BMJ Open 3Ts of low cure rate: taxonomy, themes and theory of low cure rate in Pakistan's TB control programme and gathering a 360-degree perspective through qualitative, in-depth interviewing approach

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ABSTRACT

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Objective WHO recommends cure of tuberculosis (TB) as the best prevention strategy; however, information about factors associated with low cure rate in patients with drug-susceptible TB is limited in Pakistan. Therefore, the purpose of this study was to explore the factors that account for low TB cure rate. **Methodology** The present qualitative study recruited diverse informants through purposive sampling to explore low cure rate situation in Badin between March and June 2017. Data were collected from clinicians, paramedics, lab technicians, district field supervisors, patients and treatment supporters through indepth and face-to-face interviews. Interviews were conducted in local languages (Urdu and Sindhi) and transcribed into English. Coding structure was developed inductively and applied on textual data to draw output at the levels of taxonomy, themes and theory, as proposed by Bradley *et al.*

Findings Thirty-seven individuals consented to participate in this study and provided detailed account of the subject under enquiry. Review of interview data collected from a variety of informants resulted in the identification of four broad factors (taxonomy) that contributed to the situation of low cure rate in one of the districts implementing the public–private mix intervention. These factors were (1) health-seeking behaviour, (2) technical capacity of the healthcare provider, (3) managerial capacity of the healthcare provider, (3) managerial capacity of the healthcare provider, and (4) access to healthcare facility and services. Each factor is deconstructed into key dimensions (themes) that emerged from the dialogue between the interviewer and the respondents. Moreover, dimensions were exemplified through underlying concepts that correspond to theories for low cure rate.

Conclusion Change in programme reporting requirement has demeaned the significance of having cure as treatment outcome. Therefore, returning the focus to achieving cure status for TB cases will be beneficial for assessing the effectiveness of TB control efforts. In parallel to the care delivery system, a mechanism for disseminating disease-related and treatmentrelated information should be introduced.

INTRODUCTION

Data on treatment success rate, mentioned in the report of WHO, reveal treatment success rate of 83% for drug-susceptible tuberculosis (TB) (2015 cohort), 54% for

Strengths and limitations of this study

- Factors related to low cure rate of tuberculosis (TB) are never studied in Pakistan's National TB Control Program.
- The study recruited a variety of key informants to triangulate data sources.
- The study used the well-established Guba's four-criteria framework to enhance its trustworthiness.
- Because of the rigour of study design, findings of this study can be generalised to other similar settings within Pakistan's National TB Control Program where the public-private mix model is implemented.
- The study did not recruit those patients who completely followed the treatment protocols; hence, the study might have missed best practices and perspectives that have affected treatment outcome positively.

multidrug-resistant TB (MDR-TB; 2014 cohort) and 30% for extensively drug-resistant TB (2014 cohort).¹ However, treatment success rate consisted of cure and completion rates. It means that with increase in infection severity the chance of achieving successful treatment outcome reduces.² ³ Although treatment success rates have improved over the period, adherence to treatment protocols—appointments for medicine collection and sample submission for the follow-up smear microscopy—remained low.⁴

WHO considers cure of TB cases as the best prevention strategy because it prevents death, drug resistance, relapse and spread of TB in the community.⁵ Therefore, in 1993, WHO developed and adopted a strategy (called Directly Observed Treatment Short (DOTS) course) capable of addressing these issues effectively.⁶ During the past decade, Directly Observed Therapy (DOT—a method of patient supervision recommended by WHO)



has remained a subject of discussion to conclude whether DOT is associated with improved treatment outcome or not.⁷ The global literature reports opposing results; however, it was demonstrated that the highest success rates were attributed to the national programme, where DOT was implemented as full support package including components such as incentives and other patient-centred approaches.⁸⁹

WHO characterises effective national TB programme with a high cure rate, low incidence of acquired drug resistance and a high case detection rate. Cure, being an important constituent of the effective TB programme, is defined as 'a pulmonary TB patient with bacteriologically confirmed TB at the beginning of treatment who was smear- or culture-negative in the last month of treatment and on at least one previous occasion¹⁰. However, according to the operational definition of cure given by Pakistan's National TB Control Program, a patient is considered cure if he/ she has finished treatment with negative bacteriological result at the end of treatment.¹¹

Implementation of DOTS strategy uses patient-centred care and somebody observing the patient to know whether treatment timelines are followed or not. The DOTS strategy is also helpful in identifying a patient through sputum examination under the microscope, providing anti-TB drugs and monitoring treatment progress towards a cure.¹²

Information about factors associated with low cure rate in patients with drug-susceptible TB is limited in Pakistan. Therefore, the purpose of this study was to explore and describe the factors that account for low TB cure rate in the Badin district of Pakistan, as viewed by direct stakeholders involved in the care of patients, including themselves.

METHODOLOGY

Setting

The study was conducted in one of the 75 districts of Pakistan where the public-private mix (PPM) model was implemented by Mercy Corps. All the enrolled healthcare facilities (primary healthcare clinics and laboratories) are franchised and operated within one organisational structure. Healthcare services are delivered through a multidisciplinary team including clinicians (general practitioners (GP)), paramedics and laboratory technicians (LTs), with operational support from district field supervisors (DFS) at the field level.

Selection of district and healthcare facilities

Based on the review of programme data, the district of Badin was selected based on two factors: (1) number of registered TB cases and (2) treatment outcome (ie, treatment completed). For the year 2016, the total number of enrolled cases in the district of Badin was 106 and the cure rate (average 27%; range 17%–38%) was lower than the project average, that is, 46%. Other districts where cure rate was even lower than 27% were not selected because enrolments were few in number. This information led the research team to select the district of Badin for this qualitative study. However, private healthcare facilities were uniquely selected for participation as they were trained on WHO's DOTS strategy and have been working in PPM intervention.

Study design

Qualitative research was employed for this study as it is suited for understanding phenomena within the context.¹³ Indepth and semistructured interviewing was used as a method of qualitative research.

Overall study approach, including method, sampling, recruitment, data collection, analysis and reporting, was guided by Guba's construct, which includes four criteria for a trustworthy study.¹⁴ We adhered to various strategies proposed for each criterion (credibility, transferability, dependability and confirmability) to enhance the trust-worthiness of the study.

Population and sampling

Purposive sampling was used to select both the participating district and the participants. Between March and June 2017, records of all registered TB cases-whose treatment outcomes were declared between October and December 2016-were retrieved, and patients were contacted using the given contact details (mobile number and/or home address). For the selected period, 19 cases had pulmonary bacteriologically confirmed TB (Bac +ve) out of a total of 36 cases that also included pulmonary clinically diagnosed TB (Bac -ve) and extrapulmonary (EP) TB cases. Bac -ve and EP cases were not included in the study because 'Cure' status is not associated with them. Once TB cases were identified, all care stakeholders (clinicians, paramedics, LTs, DFS and treatment supporter) involved in the care of TB cases were invited to participate in the study. The sample included a cohort of patients-of those whose results are declared in October-December 2016-and their care stakeholders. However, theoretical saturation was achieved even before the desired sample size was achieved. Therefore, sample size was not affected by theoretical saturation and final coding structure was used to analyse all transcripts.

Sixty-three respondents were planned to be interviewed, but 37 interviews were actually executed. Twenty-six respondents either were not available for interview or their contact details were incorrect (see table 1). Among 19 planned interviews for patients, 3 persons died, 8 persons were not found or not available, and 8 persons were successfully interviewed (2 of them were on treatment for MDR-TB). Those patients whose treatment outcome was declared as *cured* were not selected. Interviews were conducted with a variety of respondents, based on their role in patients' care, to ensure triangulation via data sources as urged by Van Maanen.¹⁵ This type of triangulation is helpful in constructing a complete picture of the phenomenon under study by verifying individuals' perspective and opinion with others.

Table 1 Sample distribution

Respondent type	Planned interviews	Executed interviews
Smear-positive pulmonary tuberculosis cases	19	8
Treatment supporter	19	7
Clinician (general practitioner)	10	10
Paramedic	10	8
Laboratory technician	3	2
District field supervisor	2	2
Total	63	37

Data collection

A semistructured interview guide was developed for a variety of respondents after review of relevant literature. In addition to the key questions, the interview guide included a range of supplementary questions to steer the interview and allow a respondent-led and flexible data collection. Face-to-face interviews were conducted by two trained researchers (MI and SA) in local languages (Urdu and Sindhi). During the data collection process, the interview guide was modified whenever a new code emerged.

Given consent, interviews were audio-recorded in local language and later transcribed into English language. Respondents were coded using a combination of alphabets and numbers, and the interview recordings were anonymised using similar coding system to ensure confidentiality of information.

Data quality assurance

After all interviews were taped and transcribed, two researchers (SMA and SH) randomly picked random points in each of the recorded interviews and checked the quality with its corresponding transcript, independently. Any discrepancy between quality assurers was resolved through discussion and adjudication by another researcher (NA). After all transcribed interviews have been verified, the researchers (SMA, SH, MI, NA, FN and AN) started the analysis.

Data analysis

The focus of qualitative data analysis was to draw output at the levels of taxonomy, themes and theory referred as 3Ts. This approach to analysis is helpful in developing insight into how context of an event might influence the different health outcomes.¹⁶ Using constant comparison method,¹⁷ a code structure is developed inductively. An inductive approach was used for the development of coding structure and data analysis as suggested by grounded theory. Because it is an iterative and lengthy process, new codes were added to the coding structure and the interview guide was modified accordingly.

A line-by-line review was carried out to develop and revise the coding structure, and two researchers (SMA and SH) independently coded each transcript, tagging parts of data with relevant codes. During data collection process, the researchers met periodically to compare text segment to segment to ascertain if code was assigned appropriately. Transcripts were read several times to ensure that the final code structure is consistently applied to all textual data. In case of any discrepancy, differences were resolved through discussion and negotiated consensus.

The application of the finalised code structure to the data resulted in identification of codes and subcodes suitable for taxonomy (domain) and theme (dimension), respectively. Domains are the broad factors that characterise low cure rate situation in one of the districts implementing the PPM model. However, various dimensions of the domain further elaborated its meanings in a specific context. Similarly, theory is an example of concept underlying the dimension or theme, providing systematic reasons for the events and experiences. However, the process of theorising matter of enquiry includes the subject, the context and the experience of the researcher.¹⁶ We also selected verbatim quotations from the transcribed data and edited the quotes to improve readability.

Patient and public involvement

Perspectives of healthcare providers and patients on access to services and treatment adherence were routinely collected during monitoring visits and were used to develop the research question and interview guides. None of the potential respondents were involved in the design of the study and in recruiting them. Findings of the study will be disseminated during coordination and progress review meetings held at the district, province and national levels.

FINDINGS

Overview of respondents

Eight individuals who completed TB treatment on medical records and 29 care stakeholders (treatment supporter, doctor, paramedic, LT and DFS) were interviewed face to face.

Factors contributing to low cure rate

Review of interview data collected from a variety of informants resulted in the identification of four broad factors (taxonomy) that contributed to the situation of low cure rate in one of the districts implementing PPM intervention. These factors were (1) health-seeking behaviour, (2) technical capacity of the healthcare provider, (3) managerial capacity of the healthcare provider, and (4) access to healthcare facility and services. Each factor is deconstructed into key dimensions (themes) that emerged from the dialogue between the interviewer and the respondents. Moreover, dimensions were exemplified through underlying concepts that correspond to theories for low cure rate (see table 2).

Table 2 Classification of factors affecting low cure rate among patients with TB			
Factors (taxonomy)	Dimensions (themes)	Concepts (theory)	
Health-seeking behaviour	Patient education.	General TB awareness. Role of formal education. Warn about consequences of non-compliance. Achievement of treatment milestone.	
	Relationship with healthcare provider and care stakeholder.	Providing adequate counselling. Defining responsibility for counselling.	
	Compliance to treatment protocol.	Side effects of medicine. Patient's perception about completion of treatment. Regular follow-up. Guidance on sputum production. Availability of free treatment. Availability of services at cost.	
	Objectives of DOTS.	Knowledge about DOTS strategy. Identification of treatment supporter.	
Technical capacity of healthcare providers	Guidance on sputum production.	Addressing sputum production issue.	
	Final sputum smear microscopy.	Significance of final sputum smear microscopy. Quality of sputum smear microscopy.	
Managerial capacity of healthcare providers	Availability of resources (time and cost).	Counsel patient on significance of SSM. Providing guidance on sputum production. Tracing non-adhering patients.	
	Treatment-related information.	Ensuring final sputum smear microscopy. Managing patient stress and counselling.	
Access to healthcare facility and services	Transportation.	Travel time and cost.	
	Timely uptake of service.	Long waiting time to service or appointment. Examination of patient record. Role of treatment supporter.	
	Contextual factors.	Work responsibilities of the patient. Contacting through community members/elders.	

DOTS, Directly Observed Treatment Short course; SSM, sputum smear microscopy; TB, tuberculosis.

Health-seeking behaviour

TB is one of the health conditions that are to be investigated beyond typical biomedical model of disease, which includes health-seeking behaviour. Therefore, experts suggested exploration of the social aspects of patients that are affecting their health condition. The respondents elaborated patients' health-seeking behaviour in regard to patient education, relationship with healthcare provider (and care stakeholder) and compliance to treatment protocol.

Most of the respondents (especially care providers) attributed poor health-seeking behaviour to lack of general TB awareness and emphasised inclusion of ways to raise awareness in general communities. One of the GPs said:

Most of the patients are illiterate and they also lack TB awareness...and they don't visit us because they are given awareness about TB services, they actually visit us because of their prolonged disease and deteriorating health condition.

Most of the GPs, along with DFS, warned patients and their treatment supporters about the consequences if they do not comply to treatment guidelines. Similarly, clinics' paramedic staff along with DFS guided patients on important treatment milestones that are associated with treatment success. Nonetheless, care providers (either GP or paramedic) provided incomplete information to sensitise patients for treatment adherence. However, five out of eight patients stated that they were told when to visit again for medicine collection and sputum smear microscopy, whereas none reported that their GP advised them to visit for sputum smear microscopy at the completion of treatment. One stated that:

If I can take regular medicine for 6 months upon doctor's advice, why will I not consider his advice of final sputum smear microscopy...I was not told, so I didn't visit lab upon completion of my treatment.

Almost all of the care stakeholders (including GP, paramedic, DFS and LT) gave immense value to "provider's relationship with patient" in shaping appropriate health-seeking behaviour. A doctor from the district of Badin said:

...as compared to public hospital, patients do not have to wait longer and they are given proper time for consultation, ... so they establish good relationship with us by virtue of our ability to provide sufficient details relevant to their care...as we have time to do so. Few of the care providers (GP and paramedic) mentioned "availability of free treatment" as promoting factor; however, four of the care providers recommended provision of services at cost and one GP explained it as below:

Because of free treatment services, patient do not appreciate this, so they do not follow recommended guidelines.

Another GP said:

In interior part of the province, some people have different mindset and they underrate GPs because they do not charge as high as a consultant does.

Few of the care providers mentioned "side effects of medicine" as inhibiting factor in regard to patients' compliance to treatment protocol. Almost all of the GPs have identified "patient's perception about completion of treatment" as the main challenge to ensuring compliance. This happens because symptoms of the disease start to subside and patients tend to stop treatment. To tackle this challenge, almost all of the care providers (GP, paramedic, LT) and DFS emphasised the importance of regular follow-up to ensure positive health outcome, including cure status. One GP said that:

to keep patient motivated and committed to treatment protocol, I generally advise patient to keep treatment card, because at the end of your treatment it will serve the purpose of certificate for declaring you a TB free person.

One patient explained his treatment experience as below:

treatment of TB is very difficult...sometimes I needed support and information about medicine, diet and precautions...I always received such information from people around me because doctor never gave me any information as he was always short of time.

Technical capacity of healthcare providers

Formal engagement of private healthcare providers (GP, paramedic, LT) is associated with their ability to provide standardised TB care and prevention services. As a prerequisite to providing TB services, all healthcare providers were provided training on how to detect and manage TB cases. Therefore, technical capacity involved knowledge and practice about effective TB case management in a coordinated manner, where clinics operated collaboratively with the diagnostic laboratory.

DOTS courses is WHO's recommended strategy for TB prevention and care; however, there were very few providers who were aware of the details of strategy. Most of the providers understood DOTS wrongly, hence could not give due consideration to the role of treatment supporter. In addition, they also found it difficult to identify treatment supporter. One of the GPs explained this difficulty as below: DOTS is an effective strategy of case management and it demands community's involvement in the care of the patient, however community does not appreciate this support...there are very few who are willing to provide details of the treatment supporter.

Almost all of the care providers (GP, paramedic, LT) highlighted the significance of final sputum smear microscopy, and explained that if the final test is not ensured then TB prevention and care efforts will remain compromised. At the same time, few of the GPs doubted the quality of sputum smear microscopy and indicated training need of LTs. On the contrary, LTs have discussed the issue of poor quality of sputum samples which are collected at the clinic. One LT commented on the mechanism of sputum collection as below:

...mechanism of the sputum collection should be carefully reviewed. Initially, sputum cups were placed at lab and patients used to come to lab for sample submission. This gave us opportunity to resample sputum if quality of sample was poor. I used to guide patients about how to produce sputum and why it is important to provide correct sample. Afterwards, when sputum samples were started collecting at doctor's clinic, we missed control over the quality of sample, and we started receiving saliva instead of sputum.

Half of the GPs said that they were able to address the issue of sputum production by providing local remedies, for example, advising some syrup or sachet and advising water steam in the morning, whereas others did not know any intervention if patients complained about an issue with sputum production.

Managerial capacity of healthcare providers

The private healthcare sector constitutes a major proportion of the healthcare system in Pakistan. It means majority of the population prefers to seek healthcare assistance from the private sector, hence increasing their case load and work burden. Due to these challenges, the quality of service has been badly affected and it has become part of recent discussions.

Availability of resources (time and cost) is consistently reported to be a limiting factor for all of the participating GPs; however, only one GP said that:

...despite the fact that I have limited time, I try to counsel each of the TB patients as it is critically important to counsel patient on the significance of the regular medicine intake and regular follow-up tests.

GPs have also shared their limitation in *tracing non-adhering patients* because of time shortage and limited resources. Therefore, most of them have given this responsibility to DFS, especially for those whose contact details are incorrect. Few of them have empathised focus on patients and acknowledged their need for psychosocial support, hence proved helpful in *managing patient stress through counselling*. On the contrary, one GP has

found a different way of *ensuring final sputum smear micros-copy*. He said:

...at first I ask community members, to which patient belong, to provide us support in making sure that patient complete his treatment. In case if this does not work, then I threat patient that he will be handed over to police if he does not come for medicine collection and for final sputum smear microscopy.

Data analysis showed that paramedics of clinics are relatively more active in counselling patients and providing *treatment-related information* than GPs (clinicians). However, they are also becoming a source of disseminating wrong or stigmatising information, such as separating utensils of patients with TB and avoiding sexual intercourse.

Access to healthcare facility and services

Challenges pertinent to healthcare access constituted the last factor of the low cure rate situation. *Transportation, timely uptake of services* and other *contextual factors* were identified to determine patients' access to healthcare facility and services. Nearly half of the healthcare providers (GP, paramedic, LT) mentioned *transportation* as a concern for having easy access to services because it involves *long travel time and high transportation cost*, which are limiting factors for most of the patients with TB. One of the LTs suggested that:

Generally, patients are poor and come from remote areas that involves time and cost...if financial support is given to patient then they may visit to submit sputum for microscopy at the end of treatment.

One of the patients said:

...living in poverty is very challenging as it keeps changing our priorities...mostly in taking care of my family, I forget that keeping good health is also important...if I take leave from work then how will I feed my family.

Both of the DFSs and few of the GPs mentioned their practice of reviewing patient record regularly to make sure that patients are visiting healthcare facility on time for the uptake of services. They have also identified the importance of treatment supporters' role in the same regard. However, none of the patients have mentioned that they were contacted during their treatment period for any purpose, including a reminder for follow-up visit or for final evaluation.

Most of the patients have not mentioned any constraints regarding their access to healthcare facility and services, whereas few of the patients and treatment supporters have mentioned long waiting time at the facility and long distance as concerns. One of the LTs described long waiting time as below:

There are special circumstances when patient has to wait longer, for example, sputum smear microscopy for diagnosis is challenging in terms of letting patient wait in lab for second sputum or asking him to visit again for submission of morning sample.

A patient with TB said:

I prefer to visit private clinic because of less waiting time as compared to government hospital...but now it is becoming increasingly difficult to access timely health services at private clinics too.

A couple of GPs are specific in their practice of identifying male treatment supporter so that when the patient is unavailable he should be able to visit the clinic for medicine collection. For example, if the patient is unable to leave his *work responsibilities*, a male treatment supporter can visit the clinic to collect medicine on his behalf. Keeping in mind social structure and prevailing culture, GPs also engaged elders from the community who could help the patient in complying to the treatment protocol.

DISCUSSION

Although the overall treatment success rate meets the minimum requirement for success rate, there are relatively fewer bacteriologically confirmed TB cases who receive cure status by appearing for final sputum smear microscopy at the end of treatment. Qualitative analysis of interview data reveals lack of information or awareness, high treatment-related cost, poor referral system, and insufficient case management as the main reasons for low cure rate, that is, fewer people are appearing for final sputum smear microscopy.

Triangulation of patient interviews with care provider interviews revealed inconsistency in responses, such as care providers reporting regular follow-up of cases, whereas TB cases or their treatment supporter reported that they were not followed during the course of the treatment. However, inability of care providers to follow every TB case is mentioned, which supports the assumption that follow-up of patients for ensuring final sputum smear microscopy was not rigorously conducted and only followed in situations of convenience. Conclusively, a weak system for coordinating patient care can potentially lead to fewer patients appearing at the final evaluation. Similar challenge is also reported by Dong et al,¹⁸ Edington and Hodkinson,¹⁹ and Maswanganyi et al.²⁰ With change in reporting requirement by WHO, coupled with an inadequacy in programmatic efforts, the focus shifted from 'cure' to 'treatment completed', and final evaluations started to be under-rated.

False perception of patients about the treatment completion poses serious challenge in ensuring treatment completion with the desired outcome. This perception shapes poor health-seeking behaviour of patients with TB, and further strengthened if care providers do not spend enough time on counselling or sharing treatment-related information. Hence, patient education and support are detrimental to achieving desired outcome or cure.²¹ Moreover, in an absence of proper system for

information sharing between patients and healthcare providers, it withdraws an opportunity from patients to remain informed about their treatment progress during the care process.²² The health belief model, proposed by Akinsola,²³ also observes that individuals do not change their behaviour if they do not realise that they are at risk and they can face serious consequences.

Although treatment is provided free of cost in the PPM intervention to promote adherence, there are other treatment-related costs (eg, transportation and food costs) in addition to emotional exhaustiveness that badly affect treatment adherence and treatment outcome.^{24,25} People's seriousness about consequences is dependent on the extent to which they believe they are at risk of developing serious consequences.²³ Non-adherence or treatment interruption is attributed to non-cure status, where side effects of medicine also become one reason.²¹

Hence, it is pragmatic to include important elements in a programme that will allow implementation agencies to view the programme beyond the biomedical model of the disease, especially where a particular disease is embedded in social ties and has social connotations. With constant efforts on new models of finding cases, expanded case finding approaches are rationally appropriate only if high cure rate is achieved in any TB programme. In cases where low cure rate is reported, intensified case findings can produce negative results, for example, increasing the pool of inadequately treated patients with TB and increasing incidence of drug-resistant cases.²⁶

Our study used Guba's construct to enhance its trustworthiness and implemented several strategies in this regard; however, it is not free from methodological weaknesses, and one of them is triangulation in informants' type. For example, bacteriologically confirmed TB cases who followed the treatment protocols completely were not recruited; hence, an opportunity to know patients' experiences and perspectives was missed. The response rate for patients was poor (42%); hence, their experience or perspective is inadequately presented, and this can be considered a limitation of the study. In addition, we could not reconnect with participants to validate the interpretation of the study due to stigmatisation of the TB disease in Pakistan. Lastly, with limited provision of background information due to lack of research focus on this aspect, we struggled to establish the context of the study and detailed description of the existing phenomenon.

CONCLUSION

Change in programme reporting requirement has demeaned the significance of having cure as treatment outcome; however, reversal of the change can revitalise the significance of cure status for bacteriologically confirmed TB cases. Such efforts are important to curtail relapse, death and emergence of drug-resistant TB. Even before the reversal of this change happens, implementation agencies should play their role in ensuring effective programme management by monitoring regular follow-up, especially final sputum smear microscopy, to achieve cure as treatment outcome.

Meaningful engagement of the private sector is critically important especially under the circumstances when the private sector is unregularised. Busy private practice leaves GPs with limited time; hence, time spent on consultation and counselling remains insufficient. This, along with other factors, shapes poor health-seeking behaviour and beliefs of patients and their caregivers. The need for disease-related and treatment-related information has emerged as a serious concern and should be given due consideration.

Contributors SMA, NA, FN and AN identified the problem and prepared the research design. SMA, SH and AR thoroughly reviewed the literature and developed the interview guide. MI and SA conducted the interviews and transcribed the data in English. SMA, SH, AR, MI and SA regularly met during the data collection process and kept updating the interview guide. SMA and SH developed the coding structure, and NA, FN and AR checked the coding structure for its alignment with the data. SMA prepared the initial draft of the manuscript, and all authors contributed to the final manuscript.

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Competing interests None declared.

Patient consent for publication Obtained.

Ethics approval The purpose of the study was explained to all participants, and oral consent for voluntary participation was sought prior to face-to-face interview. All respondents were given the option to quit the interview in between without explaining the reason for quitting. The ethical approval was provided by the ethical review board of Health Oriented Preventive Education (HOPE), which is recognised by the US Department of Health and Human Services Office for Human Research Protection (OHRP).

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement Transcripts of interviews are stored in a passwordprotected computer, which is only accessible to the Monitoring, Evaluation and Learning Unit of Mercy Corps.

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