ORIGINAL ARTICLE

Exploring the Concept of Health-Related Quality of Life Among People with Heart Failure in Karachi, Pakistan

Anny Ashiq Ali[1], Khairulnissa Ajani[2], and Ambreen Gowani[3]

ABSTRACT

Objective: This study aimed to explore and understand the in-depth meaning of HRQoL among HF patients in a tertiary care hospital, Aga Khan University Hospital, Karachi, Pakistan. By conducting in-depth interviews and engaging with the patients, this research aimed to uncover the shades of their daily struggles, aspirations, and adaptations
Methodolgy: A qualitative interpretive design was used to study heart failure patients' perceptions of their HRQoL. Through the Purposive sampling technique, 14 Heart Failure patients were selected from the outpatient department of AKUH. In-depth semi-structured interviews were conducted until meaningful information was achieved. A manual content analysis technique followed to analyze the data.
Results: The study's findings revealed two major themes. Theme one, "Heart Failure Patients' Perception about Health," highlighted participants valuing good health, the role of good health for maintenance, and the prioritization of well-being. Participants underscored the significance of health as a precious asset, emphasizing how HF had transformed their perception of good health and motivated them to take active measures to maintain it. The second theme identified, "Attributes of HRQoL in Heart Failure," participants described how HF had redefined their roles: It required dietary adaptation, intervened in their social and family relations, and took them on a path toward acceptance. This is the theme that showed the variation of impact of HF in changing the daily responsibilities by meeting their dietary restrictions and social and family changes that came into their lives.
Conclusion: This study highlights the perceptions and experiences of HRQoL among HF patients in Karachi. If a better quality of life in relation to health is to be promoted in Pakistan among heart failure patients, the findings bring out the need to address the physical, emotional, social, and cognitive constituents of HRQoL. Such information can help to enrich person-centered care and therapies, enhancing the quality of life for patients suffering from heart failure in Pakistan.

Keywords: Dietary adaptation, heart failure, hrqol, patient perceptions, person-centered care, social relations

How to cite: Ali AA, Ajani K, Gowani A. Exploring the concept of health-related quality of life among people with heart failure in Karachi, Pakistan. Ann Jinnah Sindh Med Uni. 2024; 10(2):74-80

DOI: https://doi.org/10.46663/ajsmu.v10i2.74-80

INTRODUCTION

Heart failure is a chronic, progressive condition that impairs the ability of the heart to pump blood efficiently. It is an extremely common and rapidly expanding health-related problem, estimated to affect about 26 million people worldwide. The major symptoms for heart failure are poor exercise tolerance, fatigue, edema in the legs and ankles, and dyspnea[1]. According to the Non-communicable diseases (NCD) country profiles 2014 of the WHO, the country has to bear the dual burden of non-communicable diseases, which accounts for 49%, and communicable diseases, which accounts for 38%. It is believed that NCDs constitute about 77% of age-standardized mortality and are among the top 10 causes of sickness and death in Pakistan. Most of the NCDs, such as diabetes, hypertension, cancer, and other associated ones, are at very high prevalencein Pakistan[2]. The mortality rate of cardiovascular disease (CVD) is increasing worldwide, with 80% to 86 % of fatalities occurring in low- and middle-income nations (LMICs). Moreover, 82% of the 16 million fatalities caused by NCDs occur in LMICs, with CVD accounting for 37 % of these deaths[3]. Heart Failure (HF) is a critical ailment for which there is typically no treatment, but when the problem is controlled with HF treatments and lifestyle modifications, many individuals with HF have full, productive lives[4]. Moreover, health care is changing worldwide, therefore every individual who

1 Assistant Professor, IQRA University College of Nursing, North Campus, Karachi Pakistan

2 Associate Professor and Director, Network of Quality Teaching and Learning, Office of Provost.

3 Senior Instructor, Aga Khan School of Nursing and Midwifery & student of PhD in Nursing, University of Alberta, Canada

Correspondence: Dr. Anny Ashiq Ali, Assistant Professor, IQRA University College of Nursing, North Campus, Karachi Pakistan

Email: annyali248@gmail.com

Submitted: Jun. 02, 2024
Revised: Dec. 12, 2024 **Accepted:** Dec. 17, 2024

is at risk of CHF or having, must modify their lifestyle and know about their health-related quality of life.

The patients' health-related quality of life (HRQoL) is greatly impacted by HF, which also causes severe morbidity and mortality HRQoL is a broad term that refers to how patients perceive the effects of their condition overall. It indicates, at the very least, social, emotional, and cognitive, as well as physical, functioning[5]. According to WHO, an individual's perspective of their life, concerning their aims, expectations, standards, and priorities is influenced by their culture and value systems[6].

There is a shortage of global evidence about how people with HF living in different contexts define their HRQoL. To expand the HRQoL of people with HF it is important to assess their HRQoL using valid and reliable tools. However, most of the HRQoL tools in HF have been developed in the West and are based on the Western population; they may or may not necessarily reflect the aspects of HRQoL that the people with HF uphold in the Pakistani context. Therefore, it is difficult to ascertain if the Western HRQoL is suitable for use in Pakistan unless an understanding is developed about the definition of what HRQoL means for people with HF. This study provides basic knowledge regarding the HRQoL of people with HF in Pakistan.

METHODOLOGY

IRB/ERC Approval:

Data in this study were collected between March and June 2023, and data collection commenced following approval by the Aga Khan University Ethical Review Committee with Ref. No:2023-8165-23834.

This was an interpretive qualitative study conducted at Karachi, Pakistan, to explore perceptions about HRQoL among HF patients. Purposive sampling was done on 14 patients with HF from an outpatient cardiac clinic of a tertiary care hospital, Aga Khan University Hospital, in Karachi, Pakistan. Objectives of the study were explained to all participants and written informed consent was taken from every participant.

Each interview took 30 to 40 minutes. A demographic tool and a semi-structured interview guide with eight open-ended questions were used for information on study participants' perceptions of health, life, and living with daily limitations following the HF diagnosis. Participants were free to respond in either Urdu or English, depending on their ease and comfort speaking any of the languages. There were no gender constraints; participants of both genders between the ages of 35 and 75 years, with a medically diagnosed case of HF, and who could understand and communicate in either English or Urdu, were eligible for recruitment. Any participant with symptoms of HF such as shortness of breath, fatigue, or swelling of the ankles at the time of the first contact was excluded. Written consent for voluntary participation and audio recording was obtained, and confidentiality was maintained. The interview transcripts were translated and transcribed according to established methods, followed by an analysis of emerging themes.

The analysis process consisted of numerous conscientious steps to maintain integrity and depth of the findings. Creswell 2013 steps of analysis was used, employing the manual approach to ensure the in- depth engagement of the data, no use of software, while Lincoln and Guba (1985) criteria of trustworthiness were applied to enhance the rigor and reliability of the findings. Firstly, data was organized with great care and stored in a secure setting to maintain participant confidentiality. Several readings of the transcribed interviews ensured that there was a much nuanced understanding of participants' perspectives. Data coding attributed these key concepts, which were subsequently identified as themes. Rigorous procedures, such as regularly going through thesis committee reviews, upheld the trustworthiness of the analysis. Other measures that further strengthened the confirmability of the findings included member checks and confidentiality safeguards. Reflective notes reduced researcher bias; credibility and reliability checks on the obtained data were embedded. There were personal biases that needed to be recognized and reduced as the process went on. The transferability in this study might be limited only to similar settings, but the purposive sampling and detailed documentation increase the potential applicability. The ethical considerations to consider and protocols for obtaining participants' informed consent, preserving their confidentiality, and securing their data.

RESULTS

The sample size included 14 patients who fulfilled the inclusion criteria and consented to the individual interviews. These patients were under treatment for heart failure and were attending the out-patient Department of Cardiology, Aga Khan University Hospital, Karachi, Pakistan.

The demographic characteristics including mean age of the participants was 64.21 years. Among the participants, 42.9% (n=6) were male, and 57.1% (n=8) were female HF patients. The majority of the participants were married (78.6%, n=11), followed by

those who were single (7.1%, n=1) or widowed (14.3%, n=2). The average household income was 75,714 PKR. The participants' educational background included 28.6% of participants with intermediate education, and 42.9% retired. The Table 1 provides the summary of demographic data.

The content analysis from the participants' narratives led to the identification of multiple codes, which were then grouped into categories. These categories were further merged to form themes, providing a deeper understanding of the participants' experiences. The concept of HRQoL of HF patients was explored and the two main themes emerged from the study. The themes and categories that emerged are given in Figure 1

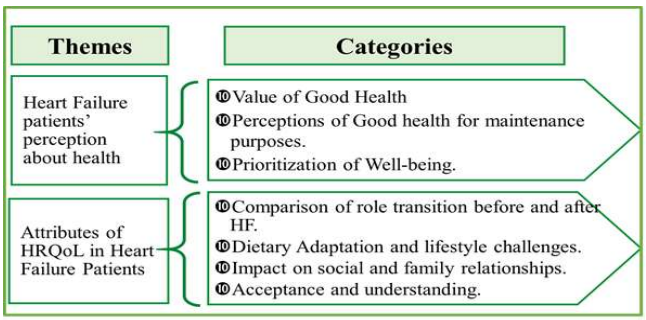

Fig 1: Themes and Categories

HF affects multiple domains of an individual's life; it was significant to explore the perspectives and significance of health after having HF. The three major categories under this theme are reflection and value of good health, perceptions about good health for maintenance, and prioritization of well-being (Figure 2)

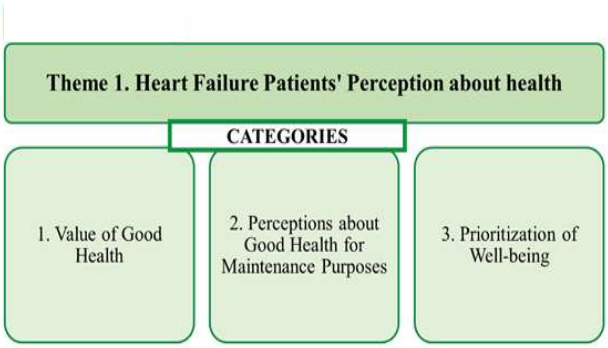

Fig 2: Theme One: HF Patients' Perception about Health

Participants had also begun to notice how their physical health was connected to their mental and emotional well-being. Realizing this connection, they realized that staying healthy had positive effects on their state of mind too. Participant recognizing the significance of good health acknowledged its unparalleled contribution to preserving and enhancing the very essence of life itself by stating,

Table 1

Demographic Variables Age (years)	**Number of Participants (n) Range 50-75**
Total Household Income (Rs)	Range 40,000-100,000
Gender	
Male	06
Female	08
Marital Status	
Married	11
Unmarried	01
Widowers	02
Occupation	
Housewife	04
Retired	06
Non-Working	03
Working	01
Level of Education	
No Formal Education	01
Primary Education	05
Secondary Education	01
Intermediate	04
Diploma/Degree	03
Religion	
Islam	13
Christianity	01
Type of Family	
Joint Family	09
Nuclear Family	05

"I have realized how important it is to stay healthy. It's like having a key to a happy life that you must take care of. My health feels like a special present, and it reminds me to be grateful and take good care of it. Seeing my health as a gift makes me thankful and determined to keep it safe". (HFP-03)

Some participants showed gratitude to Allah (God) for the blessings they had received after going through the disease process and how their health was improving after experiencing this challenge. As one of the participants shared,

"I am grateful to Allah (God) that I am alive. Whatever Allah (God) has granted us we have to accept it and modify our lifestyle to accept this challenge" (HFP-05).

Many participants acknowledged the value of life and chose to live it fully, cherishing each moment. As one participant stated, *"Every day is a chance for me to live a happy life" (HFP-11).*

Category: Perception about Good Health for Maintenance Purposes

Participants viewed their health as intertwined with the health of those around them, fostering a sense of responsibility to maintain it. While sharing their experiences, the participants showed their emotions through tears and grimaces.

"Being healthy is not just for me. It is for those I love too. Taking care of myself is like taking care of them" (HFP-01).

"After my HF diagnosis, I learned how important it is to make healthy choices. It is not just about me; I must stay well. I work hard to keep myself healthy because I want to feel better and be there for those I care about". (HFP-04)

Category: Prioritization of Well-Being

In this category, the participants showed that they cared about their health. They realized that taking care of themselves would help them follow their dreams, especially with regard to their kids.

One of them said, *"I focus on my health because it gives me the energy to chase my dreams, especially for my children. Going for check-ups regularly is important to me"(HFP-02).*

Participants also showed contentment and appreciation for the current situation, with a renewed perspective on life. As one of the participants shared, *"I had been given a second chance at life. It made me more grateful and motivated to care for myself, as health is the backbone of a fulfilling life" (HFP- 10).*

Theme Two: Attributes of HRQoL in HF

Individual perspectives regarding HRQoL and its holistic approach to their life after experiencing HF were explored. Every participant articulated a different opinion and a different viewpoint about their life in a different way, with mixed feelings (Figure 3)

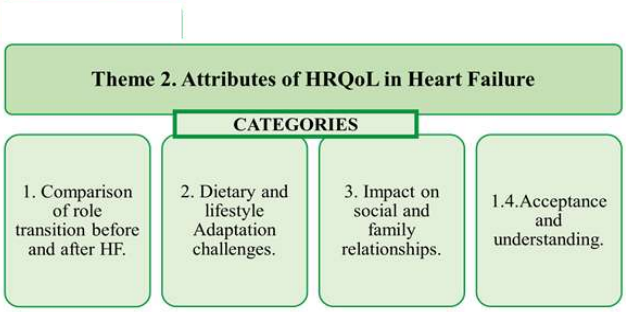

Fig 3: Atributes of HRQoL in Heart FailureF

Category: Comparing Role Tansition before and after HF

Many participants expressed feelings of frustration and sadness due to the limitations that HF had imposed on their physical abilities. One of the participants stated, *"HF has brought a lot of frustration and sadness. I feel limited in doing my household work, like cooking, and washing. It needs strength which I do not have. I experienced shortness of breath when I stand for a prolonged time" (HFP-01).*

Participants showed their frustrations with their social boundaries through their narrations. Stated, *"I cannot go anywhere, not meet anyone, and even not engage in social activities. I am stuck because of my illness"*

Female participants expressed their anxiety and fear related to their family. Participants stated, *"As women, we are the pillar of our family, we have to take care of ourselves. After HF, I always used to worry when I became sick because there was no one to take care of my family. Nobody was there for cooking cleaning, and my children, my husband also became worried about my health" (HFP-13).*

Category: Dietary Adaptation and Lifestyle Challenges

Participants adjusted their lifestyles and dietary habits in response to their health conditions and adapted to navigate their daily lives. This involved modifying eating habits, incorporating exercise routines, and embracing wellness practices to maintain a balanced and healthy way of living. One of the participants stated,

"I realized that I needed to make some changes to feel better. So, I started looking at what I eat and how I live. I began choosing foods that were good for me, even if they were not what I used to eat. And you know what? It's not just about food. I started doing exercises that my body could handle and finding ways to relax my mind. It is like I am adjusting my life to fit my health needs, and it's helping me feel better, overall" (HFP-05).

Category: Impact on Social and Family Relationship

The category of impact on social and family relationships highlighted how HF affected participants' interactions with their loved ones. The connection with families and friends after HF made them worried about their future and felt unsure about their purpose in life due to the illness. Participants verbalized that they were not as valuable as before. One of the participants stated,

"Well, since my heart became weak, I have been close to my family and friends. It is not easy. I worry a lot about what's next, you know? Sometimes I don't know what to do anymore, and sometimes I feel like I am not that important" (HFP-02).

Category: Acceptance and Understanding

Many participants described how close relationships had offered them solace and support. Indeed, many participants identified support from friends and family as quite invaluable, due to the boost it gave their confidence and strength. They shared how they overcome adversities, turn to others for emotional support, and live in the present moment toward becoming resilient.

"I used to stress about the future, but that only made things worse," one of them said. Now I focus on here and now, daily planning small pleasures. I ask for help from the people I love when I feel overwhelmed (HFP~06).

Analysis of this data provided insight into the complicated experiences of patients suffering from heart failure in Pakistan and problems related to maintaining health and wellbeing. The research directly used participant statements, therefore documenting real voices and experiences of people living with heart failure.

DISCUSSION

This study followed up the results on how patients' perceptions of their quality of life influenced the health of patients and had positive effects on QOL after HF. The primary goal of treatment for patients with heart failure is maintaining the physiological balance and the overall HRQoL of the patient with HF. This feeling of gratitude, culturally intrinsic in the Pakistani context and reinforced by religion, served as both a strong coping strategy and an emotional response. Participants expressed deepest gratitude for every day of life despite all the problems they were facing.

The findings are that the link between gratitude and well-being is partially mediated by social support and coping[7]. One of the major findings that came out of the research was the interrelation of physical health with mental and emotional well-being. This therefore implies that besides reducing the burden of disease, physical health improvements translate into activities that promote good mental and emotional conditions. In the similarly done study in Serbia, poor HRQoL in HF patients is reported as independently related with a higher possibility of cardiac mortality and HF linked readmissions[8].

The emergent code "the meaning of health" showed that despite their discontent with the restrictions imposed on them by their illness, patients participated actively in their conditions. Meaningfully[9], showed that such experiences resulted in a higher growth rate and sublimity amidst lifestyle restriction.

The importance of health, therefore, went beyond the individual to the collective, reinforcing the thinking that 'health is a collective responsibility'. Beyond believing good health to be a blessing, participants strongly reiterated it as the top priority. Moreover, the research findings emphasized the importance of timely intervention in order to avoid delay in treatment and subsequent complications and dependency. One of the studies replicates the findings and shows that health dimensions were perceived to influence each other; and physical and mental health dimensions were chosen as the most relevant items[10]. This sense of responsibility and seriousness manifested in their consistent adherence to regular doctor visits, prescribed medications, and avoidance of non-prescription drugs. These findings align with a cohort study conducted in the USA, which underscored the importance of self-care maintenance activities, such as medication adherence and dietary sodium restriction, in managing HF[11].

In Pakistani context, participants certainly exhibited a strong commitment to improving their daily routines, highlighting a holistic approach to well-being. They displayed resilience in the face of challenging HF symptoms, which catalyzed positive lifestyle changes. However, no particular study was found that talked about the holistic approach being affected, but a descriptive cross-sectional study found that sleep problems were the most burdensome symptom, and they were linked to lower HRQoL, along with worse functional status and reduced overall symptom burden[12]. The present also revealed a sense of contentment and appreciation for the current situation, accompanied by a renewed perspective on life. These findings match those from a study conducted in South Asia, which emphasized the role of personal connections, including those with healthcare providers, family, and spirituality, in shaping self-management approaches and reflecting individuals' desires to maintain balance and autonomy in managing their chronic conditions[13].

The analysis also showed the broader advantages of proactive health habits that extend beyond physical well-being but hold particular relevance within the context of Pakistan where the cultural and societal aspects play a significant role in overall well-being. Such proactive habits can empower individuals to lead healthier, more fulfilling lives, fostering a sense of control, confidence, and energy, ultimately improving

their overall quality of life. Further, the analysis showed that these practices exerted a positive influence on the mental and emotional states of HF patients, ultimately contributing to an enhancement in their overall quality of life. These outcomes resonate with a prospective interventional study conducted in Pakistan, which highlighted a robust connection between physical functioning and HRQoL, thereby reinforcing the essential role of physical health in safeguarding the quality of life among individuals grappling with HF[14].

One component emerged from this study is HF patients experienced anger and frustration, as they were not able to cope up with their daily life activities due to physical limitations and their dietary restriction which bring the need for patient centered approach. One study also emphasized on the physical health which has a directly impact on the HRQoL[14]. Along with this, dependency on family members also arise due to limitations Moreover, HF patients also struggle with their daily life restriction and also some of them are in the phase of adaptation by prioritizing and coping with their restrictions. A similar study showed that the modification in their daily activities is one of the aspects of adaptation process[15]. The financial burden can one of the emerging concept come from the participants due to HF. A similar study revealed that the role disruption and not contributing towards finance can increase the burden and reduce self-esteem[16]. Sense of support from family members and spouse is one of the crucial concept arising from this study as this contributes to overall well-being of an individual and strengthens their spirituality and find solace. By identifying the significance of support systems holistic approach to manage the care can be determined.

CONCLUSION

The qualitative study thus embarks on an important quest for HRQoL in patients with HF in Karachi, Pakistan. It focuses mainly on the perceptions and experiences of HF patients attending outpatient clinics, giving insight that is critical to their health and well-being status. It explores perceptions and experiences of patients with heart failure attending outpatient clinics, which reveals some important insight into their health and wellbeing. To the best of our knowledge, this is the first qualitative study conducted in Pakistan to explore the concept of HRQoL among HF patients. The overall contribution of this study is to deepen the understanding of the challenges HF patients in Pakistan face and to underline the necessity and importance of patient-centered care in improving their quality of life. It points out a highly relevant perspective for any comprehensive and culturally sensitive management of HF in Pakistan. Not only do they recognize the financial burden and emotional toll on families, but they also offer support for patients in their changing roles and address issues related to daily life. By addressing these challenges can improve the HRQol of patients.

RECOMMENDATIONS

This study has some strength, like innovativeness in the setting of Pakistan; it laid a foundation for the evaluation of HRQoL among HF patients. Other than addressing challenges within role shifts and lifestyle changes, the study points to values like family support, thankfulness, and good health. The research does have several limitations: it focuses on only one clinical setting and thus has limited generalizability of the results to different patient populations or health care settings.

Based on the findings, the study offers several recommendations for clinical practice, nursing education, and future research. It advocates for holistic assessments of HF patients, the integration of psychosocial support, and enhanced collaboration among healthcare professionals. Additionally, it calls for further research to explore the sexuality domain and to implement randomized controlled trials to evaluate nursing interventions.

Funding: Nil

Conflict of interest: Authors declare that there is no conflict of interest.

Authors' Contributions: AAA: Conceptualized the review, conducted the literature search, and drafted key sections. KA: Refined the analysis, contributed contextual insights, and reviewed the discussion. AG: Ensured methodological rigor and polished the manuscript.

REFERENCES

1. Jessup M, Marwick TH, Ponikowski P, Voors AA, Yancy CW. 2016 ESC and ACC/AHA/HFSA heart failure guideline update—what is new and why is it important? Nat Rev Cardiol. 2016;13(10):623-8.
2. Rafique I, Saqib MA, Munir MA, Qureshi H, Rizwanullah KS, Khan SA, et al. Prevalence of risk factors for noncommunicable diseases in adults: key findings from the Pakistan STEPS survey. East Mediterr Health J. 2018;24(1):33-41.
3. Barolia R, Sayani AH. Risk factors of cardiovascular disease and its recommendations in Pakistani context. J Pak Med Assoc. 2017;67(11):1723.

4. Ewnetu Tarekegn G, Derseh Gezie L, Yemanu Birhan T, Ewnetu F. Health-related quality of life among heart failure patients attending an outpatient clinic in the University of Gondar Comprehensive Specialized Hospital Northwest, Ethiopia, 2020: using structural equation modeling approach. Patient Relat Outcome Meas. 2021;12:279-90.
5. Seid MA. Health-related quality of life and extent of self-care practice among heart failure patients in Ethiopia. Health Qual Life Outcomes. 2020;18(1):1-7.
6. Lamesgin Endalew H, Liyew B, Kassew T, Ewnetu Tarekegn G, Dejen Tilahun A, Sewunet Alamneh T. Health-related quality of life among myocardial infarction survivors: structural equation modeling approach. J Multidiscip Healthc. 2021;14:1543-52.
7. Lin CC. The roles of social support and coping style in the relationship between gratitude and well-being. Pers Individ Dif. 2016;89:13-8.
8. Erceg P, Despotovic N, Milosevic DP, Soldatovic I, Mihajlovic G, Vukcevic V, et al. Prognostic value of health-related quality of life in elderly patients hospitalized with heart failure. Aging Clin Exp Res. 2019;31(7):935-45.
9. Farsi Z. The meaning of disease and spiritual responses to stressors in adults with acute leukemia undergoing hematopoietic stem cell transplantation. J Nurs Res. 2015;23(4):290-7.
10. Lee HJ, Ock M, Kim SY, Kim SH, Kim SH, Jo MW. Health group and disease group's perceptions of health and health-related quality of life: a focus group study and in-depth interviews. Korean J Health Promot. 2016;16(1):56-66.
11. Liljeroos M, Kato NP, van der Wal MH, Brons M, Luttik ML, van Veldhuisen DJ, et.al. Trajectory of self-care behaviour in patients with heart failure: the impact on clinical outcomes and influencing factors. Eur J Cardiovasc Nurs. 2020;19(5):421-32.
12. Thida M, Asdornwised U, Thosingha O, Dumavibhat C, Chansatitporn N. Symptom Experience, Symptom Management Strategies, and Health Related Quality of Life among People with Heart Failure. Pacific Rim Int J Nurs Res. 2021;25(3):223-226.
13. Tharani A, Van Hecke A, Ali TS, Duprez V. Perspectives on self-management of individuals living with chronic illnesses: a qualitative study in the Asian context. Res Nurs Health. 2023;46(6):591-602.
14. Mack L, Athilingam P, Adorno-Nieves J. Health literacy impacts knowledge and the use of education app in heart failure: a pilot study. Cardiovasc Res. 2021;5(5):1-5.
15. Peltzer S, Hellstern M, Genske A, Jünger S, Woopen C, Albus C. Health literacy in persons at risk of and patients with coronary heart disease: a systematic review. Social Sci & Medic. 2020;245(3):112711.
16. Mubarak N, Raja SA, Khan AS, Kanwal S, Saif-ur-Rehman N, Aziz MM, et.al. A conceptual framework of the way forward to a community pharmacist–general practitioner collaborative medication therapy management model for chronic diseases in Malaysian primary care: A qualitative study. Risk Manag & Healthcare Policy. 2021;19(2):1615-27.