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Educational Needs in Self-Care Apps for Mast Cell Activation Syndrome: Perspectives from Specialists

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ABSTRACT

Mast Cell Activation Syndrome (MCAS) is a condition that requires careful lifelong self-care. Mobile health apps are promising tools, but their content must be tailored to patient needs. This study aimed to identify and prioritize educational needs for designing a self-care mobile app for MCAS patients from the perspective of specialists. An applied, cross-sectional study was conducted using a descriptive survey. A purposive sample of 18 clinical immunologists and allergists completed a validated, researcher-developed questionnaire. They rated the importance of 58 educational items across 10 domains on a 5-point Likert scale. Data were analyzed using descriptive statistics. Fifty-two out of 58 items were considered essential (mean score ≥3.0), with the highest priority given to practical knowledge, such as proper use of an epinephrine auto-injector and trigger identification. Six items, including detailed breathing techniques and specific exercise types, did not meet the essentiality threshold. Additionally, specialists approved additional application features, such as a patient medical history section and a user feedback mechanism. This study provided an expert-validated foundation of essential educational content for an MCAS self-care app. The results offer an important blueprint for creating a targeted mHealth tool to empower patients, improve self-care, and enhance quality of life.

Keywords: Mast Cell Activation Syndrome, Mobile Applications, Self Care, Patient Education

INTRODUCTION

Mast Cell Activation Syndrome (MCAS), encompassing a spectrum of disorders including systemic mastocytosis, is a rare and complex pathophysiological condition characterized by abnormal proliferation and/or activation of mast cells (1). These cells, integral to the immune system's allergic and inflammatory responses, become dysregulated when they are not functioning properly, leading to a myriad of symptoms that can severely debilitate patients' quality of life (2). Clinical manifestations range from cutaneous symptoms like urticaria pigmentosa and flushing to systemic episodes involving severe gastrointestinal distress, neuropsychiatric symptoms, and life-threatening anaphylactic shock (3). The unpredictable nature of these symptoms, often triggered by a wide array of factors, places a significant burden on patients, necessitating constant vigilance and sophisticated self-care strategies (4). The rarity and heterogeneity of MCAS frequently result in delayed diagnosis, misdiagnosis, and a profound sense of isolation among patients, who often lack access to specialized care and comprehensive information about their condition (5).

The global epidemiology of MCAS remains incompletely characterized, primarily due to the condition's rarity and diagnostic complexities. Despite its low estimated prevalence, MCAS exerts a profound impact, resulting in significant morbidity (6). In Iran, as in many other countries, the exact prevalence remains uncertain, but patients face similar challenges in navigating a healthcare system that may be unprepared for the nuances of rare diseases (7). The diagnostic journey for MCAS patients is often long and arduous, involving multiple healthcare providers before a correct diagnosis is established (8). This delay not only exacerbates patient anxiety but also increases the risk of severe complications, including anaphylaxis and the progression of systemic disease (8). Once diagnosed, patients are confronted with the lifelong task of managing a condition that requires meticulous attention to detail in daily life, from dietary restrictions and medication adherence to recognizing early signs of severe reactions (9).

In this context, self-care emerges as a cornerstone of effective long-term management for MCAS (10). Self-care can be defined as the conscious, learned, and goal-oriented activities individuals undertake to maintain life, health, and well-being. For MCAS patients, this encompasses a wide range of behaviors, including strict trigger avoidance (e.g., certain foods, temperatures, medications, stress), correct administration of complex pharmacotherapies (e.g., H1 and H2 antihistamines, mast cell stabilizers, epinephrine auto-injectors), and the ability to implement an emergency action plan during an anaphylactic episode (10). Effective self-care has been demonstrated to improve health outcomes, enhance quality of life, increase patient satisfaction with care, and reduce healthcare costs by preventing emergency department visits and hospitalizations. In chronic conditions, particularly rare diseases where specialist contact may be infrequent, the patient's role as the primary manager of their health is paramount (11).

The emergence of mobile health (mHealth) technologies offers a transformative opportunity to support self-care in chronic disease management (12). The widespread adoption of smartphones has facilitated the development of health applications that can deliver personalized education, provide medication reminders, enable symptom tracking, and offer immediate access to action plans (13). For patients with rare diseases like MCAS, who may feel geographically and informationally isolated, mHealth applications can serve as a vital link to evidence-based guidelines and a sense of community (14). Studies have shown that such technological interventions can increase patients' ability to perform self-care, facilitate education, help maintain or modify lifestyle, promote health, and mitigate the effects of chronic illness (15). The potential of mHealth to bridge care gaps is particularly relevant given the often-exacerbated health disparities, limited access to specialized healthcare services, socioeconomic factors, and the inherent challenges of managing a complex, rare condition (16).

The development of effective mobile health applications for chronic disease management relies heavily on user-centered design principles. Recent research on diabetic retinopathy has demonstrated that employing a participatory design process followed by rigorous usability testing can result in a mobile application with high user satisfaction. This approach underscores the broader effectiveness of mHealth tools in empowering patients to manage their conditions (17). Supporting this methodology, another investigation into the needs for a gestational diabetes self-management app identified several crucial components for success. The highlighted fundamental elements included creating detailed patient profiles, access to reliable educational content, integrated medication tracking, and automated reminder systems. Together, these findings affirm that a foundational needs assessment and a focus on key, patient-identified features are vital for developing targeted and supportive mHealth interventions (18).

A critical prerequisite for developing an effective mHealth intervention is a thorough needs assessment to identify the specific educational requirements of the target population (19). While generic information on allergy management exists, the unique and complex needs of MCAS patients necessitate a tailored approach (10). Educational content must address the specifics of mast cell stabilizers, the management of comorbidities such as osteoporosis and gastrointestinal dysmotility, the psychological impact of living with an unpredictable disease, and guidance on special situations such as pregnancy or surgical procedures (20). Currently, in Iran, there is a lack of structured, comprehensive self-care programs specifically designed for MCAS patients. Therefore, determining these educational needs from the perspective of specialists who manage these patients is an essential first step. Their expert opinion is invaluable for ensuring the application's content is accurate, relevant, and empowers patients to better manage their disease. This study, consequently, aimed to identify and prioritize the educational needs for designing a mobile-based self-care application for patients with MCAS, providing a foundational evidence base for a much-needed technological solution in this patient community.

METHODS

This study was an applied, cross-sectional study conducted using a descriptive survey methodology. Data collection for this cross-sectional study was conducted over a two-month period, from May to June 2024. The study environment was chosen for its access to a concentrated group of experts whose clinical experiences directly inform the practical needs of the target patient population. This applied, cross-sectional study used descriptive survey methodology. The descriptive design was chosen as it is the established method for systematically collecting and reporting on the characteristics, opinions, and consensus of a specific population, in this case, clinical specialists

Participants and Sampling

The study was conducted in Iran, drawing participants from specialized clinics and academic centers affiliated with the target universities to ensure access to a concentrated group of experts whose clinical experience directly informs the practical needs of the target patient population. The target population for this study consisted exclusively of clinical immunologists and allergists actively involved in the diagnosis and long-term management of patients with MCAS. To ensure the inclusion of highly experienced professionals, purposive sampling was employed. The initial sampling frame included 25 eligible specialists identified from the participating clinics' staff registries. The inclusion criteria were rigorously defined as follows: (1) being a board-certified clinical immunologist or allergist, (2) having a minimum of five years of direct clinical experience in managing patients with MCAS, (3) being a faculty member of Abadan and Iran University of Medical Sciences to ensure a commitment to academic standards, and (4) providing written informed consent to participate in the study. The sole exclusion criterion was an unwillingness to cooperate or participate in the study. From the initial pool of 25 specialists, 18 participants who fully met the criteria and consented to participate were enrolled in the study. This sample size was deemed sufficient to achieve data saturation and to gather expert consensus, aligning with common practices in qualitative and descriptive health research seeking expert opinion.

Data Collection Instrument

The primary data collection instrument was a meticulously designed, researcher-made questionnaire developed specifically for this study. The questionnaire was constructed using a multi-stage process. Initially, a comprehensive review of the scientific literature was conducted. This involved searching reputable international databases such as PubMed, Scopus, and Web of Science, as well as Persian databases like SID and Magiran, using keywords related to MCAS, self-care, patient education, and mHealth. The finalized questionnaire was distributed electronically via email and professional messaging platforms (such as WhatsApp and Telegram) to the selected specialists. A follow-up reminder was sent two weeks after the initial distribution to maximize the response rate. This review aimed to identify all potential educational domains and specific items relevant to MCAS patient care. The final questionnaire was structured into three distinct sections:

Demographic Information: This section collected basic demographic data, including age, gender, and years of clinical experience in managing MCAS (3 items).

Educational Needs Assessment: This was the core section, comprising 58 specific items categorized into 10 predefined domains critical to MCAS management. These domains were: 1) Pharmacological Management (e.g., use of mast cell stabilizers, antihistamines, epinephrine), 2) Trigger Identification and Avoidance (e.g., foods, environmental factors, stress), 3) Anaphylaxis Emergency Preparedness and Management, 4) Dietary Guidance and Nutritional Considerations, 5) Management of Common Co-morbidities (e.g., osteoporosis, gastrointestinal issues), 6) Dermatological Care for Cutaneous Manifestations, 7) Mental Health and Psychological Coping Strategies, 8) Pregnancy, Family Planning, and Genetic Counseling, 9) Safe Physical Activity and Exercise Recommendations, and 10) Long-term Monitoring and Potential Complications. For each item, participants were asked to rate its necessity for inclusion in the mobile application on a 5-point Likert scale, ranging from "Very High" (score 4) to "Very Low" (score 0).

Open-Ended Suggestions: This final section provided space for participants to offer additional comments, suggest educational topics not covered in the questionnaire, and propose desired features for the application beyond pure educational content.

Validity and Reliability

To ensure the scientific rigor of the instrument, its validity and reliability were formally assessed. Face and content validity were evaluated by a panel of four independent experts comprising health information management specialists, medical informaticians, and senior clinical immunologists. They reviewed the questionnaire for clarity, relevance, comprehensiveness, and appropriateness of the items. Their feedback was incorporated, resulting in minor refinements to the wording and structure of some questions. Reliability was assessed using the test-retest method. The finalized questionnaire was administered to a separate, similar group of 15healthcare professionals not included in the main study sample. The same participants completed the questionnaire twice, with a 2-week interval, to minimize recall bias. The internal consistency of the questionnaire, calculated using Cronbach's alpha based on the main study data, was 0.88, indicating high reliability. Face and content validity were evaluated quantitatively and qualitatively by a panel of four independent experts comprising health information management specialists, medical informaticians, and senior clinical immunologists. They reviewed the questionnaire for clarity, relevance, comprehensiveness, and appropriateness. Based on their ratings, both the Content Validity Index (CVI) and Content Validity Ratio (CVR) were calculated, yielding scores above the acceptable thresholds of 0.79 and 0.75, respectively. Their qualitative feedback was also incorporated, resulting in minor refinements to the wording and structure of some questions. The questionnaire was emailed to the expert panel for content validation. They were asked to rate each item independently. This structured process, followed by a consolidation of their individual ratings and feedback, constitutes an expert panel method.

Data Analysis

The collected data were analyzed using descriptive statistics in SPSS software version 26. Frequencies, percentages, means, and standard deviations were calculated for the demographic variables and for each educational item. The primary criterion for determining an "essential" educational need was a mean score of 3.0 or higher (equivalent to attaining at least 75% of the total possible score). Items meeting this threshold were prioritized for inclusion in the application. For the open-ended suggestions, any proposal that received a mean importance score of 2.0 or higher (50% of the total score) from the participants was also considered approved for integration into the application's design. This analytical approach provided a clear, quantitative basis for prioritizing content and features based on expert consensus.

Ethical Statement

All participants were informed of the study's purpose, and their informed consent was obtained prior to participation. In addition, this study received ethical approval from the Ethics Research Committee of Abadan University of Medical Sciences with the number IR.ABADANUMS.REC.1404.072.

RESULTS

A total of 18 clinical immunologists and allergists participated in the study. The demographic characteristics of the specialists are presented in Table 1. The majority of respondents (66.6%, n=12) were in the 40-50 years age group. Male specialists constituted 72.2% (n=13) of the participants. Regarding work experience, the largest group (50.0%, n=9) had 11-15 years of experience managing patients with Mast Cell Disease. Those with over 15 years of experience constituted 44.5% (n=8) of the sample.

TABLE I. FREQUENCY DISTRIBUTION OF THE SPECIALISTS' DEMOGRAPHIC CHARACTERISTICS (n=18)

Variable	*Category*	*Frequency (n)*	*Percentage (%)*
Age (years)	<40	2	11.1
	40-50	12	66.6
	>50	4	22.3
Gender	Female	5	27.8
	Male	13	72.2
***Work Experience** (years)*	5-10	1	5.5
	11-15	9	50.0
	>15	8	44.5

Essential Educational Needs

The analysis of the 58 educational items across the 10 predefined domains revealed that 52 items were confirmed as essential for inclusion in the mobile application, achieving a mean score of 3.0 or higher. The ten main domains were: 1) Medications, 2) Trigger Identification and Avoidance, 3) Anaphylaxis Management, 4) Diet and Nutrition, 5) Co-morbidities, 6) Skin Care, 7) Mental Health, 8) Pregnancy and Family Planning, 9) Physical Activity, and 10) Long-term Complications.

The results indicated that within the core concepts of MCAS management, the majority of proposed items were recognized as necessary. However, six specific items did not meet the essentiality threshold (mean score < 3.0). These items were: detailed breathing techniques for anaphylaxis (mean=2.9), specific types of low-impact exercises (e.g., yoga vs. swimming, mean=2.8), in-depth information on monoclonal antibody therapy (e.g., dosing details, mean=2.7), managing reactions to specific dental materials (mean=2.9), detailed guidelines for air travel (mean=2.8), and the management of rare neurological complications (mean=2.7).

Table 2 provides a sample of the essential educational items from two key domains, 'Medications' and 'Trigger Avoidance,' along with their mean scores and standard deviations. As shown, items such as the correct use of epinephrine auto-injectors and identification of environmental triggers received the highest possible mean score (4.0), underscoring their critical importance. Other items, such as managing corticosteroid side effects, were also deemed essential, but with slightly greater variation in specialist responses.

TABLE II. SAMPLE OF CORE EDUCATIONAL NEEDS RELATED TO MEDICATIONS AND TRIGGER AVOIDANCE

Educational Need Item	*Mean Score*	*Standard Deviation*	*Result*
Domain: Medications			
Purpose and dosing of H1/H2 antihistamines	3.9	0.12	Essential
Correct use of Epinephrine auto-injectors	4.0	0.00	Essential
Side effects and monitoring of Cromolyn Sodium	3.7	0.28	Essential
Managing side effects of corticosteroids	3.6	0.37	Essential
Domain: Trigger Avoidance			
Identification of common food triggers (e.g., histamine-rich foods)	3.9	0.12	Essential
Identification of environmental triggers (e.g., perfumes, smoke)	4.0	0.00	Essential
Understanding temperature extremes as a trigger	3.8	0.23	Essential
Managing stress and emotional triggers	3.7	0.28	Essential

Suggested Features

In the open-ended section, participants proposed additional features for the application beyond the educational content. All six proposed suggestions received a mean score above 2.0 and were therefore approved for inclusion. These features, detailed in Table 3, focus on personalization and resource access. The highest-rated suggestions were including a "Patient Medical History" section (mean=3.6) and a "User Feedback" section (mean=3.6). Suggestions such as a directory of specialized clinics, while approved, had a lower mean score (2.0) and a higher standard deviation, indicating less consensus about their priority. The questionnaire's internal consistency, as measured by Cronbach's alpha, was 0.88, indicating high reliability.

TABLE III. Specialists' recommendations for features beyond educational purposes

Suggestion	*Mean Score*	*Standard Deviation*	*Result*
Include a "Patient Medical History" section	3.6	0.31	Approved
Add a "Time Since Diagnosis" tracker	3.2	0.64	Approved
Include a section on "Common Complications"	3.5	0.37	Approved
Directory of specialized MCAS clinics in Iran	2.0	1.40	Approved
Provide information on various low-histamine diet plans	2.1	0.98	Approved
Include a user feedback and suggestions section	3.6	0.29	Approved

DISCUSSION

This study successfully identified and prioritized the essential educational needs for developing a self-care mobile application tailored for patients with MCAS, as perceived by clinical immunologists and allergists. The findings provide a crucial evidence-based framework for creating a targeted digital health intervention to empower patients to better manage this complex and rare condition. The high consensus across 52 of 58 items underscores a core set of knowledge areas that specialists deem critical for patient education and daily self-care.

The results highlight the paramount importance of practical, actionable knowledge in MCAS management. The highest-priority items, such as the correct use of epinephrine auto-injectors and identification of environmental triggers, directly relate to preventing and managing life-threatening anaphylactic reactions. This aligns strongly with studies emphasizing that patient competency in emergency preparedness is a cornerstone of effective care in mastocytosis and mast cell activation syndromes (21). Furthermore, the emphasis on comprehensive medication education, including the purpose and side effects of drugs such as H1/H2 blockers and cromolyn sodium, aligns with broader literature on chronic illness management, where understanding pharmacotherapy is key to adherence and safety (22). The necessity of topics related to trigger avoidance, including dietary management and stress, reflects the unique pathophysiology of MCAS, where external stimuli can directly provoke symptoms. This finding is consistent with patient-led surveys that consistently identify trigger identification as a major unmet need (23).

The study also revealed specific areas where specialist opinion diverged regarding the essentiality of the issues. Items such as detailed breathing techniques for anaphylaxis and specific low-impact exercises were not deemed universally essential. This may indicate that specialists view these as supplementary skills to be addressed in personalized clinical settings rather than as core application content. Similarly, the lower priority given to highly specific information, like managing reactions to dental materials or details on monoclonal antibody therapy, suggests a focus on foundational, broadly applicable knowledge for a general patient audience first.

The approved suggestions for application features, particularly the "Patient Medical History" section and the "User Feedback" mechanism, point to a desire for personalized, interactive tools. This echoes the principles of user-centered design in mHealth, which advocate for applications that adapt to individual patient profiles and foster engagement (24). The inclusion of a clinic directory, despite lower consensus, addresses a significant challenge in rare disease care: connecting patients with appropriate specialists.

When compared to other studies, our findings share common ground with educational needs assessments in chronic conditions like liver transplantation or diabetes, which also stress medication adherence, lifestyle management, and complication monitoring (25, 26). However, this study uniquely tailors these universal needs to the specific and often overlooked context of a rare disease, where information scarcity is a major issue. For instance, the focus on co-morbidities like osteoporosis and gastrointestinal issues specific to MCAS fills a gap not typically covered in generic allergy applications.

A potential limitation of this study is its conduct within a single geographic region and specialty group, which may limit the generalizability of the findings. Future research should incorporate the perspectives of patients and caregivers to ensure the application meets their lived experiences and practical challenges.

CONCLUSION

This needs assessment provides a vital blueprint for the next phase: the design and development of a dedicated mHealth application for MCAS patients. By establishing an expert-validated foundation for educational content and desired features, this study paves the way for an intervention with strong potential to increase patient knowledge, enhance self-efficacy, improve adherence to treatment regimens, and ultimately improve the quality of life for individuals navigating the complexities of MCAS. The implementation of such a tool could serve as a model for addressing the educational gaps prevalent in the management of other rare diseases.

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Declaration of the Use of Artificial Intelligence Tools

During the preparation of this work, the authors used DeepSeek solely to translate the manuscript from Persian to English and to polish the English grammar and style. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the publication's content.

Contributorship Statement

SS and ZN contributed to the conception and design of the study. GA and NN were responsible for data collection. Data analysis was performed by NN. SS, AMP, and ZN interpreted the results and drafted the manuscript. In addition, all authors reviewed and approved the final version of the manuscript, and all are responsible for the content of the manuscript.

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Declaration Of Conflicting Interests

The authors declared there are no conflicts of interest regarding the research, authorship, and publication of this article.

Data Availability Statements

The data will be made available by the corresponding author upon reasonable request.

REFERENCES

1. Beyens M, Elst J, van der Poorten ML, Van Gasse A, Toscano A, Verlinden A, Vermeulen K, Maes MB, Oude Elberink JNGH, Ebo D, Sabato V. Mastocytosis and related entities: a practical roadmap. Acta Clin Belg. 2023 Aug;78(4):325-335. DOI: https://doi.org/10.1080/17843286.2022.2137631
2. Brock I, Eng N, Maitland A. Adult-onset mast cell activation syndrome following scombroid poisoning: a case report and review of the literature. J Med Case Rep. 2021 Dec 18;15(1):620. DOI: https://doi.org/10.1186/s13256-021-03190-w
3. Bossi G, Brazzelli V, De Amici M, Pietra D, Raviola C, Naso M, Regalbuto C, Boselli F, Fortina V, Marseglia GL. Successful treatment with Omalizumab of a child affected by Systemic Mastocytosis: clinical and biological implications. Ital J Pediatr. 2023 Jan 13;49(1):6. DOI: https://doi.org/10.1186/s13052-022-01402-7
4. Vacheron N, McClinton T, Lynch-Smith DJ, Umberger R. Mast cell activation syndrome. J Am Assoc Nurse Pract. 2020 Apr 8;33(7):545-552. DOI: https://doi.org/10.1097/JXX.0000000000000396
5. Özdemir Ö, Kasımoğlu G, Bak A, Sütlüoğlu H, Savaşan S. Mast cell activation syndrome: An up-to-date review of literature. World J Clin Pediatr. 2024 Jun 9;13(2):92813. DOI: https://doi.org/10.5409/wjcp.v13.i2.92813
6. Gulen T. Using the Right Criteria for MCAS. Curr Allergy Asthma Rep. 2024 Feb;24(2):39-51. DOI: https://doi.org/10.1007/s11882-024-01126-0
7. Jahanshahi R, Nasirzadeh A, Farzan M, Domaradzki J, Jouybari L, Sanagoo A, Farzan M, Aghazadeh-Habashi K, Fallah Faraghe A, Bagheri S, Samiee M, Ansari A, Eskandari K, Namakkoobi N, Soltanimoghadam F, Mashali H, Yavari E, Bay S, Memaripanah N, Meftah E, Amanzadeh S, Talati F, Bahramzadeh S. Iranian future healthcare professionals' knowledge and opinions about rare diseases: cross-sectional study. Orphanet J Rare Dis. 2022 Sep 29;17(1):366. DOI: https://doi.org/10.1186/s13023-022-02458-8
8. Weiler CR. Mast Cell Activation Syndrome: Tools for Diagnosis and Differential Diagnosis. J Allergy Clin Immunol Pract. 2020 Feb;8(2):498-506. DOI: https://doi.org/10.1016/j.jaip.2019.08.022
9. Bonadonna P, Bonifacio M, Lombardo C, Zanotti R. Hymenoptera Allergy and Mast Cell Activation Syndromes. Curr Allergy Asthma Rep. 2016 Jan;16(1):5. DOI: https://doi.org/10.1007/s11882-015-0582-5
10. Castells M, Giannetti MP, Hamilton MJ, Novak P, Pozdnyakova O, Nicoloro-SantaBarbara J, Jennings SV, Francomano C, Kim B, Glover SC, Galli SJ, Maitland A, White A, Abonia JP, Slee V, Valent P, Butterfield JH, Carter M, Metcalfe DD, Akin C, Lyons JJ, Togias A, Wheatley L, Milner JD. Mast cell activation syndrome: Current understanding and research needs. J Allergy Clin Immunol. 2024 Aug;154(2):255-263. DOI: https://doi.org/10.1016/j.jaci.2024.05.025
11. Schwarz T, Schmidt AE, Bobek J, Ladurner J. Barriers to accessing health care for people with chronic conditions: a qualitative interview study. BMC Health Serv Res. 2022 Aug 14;22(1):1037. DOI: https://doi.org/10.1186/s12913-022-08426-z
12. Wyatt TH, Bayless AK, Krauskopf P, Gaylord N. Using mHealth Applications to Promote Self-Managed Health Behaviors Among Teens. J Pediatr Nurs. 2021 Jul-Aug;59:164-172. DOI: https://doi.org/10.1016/j.pedn.2021.04.025
13. Ventola CL. Mobile devices and apps for health care professionals: uses and benefits. P T. 2014 May;39(5):356-64. PMID: https://pubmed.ncbi.nlm.nih.gov/24883008
14. Khokhar D, Akin C. Mast Cell Activation: When the Whole Is Greater than the Sum of Its Parts. Med Clin North Am. 2020 Jan;104(1):177-187. DOI: https://doi.org/10.1016/j.mcna.2019.09.002
15. Samal L, Fu HN, Camara DS, Wang J, Bierman AS, Dorr DA. Health information technology to improve care for people with multiple chronic conditions. Health Serv Res. 2021 Oct;56 Suppl 1(Suppl 1):1006-1036. DOI: https://doi.org/10.1111/1475-6773.13860
16. Dos Anjos GR, Machado GF, de Barros CP, de Andrade VP, Maciel RMB, Cunha LL. Cancer survivorship in low- and middle-income countries: challenges, needs, and emerging support strategies. Front Public Health. 2025 Jul 16;13:1601483. DOI: https://doi.org/10.3389/fpubh.2025.1601483
17. Laktarashi HV, Bazrmanesh SM, Naseri Z, Daeechini A, Sharafi S, Mirzazadeh MN, et al. Design and Evaluation of a Mobile Health Application for Self-care of Diabetic Retinopathy Patients: Participatory Design Study. Jundishapur Journal of Chronic Disease Care. 2024;14(14):e158681. DOI: https://doi.org/10.5812/jjcdc-154556

18. Paghe A, Daeechini AH, Valizadeh Laktarashi H, Naseri Z, Bornasi E, Sharafi S. Designing the Critical Informational Components of a Smartphone Application for Self-Management of Gestational Diabetes. Health Education and Health Promotion. 2025;13(2):1001-9. DOI: https://doi.org/10.58209/hehp.13.2.297
19. Kopelovich SL, Buck BE, Tauscher J, Lyon AR, Ben-Zeev D. Developing the Workforce of the Digital Future: mHealth Competency and Fidelity Measurement in Community-Based Care. J Technol Behav Sci. 2024;9(1):35-45. doi: 10.1007/s41347-024-00385-y. Epub 2024 Jan 13. PMID: https://pubmed.ncbi.nlm.nih.gov/38571682
20. Cao M, Gao Y. Mast cell stabilizers: from pathogenic roles to targeting therapies. Front Immunol. 2024 Aug 1;15:1418897. DOI: https://doi.org/10.3389/fimmu.2024.1418897
21. Pyatilova P, Akin C, Alvarez-Twose I, Arock M, Bonadonna P, Brockow K, Butterfield JH, Broesby-Olsen S, Carter MC, Castells M, George TI, Gotlib J, Greiner G, Gülen T, Hartmann K, Hermine O, Horny HP, Jawhar M, Lange M, Lyons JJ, Maurer M, Metcalfe DD, Nedoszytko B, Niedoszytko M, Orfao A, Reiter A, Schwaab J, Sotlar K, Sperr WR, Triggiani M, Valent P, Siebenhaar F. Refined Treatment Response Criteria for Indolent Systemic Mastocytosis Proposed by the ECNM-AIM Consortium. J Allergy Clin Immunol Pract. 2022 Aug;10(8):2015-2024. DOI: https://doi.org/10.1016/j.jaip.2022.05.037
22. Ko, Dami, Lisa C. Bratzke, and Tonya Roberts. "Self-management assessment in multiple chronic conditions: a narrative review of literature." International journal of nursing studies 83 (2018): 83-90. DOI: https://doi.org/10.1016/j.ijnurstu.2018.04.009
23. Kurtin, Sandra, et al. "Patient and Advanced Practitioner Perspectives on Symptom Burden and Symptom Management in Indolent Systemic Mastocytosis." Journal of the Advanced Practitioner in Oncology (2025): 1.
24. Chatterjee A, Prinz A, Gerdes M, Martinez S, Pahari N, Meena YK. ProHealth eCoach: user-centered design and development of an eCoach app to promote healthy lifestyle with personalized activity recommendations. BMC Health Serv Res. 2022 Sep 4;22(1):1120. DOI: https://doi.org/10.1186/s12913-022-08441-0
25. Langarizadeh M, Moghbeli F, Ahmadi S, Maghsoudi B, sarpourian F, Nikokaran J. Needs Assessment of Self-Care Training Based on Cellphone to Design an Application for Liver Transplant Patients. TB 2023; 21 (5) :95-105. DOI: https://doi.org/10.18502/tbj.v21i5.11757
26. Zhu L, Shi Q, Zeng Y, Ma T, Li H, Kuerban D, Hamal S, Li M. Use of health locus of control on self-management and HbA1c in patients with type 2 diabetes. Nurs Open. 2022 Mar;9(2):1028-1039. DOI: https://doi.org/10.1002/nop2.1140