The Advocacy Resources in Adjustment with Lower Limb Amputation in Iran: A Qualitative Study

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ABSTRACT

Loss of lower limb brings several physical, mental, and social problems. The people with lower limb amputation use advocacy various resources for adjustment with their problems. This study was performed to determine from advocacy resources in adjustment among people with lower limb amputation. This study was conducted with qualitative research approach and content analysis method. The participants were 16 people with lower limb amputation in Red Crescent Rehabilitation Center, Iran. Purposeful sampling began and continued up to data saturation. Unstructured interview was the main method for data collection. The data were analyzed using qualitative content analysis method and constant comparative method. In content analysis process, finally 6 themes emerged that indicated of patients’ advocacy resources. These themes included 1. Family attendance, 2. Relying on religious beliefs, 3. Acquiring information, informed trust and hopefulness to physician and rehabilitation team, 4. To be encouraged with adjusted loss limb, 5. Feeling worthy with friends’ companionship, 6. Assurance and satisfaction with advocacy organizations. Family support was found as the main advocacy resources to adjustment followed by religious beliefs such as God’s will, and praying. These results can help the managers and planners of health field to facilitate the adjustment of the new amputee so that in what fields and aims they must focus and plan.

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Introduction

The loss of a limb confronts individuals with a wide range of extensive and evolving threats and challenges to their physical, psychological and social functioning (1). These may include impairments in physical functioning (2), the experience of amputation-related pain (3), learning how to use a prosthesis (4), alterations in one’s body image (5), sexuality (6) and self-concept (7), changes in personal relationships (8) and occupational status (9), limitations in carrying out every day and valued activities (10), and restrictions in participating in the community and wider society (11). Amputation is a distressing experience that is likely to pose considerable challenges in terms of psychological and social adjustment. Not only does this procedure incur permanent physical loss, but it may also lead to restrictions in many other important life domains. The negative impact of limb loss on psychological well-being has been the central focus of most of the research on psychosocial adjustment to this condition (12). There is still little agreement in the literature regarding the prevalence of clinically significant psychological morbidity in this patient group, however, either during the initial post-amputation period or in the longer term (13). Thus, following amputation, people need to adjustment with the new problems by finding effective approaches (14). Finding the and using them is essential to reduce stresses (15). On the other hand, amputation of lower limbs increases dependency to external helps to adjustment in the new situation (16). Researchers have shown that people are more successful to adjustment with stress causing events of life when they receive mental and social supports. Feeling the social support can prevent the negative physiological consequences of amputation, improve self-care, induce positive effect on physical/social/mental condition, and eventually improve in performance (17). Perceiving availability of social support can lessen the negative outcomes of amputation and help the individual to adjustment with the new.
condition (18). By developing deeper insight to what is experienced by the individuals who lose the limb, health service providers can be of better help to them. In addition, understanding such experiences and culture-based preferences are essential for provision of supporting services (19). There has been a new surge of attention to personal traits of the patients such as: their reaction to amputation, social and economic conditions, and the role of physician and rehabilitation team, spouse and family members. Personal beliefs regarding health, family structure, genetic and race factors, cultural beliefs, economic/social condition all are the factors that are effective in the way people react to the challenges and stressful situation (20). In spite of general agreement regarding the importance of such factors, there is a paucity of research work on effective cultural variables of such problems and coping mechanism adopted by people who undergo amputation. A key point in this regard is support sources used by the patients. In fact, it is essential for the patients to find and use the support sources. In addition, the practitioners of health support services need to know and predict the reaction of the patients to amputation and the support resources they use. Given that social support and solidarity are the key factors in ad with acute and chronic diseases, and the importance of the patient's understanding of the available support (21); and taking into account that researches have confirmed the relationship between patients’ perception of the support and cultural, race, and tribal factors; and keeping in mind the lack qualitative research to adjustment with the perception and experience of the patients regarding advocacy resources in Iran the researcher decided to carry out the present study to survey the advocacy resources for adjustment with lower limb amputation in the Iranian society context.

**Methodology**

This study was conducted with qualitative research approach and content analysis method. The setting of study was the general center of rehabilitation in Red Crescent Society, Iran. Purposive sampling began and continued up to data saturation. Unstructured interview was the main method for data collection. Before starting the interview, the participants were informed about the goal, interviewing method, confidentiality basis, and their right to leave the study. The interview session was arranged as preferred by the participants so that no interruption in their daily programs was caused. Inclusion criteria consisted of (1) At least six months had been passed since the amputation operation; (2) being 18 years or older and having a unilateral below knee from trauma, (3) having sufficient cognitive skills, (4) to be able to accurately respond to questions, (5) No other serious diseases or disability; (6) Desire to take part in the study and share their experiences. Totally, 16 patients participated in the interview. It was tried to keep maximum variation in terms of amputation, for example: extent of amputation, reason of amputation, age, gender, marital status, level of education, and occupation. The interview session was hold privately. The main data-gathering tool was deep and semi-structural interview by using open-ended questions. Each interview was lasted 45-60 min and all was recorded and immediately transcript for further analysis. Data analyses were done simultaneously with data collecting process using qualitative content analysis method and through constant comparison. The reliability and validity of the data gathering methods were ensured using variety of techniques. Dependability, credibility, fittingness, and conformability were used as the measures of quality of the study.

**Findings**

In content analysis process, finally 6 themes emerged that indicated of patients’ advocacy resources. These themes included 1. Family attendance, 2. Relying on religious beliefs, 3. Acquiring information, informed trust and helpfulness to physician and rehabilitation team, 4. to be encouraged with adjusted limb loss, 5. feeling worthy with friends’ companionship, 6. assurance and satisfaction with advocacy organizations.

1. **Family attendance**

The participants clearly expressed the importance of family support as advocacy resource, that the first them was “family attendance.”

The participants held that family support help them to change their isolated life and forget their amputated limb and the problems. “I never could rebuild my life, without the support that my family gave me after the accident,” said one of the participants, “I am indebted to my family as they really helped me to return to normal life.”

Married patients named their spouse a key supporter and expressed that they expected much more support from their spouse than their family members such as their children. One of the male participants said:

“My wife was a real support and she undertook all the works inside and outside the house.”
2. Religious beliefs
The participants stated that their religious beliefs, praying to God and Imams, Reading the holy Quran, and believing in God were of great help to adjustment with their new situation. One said:
“When I lost my leg, I told God that I accept you will and thought that this must be the price I’m giving for all my sins, so by taking my leg, God is forgiving my sins.”

3. Acquiring information, informed trust and hopefulness to physician and rehabilitation team
It was emphasized by the participants that informing and emotional supports by the physicians and rehabilitation team built a sense of trust and reasonable hope in them. Many think that the physicians have made a wrong judgment about their situation when they learn that their injured limb must be amputated. They start searching for the best physicians and make sure if they need to amputate their limb or not. In fact, the physician is the first medical service expert that the patient encounters and learns about the horrible decision. Therefore, the way of informing the patients and behavior of the physician is of great importance. Many participants said that they managed to come up with their fear after they receive sympathy of the physician. One of the participants mentioned:
“I was so afraid when I learned that my leg must be amputated. I couldn’t believe it; however I overcame my fear when the doctor and my family talked to me.”
The directions given by the physician and rehabilitation team and consultations create trust and help the patient to accept the imputation. One of the participants stated:
“I told the doctor: I’ll never let to amputate my leg no matter what happens. However, the physician was very good in convince me and finally I accepted and signed the papers and..... later I was so upset when I went to rehabilitation center to get the prosthesis, but the employees there had a friendly manner and convinced me to use the prosthesis. They’ve been so helpful in this regard and took all the time needed to answer my questions.”

4. To be encouraged with adjusted limb loss
The participants mentioned the supportive role of the similar patients who had managed to adjustment with their situation in rebuilding their spirit. Such positive role was more evident when they were sharing their story and experience and conveying that someday they will cope with their new situation. Interaction with similar patients also helped the new patients to learn about the problems ahead. One of the participants said:
“I visited them and gain spirit... their normal behavior and negligence of their lost limb made me to try to be like them and stop being too much worry.”

5. Feeling worthy with friends’ companionship
The participants suggested that their friends ensured them that they would not leave them alone in the hardships. By paying routine visit, showing sympathy, helping in doing things, and even extending financial support the friends provided a valuable mental support. Communicating and talking with friends is a mental relief for the patients. A participant said:
“When my leg was amputated, my friend came and tried to make me calm. At first I didn’t want to see them around, however, later I was so eager to see them, as their presence made me forget about my leg and also helped the time pass. Visiting them was a great help in rebuilding my spirit and peace.”

6. Assurance and satisfaction with advocacy organizations
Supporting social organizations were of great help for the patients to cope with their hardships. Patients confirmed that such organizations were true support for them. As the treatment and the prostheses are expensive, and that may such patients experience hard financial condition, social support such as rehabilitation insurance supports are of great help and support for the patients. A participant mentioned:
“They helped me to get prosthesis and even they helped me to get married and find a place to live by granting me loan. It wasn’t much but it was helpful.”

Discussion
The findings of the study showed that patients receive support from different resources during the process of coping with amputation. Given that losing a limb is a multi-aspect experience and affected by personal traits and the process of the disease (22), our findings showed six different aspects for the support resources. The participants noted that their family was the first and main resource of support for them. The family support creates hope and strength in the patients and conveys the felling that they are not alone in the hardship. The findings are consistent with other works
In fact, the family is the first and greatest resource of support of the patients. Among the family members, life partner undertakes the main role in providing support. The supportive role of the spouse is the most dominant supporting role for the patients after the surgery and during rehabilitation. After the spouse, the children play the next main supportive role. Presence of the spouse as one, who improves the sense of solidarity with others, can be effective in health and performance of the patient. In addition, the spouse plays a role in lessening the stress and improves satisfaction with life throughout the process. Other studies have shown that married patients who undergo an amputation operation experience better life than the unmarried patients. The participants’ experience showed that religious beliefs play a notable role to adjust with losing a lower limb. The supportive attitudes of the physicians and rehabilitation team also helped rebuilding reasonable hope in the patients. The patients noted that such support was more of emotional (showing sympathy and giving hope) and informative nature. This is consistent with other studies. Such supports create satisfaction with the physicians and rehabilitation teams’ services, which is vital as more satisfaction with the services of the physician results in easier acceptance of the fact and using prosthesis. Another finding of the study was the positive effect of other patients, which was more notable in early days after amputation, rehabilitation, and using prosthesis. The patients helped each other accept their new situation and keep working to return to normal life. The participants stated that watching other patients who have managed to cope with the amputation and use prostheses gave them hope and strength to carry on. Other studies on chronic diseases confirmed the positive effect of similar patients. The participants also highlighted the supportive role of their friends in the process of coping with lake of a body limb. The supportive behavior of the friends by expressing attentions and feelings to the patient made the patients believe that they steel can enjoy the presence of their friends even after losing a limb. This part of the findings was unprecedented and can be of more importance as friends support improves social relations of the patient and lessens the chance of development of depression, following an isolated life, and anxiety. In addition, such relations result in satisfaction with the health condition and attenuation of worries. Thus, support from the friends improves self-esteem in the patients. Social support organizations also play a role in creating hope to follow a normal life even without a limb. Another study emphasized the role of social bodies such as rehabilitation centers. The majority of the participants expressed their satisfaction with the supportive services by the social organizations. Many patients after amputation are no longer able to keep their social and economic activities and cover the living costs. The patients participating in another study expressed that economic hardships prevents replacing the prosthesis at scheduled date. Taking into consideration the mentioned issues, social supports such as medical insurance, and free rehabilitation services are vital for the patients and need to be more emphasized.

Conclusion
Analyses of the findings showed that the dimensions of supports for the people with lower limb amputation throughout the returning to normal life have six aspects. These results can help the managers and planners of health field to facilitate the adjustment of the new amputee so that in what fields and aims they must focus and plan.

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