

## Nonprofessional Care in Chronic Critically Ill Patient: A Qualitative Study

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**How to cite this article:** Dehkordi LM, Babashahi M, Irajpour A. Nonprofessional care in chronic critically ill patient: A qualitative study. *Int J Prev Med* 2016;7:125.

### ABSTRACT

**Background:** Decision-making about patients with critical condition transfer from Intensive Care Unit to the general wards be delegated to their families. The aim of the study was explaining the experiences of family caregiver's about care of chronic critically ill patient.

**Methods:** This study was conducted with a qualitative content analysis using unstructured interview. Participants were selected purposively from May 2014 to May 2015 and data collection continued until data saturation. Analysis was based on conventional content analysis.

**Results:** Participants' experiences classified into three main categories as following: nonprofessional care, enhancing factors of care, and inhibiting factors of care.

**Conclusions:** Finding of the current study showed different aspects of care. Care of chronic critically ill patients is a long-term process that affected by different factors. It seems that the exploration of caregivers needs and planning supportive interventions based on their needs improve the quality of care.

**Keywords:** Care, chronic critical illness, family caregiver, Iran

## INTRODUCTION

Recently, patients with critical condition as soon as possible discharge from Intensive Care Unit (ICU) and transmitted to the general wards.<sup>[1]</sup> Because of critical conditions, these patients need accurate care, and care of them is more complicated than usual cares in ward.<sup>[2]</sup> These patients that introduced as chronic critically ill patients because of their conditions such as connection to mechanical ventilation, comatose or confusion are unable to communicate with other, and express their needs.<sup>[3,4]</sup> This issue devolves greater

responsibility to their family for helping them in recovery phase.<sup>[5]</sup> Many of them with high levels of dependency and disability<sup>[6]</sup> dependent to their family for meet their physical and emotional needs after discharge.<sup>[7]</sup> Hence, decision-making and select of cure for them transfer to their family,<sup>[8-10]</sup> and family has a specific role in recovery of patient.<sup>[11]</sup> As a result, crisis of critical condition influence on family<sup>[12,13]</sup> and they sense experience of critical care.<sup>[4,14]</sup> Unfortunately, some disorders were seen in these people such as depression, anxiety, and sign of poststress trauma that influence on their ability to support patients.<sup>[15]</sup> Hence, preparing family members for caring roll, pay attention to them as the most important source of patient's support, and informational support of them is needed.<sup>[16,17]</sup> Some

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DOI:  
10.4103/2008-7802.195209

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prior studies explained the emotion of patients and family,<sup>[12,13]</sup> but based on evidence, health-care provider notice to the patient needs and neglect support of family and their need.<sup>[18]</sup>

Whereas detection family experience of care helps health-care provider to prepare family caregivers for patient care. In fact, support of caregiver ensures continues care of patient. There was not specific information about it in issue of Iran; so this study aimed to identify family caregiver's experiences about care of chronic critically ill patient.

## METHODS

This study was conducted as a qualitative content analysis. Content analysis has been mentioned and used as a qualitative research approach in the references.<sup>[19-21]</sup> In this study, ten participants who were family members of patient or had a close relation with patient such as mother, son, sister, girl, grandson, and spouse of patients, selected purposely. They take care of their patient in post-ICU, respiratory or medical wards, and can be able to speak Persian language very well. The participants were selected from May 2014 to May 2015, and sampling was continued until data saturation. After getting consent to participate in the study, family caregivers were asked to answer an open question: "Please explain about a day of care of their patients." For more clarification, exploration questions were used including: Can you explain more? What did you mean by this? Can you give an example? The mean time of the interviews was 20–40 min, and all of them were recorded on an MP3 player. Conventional content analysis was used for analyzing the data generating of codes and themes was inductive and produced based on interviews. Data collection continued to reach data saturation, that is, no new themes or ideas were found during the discussions. Data were transcribed verbatim immediately. Every interview was studied line to line, highlighted the key words and sentences, labeled each with a code and integrated where codes with similar meanings fell under the same category and created initial data classification.

Then, the research team did the same categorization process on each class that was once applied to all codes.

Member checking was done for ensure that data were reliable and realized the perceptions researcher of the data. After one researcher initially coded the data, co-researchers and participants reassessed the transcriptions.

Furthermore, the credibility of the findings was found by analysis of the raw data by other researchers independently and comparing their interpretations with those of the study researchers, to arrive at a primary category list.

## Ethical issues

Isfahan University of Medical Sciences Ethics Committee approved the study protocol with the number 293,195 then directors of the corresponding Al Zahra and Kashani Hospitals were informed and agreed for starting study. The purpose of the study was explained for all participants. They are free to participate in the study and withdraw at any time. They assured that their information would be confidentiality. Then, their consent, verbal or written, to record the interview was obtained.

## RESULTS

One hundred and sixty-seven primary codes were extracted from the participants' descriptions. After several reviews, these codes classified into categories of similar meanings. The finding showed that the care of chronic critically ill patients is a long path and acceptance the role of caregiver was affected by various factors. One of the main themes in this study was "nonprofessional care" that contains two subthemes: Physical and emotional care, another theme was "enhancing factors of care" that contains stress and motivation (internal and external), and the other theme was "inhibiting factors of care" that contains attitudinal, informational-practical, and financial barriers.

### Nonprofessional care

This theme experienced by caregivers as a noticeable function that seen in all the interviews and include two subthemes: Physical and emotional care. That was done by caregivers unprofessionally.

#### Physical care

Caregivers told about patient's physical care in all the interviews. They talked about care with the long period that sometimes included months or years. Sometimes, they help patient doing activities of daily living, and sometimes they performed specialty care of patient unprofessional.

A 65-year-old woman who was caring for her son saying:

**This accident happened ten years ago... bedsores were developed... I cut darkened areas of wounds...**

**Washed the white cloth... and dressing his wound...**

A 62-year-old woman who was caring for her spouse saying:

**We do Gavage for him... physiotherapy... turn him in the bed every two hours...**

A 50-year-old man who was caring for his mother saying:

**I do all things myself... Massage her hands and feet... cleaning... I had learned here Disconnect the ventilator and put the Venturi too...**

### *Emotional care*

Caregivers were talking about patient's need for emotional support. They performed emotional support for the patients during care.

A 62-year-old woman who was caring for her spouse saying:

His body is sick... his psyche should not be sick too... Resuscitation was performed for him 4 times and he stayed alive... because my daughter and son inspire him...

A 40-year-old woman who was caring for her sister saying:

I am praying loudly... to find calm for myself and my patient...

### **Enhancing factors of care**

This theme contains stress and motivation (internal and external). Caregivers expressed that how stress affects the process of patient care and talked about the motivations that encourage them to participate in the care.

#### *Stress*

Faced with the responsibility of patient care was stressful for caregiver. This process was like grief that faced with the patient's condition began it.

A 40-year-old woman who was caring for her sister saying:

Within 12 hours, said there is a mass in her head and must be have a surgical emergency... she was conscious, but after surgery level of her consciousness was decreased...

A 26-year-old man who was caring for his grandfather saying:

Because resuscitation was performed for him 7 times, our spirit was too weak... But in recent 2 weeks that he gained consciousness, our spirit was better and we hope again.

A 50-year-old man who was caring for his mother talked about fear of outcome as another stressor.

When I hear that she may be tracheostomy... her throat may be cut... then connect to ventilator... maybe she can't walk easily... and she may be complicated in future... these issues make me sad...

Caregivers after facing with the condition of the patient experience denial, anger, bargaining, and depression.

A 47-year-old man who was caring for her mother saying:

One day morning when my father wants to wake her up, saw that she had no movement and just breathes. It is so uncomfortable...

A 40-year-old woman who was caring for her sister saying:

Did you see my mother?... she was aggressive... she has not Patience...

A 35-year-old woman who was caring for her spouse saying:

Why is God testing me?... (She was crying)... sometimes I say God! you test your best bondmen like this... but I am not very good...

A 40-year-old woman who was caring for her sister saying:

Not only me but also all of us... I think everyone was depressed

Finally, they noted coping with situation and acceptance the role of caregiver.

A 52-year-old woman who was caring for her spouse saying:

I don't be tired... I don't say why I doing this task for him... I take care of him

#### *Motivations*

Participants spoke about internal and external motivations that induce them to accept the role of caregivers. Individual satisfaction and personal interest to client as internal incentives encourage them to take care of the patient.

A 62-year-old woman who was caring for her spouse saying:

I'm very satisfied that I can serve him... caring is so hard but enjoyable... I love my husband... my children love their father... this is lucky

A 26-year-old man who was caring for his grandfather expressed his interest to his grandfather as an internal motivation that induced him to take care of his grandfather:

I'm so interested to my grandfather that if I didn't see him, I could not go to my home... this fixation induce me to take care of him and I have no problem.

A 50-year-old man who was caring for his mother saying:

I'm here only 20 days but she serves their children all life... her work is above my work. I feel appreciated perfectly and I like to do these tasks for herself... and for myself

Sometimes, obligation and assistance induced caregiver to take care of their patient:

A 47-year-old man who was caring for her mother saying:

When we are obliged, we are doing the care... this is not a good feel... however I thought that she need such assistance and willy-nilly we should support her

A 52-year-old woman who was caring for her spouse saying:

Families want to help but I want to assistance them... if they come here they could not go to work and may they

could not provide their livelihood... So I tell it is better that I stay myself

### Inhibiting factors of care

Caregivers talk about problems and limitations that disrupt or prevent patient care. This theme contains attitudinal, informational-practical, and financial barriers.

#### Attitudinal barriers

Sometimes, attitude toward care interferes with care.

A 53-year-old woman who was caring for her son saying:

**When I think that he may have pain during suction I be sad... so I don't do this work unless I be oblige... this my fell prevents doing this work**

#### Informational-practical barriers

Another barriers that noted by a participant was informational and practical barriers.

A 47-year-old man who was caring for her mother saying:

**When we want to turn my patient I don't know how to move her hand that her IV line doesn't displace or endotracheal tube doesn't exit.**

A 62-year-old woman who was caring for her spouse saying:

**I can do physiotherapy but my daughter doses his suction... because she has learned this skill in Red Crescent.**

#### Financial barriers

Another factor that disrupts to patient care was the financial barriers.

A 65-year-old woman who was caring for her son saying:

**He had bed sore... I should dress him myself... I want his father to buy serum, he did not buy and I didn't have money too...**

A 52-year-old woman who was caring for her spouse saying:

**Doctor said if you want to convey him to home you should transfer him with this equipment but the cost of ambulance is very high and I have no money... I have no money for his diaper too so use sheet instead...**

## DISCUSSION

One of the main themes in this study was nonprofessional care that caregiver experienced it as participation in physical and emotional care. Other studies show that caregiver participated in physical care.<sup>[21-23]</sup> In a study by Fatemeh *et al.*, physical care contains physiotherapy, drug therapy, and helps patient for doing activities of daily living.<sup>[22]</sup> In the current study, what noted by a caregiver was participation in specialized care such as suction

and gavage because of critical condition of patients, which caregiver did it in a nonprofessional way.

Another caring role mentioned by caregivers was emotional care and psychological support of patients that seen in other studies too.<sup>[24]</sup>

Other main subject in this study was enhancing factor of care that contains stress and motivations of the participant. Experienced stress due to denial, anger, bargaining, and depression. In other study, family caregiver also experiences stress and its outcomes.<sup>[21,25]</sup> Evidence shows that 61% of caregivers, even without considering patient's medical diagnosis and his specific need for care, experience stress of caring.<sup>[26]</sup> The unpredictable path of chronic disease in critically ill patients causes high levels of psychological distress in patients and families.<sup>[27]</sup> In fact, the critical condition of the patient, his unconscious, and the equipment that connected to him and doubt about recovery or surviving of patient, bother caregivers. However, finally, they accept the role of caregiver and their motivation encourage them to take care of patients. Sometimes, individual satisfaction and personal interest and sometimes obligation and assistance induced caregiver to take care of patients. Etemadifar *et al.* pointed that this is a God-focused care.<sup>[24]</sup> It seems that long-term caring needs some things such as love and emotional attachment.

However, caregivers like to take care of their patient, but they talked about some factors that inhibited caring. One of these factors was knowledge and skill deficit that consistent with findings of other study.<sup>[28]</sup> This issue emphasizes to the importance of having knowledge and experience as care requirements for caring of patients not only in nonprofessional caregivers but also in professional caregivers.

Attitude of caregiver toward care intervention was another inhibitor of caring, other studies inconsistent with this finding pointed that educational programs that improve knowledge and attitudes and cause reducing negative behaviors of caregivers during caring.<sup>[28,29]</sup>

The other inhibitor of caring was high cost of caring that was considered as a challenge in other studies too.<sup>[20,30]</sup> Given *et al.* noted that familial and personal low income and limited available resources can be lead to improper outcomes.<sup>[30]</sup> In fact, special interventions have high costs that some caregivers are not able to provide it, and this leads to disruption in care.

## CONCLUSIONS

Finding of the current study showed different aspects of care. Care of chronic critically ill patients is a long-term process that affected by different factors. It seems that the exploration of caregivers needs and planning

supportive interventions based on their needs improve the quality of care. So doing more researches in this area is recommended.

### Acknowledgments

We thank and appreciate all the participants and respectful of deputy of research appreciate from the Isfahan University of Medical Science because of project funding. This study approved by the Ethics Committee of Isfahan University of Medical Science with the number of 293195.

### Financial support and sponsorship

Nil.

### Conflicts of interest

There are no conflicts of interest.

**Received:** 04 Jan 16 **Accepted:** 04 Oct 16

**Published:** 05 Dec 16

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