

Is the unrealistic expectation of getting cured related to poor treatment adherence among Indian Asthma patients? A hospital based mixed methods study from central India

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ABSTRACT

Background: Prevention of premature deaths due to asthma requires continued disease control through efforts of both patients and healthcare providers. The expectations of patients have been shown to influence treatment adherence and disease control. **Methodology:** We conducted a hospital-based sequential exploratory mixed methods study and used definitions of the Global Initiative for Prevention of Asthma (GINA). We recruited 80 asthma patients in a tertiary public health facility of central India. We assessed treatment expectations, health literacy, awareness, behavioural risk factors, self-care, treatment adherence, and disease control. We conducted a thematic analysis of qualitative data through manual inductive coding and used statistical software R version-3.6.1 for quantitative analysis. **Results:** Sixty-seven (83.75%) patients expected that the current doctor would help them achieve 'cure', while 28 (35%) expected to obtain information about asthma. 81.2% and 77.5% of participants had inadequate health literacy and inadequate awareness, respectively. 73.8% were using inhalers and 21.2% were not using any treatment. Forced expiratory volume in 1 (FEV1) and Forced vital capacity (FVC) values were available for only 46.25%, while a meagre 6.25% were using peak-flow meter for self-monitoring. Though 21.2% reported optimal treatment adherence, 27.5% had good control. We found the expectation of cure and poor health literacy being significantly related to sub-optimal treatment adherence. We didn't find any association between the expectations of patients and their disease control. **Conclusion:** Asthma patients in our setting mostly expected to get cured. The unrealistic expectation of 'cure' is related to poor treatment adherence and possibly poor disease control.

Keywords: Asthma, cross-sectional study, health literacy, NVS, primary care, treatment adherence, treatment expectations

Introduction

Asthma is one of the most common diseases encountered in primary care or general practice around the world. Along with

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Chronic Obstructive Pulmonary Disease (COPD), it contributes to approximately 10.7% (i.e. 4 million) of annual global deaths. Three hundred thirty-four million people are estimated globally to be suffering from asthma.^[1] An additional 100 million new cases will be added by the year 2025. Approximately 14%, 4.5%, and 8.6% of children, young adults, and adults (aged 18–45 years) respectively experience asthma symptoms every year globally. Children aged 10–14 years and elderly aged 75–79 years are the most vulnerable groups.^[1] It is estimated that nearly 1.2–2.5%

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of total deaths and 0.9–1.6% of total disability adjusted life years (DALYs) in India is contributed by asthma.^[2,3] It is responsible for 20% of chronic respiratory diseases' DALYs in India. The prevalence of asthma in India has been reported to be nearly 2%.^[4] Unlike other NCDs, asthma or COPD has not been included in the National Programme for Control of Cancers, Diabetes, Cardiovascular Disease, and Stroke; the NCD programme of India started in 2011.^[5]

The optimal treatment for asthma is inhaled bronchodilators and corticosteroids. Since asthma is a chronic disease, the treatment has to be given for a long duration and usually lifelong. Optimal management strategy includes self-care through monitoring with peak flow meter and written action plans. But availability and affordability of the recommended treatment is often an issue.^[6,7] This increases the pool of asthma patients who are either treated with toxic medicines or not treated at all. In both the scenarios, the risk of preventable premature deaths and disability increases. This is in contravention to national NCD targets, which strives to reduce 25% of premature death due to NCDs among adults aged 30 to 70 years.^[8]

Medical advancements in the form of a better understanding of the pathophysiology of asthma; availability of better and more efficacious drugs; is underscored by poor asthma control among Indian patients. According to a multicentric study, nearly half of the Indian asthmatics have 3–10 exacerbations per year, one-fifth have more than 11 exacerbations per year, and 7% need intensive care.^[9] The majority believe wrongly to have either well-controlled (29%) or reasonably controlled (60%) asthma, in spite of 40% found to have uncontrolled asthma.^[9] Poor asthma outcomes in India could be due to both physician-related as well as patient-related factors. In general, physicians in India seem to lack adequate knowledge and skills about asthma diagnosis, management, communication skills, and follow-up.^[9-11] Clinical communication skills form a vital component of an asthma management plan because most patients have myths and misconceptions associated with asthma. Other factors include socio-demographic factors (socioeconomic status, education, residence, caste, etc.), personal factors (smoking, obesity, heredity, etc.), environmental factors (indoor and outdoor air pollution, weather, other triggers), treatment practices (poor adherence, self-treatment) health system factors (accessibility/affordability/acceptability of trained health providers, etc.), health literacy level, various realistic and unrealistic expectations of patients, influence medication adherence and disease control, quality of life, cost of care, premature mortality, etc.^[12,13] Adults having asthma are more prone to various psychological stresses like depression and anxiety, which indirectly impact their adherence to the treatment.^[14] Hence, the management of asthma relies not only on clinical therapeutics but also on collaboration among physicians and patients.^[15] The continued and comprehensive whole-person care principles of family medicine, which is often practiced in primary healthcare settings (both public and private), have been shown to improve trust in physicians and improve health status.

In the background of low doctor-patient ratio in general and presence of trained health providers for the management of asthma in particular in India, it becomes imperative to empower the asthma patients in skills of self-care through the provision of asthma action plans and self-monitoring of peak-flow.^[16] There is a scarcity of studies at the national-level as well as in states like Madhya Pradesh on patient-centred outcomes in asthma care, including treatment expectation, quality of life, self-enablement, self-care, asthma-related health literacy, and awareness. Exploration of levels and predictors of self-efficacy of patients in self-care and treatment expectations may be used to identify patients to enrol in hospital-based or community-based asthma self-care programmes.

Considering these gaps, we intended to explore and quantify treatment expectations of adult bronchial asthma patients and their relatives. We also assessed the general and asthma-related health literacy levels, adherence to treatment, control status, self-care using cheap and easy peak flow measurement techniques, which can be better monitored in primary care settings of both public and private general practitioners. We tried to identify the association between treatment expectations and treatment adherence, status of disease control, health literacy, and other socio-economic determinants.

Materials and Methods

The study was conducted in the setting of a tertiary care public hospital in central India. In this hospital, the department of Community & Family Medicine (CFM), general medicine, and Pulmonary Medicine provided ambulatory care to bronchial asthma patients through their Outpatient departments (OPDs). While CFM and general medicine departments provided OPD services on all working days, the Pulmonary Medicine department did so twice a week during the study period. Total OPD footfall in the hospital was approximately 2500–3000 during the study period with approximate daily OPD visits of 150–250 and 250–350 in CFM and medicine departments, respectively. The Pulmonary Medicine department had a footfall of 100 every week. The study was approved by the Institutional Human Ethics Committee (IHEC) of the institute.

We included diagnosed adult asthma patients aged 18 years and above without any other previous or current self-reported co-existing chronic respiratory disease. Participants were considered to be having a diagnosis of asthma if they had a written record of spirometry testing showing low FEV1 with reduced FEV1/FVC <0.8, and increase in FEV1 of >12% and 200 mL after inhaling a bronchodilator, or written record of >10% of average daily diurnal variability of Peak Expiratory Flow (PEF) measured using a standard Peak flow meter over 2–3 weeks, or FEV1 increases by >12% and 200 mL from baseline after four weeks of anti-inflammatory treatment (outside respiratory infections); or written record of diagnosis mentioned in case sheet/health record by a pulmonologist or internist.^[1,17,18] We measured treatment adherence in the number of days the

patient consumed the prescribed treatment in the last 15 days. We defined asthma as well-controlled, partially controlled, or uncontrolled using GINA guidelines.^[1] We measured health literacy using Newest Vital Sign (NVS) scale.^[19]

We used a sequential exploratory mixed methods design for our study. We used a phenomenological approach to identify themes related to expectations among adult bronchial asthma patients. We conducted In-depth Interviews (IDIs) with these participants in either English or Hindi till saturation of themes was obtained. We achieved saturation of themes by enrolling six patients and their relatives. We conducted five interviews in Hindi and one in English. The IDIs were audio-recorded, transcribed in a word-processor document manually, and then translated into English. We used thematic content analysis and used inductive coding to identify themes to revise our study tools for the cross-sectional quantitative phase. The tool had sections to capture personal identifiers, socio-demographic determinants, treatment expectations, general health literacy, asthma-related awareness, treatment history, treatment adherence, and disease control status, etc., For the cross-sectional survey, we anticipated 36% of participants to report cure as their expectation as reported in another study.^[12] At a 95% confidence limit, for 20% relative precision and 20% anticipated non-response rate, we required to recruit 205 participants using sample size calculation formula for proportion in the online platform OpenEpi.^[20] We collected data through an open-source mobile-based Open Data Kit (ODK) platform KoboToolbox.^[21]

We collected data between June and September 2018. We exported the survey data collected on KoboToolbox into Microsoft Excel 2016 and analysed it through the open-source statistical package R version 3.6.3.

Results

We could approach a total of 159 participants (45 from the CFM and 114 from Pulmonary Medicine OPD). Among these, 124 participants had confirmed diagnosis of asthma (all 45 from CFM and 79 from Pulmonary Medicine). We could enrol 80 participants (5 from CFM and 75 from Pulmonary Medicine) due to non-response and refusal. The mean age of the study participants was 41.7 ± 16.28 years with equal gender distribution (41 females and 39 males). The majority of the participants (93.75%) had some form of formal education, with mean years of schooling reported as 12.9 ± 5.0 years. The median monthly family income was 25,000 rupees (with an interquartile range of 35,500) [Table 1]. The majority of the study participants were married (72.5%), and almost all (95%) belonged to the Hindu religion. The majority of the participants (75, 93.75%) had high standards of living according to the Standards of Living Index [Table 2]. Only three individuals (3.8%) reported current daily smoking and consumption of alcohol.

When asked about the expectations for asthma treatment, 64 (80%) of the study participants stated that they wanted “full

relief”, while the rest wanted “control of symptoms” [Table 2]. The majority (38, 47.5%) reported “no relief”, while 12 (15%), two (2.5%), 27 (33.8%) and one (1.2%) reported “less relief”, “very less relief”, “much relief”, and “very much relief” due to the previous treatment. Regarding expectations from their current doctors, 67 (83.75%) participants expected “to get fully cured”, 28 (35%) expected information regarding asthma, 3 (3.8%) expected moral support, and 4 (5%) did not have any expectations.

We found that only 15 (18.8%) participants had adequate health literacy, i.e., scored >4 on the Newest Vital Sign (NVS) scale for health literacy, while 22.5% of participants had adequate awareness [Table 2]. The cut off for adequacy of awareness was set at 50% of the maximum possible score obtained from the awareness questionnaire. Table 3 shows that individuals with higher treatment expectations (“full relief”) had inadequate health literacy (OR = 8.64, 95% CI 2.51-31.64). This association

Table 1: Characteristics of the study participants (n=80)

Parameter	Frequency (n) (%)
Marital Status	
Married	58 (72.5)
Unmarried	22 (27.5)
Religion	
Hindu	76 (95.0)
Muslim	4 (5.0)
Caste	
General	54 (67.5)
Backward Caste	13 (16.2)
Scheduled Caste	8 (10.0)
Scheduled Tribe	4 (5.0)
Don't want to reveal	1 (1.2)
Years of Schooling (mean, SD)	12.9±5.0
Monthly Income in INR (Median, IQR)	25000 (10000-45500)

Table 2: Distribution of study outcomes among participants (treatment expectations, health literacy, awareness, and treatment adherence) (n=80)

Parameter	Frequency (n) (%)
Expectations	
Full relief	64 (80.0)
Control of Symptoms	16 (20.0)
Health Literacy	
Adequate (>4)	15 (18.8)
Inadequate (<5)	65 (81.2)
Awareness	
Adequate ($>50\%$)	18 (22.5)
Inadequate ($<50\%$)	62 (77.5)
Adherence	
100% Adherence	17 (21.2)
75% Adherence	37 (46.2)
50% Adherence	51 (63.7)
25% Adherence	60 (75.0)
$<25\%$ Adherence	20 (25.0)
0% Adherence	16 (20.0)

Table 3: Association of patient expectation with health literacy, disease control status, and treatment adherence amongst study participants (n=80)

Parameter	Expectations		Chi-Sq*	P
	High (n=64)	Low (n=16)		
Health Literacy				
Inadequate	56 (86.2)	9 (13.8)	6.28	0.012
Adequate	8 (53.3)	7 (46.7)		
Status of Control				
Good Control	17 (77.3)	5 (22.7)	1.521	0.467
Fair Control	16 (80.0)	4 (20.0)		
Poor Control	31 (81.6)	7 (18.4)		
Treatment Adherence				
100% Adherence	15 (88.2)	2 (11.8)	0.378	0.539
75% Adherence	28 (75.7)	9 (24.3)	0.381	0.538
50% Adherence	41 (80.3)	10 (19.7)	0.001	1
25% Adherence	48 (80.0)	12 (20.0)	0.001	1
<25% Adherence	16 (80.0)	4 (20.0)	0.001	1
0% Adherence	14 (87.5)	2 (12.5)	0.239	0.625

Figures in round parentheses represent row-wise percentages. *Chi-square test, Fischer's Exact test

was statistically significant with a Chi-square value of 6.28 and a *P* value of 0.012.

Regarding the use of medication for asthma, it was found that the majority of the individuals used inhalers/pumps (73.8%), followed by tablets/capsules (35%). Seventeen individuals (21.2%) reported not taking any medication for their condition. The mean treatment adherence in the past 15 days was 8.8 days (SD 5.7), while the median was ten days [Table 2]. The median percentage of adherence was estimated to be 67%. A total of 17 (21.2%), 51 (63.7%), 20 (25%), and 16 (20%) had treatment adherence of 100%, at least 50%, <25% and zero in the last 15 days [Table 2]. It was found that individuals with higher expectations had less adherence to treatment as compared to those who had lower expectations (median adherence percentage 63% vs. 80%). However, this difference was not statistically significant. Only 22 (27.5%) participants had good control of asthma, while 20 (25%) had fair control and 38 (47.5%) had poor control using the GINA guidelines. Further analysis of the socio-demographic with variables such as expectations, health literacy, asthma status, and treatment adherence did not reveal any statistically significant association.

Discussion

Our study showed that the majority of the patients expected full relief with the treatment and expected that the doctor would cure the disease. A study in urban Delhi reported that 60% of patients believed that asthma cannot be cured.^[11] In this study, 60% of the participants were informed about their disease. This study didn't report on the expectations of patients from their doctors. In America, Australia, and Europe, studies have been conducted to explore patient expectation and its relation to various asthma-related clinical outcomes.^[12,15,22] In our study, the participants having expectations of cure were more likely to

have poor treatment adherence similar to these studies conducted in Europe, America, and Australia. Such unrealistic expectation also leads to a higher rate of hospitalization, poor continuity of care, severe disease status, and wrong perception of disease control.^[12,13] Nearly half of our participants were not satisfied with the prescription provided by their previous healthcare provider. Healthcare provider switch or doctor shopping is quite common in India.^[23,24] The concept of continuity of care is not prevalent due to a mixed healthcare delivery system consisting of public health facilities, private providers (for-profit and not-for-profit), rampant self-treatment through pharmacy shops, informal health providers (quacks), and faith healers.^[25] Unrealistic expectations may lead to a repeated change of doctors and poor disease control status. Since asthma is a chronic disease, the expectation of a cure is unrealistic, and patients and/or relatives should be communicated appropriately. Communication skills such as breaking bad news and risk communication can be used by the physician who diagnoses the disease in a patient for the first time. This requires strict implementation of medical curriculum on communication training in India. On the contrary, if these patients had consulted a family physician or general primary care provider, then continuity of healthcare is more likely, as is the focus of family medicine.

In our study, it was found that only 18.8% of the participants had adequate health literacy measured using the NVS scale. We believe that our study is the first to report health literacy among asthma patients since we could find similar published articles on PubMed and google scholar. Health literacy as an outcome measure has recently gained importance as it can be objectively measured, and improvements can be assessed.^[26] Newest Vital Sign (NVS) is one of the most commonly used tools for the measurement of health literacy.^[19] We have validated this tool in Hindi and are reporting this process in a separate paper. In our study, 22.5% of the participants had adequate awareness regarding asthma. Similar poor awareness has been reported in various studies in the last two decades.^[11,27,28] General practitioners or family physicians are more likely to indulge patients with toned-down messages more suited to their understanding. Focus on family practice models in India would help in improving health communication.

Regarding the use of medication for asthma, we found that the majority of our study participants (73.8%) used inhalers/pumps, followed by tablets/capsules (35%), while 21.2% were not taking any medication for their condition. It is contrary to the findings of previous studies, where authors have reported tablets/capsules as the most common type of medication. In a multicentric Indian study, most of the asthmatics were using oral medication.^[29] Another study conducted in Pune city reported that less than 50% of doctors prescribe inhalers solely.^[30] Since our study was conducted in a tertiary care academic hospital, the clinicians here prescribe mostly inhalers as per GINA guidelines, which might explain the difference. But even for family physicians and general practitioners, it is prudent to rely on the use of inhalers which are more efficacious and safer.

Median treatment adherence was reported to be 67% in our study. In our study, 21.2%, 63.7%, 25%, and 20% of participants reported treatment adherence of 100%, at least 50%, < 25%, and zero respectively in the last 15 days. This is consistent with previous studies which have reported poor adherence to treatment by asthmatics. Rastogi *et al.*^[28] reported that only 9% of asthma patients were on controller medication, while another study reported 68% of patients to be non-adherent. Cost of treatment and satisfaction with the prescription can be major drivers for adherence to treatment.^[31,32] Discordance with expectation would further influence treatment adherence as it influences satisfaction with prescription.^[33] Patient and caregiver education programmes, as well as the use of reminders through mobile applications have been shown to improve treatment adherence.^[34,35] Unrealistic expectations should be a part of such education programmes. As family physicians are usually the first point of contact for healthcare, training programmes in health communication should be provided to them either as part of a curriculum or continued medical education (CME) activities.

Only 27.5% of our participants had good control over their asthma, while 25% had fair control, whereas nearly half had poor control. This is consistent with the prior findings of poor control among asthmatics. The results in our study are better than previous studies, which had shown that when control of asthma was analysed using the objective criteria as promulgated by the GINA guidelines, none (0%) of the asthmatics had controlled asthma; 60% of the asthmatics had partly controlled asthma, and 40% had uncontrolled asthma. The Whole-person care concept of family medicine has been shown to achieve improved disease control.

Our study also found that individuals with higher expectations (full relief) significantly had inadequate health literacy. We believe that we are reporting this predicting parameter for the first time. This association reinforces the need for better patient-physician communication using skills of breaking bad news, risk communication, and shared decision making to optimize the unrealistic treatment expectations.^[36-38] This, in turn, is expected to improve treatment adherence, disease control, and more distal outcomes such as hospitalization rates and mortality. These principles are given due importance in the curriculum of Family Medicine in India. The fractured healthcare delivery system of India needs to be driven properly through the gateway mechanism of general practitioners or family physicians. We also looked for associations between patient expectation and treatment adherence which was not statistically significant. This was most likely because of an insufficient number of participants recruited in our study. This issue needs to be explored with adequately powered longitudinal studies.

Conclusion

Asthma patients in our setting mostly expected to get cured of the disease, and this expectation is related to poor treatment adherence and possibly poor disease control. Longitudinal studies need to be conducted to determine how much unrealistic

expectations predict treatment adherence, disease control, and other asthma outcomes. Such unrealistic expectations need to be changed through improved patient-physician communication using breaking adverse news scenarios, assessment of coping with the presence of chronic, incurable disease, and training in self-monitoring and self-care.

Key Take Home Messages: Healthcare providers in India should ask for treatment expectations of asthma patients. Unrealistic expectations of cure from asthma should be dealt with using appropriate communication channels. General practitioners and family physicians have a large role in sensitizing these patients about the chronic nature of asthma.

Novelty emerging from this manuscript: We have used principles of family medicine (*viz.* RICE model under individual assessment component) to understand treatment expectations of asthma patients in India. Our results point to the hypothesis that unrealistic expectation of 'cure' leads to poorer adherence to medication and poor control of the disease.

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Conflicts of interest

There are no conflicts of interest.

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