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Community-based palliative care needs and barriers to access among cancer patients in rural north India: a Participatory action research

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Abstract

Background This paper aimed to explore the palliative care (PC) needs and barriers to access among cancer patients in a rural region of North India with a high cancer burden.

Methods A Participatory action research (PAR) approach was employed. Situational assessment, community sensitization workshops (CSWs) and door-to-door surveys were planned, conducted and developed over three PAR cycles. A parallel convergent mixed-methods approach was adopted wherein the quantitative data from door-to-door surveys and qualitative data from CSWs and investigator field notes were collected and analyzed to provide a comprehensive understanding of PC needs and barriers to access. Descriptive statistics and thematic analysis were used.

Results A total of 27 CSWs involving 526 stakeholders were conducted. A total of 256 cancer patients were assessed for PC needs and symptom burden using the Supportive and Palliative Care Indicators (SPICT-4ALL) and the Edmonton Symptom Assessment System (ESAS) tool, respectively. Based on the SPICT assessment, all patients ($n = 256$) satisfied general and/or cancer-specific indicators for PC. The majority (56.6%) had \geq one moderate-severe symptom, with the most common symptoms being tiredness, pain and loss of appetite. Analysis of qualitative findings generated three themes: unmet needs, burden of caregiving, and barriers and challenges. Cancer affected all domains of patients' and their families' lives, contributing to biopsychosocial suffering. Social stigma, discrimination, sympathizing attitudes and lack of emotional and material support contributed to psychosocial suffering among cancer patients and their caregivers. Lack of awareness, nearby healthcare facilities, transportation, essential medicines, trained manpower and education in PC, collusion, fear of social discrimination, faulty perceptions and misconceptions about cancer made access to PC difficult.

Conclusions The study emphasize the need for and provide a roadmap for developing context-specific and culturally appropriate CBPC services to address the identified challenges and needs. The findings point towards education of CHWs in PC; improving community awareness about cancer, PC, government support schemes; ensuring an uninterrupted supply of essential medicines; and developing active linkages within the community and with NGOs

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to address the financial, transportation, educational, vocational and other social needs as some of the strategies to ensure holistic CBPC services.

Trial registration Clinical Trial Registry of India (CTRI/2023/04/051357).

Keywords Cancer, Community, North India, Palliative care, Participatory action research, Rural

Background

Cancer is the second leading cause of death worldwide [1]. India ranks third worldwide, accounting for 1.3 million cancer cases and 0.85 million cancer deaths per year [2, 3]. Palliative care (PC) aims to improve the quality of life (QoL) of individuals and their families suffering from chronic life-limiting illnesses through early detection, prevention, and relief from biopsychosocial suffering [4]. In India, approximately 80% of cancer patients are diagnosed in advanced stages, amenable only to PC [5]. Despite being an integral component of India's universal health coverage plan, less than 4% have access to PC in India [5]. PC services in India are concentrated in tertiary hospitals in large cities with limited, if any, accessibility to the rural population [6, 7]. To meet the growing need, the World Health Organization (WHO) recommends that PC be integrated into primary health care to make it accessible and sustainable [8].

Community-based PC (CBPC) aims to integrate PC into local healthcare systems and has been shown to improve patient and caregiver satisfaction and QoL and reduce healthcare expenditure and hospital admissions at end-of-life (EOL) [8, 9]. However, CBPC services are scarce in India [10–12]. One unique and sustainable CBPC model is the neighbourhood network in PC (NNPC), operational in the southern Indian state of Kerala [13]. However, NNPC is exclusive to the region because of its unique socio-political-economic environment, availability of resources and their mobilization strategies, awareness, and varying degrees of economic self-sufficiency, which were integrated through innovative approaches [11, 13]. The above factors responsible for NNPC's sustainability limit its applicability to other regions with different socio-political contexts [13, 14]. For CBPC services to be context-specific, it is important to first identify the local PC needs and barriers to implementation [6]. These needs and barriers remain largely unknown in rural north India. With this background, this study was undertaken to assess the PC needs and barriers to assessing PC in rural North India.

Method

Study setting

The study presents findings of the first phase of a multiphase mixed-methods research as described elsewhere

[15]. The study was conducted in a rural block of North India (Fig. 1) with an approximate population of 2,09,650 [15]. The study block comprises six sectors with 27 sub-centres, one community health centre and 66 villages. Its rural location, high cancer burden, ease of accessibility, and positive rapport with the various stakeholders led to its selection as the study area.

Study population

The study population, as described in the protocol paper, comprised cancer patients and their caregivers, community health workers (CHWs), medical officers, village heads, representatives of non-government organizations (NGOs) and program officers [15]. All the cancer patients in the study block were recruited for the study, and other study participants were selected through purposive and convenient sampling.

Ethics

The study was established at the organizational and inter-organizational levels. The study was conducted by a tertiary care institute after obtaining permission from the institutional ethics committee (IEC/AIIMS/BTI/157), Indian Council of Medical Research (No. 5/13/17/MG/ICRC/2022/NCD-III) and registration with the clinical trial registry of India (CTRI/2023/04/051357). Approvals were also sought from the National Programme for Prevention and Control of Non-communicable Diseases (NP-NCD) and other concerned authorities. A participant information sheet (PIS) providing information on the study objective, methods, role of study participants, benefits to study participants, voluntary participation and details of the principal investigator was given to each study participant. Written informed consent was taken from all the participants on an Informed consent form (ICF). Participants were made aware that they could deny or withdraw consent at any time without any impact on their care or information provided regarding treatment or social support schemes available. The information about community sensitization workshops (CSWs) was given by the Senior Medical Officers of the study block to CHWs and other stakeholders. The stakeholders were informed that participation in CSWs was voluntary and that discussions would be audio-recorded, analysed and reported along with anonymized verbatims. All the

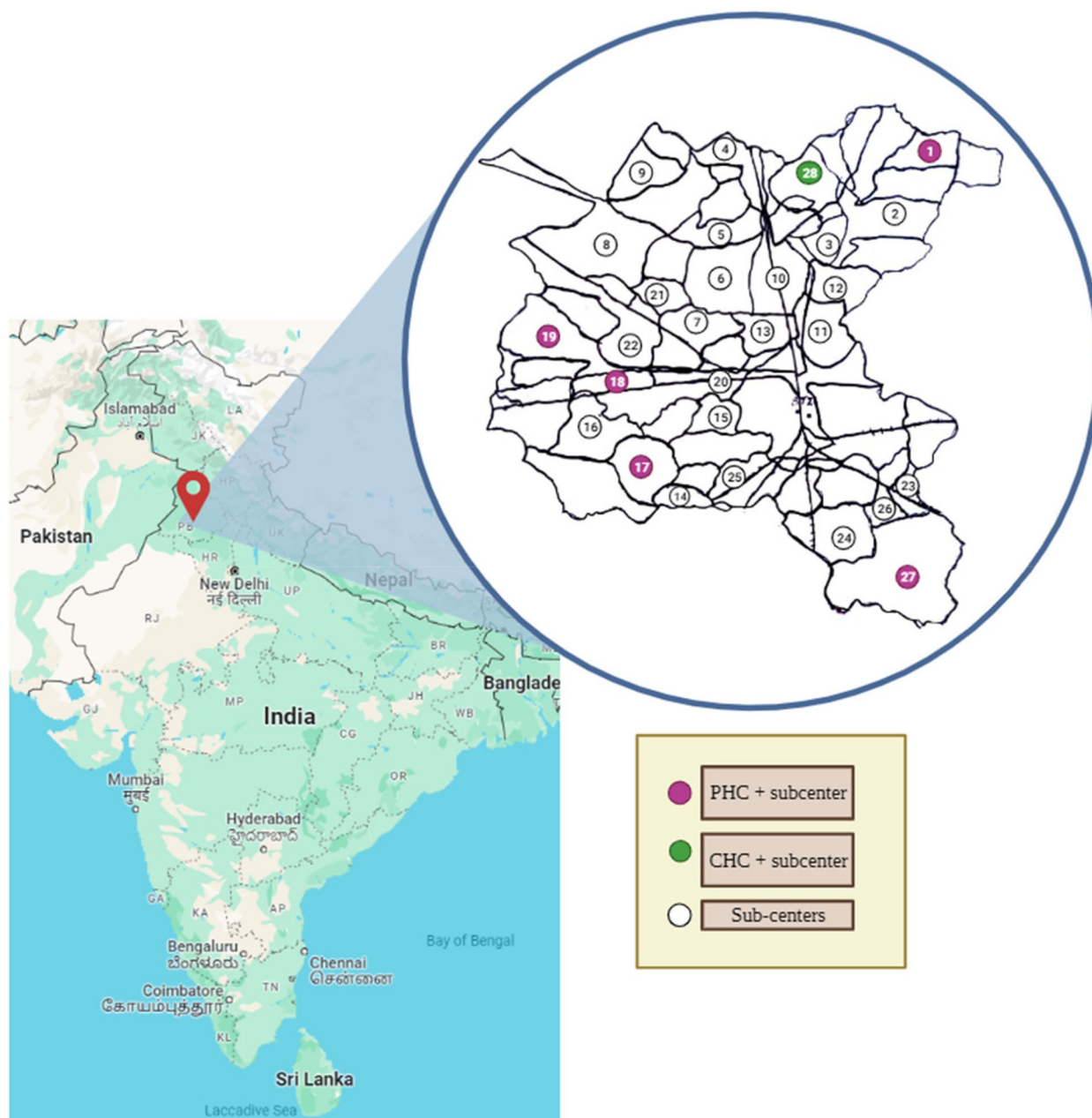


Fig. 1 Map depicting the study block, its subcentres, primary and community health centres. (Adapted from Google Maps and map of study block obtained from the district health administration)

research data were stored in a password-protected file and was accessible only to the principal investigators.

Study design

A Participatory action research (PAR) approach was employed to explore the PC needs and barriers to PC access. PAR’s problem-focused, context-specific and iterative approach to problem-solving suited the overall project objective, i.e. to develop a comprehensive

coordinated community-based PC model for cancer patients (C3PaC) for the study block [15]. We envisaged that the collaborative nature of PAR would facilitate and empower those within the system to understand the PC needs and barriers and help co-design contextually competent solutions. Three PAR cycles were conducted from March to December 2023, with reflections from one cycle informing the actions during the next cycle (Table 1). Each PAR cycle involved defining the problem,

Table 1 PAR Cycles

Cycle	Plan	Action	Observation	Reflection
1	Situational assessment	<ul style="list-style-type: none"> • Formation of Project advisory Group (PAG) • Recruitment and training of dedicated project staff • Continued mentoring and supervision of the project staff by the PC experts and PAG • Identification of stakeholders and formation of a key stakeholder group (SG) • Mapping of health facilities and cancer patients 	<ul style="list-style-type: none"> • Cancer burden is high • One NGO is providing home-based care in limited areas • The local health system will provide support • Sub-centres did not have data for all the cancer patients • Patients had unrelieved symptoms 	<ul style="list-style-type: none"> • Need for sensitization meetings in the community • Need to plan logistics and transport for meetings • Door to door assessment to identify cancer patients, their PC needs and symptom burden • Need for liaising with NGO
2	Conduct Community Sensitization workshops (CSWs) and door-to-door survey	<ul style="list-style-type: none"> • Organization of CSWs (n = 3) with the aim to know participants views on • Problems faced by Cancer patients and caregivers • PC and its need • Ongoing PC services • Training of health workers in PC • Orientation about PC, project and its team <p>Door-to-door survey to assess PC needs and symptom burden among cancer patients</p>	<ul style="list-style-type: none"> • Participants were unaware of cancer symptoms • Stigma and myths about cancer • Lack of accessibility to community-based PC • Lack of awareness on government schemes 	<ul style="list-style-type: none"> • Need to develop health promotion material on cancer symptoms and risk factors • Need to develop a web-based app for triaging and follow-up of identified cancer patients
3	CSWs and door to door assessment	<p>Based on previous reflections following activities were incorporated in CSWs at remaining sub-centres (n = 24):</p> <ul style="list-style-type: none"> • Printed information in local language on cancer symptoms, risk factors • Awareness and information on various financial schemes available for the cancer patients <p>Door-to-door surveys were continued. Designing of a web-based application to integrate patient information from door-to-door survey and triage patients</p>	<ul style="list-style-type: none"> • Some patients had left treatment in between • Lack of social support in form of money, nutrition, employment • Patients had unmet biopsychosocial needs • Low screening uptake for common cancers 	<ul style="list-style-type: none"> • Need to identify NGOs working in areas for nutritional and vocational need • Need to motivate patients for completing the treatment • Need to develop a plan for early detection of cancers • Continue and reinforce coordination of referral and follow-up of patients

developing and implementing an action plan, observing the impact of actions, and reflecting on and taking corrective measures [16]. During these cycles, qualitative and quantitative methods were employed to collect data detailed in subsequent sections.

First PAR cycle

Stakeholder identification and engagement are central to PAR. For supervising project implementation, a project advisory group (PAG) was formed comprising the district NP-NCD program officer, the medical officer (MO) of the study block and a multidisciplinary team of PC experts, community medicine experts and oncologists. The PAG deliberated on the action plan and identified cancer patients, caregivers, CHWs, village heads and local NGOs as the stakeholders to be involved in PAR. A key stakeholder group (SG) comprising the PAG and representatives from different stakeholders was formed and provided inputs throughout the research process [17].

The project team visited all the sub-centres and interacted with various stakeholders to explore the geographical and demographic context of the study block, including the existing healthcare facilities, CHWs working there and cancer patients registered at each sub-centre. This provided insights into the existing healthcare infrastructure and cancer prevalence within the study area. The identified sub-centres and primary (PHC) and community (CHC) health centres were marked on the geographical map of the study block obtained from the district health administration (Fig. 1), which facilitated the planning of subsequent CSWs and door-to-door surveys. Discussions with various stakeholders and mapping of existing PC services by accessing the PC directory of the Indian Association of Palliative Care and Pallium India (an NGO working extensively in PC in India) identified an NGO providing limited PC services in the region [18, 19] and an organization providing social support as a community outreach program.

Based upon reflections from the first cycle, CSWs and door-to-door surveys were planned to explore the stakeholders' PC awareness, needs and challenges. Liaising and collaboration with the identified NGOs and organizations for additional support to the identified patients and their families was planned.

Second PAR cycle

CSWs in local languages (Punjabi and Hindi) were organized at each sub-centre with the stakeholders. CSWs aimed to discuss the study objective, the current status of PC and the role of stakeholders in developing a CBPC model. The discussions were structured and evolved around PC understanding, needs and challenges and the current care pathway of cancer patients. The SG

identified local site coordinators at each subcentre who provided a list of potential stakeholders and helped liaise with them. Phone call invitations and reminders ensured maximum stakeholder participation during the CSWs. These meetings gave an opportunity to cross-verify the cancer patients registered at each subcentre. Simultaneously, a sub-center-wise door-to-door survey of cancer patients was done to assess their PC needs and symptom burden. All households with an adult (≥ 18 years of age) informant and willing to provide information about the presence of and details about diagnosed cancer patients in the household were included. PIS was given and written informed consent was taken from all the participants. Those not consenting were excluded.

Following three CSWs, we discovered that the communities were not well informed about cancer, its aetiology and the symptoms and benefits offered by the existing financial schemes. There was a need to develop a tool to triage and follow up identified cancer patients with PC needs.

Third PAR cycle

Based on reflections of the second PAR cycle, the subsequent CSWs incorporated an action strategy for distributing information, education and communication (IEC) materials providing information on cancer symptoms, treatment options and available financial schemes. The IEC was provided to all the participants irrespective of their consent to participate. Door-to-door surveys were continued. A web-based tool was designed in consultation with the SG to help triage patients based on the symptom severity. The SG reflected on the need to identify means/agencies to provide nutritional and vocational support and early detection of cancer.

Data collection and analysis

A parallel convergent mixed-methods approach was adopted wherein the quantitative data from door-to-door surveys and qualitative data from CSWs and investigator field notes were simultaneously and independently collected and analyzed to provide a comprehensive understanding of PC needs and barriers to accessing PC [20, 21]. Evidence suggests that the mixed-methods design used depends upon the study's purpose, with the convergent approach being the most commonly employed mixed-methods design in studies assessing PC needs [20].

Quantitative data

A list of cancer patients in the study block was obtained from the NP-NCD program office. This list was continuously updated during the door-to-door survey and from the list of cancer patients registered at each subcentre. As

a part of the NP-NCD program, ASHAs maintain a list of cancer patients from their villages and update them regularly. The door-to-door survey included PC need assessment of the diagnosed cancer patients in each household comprising of socio-demographic, disease and treatment details (Supplementary File 1); Supportive and palliative care indicators (SPICT-4ALL) tool; and Edmonton Symptom Assessment System (ESAS) tool. The tools were selected based on systematically conducted reviews of literature [22, 23] and were finalized in consultation with the SG. The tools were translated into regional languages (Punjabi and Hindi) where not available using EORTC forward and back translation [24]. The translated tools were piloted on ten cancer patients attending the radiation oncology and palliative care outpatient departments (OPD) of the hospital.

All cancer patients satisfying \geq two general indicators or \geq 1 specific indicator for cancer with or without general indicators on the SPICT-4ALL tool were recruited [25, 26] and assessed for the intensity of symptoms using ESAS [27]. The tools were completed by the research team based on the information obtained from the patient and/or caregiver [26]. All the data were entered into a web-based application (app) designed specifically for the study. The app streamlined data accessibility and facilitated efficient patient triaging and navigation. Patients were triaged into high (score \geq seven for \geq one symptom on ESAS), medium (score four to six for \geq one symptom on ESAS), and low (score \leq three for \geq one symptom on ESAS) priority to facilitate timely home visit (within three, ten and fifteen working days for high, medium and low priority patients respectively) and intervention by the PC team [28].

The data from the app were retrieved into an Excel sheet for statistical analysis. The data analysis was performed using statistical analysis using the Statistical Package for Social Sciences version 29.0 (SPSS). Descriptive statistics such as Mean \pm SD/ Median (IQR) and frequency (%) were used to represent continuous and categorical variables, respectively.

Qualitative data

A total of 27 CSWs were conducted (one in each sub-centre) with 526 stakeholders comprising community members ($n=192$), ASHA workers ($n=172$), village leaders ($n=19$), doctors ($n=nine$), community health officers (CHOs) ($n=18$), ANMs ($n=ten$), other CHWs ($n=69$), cancer patients ($n=29$) and caregivers ($n=eight$). The CSWs lasted an average of 16–50 min in duration. The discussions during CSWs were audio recorded (Sony ICD-PX470F). After each CSW, research team debriefing was done, and reflections were documented. The research team transcribed the audio recordings of the

CSW sessions from each sub-centre verbatim. Inductive data analysis was conducted using thematic analysis, which involved reading, familiarizing and immersion in the data [29]. Anonymized data from the SG meetings, discussions and the investigator field notes were collected, reflected upon and supplemented the transcribed data from audio-recorded CSWs. The transcribed data were coded, followed by arranging codes into sub-themes and broader themes in an iterative process. Two researchers carried out the coding independently, and themes and sub-themes were developed in consultation with the SG.

Trustworthiness was ensured using Lincoln and Guba's evaluative criteria of credibility, dependability, confirmability and transferability. Credibility was ensured by regular SG debriefing, prolonged engagement of the field staff in the community and triangulation of data from the transcribed recordings and field notes. This eliminated individual researcher bias due to preconceived notions and perceptions and ensured the findings were grounded in the data [30]. Detailed descriptions of the methods, SG checking and an audit trail of the process ensured dependability. Confirmability was ensured using reflexivity during regular SG debriefings. Multiple SG discussions were held to exchange inputs and contribute to data synthesis and interpretation. Stakeholder engagement, representation of multiple stakeholders and data saturation (achieved after the first 19 CSWs) ensured the transferability of the findings [31]. The coded transcripts were reviewed multiple times to ensure that no perspectives expressed by stakeholders were omitted and themes were supported by illustrative verbatims and organized into a thematic map. Findings from qualitative data were used to expand upon the findings from the quantitative data.

Results

A contiguous narrative approach has been used to integrate and describe the findings wherein first, the quantitative results describe the magnitude of symptom burden among the identified cancer patients, complemented by the qualitative findings presented as themes [32].

Demographic and baseline characteristics of identified cancer patients

A total of 256 cancer patients were identified through multi-faceted strategies. The majority (70%) were identified from the record of cancer patients maintained at the sub-centres and district hospital level, with the rest identified during door-to-door surveys (15%) and information provided by the NGOs (10%) and village heads (5%). The mean age of the cancer patients was 55.95 ± 15.16 years. The majority were in the economically productive age group of 18–65 years, females, followed Sikhism as their

Table 2 Demographic and disease characteristics

Characteristics	Categories	N (%) (n = 256)
Age, years	< 18	10 (3.91%)
	18–65	191 (74.61%)
	> 65	55 (21.48%)
Gender	Female	178 (69.53%)
	Male	78 (30.47%)
Religion	Sikh	238 (92.97%)
	Hindu	17 (6.64%)
	Muslim	1 (0.39%)
Marital status	Married	239 (93.36%)
	Unmarried	17 (6.64%)
Education	Illiterate	128 (50%)
	Up to Primary (5th)	73 (28.52%)
	Up to Secondary (10th)	31 (12.11%)
	Senior secondary (12th)	11 (4.30%)
	Graduate and above	13 (5.08%)
Occupation	Unemployed	126 (49.22%)
	Student	10 (3.91%)
	Homemaker	92 (35.94%)
	Daily wager	22 (8.59%)
	Salaried	3 (1.17%)
	Retired	3 (1.17%)
	Ration card ^a	Yes
	No	32 (12.5%)
Health Insurance	Yes	189 (73.83%)
	No	67 (26.17%)
Site of cancer	Breast	67 (26.17%)
	Digestive/Gastrointestinal	48 (18.75%)
	Genitourinary	19 (7.42%)
	Gynaecologic	42 (16.41%)
	Head and Neck	31 (12.11%)
	Hematologic/Blood	35 (13.67%)
	Musculoskeletal	4 (1.56%)
	Neurologic	5 (1.95%)
	Respiratory/Thoracic	5 (1.95%)
Treatment Place	Public	206 (80.47%)
	Private	50 (19.53%)
Treatment Undergone	Chemotherapy	13 (5.08%)
	Surgery	16 (6.25%)
	Radiotherapy	5 (1.95%)
	Others including palliative care	31 (12.11%)
	Any of the two	94 (36.72%)
	Any of the three	62 (24.22%)
	All	19 (7.42%)
No treatment	16 (6.25%)	

^a "A document issued under an order or authority of the State Government for the purchase of essential commodities from the fair price shops under the Targeted Public Distribution System" (Available from: https://dfpd.gov.in/WriteReadData/Other/nfsa_1.pdf. Accessed 13 Aug 2024

Table 3 Disease-specific indicators for PC requirement among cancer patients

Morbidities	N (%) (n = 256)
Liver problems ^a	40 (15.63%)
Nervous system problems ^a	34 (13.28%)
Other conditions ^a	29 (11.33%)
Dementia/fragility ^a	23 (8.98%)
Lung problems ^a	6 (2.34%)
Heart or circulation problems ^a	5 (1.95%)
Kidney problems ^a	2 (0.78%)

^a As per the SPICT criteria

religious faith, married and either illiterate (Table 2). Only three patients were in organized employment and salaried. The most common cancers among females and males were breast and head and neck cancer, respectively. The majority received or were undergoing multiple anti-cancer-directed treatments.

PC need and symptom burden

Based on the SPICT assessment, all patients (n=256) satisfied either general and/or cancer-specific indicators for PC. Considering an estimated block population of 2,09,650, this equates to an approximate 122 per 100,000 population in need of PC. Apart from cancer, more than half (n= 139) satisfied disease-specific indicators for other chronic diseases for the requirement of PC (Table 3).

The majority (56.6%) of patients had either one or more symptoms in the moderate-severe category, with the most common symptoms in the moderate-severe category being tiredness, pain and loss of appetite (Table 4).

Figure 2 depicts the priority-wise classification of identified cancer patients based on symptom severity.

Themes

Analysis of qualitative findings generated three overarching themes and ten sub-themes. Figure 3 depicts the thematic map of findings and how barriers and challenges contributed to the biopsychosocial suffering of patients and their caregivers.

Theme 1: unmet Needs

Unmet needs are the needs perceived as “important or very important yet unfulfilled “ [33]. One of the most consistent themes to emerge across the CSWs and iterated by all the stakeholders was the unmet physical, psychological and financial needs of cancer patients.

Table 4 Symptom severity among study participants based on ESAS assessment (n = 256)

ESAS symptoms	No symptom N (%)	Mild symptom N (%)	Moderate to severe symptom N (%)
Pain	62 (24.22%)	168 (65.63%)	26 (8.98%)
Tiredness	39 (15.23%)	186 (72.66%)	31 (12.11%)
Drowsiness	44 (17.19%)	200 (78.13%)	12 (4.69%)
Nausea	55 (21.48%)	191 (74.61%)	10 (3.91%)
Appetite loss	56 (21.88%)	177 (69.14%)	23 (8.98%)
Shortness of breath	63 (24.61%)	178 (69.53%)	15 (5.86%)
Depression	45 (17.58%)	196 (76.56%)	15 (5.86%)
Anxiety	52 (20.31%)	190 (74.22%)	14 (5.47%)
Wellbeing	75 (29.3%)	175 (68.36%)	7 (2.73%)
Other problems (constipation)	78 (30.47%)	165 (64.45%)	13 (5.08%)

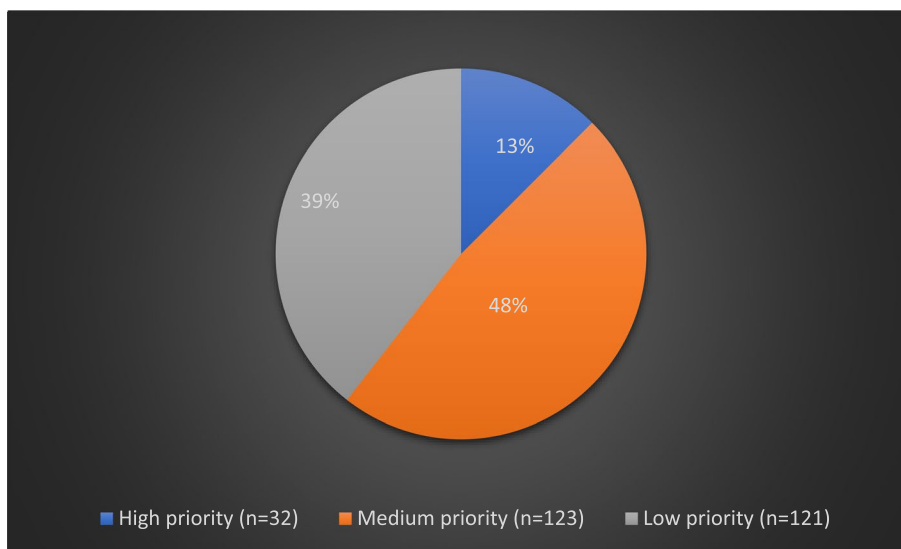


Fig. 2 Priority-wise classification of cancer patients

Unrelieved physical symptoms

Participants expressed that patients were frequently diagnosed in advanced stages and experienced severe pain and side effects from radiation and chemotherapy. Common symptoms included widespread body pain, diarrhoea, vomiting, nausea, fatigue, appetite, hair and weight loss. A few participants iterated the difficulty and intense pain associated with food intake in patients with throat cancer.

“When a patient is undergoing chemotherapy, then there are a lot of problems for the patient. Diarrhoea also takes place, vomiting also take place. It becomes difficult to travel also in hospitals at that time.” [Community member 5]

“Hair loss is seen, pain in the whole body takes place” [ASHA 50]

Physical symptoms made it difficult to perform daily chores like personal hygiene and housework and made patients dependent on others.

“Swelling takes place in my legs. Difficulty is there while walking” [Patient(Breast cancer) 5]

“These symptoms have a significant impact on a patient’s quality of life and ability to perform daily activities” [CHW 9]

Some CHWs had concerns that patients hesitated to discuss physical concerns with them as they were either accepted as typical in cancer or dealt with by consuming



Fig. 3 Thematic map

painkillers on their own. Patients and caregivers found it challenging to travel long distances to the hospital for pain management.

“The problem is travelling on the bus. [Caregiver 2].

Unaddressed emotional needs

Participants reported that cancer patients experienced anxiety, sadness, depression, helplessness, lack of belief in treatments, hopelessness, and fear of facing death.

“Main problem is mental problems of anxiety and emotions” [CHO 2].

“Patients are mentally disturbed and think that their cancer is incurable and in their last stage.” [CHO 7]

“Psychologically, they get problems when they have cancer. The patient becomes very sad” [CHW 11]

A sympathizing attitude of viewing cancer patients as "unfortunate" contributed to their social isolation and emotional distress.

“Patients are in tension and stress” [Community member 68]

CHWs acknowledged their inability to provide psychological support and help due to a lack of understanding of how to handle psychological issues.

Need for financial assistance

The requirement for financial assistance was high and uniformly expressed by all the participants. Rural households found it challenging to afford expensive medical treatment and struggled to meet the family and treatment needs as the main source of income was daily wages.

“Patients are concerned about the financial burden it places on them and their families.” [CHO 9]

“Yes, people do face it, they know that they have to sacrifice their hunger for the medicine. His profession does not bring much, the cost of his medicine is also very high.” [CHW 51]

This was more so when the only bread earner in the family was affected and bedridden, hampering their ability to support themselves and their children from receiving the right care, food, and education.

“A poor patient has 4 daughters with no earning member in their family. The only earning member responsible is also bedridden.” [ASHA 80]

“Their family requests vegetables from their neighbours” [ASHA 62]

The need to be continuously present near bedridden patients prevented other family members from going to work and contributed to the financial burden. Families ultimately became financially unstable due to the direct and indirect costs of cancer care.

Theme 2: burden of caregiving

Caregivers provide unpaid support to people with chronic diseases (like cancer) who cannot take care of themselves [34]. The theme describes the physical, psychological and social impact of caring for cancer patients on the caregivers.

Impact on physical health

Caregiving impacted the everyday lives of the family members. Participants expressed that it was exhausting and challenging for the caregivers to be continuously present near the patients or to transport them to hospitals for simple necessities like changing feeding tubes and dressings.

“The problems get transferred to their family.” [Community member 46]

“Patient has to face problems. But, surrounding people also face many problems.” [ASHA 22]

“Family at the last stage remained in hospital only” [Community member 14]

“The patient who is undergoing treatment has some problems but his family members face a lot of problems like giving medicines to the patient on time, feeding him, taking care of him, all the members of the family get attached to him.” [CHW 10]

Psychological impact of caregiving

Lack of time, sleep, money, emotional and material support and fear of losing loved ones impacted caregivers' psychological well-being.

“Family members were also unable to sleep or eat when the victim was in pain.” [Community member 14]

Lack of proper guidance made them helpless and confused, leading them to be influenced or convinced by others to try treatments other than the one going on.

“Because Mam as there is such a disease that the whole family is troubled in different ways. These villagers are poor and working daily, doing daily labour work, but any proper guidance is not available at the moment. The caregivers are also in tension, apart from the patient who is suffering.” [CHW 17]

Social impact of caregiving

Full-time caregiving hampered the ability to maintain active peer groups, contributing to social exclusion, loneliness and depressive symptoms, especially among young caregivers. Female family members had to handle all responsibilities when a male family member was affected.

“His wife works as a maid locally and collects money for his well-being” [Community member 106]

Cancer impacted the education of affected children as well as children of the family with an affected member. Children of cancer patients' families were unable to attend classes regularly because of their caregiving responsibilities. At a very young age, the only children in the families took on the responsibility of managing the family's finances and other responsibilities alongside their education.

“Her son was forced to earn money for his family, leaving his studies in between.” [ASHA 140]

“Their children cannot go to school. So, they must be actually helped” [ANM 1]

Theme 3: barriers and challenges

This theme highlights the barriers and challenges in accessing PC from the perspectives of patients, caregivers and CHWs.

Lack of awareness

Stakeholders conveyed a lack of knowledge about cancer, its symptoms, aetiology, treatments and government support schemes for cancer patients.

“The thing is that there is a lack of awareness. The second is that cancer is an unfortunate disease. No guaranteed treatment is available.” [Community member 114]

There is a lack of guidance of treatment among the patients in our community” [CHW 3]

There was a stated need to carry out public health awareness campaigns regarding cancer and its screening.

“Please give some information about this mouth cancer. Can we get some information about that? Can we get some treatment for that?” [Patient 15]
“Why is this cancer spreading so much” [Community member 2]

The majority were unaware of PC as a treatment approach and option.

“Sometimes nearby surrounding people and local health care staff consider their pain for granted and think that they will have to suffer. We were unaware of palliative care.” [CHW 11]

Lack of awareness campaigns and education in the medical and nursing curricula were cited as the reasons for ignorance about PC. This lack of awareness often resulted in delayed diagnosis and, ultimately, a challenging death. Stakeholders were receptive to and expressed interest in more information on PC and its benefits.

Lack of access to facilities and resources

The lack of PC initiatives and services compounded the limited awareness about PC, hindering its uptake. The lack of available facilities providing PC and health-care professionals trained in PC restricted the available options for those in need.

“No. No such team has ever come here. It’s just you visited here for the first time.” [CHW 13]

CHWs iterated non-availability of essential narcotic drugs (ENDs) and other essential medicines.

“We have only paracetamol and diclofenac. Even tramadol is not available” [Doctor 1]

“Yes, but many medicines, the injections have to be taken from outside.” [Caregiver 11]

Community members reported a perceived lack of good local healthcare centres nearby.

“Also, patients have limited access to medical facilities and specialized cancer treatment centres” [CHW 6]

The geographical distance of tertiary care centres from villages restricted access and posed a significant hurdle. People travelled far distances to urban centres to receive cancer treatment. These contributed to delayed diagnosis of cancer and timely access to PC.

“We have to go outside for treatment, leaving the work. Villagers find it difficult to travel to distant places. We have to go on buses, buying tickets and other expenses also being involved. It requires a lot of time on hospital visits that cannot be ignored also.” [Patient 21]

Collusion

Participants indicated that families intentionally withheld or distorted critical information about patients’ diagnoses and prognoses to shield patients from emotional distress. This consequently impeded the patients’ ability to make informed choices regarding their care and receive timely care.

“Nowadays, if someone gets cancer, then he dies just after hearing its name.” [Community member 1]

“If we tell him, his health, especially his mental health will go down immediately. Suppose we tell a patient that he is suffering from oral cancer and he has to be taken for radiotherapy, then he will lose hope of life immediately.” [CHO 17]

Myths and misconceptions

Misconceptions about cancer as a communicable disease fostered unwarranted fears, apprehensions and stigmatization.

“Patients think of this disease not to be disclosed. Didn’t knew why people had this mentality. Though she tries to counsel the patients and explains that cancer is a non-communicable disease, but still the mentality of people with this disease remains.” [CHW 14]

Not just cancer patients, even their family members faced the brunt of discriminatory attitudes. Fear of

reaction from society hindered individuals from seeking timely care, empathy, and support from the community.

“They do not want to disclose their problem and fear, thinking how others will react to it...Patients may fear being discriminated against by their community, leading them to keep their diagnosis a secret.” [CHW 23]

They preferred not to inform anyone as others would exhibit needless compassion and pass judgment based on their condition.

“Even they do not tell us, Maam. Later on, we come to know. Cancer has also appeared. Still even then, they do not disclose. Later on, we come to know. When the treatment becomes so costly, then they come to us for help.” [CHO 24, ANM 2]

Perception of no hope for life and treatments, as well as cultural reliance on traditional and ayurvedic medicines, further discouraged individuals from seeking treatments.

“Second is that cancer is an unfortunate disease. No guaranteed treatment is available...Another is that people fall into false magical treatment possibilities in these situations.” [Community member 7]

“Patients divert from the actual treatment towards unnecessary rites and rituals...If the patient is diagnosed with cancer, he first goes into superstition. Later, they consider it necessary to get treatment using local medicines” [CHW 7]

These misconceptions perpetuated by close ones and society at large created an environment of misinformation, social exclusion and abandonment, contributing to psychological problems and influencing individuals to make decisions contrary to their best interests.

“But, he couldn’t tell about the internal problems of him or his family as cancer patients do resist to talk about their disease.”[A CHW]

Discussion

To the best of the authors’ knowledge, this is the first study to comprehensively assess PC needs and barriers to accessing PC in Rural North India from the perspectives of those living within the community. A total of 256 cancer patients (122 per 100,000 considering an estimated block population of 2,09,650) required PC which aligns with our studies which have reported PC need among cancer patients to be 70–140 per 100,000 population [15, 35]. However, some others have reported the prevalence of CBPC need in India to be 200 to 610 per 100,000 population [36–38] as they included chronic life-limiting illnesses other than cancer. Considering the

high prevalence of chronic life-limiting illnesses and PC needs, most PC programs in India pragmatically started with cancer and later expanded their spectrum to include other illnesses [39–41]. Cancer represents the most common chronic life-limiting illness in need of CBPC in India [10, 42] and the patient population catered by CBPC services worldwide [43]. Heterogeneity in the tools used, definition of PC population and socio-demographic background might be the other reasons for the observed differences.

SPICT helped evaluate cancer patients for other disease-specific clinical indicators for PC referral; facilitating care planning and appropriate referrals. Evidence suggests multi-morbidity to be a norm rather than a departure, justifying the use of SPICT as a PC screening tool in the community [26, 44, 45]. In our study, the most common moderate-severe symptom were tiredness, followed by pain, loss of appetite and constipation. While some have reported pain as the most common symptom [46, 47], others have reported tiredness and depression as significant contributors to PC needs. [48–50]. To provide efficient and timely PC, patients were triaged and categorised as high, medium and low priority for PC. Compared with the available evidence [28], a relatively high proportion of cancer patients were categorized as high (13% vs 6.32%) and medium priority (48% vs 20.75%) and were provided with timely home-based PC [28]. The impact of triaging, although outside the scope of this article, has previously been shown to be effective in the timely management of symptoms, improving family satisfaction, reducing unnecessary hospitalizations and optimizing the utilization of scarce resources like trained manpower in resource-limited home-care settings such as ours [28].

Barriers and challenges to PC

Qualitative findings allowed in-depth exploration of PC needs and challenges faced by community-dwelling cancer patients, caregivers and CHWs. Lack of awareness and fear of discrimination led to delayed diagnosis and silent suffering. This was worsened by the non-availability of essential medicines, geographical distance of the treatment centres, and the absence of PC services. Lack of resources and trained manpower hinder accessibility to PC in rural areas, even in developed countries like the USA [51]. Inaccessibility to ENDs is one of the uniformly cited reasons challenging PC delivery and jeopardizing the quality of death of cancer patients in India [5, 17, 52–54]. The lack of healthcare facilities and availability of opioid analgesics nearby meant long-distance travel to access pain relief. Our findings corroborate with others have also highlighted the difficulties patients face while travelling long distances to access PC and pain relief; which includes selling physical assets with long-term

consequences for both the patients and their families [55, 56].

Poor general condition and public transport system limits access to hospital-based PC services in India; underscoring the need for CBPC [41]. CBPC has been shown to reduce travel costs and caregiver exhaustion [56]. Addressing the shortage of trained manpower, unawareness, and other community-specific barriers is essential to implement sustainable CBPC services [53, 57, 58]. Training and continuous engagement of CHWs are effective strategies to address the need-supply mismatch in resource-poor settings [59, 60]. CHWs can effectively identify patients in need of PC, manage their symptoms, provide psycho-social-spiritual support to them and their caregivers and help them become independent and productive in the community [61]. However, in sync with our findings, lack of training in PC and handling emotional issues hinder their involvement in low- and middle-income countries [61]. With proper education and training, CHWs can effectively manage pain and dispense analgesics at patients' doorsteps, thereby reducing the need to travel long distances just to access pain relief [55, 56, 61].

Psychosocial needs were the other major contributors to suffering. Socioeconomic status dictates the burden of unmet needs among cancer patients with socio-economically disadvantaged [as in our study: rural population with majority being illiterate (50%), no source of regular income (98%) and health insurance (26%)] known to suffer the most [50]. Empirical research shows the inadequacy of hospital-based services to address the non-physical and non-clinical needs of cancer patients, contributing to unrelieved suffering [50]. Social stigma inhibited individuals from disclosing their diagnosis; hindering community support and exacerbating psychosocial issues. Collusion further hindered receiving crucial information and seeking timely treatment. Our findings corroborate with others who have shown patients' ignorance of their illness trajectory and impending death as barriers to early PC [36]. Effective communication is the key to facilitating disease acceptance and appropriate adjustment [48]. CBPC has been shown to improve family and societal attitudes towards cancer patients [43].

Burden of caregiving

Analysis of CSW and field notes reflected the domains and determinants of caregiver burden in Rural North India, which have been largely unknown so far [62]. Financial constraints, coupled with caregiving responsibilities, impacted every aspect of their life. The biopsychosocial impact of cancer on informal caregivers matches or even supersedes that of the patients, leading to self-neglect, fatigue, social exclusion, sleep

and psychological disturbances [62]. With majority of patients in the economically reproductive age group yet unemployed or without any regular source of income, lack of health insurance; and lack of support and constant caregiving responsibilities contributing to loss of caregivers' wages; families found themselves trapped in a vicious cycle of limited resources and high medical care costs. Cancer is the leading cause of catastrophic health expenditure and distress health financing (Supplementary File 2), pushing millions below the poverty line each year in India [63]. Similar findings of direct and indirect costs associated with cancer contributing to financial burden, toxicity and liability, extending even beyond patients' death have been reported in other parts of India [62, 64–66]. Financial concerns are the most common significant needs considered unfulfilled by cancer patients, even in developed countries [51]. Our findings emphasize the need for continuous caregiver support, as caregiving can be intimidating and may lead to burnout, fatigue and depression [33]. The urgent need for holistic CBPC services to relieve the biopsychosocial impact of cancer on patients and their families in rural North India cannot be overemphasized.

Strengths and limitations

The present study was done in a geographical location with a high cancer burden. PAR facilitated community engagement and encompassed the perspectives of all the concerned stakeholders, thereby reducing the power imbalance between the researchers and the participants. Community engagement is essential to ensure the sustainability of CBPC services [67]. The involvement of CHWs as co-researchers helped in a better understanding of the current situation and collaborative thinking of strategies to address the same. As realized in this study, CHWs, due to their acquaintance with the community, were well-apprised of the social concerns faced by the patients and their families [68]. PAR's mixed-methods approach allowed triangulation and improved the validity of findings [32]. The qualitative findings (unmet needs) validated the quantitative results of high symptom burden and expanded them by capturing individuals' experiences of cancer and its symptoms, their impact and contextual barriers to managing them. They further helped identify the factors contributing to psychological morbidity among the patients and caregivers, Our study fills an evident gap in the literature as a recent review highlighted a dearth of PC studies employing mixed-methods design with the majority of those identified being from developed countries and only a minority from Asia (<5%) [20].

Our limitations include the potential for response bias in the self-reported data and the specific regional focus,

which limits the transferability to other settings with different socio-cultural contexts. However, strategies adopted and findings might apply to other similar socio-cultural contexts. Some of the participants in the study exhibited hesitancy in providing information, whereas others were uncertain regarding their cancer stage. This observed lack of clarity in self-reported cancer staging would have introduced challenges to the research's data accuracy, which is why it was excluded. Noteworthy, not all stakeholders would have felt comfortable in sharing their views publicly during CSWs which might be the reason for limited insights from patients and caregivers. An in-depth exploration of the views of all the stakeholders without any intimidation requires in-depth interviews in a place and time both convenient and comfortable for the individual stakeholders and is currently underway.

Implications

Our findings of high symptom burden among cancer patients in the community underscore the importance of establishing CBPC services to reduce serious health-related suffering. The study underscores the importance of community-based PAR, engagement, and establishing rapport to identify contextual barriers to PC accessibility. The findings provide a roadmap for program managers, policymakers and healthcare providers to develop context-specific and culturally appropriate strategies to address the identified gaps. Some of the strategies include 1) education, training and mentoring of CHWs in symptom assessment and management, communication skills, safe use of ENDS, goals of care discussions and coordination of care of cancer patients between community and hospital; 2) improving community awareness about palliative care, cancer, its symptoms, aetiology (clarifying faulty perceptions), available treatments and financial support services; 3) ensuring uninterrupted supply of opioids and PC medicines, 4) capacity building of PHCs and CHCs to provide home-based PC; and 5) establishing linkages within the community and with the NGOs to address the financial, educational, vocational and other social needs of cancer patients and their families.

Conclusion

The need for CBPC among cancer patients in rural north India is high as cancer affects all domains of patients' and their families' lives, contributing to biopsychosocial suffering. Community-based PAR and stakeholder perspectives helped uncover real-world determinants of unmet PC. Social stigma, discrimination, sympathizing attitudes and lack of emotional and material support contribute to psychosocial suffering among cancer patients and their caregivers. Lack of awareness, nearby healthcare facilities, transportation, ENDS, trained manpower and

education in PC, collusion fear of social discrimination, cultural reliance on traditional medicines, faulty perceptions and misconceptions about cancer make access to PC difficult. Our findings emphasize the need for and provide a roadmap for developing comprehensive coordinated CBPC interventions that are integrated with primary health care. The findings helped identify pragmatic strategies to integrate C3PaC within the primary healthcare system and improve the QoL of cancer patients and their caregivers. The findings point towards capacity building of existing healthcare facilities by education and training CHWs in PC and ensuring an uninterrupted supply of essential medicines, improving community awareness about cancer and PC and developing active linkages within the community and with NGOs to address the social needs of cancer patients and their families as some of the strategies to ensure equitable, sustainable and holistic CBPC services.

Glossary

Block is an administrative unit of a district in Indian states. Bathinda district in Punjab has 6 blocks. (Available from: <https://bathinda.nic.in/subdivision-blocks/>; last accessed 07/08/2024).

Community Health Workers: "Health workers who work in the community they live in but without any professional or para-professional certificated tertiary education." (WHO Study Group on Community Health Workers & World Health Organization. Strengthening the performance of community health workers in primary health care: report of a WHO Study Group [meeting held in Geneva from 2 to 9 December 1987], 1989. Available: <https://apps.who.int/iris/handle/10665/39568>).

Ration Card: "A document issued under an order or authority of the State Government for the purchase of essential commodities from the fair price shops under the Targeted Public Distribution System" (Available from: https://dfpd.gov.in/WriteReadData/Other/nfsa_1.pdf; Last accessed 13 Aug 2024).

Abbreviations

ANM	Auxiliary Nurse Midwives
ASHA	Accredited Social Health Activists
C3PaC	Comprehensive Coordinated Community based Palliative care for Cancer patients.
CBPC	Community-based Palliative Care.
CHO	Community Health Officer.
CSW	Community Sensitization Workshops.
CTRI	Clinical Trial Registry of India.
ESAS	Edmonton Symptom Assessment Scale (ESAS).
LMICS	Low-and middle-income countries.
MO	Medical officer.
NGO	Non-Government Organization.
NP-NCD	National Program for prevention and control of Non-Communicable Diseases.
NNPC	Neighbourhood Network in Palliative Care.
PAR	Participatory Action Research.
PC	Palliative Care.

QoL Quality of Life.
SPICT-4ALL Supportive and Palliative Care Indicators Tool.

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

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Availability of data and materials

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

Declarations

Ethics approval and consent to participate

The study was conducted in accordance with the declaration of Helsinki after obtaining permission from the All India Institute of Medical Sciences, Bathinda institutional ethics committee (IEC/AIIMS/BTI/157) and written informed consent from the participants or parents/legal guardians of the illiterate participants.

Consent for publication

Taken.

Competing interests

The authors declare no competing interests.

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