

# Life associated with fear and worry: A major concern among the cardiac valve-replaced patients

Mohsen Taghadosi<sup>1</sup>, Robabeh Memarian<sup>1</sup>, Fazlollah Ahmadi<sup>1</sup>

## ABSTRACT

**Background:** Few attempts were made for alleviating the physical/psychological problems among the cardiac valve-replaced patients and no comprehensive study was done based on the experiences of such patients. This study was undertaken to describe the stressful experiences of the heart valve-replaced patients.

**Materials and Methods:** In this qualitative study performed during 2012-2013 with a content analysis approach, 13 patients from Tehran and Kashan therapeutic centers participated. The study sampling was accomplished with purposeful sampling using a semi-structured interview that continued until data saturation. All interviews were recorded, and were immediately handwritten word by word and finally typewritten. Description and analysis of the data were done by Graneheim and Lundman content analysis.

**Results:** One hundred and seventy-five primary codes were derived among the 680 codes taken from the participants interviewed. Using abstract and deep perception of the categories, 14 subcategories and 5 themes were derived. The themes are as follows: worry of care conditions, worry of life with the ongoing condition of having prosthetic cardiac valve, worry regarding the instability in life, fear of hospital, and fear of unknown factors. Each theme consisted of special subsidiary themes with specific functions.

**Conclusions:** The main themes of fear and worry about losing the valve were identified and introduced in the cardiac valve-replaced patients. As the nature and function of these themes are different in different societies, recognition and discrete definition of them are necessary for care planning and promotion.

**Key words:** Content analysis, fear, heart valve prosthesis, Iran

## INTRODUCTION

The first transplantation of mechanical heart valve performed in August 1960 has saved the lives of thousands of heart patients.<sup>[1]</sup> Since that time, each year, a huge number of patients benefit from this advancement. Heart valve disease is one of the complications of rheumatic heart condition.<sup>[2]</sup> The success in valve replacement depends on the myocardial function, health condition, technical skills of the surgical team, and the quality of postoperative care.<sup>[3]</sup> New bioprostheses and anticoagulants are among the alternatives that are important in valve replacement.<sup>[4-7]</sup> Kortke reports that patients' recovery process after heart replacement is slower than in other heart surgeries.<sup>[8]</sup> In addition, Nassar, in his descriptive study, revealed that the mother mortality rate in mechanical valve transplantation was 3-4%.<sup>[9]</sup> During the long years of waiting for the valve replacement,

these patients had catastrophic experiences. Postoperative complications (e.g. long-term hospitalization, social isolation, and the outcomes of valve replacement) are of utmost significance.<sup>[10]</sup> Hence, protecting the replaced valve and taking care of it are of greatest importance and require the mutual support of family and the patient.<sup>[11]</sup> After the valve replacement, these patients need long-life care and are at risk for thromboembolism, which obligate them to use anticoagulants.<sup>[3]</sup> A right dose of an oral anticoagulant significantly reduces thromboembolism.<sup>[12]</sup> The annual thromboembolic risk among warfarin users and non-users is 1% and 4%, respectively.<sup>[13]</sup> International Normalized Ratio (INR) for the patients with mechanical aortic and mitral prosthesis is 2-3 and 2.5-3.5, respectively.<sup>[14-16]</sup> According to Menendez, the late-onset complications of valve replacement are: anticoagulant-induced bleeding, prosthesis malfunction, infectious endocarditis, recurrent thrombosis, and valvular insufficiency, which represent the outcomes of failure in the care system.<sup>[17]</sup> More than the half of the patients did not use the right dose of anticoagulants and had no information on the drug side effects and on the relevant lifestyle.<sup>[18]</sup> In the present condition, most patients die due to problems in care and warfarin intoxication.<sup>[19]</sup> Christensen points out that the rate of complications and problems related to treatment with anticoagulants due to self-care and conventional management method are 2.5%

<sup>1</sup>Department of Nursing, Faculty of Medical Sciences, Tarbiat Modares University, Tehran, IR Iran

**Address for correspondence:** Dr. Robabeh Memarian, Department of Nursing Faculty of Medical Sciences, Tarbiat Modares University, Tehran, IR Iran.  
E-mail: memari\_r@modares.ac.ir

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and 7.3%, respectively.<sup>[20]</sup> In addition, the INR was normal among the self-managed patients.<sup>[21,22]</sup> Warfarin use in pregnancy results in some complications (e.g. abortion and physical anomalies).<sup>[22,23]</sup> There is no agreement on the right dose of warfarin during pregnancy for supporting both mother and fetus.<sup>[24]</sup> The doses of warfarin prescribed for valve-replaced patients depend on different factors, which by themselves have different effects on INR.<sup>[25-28]</sup> The administration of herbal drugs along with warfarin has different effects on INR.<sup>[29-32]</sup> In Deccache and Aujoulat's report on hospitalized patients, 20% of the cases had received adequate information on their disease/health condition through advising, 20% of them were not satisfied with their care condition, and the remaining 60% were required to receive more education.<sup>[33]</sup> Heart valve-replaced patients, due to their susceptibility and the risky outcomes of the procedures, have different levels of worry and anxiety,<sup>[34]</sup> and continue to live with anxiety, doubt, and worry.<sup>[35]</sup> The preoperative physical problems and also the postoperative physical complications in valve-replaced patients are associated with a feeling of worry.<sup>[36]</sup> Hence, identification of the needs of such patients from their own experiences is necessary for providing nursing care and lessening the fear and anxiety in them.<sup>[37]</sup> It seems that the worries, experiences, and attitudes of the patients are ignored by the nursing staff as they are classified as their least important priorities and usually are not considered in routine care planning.<sup>[38]</sup> Stressful conditions could result in unfavorable physiologic, psychological, and behavioral complications.<sup>[39]</sup> Assessing the potential sources for fear, worry, and emotional status (doubt, denial, aggressiveness, and isolation, often as a general reaction to illness or self-awareness) is of importance.<sup>[40,41]</sup> Moreover, to our knowledge, till the present time, no qualitative study has been reported on the experiences of these patients while facing the problems following heart valve replacement. Given the special cultural, social, and religious contexts in which the heart valve-replaced patients are cared for, the present study was done with a qualitative approach to describe the stressful experiences of heart valve-replaced patients.

## MATERIALS AND METHODS

In this qualitative study, qualitative purposeful sampling was performed to obtain the perceived experiences of the heart valve-replaced patients. Subjects consisted of cases with experiences of valve replacement and the tendency to cooperate and report their experiences. Data collection was done by conducting a deep, semi-structured interview using an MP4 voice recorder. Each interview was started with an open question, "What were your experiences in facing and living with the reality of valve replacement?"

In addition, to receive further information and for a deep perception of words, some explorative questions like "Can you give more explanations?" and "Can you give an example about it?" were asked. The exclusion criterion was having no willingness to continue the interview. The time length for an interview session was 45-60 min. A convenient place for the patients was chosen as the place of interview. The next participants were determined by studying the collected data. Data collection was done until saturation was reached. Using the Graneheim and Lundman content analysis for qualitative data, the synchronous description and analysis of the interviews were done as follows: (1) typing the entire interview script immediately after each session; (2) reading through the whole text for a general perception of its content; (3) determining the meaning units and the initial codes; (4) classifying similar initial codes into more comprehensive categories; and (5) determining the main themes of categories.<sup>[42]</sup> The explanation and analysis were done in the following sequence: immediately after each interview session, its content was re-written in the Word software, imported to MAXQDA-V7, and then the scripts were read several times to find general perceptions of the patients based on the aim of the research. Then the meaning units/initial codes were derived, merged, and classified based on similarities. All efforts were taken to keep maximal homogeneity within the categories and also maximal heterogeneity between categories, and avoid the inclusion of the same data in two categories. Ranking was done for new category based on aims and the main concepts were taken for the validity and reliability of results. Based on Polit and Beck's approval, for the accuracy of research findings, the criteria of validity, reliability, and transferability were used.<sup>[43]</sup> In addition, for the acceptance of the data, all academic members with an experience of qualitative research were requested to evaluate the codes derived. Through reviewing the handwritten scripts by the participants and peer-reviewing it by the research team colleagues, the validity of data was checked. For transferability, the participants were requested to declare some items for completing and correcting the codes. The study was approved by the Ethical Committee of Tarbiat Modares University. The written informed consent and the signed agreement of having the right to withdraw from the study or continue with the study whenever they wanted to were obtained from all participants.

## RESULTS

Thirteen patients were interviewed in the study. Their demographic data are shown in Table 1. From the rich and informative description of participants, 680 codes were extracted. After the exclusion of overlapping and

**Table 1: Demographic features of the participants**

Gender
Male (5)
Female (8)
Age (mean)
48.7 years
Marital status
Married (11)
Widow (1)
Single (1)
Education level
Illiterate (1)
Primary (8)
High school (4)
Type of prosthetic valve
Mitral (9)
Aortic (2)
Both (2)
Occupation
Retired (2)
Housewife (7)
Farmer (1)
Worker (1)
Time after replacement
2 weeks-27 years
Interview length
45-65 min

repetitive codes, 175 initial codes were derived. Then, based on similarities, they were classified and summarized into 14 subcategories. Based on the conceptual and abstract exploration of the themes and using analysis and comparison, five subsidiary themes and a main theme of “a life associated with fear and worry” were extracted.

### Worry on care condition

Heart valve-replaced patients have multiple worries. One of them is the capability/tactfulness of the therapeutic team. Most therapeutic centers in Iran lack the facilities for valve replacement surgery, and this is also the case regarding experiences of the care team. These patients were often referred to the main centers.

*“For removing my womb, I was hospitalized for 2 months. All my friends instructed me to go to Tehran. I was referred to one of them (doctors) for surgery. Most of the doctors rejected me due to the lack of therapeutic facilities.”* (participant # 3, 32 years female, mitral valve replacement).

In case of need for treatment or surgery, most therapeutic centers reject patients or refer them to other centers.

Otherwise, those patients are always worried. The second source of worry for participants is the carelessness and failure of the therapeutic team. The patients are worried about the lab reports. They have the right to be informed about the results of their test reports. This is because any decision taken for them is based on INR test. The patients are bothered about any carelessness from the team side. So, the patients do not refer to the doctors unless they are assured about them. Most often, such doctors are not accessible. The reason for their worry is that if these patients face a problem, what do they do? They desperately refer to other doctors and therapeutic centers which gives them a sort of worry.

*“I fear everyone and everything and I told myself about the failure in surgery and its bad outcomes, i.e. dying for nothing.”* (participant # 2, 47-year-old female, mitral valve replacement done twice).

Or

*“They operate us and prescribe medicines and then give up us.”* (participant # 7, 67-year-old female, mitral valve replacement).

*“For a cheaper PT, I often refer to hospitals, I always have the anxiety of a wrong PT.”* (participant # 13, 45-year-old female, aortic valve replacement).

The second theme was worry related to specific conditions. These worries are: worry of unexpected events, worry of the outcome of warfarin use, worry of the functioning of prosthetic valve, and worry of coagulatory test results. All the time the patients are worried about an unexpected event happening for different reasons, e.g. shortage of drugs and the discontinuity of valve function.

*“Sometimes I no longer bear it and have anxiety. For instance, when I have no warfarin, I think if the valves were non-functional, what can I do for it, how long really it works for me.”* (participant # 13, 45-year-old female, aortic valve replacement).

These worries are intensified with a high risk of endocarditis, angiography, tooth extraction, or less education.

*“I have a hard job, I must lift heavy loads of construction materials as a constitutional worker. I fear that doing such heavy tasks may worsen my condition.”* (participant # 12, 34-year-old male, both mitral and aortic valve replacement).

*“I am really worried about a new event.”* (participant # 10, 70-year-old female, mitral valve replacement).

Or

*“Everwhere I am hearing the patients’ words on the unsuccessfulness of their operation. Well, we have the fear*

of dying for nothing. Nobody in hospital speaks about these items.” (participant # 2, 47-year-old male, mitral valve replaced twice).

Sometimes these worries result in the patient not following the treatment.

“When they performed angiography for me, I feared of dying for no reasons. So, I signed an informed consent and accepted the outcomes. Despite the instructions of the doctor, I left the hospital for home, but desperately I came here again.” (participant # 8, 50-year-old male, both mitral and aortic valve replacement).

Another reason for worry among the heart valve-replaced patients is the outcome of warfarin use. These patients should continue using warfarin until the end of life and all team members emphasize on this. So, patients are worried about forgetting the drug or its overdose, especially in some conditions like pregnancy and/or surgery.

“I fear again on the outcome of a bad event. I have lost confidence in doctors and hospitals. Sometimes ago I had a similar experience that approached me to death. Now, I fear everything, even going to a dentist and a bad luck.” (participant # 4, 40-year-old male, mitral valve replacement).

When patients face a new situation (a change in weather, travel and food regimen, using new drugs, and change in body metabolism, all of which have an effect on INR), they have to repeat the test and report its results to their doctors. The facilities are not available all the time and in case of inadequate education, it results in recurrent referrals and longer hospitalizations.

### **Worry on the effect of disease on life stability**

These worries are as follows.

Disturbances in daily living and transmission of the disease to offsprings are one of the worries. For a long time during their life, these patients are involved in rheumatic heart disease, valvular involvement and replacement, and its outcomes to the extent that the condition affects their routine life which results in a busy mind and constant worry.

“There was a great fear and threat in my mind on living with this sort of valve. My life has changed completely, this heart is not my previous heart. I think something is added to my heart.” (participant # 3, 32-year-old female, mitral valve replacement).

Another source of worry among the valve-replaced patients, especially affecting the offspring, is the repetitive nature

of the exacerbation of the disease and the results of lab reports. Family support in these conditions can alleviate the worries. However, in the present time, majority of the society members and their families, for different reasons, do not provide the required support.

“One thing that made me have more fear on operation and reject its proposal was my children’s fear of losing me and dying, and hence I bore the pain and rejected the operation.” (participant # 8, 50-year-old male, both aortic and mitral valve replacement).

The other source of worry is the transmission of disease to the children. These patients receive different information during their disease process. For instance, during pregnancy, a change in the anticoagulant regimen (e.g. warfarin, heparin) should be made.

“Another stressor that worsened my conditions was that everyday I heard words on the condition of my newborn baby. Will it be healthy or have some problems in its heart?” (participant # 4, 40-year-old female, mitral valve replacement).

When these patients use the teratogenic drug warfarin, especially in the initial stages of the pregnancy, they have a troublesome life. Because all the time, they hear about the teratogenicity of these agents and are worried about the defects it causes in their babies.

Fear of hospital is one of the themes that consisted of the following: fear of re-operation, fear of hospital milieu and the facilities of the hospital. The patients are not aware of most of the therapeutic/diagnostic methods used for valve-replaced patients during their life period to the extent that they think that most of their problems could be solved with some ordinary lab tests. Sometimes the unfavorable outcomes of these tests made them reject the diagnostic procedures or re-operation.

“I am feared of hospitalization and doing the angio. My fear’s origin is in having no information, forgetting the instructions and not obeying the orders.” (participant # 5, 55-year-old male, mitral valve replacement).

Sometimes the patients’ fear originated from their previous experiences or, in most cases, the information they received in relation to dying or related to the matter that they thought that they died because of their inadequate search for a better hospital and hurry in operation. So, they are much worried about the facilities and the capability of the surgeons.

*"It took 6 months that I decided for the operation. I was so feared of signing the informed consent and took the responsibility of discharging from hospital."* (participant # 8, 50-year-old male, both aortic and mitral valve replacement).

These patients are asking and searching much for their obligatory operation "valve surgery" and also the alternatives, especially the non-surgical ones. One of their concerns in this regard is the carelessness of the surgeons, their insufficient experience, or the lack of facilities of the care team.

Another subcategory of this is fear of the hospital milieu. The common source of fear for these patients is the unfamiliar environment and people. Among the multiple sources of fear, one important thing is the patients' worry on the conflict and disagreement between the therapeutic team, mostly on diagnostic and treatment issues. The patients' minds are occupied with problems on the follow-up and post-treatment risks and outcomes, which mostly begin after the valve replacement.

*"In such big cities, like Tehran, you can find the tactful doctors, only a few of them are here and they are busy all the time."* (participant # 11, 45-year-old male, mitral valve replacement).

Because of their worry, patients are trying to communicate with the nurses and doctors and ask them about the disease, treatment, and lifestyle. But because of inadequate education and the lack of opportunities to communicate with the therapeutic team, the patients receive information from other sources which results in having doubts about the treatment or the fundamental errors that, by itself, aggravates their anxiety.

The theme of fear for unknowns consists of fear of the unexpected and unfavorable events and fear of the establishment of new condition. In these instances, the cause of fear is often similar previous experience of the patients, i.e. the risk of infection, disturbances in INR, bleeding, and clotting, that the probability of their occurrence increases in exposure to the new situation. In addition, often in therapeutic settings, the newly arrived non-professional personnel lack the required capability to care for the patients. These situations are fearful for patients; especially on hospitalization and during the diagnostic/therapeutic procedures, the patients are worried about the occurrence of unknown events.

*"I am afraid of being hospitalized, I am afraid of the doctors' act, they do in a way that my valve be occluded and instruct me to the operation. In this case, it would be*

*my third operation."* (participant # 9, 55-year-old male, mitral valve replacement).

When the patients are worried, they try not to get hospitalized as much as possible; otherwise, they try to get discharged earlier, all of which signify the lack of confidence in the therapeutic/health system that definitely has some negative effects on the patients' treatment.

Knowing nothing about the problems, their reasons, and problem-solving strategies aggravates the patients' worry.

*"Spontaneously, I felt a sort of post-operative anxiety in myself, I thought maybe my condition got worse, I am feared of the noise in my valves, It causes me not to have a comfortable sleep overnight, all the time it occupies my mind."* (participant # 7, 67-year-old female, mitral valve replacement).

Sometimes fear following the valve replacement is productive in nature and acts as a motive for following the lab results and the efficacy of treatment and education. For example, it results in a feeling of lack of confidence on the therapeutic team, which causes worry, injury, and anxiety.

## DISCUSSION

Valve replacement is a successful option for heart valve malfunctions. Findings from the main themes of fear and worry signified the actual experience of the patients. Analysis of the participants' experiences showed that the patients got their fear and worry from the following sources: worry on care condition, worry of the specified conditions of the patients, worry on the instability in life, fear of hospital, and fear of unknowns. Of these fear sources, three sources are related to human sources and the remaining two sources to non-human (environmental and facilities) sources. These novel findings signify the role of therapeutic team, especially nurses, its presence, quality, and communication with patients for eliminating their fear and worry. The findings of our study reveal that when the participants are unable to communicate with the therapeutic team, they do have a feeling of fear and worry.

On facing the stressful conditions, patients require nursing care followed by their understanding of the condition. In situations where the nurses had no intimate and emotional relations with their clients, the patients feared and were worried. These findings are in line with the studies of Hawley who revealed that a positive conversation between the emergency ward nurses and patients resulted in confidence, sympathy, insurance, and relieving the worry on the unknowns of the disease.<sup>[44]</sup> Baldursdottir and

Jonsdottir pointed out that the patients reported capability as the most important care behavior of the emergency ward nurses.<sup>[45]</sup> In our study, we found from the participants' experiences that worry on the therapeutic team and worry on the carelessness of the team are the sources of unexpected events. Holroyd *et al.* revealed that the most important worries among Chinese patients were about delay in administering the drug, no on-time treatment, and the non-constant sitting on patient's bedside.<sup>[46]</sup> Also, Jooybari *et al.* showed that being in the same room, patients could have an intimate relationship among them and in the absence of the nurse, this relationship develops a sort of robust motivation for cooperation and social interactions.<sup>[47]</sup> Badir stated that family members have a significant role in patients' health and recovery process.<sup>[48]</sup> Tensions in valve-replaced patients are the psychosocial effects of the problem (e.g. waiting for the result of clinical test, fear of losing the valve, etc.). These sources of tension in everyday life require adaptation and, in some cases, are among the routine problems, like using warfarin or not using it and also its effects on the body. These usual events, by themselves, are not catastrophic and ailing, but due to their cumulative effects on the individual's life, they could result in some somatic problems for the patient. Other stressors with regard to patient's condition are the ones that have an effect on his/her life, e.g. life events that, in some cases, cause social/psychological crises like physical disability, permanent disability, or problematic life with a prosthetic valve. These stressors are often constant in nature or have the potential of getting chronic. Rybarczyk *et al.* revealed that some factors (e.g. physical inactivity, low salary due to inactivity, lack of entertainment, and lower satisfaction in emotional support) are among the factors causing post-heart transplantation disappointment in patients.<sup>[49]</sup> The constant noise of prosthetic valve, the financial problems, and the physical disability result in more anxiety. Losing the role function or perceived aim in life can cause tension and discomfort. Each of these specified variables or the extra needs of the patients results in ineffective adaptation which can be resolved with post-replacement recovery and rehabilitation. In line with these findings, Karapolat *et al.*, in their study on heart recipients, revealed that the group of recipients who followed a regular training program and received emotional support postoperatively had a significant improvement in psychological function.<sup>[50]</sup> Gross and coworkers reported that anxiety is an inseparable problem of chronic disease and these patients have no favorable quality of life. Hence, their anxiety must be assessed and managed because of its effect on treatment and in following the prescriptions.<sup>[51]</sup> In their study, Corruble *et al.* emphasized on anxiety as a leading issue which, especially in post-transplantation period, could be due to the drug misuse and other factors

and results in an increased mortality rate.<sup>[52]</sup> Overall, the actual assessment of the stressful situation and its sources can improve the care condition of such patients.

## CONCLUSION

The worry and fear after heart valve replacement originate from two main sources, namely human sources or the personnel involved in care and the non-human sources which relate to the environment and logistic facilities. Being aware of these fears and worry sources and stressors helps the caregivers in providing care, essential education, and promoting the quality of life and survival. Identifying the actual problems of the heart valve-replaced patients and detection of the unknowns of these patients signify their needs for support, advice, and psychological rehabilitation.

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