

International Journal of Nursing and Health Care Research

Al-Ananbeh E, Abu-Moghli F. Int J Nurs Health Care Res 9: 1111.

DOI: 10.29011/IJNHR-1111.101111

Research Article

Cardiac Patients Experiences Regarding Health Care Decisions

Enaam Al-Ananbeh^{1*}, Fathieh Abu-Moghli²

¹Mutaa University, Prince Muna College of Nursing, Amman, Jordan

²Community Health Nursing Department, The University of Jordan, School of Nursing, Amman, Jordan

*Corresponding author: Enaam Al-Ananbeh, Assistant Dean, Mutaa University Prince Muna College of Nursing, Amman, Jordan. Tel: +962-779290338; Email: enaam_enab@yahoo.com

Citation: Al-Ananbeh E, Abu-Moghli F (2019) Cardiac Patients Experiences Regarding Health Care Decisions. Int J Nurs Health Care Res 9: 1111. DOI: 10.29011/IJNHR-1111.101111

Received Date: 16 August, 2019; Accepted Date: 16 September, 2019; Published Date: 20 September, 2019

Abstract

Background: Patients' involvement in health care decisions has been associated with improved treatment outcomes. Little is known about cardiac patients' experiences regarding involvement in health care decisions in Jordan. Therefore, it is of vital role to explore the level of involvement in health care decisions from patients' perspectives.

Aims: To explore the subjective experiences of cardiac patients regarding their involvement in health care decisions in Jordan.

Design: Descriptive phenomenological approach has been selected to underpin this study.

Methods: A purposive sample consisting of sixteen cardiac patients who were admitted to cardiac center at one public hospital in Jordan were interviewed. Data were generated through semi-structured interviews. Data generation took place over a period of six months (December 2017-May 2018). Data were analyzed using a five - step technique proposed by Giorgi [1].

Results: Findings revealed five major themes: 1) Patients' problems that require decision-making are being attended to by HCPs., 2) The approach used by HCPs in communicating with patients is comforting, 3) Information provided to patients is helpful, 4) patients preferences regarding D.M style vary, 5) Sociocultural influence and religious factors influence patient's role in D.M.

Conclusion: patients have positive attitudes toward active involvement and sharing role in health care decisions. Most patients preferred to rely on HCPs to take the final decision. Patients' preferences were influenced by communication, sociocultural and religious factors, as well as their health status. The differences in patients' preferences and values should be considered and recognized when considering patients' involvement for best outcomes.

Keywords: Cardiac patients; Decisions making; Patient involvement; Shared D.M

Introduction and Background

The increasing emphasis on the individual's choice in health care treatment has contributed to the growing trend for Patient Involvement (PI) in decision-making so that the decision is shared between the patient/client and the health care team [2,3].

Patient Involvement (PI), as a concept, is associated

with other terms such as patient engagement, collaboration, empowerment, partnership and participation [4,5]. Arnetz, et al. [4] defined PI as "Shared perceptions about, and behaviors aimed at involving patients in decisions and care processes throughout their hospitalization" [4]. Patient involvement in nursing and caring research was described by Barello, et al. [6] as the patients' awareness. It can be described as a continuum ranging from answering questions to actively participating in decision-making. In the field of shared decision-making studies, Elwyn, et al. [7] related PI to patients' beliefs, values and preferences where nurses

and physicians are actually responsive to patients' subjective needs. Active involvement of patients in D.M as a component of patient-centered care [8] has been considered as an approach to amend clinical care for patients by encouraging Health Care Providers (HCPs) to present accurate, understandable health information to increase patients' participation in their care [9].

Patient involvement in health - related decisions has been shown to improve patients' understanding of the available treatment options, increases their realistic expectations of health benefits and harms, and improves agreement between patients' values, preferences and treatment choices [9]. It may also lead to improve patient well-being through better adherence to treatment, fewer concerns about illness, and higher satisfaction with health outcomes [9,10] as well as selecting less intensive treatments with lower cost [11].

The need for HCPs patient sharing is mainly needed when the patient presents with a serious or life threatening illness; different treatment options exist, with different benefits and risks; and health outcomes are uncertain. In these situations, there is no one "Right" option [12]. Therefore, active involvement of patients is crucial among cardiac patients [3,4]. Cardiac patients usually complain of physical problems as fatigue, pain, lack of sleep, and psychosocial factors such as depression that affect their health prognosis and outcome [13]. Their management plan usually has many alternatives in term of medication, lifestyle modifications and medical and surgical interventions [14,15].

Patients preference for D.M style may vary according to his role in the D.M process [16]. In one extreme, the "Paternalistic" style, patients allow the healthcare providers to undertake the responsibility of the health- related decision with no or minimum involvement. In the other extreme, "Consumerism" style, the health- related decision is made by patients and potential others as family members. In this style patient is able to make an appropriate decision after obtaining all needed health information [16,17]. Shared Decision Making (SDM) is between the two previous styles of this continuum [17] where both patient and HCPs must be willing to engage in the D.M process [16].

Several studies conducted worldwide, have revealed that PI in decisions related to health issues is rarely implemented in current clinical practice and HCPs often do not involve them in these decisions and rarely respond to their preferences [18-20]. Involvement in D.M process have been discussed in the literature mainly through quantitative studies and statistical inferences with little knowledge of the lived experiences of cardiac patients [11,21].

In Jordan there is no published qualitative studies on the experiences of involvement in decisions related to health issues within Jordanian culture from cardiac patients' perspectives. Therefore, this study was conducted to explore the subjective

experiences of cardiac patients' involvement with decisions related to health issues, to produce first-hand descriptive data of the experience as it is concretely lived by cardiac patients in a military institution in Jordan. Better understanding of patients' choices processes on cardiac management plan as well as understanding of sociocultural and disease context regarding health related decisions; enable policy makers and HCPs to create specific decisional aids and support strategies according to patients' preferred style to fit their needs.

Purpose of the Study

This phenomenological study was conducted to explore subjective experiences of involvement in health care decisions from cardiac patients' perspectives in a military institution in Jordan. The study tried to answer the question "What are the subjective experiences of cardiac patients regarding their involvement in health care decisions? In another way: How do cardiac patients describe their experiences regarding their involvement in health care decisions?"

Methodology

Study Design

This study followed a qualitative approach to achieve its purposes. Qualitative approach allows studying human traits such as: perceptions, thoughts, feelings, and attitudes, as well as experiences [16,22].

Study Setting

The study was conducted in a military institution in Amman City, Jordan. The military institution is a specialized institution in cardiac diseases. It consists of hundred and ninety-three (193) bed distributed on ten wards.

Participants' Selection

A non-probability, purposive sampling technique was used for selecting the participants to better understand the present phenomena and to answer the research question.

Purposive sampling of cardiac patients suits this qualitative study, because it is used when the researchers call for data saturation rather than representativeness. The sample included cardiac patients who consented to perform any surgical intervention such as cardiac catheterization, cardiac stenting or open heart surgery, or those who underwent such surgical intervention. The patients were diagnosed with cardiac disease for at least one year to ensure that participating patients have been subjected to some interventions that needed decisions. they were ready for discharge from the institution to confirm, to some extent their stable health status, informed about her/his diagnosis, willing to participate in the study, conscious, without mental illnesses, able to communicate verbally and able to speak and understand Arabic to sign the Informed

Consent (IC), of ages of more than 18 years old [12,13].

Ethical Considerations

The three ethical principles identified by Belmont Report relevant to the conduct of research involving human subjects; respect for persons, beneficence, and justice [22,23] were guaranteed. The approval of the Institutional Review Board at the University of Jordan, School of Nursing and the Royal Medical Services to conduct the study were obtained. Informed consent was also obtained from each eligible participant after they understood the purposes and the procedures of the study (Appendix A/1). Each participant was asked for a permission to use tape record during interviews. All participants were reminded that involvement in this study is strictly voluntary; they are free to stop the interview at any time, or withdraw from the study at any time and their care will not be influenced negatively. Each participant was given a code such as: (C1, C2...) to ensure anonymity and confidentiality.

Data Collection Tools

Data was collected by in-depth, individual semi- structured face to face interview. An interview guide and a demographic data sheet were developed by the researchers based on involvement in decision making - related literature (Appendices B & C). Both tools were tested for validity by three expert nurses.

Data Generation Procedure

After obtaining ethical approval and All permissions the patients who fulfilled the inclusion criteria were identified with the assistance of registered Nurses in the targeted institution. Then the interview date, time, and place was set with each participant. The principal researcher herself conducted the individual face-to-face interviews with each participant; Each interview was audio-taped and transcribed verbatim after getting a permission from participants. Based on patients' health status and the literature [13,24,25]. Each interview was conducted over one hour. The demographic data form was completed at the end of each interview.

Method of Analysis

A five-step approach of data analysis based on Amedeo Giorgi's phenomenological philosophy [1] was used [26,27]. Each taped interview was repeatedly reviewed after its completion. The researchers then read and read each interview to get a sense of the whole experience, then divided data into manageable parts that reflect the participants own meaning of the experience. Qualities of data as essential parts and as accidental parts were distinguished. The constituents were joined with each other to form a general (whole) structure. The structure is the outcome (results) of the analysis. Researchers explored themes' descriptions within and between participants, similarities and differences in participants' reports within a theme including the variations, inter and intra

themes and cases to determine relative importance of themes.

Rigor of Trusting

Steps suggested by Guba and Lincoln were taken to address rigor of study methods [28]. Credibility was achieved by peer debriefing, and frequent member checks sessions which included testing the findings by the researchers. Transferability was assured by the use of thick description from the participants' interviews. Dependability and conformability were fostered through presenting the readers with full and in- depth design description so, they will be able to judge the effectiveness and integrity of the research practices.

Results

Patients characteristics	Number (16)	(%)
1-Age		
18-28	None	
29-39	2	12.5
40-50	2	12.5
50 and above	12	75
2-Gender		
Male	10	62.5
female	6	37.5
Marital status		
Married	14	87.5
Single	None	----
Divorced	None	-----
Widow	2	12.5
Others	None.	
3-Level of education		
Less than (high school) Tawjihi.	9	56.25
High school.	5	31.25
More than high school.	2	12.5
Medical diagnosis		
For operation:		
Cardiac Cath	1	6.25
Cardiac Stent	1	6.25
Open heart	6	37.5

Post operation	8	50
Co-morbidity		
DM	9	56.25
HTN	8	50
DM & HTN	7	43.75
Hyperlipidemia	3	18.75
Others	6	37.5
Employment		
Employed	7	43.75
Not Employment	9	56.25
Living conditions		
With family	14	87.5
With spouse	2	12.5
Alone	None	
Insurance type		
Military	8	50
Civilian	5	31.25
Others	3	18.75
Income Average		
<500 JD	6	37.5
>500 JD	10	62.5

Table 1: Demographic details of the participating patients.

Analysis of generated data based on Giorgi [1] revealed five major themes across patients, 1) Patients' problems that require decision-making are being attended to by HCPs, 2) The approach used by HCPs in communicating with patients is comforting, 3) Information provided to patients is helpful, 4) patients preferences regarding D.M style vary., 5) Sociocultural and religious factors influence patients' role in D.M.

1- Patients' Problems that Require Decision-Making are being Attended to by HCPs

Patients felt involved in health care decisions when HCPs paid attention to their problems that require D.M. Many patients revealed that HCPs support them physically and psychologically, collaborate with them and follow up their conditions. An old male patient expressed his acknowledgment and appreciation of HCPs: He said: "Sure, first thing they (HCPs) comfort you psychologically then they treat you. I mean that nursing and medicine are the most

important. Physician and nurses are a source of pride not only in Jordan but also in the Arab region.

According to the majority of patients, responsiveness and concern about their health issues contributed to a feeling of being attended to and cared for by HCPs. Patients indicated that when they complain or ask, HCPs immediately respond.

A male Patient said; "Wallah (swear to God), really they are attentive, if I have any complain they immediately respond to me straight away, and when I face any problem they come and answer me quickly".

Another male patient said: They (HCPs) are specific in their talk. They say to you, for example, we have a problem and we will use so and so and we should reach a result. I mean that they do not give up hope..."

2- The Approach Used by HCPs in Communicating with Patients is Comforting

Most patients experienced comfortable approach from HCPs; they appreciated their verbal and nonverbal communication and felt it improved their morale. One male patient expressed his comfort with HCPs polite approach, saying: Yes, yes they(HCPs) care, when a nurse approaches you with a smile on his face and addresses you by: "My Uncle" and gives you treatment, of course this raises one's morale very much.

Patients expressed that welcoming, comforting and informative communication made them feel involved. A young male patient's own words indicated his comfort and positive experience with HCPs approach that assisted him to decide on cardiac catheterization: I faced an approach, as you can say, they talk to me in a kind or humorous manner or somehow psychologically comforting, so if I feel afraid to do the operation as I view it a big deal, they (HCPs) by their approach comfort and motivate me to decide to go ahead and do it.

3-Information Provided to Patients is Helpful

Most patients indicated that HCPs were helpful in improving their understanding of their health situation and taking a decision. A young male patient described his interesting experience with HCPs in providing him information and said that HCP fully informed and explained to him his health problem and that he felt encouraged to ask them questions: They (HCPs) informed me that surgery is the only option for my case; no other alternative. As I am not educated he (my Dr.) taught and explained to me and then I got the interest in asking him questions

Patients expressed their experiences as being involved when HCPs facilitated their understanding of their situation; They acknowledged HCPs approach in discussing and clarifying the case in details. Added to that, they expressed that nurses continuously

advise and follow them up, they are always polite.

A male patient said: My Doctor clarified and showed me using drawing, and he clarified to me that this artery (pointed to his hand) is clean. Look at this occlusion here coming from the end (of the artery), and we can open it (used drawing on his hand for clarification). When there is an overall damage with occlusion and we close here and open there, after a period of time in your case it will be blocked (the artery).

Some patients perceived that patients-HCPs interaction as primary for them to make a decision. A male patient viewed his awareness about his case as primary to making a decision in addition to HCPs, approach in providing information. He added: Information given by HCPs are hundred percent right for those patients who want to comprehend it. Some patients may not understand it. Those who know their case when they receive the information, they should think well about it. There should be reciprocity between patients and Dr. HCPs approach in providing information is primary to make patients understand what they prefer otherwise, they will get confused.

Some patients, interestingly found excuses to physicians for not giving them time to question as they perceived that they are too busy and have limited time to talk with and see their patients. One of those patients expressed his sympathetic feelings with physicians, he said: Frankly, God help them (Dr.) they do not have time; we overwhelm them and call for them. I saw my Dr. once or twice because he is not free to explain to me, he has no time.

Another educated male patient indicated that his Dr. did not talk to him or provide information needed to take a decision. He said: My Dr. said two words and left without any clarification.

Four patients shared the experience of being unable to understand their health issues. They felt not willing to engage in such specialized medical information. An old male patient who was scheduled for heart surgery stated that he does not know what will be done during the surgery: I know nothing about medicine or medical issues. I do not know what will be done during the surgery. The surgeon knows, it is his job. He added: As patients, we understand nothing in medicine, we do not interfere with medical and technical issues. medicine is the concern of medical staff.

Several patients, mostly females talked about their experiences and how HCPs involved their family in providing the needed information. A male patient reported: “The physician told me he will come during visit hours. He came and talked to my sons. They are doctors and they know more about medical issues. After they discussed with my doctor they explained to me”.

4-Patients Preferences Regarding Involvement in D.M Style Vary

The majority (15) of patients preferred an active role in

health care decisions, but they often do not experience such a role in making their decisions. They rarely have their preferences met by their HCPs.

The range of options available to patients, the severity of their illness and the probable risks and benefits of the intervention all influence patients’ decision making preferences. a male patient who felt helpless to choose his preferred option expressed complete faith in the physician that he did not question his decision: I hoped that physician would find another option other than the operation after watching the CD, but he informed me that I needed to do the open heart as the only option. It happened like this, what shall I do? If there were other solutions, he would have informed me, but, as he said, the open heart is inevitable.

On the other hand, three patients expressed their self-determined decision. One of those patients a female, experienced Shortness of Breath (SOB) that forced her to decide on making the operation.

I took the decision myself. They (people around her) advised me not to do the operation... and to take a treatment, I said I decided to do the operation as it is inevitable. I complain of discomfort and unable to walk from (SOB).

A male patient expressed that he was surprised by the unexpected decision from his physicians and indicated that they decided everything related to his operation without his involvement. He said: They told me: you will have an operation on Monday. We (physicians) met and made a decision. They surprised me; the doctor just came and said you have an operation. They did not ask me but they decided and they did not even inform me about its complications.

Around two third of patients, mainly males, indicated their utmost trust in their doctors and how being informed about the risks/benefits rate helped them in accepting their doctor’s decision of the intended intervention. Mostly what helped them and motivated them to agree was being informed that the operation has a high success rate. A male patient explained: “I agree with whatever my doctors see appropriate. The doctor informed me that my operation has 90% success rate, this success rate encouraged me to take the decision to undergo the operation. We depend on Allah after all.”

Only two patients (one male and one female) put unconditional, full trust in HCPs to the extreme that they did not seek or mention a need to be informed. They preferred a passive role in the decision making process. One of them stated that: “I am not a doctor to know all about my condition, they are doctors and they know more than I do.”

The majority of patients (75%) mainly females mentioned that there is a role to their families in D.M. Of those females, three

shared their experiences in that their families have main roles in health care decision; one female patient said: “My brothers, family, sisters and sons all have a role in the decision. My kids are educated and some are medical doctors”.

5-Sociocultural and Religious Factors Influence Patients’ Role in D.M

Patients perceived that Involvement in D.M has been influenced by various sociocultural factors and religious issues. Such influences include social support or social pressure, culture and beliefs, as well as certain religious rituals. A married female patient indicated her inability to take her own decision. She believes in her extended family role in making the decision, and said: “My brothers, family, sisters and sons have a role in the decision (on my operation). I cannot impose my opinion on my sons and family”. Some patients believe completely in Allah which in turn influences their decision. For example, some high risky patients experienced a contradicting decision with that of their physicians as they perceived that life is in Allah hands.

One female Patient said: “I rely on Allah; life is out of our hands. What Allah wants will happen, hoping Allah will choose what is best for me”. A significant number (55%) of patients held the belief that disease comes from Allah, death and life is determined by Allah. One of those patients described his deep faith in Allah. He perceived that life is determined by Allah not by physicians or success rate of the operation. “There are options, the issue is not easy to decide, physician knows that life is in Allah hands. The operation success rate, as he (physician) told me, is 85%.....but even if he told me the success rate is 1%, as long as I believe in Allah it is over. Death does not precede disease”.

He added: “I do not let anyone take a decision on my behalf even the physician. If he informed me to do the operation tomorrow and I do not want to do it, I will not do it. The decision is mine not even for my sons. It is the faith; if you separate disease from death it is determined. That is, because it is a science can be learned but life is in Allah’s hands, no one can interfere with it, Allah grants death and grants life”.

Discussion

The emerging themes of this study are in accord with results of previous studies conducted in different cultures. Attention to patients’ problems is well documented in the literature, [3,29,30] found that patients who experienced good relationship with HCPs often demonstrated more satisfaction with their care and they followed their HCPs instructions and recommendations.

Several studies concluded that patients who feel that HCPs communicate well with them, and encourage them to be involved in their own healthcare, tend to be more motivated to share in health care decision [3,24,31,32] confirmed the findings of this

study, as patients felt involved through experiencing supportive and comfortable communication despite not being actively involved in decision-making. This emphasizes the use of supportive communication and equal partnership to create an environment for active patient involvement. Without an environment of shared decision-making, patients may act on their own to manage their health issues, this can negatively impact health care outcome [33].

Literature further supports the findings of this study, as patients felt that HCPs were helpful in improving their understanding of their health condition. More than half of patients reported that HCPs offered them opportunities to ask questions. They expressed their feeling of being involved as HCPs maintained open channels of communication. Yasien, et al. [30] confirmed the findings of this study as patients rated the item of providing enough information significantly low. Similar responses were mentioned by patients in [34] study on patients’ preferences for involvement in clinical D.M, they found that patients lacked the opportunity to talk to HCPs mainly doctors as they always seemed too busy.

Two patients admitted that they usually seize the opportunity of doctor’s presence to ask a lot of questions. Participants in this study are treated in public health sector where the time limits and heavy work load are clearly visible. Thus, HCPs are unable to provide adequate opportunity for each patient to express his concerns. Further, the paternalistic medical model of care is dominant in the public health care sector. Military health institutions in Jordan reflect this model of care as evident by the structural style of leadership and military ranks. Therefore, the provided care at the public health sector is physician-centered rather than patient-centered and patients are not given enough information about treatment alternatives and the disease [35]. Health organization policies should consider the limited time and high workload in the public health care sector. According to Gainer, et al. [31], meaningful engagement in decision making by patients and families is best achieved by involving them both earlier in the patient’s course and over multiple conversations as compared with a single, typically brief, encounter [31].

Findings from this study were found to be contradicting to the findings of Wong, et al. [5] and Gainer, et al. [31]. They indicated that patients experienced an asymmetric power relationship with HCPs that hindered their expressions of personal autonomy through individual choice. In this study, only one young male patient expressed his comfort in communicating with a busy, high military rank physician who offered him an open channel of communication. Patients felt involved when they sensed that physicians facilitated mutual understanding between them. This emphasizes on the importance of decreasing the unbalanced power in supporting patient autonomy through shared D.M process. Providing information, including offering options and

clarifying pros and cons of the needed intervention, facilitate patients' understandings and motivate them to be actively involved in D.M [21,25,35,36]. It has been evident in this study that patients considered gaining information about health condition is prerequisite to be actively involved in health care decision.

Findings of this study support the findings of Siouta, et al. [3] in which they reported that patients would need to acquire knowledge, build up confidence and ability in order to be effectively involved in the decision-making process about treatment. In this study, seven patients were not well- informed about their health conditions. Some of those patients experienced passive role as they lacked the needed information and treatment alternatives. Similar responses were expressed by patients in Ernest [21,35] as patients perceived passive role in D.M due to poor knowledge. This consistency of findings asserts that patients' awareness and understanding are crucial for being actively involved in health care decisions. Interestingly, patients with passive role preferences, feel involved in D.M when they just seek information, believing that information gained enable them to talk more and tell their story confidently to their HCPs [21,24,34].

Literature has revealed that patients, including cardiac patients are often misinformed about treatments options and their risks and benefits. This misinformation can lead patients to have little or even no involvement in decisions of health issues [16,18-20]. Knowledge of treatment options was negatively perceived by some patients in this study, while the desire for information was clear. Patients experienced poor discussion of their treatment options, which was in agreement with Protheora, et al. [37] and Siouta, et al. [3].

The range of options available to patients has influenced patients' decision making preference. The number of treatment alternatives influence the degree of patient autonomy. For example, one female patient stated that there was only one option for her case and she was forced to decide taking it as inevitable option. On the other hand, some patients in this study, preferred to review treatment options but not to decide on them. Findings of this study provided support to findings of Peek, et al. [24] in which they found that patients were interested in discussing treatment options, but were not willing to actually decide on them. Language used by HCPs in providing information is a prominent factor affecting the level of involvement of patients in D.M process [17]. Similar experiences (including HCPs being accustomed to use medical terms, patients unable to understand their health issues and felt unwilling to engage in specialized medical information issues) have been reported by others [3,17,21,34].

In the current study, some patients expressed the importance of physicians' opinion in spite of the extensive external search about their health conditions. Such findings were supported by others [3,34,35], where they indicated to the importance of

a dialogue between patients and HCPs as it enhances a sense of being listened to and understood. It has been evident in the literature that lacking information and support puts individuals at increased risk for psychological distress, reduced sense of well-being, and dissatisfaction with care [35]. Moreover, they tend to make the final decision based on the incomplete information they were offered [25].

Findings of this study revealed that seven out of sixteen patients (44%) in this study, indicated that physicians rather than nurses provide them with needed information. They viewed that nurses provide them care and services only. Similar findings were found in this regard by Dorthea& Dorthea [34]. Contradictory findings were found by Ernest [21] as few patients wanted more involvement in decision- making with nurses, seeing them as more easily accessible. A plausible explanation for Ernest, [21] findings entails that patients may think nurses are involved in decision-making about minor issues and patients themselves prefer to be involved in minor decisions.

In addition, patients in this study, perceived that asking questions was not a part of their expected role. Some patients wondered why they should ask HCPs, they perceived that HCPs know their duties and responsibilities. Therefore, they reported their full trust in and deference to HCPs recommendations and instructions, which was consistent with Protheroe, et al. [5,25,37]. Some patients do not consider it appropriate to ask questions at all, feeling that this is may be viewed as a lack of trust in the HCPs [5,37]. Different roles in the health consultation process can determine the extent of patients' involvement in the decision making process and patient management [17]. Some patients prefer taking the active or autonomous role in their health care decisions. While others prefer a passive role or they let their HCPs make the decisions [16,24,29]. The distinction between passive patient and active consumer is important because shared decision making targets passive patients and seeks to improve their quality of care by empowering them to become active consumers [21].

The majority of patients, in the current study believed that HCPs know more and have specialized knowledge which enable them to take the ideal decision. Therefore, they tended to comply with their decisions. Findings of this study were supported by several studies on this topic [3,32,35]. Siouta, et al. [3] indicated that cardiac patients preferred unipolar decisions rather than shared decisions. The majority of patients in this study, had positive attitudes in regard to be involved and to share in the health care decision. They preferred to be involved in health care decisions, but they did not experience such a role in making their decisions. They experienced feelings of involvement through acquiring knowledge about their disease and its treatment. These experiences were congruent with the literature from different cultures on this topic [12,24,35,36].

This congruence in the literature entails HCPs responsibilities to discuss the risks and benefits, treatment options and health condition to patients in order to be actively involved in decision making about this treatment. It was found that as patients became more knowledgeable about their conditions, they desired more active role in the healthcare decisions [3,31,38]. The traditional paternalistic model of medical practice is still dominant in many healthcare sectors in Jordan especially the public sector, which might have played a role in the patients' preferences. Jordanians, still view physicians as having the ultimate control over specialized health knowledge.

Other patients, in this study preferred to share and discuss health information with HCPs and then they let them decide. This reflects patients' perception of being involved in health care decision through sharing in information rather than sharing in decision-making process. Findings of this study confirmed the findings of [16,18-20]. In which they found that cardiac patients are often misinformed about their health conditions and treatments. Therefore, they have little or no involvement in health care decisions. Similarly, Dorthea& Dorthea [34] found that people did not want to bear their decisions' responsibility but had strong interest in being informed.

Patients who hold specific preferences toward some type of the healthcare decisions do not necessarily experience such type in the health encounter [34]. Experiencing the preferred style is associated with some factors. Findings from the available literature revealed factors HCPs-patient's therapeutic relationship [16,39]. Literature findings supported the findings of this study in that D.M was strongly associated with developing trust and faith in HCPs rather than trading off risks and benefits of decision options. Some patients were afraid to perform some cardiac interventions due to the possible risks and complications.

Olsson, et al. [12] clarified the need of cardiac patients to undergo major interventions and because such interventions have risk and benefit rates, patients expressed their fear related to potential complications. Findings of this study showed consensus among most patients' narratives that they felt afraid to decide on major interventions such as open heart surgery for its risky complications. This was common findings in other research on this topic [31]. Findings of this study supported that of Jansaski, et al. [40] and Noor, et al. [41] as patients my experience non adherence to the recommended interventions. Patients experiences and beliefs seem to challenge the traditional medical view that decisions are made primarily by HCPs based on clinical investigations [40]. This finding contradict Obeidat& Lally [25] and Sekimoto, et al. [36], as eastern cultures.

Jansaski, et al. [40] and Noor, et al. [41] concluded that patients' attitudes and background experiences affect the ultimate treatment decision. Patients can influence their

HCP's recommendation about the intervention. Those findings contradicted the findings of this study as the majority of patients in this study did not influence their HCP's recommendations. Some of those patients, experienced feelings of helplessness to choose their preferred option, instead they adhered to HCPs, recommendations. Only one patient perceived that he had the ability to determine his own decision regardless HCPs recommendations. This individual experience can be explained by what the patients initially intended regarding the recommended intervention, before his encounter with HCPs.

Literature showed contradicting results related to PI with the type of decision to be made. Some studies [3,29] found that the majority of patients preferred more involvement in the healthcare decisions corresponding to a major than to a minor illness, while others found the opposite results [7,34]. This incongruence might be explained by the change in patients' behaviors when faced with real life situation [42]. Within different societies, the experience of PI in health care decisions is influenced by social, cultural, and religious morals. Findings from this study supported the previous studies on this topic [35,43,44]. In Jordan, husband, Family Members (FMs) and relatives provide social support. Family support was prominent in this study and was highly appreciated by patients, particularly females.

Family members have a key role in the decision-making process [36,43,45]. They support and encourage both patients and medical teams therefore, they facilitate the process of D.M [45]. Family support may reduce the patients' burden and their uncertainty in treatment decision-making [45], and provide a sense of relief and security, as well as support, comfort and hope, [43]. In this study, trusting family members was strongly prominent. Confirmed the findings of this study as most of the patients relied on their immediate FMs to educate them about their health conditions, because some of their FMs were well educated in the health field.

Surprisingly, Banning, et al. [43] found four women with chronic disease who experienced a lack of social support from their husbands and family members. It might be related to blame culture in Pakistani society. Patients in this study particularly females experienced failure to make their own decision without involving their FMs. Married female patients often concerned with their husband's opinion to make the final decision, while old ages considered their sons as key elements in decision involvement. This is similar to what Lamore, et al. [45] and Olsson, et al. [12] reported in this regard, that FMs can have a more dominant role during the decision-making. In accord with Jordanian culture, the involvement in D.M is influenced by the judgment of significant others as parents, spouse and relatives.

During illness, religious and spiritual beliefs as a strategy of coping is well documented in the literature [35,36,43]. In this

study, patients frequently displayed spirituality and religiosity by acknowledging “Allah” for their wellness and illness. Banning, et al. [43] concluded that spirituality was viewed as a source of comfort; it reduced patients’ fear and uncertainty and gave them the strength to tolerate the treatment. In this study, some patients with high risky conditions experienced a contradicting decision with that of physicians. They decided to perform the operation against medical advice believing that life is in Allah hands.

This study confirmed the findings of in which, to control their fear, patients unconditionally trusted Allah and often accepted options offered by their HCPs without questioning. One patient in this study, perceived that life is determined by Allah not by physicians or success rate of the operation. He expressed his acceptance to death as an attempt to cope with the risky situation of his major operation. As Islamic culture is rooted among Jordanians; this belief was originated from Islamic teachings that Muslims should accept good and bad fate, thanking Allah for both, and leaving the final results on Allah.

Conclusion and Implications of the Study

The findings of the present study may help in understanding patients, subjective experience in regard to involvement in health care decisions. This can be beneficial to understand the discrepancies and commonalities of patients’ perceptions regarding the involvement in health care decisions. The findings from this study indicated that preferred style of D.M had impacted the level on PI. Patients in this context had faced some factors/barriers to be actively involved in D.M. It was evident that certain sociocultural influences and beliefs may have had influenced participants’ experiences that could be an area for nurses to reinforce the positives and modify the undesirable ones.

Religiosity was also found to play a role during this experience. Further, social support through family role in health care decisions had influenced patients experience regarding their involvement in their decisions. This exploration, has important implications for nursing education, nursing research, practice and policymaking.

Limitations of the Study

Descriptive phenomenology approach limited the researcher to only describe participants’ experiences without interpretation or elaboration on those experiences. Like all qualitative studies, generalization of the results is limited.

Recommendations for Future Research

Longitudinal studies would be useful in exploring the long term impacts of health status upon patients’ preferences regarding their involvement in D.M. As it was evident in the findings of this study that stages of the disease have some impact on patients preferred style of D.M. Experiences of patients, families from

different health care settings and other cultures, may need to be explored. Different context regarding data collection time such as post patients discharge from the hospital may reveal significant findings.

References

1. Giorgi A (1985) Sketch of a psychological phenomenological method. In: Giorgi A (Editor), *Phenomenology and psychological research*. Pittsburgh, PA: Duquesne University Press. Pg No: 8-22.
2. Desroches S, Gagnon M, Tapp S, Légaré F (2008) Implementing shared decision-making in nutrition clinical practice: A theory-based approach and feasibility study. *Implementation Science* 3: 48.
3. Siouta E, Hedberg B, Muhli U, Fossum B, Karlgren K (2016) Patients’ experiences of communication and involvement in decision-making about atrial fibrillation treatment in consultations with nurses and physicians. *Scand J Caring Sci* 30: 535-546.
4. Arnetz J, Zhdanova L (2014) Patient involvement climate: views and behaviors among registered nurses in myocardial infarction care. *JCN* 24: 475-485.
5. Wong ELY, Lui S, Cheung AWL, Yam CHK, Huang NF, et al. (2017) Views and Experience on Patient Engagement in Healthcare Professionals and Patients-How Are They Different? *Open Journal of Nursing* 7: 615-629.
6. Barello S, Graffigna G, Vegni E (2012) Patient engagement as an emerging challenge for healthcare services: mapping the literature. *Nurs Res Pract* 7: 905934.
7. Elwyn G, Stiel M, Durand MA, Boivin J (2010) The design of patient decision support interventions: addressing the theory-practice gap. *J Eval ClinPract*; (17) 565-574.
8. Pryce H, Hall A (2012) The Role of Shared Decision-Making in Audiologic Rehabilitation not reported Quality Assurance Department, face to face interview.
9. Lin G, Fagerlin A (2014) Shared Decision Making State of the Science. *Circ Cardiovasc Qual Outcomes* 7: 328-334.
10. Edwards A, Elwyn G, Wood F, Atwell C, Prior L, et al. (2005) Shared decision making and risk communication in practice. A qualitative study of GPs’ experiences. *British Journal of General Practice*; 55: 6-13.
11. Coulter A, Collins A (2011) Making Shared Decision Making a Reality. No Decision about Me, without Me. *Kings Fund* 1-56.
12. Olsson K, slund U, Nilsson J, Hornsten A (2016) Patients’ Decision Making About Undergoing Trans catheter Aortic Valve Implantation for Severe Aortic Stenosis. *Journal of Cardiovascular Nursing* 31: 523-528.
13. Blair J, Volpe, Aggarwal B (2014) Challenges, Needs, and Experiences of Recently Hospitalized Cardiac Patients and Their Informal Caregivers. *Journal of Cardiovascular Nursing* 29: 29Y37.
14. Kroner T, Keller H, Snnichsen A, Sadowski E, Baum E, et al. (2008) Absolute Cardiovascular Disease Risk and Shared Decision Making in Primary Care: A Randomized Controlled Trial. *Ann Fam Med* 6: 218-227.
15. Decker C, Garavalia L, Chen C, Buchanan D, Nugent K, et al. (2007) Acute Myocardial Infarction Patients’ Information Needs Over the

- Course of Treatment and Recovery. *Journal of Cardiovascular Nursing* 22: 459-465.
16. Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: What does it mean. (or it takes at least two to tango)? *SocSci Med* 44: 681-692.
 17. AlHaqwi A, AlDrees T, AlRumayyan A, AlFarhan A, Alotaibi S, et al. (2015) Shared clinical decision making A Saudi Arabian perspective. *Saudi Med J* 36: 1472-1476.
 18. Michael J, Barry Susan Edgman-Levitan N, Engl J (2012) Shared Decision Making - The Pinnacle of Patient-Centered Care. *England journal of medicine Engl J Med* 366: 780-787.
 19. O'Connor A, Llewellyn-Thomas H, Flood A (2004) Modifying Unwarranted Variations in Health Care: Shared Decision Making Using Patient Decision Aids -A review of the evidence base for shared decision making. *Health Affairs-Web Exclusive* VAR-67.
 20. Sheridan S, Harris R, Woolf S (2004) Shared Decision Making About Screening and Chemoprevention. *Am J Prev Med* 26: 56-66.
 21. Ernest A (2013) Shared Decision Making: Engaging Patients to Improve Health Care. by Families USA Report.
 22. Streubert H, Carpenter D (2011) *Qualitative research in nursing: Advancing the Humanistic imperative* (5th edition). Lippincott.
 23. Polit DF, Beck, CT (2012) *Nursing Research: Generating and Assessing Evidence for Nursing Practice*. Philadelphia, Lippincott Williams & Wilkins.
 24. Peek M (2008) How is shared decision-making defined among African-Americans with diabetes? *Patient Educ Couns* 72: 450-458.
 25. Obeidat R, Lally R (2014) Health-Related Information Exchange Experiences of Jordanian Women at Breast Cancer Diagnosis. *J CancEduc* 29: 548-554.
 26. Giorgi A (2014) Phenomenological Philosophy as the Basis for a Human Scientific Psychology. *The Humanistic Psychologist*, 42: 233-248.
 27. Castro A (2003) Introduction to Giorgi's Existential Phenomenological Research Method. *Psicologadesde el Caribe. Uoiversidad del None* 11: 45-56.
 28. Creswell J (2013) *Research design: qualitative, quantitative, and mixed methods approaches* (3rd Edition). Thousand Oaks, CA: Sage Publications, Inc.
 29. Teh C, Karp J, Kleinman A, Reynolds C, Weiner D, Cleary P (2009) Older People's Experiences of Patient-Centered Treatment for Chronic Pain: A Qualitative Study. *Pain Med* 10: 521-530.
 30. Yasein N, Shakhathreh F, Shroukh W, Farah M, Jaber R (2017) Comparison between Patients' and Residents Perceptions of Patient Centeredness and Communication Skills among Physicians Working at Jordan University Hospital'. *Open Journal of Nursing* 7: 698-706.
 31. Gainer RA, Curran J, Buth KJ, David JG, Hirsch GM, et al. (2017) Toward Optimal Decision Making among Vulnerable Patients Referred for Cardiac Surgery: A Qualitative Analysis of Patient and Provider Perspectives. *Med Decis Making* 37: 600-610.
 32. Dierckx K, Deveugele M, Roosen P, Devisch I (2013) Implementation of shared decision making in physical therapy: observed level of involvement and patient preference. *Phys Ther* 93: 1321-1330.
 33. Towle A, Godolphin W (1999) Framework for teaching and learning informed shared decision making. *BMJ* 319: 766-771.
 34. Dorthea C, Dorthea W (2005) Patients preferences for involvement in clinical decision-making within secondary care and the factors that influence their preferences. *Journal of Nursing Management* 13: 119-127.
 35. Obeidat R, Khrais HI (2016) Jordanian Physicians' Attitudes toward Disclosure of Cancer Information and Patient Participation in Treatment Decision-making. *Asia-Pacific Journal of Oncology Nursing* 3: 281-288.
 36. Sekimoto M, Asai A, Ohnishi M, Nishigaki E, Fukui T, et al. (2004) Patients' preferences for involvement in treatment decision making in Japan. *BMC Fam Pract* 5: 1.
 37. Protheroe J, Brooks H, Chew-Graham C, Gardner C, Rogers A (2012) Permission to participate? 'A qualitative study of participation in patients from differing socio-economic backgrounds. *Journal of Health Psychology* 0: 1-10.
 38. Bonny B, Amanda H (1996) Nature of decision-making in the terminally ill patient. *Cancer Nursing* 19: 384-391.
 39. Murray E, Pollack L, White M, Lo B (2007) Clinical decision-making: physicians' preferences and experiences. *Patient Educ Couns* 65: 189-196.
 40. Jasinski M, Lumley M, Mandel S (2017) Patient factors in decision-making for orthopaedic surgery: a prospective analysis. *Current Orthopaedic Practice* 28: 287-292.
 41. Noor N, Rahimi S, Pereira E, Treszezamsky A, Michael G, et al. (2015) Patient Preferences for Abdominal Incisions Used for Pelvic Organ Prolapse Surgery. *Female Pelvic Med Reconstr Surg* 21: 348-35.
 42. Javadi M, Kadkhodae M, Yaghoubi M, Maroufi M, Shams A (2013) Applying Theory of Planned Behavior in Predicting of Patient Safety Behaviors of Nurses. *Mater Sociomed* 25: 52-55.
 43. Banning M, Faisal S, Hassan M, Zafar A, Hafeez H (2009) The Impact of Culture and Sociological and Psychological Issues on Muslim Patients with Breast Cancer in Pakistan. *Cancer Nursing TM* 32: 317-324.
 44. Doumit M, Huijjer H, Kelley J, Nassar N (2008) The Lived Experience of Lebanese Family Caregivers of Cancer Patients. *Cancer Nursing* 31: E36-E42.
 45. Kristopher L, Lucile M, Aur'elie U (2017) Treatment decision-making in chronic diseases: What are the family members' roles, needs and attitudes? A systematic review. *Patient Education and Counseling* 100: 2172-2181.

Appendices A-C

Appendix A/1: Consent Form (English)

The University of Jordan- Faculty of Nursing

Consent to Act as a Participant in a Research Study Interview

EXPERIENCES OF CARDIAC PATIENTS REGARDING INVOLVEMENT IN HEALTH CARE DECISIONS: A

PHENOMENOLOGICAL STUDY.

[Name of Principle Investigator: Enaam Al-Ananbeh.

[Name of Organization: Mauta University]

This Informed Consent Form has two parts:

- Information Sheet (to share information about the study)
- Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Part I: Information Sheet

Introduction

We, at the University of Jordan, are conducting a study entitled “Experiences of cardiac patients regarding involvement in health care decisions: a phenomenological study.

This study will yield deep understanding of patients’ experiences about their involvement in health -related decisions. HCPs will be able to respond to differences in patients’ preferences and willingness to be involved in clinical DM of their health care. Such understanding improves patients’ empowerment and satisfaction with provided care.

You are invited to participate in the current study. I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as I go through the information and I will take time to explain. If you have questions later, you can ask me about.

Purpose of the Research

The present study aims to explore and understand the cardiac patient’s experiences regarding involvement with health care decisions at a Military Institution in Jordan. Specifically, this study will try to answer the following Questions:

1-What are the cardiac patient’s experiences of involvement with health care decisions?

2-How do cardiac patients perceive their experiences of involvement with health care decisions?

Type of Research Intervention

This research will involve your participation in filling a demographic sheet and an in-depth, individual semi - structured, face to face interview that will take about 60 minutes. Each interview will be audio-taped and transcribed verbatim after

getting a permission from participants.

Participant Selection

You are being invited to take part in this research because you will provide a deep understanding of your experiences of involvement with health -related decisions in your own words.

Voluntary Participation

Your participation in this research is entirely voluntary. It is your choice whether to participate or not. The choice that you make will have no bearing on your healthcare services. You may change your mind later and stop participating even if you agreed earlier.

Procedures

I am asking you to help me understand more about your experiences of involvement with health -related decisions. I am inviting you to take part in this research project. If you accept, you will be asked about your subjective experiences of D.M you have been experienced.

Interview procedure

An in-depth, individual semi - structured face to face interview will be conducted (read the information sheet for more details)

Duration

Interviews will be audio-taped and transcribed verbatim after getting a permission from participants. Each interview will take about 60minutes in a special room of the institution. A second interview might be needed if so it will be by phone and will be scheduled in advance with all participants.

Risks

You do not have to answer any question or take part in the interview if you feel the question(s) is too personal or if talking about them makes you uncomfortable.

Benefits

There will be a direct benefit to you, your participation is likely to help me to better understand the unique experience towards your involvement in decisions related to your health issues. Therefore, all HCPs will be well prepared to respond to your unique needs. Moreover, this study will elicit barriers regarding your participation in DM, which will be a challenge for HCPs to overcome such barriers.

Confidentiality

I will not be sharing information about you to anyone. The information that I collect from this study will be kept private. Any information about you will have a number on it instead of

your name. Only the researcher will know what your number is. It will not be shared with or given to anyone. If this study will be published or presented in any conference, it will be without any name of the participants.

Sharing the Results

Nothing that you tell me today will be shared with anybody, and nothing will be attributed to you by name. The knowledge that I get from this study will be shared with you before it is made widely available to the public. Each participant will receive a summary of the results.

Right to Refuse or Withdraw

You do not have to take part in this research if you do not wish to do so, and choosing to participate will not affect your health care services in any way. You may stop participating in the interview at any time that you wish without your health care being affected. I will give you an opportunity at the end of the interview to review your remarks, and you can ask to modify or remove portions of those, if you do not agree with my notes or if I did not understand you correctly.

Who to Contact

If you have any question, you can ask them now or later. If you wish to ask questions later, you may contact: [Enaam Al-Ananbeh, Mobile: 00962779290338, E mail: enaam_enab@yahoo.com]

Voluntary Consent Statement

All of the above has been explained to me and all of my current questions have been answered. I understand that I am encouraged to ask questions about any aspect of this research study during the course of this study, and that such future questions will be answered by the researcher. By signing this form, I agree to participate in this research study interviews. A copy of this consent form will be given to me.

Participant's Signature

Date

Researcher's Signature

Date

Appendix B/1: Demographic Sheet

Date:

1. Age: _____ 18- 28 years old _____ 29-39 years' old

_____ 40-50 years old _____ Above 50 years' old

2. Gender: _____ Male _____ Female

3. Highest educational degree obtained: _____

4. Marital status: married _____ single _____ divorced _____ widowed-----other:

5. Medical diagnosis: -----

6. Co- morbidities: Yes-----No-----

7. Living condition: - Alone ----- With whom-----

8. Insurance type: -----

9. employment: Yes _____ No _____

10. Income average: -----

11. Contact information: Phone number:

Appendix C/1: Interview Guide

Would you please share with me your experience about your involvement in decisions related to your health issues?

Some probing questions were asked as the following examples: "Please tell me more about your experience? What does that mean to you? Is it possible to give an example? Describe to me what that was like for you? What comes to mind when you hear the word D.M involvement? [44].

Appendix C/2:

تبيبر علا ةخلل تم حرتم ةحرتقملا ةلباقملا ةلىس

تارارقلل ذاختا يف ةكتكراشم لوح ةكتاربخ ينكراش لكلضف نم ةيحصلا كنؤوشب ةقول عتملا؟

Interview guide for patients

Time of Interview:

Date:

Place:

Interviewer:

Interviewee:

Position of Interviewee:

Questions:

1-Tell me how do HCPs draw attention to an identified problem as one that requires a decision-making process?

2-Explain to me how do HCPs state that there is more than one way to deal with the identified problem?

3-would you tell me how do HCPs assess your preferred approach to receiving information to assist in decision making?

4-Tell me how do HCPs list "options," which can include the choice of "no action"?

5-Tell me how do HCPs explain the pros and cons of options to you (taking “no actions” is an option)?

6-Tell me how do HCPs explore your expectations (or ideas) about how the problem(s) are to be managed?

7-Tell me how do HCPs explore your concerns(fears) about how problem(s) are to be managed?

8-Tell me how do HCPs check that the you have understood the information?

9-Tell me how do HCP offer you explicit opportunities to ask questions during the decision-making process?

10-Tell me how do HCPs elicit your preferred level of involvement in decision making?

Questions related to HCPs’ perceptions of patient preference:

11-Tell me if you prefer to make health care decisions alone?

12-Tell me if you prefer that HCPs make health care decisions on behalf of you?

13-Tell me if you prefer to let your family take the health care decision?

14-Tell me if you prefer to make health care decision after HCPs informed you all the health information needed?

15-Tell me if you prefer to let HCPs take the health care decision after they informed you all the health information needed?

16-Explain to me more whether you prefer to share with HCPs the health care decisions?

The Observing Patient Involvement(OPTION) instrument by: Elwyn G, et al. [10] Shared decision making: developing the OPTION scale for measuring patient involvement. *QualSaf Health Care*. 2003;12: 93-99.