# Ethnographic Exploration of Elderly Residents' Perceptions and Utilization of Health Care to Improve Their Quality of Life

Seyed Ziya Tabatabaei, Azimi Bin Hj Hamzah, Fatemeh Ebrahimi

Abstract—The increase in proportion of older people in Malaysia has led to a significant growth of health care demands. The aim of this study is to explore how perceived health care needs influence on quality of life among elderly Malay residents who reside in a Malaysian residential home. This study employed a method known as ethnographic research from May 2011 to January 2012. Four data collection strategies were selected as the main data-collecting tools including participant observation, field notes, in-depth interviews, and review of related documents. The nine knowledgeable participants for the present study were selected using the purposive sampling method. Two themes were identified: (1) Medical concerns: Feeling secure, lack of information, inadequate medical staff; and (2) Health promotion: Body condition, health education, physiotherapy and rehabilitation. These results could evoke the attention of policymakers and care providers to better meet elderly residents' health care needs.

**Keyword**—Ethnographic study, health care needs, elderly Malay people, Malaysia, quality of life, residential home.

## I. INTRODUCTION

THERE is a widespread concern among policy-makers and I care professionals about the rapid growth of the ageing populations in Malaysia and the rising challenges of providing health care services for this group of people [1]-[3]. The rapidly growing numbers of older people mean that more and more people will be entering a period of life where the risk of developing certain chronic and debilitating diseases is significantly higher [4], [5]. Moreover, the total dependency ratio of the elderly in Malaysia is expected to increase from 10.2% (1991) to 12.1% (2010) and is projected to further increase to 16.5% (2020) [6]. A study in Malaysia [7] found that, about 77.7% of elderly people have at least one chronic disease and most of them had at least 1-2 morbidities (56.4%). Additionally, as the Malaysian population ages, older people will form a larger percentage of admissions to residential homes [8]. Older people in institutional setting are more likely to have a long-term illness compared to older people in the community. Due to some chronic diseases such as diabetes

Seyed Ziya Tabatabaei (PhD) is with the Rafsanjan University of Medical Sciences, Rafsanjan, Iran. (corresponding author, phone: +989133934410, e-mail: seyedzia2003@yahoo.com).

Azimi B Hj Hamzah (Professor, Head) is with the Youth Development Studies Unit, Department of Professional Advancement and Continuing Education, University Putra Malaysia, 43400, Serdang, Selangor, Malaysia (e-mail: azimi@putra.upm.edu.my).

Fatemeh Ebrahimi (MSc), is with the Rafsanjan University of Medical Sciences, Rafsanjan, Iran (e-mail: faty545@yahoo.com).

and stroke, disability trends have a substantial effect on demands for institutional settings [9]. An important point made by Chen et al. noted that, about 85% of the elderly residents had at least one chronic disease and about 55% of them had more than one problem [10]. With an increasing proportion of elderly in residential homes, health care providers need to be alert and informed of the health care needs of the elderly [11], [3].

## II. LITERATURE REVIEW

Care of the elderly is a complex and costly process and health care systems need to be pioneering and capable. The health care system must be generous to the older population, that is, older people aged 60 years and over can have access to good health care. Since the residents spend some of the most important years of their lives in long term care facilities, managers and caregivers should orient their services towards respecting the residents' opinions [12]. On the whole, elderly people should have the right to express their opinions about their individual needs and wishes regarding the health care they receive, if it is to be meaningful to them. In order to guarantee a good life and fulfill the residents' individual needs in long term care facilities, the elderly people themselves must be given the opportunity to describe the kind of health care they want [13]. This group of people may need various levels of health care as provided in residential homes or outside of settings, either for short-term or extended periods of time [12], [14]. Policy makers have to focus on the needs of their residents through new lenses to see the subject from another angle, new strategies for removing weaker points and improving the strong points, and new attitudes that could help them better explore and understand the health care needs of elderly residents living in residential homes.

Nursing care that fits the needs of residents will improve their health conditions and quality of life. On the other hand, vast discrepancies between needs and health care received may negatively affect the happiness and health conditions of the elderly [15], [16]. Obviously, in order to provide better quality of life and care, assessing the residents' health care needs is fundamental and crucial. That is, only after the residents' needs are understood can appropriate health care be provided [17].

According to our review, although several studies have examined the elderly Malay residents' quality of life, still relatively little is known about the health care of elderly Malay residents. In other words, there is no evidence or

comprehensive ethnographic study on the health care related to the quality of life of elderly Malay residents.

#### III. THE STUDY AIM

The aim of this ethnographic study is to explore the health care of elderly people living in a Malaysian residential home to improve their quality of life.

#### IV. DESIGN

This study employed a method known as ethnographic research in Hill House (pseudonym) to elucidate the elderly Malay residents' health care needs from May 2011 to January 2012 in a Malaysian residential home.

#### V. SAMPLE/PARTICIPANTS

Purposive sampling was used to select nine knowledgeable participants including eight elderly residents and one head nurse for gathering data. This research study entailed Bumiputera people (ethnic Malays and other indigenous groups), aged 60 years and over that have lived in the studied setting for at least five months continuously; hear, see and have a normal voice, able to understand and answer the questions, have had no documented conditions of dementia or cognitive progressive impairment, want to share information, knowledge and experience and are able to give informed consent.

## VI. DATA COLLECTION

Four data collection strategies were selected as the main data-collecting tools. The main and first method was participant observations and other methods consist of in-depth interviews, field notes, and review of documents to collect and reap much rich data from informants' viewpoints. To record the interviews, a small recording device was used with the participants' permission. Each in-depth interview with participants lasted between 35 and 121 minutes.

## VII. ETHICAL CONSIDERATIONS

Ethical approval has to be obtained from the Faculty of Medicine and Health Sciences' Ethics Committee at University Putra Malaysia (UPM) and the Social Welfare Department as well. Moreover, informants were informed that they have a right to refuse or stop any cooperation with researchers during the study.

## VIII. RIGOR

The trustworthiness of the research study was ensured through prolonged engagement (nine months) in the field of study, selecting knowledgeable and appropriate participants, triangulation, member checks, and peer examination.

## IX. DATA ANALYSIS

Analysis of data initially occurs following the first day of the data collection process until all the information was gathered. This prompted us to allow time to address these issues in future observations and interviews. Foremost, data were recorded as much information as possible during indepth interviews that would help in understanding such details as speech patterns (pauses, inflexions, stutters, mannerisms, and slang) and body language.

All interviews from the digital-recorder were transcribed verbatim by a Malay person who was a student in English as a Second Language (ESL), because the transcription of audiotapes was very time consuming. And then, to ensure the accuracy of the transcribed data, all the transcripts and audio tapes referred to another Malay person who had an IELTS test score of 6.5 in total. After transcribing, all the data entered into a logical format that could be easily understood and analyzed. Before beginning analysis, the data read several times to obtain a general sense of the information, and to organize and clean the raw data.

Data were organized to analyze them and to find meaningful units, develop codes, code data, find subcategories and categorize. The transcripts reviewed several times with the intention to search for meaningful units and label them into codes. It should be noted that a meaningful unit is defined as words, sentences or paragraphs containing aspects related to each other through their content and context. The label of a meaningful unit is referred to as a code. At the end of the analysis, all of the documents, interview transcripts and field notes reviewed again for seeking the data that may have initially left out. NVivo (version 8), a software program, was used to analyze the data to assign codes for each transcript and also for data management.

# X. FINDINGS

Eight Malay elderly residents consisting of four males and four females participated in the current study (Table I). The participants of the study ranged in age from 60 to 84 years, with an average of 68.6 years and all Muslim Malays. They lived in Hill House for different lengths of time from 15 to 186 months with an average of 54 months. The need for health care among residents is a serious issue. Two basic and vital needs for health care have risen from the participant observations, related documents, informants' point of views and field notes. They include medical concerns and health promotion.

TABLE I PROFILE OF ELDERLY MALAY RESIDENTS

PROFILE OF ELDERLY MALAY RESIDENTS					
Name	Age Sex		Length of Stay	Educational	Disease
(Pseudonym)			(Month)	Level	Diagnosis
Akmal	61	M	15	С	Stroke
Fadila	84	F	49	S	HBP, Heart
					Disease
Hilmi	80	M	18	P	Gout, HBP,
					Asthma
Nabil	61	M	18	S	Gout, HBP, Joint
					Pain
Raama	70	F	84	P	HBP and Gastric
Sabrina	70	F	24	N	Chronic' Cough
Shoaib	63	M	39	P	Stroke
Zaynab	60	F	186	S	Joint Pain

HBP: High Blood Pressure, Educational level: N=None, P=Primary school, S=Secondary school, C=College and U=University.

#### A. Medical Concerns

When elderly people entered to Hill House, they brought with themselves a collection of diseases. One of the most important concerns emphasized by the elderly people was medical concerns. Further to this, the most focus of Hill House is prevention and management of chronic diseases, providing primary medical care, physiotherapy, rehabilitation, palliative care and end of life care.

#### 1.Feeling Secure

There is a small building belonging to the clinic for nursing care, outpatient's treatment and first aid with a small drugstore and medical records space. This clinic provides care and cure for residents, who are treated free of charge. The caregivers constantly monitor elderly residents in order to protect them and the two assistant nurses and a head nurse have rounds every morning in all dormitories. Furthermore, a physician visits residents in their bed once a month. Therefore, this makes the residents feel secure and satisfied.

"The Doctor together with the nurses will go around seeing all the residents here, but we just look each other and smile. Overall, I feel comfortable to be treated here "(Ms. Zaynab).

"Beside the office is the clinic and if I feel not very well I will go there. The service they give me is good "(Ms. Raama).

There is a geriatric hospital and also a public hospital near Hill House, hence for any emergency cases, the head nurse or her assistant fixes an appointment and sends sick residents to the hospital.

"The doctor will visit us for treatment once a month. If I were to fall sick unexpectedly, the staffs will send me to the hospital. The staffs and the nurses will fix an appointment with the doctor for us "(Mr. Shoaib).

#### 2.Lack of Information

Lack of health information support regarding diseases, medicines and residents' health status were defined as barriers by Malay elderly residents. These people with chronic diseases were more interested to receive information from care providers.

"The nurses never explain why we need to eat the particular medicines. But I do not know the others, whether they explain to them or not "(Ms. Zaynab).

"Sometimes, I tend to throw away medicines given by the staffs because I don't know why I have to eat this medicine "(Mr. Shoaib).

One of the requirements of residents who participated in the study was they had to have resided in Hill House for five months. Ms. Fadila had lived in Hill House about eight months (plus 41 months in another residential home) when she participated in the study but she still did not know who the doctor was. Maybe the doctor had a fast round or came only once a month.

"She (doctor) only asks around and I don't see her attending to patient. They told me she is a doctor but I myself wasn't so sure."

#### 3.Inadequate Medical Staff

Despite more than 300 elderly people living in Hill House, the management unfortunately did not provide enough medical equipment, nurses and physicians to meet the elderly residents' medical care needs. A small clinic, one head nurse and two novice assistant nurses with some simple medical equipment were the entire Hill House medical facility.

"A doctor comes once a month, in the afternoon for two hours. When she comes to visit, I take her for a quick round to every ward. A very fast round. They (residents) are happy when they see the doctor (head nurse)".

"They have their own schedules to treat the patients. They will make the announcement before coming here. Actually, the doctor will have the list of their patients. So, we cannot see the doctor as simple as that "(Mr. Nabil). Mr. Nabil in the other part of interview stated that:

"It is common to us to get sick, and we always refer to the clinic. It's difficult to say that it will totally cure our sickness, but the medicines given can actually reduce our pain, not more than that (Mr. Nabil)".

But, due to lack of medical facilities, most residents are not satisfied with the medical care provided by Hill House.

"Not very satisfied with the care provided by clinic I just feel it is average because there is no doctor to treat me well. Sometimes it takes time for them (nurses) to respond. Until now I cannot see a dentist. They always ask me to wait and wait... until today. Now I only have two teeth. They gave many excuses when I asked them to take me to see a dentist "(Ms. Raama).

"I'm not very satisfied with the care here. They just give whatever medicines without referring to a doctor. In here, they just give medicines without taking me to see the specialist. I'm not very satisfied with the medicines they give me. Because of these medicines my body has become weak" (Mr. Hilmi).

When we asked the head nurse what her biggest concern was and what were her suggestions regarding Hill House's medical services, she answered:

"A shortage of staff and maybe a doctor who can stay here in the clinic (of work)".

Perhaps due to insufficient nurses (one head nurse and two assistant nurses for 301 residents), inadequate work experience among assistant nurses and inadequate understanding of the work environment and situation, the elderly residents are not properly cared for by the nurses.

"That nurse is a bit lazy (laughs). Because when I say I'm sick, she will say "ah, yes ah? We will take note." But after one week, she never showed up (Ms. Hafizah)"

The head nurse was aware that the behavior of care providers could influences the well-being of elderly residents. How nurses care for aged residents and how elderly people respond to this care is greatly influenced by behavior and culture. Caregivers and nurses should improve their communication skills and knowledge to better manage and care of elderly residents and build it as a culture. This issue was remarked upon by the head nurse of Hill House during an in-depth interview.

"I have to train these young nurses to treat them (elderly residents) just like their uncle or aunty. If my uncle or aunty is here, I'll do what I do. That's how you can perform your nursing (care). If you have sympathy alone it's not enough, you must have empathy (head nurse)".

## B. Health Promotion

Health is an important concern for each person but this matter is more significant for the elderly, because they are the largest group of people with special health care needs. Up to this point, key participants' were concerned regarding their body condition, health education and physiotherapy.

## 1.Body Condition

Based on a review of the clinic's medical documents and interviews, a majority of the elders in the Hill House suffered from chronic health conditions or long-term pain. Furthermore, the type and incidences of their chronic diseases differed with age and sex.

"I do not go to the Prayer Room because I cannot walk very well, because my body condition is not very good. I also sit when praying because I cannot stand well "(Mr. Hilmi).

"I cannot continue my previous job because of my eyes. I cannot see well. Before this I can still work because the stroke affected only my legs and arms, but now it has affected my mouth and eyes. One of my eyes is already blind. The other one causes my sight to blur. I can still use one of my eyes "(Mr. Akmal).

## 2.Health Education

Elderly people need more knowledge about their health status and behavior to maintain their health. In other words, health education helps elderly people to improve their health, by increasing their knowledge or influencing their attitudes. Formal and informal health education by the head nurse, assistant nurses, caregivers or personnel from health care centers can provide a direct benefit to elderly residents in their conditions. This matter was brought up by several key informants:

"The attendants always remind us not to eat the sweet foods. It is better to take tasteless food or less sugar for our health. According to them, they want us to be fit and remain healthy, so it will easy for them to look after us" (Ms. Sabrina).

"If we just lie down and sleep the whole time they will scold us, saying "Sleeping all the time? It's not good to sleep all the time". We need to move our body too... If I'm not allowed to do certain things, they will give an explanation. Like for my high blood, they say "You cannot eat salt or salted fish. Not even a little" (Ms. Fadila).

## 3. Physiotherapy and Rehabilitation

Hill house hired two trained personnel to work in the physiotherapy and rehabilitation unit and provided some physiotherapy equipments to maintain resident's health and activeness. There were two sessions for physiotherapy per day on weekdays. The morning section was for the men while in the evening for females. Thus, there is no mixing of genders during physiotherapy activities.

"Generally, there are many facilities provided here for use by the residents, for instance; cycling, games, weightlifting, massage chairs and tools for stroke patients. I just follow the activities planned for us. We are free to do any activities we like, according to our physical condition" (Mr. Nabil).

"I did not participate in other activities; I just sit or walk a little. I like the exercises like walking, lifting my legs. The person in charge of physiotherapy always asks me to walk so that I can walk again "(Ms. Fadila).

Although the aim of the physiotherapy unit is to make this facility a place for living and not a place for dying, they still need more space, staff and physiotherapy equipment to reach to this goal.

#### XI. DISCUSSION

Medical concerns and health promotion were two health care needs identified by the elderly for the current study. Generally, ageing people experience many health problems; therefore, it is common to have at least one chronic condition [18]. Ensuring access to quality care to create a feeling of security for elderly residents was a specific priority for Hill House's management, but a number of elderly residents were unsatisfied with the health care services, especially insufficient medical staff and lack of information regarding their own diseases and body condition. A qualitative study of Norwegian nursing homes in the aspect of clinical and health care services for elderly people has revealed similar findings in that a lag in communication and overall knowledge about disease and shortage of medical personnel were health care concerns among patients [19]. Furthermore, an increasing number of studies have shown that higher nurse staffing levels are associated with the improvement of care outcomes for residential home residents. In other words, relationships between residents and health care staffs are viewed as the main determinant of care quality, while sufficient staffing upholds those relationships [20]. It has been reported that adequate health care personnel in residential homes tend to lower workloads and extend the time available to assist residents with other needs [21], [22]. In truth, the shortage of skilled care providers leads to the inadequate care of residents with more complex caring needs. The elderly did not feel that they were respected and regarded that unique individuals like caregivers did not seem to have the time to attend to the residents properly. They felt that they were taken care of, but the standard of care could be enhanced if there had been more personnel. On the contrary, a study [21] claimed that although the number of staff is a key factor in guaranteeing the quality of care in residential homes, the staffing ratio cannot always guarantee the intensity or complexity of the nursing care of residents. On the other hand, there is a considerable breadth of research which indicates that the patient's needs regarding information on their disease and body conditions are crucial

#### International Journal of Medical, Medicine and Health Sciences

ISSN: 2517-9969 Vol:10, No:7, 2016

[23]-[25]. Also claim that care providers must be aware of the patients' needs to provide information, understand their concerns, explain the psychosocial aspects of disease and gauge their level of satisfaction with the information provided. Moreover, effective communication with the elderly residents regarding their health is a key point in the management of patients' care, as many key participants were curious about their disease, medical treatment, risks and health progress. Elderly residents have specifically reported difficulty in gaining information about their disease(s) and how to manage it. Recent research conversation suggests that communication between patients and health care' providers, including information-giving and information-seeking' behaviors and patient involvement in the treatment process, can affect the healing process. On the contrary, a lack of knowledge regarding their condition can lead to a high degree of uncertainty and may contribute to patients' depression [26], [27].

#### XII. LIMITATION

This study is facility-specific and cannot exactly extend to the health care needs of all elderly residents and of all cultures for a long-term care setting [28]. Furthermore, according to the research criteria and goals of the study, this project focuses only on elderly residents who have intact cognitive skills and good functions and focused only on the Malay elderly residents (Chinese and Indian elderly residents were not included) at the chosen residential home.

#### XIII. CONCLUSION

This ethnographic study has explored health care needs of elderly residents in a Malaysian residential home. Results indicate benefits on in two areas; medical concerns and health promotion. These two themes appear to play a valuable part in improving health for the elderly residing in Malaysian residential homes. Compared to other age groups, the ageing population has become a formidable challenge for governments because elderly people are, by far, the most significant users of the health care services. Findings from the current study identified several barriers to health and wellbeing for residents. The most important challenges from the key participants' viewpoints were the inadequate medical care and health promotion inside residential home.

# ACKNOWLEDGMENTS

The authors offer great thanks to the elderly Malay residents and staffs of Hill House in Malaysia for their cooperation and assistance during data collection phase.

# REFERENCES

- Beswick AD, Gooberman-Hill R, Smith A, Wylde V, Ebrahim S. 'Maintaining independence in older people'. Reviews in Clinical Gerontology. (2010); 20(2): 128–53.
- [2] Ahmad A, Purewal TS, Sharma D, Weston PJ. 'The impact of twice-daily ward rounds on the length of stay in two general medical wards'. Clinical Medicine. (2011); 11(6): 524–8

- [3] Liu L. The Health Heterogeneity of and Health Care Utilization by the Elderly in Taiwan. Int. J. Environ. Res. Public Health. (2014); 11: 1384-1397
- [4] Naughton, C., Bennett, K., and Feely, J. Prevalence of chronic disease in the elderly based on a national pharmacy claims database. Age and Ageing. (2006); 35(6): 633-636.
- [5] Wauthier, V., Verbeeck, R.K. and Buc Calderon, P. The Effect of Ageing on Cytochrome P450 Enzymes: Consequences for Drug Biotransformation in the Elderly. *Current Medicinal Chemistry*. (2007); 14: 745-757
- [6] Selvaratnam, D.P. and Tin, P.B. Lifestyle of the Elderly in Rural and Urban Malaysia. Annals of the New York Academy of Sciences. Healthy Aging and Longevity. Third International Conference. (2007); 14: 317-325.
- [7] Momtaz, Y.A., Hamidi T.A., Yahaya N., Ibrahimi R. Effects of Chronic Comorbidity on Psychological Well-being Among Older Persons in Northern Peninsular Malaysia. Applied Research Quality Life. (2010); 5: 133-146
- [8] Poi, P.J.H., Forsyth, D.R. and Chan, D.K.Y. Services for older people in Malaysia: issues and challenges. *Age and Ageing*. (2004); 33: 444-446.
- [9] Gallagher R, and Gallagher P. Emergency department nurses' perceptions and experiences of providing care for older people. *Nursing and Health Sciences* (2014); 16, 449–453.
- [10] Chen H., Chiu PY.A., Lam P.SS., Poon WK., Chow SM., Ng WP., Yung R.WH. Prevalence of infections in residential care homes for the elderly in Hong Kong. *Hong Kong Med.* (2008); 14:444-50
- [11] Sherina, M.S. Zulkefli, N.A.M. and Shah, S.A. Factors associated with depression among elderly patients in a primary health care clinic in Malaysia. Asia Pacific Family Medicine. (2003); 2: 148–152.
- [12] Robichaud, L., Pierre, J., Durand, R.B. and Jean, P.O. Quality of life indicators in long term care: Opinions of elderly residents and their families. *Canadian Journal of Occupational Therapy*. (2006); 73(4): 245-251.
- [13] Berglund, A.L. Satisfaction with caring and living conditions in nursing homes: Views of elderly persons, next of kin and staff members. *International Journal of Nursing Practice*. (2007); 13: 46–51.
- [14] Onder, G., Carpenter, I., Finne-Soveri, H., Gindin, J., Frijters, D., Claude Henrard, J., et al. Assessment of nursing home residents in Europe: the Services and Health for Elderly in Long TERm care (SHELTER) study. BMC Health Services Research. (2012); 12:5
- [15] Gregory L.A. An Analysis of Nursing Home Quality Measures and Staffing. Qual Manag Health Care. (2008); 17(3): 242–251.
- [16] Kehusmaa, S., Autti-Rämö, I., Helenius, H., Rissanen, P. Does informal care reduce public care expenditure on elderly care? Estimates based on Finland's Age Study. *BioMed Central Health Services Research*. (2013). 13:217
- [17] Slade, M. and McCrone, P. The Camberwell Assessment of Need (CAN). In G. Thomicroft (Ed.), Measuring Mental Health Needs (2nd ed., pp. 291-303). London: Gaskell. (2001).
- [18] Wild, B., Lechner, S., Herzog, W., Maatouk, I., Wesche, D., Raum, E. et al. Reliable integrative assessment of health care needs in elderly persons: The INTERMED for the Elderly. *Journal of Psychosomatic Research*. (2011); 70: 169–178.
- [19] Pedersen, R., Nortvedt, P., Nordhaug, M., Slettebo, A., Grothe, K. H., Kirkevold, M. et al. In quest of justice? Clinical prioritisation in healthcare for the aged. *Journal of Medical Ethics*. (2008); 34(4): 230-235.
- [20] Bowers, B.J., Fibich, B. and Jacobson, N. Care-as-service, care-as-relating, care-as-comfort: Understanding nursing home residents' definitions of quality. *Gerontologist*. (2001); 41(4): 539-545.
- [21] Muller, C.A. Framwork for nurse staffing in Long-Term Care facilities. Geriatric Nursing. (2000); 21(5): 262-267.
- [22] Murphy, G.T., Birch, S, MacKenzie, A., Alder, R, Lethbridge, L. and Little, L. Eliminating the shortage of registered nurses in Canada: An exercise in applied needs-based planning. *Health Policy*. (2012); 105: 192–202.
- [23] Politi, P., Bodini, P., Mortilla, M.G., Beltrami, M., Fornaciari, G., Formisano, D., et al., Communication of information to patients with inflammatory bowel disease: A European Collaborative Study in a multinational prospective inception cohort. *Journal of Crohn's and Colitis*. (2008); 2: 226-232.
- [24] Loguercio, C., Tiso, A., Cotticelli, G., Blanco, C.D.V., Arpino, G., Laringe, M., et al. Management of chronic liver disease by general practitioners in Southern Italy: Unmet educational needs. *Digestive and Liver Disease*. 43: 736–741.Muller, C.A. (2000). Framwork for nurse

## International Journal of Medical, Medicine and Health Sciences

ISSN: 2517-9969 Vol:10, No:7, 2016

- staffing in Long-Term Care facilities. Geriatric Nursing. (2011); 21(5): 262-267.
- [25] Budych, K., Helms, T.M. and Schultz, C. How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction. *Health Policy*. (2012); 105: 154–164.
- [26] Harding R., Selman L., Beynon T., Hodson F., Coady E., Read C., et al. Meeting the Communication and Information Needs of Chronic Heart Failure Patients. *Journal of Pain and Symptom Management*. (2008); 36(2): 149-156.
- [27] Attard A. and Coulson, N.S. A thematic analysis of patient communication in Parkinson's disease online support group discussion forums. *Computers in Human Behavior*. (2012); 28: 500–506.
- [28] Horsburgh, D. Evaluation of qualitative research. *Journal of Clinical Nursing*, (2003); 12(2): 307-312.