work it is difficult for us to finish the livestock-related work within the stipulated time. We, therefore, sold all our livestock."

e. Psychosocial liability

Some of the participants were of the opinion that cancer diagnosis had a profound effect on all members of the family and the caregiver felt duty bound to provide psychosocial support further enhancing their burden. As shared by a 50-year-old husband:

"My mother started crying when she came to know (about my wife's cancer). (...) I had to console her that it can be controlled with treatment."

Some caregivers were pressured with multiple caregiving duties especially if the household had more than one person who was ill or consisted of the elderly and the very young. A 17-year-old son caregiver mentioned:

"My mother has been ill with breast cancer but additionally my sister who is just 20 years old is suffering from heart-related ailments. She was advised hospitalization but we could not. My father must work; he cannot be in the hospital every time".

Young caregivers reported being overstretched and had specific issues that were concerning. Most often it affected their ongoing education and this appeared to be a source of great stress. One caregiver discontinued education so as to supplement the income as her mother was affected with the disease. In another scenario the care-receiver, compelled her son to take on the role of the caregiver thereby forcing him to give up his higher education plans. At other times they were forced to skip classes to accompany the care-receiver to health care centers.

Caregivers, with small children to care for expressed concern that patient's mood swings affected the children. One caregiver narrated how his nine-year-old son was distressed when his mother turned bald during the course of treatment. Some caregivers expressed helplessness in their inability to convey the correct information to their minor children.

Discussion

This study is a pioneering work that explores the perspective of caregiving burden among the caregivers of breast cancer patients in South India. Caregivers in the study ranged in their role from being a spouse to an offspring or a member of the extended family. Findings of this study is partially in sync with a model proposed by Fletcher et al., (2012) but illustrates substantial evidence beyond it, especially in the context of prevailing socio-cultural factors in South India (supplementary information).

Emotional culpability emerged as a major theme among the caregivers of our study and it was observed that the perceived emotional stress among them is at times equivalent or more than that of care-receivers. This

finding is in sync with some of the other studies conducted among caregivers (Bhattacharyya and Chatterjee, 2019; Benyo et al., 2022; del-Pino-Casado et al., 2021; LeSeure & Chongkham-Ang, 2015; Kusi et al., 2020; Mbozi et al., 2020). There is a perception in the Indian society that cancer is incurable due to which caregivers experience a constant fear of losing the loved one. This sentiment is echoed by some of the studies conducted in India (Nyblade et al., 2017) and elsewhere (Hashemi-Ghasemabadi et al., 2016; Segrin et al., 2018).

A sub-theme that emerged was the stress of not finding a definitive answer to the cause for the disease and a sense of regret if there was a delay in diagnosis. A distinctive sense of alarm was also evident among young female caregivers who knew about the genetic predisposition of the disease. Similar findings emerged from a study conducted in the USA (Patenaude et al., 2013).

Some of the participants in the current study reported an increasing emotional burden as time progressed. Some others however, opined otherwise as they felt that improving health of the care-receiver coupled with family support substantially brought down stress levels and this finding is similar to a systematic review (LeSeure et al., 2015).

Our study highlighted the dependence on spiritual leaders and oracles to cope with stress, which was congruent with studies undertaken in India. These are inherent practices unique to the Indian subcontinent and these to a certain extent act as a stress buster (Bedi and Devins, 2016; Antony et al., 2018). Faith healing as a coping mechanism has also been reported by Kusi et al., (2020).

Caregivers in our study reported being intimidated by large hospital settings and stressed with repeated hospital visits while experiencing decisional conflict when asked to choose the preferred line of management. This is unique to India as most patients and their caregivers are unfamiliar with the disease process and the outcomes. Caregivers and patients consider the treating physician akin to God and looks for their guidance at every step during the course of the disease. Similar findings have been reported by (Bedi and Devins, 2016) in a review conducted among south Asian women with breast cancer.

Cancer care is expensive and this was echoed by most participants of this study. The underfunded public health system in India leads to catastrophic out-of-pocket spending for most people especially for diseases like cancer (Goyanka, 2021). Similar findings have been reported by studies conducted in India (Alexander et al., 2019; Joshi et al., 2021) and other Asian countries (Hashemi-Ghasemabadi et al., 2016; Kusi et al., 2020).

Globally (Kamal et al., 2017; de Moor et al., 2017; Bradley, 2019; Junkins et al., 2020; Kusi et al., 2020) it has been shown that caregiving affected work productivity and changes in employment like that reported in our study. Our study also highlighted the impact on the caregiver and the family finances when the primary earning member gets affected with the disease. Similar findings have been reported from other parts of India as well (Joshi et al., 2021; Wajid et al., 2021; Bhattacharyya and Chatterjee, 2019).

Role overload burden was particularly reported by participants belonging to nuclear families and those who had little children to take care of. This finding is consistent with studies conducted in India (Ugargol and Bailey, 2018; Fereydooni et al., 2020) and elsewhere (Anderson and White, 2018; Junkins et al., 2020). Our study participants reported shifting back to their ancestral homes and extended families to cope with caregiver burden. Studies have shown that when families work together as a team it helps the caregivers cope better and, this finding is consistent with other studies conducted in India (Ugargol and Bailey, 2018; Alexander et al., 2019) and in the USA (Bedi and Devins, 2016; Anderson and White, 2018). Daughters as caregivers experienced a higher role conflict especially if they were married and running their own home. Studies have reported that guilt and societal expectations force them to take on dual roles that burden them (Bedi and Devins, 2016). This was probably the reason that some of the caregivers (mostly women) in our study gave up their jobs despite being in a situation of increased financial pressure. This finding is consistent with a study carried out in India (Ugargol and Bailey, 2018).

This study has explored some of the stressors among caregivers of breast cancer patients in the context of a coastal region in southern India. However, since the participants of the study were from diverse regions in this coastal belt there were differences in the language and dialect spoken. Although care was taken to retain the essence of the spoken language, there might have been some minor difference in the translation of the colloquial words. Some of the interviews took place in a hospital setting with lack of adequate privacy. This might have resulted in some of the participants not sharing complete details of their caregiving related stress.

Unlike while this has certain positive ramifications, the related social and cultural factors play a substantial role in determining the informal caregiver burden. This study provides an insight into some of these elements that will need to be dealt with while providing support to informal caregivers, which in turn will ensure a better survivor experience. Developing a context and disease specific tool to measure and quantify the caregiver burden could be the way forward.

Author Contribution Statement

Shradha S Parsekar (SSP) and Suma Nair (SN) contributed to the study conception and design. SSP acquired the data and along with Louise Meijering (LM) and SN analyzed the data. The first draft of the manuscript was written by SSP, which was subsequently evaluated and revised by all authors. All authors reviewed and approved the final manuscript.

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Scientific body approval

This research paper is part of PhD thesis of first author, approved by Manipal Academy of Higher Education, Manipal.

Ethics approval

This study was performed in line with the principles of the Declaration of Helsinki. The study protocol was approved by the institutional review board (Registration no: ECR/146/Inst/KA/2013; Project Approval no: IEC 430/2016) prior to initiation of the study.

Consent to participate and publication

Informed written consent was obtained from the participants that included consent to audio record the proceedings and publish the data anonymously.

Availability of data and material

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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