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LIVED EXPERIENCES, TREATMENT PERCEPTIONS, AND SELF-MANAGEMENT STRATEGIES AMONG ADULTS WITH GASTROESOPHAGEAL REFLUX DISEASE (GERD): A QUALITATIVE SYSTEMATIC REVIEW

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ABSTRACT

Background:

Gastroesophageal reflux (GERD) is a lifelong gastrointestinal condition that alters the physical, psychosocial, and lifestyle areas of an individual adversely. Pharmacological interventions still form the core of intervening strategies, but numerous sufferers still have sporadic symptoms and difficulties in long term self-management. The purpose of his qualitative evidence review was to synthesize the evidence concerning lived experiences of adults and perceptions of and self-management approach of GERD.

Methods:

The search strategy consisted of a qualitative systematic review that was carried out in March 2025 on PubMed, web of science, and Google Scholar using PRISMA. The qualitative or mixed-methods study was qualified if it had a definite qualitative part, and it was aimed at adults (≥ 18 years) and was diagnosed with GERD. The analysis involved extraction of data with a predetermined template, evaluation with CASP Qualitative Checklist, and syntheses to follow up using the analysis method proposed by Thomas and Harden thematic synthesis outline.

Results:

The researchers included nine articles published between 2017- 2025 in different settings (USA, Canada, China, Taiwan, the Netherlands, and multi-country cohorts). There were three general themes, namely: (1) lived experiences and quality of life, which describes the extensive effect of physical, emotional and social burden of GERD; (2) perceptions of diagnosis and treatment, which indicated the existence of communication breakdowns, the impacts of long term use of medications as well as the need to educate individuals in an individualized manner; and 3) self-management desires and constraints, in which description of the complexity in maintaining lifestyle and dietary changes, due to cultural, social and logistical limitations.

1. INTRODUCTION

Gastroesophageal reflux disease (GERD) refers to a digestive condition with chronic and progressive nature which is associated with reflux of the gastric substances into the esophagus and results in manifestation of such symptoms as heartburn, regurgitation, chest discomfort, and esophageal complications in the worst cases(Richter and Rubenstein, 2018). GERD has a prevalence of 10-20% in different parts of the world with most of the incidences being reported in western regions of the world and in Asia with India and China as some of the regions that are on the increase due to the changing dietary pattern, urbanization and older populations(Wickramasinghe and Devanarayana, 2025). Although GERD is very common, significantly affects everyday habits, it is still a complicated condition to treat, and it needs a variety of approaches like pharmacologic therapy, lifestyle change, and continuing behavior modification.

Basing its management on pharmacological treatment (PPIs) has long been the existing cornerstone of GERD treatment(Visaggi et al., 2024). Nonetheless, a group of patients still has objective indicators to suggest that their condition is stable even after their observance of medical treatment. In addition, side effects of PPIs when taken over long periods of time and ineffective compliance with lifestyle changes make control of the disease problematic(Guadagnoli et al., 2022). The patient experiences and perceptions must therefore be fully understood to come up with management strategies that must be effective and acceptable.

Although GERD is one of the most widespread diseases, and clinical guidelines are widely used, there is a lack of the comprehensive synthesis of qualitative evidence, which is aimed at considering how patients perceive their disease, its management, and its interpretation within the context of their experience. Qualitative research is special because it provides details and information on patient attitudes, views about treatment choices, perceptions on obstacles to care, and identification on what to do to overcome barriers that cannot be obtained using quantitative research. Learning of such lived experiences is essential in designing personalized models of care, enhancing compliance and in health policy as well as the development of educational programs to patients.

There have been mainly pharmacological or surgical outcome reviews in the past. Nevertheless, there has been no systematic review that has fused the increasing number of qualitative research studies that delve into the lived experiences of the people living with GERD in various healthcare institutions and sociocultural backgrounds. The purpose of this systematic review is to contribute to the existing gap by synthesizing the qualitative research outcomes on how individuals with GERD experience their disorder, perceive the interventions and how they manage their conditions.In such a way, this review will help to achieve a more comprehensive picture of GERD and assist in the creation of particularized intercessions which would agree to the lived requirements and preferences of patients and in the long-run would improvise clinical consequences and patient satisfaction.

2. METHODS

The literature search was conducted in March 2025 using publicly available databases such as PubMed, Web of Science, and Google Scholar. The qualitative systematic review has been reported according to the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA).

Search Terms

("Gastroesophageal Reflux" OR GERD OR "acid reflux") AND ("patient experience" OR "lived experience" OR perception OR attitude OR self-management OR coping OR adherence) AND ("qualitative" OR "focus group" OR interview OR "thematic analysis" OR "grounded theory" OR phenomenology)

Study Selection Process

All the retrieved articles were imported to EndNote 21; duplicate articles were then removed after which the remaining articles were screened. The titles and abstracts of the articles were screened by two independent reviewers with the help of the inclusion and exclusion criteria that were decided beforehand. A full-text review was followed with studies that could have met the eligibility. Any difference in opinion was worked out in the discussion and where conviction cannot be held, a third person reviewer was used to come up with an agreement. The selection of the studies and its respective numbers were placed and documented in a PRISMA flow chart to create transparency and replicability to the study.

Inclusion criteria

- Study Design: Qualitative studies (e.g., interviews, focus groups, ethnographic research, grounded theory, phenomenology)
- Participants: Adults (≥18 years) diagnosed with Gastroesophageal Reflux Disease (GERD)
- Phenomenon of Interest: Reported experiences, perceptions, treatment interactions, coping strategies, and/or self-management behaviours
- Language: English
- Date Range: January 2015 – March 2025
- Setting: Any clinical or community setting globally

Exclusion Criteria

- Quantitative or mixed-methods studies without extractable qualitative data
- Studies focusing exclusively on pharmacological efficacy without patient perspectives
- Editorials, commentaries, narrative reviews, or conference abstracts without full texts
- Studies focused on paediatric populations (<18 years) or solely healthcare provider perspectives
- Articles not in English

Quality Appraisal and Data Extraction

Each of the included studies was appraised independently by two reviewers regarding their methodological quality, and the Critical Appraisal Skills Programme (CASP) Qualitative Checklist was used to do so. This evaluation revolved around issues like, clarity of objectives, suitability of the methodology and design, the strengths of data collection and analysis, address of ethical issues as well as usefulness of the research. Any differences between reviewers were discussed with the aim of resolving them, and where this was not possible a third reviewer was consulted. Notably, no study was refused based on quality score, but the quality evaluation played the role of informing the findings interpretation on the synthesis level.The extracted data of the studies included were done using standardized data extraction form. Other significant study features were noted such as the author(s), year of publication, the country, the purpose of the study, study design and methodology, the participants and the sample size, the data collection and analysis methods, the key findings, emerging themes and representative quotations of the participants. The process was used to make a comprehensive and similar summary of evidence in all the studies found to be inclusive.

Data Synthesis

The synthesis of the qualitative data was performed based on the three stage approach of thematic synthesis outlined by Thomas and Harden (2008)(Thomas and Harden, 2008). Primarily, all qualitative data (quotes said by the participants and the interpretation of the authors) were line-by-line coded to reveal the main concepts and the experiences under consideration. All these initial codes were then grouped together in descriptive themes that very much touched upon the content and context of the primary studies. Lastly, there were the higher-order analytical themes developed, which went beyond the discovery of the individual studies to bring novel insights and conceptual knowledge regarding how people with GERD experience their phenomena, what their treatment experiences and their self-management measures are. In such a back and to procedure, the research team would have regular meetings during which the codes and themes would be discussed and adjusted so that they are emotionally clear and conceptually relevant to the objectives of the review.

3. RESULTS

The systematic search strategy that applied in PubMed, Google Scholar, and grey literature yielded 18,800 records. There were 24,451 records that underwent an initial filtering process, cutting 13,100 records as not eligible by title and abstract and 8 duplicates were removed resulting in 3,202 records being screened by their titles and abstracts. Out of which 3,000 records were discarded, the records do not fit the review criteria. Two hundred articles were retrieved and 140 of them were not accessed. The number of full-text articles which were considered eligible was 60, and 51 were rejected (42 were quantitative, 1 non-English, and 8 due to other details like an inadequate number of qualitative data). There were, nevertheless, 9 qualitative studies that fulfilled the inclusion criteria and were added to the review.

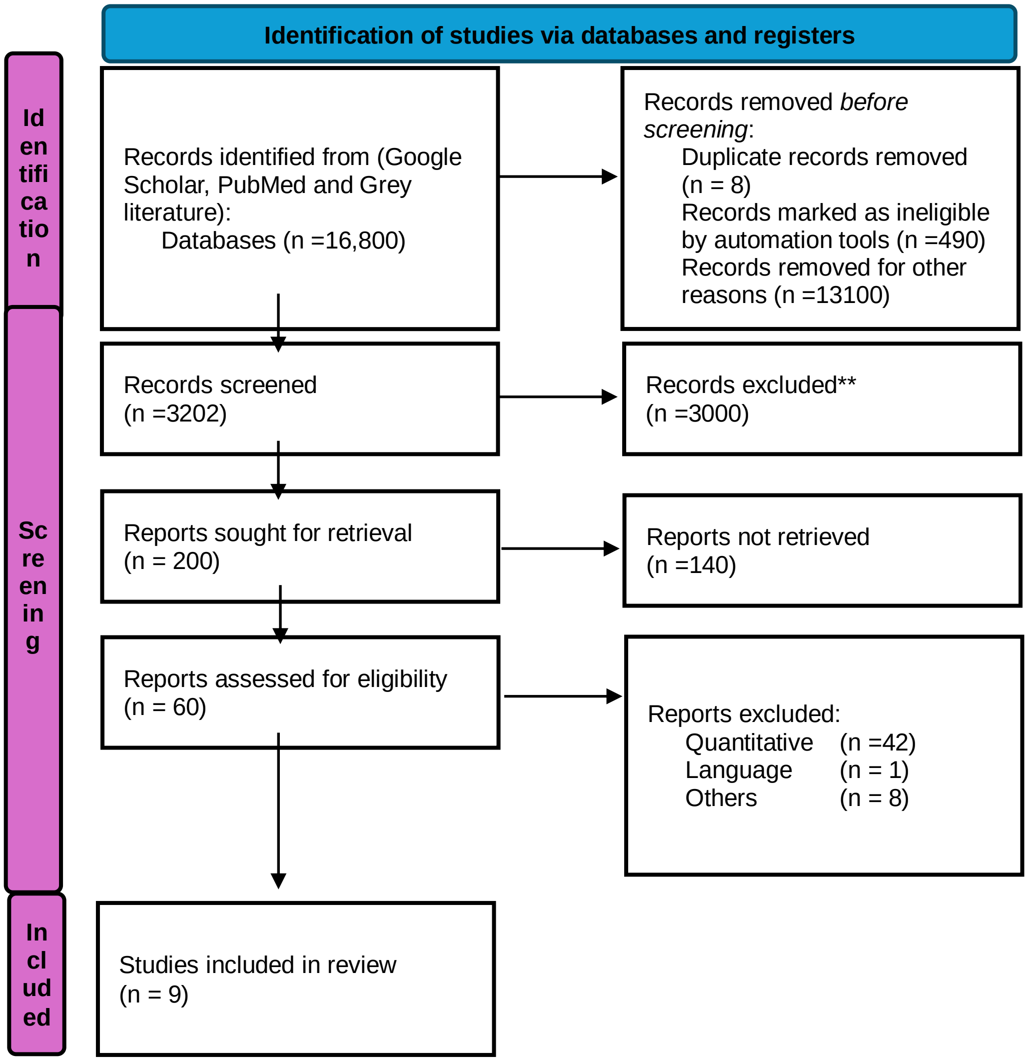

Figure 1 PRISMA 2020 flow diagram for the qualitative systematic review

The investigated studies were carried out in various environments (USA, Canada, China, Taiwan, Netherlands and in multi-national cohorts), to examine the experiences of life, treatment perceptions and self-management approaches in adults with GERD. Study eligibility and screening is summarized in the PRISMA flow diagram (Figure 1), and study characteristics included in those mentioned table 1.

Table 1 Characteristics of Included Studies

Study (Author, Year)	**Country**	**Aim of the Study**	**Study Design**	**Participants (n, characteristics)**	**Data Collection Method**	**Analysis Method**	**Key Findings / Themes**
(Lin et al., 2019)	Taiwan	To explore perceptions of COPD exacerbations in patients with comorbid GERD.	Qualitative (Grounded Theory)	12 patients with COPD and GERD	Semi-structured interviews	Grounded theory	Themes: ineffective symptom management, overlapping symptoms of COPD/GERD, anxiety, helplessness
(Yu et al., 2020)	China	To describe individuals ™ experiences with lifestyle changes after sleeve gastrectomy.	Qualitative (Interpretive thematic analysis)	15 SG patients, post-surgery (2012â 2018)	Semi-structured interviews	Thematic analysis	Themes: benefits vs. side effects, self-management strategies, cultural barriers
(Youssef et al., 2021)	Canada	To examine bariatric patients' self-management experiences post-surgery.	Qualitative (Thematic)	23 post-op patients (majority female, median 2 years post-surgery)	Semi-structured interviews	Constant comparative analysis	Themes: self-esteem, emotion regulation, long-term lifestyle changes
(Craven et al., 2017)	USA	To analyze patient attitudes and perceptions related to GERD.	Qualitative (Focus groups)	10 GERD patients	Focus groups	Thematic analysis, Health Belief Model	Themes: psychosocial barriers, PPI dependency, provider communication gaps
(Sowell et al., 2025)	USA	To explore symptoms and HRQoL in patients with advanced GEJ cancer.	Qualitative interviews + targeted literature review	20 patients with aGC/GEJC	Concept elicitation interviews	Content analysis with conceptual model	Themes: 12 major symptoms, emotional burden, treatment vs. disease impacts
(Van der Ende-van Loon et al., 2022)	Netherlands	To identify factors influencing HRQoL in patients with	Qualitative (Focus groups)	34 patients with non-dysplastic and dysplastic Barrett's esophagus	Focus groups	Content analysis	Themes: reflux symptoms, cancer fear, trust in treatment,

		Barretta™s esophagus.					emotional burden
(Chouhdry and Villwock, 2023)	USA	To explore patient perspectives on lifestyle modifications for GERD/LPR.	Qualitative	23 patients (mean age 61) with GERD/LPR	Semi-structured interviews	Thematic analysis	Themes: motivation to change, implementation barriers, dietician need
(Ho et al., 2025)	Multi-country (trial-based)	To characterize patient experiences with EoE symptoms and daily life impacts.	Qualitative (In-trial interviews)	34 recruited, 15 completed follow-ups	Longitudinal interviews	Qualitative thematic profiling	Themes: swallowing difficulty, pain, psychosocial impact, emotional relief during trial
(Lin et al., 2020)	USA	To explore symptom experiences and self-management in gastric cancer patients.	Qualitative descriptive	10 gastric cancer patients	Semi-structured interviews	Content analysis	Themes: multiple co-occurring symptoms, personal strategies, information-seeking

Nine qualitative studies that were published between 2017 and 2025 were found to meet the inclusion criteria and were synthesized in this review. The research papers have been made in a variety of geographical locations with the USA (n=4), Canada (n=1), China (n=1), Taiwan (n=1), the Netherlands (n=1) and one multi-country cohorts (n=1). The number of samples used was between 10-34 people and the participants were mostly adults and had GERD or other esophageal diseases. Data collection had a variety of methods used such as semi structured interviews (n=6), focus groups (n=2), longitudinal interviews (n=1) that gave the ability to examine the experiences of the patient at a depth.The research studies used different qualitative methodological approaches e.g. grounded theory, thematic analysis, content analysis and phenomenological research. Most of the studies have concentrated on lived experiences and self-management practices of the patients, the others have concentrated on treatment perceptions, emotional and psychosocial effects and adherence barriers. In the studies, there were major themes which involved the effects of enduring symptoms on the living quality, fear of developing the illness, emotional sufferings and difficulty in implementing long-term alterations on the lifestyle. Some of the reports pointed to the existence of variation of follow through regarding treatment schedules, the role of cultural and social factors in the management of chronic diseases, the significance of patient-provider communication and their education. The combination of these studies gave meaningful impressions on the complexity of how people live with GERD in various healthcare environments and among different people.

Review findings

The synthesis of the nine included qualitative studies which contained three themes in common (1) lived experiences and quality of life effects, (2) perceptions of diagnosis and treatments, (3) self-management approaches and obstacles to compliance. Throughout the studies, individuals tended to discuss the adverse effects that GERD symptoms have had on their physical and emotional states, and, in most cases, they express their fear, frustration, and disruption of their routine (Craven et al., 2017; Lin et al., 2019; Van der Ende et al., 2022). The element of combinations of attitudes towards diagnostic procedures and interventions was mentioned by many patients who indicated they did not understand what the consequences of using medicines might be and were worried about consistent intake of proton pump inhibitors (Choudhry et al., 2023; Youssef et al., 2021). Ultimately, the significance of self-management was traced as one of the central themes because patients have tried to make dietary changes, lifestyle changes, stress management approaches but it is often driven by social, cultural, and practical obstacles (Yu et al., 2020; Ho et al., 2025; Lin et al., 2020).

Lived Experiences and Quality of Life Impacts

The participants of the studies that were included in the research unanimously reported the type of impact that their GERD symptoms had in their everyday lives, which were exceptionally high levels of physical and emotional discomfort. Such symptoms as heartburn, regurgitation, chest discomfort, bloating, and dysphagia are often mentioned but understood to be unpredictable and not easily manageable (Craven et al., 2017; Lin et al., 2019; Van der Ende et al., 2022). Such burden of unprediction was especially hard on participants since it caused them to be always on diet and lifestyle vigilance and fear of an outbreak of symptoms. One of the participants in Craven et al. (2017) said that GERD is a painful illness, which makes someone feel the loss of control over his or her body, which demonstrates anxiety and frustration that most people developed.

In the other literature, patients said that GERD interfered with sleep, and more often than not, it woke them up at night because of the acid that came back up or because of the feeling that they could not swallow properly, which also led to the development of fatigue and the inability to properly perform the daily tasks (Lin et al., 2019; Ho et al., 2025). The participants also identified that they tried to prevent some social circumstances, including having dinner with their families and friends to decrease shame or awkwardness of symptoms (Van der Ende et al., 2022). This social isolation was further worsened by dieting that could be prescribed to the management of GERD thus they start experiencing such feelings of seclusion.The pattern of emotional distress was common in patients who had apprehensions of getting worse. According to Van der Ende et al. (2022), patients who had diagnosis of Barrett esophagus said that they had more anxiety regarding the possibility of developing esophageal cancer and one of the respondents said, (Every time I feel discomfort, I will be nervous that it is the cancer that is coming) Likewise, Lin et al. (2019) found that their study participants had comorbid COPD and GERD and therefore exhibited a high incidence of feelings of helplessness because the congruent symptoms did not allow the patient to disentangle the causative factors of their discomfort and result in hesitation and fear.

The suffering brought by GERD was not bulkheaded to physical, emotional points, but it interfered with the rates of quality of life and productivity of patients. Respondents of several studies complained that the diseases impaired their ability to sustain regular performance at the workplace or home duties because of tiredness and symptomatic exacerbations (Sowell et al., 2025; Choudhry et al., 2023). According to one of the participants in Yu et al. (2020), she is always redesigning her day around her symptoms; it seems that the GERD is tailoring her life and not her managing the GERD.The essence of the studies in general was highlighted as to the extent of GERD effects, as far as the condition is not just a physical health problem but has many psychosocial and lifestyle implications. These diagnoses confirm the necessity of assessment-requests of quality comprehensive care that is both patient-based, and one that gives credence and recognizes/appreciates the overall quality issues in life with GERD.

Perceptions of Diagnosis and Treatment

Patients involved in the reviewed studies voiced a variety of attitudes towards the diagnostic process and treatment measures in GERD which most of the time included frustrations, lack of understanding and confusion. Some of them spoke of the process of being diagnosed as taking a very long time, and, in some cases, being inconclusive, which explained both anxiety and dissatisfaction with their care (Craven et al., 2017; Choudhry et al., 2023). In one of the cases in Craven et al. (2017), a participant shared that talking to doctor after doctor he or she received no clear answers, and it seemed that no one knew what exactly happened to the participant, which is a common complaint against inaccurate or late diagnoses.Whilst the types of pharmacological interventions (primarily proton pump inhibitors (PPIs)) have generally been considered effective in managing acute symptoms, there was a lot of concern by the participants regarding using them long-term. Others were concerned about side effects or even the possibility of tendencies of dependency as one of the representatives of Choudhry et al. (2023) said: I am afraid of what will happen to my body in case I spend years on these pills, yet I cannot live without them. Such issues were also indicated in the study conducted by Youssef et al. (2021), according to whom participants discussed PPIs as a kind of double-edged sword, i.e., a product that brings a sense of ambivalence as the people mention that it relieves but also evokes fear due to its potential to cause harm in the long run.

Certain communication failures with medical professionals were also observed, with the participants, feeling like consultations were too fast and lacked any proper explanation of the condition and how they should manage it (Sowell et al., 2025; Ho et al., 2025). As an example, the researchers of Choudhry et al. (2023) discovered that the patients had expectations of more in-depth counseling, especially when it comes to changes to their lifestyle, with one of them providing a quote describing this: the doctor simply instructed me that I needed to avoid foods, yet why and how they could assist me was not explained. This was because of the lack of individual education that brought about confusion in the implementation of the self-management practices.

Execution According to several studies it was emphasized that multidisciplinary approach to care is necessary. According to the participants, the barrier to getting dietitians, patient educators, and psychological assistance could increase both compliance and treatment satisfaction levels (Choudhry et al., 2023; Craven et al., 2017). According to Sowell et al. (2025), patients with the cancer of the gastroesophageal junction were happy with structured counseling sessions as they mentioned the proper guidance being helpful due to the patients feeling better informed and prepared to deal with their disease.In general, the perception of patients towards diagnosis and treatment depended on such factors as misguided or lengthy diagnostic process, the dependence on medication treatment and the lack of communication between the patient and provider. These results put more emphasis on the practice of shared decision-making and patient-centered education to establish trust and increase the adherence to the treatment regimes.

Self-Management Strategies and Barriers to Adherence

The ability to manage oneself appeared as a major theme in the analyzed papers where the participants witnessed several strategies that strive to manage GERD symptoms. Such tactics included changes in diet which required some people to decrease eating spicy or fatty foods, reduce the use of caffeine and alcohol and eat fewer but more often (Yu et al., 2020; Choudhry et al., 2023). An interview in Choudhry et al. (2023) cited the case that one of the participants tries not to eat at a late hour but due to his work schedule, it is not always easy, highlighting the possibility of lifestyle requirements going against health habits. On the same note, Yu et al. (2020) pointed out that cultural and family eating habits rendered some of the participants unable to adhere to dietary recommendations on a regular basis.

They also reported that they made the change in their lifestyles by making weight-loss attempts, keeping the head of the bed elevated, refusing to lie down after having a meal, and involving themselves in activities that alleviated stress (like yoga or meditation) (Lin et al., 2020; Ho et al., 2025). The problem however was that sustaining such changes in the long term was not easy. One participant in the study by Lin et al. (2020) stated, I have good intentions at first, but after the symptoms have improved, I find myself back into the bad habit and therefore, the ability to continue behavior change.The factors that were a barrier to adherence were psychosocial and environmental. Spending time with friends or family, where individuals must eat with them according to their social norms, has been discussed as one of the most frequent social requirements that made study participants feel pressured into breaking their diet plans (Yu et al., 2020). Other people also gave up in frustration and discouragement after lifestyle alterations failed to deliver results in a short period. Similarly, in Choudhry et al. (2023), the study participants reported that the feeling of being overwhelmed and losing motivation could occur when viewing the list of prohibited foods, as one of the participants said, they were under the impression that when seeing such a long list of foods, they are not allowed to eat, they feel discouraged.

Some others expressed that they tried to get information and support elsewhere, including online networks or groups of peers, when they did not get enough advice or care from the ones that provided their healthcare (Craven et al., 2017; Choudhry et al., 2023). On the one hand, these sources offered useful suggestions, whereas, on the other hand, they result in misunderstanding as to different pieces of advice. The results indicate that patients are willing to undertake self-management in respect to GERD but maintaining self-management strategies is difficult with all the other extenuating factors of lifestyle needs, social and cultural pressures, the absence of specific information and the sense of frustration when their GERD symptoms persist. All these impediments indicate the importance of having patient-specific support strategies with recognition of social settings of the patients and positive reinforcement.

CONCLUSION

The aim of the present qualitative synthesis was to shed light on the experience of adults with GERD, their perceptions of the path to diagnosis as well as the treatment, and the underpinnings associated with self-management of the disease in their lives. Collectively, the studies incorporated put GERD in the center of attention as a biopsychosocial disorder, the burden and treatment of which cannot be confined to symptom management. Lived experience is influenced by a variable symptom course, cross-cutting comorbidities, and eating, work and sleep social conditions. The perceptions about diagnosis and treatment are, in their turn, formed because of clarity, timeliness, and person-centered clinical communication. Self-management is everywhere, but precarious: patients take proactive measures regarding diet, behavioral approaches, and means of stress management, but compliance is regularly challenged by other priorities, cultural eating habits, minimal direction aimed at specific needs and ambivalence about future pharmacotherapy.Such implications have direct implications on practice. To begin with, GERD care is to be treated as a multidisciplinary and longitudinal task that brings gastroenterology together with dietetics, behavioral health and patient education. Such practical counselling, in which the counsellor and client collaborate to go beyond the lists of foods to avoid and devise culturally sensitive meal planning and plans to realistically change the behaviour will be more sustainable. Second, clinicians must embrace the formulated, precise PPI stewardship in shared decisioning of indications, anticipated benefits, monitoring strategies and descending routes to supplement issues related to the long-term use of PPI and remain in control of symptoms. Third, screening assessments of psychosocial stressors and interruption of sleep should be conducted in a brief way with expedited access to self-management options (such as CBT-i strategies, relaxation training and graded activity) when indicated during routine care visits.

In the case of health systems, the findings recommend scaling of supports that can be delivered in the areas where patients are dealing with GERD most i.e. their homes and in the community. Examples would be group education led by a dietitian, digitally (or app software)-mediated goal tracking with immediate feedback, and messaging to solve flare-ups in an asynchronous manner. Incorporating them into the primary care and specialty care pathways may lower unnecessary escalation and enhance contentment and enable lifestyle advice to be provided in an act-upon-it manner. Equity must be a design principle: the materials and interventions must be available to people with different levels of literacy, they must be available in different languages, in different resource settings and they do not necessarily have to pathologize cultural practices of eating but are rather to recognize them.The methodological approach to the body of evidence is that the evidence supports the worth of the qualitative inquiry in finding the reasoning behind the adherence issues and ambivalence of treatments. Future studies ought now to build upon this base by: (1) co-designed interventions, expressly guided by patient narratives, and tested in the real world; (2) such longitudinal qualitative research that tracks patients through diagnostic transitions, changes in medication, life events; (3) inclusion of under-represented settings (e.g. low and middle income settings, rural settings), caregiver perspectives; and (4) reporting standards (e.g. COREQ) that enhance transparency and transferability.

This review presents a coherent idea consistent with their goals and objectives: to have better outcomes in GERD, the care models will need to combine a good pharmacology with culturally informed, individualized self-management support and good high-quality rapport. By effectively factoring in the lived priorities of patients into counselling, follow-up and design of service, the adherence is more long term, the anxiety is minimized, and the patient-centered GERD care is a possibility.

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