



Gülcan Bakan

Pamukkale University, gbakan@pau.edu.tr, Denizli-Turkey

Asiye Akyol

Ege University, asiye.durmaz@ege.edu.tr, İzmir-Turkey

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ORCID ID	0000-0002-9994-6124	0000-0003-1018-4715
Corresponding Author	Gülcan Bakan	

I LEARNED TO SAY NO TO ANYONE.....UNDERSTANDING HEART FAILURE PATIENTS' LEARNING PROCESS AND BEHAVIOUR: A QUALITATIVE STUDY

ABSTRACT

Becoming a patient with chronic HF involves a process of taking on a new identity. The behaviours of the patients have been based on their experience of the disease. The aim of this study was to explore HF patients health behaviours, beliefs, experiences, adaptation, coping strategies and learning process. The design is qualitative descriptive. Semi-structured in-depth interviews were conducted with 21 HF patients. Content analysis was used to analyse. Patient learning process and behaviours in chronic heart failure were determined by using basic principles of SLT. Four main themes that emerged from the the qualitative data: restrictions, fellowship, learn to cope, roles. Heart failure patients explain their restriction about daily activity and sexuality. Also, they state about spouse's support, coping with chronic disease, changing of their roles, fear particularly when experiencing severe shortness of breath. SLT indicate that an individual's representation of illness affects how they cope and view their quality of life. This is the first study that SLT being used to study patients with HF in Turkey. The results of the study will be helpful in developing new strategies and interventions to improve patient coping behaviours.

Keywords: Heart Failure, Learning Process, Qualitative Study, Social Learning Theory, Patients' Experiences

1. INTRODUCTION

Heart failure (HF) is an epidemic worldwide, especially in ageing populations [1 and 2]. HF is characterized by poor quality of life, high mortality, and frequent hospitalization [3]. Roughly 5.1 million people in the United States and 15 million people in Europe have clinically manifest HF, and the prevalence continues to increase [2,4 and 5]. HF is one of the many chronic diseases that cause physical, psychological and social problems [6]. The behaviours of the patients have been shown to be based on their experience of the disease. Researches show that becoming a patient with chronic HF involves a process of taking on a new identity [7 and 8]. This study aims to explore health behaviours, learning process, beliefs, experiences, adaptation and coping strategies of patients with HF. Targeting the preferred coping strategies and developing new strategies can improve the person's management of the condition can lead to decreasing morbidity and increasing meaningful adaptation to changed functioning. The results of the study will be helpful in developing interventions to improve patient coping behaviours.

- **Conceptual framework:** Theories are useful for explaining health behaviours that are influenced by social and psychological

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determinants and can be a framework for guiding interventions to develop positive behaviour change [9 and 11]. People who begin to adapt to limitations imposed by the disease and who are also in healing process are searching for information about their status [12 and 13]. Learning is formed by the interaction of many variables such as cognitive, social, psychological, language and thought, perception and memory, attention and motivation. It can be defined as changes which are permanent and have left a mark that occur in behaviour through life [14]. Learning involves imitation and reinforcement, comprehending, problem-solving and decision-making process. This study was guided by SLT which emphasizes the reciprocal interaction among personal, environmental and behavioural factors in human learning. Basic principles of SLT are reciprocal determinism, self-efficacy and symbolizing, forethought, vicarious, self-regulatory, self-reflective capability [13 and 14]. A focus of SLT is on the self-regulation processes and how various social-cognitive possesses relate to behaviour. According to Bandura, when learning by observing, a person not only simply imitates the other person's activities but also cognitively processes the information obtained from the surrounding events [9].

2. RESEARCH SIGNIFICANCE

In the present study, learning process, behaviour and life experiences of patients with HF will be determined with guidance SLT and a different approach from the patient's perspective will illustrate on living with the disease. Understanding how people learn to adapt can lead to initiatives that encourage better patient participation in their care. Development of self-management skills require both knowledge and behaviour change [13 and 15].

3. METHODS

3.1. Design

A qualitative study design was used through in-depth interviews with HF patients.

3.2. Data Collection

The was collected between February 2012 and January 2013.

3.3. Instruments

In the study, all data were collected by using an Individual Diagnostic Form that includes socio-demographic characteristics and a semi-structured interview guide with general open-ended questions. An expert opinion was took from a professor and associate professor in nursing department and associate professor sociologist to be evaluated in terms of a purpose, meaning and content validity of questionnaire. After the necessary corrections were made in accordance with the expert opinion, the 2 pre-interview research applications were made and the final version was given by utilizing the information obtained.

3.4. The Interviews

The interviews were conducted in the private consultation room, obtaining informed consent, and undertaken by the same researcher. A semi-structured interview guide was used and key questions were asked of every participant, but was sufficiently flexible to determine new areas. All interviews with patients were done by in-person interviews (40 min average). The interview started with a "warm-up" question which asked patients to explain what they understood from their heart condition.



3.5. Data Analysis

The interviews were transcribed verbatim. Content analysis was used as the method for analyzing the data. The interviews were listened repeatedly to determine any nuances in intonation and the transcripts were read several times. Significant words were highlighted and examined for patterns of themes, subthemes, and illustrative quotations for each theme. Interpretation of the themes and the meaning of the patients' beliefs, behaviours and coping strategies in dealing with HF was written into a report. To ensure rigour in the process two researchers coded these data and agreed the emerging themes. The patients' comments were categorized into the 6 major themes agreed upon by the researchers. Interviews were notified by assigned numbers and patient names were not used.

4. FINDINGS

4.1. Study Demographics

The mean age of the study population was 50 years (age average from 28-74 years) and 66.7% were male and 90.5% were married. Patients' period of HF were from 1-14 years. The total sample incorporated a mix of disease severities, ranging from New York Heart Association (NYHA) I-IV. Patients had HF for a long time (mean period 5.4 years) and most of them (57.1%) were in NYHA class III. Patients with HF living below the poverty line were 57.1%.

4.2. Conceptual Categories

Patients may develop their own constraints, feelings, reactions and responses, shaped by attitudes, beliefs, experiences and expectations as individuals living with HF [34]. In the present study, the main themes that emerged from the interviews were restrictions, fellowship, learn to cope, roles.

4.3. Restrictions

Most of the patients expressed that they experienced symptoms fatigue, breathlessness, insomnia, respiratory distress because of HF. The breathlessness is the worst symptom they experience. Patients were limiting their daily physical activities in fear of experiencing the symptom. They expressed that the severity of the symptom was more intimidating than death.

"I get lack of breath as if some one is strangling me. There was always a fear inside me as if I won't be able to open my eyes and wake up from my sleep this is very scary, even scarier than death." (P.11)

When experience emergency cases such as difficulty in breathing and edema, majority of patients say that they first try to treat the symptom by increasing the dosage of desal. But when the symptoms are severe they go to emergency room.

"I am increasing my desal drug, other than this, I am coming to the emergency room. There is nothing else to do because every part of my body is swollen." (P.13)

They knew the relationship between HF and a use of salt, but they were not willing to give up using salt because they do not like the taste of a meal without it and they consider the unsalted food is "like hospital food". On the other hand, some patients who gave up using salt stated that they used diet salt and did not find it difficult to get used to eating a salt-free meal and also their partners got used to a salt-free diet.

"I know it is forbidden but I can not eat anything without salt ... without salt the meals are like those can not eat like the food in the same hospital" (P.9)



All of the patients stated that their life was effected negativeley. They had to work to survive, but they could not work because of fatigue, edema, etc. and experienced economic hardship. Most of them stated that they had to retire due to disabiliy. A patient who was fired after being diagnosed said "My job has left me first".

"I was retired due to disabiliy. In fact I used to have an intense work life. Working as a kindergarten teacher is very exhaustive profession...I loved my profession. I wish I could continue." (P.14)

"When I was working in this firm I used to get job offers everyweek....now that I had a sickness, my job has left me first. It was my work place for 15 years." (P.15)

Most of patients felt that decreasing at their sexual life due to prohibition of excitement, fatigue and weakness or age-related deficiency was not a problem between spouses, who understand each other. In addition, patients attributed a negative meaning to sexuality such as, frigidity, deficiency, lack of desire, poor performance, and fear. Only one patient expressed that sexual activity was a pleasure.

"..... I didn't have any desire because I was feeling very tired. Thanks god my husband was very patient and he didn't pressure me for it." (P.18)

"At the beginning you are having problem with your partner. When I felt that I was having difficulty in breathing.....I was losing my appetite for sex and I felt under pressure. So I didn't want to do it. You cannot catch up even if you want to do it." (P.11)

4.4. Fellowship

Majority of the patients stated that they got the greatest support from their spouses. Interaction among the family members has increased. They got attched stronger.

"At the beginning, my spouse was remanding me whether I got my medicine in time, even when he was at work (smiling). Well, I got support from my husband most. When I was hopeless, he was always comforting me by saying that we are going to overcome this disease." (P.18)

However some patients stated that they cannot get adequate support from relatives or friends. The patient learned coping with the disease by altering her social environment.

"Our close friends stopped seeing us. I suffered a lot. When they stopped seeing us, we became upset because we had alot in common. Now, I have new friends, I have a new life." (P.11)

When patients are asked from where they get information about HF, they stated that they received information from the mass media and medical personel.

"I did alot of search in the internet about my HF, what are the stages, treatment options, what is in the treatment with medicine, is the transplantation last solution" (P.15)

"Sometimes there are programs on HF on tv. In the programs, doctors are showing the human body and making explanations about the disease." (P.19)

4.5. Learn to Cope

Patients stated that they change their lifestyle and cope with disease.

"We learned to live a better quality life. We do not postpone anything anymore. In any case, if something happens it happens with



God's will. It doesn't metter who says what. I learned to say no to anyone." (P.11)

"I was also saying to myself that I am going to overcome this disease for my children." (P.18)

Patients said that they have accepted being HF patients as time went by:

"I have learned to live with this now...I say life is short. Who can guarantee we will be alive tomorrow... I enjoy the moment and I am happy. After having experience with death, I mean, returning from the thin line, everything sounds meaningless to you." (P.14)

"It was not that hard for me since I am a believer. I said to myself we live as long as God permits." (P.12)

4.6. Roles

Our study showed that the patients generally held the roles of mother, father or partner in the family. The majority of the patients expressed that they were not able to perform their roles in the family completely but family members did not make them feel that way.

"My husband was not complaning about this even if I was not showing enough attention to him.... I was not able to provide food for little child. I was not providing sufficient care for my elder child either. I felt like I was unfair to him...Taking him to the toilet at night was difficult for me. Therefore, my husband was taking him there." (P.18)

5. DISCUSSIONS

The present study explored learning processs, beliefs, behaviours, experiences, and adaptive strategies of patients with HF by using Bandura's social learning theory. Theory offers the practioner a basis for making informed decisions that are based on deliberation and practical judgment. It is important to use theory as a framework to provide perspective and guidance to a research study [10, 16 and 17]. In this qualitative study, we determined that the identification of four main themes (restrictions, fellowship, learn to cope, roles) serve to better understand the behaviours, experiences and needs of patients with HF. In recent years, research in chronic disease has focussed on the transformation process as people adjust to living with a chronic disease and self-manage their condition [15].

In our study, it has been found that the patients suffered from some restrictions like symptoms such as breathlessness, fatigue, weakness, sleep problems, limitation of physical activities, pain and such symptoms had adverse effects on their activities in their daily lives. In many studies, it has been found that the HF patients had similar symptoms [18 and 19]. It has been identified that the biggest problem they experience was difficulty in breathing and the severity of the symptom frightened them more than dying. This confirms findings of previous qualitative studies linking fear and breathlessness [8 and 20].

In our study, we found that the patients are afraid in emergency cases, especially from a sudden cardiac death and they would not want to be left alone. In a qualitative study, one of the themes was determined as "living in the shadow of fear" and the patients stated "I have a constant fear am I going to die in the next step? I hope I can overcome this fear" [21]. The patients are aware that they could live emergency cases associated with the HF, based on their impressions they concluded from their experiences. This is in compliance with the "**symbolizing capability**", which is the skill of predicting the future based on impressions of the individual from the past life, and which is one of the basic principles of the SLT.



The patients involved in our study are aware of the fact that they need to change their feeding habits. They knew the relationship between the use of salt and HF, but some of them could not avoid using salt completely, and increased the dose of desal to prevent oedema. They described the unsalted meals "like" hospital food", and said that they could not get the taste. Whereas the patients who gave up using salt were using diet salt and also their spouses got used to eat without salt. This fact may be explained by the principle of "**reciprocal determinism**", which is one of the basic principles of SLT, and stating that the individuals impact and alter their environment through various ways and the environment would change the individual. The studies showed that more than half of the patients did not limit the use of salt and not checked their weight daily [22 and 23]. In our study, it has been found that the patients reduced smoking after receiving a diagnosis of HF because it aggravate the symptoms because but not gave up smoking totally. Despite of using medications to quit smoking, the patients could not stop smoking, saying that 'they could not finish it in the brain'. The patients want to quit, not being able to do that and being an addicted is disgraceful and painful but they could not stop because they have not reached the consciousness. This conclusion explains the "**self-judgement capacity**", which is one of the basic principles of the SLT and in which the individuals can judge themselves by assessing the conclusions after implementing their opinions and thoughts. Behaviour change is emotional and cognitive responses and the patient's view of their ability to control their condition and life. The lived contradictions related with the person's behavioural change are a problem frequently experienced [14, 15 and 24].

The patients consider the sexuality as a part of life. Most of them they had a discrepancy due to their disease, because of ban of excitement, feeling of weakness and fatigue and age, however that was not a problem among the couples and their spouses would have an understanding in this regard. The studies show that patients perceived sexual inability, some of them thought the cause was because of medicines. A younger patient explained his thoughts saying "we still share the bedroom but I can't ask my wife to spend the rest of her life lonely" [7 and 25]. We also found similar results in our study, and the patients described the failure in the sexual performance as a disability.

Social support has been defined as emotional, i.e. talking about the problems with each other, and instrumental, i.e. having some people for assisting in their daily activities [26 and 28]. In our study found that fellowship is an important method for social support. The patients got the most social support from their spouses. It has been reported that the most of the support is received from the spouses with the explanations "If I don't get my medication my spouse will give them to me". Relationships with the family and friends affect the patient. The support of the people close to the patient, especially spouses is an important factor in ensuring the adoption of the treatment [2 and 29]. In our study, a patient explained that the domestic communication after the diagnosis increased even more and they were bound to each other more tightly by saying "We can tell our problem to each other, if we could not do that there's no point in being a family, anyway,". In Turkish society, it is common that the individuals who lost the spouse live greatly with their children or with their parents and get social support. However the patients said they had not got any supports from their friends or relatives in general. A patient, saying "I always ran for my associates firstly.....none of them is around after I got sick so I've made a new



environment.", has formed his behaviours according to the reaction of his/her environment and made a new environment. The patient has learned to restrict his/her social relations and to adapt to the disease with an appropriate environment by setting out from the reactions of the environment through the "**self-regulation capacity**", which is one of the basic principles of the SLT. Similarly, the patients stated they could not deal with the demands of their previous social lives because they did not have the same physical and mental capacity anymore and they lost their friends like one of the patient explained "when I feel bad, I would not like to be with my spouse or others, I'd like to be by myself" in the study [7].

In the studies, the patients cannot get enough information from the medical staff and strive to get the information from their friends, HF patients, books and internet [20]. It has been reported that the nursing initiatives usually focus on the drug applications [30]. Similarly to other studies, our study also showed that the patients have not received information about the treatment received and found out by searching by themselves at internet and by reading the prospectuses of the medications or adjusted the dose of the drugs based on similar experiences in the past. This conclusion is explained by the "**indirect learning capability**", which is one of the basic principles of the SLT, based on learning from his/her own behaviours and consequents thereof by observing the behaviours of others and consequents thereof. Providing care that makes the individual's situation more comprehensible involves supporting them to make sense of it. Setting the training of the patient into the practice must be an actual issue of the society, politicians and health care workers. Informing the patients sufficiently about their disease will increase the adaptation levels to the disease [31 and 33].

It has been determined that the patients delivered emotional and behavioural reactions when they received the diagnosis. The majority of patients have experienced sadness, fear, depression, their personality changed after diagnosis, they became harsher and angrier. But the patients exhibit that they accept the situation over time. They also stated that the death will come one day, so there is no need for being pessimistic, they got to know there is no further than death after returning from the point of death a couple of times, and they stick on the life even more. The patients created their future plans by coding their past experiences in their minds through thoughts and symbols in accordance with the "**visionary capability**", which is one of the basic principles of the SLT. The patients implement their own ideas and thoughts and judge themselves by assessing the results. The majority of the patients explained how they could handle the disease actively with the expressions 'being brave', 'being able to do everything for himself/hersel', 'if I stick on it, I cannot overcome the disease' 'everything that does not destroy me makes me stronger'. These statements explain the "**self-efficacy**", which is one of the basic principles of the SLT, and meaning the belief of the individual for managing to perform a behaviour. It has been found that the patients reached the ways for overcoming the disease by changing their environment, motivating themselves, reducing their wishes and moreover, they could cope with the psychological effects of the disease through self-control, support of the family, spouse, friends, future plans of patients had changed but none of them would not want to give up the life [28,34 and 35].

6. CONCLUSION AND RECOMMENDATIONS

Conclusively, it has been found in this study, which is planned according to the SLT, that the patients learn to adapt to the disease



through their experiences. Learning is the permanent and traced changes occurring in the behaviours through life experiences. The study findings provide guidance for healthcare providers caring for patients with HF.

CONFLICT OF INTEREST

The authors declared no conflict of interest.

FINANCIAL DISCLOSURE

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ETHICAL COMMITTEE APPROVAL

The study was approved by the ethics committees of The Pamukkale University Hospital and The Nursing Faculty (B.30.2.EGE.0.42.72.00-801). Written consent was obtained from participants for their involvement and for the recording of their interview.

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