Concept and quality of life construct elements in chemical injured: A qualitative study

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Abstract

Aims: The delayed complications of mustard gas poisoning begin after several months even to several years after exposure. One of the highly principal concepts in the chronic diseases is the quality of life of the patients. The aim of this study was to clarify the concept and construct elements of quality of life in the chemical patients with mustard gas.

Methods: In this descriptive study with qualitative approach, 20 injured male and female (military and non-military) which were in the chronic disease phase were selected based on purposive sampling. The study was conducted with semi structured individual interview and focused group discussion. The data were analyzed using content analysis method and key concepts were extracted.

Results: A group of participants considered health as physical, intellectual and ability of perform duties and common expectations from every person and the other group considered it as having welfare and general comfort. The chronic nature of disease in the chemical patients and delayed effects of the disease had led to changes in all aspects of their health so that they had been affected by serious physical troubles especially in the respiratory organs, skin, eyes, etc.

Conclusion: The quality of life is a relative concept influenced by the disease nature (physical, psychological, emotional and social health), health concept (wellness, Personal efficacy and Welfare) and adaptation factors.

Keywords: Chemical Victims, Quality of Life, Chronic Disease, Qualitative Research

Introduction

The delayed complications of mustard gas poisoning begin after several months to several years [1]. Khateri, in a study on 36 thousand Iranians who had been exposed to mustard gas after 13 to 20 years, states that the main complications are respiratory (42.5%), ocular (39%) and cutaneous (24.5%), respectively [2]. Extensive studies show that late complications of chemical warfare exposure affect injured patients with chronic diseases. As a result, many changes are irreversible [3].

Very important concept in chronic patients is the quality of life. Moreover, improvement in chronic patients is impossible, but death is a distant event. In such a situation, the target aim of health care is to optimize the quality of life [4].

World Health Organization defined the quality of life, in 1995, as the people’s understanding of their situation in life, with regard to the cultural field and value systems in which they live and also in relation with objectives, expectations, standards and their concerns [5]. Medical researchers believe that the quality of life should focus on promotion and usefulness of patients’ life. It seems that there are as many definitions for this concept as the people who use the concept of quality of life. Some consider the mental wellbeing as a part of quality of life and most consider it to be multi-dimensional [6].

Mandzuk and Mc Millan in their study represent the three following introductive attributes for quality of life:
- Individuals carry out the subjective assessment of their life.
- Individuals determine their satisfaction with life which is related to physical, mental, and social aspects of their life.
- Objective measurements can be used as a supplement for the subjective evaluations of people [7].

In chemical victims, studies in the field of quality of life are generally performed by means of general translated tools or specific ones associated with a particular disease. Other studies concerning the QOL of this group show that it has a remarkable drop. Otherwise the loss of the quality of life is not limited to people with obstructive pattern in spirometry. They also believe that, the ultimate aim of therapeutic interventions should not be limited to the symptoms of patients. But should increase the wellbeing of patients and the scientific method of it is to measure their quality of life. Moreover, their study also showed that the concurrent cutaneous, ocular, neurological and...
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Psychological involvement is associated with more adverse quality of life, indicating the doubled role of accompanying diseases on the quality of life. They continue that increase in quality of life in these patients needs the attention to bronchiolitis as much as it needs special attention to accompanying disorders, such as psychiatric, ocular and skin problems. Therefore, it is necessary for professionals of different fields to cooperate, aiming at improving the health of chemical patients [8, 9, 10].

What is of particular importance, first, for the tool making research, is the theoretical explanation and accurate definition of the investigating concept. In this regard, researchers believe that in a tool making research study, only in 15% of studies the main concepts such as the quality of life has been clarified accurately and based on the view of the reference population. Lack of theoretical explanation of the concept will follow two major problems. First, if the researcher does not scientifically clarify the concept, the definition will not be competent enough to develop tool structures and secondly, without accurate information about the concept, the construct validity of the tool will not be determined [11]. In addition, the content of the tools must be corresponded and matched with the culture and lifestyle of the countries and communities in which the tool is supposed to be employed for. An instrument which is designed in a particular country only reflects the culture and language of that community; in this case, when used in another community, even in case of precise translation, will cause several problems due to the disproportion of content [12]. Numerous cultural and social differences between Iran and other countries show that this concept must be studied specifically. Moreover, if the quality of life is supposed to be used as an indicator for therapeutic and care measures, more research should be done in this regard and its dimensions particularly in chronic diseases must be investigated. The purpose of this study was to explain the concept and construct components of the quality of life in patients injured by mustard gas.

Methods

In this qualitative study, 10 military chemical victims living in different parts of Iran referred to a hospital in Tehran for treatment and four civilians chemical patients referred to a chemical non-military clinic in Sardasht, from December 2006 to June 2007, were selected by convenient available sampling. Before each interview, while explaining the aims of the research, the reason of recording the interview, voluntary participation, confidentiality of information and interviewees’ identity was explained and the informed consent and permission for voice recording were obtained. The required personal information (age, marital status, social support system, the years of injury, percentage of injury, associated lesions, etc.) was obtained using files and by asking patients. Initially, main questions were asked from the patients. General questions were designed just as interview guide that included open and interpretative responses; the type of participants’ responses guided the interview process and the questions. All participants were interviewed individually; also six injured people were involved in a group interview to confirm the validity of the data [13]. In the group interview, participants were given a list of topics extracted from individual interviews and they were asked to discuss them and add what they thought to be omitted. At the end of discussion participants were asked to jot down individually a list of 10 important subjects associated with the quality of life of chemical victims and handed the paper to the researcher. Participants were free to mention even issues that were not raised in the group discussion in their own individual list. All interviews were conducted by a single individual and continued to achieve adequate enrichment and data saturation. Interview duration, depending on patients’ condition, was 40-110 minutes and the group interview lasted around 150 minutes. After complete implementation of recorded interviews the ambiguous cases were more investigated in following sessions of interview. All interviews were codified line-by-line and the basic codes were identified. Data were analyzed using content analysis by conventional methods during the seven following steps: 1- Formulating of the research questions in order to obtain answers; 2- Sample selection and sampling; 3- The blueprint of analysts training and the coding process; 4- Coding process implementation; 5- Defining of the classes; 6- determining the validity and 7- Analyzing the results of coding procedures.

Researchers avoided, in this method, employing the pre-determined classes and allowed the classes and their names be excluded from data. Based on the subclasses relationships some of them were mixed and organized in new classes and their relations were developed into a schematic tree based on hierarchical structure to develop and help reorganization [14]. To confirm and improve the accuracy of data and extracted codes, additional comments and suggestions, and also the reviews of the interviews were used [15].
Results

The mean age of participants was 49±7.6 years; the average rate of injury was 42±11.7% and the average injury duration was 22.28±1.2 years.

From the chemical patients’ point of view, the quality of life was a relative concept influenced by the concept of health (health and personal efficiency and welfare and comfort), the effects of disease (on physical, psychological, emotional and social health) and factors affecting the adaptation of chemical patients. Constructive elements of this concept were extracted based on conceptual models of charts 1 and 2.

Participants were obliged to answer the questions of "What is health?" and "When do they have a desirable life?" Their answers were the representation of the health concept and included two sub-concepts of "health and personal efficacy" and "welfare and comfort".

Participants considered health as physical and intellectual health and ability of fulfilling duties and common expectations of each person. Some of their opinions are presented as follows:

"...A healthy person, first, should have physical power, and secondly should have intellectual power to be able to differentiate his/her behaviors, economically and psychologically and also in terms of environment, and psyche and economics are supplements. If one of this is imperfect, for example just money-making will not work, because this disables the other one. All of the above require a healthy body. My body should be in the state that my breath can be good to absorb oxygen better." "Health means being well, this is of two kinds: soul sanity and physical health." 

...Health is the best blessing. The
person who is healthy, mentally, physically, visually, aurally, etc. with no defect and one should be healthy from all aspects." "...Healthy means a person who believes in God and is doing his/her duties." "...the household, my wife or my children should be physically healthy, and do not think of illness and in case of illness facilities should be available for us to take him/her somewhere, treat him/her and put him/her out of that discomfort. Facilities should be available at home." "...Health means being happy, relaxed and having a comfortable house.

From the chemical injured patients' view, health is a relative concept and consists of having sufficient physical strength, happiness, healthy body, easier breathing and overall, lack of need for medication and treatment for self and family, also, having a healthy mentality, the ability to solve problems, proper communication with others, serving people and God. Chemical injured patients considered another part of health concept as having general wellbeing and comfort and considered it as a basis for having appropriate function. Some of their statements were as follows: "...The quality of life means that someone has wellbeing and peace, comfort." "A good life is one that every person can move toward God and do the tasks that God wants and be nice with people." "...The good ones are those whose life condition is good and are in comfort in terms of facilities, transportation, eating and drinking and in terms of their housing etc." "...The quality of life and other staffs firstly originate from God's existence. The person who is Godly would have a Godly quality of life." "...Quality of life means that I establish a healthy family, live healthy, do not bother people, follow what God has said, and respect the religion frameworks and rules. This would be the quality of life." "...To be independent in life and obtain God's satisfaction.

Due to the chronic nature of the disease and changes in all health aspects due to the late complications of disease and risk of being affected by serious physical problems, especially in respiratory organs, skin, eye, etc., some quotes in this regard were as follows:

"...Since then, I have been under the supervision of lung, skin and eye physicians. I'm not still treated and my condition gets worse day by day. Right now it's my fifth hospitalization due to chemical issues." "...I had asphyxia attacks in a way that I could not even tell "Shahadateyn". It's very hard, anyway, the eye can be dropped or tolerated or be shut or itching at last will be wounded. My body is always wounded especially my back. It is wounded as a result of scratching in bed, but lung is another issue." "...I do have problem with my eyes. Generally my breath, stomach, kidney, liver and all organs are unhealthy. My skin is itchy. Sometimes I like to take off my skin." In addition to serious physical problems, this group of patients suffered from sleep disorders, marital relationship, chronic fatigue, mental and emotional problems, and problems related to role playing.

"...Sometimes I can't sleep for some 2 or 3 nights. On average, I have 3, 4 hours of sleep." "...I sleep in the semi-sitting position, because my breath is exhausted." "I'm awake in the Morning Prayer; I cannot sleep so much, three or four hours a day recently, because of this breath aid apparatus." "I cannot sleep without pills. I have to put pillows under my head." "...It has affected sex. It is more than two years that I'm so." "...Considering the problems that I have, sometimes I cannot have sexual relationship with my wife for two or three months. There is an excuse that sometimes I cannot perform well. The drugs that I use sometimes cause apathy." "...I get tired soon, I have cold sweat. I cannot talk." "...In terms of the things that I'm supposed to do, I get tired soon. In terms of physical ability I get tired soon and also regarding the intellectual aspect..."

"...I become angry too quickly and I'm irritable." "...I become upset quickly. Soon I'm brought to tears." "...I do not assume a good future; therefore, I'm pessimistic. No life expectancy... I was already a very good athlete. I realized since eight years ago that my abilities have been less and I have been ill-tempered." "...I liked to serve my wife and children, but I could not and of this, I'm truly sad." "...When I was exposed to chemical weapons I wanted the doctor to tell my husband to leave my and marry someone else, I cannot do my duties anymore. I cannot serve him, but my husband did not accept." "...If someone is healthy he/she can have two jobs, but when one is not healthy he/she cannot do so.

**Discussion**

In this study, the construct elements of the quality of life and their concepts are described in chemical patients affected by sulfur mustard who are in chronic phase of the disease. The findings of this study contained the main three categories, including "The concept of the quality of life", "disease impact" and "adaptation resources" in chemical patients. Presence of adaptation resources leads to partial adaptation of patients with their disease. Ebadi et al. in the study of adaptation resources in this group mentioned the main four categories of religious, patriotism, social support and attitude towards the disease. The most important source of religious factors
such as divine providence, disease as a sin-purifying factor, prayer and then patriotism such as homeland defense, repaying a debt to the country and then the family support, especially wife and finally compliance of disease were among the subcategories of these groups [16]. Three concepts extracted from chronic diseases are of particular importance and are used as an indicator to evaluate the effects of the disease, treatment and care [17]. Quality of life is a complex concept. Often, the quality of life, health and life satisfaction are used as synonyms.

World Health Organization defines the quality of life as the individuals’ beliefs of their life, with regard to the culture community, personal value system, expectations and their priorities and standards [5]. Despite the different definitions, there is still no definition involving various dimensions of this concept but experts have agreement in this field that the quality of life is a multidimensional, dynamic and subjective concept [18]. In the present study also the concept of quality of life includes the relativity and its affectability of different factors such as cultural context of the research community, personal value system, expectations, the attitude toward the disease and physical, mental, emotional and social effects of disease, which is consistent with the definition of the World Health Organization.

Mehrban et al. wrote that despite the lack of clear and single definition of the quality of life, it can be described using the following hypotheses:
1- Its nature and structure is not directly visible and measurable.
2- Its multi-dimensional structure includes physical, mental and social health aspects.
3- It is influenced by one’s experience and understanding of life and changes by the living and time. Thus, the health-related quality of life is associated with physical, mental and social health dimensions which are clearly affected by one’s activities, beliefs, expectations and perceptions. Each of the above dimensions is measurable from both subjective and objective aspects. Although the objective aspect is important in describing the individual health, the expectations and mental perception of patients express the quality of real experienced life [19]. But considering the context of the life of this group at the time of injury, while having points in common with Iranian society, they have some differences as well. Regarding the effect of disease compliance as an adaptation factor in this study, most injured patients have accepted their illness and have come up with it. Ebrahimi in his study found that there is a relationship between being volunteer for deploying to the front and mental health after injury. Volunteers had significantly reported less depression. These findings may indicate the feeling responsibility for the event, internal control, more belief and faith to the goal and the selected way. He continues that faith and belief in anything enhances the individuals’ tolerance in dealing with its consequences. Also there is a positive correlation between the internal control and knowingly acceptance of the responsibility and mental health and adaptation [20]. Considering the variety of physical, psychological and social problems in chemical patients, strengthening the adaptation resources and identifying the stress factors can be effective in adaptation of these patients with the disease and improvement of their quality of life. This means that generally, people who show more compliance with their disease relying on the factors mentioned above, have more satisfaction with their quality of life [16].

Conclusion
The results of this study, by direct extraction of chemical patients’ experience, defining the concept of life quality and identifying its dimensions and construct elements have taken the first steps in designing local tools. Content extraction through patients’ participation using a structured and scientific method in various countries, is considered a scientific necessity that maximizes the cultural adaptation of measurement and tools. Since culture, ethics, religion and religious values affect the concept of life quality, they make the defining and measuring of the concept of quality of life problematic. What is defined as the quality of life in a culture may be quite different in other cultures.

Acknowledgement: This paper is extracted from the findings of a doctorate thesis of the Tarbiat Modarres University and the research project approved by war chemical victims’ medical and engineering research Institute. All chemical injured patients that cooperated and helped in this study are sincerely appreciated.

References