An explanation on the process of production to the utilization of patient education media in chronic diseases in Iran: Protocol for a grounded theory study

Faezeh Amini, Parvaneh Khorasani[1], Hasan Ashrafi-rizi

Abstract:

BACKGROUND: Chronic diseases are always considered one of the most critical challenges of the health system in any country. Patient education on self-care is one of the basic strategies in controlling the disease process and minimizing complications in patients with chronic diseases. It seems that in the process of patient education, from the preparation of materials to their delivery to the final user, many problems prevent the proper and practical education. The study aims to explain the process of production to the utilization of patient education media in chronic diseases in Iran.

MATERIALS AND METHODS: This study employs a grounded theory (GT) methodology and the data will be analyzed by Strauss and Corbin method. Participants in this study include groups involved in the field of patient education, including policymakers, managers at all management levels, clinical, educational, and public health service providers (physicians, nurses, medical librarians, medical, and nursing professors, NGOs in the field of patient education, physiotherapists, nutritionists, and psychologists) as well as service receivers such as patients, their family, and caregivers whom will be all selected through theoretical as well as snowball sampling method. The interview method will be semi-structured and will not be ceased until the data is saturated.

CONCLUSIONS: It is anticipated that in this study, the pros and cons of the process of production to utilization of patient education media will be identified and appropriate solutions to improve this process will be provided.

Keywords:

Chronic diseases, grounded theory, Information sources, patient education, public health system research

Department of Medical Library and Information Sciences, Isfahan University of Medical Sciences, Isfahan, Iran, ¹Nursing and Midwifery Care Research Center, Department of Community Health and Geriatric Nursing, School of Nursing and Midwifery, Isfahan University of Medical Sciences, Isfahan, Iran

Address for correspondence:
Dr. Hasan Ashrafi-rizi, Department of Medical Library and Information Sciences, Health Information Technology Research Center, Isfahan University of Medical Sciences, Isfahan, Iran. E-mail: hassanashrafi@ mng.mui.ac.ir

Introduction

Chronic diseases are always considered as one of the most critical challenges in the health system in any country. There are four main types of chronic diseases: cardiovascular diseases (such as heart attacks and strokes), cancer, chronic respiratory diseases (such as chronic obstructive pulmonary disease and asthma), and diabetes.[1,2] These non-communicable diseases cause the death of about 38 million people worldwide annually, three-quarters of which occur in developing countries.[3]

The ever-increasing prevalence of these diseases imposes great economic losses on countries and health systems.[4] The reason for creating opportunities and increase in risk factors for these diseases in recent years are: changes in lifestyle, smoking, lack of proper physical activity, and poor diet. However, the general increase in life expectancy in many countries that

relevantly increase the rate of the aging population and, consequently, the risk of developing chronic diseases is another reason.[3,5]

Chronic illnesses affect everyone regardless of age, economic status, or culture and can be a significant cause of disability, dependence on others, job loss, increased risk of hospitalization, and increased mortality. There are also others who face minor discomfort while some others fail in their daily life activities.[6]

As the control of chronic diseases requires the active participation of patients, thus, lack of patients' perceptions of their illness severity and lack of involvement in self-care behaviors affects the treatment cycle.[7]

Patient education is aimed at empowering patients to acquire self-care skills. Patient education includes a wide range of programs and materials (or media, e.g., audio, video, and print) designed to help patients and their families achieve, maintain, or promote their optimal health. It can also lead to control symptoms, slow the disease progression, significantly improve the quality of life, and reduce the term of hospitalization that in turn cutting down the costs.[8-10]

It seems that in the process of patient education on self-care, from the beginning of preparing materials to their delivery to the final user, many problems and challenges prevent proper and practical education.[11-13] Since inadequate and ineffective use of patient education causes patients to make mistakes in self-care and, in some cases, injure themselves.[14] The present study tries to explain the process of production to utilization of patient education media in chronic diseases, from the point of view of the most involved and important factors, through the grounded theory (GT) method. Besides that, the challenges (obstacles and problems) of the process are explored to provide the necessary solutions that lead to process improvement. This study aims to develop a comprehensive and contextualized explanation of participants' experiences in the process of production to the utilization of patient education media in chronic diseases.

Materials and Methods

Study design and setting
The research method is grounded theory (GT) and the type of study is fundamental-applied. As the outcome will be a paradigm model that can be used in policymaking, GT is the best way to study the processes and experiences that are depicted in different ways. It is also a helpful method for studying the social processes in human interactions in addition to the structure and process that lead to them.[15] GT can help researchers to study the process-based phenomena that are related to cultural aspects, interactions, or social and organizational experiences.[16]

The patient education phenomenon is a complex process closely concerned with the cultural and organizational conditions of each country and affected by various human and environmental aspects that may influence patients' social interactions, families, and the medical care team. Therefore, it can be examined using qualitative research methods such as GT. It is a research method that uses strict procedures for data analysis and will enable the researcher to search for and conceptualize the hidden social and collective patterns and constructions in the area of interest. Thus, it is appropriate for this study because the researcher intends to study the process of production to the utilization of patient education media in chronic diseases in Iran.

The research setting can be seen as the physical, social, and cultural sites where the people being studied live, experience life, and where the researcher conducts the study. In qualitative research, the focus is mainly on meaning-making, and the researcher examines the participants in their natural settings.[17] As a result, the research setting in this study will be hospitals, medical centers, physicians' offices, and any place chosen by the participants.

Study participants and sampling
Participants in this study include informed groups involved in patient education as well as the patients themselves throughout Iran and as follows:
- Politicians (Ministry of Health, Treatment and Medical Education, Deputy for Public Health, and Deputy for Nursing)
- Managers at all levels of management (managers of hospitals, supervisors, patients, and staff educators)
- Providers of clinical, educational, and research services (physicians, nurses, medical librarians (specialized in health resources to provide medical information for physicians, allied health professionals, patients, consumers, etc.), medical and nursing lecturers, non-governmental organizations interested in patient education and physiotherapists, nutritionists, and psychologists (as helping hands in the treatment course of chronic diseases)
- The service receivers (patients, their families, and the caregivers).

Participants will be selected through theoretical sampling and the snowball sampling method. In theoretical sampling, known as the dominant method in Grounded theory, samples are selected in a way that helps to create the theory. The researchers first make the best choices based on their judgment of the best sources of

information such as observation, interviews, or written sources and then look for samples that complete the theory.[18]

Inclusion criteria
To have experience in the patient education process (producing, presenting, or using patient education media). Be able and willing to participate in the research and be able to speak Persian.

Exclusion criteria
Participants will be excluded for not providing consent.

Data collection tool and technique
The main data collection approach in this research is interview and it is anticipated that approximately 30 participants will be recruited from different groups (politicians, managers, service providers, and service recipients) are being interviewed to fully develop patterns, concepts, and categories.[19] The interviews will be conducted as far as the data saturation is achieved. Since the research method of grounded theory seeks to fathom the world of people from their perspective, the interview is the best and the most common method of data collection in this method.[17] In this study, the approach is a semi-structured interview as it combines both the structured and unstructured interview styles in which the interviewer asks only a few predetermined questions while the rest of the questions are not planned in advance. This method is the most common interview method in qualitative research. It proceeds with effective interaction between the participant and the researcher and in the direction of the initial guidance of an interview guide.[11]

The Interviews will be conducted at three levels: local, provincial, and, national. Also, the interviews will be conducted face-to-face or through a third party (due to the conditions caused by the COVID-19 pandemic), and if the participants agree, the time and place of the interview will be determined with their consent.

At the beginning of each interview, the purpose of the interview is stated and permission is obtained to record the session, and if the participants are reluctant, the main points will be noted down to be approved by them later. Participants are also reassured about the confidentiality of the information and the recordings. At the time of writing, 19 participants have been recruited and data collection is in progress.

The field notes can also include descriptions of the situation and some informal interviews. The memo is also a step between data collection and writing the original text of the research report and plays an essential role in constructing the theory and allows the researcher to analyze the data and codes at the beginning of the research. Setting notes and memos will be other approaches to data collection in this research.

Data management and analysis
Simultaneous with data collection, their analysis will be performed with the approach of Strauss and Corbin. Strauss-Corbin's approach is more open and flexible than the Glazer. Also, in the Strauss-Corbin approach, a clear and more explicit guide is provided.[20] Another reason for using the Strauss-Corbin method is that it has evolved and is more consistent with the contemporary constructivist theory. In this method, data is systematically collected and analyzed during the research process and has more explicit instructions applied for data analysis.[21] To analyze the data, the content of the interviews is transcribed immediately after each interview and saved in MAXQDA 2020 to be coded.

The Strauss-Corbin approach has three main stages: open coding, axial coding, and selective coding. During these three stages, concepts gradually emerge from within the codes, from within the concepts of the categories, and from within the categories. The boundary between coding types is artificial; that is, we may go from one coding stage to another without realizing it, and this happens more in the open and axial coding stages.[22] In this way, each transcript is divided into meaning units and coded descriptively. Formed concepts are examined in relation to each other and categorized with similar concepts and labeled to show their similarity. Subsequent interviews are coded using existing codes and newly created codes. Comparisons between concepts and categories are made within and between items, and codes are either added to existing categories or created new categories. As the interviews proceed, the dimensions and characteristics of each category are determined to form distinct and rich saturation categories. Then, by moving from inductive interpretation of data to argumentative analysis of how categories relate, theory building begins.

Theory development
The Strauss-Corbin storyline approach will be used to construct and express a descriptive narrative about the central phenomenon. Once the main line of the story and the central category are identified, at this stage, the rest of the categories should be related to it. This connection is made within the framework of a paradigm model because it helps the researcher to know how the categories should be placed back and forth.[23] The theory will be made when the categories are related to each other and the system of communication between them is expressed in terms of time and concept. This step is accomplished, the researcher goes back and adapts the completed model to the data and finalizes it.

Rigor and trustworthiness

Lincoln and Guba's evaluative criteria will be used to ensure the trustworthiness and accuracy of the research. According to their criteria, trustworthiness involves establishing credibility, confirmability, dependability, and transferability.[24,25] The credibility of the data is reached by reviewing the gathered manuscripts of the participants and the researcher's activities such as prolonged engagement and persistent observation while the researcher is present in the hospitals, health promotion offices, and related units to observe the patient education process closely. For a prolonged engagement, the participants are interviewed in more than one face-to-face session to gain a deeper understanding. The interviews are then returned to the participants and the advisors to review the content. At various stages of data collection and analysis, the researcher will check with the participants to ensure the researcher expresses the actual experiences of participants- just as they understood them. Another approach taken to increase the credibility of the research is four types of triangulation: (1) data triangulation; meaning using multiple data sources in an investigation to produce understanding the subject from different angles. For this purpose, the subject is examined from the perspective of different groups involved in the production process of patient education media. Sample selection with maximum diversity (selection of different medical specialties, patients with various chronic diseases in age levels, cultural, economic, and social discrepancies) will increase the credibility of the data, (2) researcher triangulation; for this purpose, supervisors will help to analyze the data (member checking), (3) theory triangulation: the use of multiple perspectives to interpret the results of a study, and (4) and the last is methodological triangulation: the use of multiple methods to conduct a study (interview, observation, field notes, etc.) and to collect data.

Confirmability, a degree of neutrality where findings are not shaped by biased interest, is acquired by agreeing on the codes and categories extracted by the researcher and the peer check. Dependability shows that the findings are consistent and could be repeated, using external checks and re-reading all data as well as peer review (supervisors review findings and comment on them).

In transferability, the researcher will also try to write all the process that has taken place in all the stages of the study (working method, analysis, results, etc.) in detail so that the readers can adapt to the context and use it if they will.

Ethical consideration

- Ethical approval has been obtained from the ethics committee of Isfahan University of Medical Sciences (IR.MUI.RESEARCH.REC.1399.573).

- Participants will be explained the objectives of the study, as well as the voluntary of their participation in the research. If they wish to participate, the consent form will be provided to them.
- Any recording is done with the participants' permission and their agreement.
- Participants are assured of the confidentiality of the information provided by them.
- The results of the research will be offered to the participants upon request.
- To respect the rights of the participants, before the session, the objectives of the research and methodology are explained to each of them.
- The priority of time and place of the interview is suggested by the participants.

Discussion

This study avails the grounded theory method to explain the production to utilization process of patient education media in chronic disease. The theory developed in this study will be based on the experiences of a specific sample in a particular socioeconomic context, and obviously others may have different experiences. However, the study, based on the views of different groups involve in the process of production to utilization of patient education media will examine the current situation in this process and will show its pros and cons and will provide the necessary solutions to the process improvement. The study will support policymakers in decision-making to improve patient education services by giving the experience of the different groups of people involved in this process.

Limitations and recommendation

Due to the COVID-19 pandemic, it is very likely that face-to-face interview will not be possible in some cases. Interactive virtual interviewing using web-based video conference platforms will be considered for these participants.

Study novelty

Based on the studies carried out so far, it seems that the process of production to the utilization of patient education media have not been investigated comprehensively. Although various studies have investigated the barriers of patient education, the production process of patient education media is neglected. In this study with grounded theory method, the authors will examine this process from the perspective of healthcare workers and staffs at all levels of the health system that are involved in this process. the findings will inform us about current process, its barriers and facilitators and will provide appropriate solutions to improve this process in Iran's health-care system.

Conclusion

The process of production to the utilization of patient education media will be determined. It is anticipated that the pros and cons of this process will be identified and appropriate solutions will be provided.

Declaration of patient consent
The authors certify that they have obtained all appropriate consent forms. The participants understand that their names and initials will not be published and due efforts will be made to conceal their identity, but anonymity cannot be guaranteed.

Conflicts of interest
There are no conflicts of interest.

References

1. GoliI S, Mahjub H, Goli M, Sadeghi far M. Risk factors ranking of non-communicable disease in different provinces of Iran using multivariate factor analysis methods. J Knowl Health 2018;12:7-15.
2. Kivelä K, Elo S, Kyngäs H, Kääriäinen M. The effects of health coaching on adult patients with chronic diseases: A systematic review. Patient Educ Couns 2014;97:147-57.
3. Ministry of Health and Medical Education. National Committee for the Prevention and Control of Non-Communicable Diseases. National document for prevention and control of non-communicable diseases and related risk factors in9/Islamic Republic of Iran from 2015 to 2025. Tehran: Aftab Andisheh; 2015.
4. Williams J, Allen L, Wickramasinghe K, Mikkelsen B, Roberts N, Townsend N. A systematic review of associations between non-communicable diseases and socioeconomic status within low-and lower-middle-income countries. J Glob Health 2018;8:020409.
5. Senapati S, Bharti N, Bhattacharya A. Modern lifestyle diseases: Chronic diseases, awareness and prevention. Int J Curr Res Acad Rev 2015;3:215-23.
6. Nia HS, Hatef M, Allen KA, Shafipour V, Esmaeili R. The psychometric assessment of the chronic disease self-efficacy scale in Iranian patients with chronic diseases. Int J Community Based Nurs Midwifery 2019;7:97-108.
7. Dunn P, Conard S. Improving health literacy in patients with chronic conditions: A call to action. Int J Cardiol 2018;273:249-51.
8. Memarian R, Vanaki Z. The effect of implementing clinical supervision model on the patient education outcomes. J Health Promot Manage 2012;1:28-36.
9. Collinsworth AW, Brown RM, James CS, Stanford RH, Alemayehu D, Priest EL. The impact of patient education and shared decision making on hospital readmissions for COPD. Int J Chron Obstruct Pulmon Dis 2018;13:1325-32.
10. Mohebbi B, Sabouri M, Tol A. Application of health education and promotion theory-based interventions on patients with cardiovascular disease: A systematic review. J Edu Health Promot 2021;10:236.
11. Adib-Hajbaghery M, Zare M. The barriers to patient education from the viewpoint of nurses in Iran: A systematic review. J Urmia Nurs Midwifery Fac 2017;15:544-58.
12. Vaartio-Rajalin H, Huumonen T, Iire L, Jekunen A, Leino-Kilpi H, Minn H, *et al.* Patient education process in oncologic context: What, why, and by whom? Nurs Res 2015;64:381-90.
13. Lipari M, Berlie H, Saleh Y, Hang P, Moser L. Understandability, actionability, and readability of online patient education materials about diabetes mellitus. Am J Health-Syst Pharm 2019;76:182-6.
14. Luker K, Caress AL. Rethinking patient education. J Adv Nurs 1989;14:711-8.
15. Speziale HS, Streubert HJ, Carpenter DR. Qualitative Research in Nursing: Advancing the Humanistic Imperative. Philadelphia: Lippincott Williams & Wilkins; 2011.
16. Tenny S, Brannan GD, Brannan JM, Sharts-Hopko NC. Qualitative Study. StatPearls. Treasure Island (FL): StatPearls Publishing; 2021.
17. Polit DF, Beck CT. Nursing Research: Generating and assessing Evidence for Nursing Practice. Philadelphia: Lippincott Williams & Wilkins; 2008.
18. Ranjbar H, Haghdoost AA, Salsali M, Khoshdel A, Soleimani MA, Bahrami N. Sampling in qualitative research: A Guide for beginning. Ann Mil Health Sci Res 2012;10:238-50.
19. Thomson SB. Sample size and grounded theory. JOAAG 2010;5 (1):45-52.
20. Corbin J, Strauss A. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. 4th ed. Los Angeles: Sage Publications; 2015.
21. Heath H, Cowley S. Developing a grounded theory approach: A comparison of Glaser and Strauss. Int J Nurs Stud 2004;41:141-50.
22. Strauss A, Corbin J. Basics of Qualitative Research: Grounded Theory Procedures and Techniques. Newbury Park, CA: Sage; 1990.
23. Birks M, Mills J, Francis K, Chapman Y. A thousand words paint a picture: The use of storyline in grounded theory research. J Res Nurs 2009;14:405-17.
24. Araghian Majarad F, Sanagoo A, Jouybari L. Critical appraisal of the quality of grounded theory studies. Nurs Dev Health 2017;8:37-45.
25. Heshmati H, Shakibazadeh E, Foroushani AR, Sadeghi R. A comprehensive model of health education barriers of health-care system in Iran. J Edu Health Promot 2020;9:106.