

# Adaptation of Caregivers of Individuals on Mechanical Ventilation to Caregiving Role

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## ABSTRACT

**Aim:** The aim of this study is to investigate the adaptation of caregivers of individuals on mechanical ventilation (MV) at home to their caregiver role.

**Study design:** The phenomenological research method, one of the qualitative research methods, was employed in the study.

**Materials and methods:** The sample consisted of 21 individuals who agreed to participate in the research. Necessary legal permissions were obtained to conduct the study.

**Results:** The data were analyzed according to the Roy adaptation model (RAM). Accordingly, the domains of the RAM were expressed with the following themes: Physiologic domain: The effects of care on the caregiver (reluctance toward self-care, psychological fatigue, insomnia, and limitation of social life); Self-concept domain: Supportive situations (trust in God and spiritual practices) and non-supportive situations (fear of losing and self-blame); Role-function domain: Adaptation of the caregiver role (thinking no one else can give similar care) and maladaptation of the caregiver role (fear of failing to cope with suddenly emerging situations, failing to fulfill roles and responsibilities, and economic inadequacy); Interdependence domain: Receiving support (support of healthcare professionals and support of family members) and lack of support (inadequacy of health services and loneliness).

**Conclusion:** It was concluded that individuals who provided care for patients on MV experienced many difficulties and that these difficulties increased their care burden and made it difficult to adapt to their caregiving roles.

**Keywords:** Adaptation, Care, Home care, Home healthcare services.

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## HIGHLIGHTS

It is thought that the results of this study, which was carried out consistent with the theoretical framework of the Roy adaptation model (RAM), will contribute to understanding the adaptation of caregivers of individuals on mechanical ventilation (MV) at home to the caregiving process and to developing care strategies. According to the results of the research, it may be recommended that care processes and training programs should be organized in informal caregivers' home environments. As individuals providing home care services have to accompany their patients for 24 hours, they need a professional with whom they can safely leave their patients. It is recommended that caregivers of individuals on MV should be supported psychosocially in terms of psychological and social changes. It may also be recommended to conduct studies to evaluate the loneliness of caregivers. It will be beneficial to activate and strengthen social support systems to increase the psychological and spiritual well-being of caregivers.

## INTRODUCTION

Mechanical ventilation is defined as a life support system designed to replace or support lung function. It can be applied noninvasively and invasively through a tracheostomy or endotracheal tube.<sup>1</sup> Developments in MV devices make it easier for patients on MV to receive home care services. It is known that chronic respiratory failure diseases with alveolar hypoventilation, such as neuromuscular and chest wall diseases, obstructive airway diseases, and obesity-related respiratory failure, are important reasons for the use of home-type MV.<sup>2,3</sup>

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It has been stated that using MV at home reduces costs, increases the quality of life, and maximizes integration with society.<sup>4</sup> On the contrary, MV represents the most advanced and complex type of medical treatment provided outside the hospital setting.<sup>5</sup> It has been shown that 13% of patients who are provided with care at home and connected to MV experience negative events, such as the complexity of the medical condition, failure to identify and control possible risks, and management and use or misuse of the equipment.<sup>6</sup> There are also disadvantages such as inadequate medical assistance and the development of complications due to misuse of medications or devices at home.<sup>3</sup> Research has shown that increased psychological stress resulting from fear of dealing with emergencies among patients and caregivers is the primary reason for refusing home care.<sup>7</sup> It is known that caring for a patient

**Table 1:** Characteristics of the family caregivers of patients on MV

Gender	Age	Marital status	Relation to the patient	Education	Duration of caregiving (years)
F	32	Married	Mother	Elementary school	6
F	49	Single	Daughter	Elementary school	1
F	26	Married	Daughter	Literate	4
F	23	Married	Mother	Middle school	0.5
F	33	Married	Mother	Elementary school	10
M	35	Married	Father	Elementary school	1.5
F	37	Married	Mother	Elementary school	5
F	26	Married	Mother	Middle school	1
F	59	Married	Grandmother	Elementary school	6
M	32	Married	Father	Middle school	1
F	54	Married	Sibling	Literate	4
F	51	Married	Daughter	High school	3
F	37	Married	Mother	Undergraduate degree	3
F	38	Married	Mother	Elementary school	6
F	36	Married	Mother	Elementary school	4
F	32	Single	Daughter	High school	10
M	30	Single	Son	High school	2.5
M	55	Married	Mother	Elementary school	7
F	37	Married	Mother	Elementary school	2.5
F	50	Single	Daughter	Undergraduate degree	5
F	40	Married	Mother	Undergraduate degree	5

F, female; M, male

on MV at home leads to a heavy physical and psychological burden on caregivers and that their interaction with the outside world decreases because they cannot leave patients alone at home.<sup>7</sup> Caregivers may fail to manage the effects of care on themselves, may not adapt to their caregiving roles, and may experience feelings, such as helplessness, guilt, anger, and fear.<sup>8</sup> A review of the literature indicated that there were studies on the effects of care on caregivers of individuals dependent on MV at home,<sup>7</sup> but qualitative studies on the adaptation of caregivers were limited. This study was conducted to examine the adaptation status of caregivers of individuals with a tracheostomy receiving MV.

### Theoretical Framework

The concept of self, which is another basic concept of the model, is defined as the whole of the emotions, thoughts, beliefs, and perceptions that the individual has acquired regarding himself/herself.<sup>9</sup> The role-function domain, the third concept of the model, is defined as the behaviors that a person must do to fulfill his/her role in accordance with his/her relationship with other people in the culture where he/she exists, to meet the expectations of the society, and to integrate with society.<sup>10</sup> It is also stated as a basic psychological need that emerges as the ability of individuals to act in a self-determined manner and with an internally perceived locus of control.<sup>11</sup>

## MATERIALS AND METHODS

### Type of the Study

A phenomenological research method, one of the qualitative research methods, was employed in the study. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used as a guide for reporting the research.

### Population and Sample of the Study

The study was conducted between April 2019 and June 2019 with individuals who lived in a province of the Black Sea Region, provided care for patients with a tracheostomy on a respirator, and agreed to participate in the study.

Caregivers of patients receiving home health services in the province where the research was conducted were contacted using the snowball sampling method. During the interviews, two caregivers did not agree to join the interviews because their relatives were receiving treatment in the hospital. Data were collected from 21 participants and data collection was terminated when the data reached a saturation point (Table 1).

It was determined that 17 of the caregivers of individuals on MV were female, their mean age was  $38.7 \pm 10.3$  (minimum: 23, maximum: 59), and 17 of them were married. Eleven of the participants were mothers of the individuals they provided care for, five of them were daughters of the individuals they cared for, and 10 of the caregivers were primary school graduates. It was found that the caregiving duration of the participants providing care for individuals with MV was  $4.2 \pm 2.7$  years (minimum: 0.5, maximum: 10).

### Data Collection Tools

Study data were collected using a semi-structured interview form that was based on the Roy adaptation model (RAM; physiologic, self-concept, role-function, and Interdependence domains) and a literature review. The form was piloted to two caregivers who met the inclusion criteria, and then it was revised. At the beginning of the semi-structured interview form, there were 13 questions about the sociodemographic characteristics of individuals with a tracheostomy on VM and their caregivers, such as age, education level, marital status, income status, social security, etc. Following

this part, there were 15 questions which were prepared by the researchers following a review of the literature and expert opinions to question the physiologic, self-concept, role-function, and interdependence domains of the caregivers. Some of the questions were as follows: Could you tell us how your caregiving role has affected your life physiologically? Could you tell us how your caregiving role has affected your life psychologically? How do you feel about whether the people you interact with understand you? How do you feel about dealing with situations that may arise during caregiving? How do you evaluate the attitudes of the people around you toward you?<sup>12</sup> In addition to these questions, a series of questions were used to encourage caregivers to give answers or provide clarification (Can you explain this a little more?).

### Data Collection

During the research, people who were providing care for patients on MV receiving home health services were called and asked whether they agreed to participate in the research. The addresses of the individuals who agreed to participate in the study were taken, they were visited on the day and time when they were available, and data were collected from the caregivers using demographic characteristics form and the semi-structured questionnaire. A voice recorder was used during the interviews after the participant's permission was obtained. Each interview lasted 30–60 minutes. The recorded data were later transcribed. An 89-page long transcription was obtained. During the transcription of the data, behavioral data of the participants expressed through voice and silence (laughing, expressions of distress or strain, crying or silence/pauses, etc.) were also recorded to increase the data quality. All three authors were female public health nurses. All authors were academics who had education in qualitative research and had publications in qualitative research.

### Data Analysis

Data were analyzed deductively using content analysis based on the conceptual framework of the RAM. This approach is used when there is pre-existing knowledge or theory on the subject. The in-depth interviews were transcribed during the analysis. Then, meaningful data units were determined. Adaptive and maladaptive behaviors were coded and categorized according to the adaptation domains included in the RAM (physiologic, self-concept, role-function, and interdependence). The main themes of the study were based on the adaptation domains of the RAM. The arranged data were supported with quotations where necessary.

### Validity and Reliability of Data

The criteria suggested by Lincoln and Guba were taken into consideration for the validity and reliability of the research.<sup>13</sup> Lincoln and Guba suggested using the concepts of credibility instead of internal validity and transferability instead of external validity. In this study, the in-depth interview and expert review methods were used to achieve the credibility of the research. For this reason, data collection continued until the data saturation point was reached, and it was terminated when data saturation was achieved with 21 people. All statements were recorded on a voice recorder. Two researchers collected data. One researcher was the moderator throughout the research, and the other made recordings and took notes during the interview. During the evaluation process of the research, the researcher constantly questioned herself and the research processes critically and checked whether the findings obtained reflected the truth.

The purposive sampling and detailed description methods were employed in the study for transferability. The researchers presented the raw data in the findings section of the study, by rearranging them according to the resulting codes, without adding any comments and in accordance with its nature.

In qualitative research, the concept of "dependability" is used instead of "internal reliability" and "confirmability" is used instead of "external reliability." For dependability, the researcher treated all the people in the interviews in a similar/consistent manner during the collection and analysis of research data and used the same interview form and voice recorder in all interviews. In addition, the data of the study were analyzed independently by a faculty member who was interested in the subject and experienced in qualitative research. For confirmability, the results obtained by the researchers were conveyed to the reader in a clear and understandable manner. In addition, all data collection tools, codes elicited during the analysis phase, observation notes that formed the basis of the report, and in-depth interviews were stored to be submitted for confirmation review when necessary. At the end of each interview, participants were informed that the transcripts would be sent to them for checking after the data were transcribed. Nineteen participants confirmed the transcription of their interview data and stated that no change was necessary. Following the interviews, the remaining transcriptions were sent to the two caregivers and their approval was obtained.

## RESULTS

It was found that 11 of the care recipients were female, 11 were adults, two did not have social security, the family of 11 had less income than their expenses, and 18 had nuclear families (Fig. 1; Table 2).

## DISCUSSION

The participants in this study revealed that each individual was unique and had a different story to tell. In the study, the adaptation of caregivers of individuals on MV at home was investigated.

At the end of the interviews with the caregivers, codes such as "reluctance toward self-care, psychological fatigue, and insomnia" were created. These codes were defined within the physiological domain of the RAM. The results related to this domain were evaluated as the subtheme of "the effects of care on the caregiver." In a study, it was reported that those who provided care for a person with disabilities at home experienced physical problems, such as difficulty lifting the patient, lack of self-care, insomnia, and inability to rest.<sup>14</sup> In a study on the comparison of individuals caring for patients on MV at home and those caring for patients on MV at a nursing home, it was found that the physical burden (sleep, physical fatigue, back pain, and poor health level) was significantly higher in caregivers at home than in caregivers in a nursing home.<sup>7</sup> In another study conducted with caregivers of 55 patients on MV at home, social, mental, physical, and daily life fatigue levels were found to be very high.<sup>15</sup> It has been determined that caregivers of family members with disabilities do not have time to care for themselves and often complain about pain in their limbs and back.<sup>16</sup> Our study findings are consistent with the literature. It is thought that the increase in the roles of caregivers in the process of caring for an individual with MV at home caused caregivers to take on more responsibilities, and as a result, physical problems may have arisen in the caregiver.

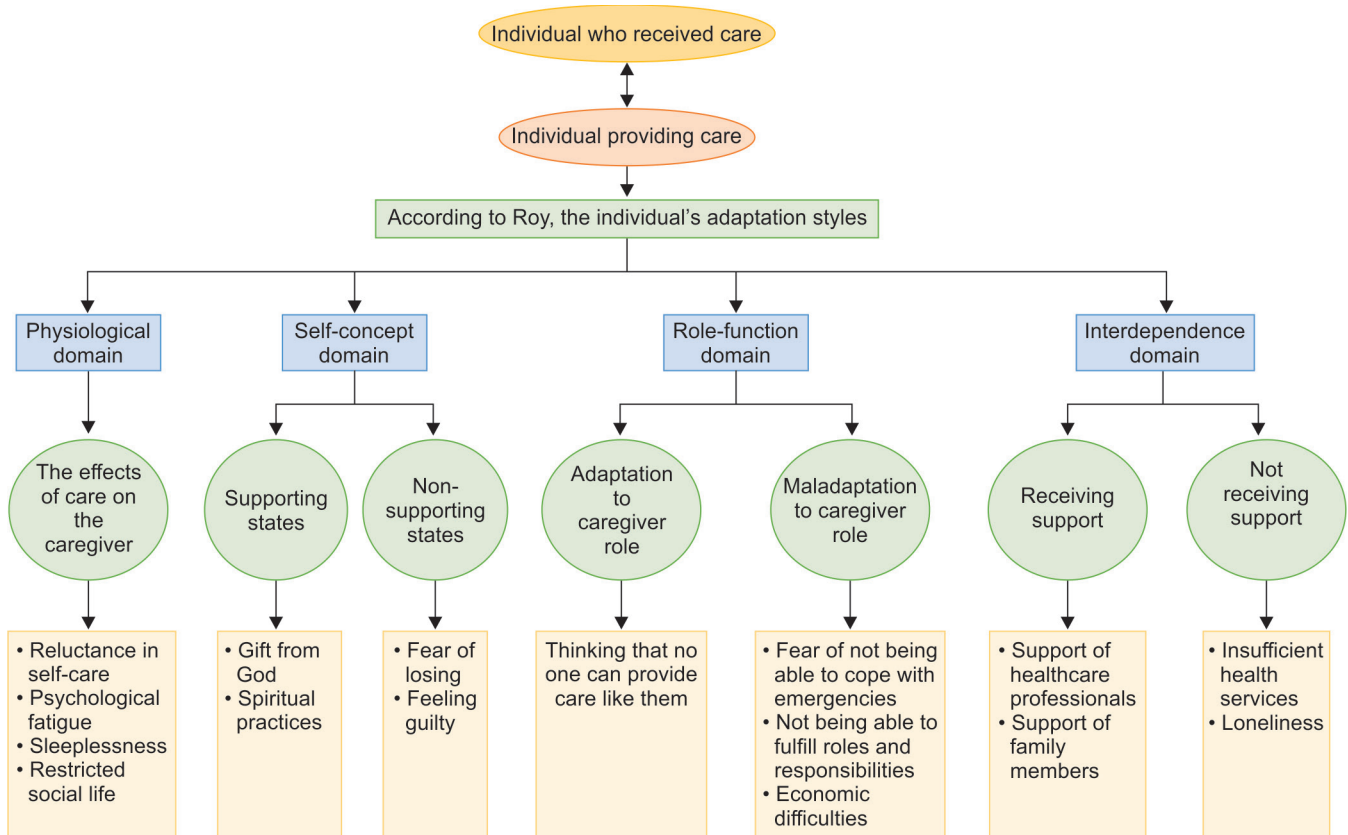


Fig. 1: Themes, subthemes, and RAM as a result of the qualitative analysis

Table 2: Main themes, subthemes, and examples of quotations obtained from interviews

Concept	Themes	Subthemes	Examples of quotations
Physiologic domain	The effects of care on the caregiver	Reluctance in self-care	<i>I cannot go out. I'm in front of the television. I eat all the time and I have gained weight. I don't take care of myself. I have never been out without nail polish before. I can manage my son's situation, but I think I cannot manage that of mine. Actually, I can achieve that, too, but I don't do it (P1).</i>
		Psychological fatigue	<i>I think I'm doing something wrong. I will go and get psychological support from somewhere, but I cannot do it because someone has to come to this house, so that I can leave. I'm not very young, but I have two children, they will get married and meet other people. I don't want to be intolerant and offend people. I don't want to be sharp-tongued (P2).</i> <i>I feel exhausted psychologically. She is a special child, and our process of acceptance ... no matter how I stand against this, I am waging a war inside me. She takes medicine every two hours and needs feeding every three hours. I sometimes take a nap. Then I wake up in distress. I don't feel comfortable at all (P4).</i> <i>I am very sentimental. I cry all the time, even over the smallest things. It would be great relief if I am provided with psychological support. For example, talking to you felt so good. If I consult a psychologist once a month, it will make me feel good for a month (P5).</i>
		Insomnia	<i>My mother has difficulty breathing at night; she calls out, but her voice does not come out. That's why I don't sleep until the morning. My bedtime is 5 to 6 O'clock in the morning (P3).</i>
		Limitation of social life	<i>Our whole life has changed. I can say that I can never sleep at nights. There is nothing good. For example, my social life is over. I don't ever want to go out. Sorry for my tears (P8).</i>
Self-concept domain	Supportive situations	Trust from God	<i>If my daughter had been in another family, she might not have been cared for like this. We are doing our best. She is a trust from God to us (P7).</i>

(Contd...)

Table 2: (Contd...)

Concept	Themes	Subthemes	Examples of quotations
Non-supportive situations		Spiritual practices	<i>I am not resting; I am reading the Quran. It is my biggest relief, and also looking at my mother for a long time. I don't know, maybe, I want to spend quality time, but sometimes I just look at her without sleeping at all (P2).</i>
		Fear of losing	<i>I feel nervous, and my psychology is bad. My fear of losing has peaked. As I have lost people around me since I was very young, my fear of losing has reached its peak. I don't know what I would replace her (my mother) with (P2).</i>
		Self-blame	<i>Genetic analysis has shown that the problem has been caused by me. My husband's attitude started to change over time. I've never talked to him, but I wonder if he thinks this child's condition is because of me. But, I have also blamed myself (P1). My son-in-law's family has blamed my daughter for my grandchild's condition. They said that there was no such thing in their lineage and that my daughter was the cause of this situation (P9).</i>
Role-function domain	Adaptation to the caregiver role	Thinking no one else can give similar care	<i>I have been completely focused on my mother. I can't go to the market or anywhere. I don't even go down those stairs. No one clears her throat, no one, except me, aspirates her. Otherwise, everyone can feed her. Anyone can change her diapers, even if they are scared. I've never left it to anyone so far. I have never left it even for a day. I left her to my brother for a few hours at most (P2).</i>
	Maladaptation to the caregiver role	Fear of failing to cope with suddenly emerging situations	<i>Don't get me wrong, but those who do this job study this field for years. How can we learn it in three to four days? I wonder how experienced I can be. I've been told how to use the Ambu in an emergency, but I've never used it. I don't know what I will do if I am alone at that moment. I clean my son's tracheostomy twice a day so that I will not have to use the Ambu (P4).</i>
		Failing to fulfill roles and responsibilities	<i>My daughter is the youngest in the family; we see her like a baby. Sometimes I tell the children that our priority is your sister. They are also deprived of playing with other children, but there is nothing to do. They want to go out, but they can't; they want to go somewhere, but they can't (P7). I don't have weekends, I don't have Sundays, and I forgot my husband. Look, I have only one son, and I even forgot him (P11).</i>
		Economic inadequacy	<i>Good support is needed for such patients... While raising my other son, we had to live frugally. But what can I restrict on this child of mine? If it means saving electricity, which machine should I turn off and which savings should I make? Let's not use NG, how should I give him food then? It is not possible. I can't make it on minimum wage. They say that an intensive care environment should be provided and he should be cared for accordingly but they do not ask if I can manage it (P4). We try to cope, but sometimes we can't. All devices are connected to electricity. I petitioned the electricity company so that they would not cut off my electricity. Sometimes they have to do it. These devices consume five times the electricity required by a normal family. Our bills are enormous (P18).</i>
Interdependence domain	Receiving support	Support of healthcare professionals	<i>The healthcare professionals at the hospital told me that they had never seen a caregiver like me. "If we didn't rely on you, we wouldn't send this patient home anyway," they added. They said, "You look after your sister very well, we trust you and send this patient home." When I took my sister to the hospital, a doctor saw us and asked, "Is this your sister?" and he was very surprised. He told me, "This is the caregiver, and this is how a patient is given care" (P11).</i>
	Lack of support	Support of family members	<i>My family has been supportive. They never left me alone. We were hospitalized, and they were with me all the time. Now my sisters are substituting me in turns (P8).</i>
		Inadequacy of health services	<i>Sometimes even medical teams are not very conscious about such children. They say, "There is nothing we can do for you. Such children may seem good, but everything can turn upside down in an instant." Nobody takes responsibility. I can't blame them because they don't know this (P21). The home healthcare team comes once a month. They come when I call when I have a normal fever, but they don't come on the weekends. I wish there was such a chance. If only I wouldn't take the child to the hospital by ambulance just to get him prescribed antibiotics. I wish there was such an application (P7).</i>
		Loneliness	<i>I am always alone with my son in hospitals. My husband! My mother-in-law is very authoritarian. She has learned everything about taking care of my son, but she has never supported me. I don't blame her. She doesn't have to take care of my son, either. Am I wrong? I don't know (P1). My neighbors always tell me I don't go to visit them; they don't understand me (P13).</i>

At the end of the interviews with the caregivers of the individual on MV at home, one of the subthemes elicited from the data was "spiritual practices." In a study, it was determined that patient relatives had spiritual care needs.<sup>17</sup> Another study showed that when home caregivers were approached from a psychosocial perspective and supported to improve their problem-solving skills and ability to cope with stress, their quality of life increased and they were supported in solving minor health problems before they turned into a crisis.<sup>18</sup> Erenoğlu and Başer stated that utilization of spirituality had positive effects on caregivers' physical and mental health.<sup>19</sup> The findings of this study are consistent with those in the literature. It is thought that this is because long-term care increases the spiritual needs of caregivers as well as their physical and social needs.

"Fear of losing" was another subtheme elicited from the data obtained from interviews with the caregivers. Individuals who provide care at home are emotionally affected by the fear of losing their loved one.<sup>20</sup> A study indicated that the psychological and social status of caregivers was negatively affected due to the illness of a family member, and they experienced fear of losing.<sup>21</sup> This finding is consistent with the literature. It is thought that this is because the individuals they provide care for have incurable diseases.

One of the subthemes that was created at the end of the interview with the caregivers of patients on MV at home was "self-blame." In a study conducted with families who had individuals with disabilities, it was found that mothers and fathers felt guilty.<sup>22</sup> In a study by Balcı et al. with families who had children with mental disabilities, it was found that 14.4% of mothers felt guilty about their child's condition.<sup>23</sup> It is thought that this situation arises from the fact that caregivers are family members of the patients they provide care for and that their children have a genetically transmitted disease.

One of the subthemes that was evaluated under the role-function domain of RAM and elicited from the data in this study was "fear of failing to cope with suddenly emerging situations." Some studies have shown that MV treatment at home is seen as a major challenge.<sup>24,25</sup> In addition, it was observed that the family-member caregivers of patients on MV developed posttraumatic stress disorder, depression, or anxiety after starting home care.<sup>26</sup> Research findings have shown that home caregivers experience fear of failing to cope with emergency situations.<sup>27,28</sup> In another study, it was determined that those who provided care for an individual on MV at home did not consider themselves competent, even though they received training about MV.<sup>29</sup> It is thought that this may be because informal caregivers with different education and experience levels have to use complex medical devices, which are actually used by healthcare professionals, in the home environment.

In this study, individuals who cared for patients on MV at home stated that they suffered from financial difficulties. Research has shown that families who have patients on MV at home have to quit their jobs, have economic difficulties, and cannot meet the needs of their family and the patient who is provided care at home.<sup>7,30,31</sup> Meeting the needs of individuals receiving home care requires financial means.<sup>32</sup> The care provided for individuals may be inadequate due to financial difficulties. It is thought that this situation negatively affects caregivers' adaptation to their role.

In this study, two of the subthemes elicited from the interview data were "inadequacy of healthcare services" and "not being understood." A study conducted in Canada showed that approximately 13% of those providing care for sick individuals at

home experienced at least one negative event.<sup>33</sup> A study indicated that activities of home care services such as helping the informal caregiver rest would help alleviate the care burden.<sup>34</sup> Aşiret and Çetinkaya determined that the needs of all patients were met by family members and that home care services did not provide enough information about the use of drugs and medical devices that the patient would use.<sup>35</sup> These findings are described within the interdependence domain of the RAM.

## Limitations

A limitation is that the study was conducted in a single province. A limitation is that most of the caregivers in the sample group in which the research was conducted were women.

## CONCLUSION

The following results were obtained according to the RAM:

- Individuals who provided care for a patient on MV at home experienced effects of care" and problems with reluctance toward self-care, psychological fatigue, insomnia, and limitations in social life, which were handled under the physiologic domain.
- In the domain of self-concept, the "supportive situations" theme included "a trust from God" and "spiritual practices" subthemes, while "non-supportive situations" involved "fear of losing" and "self-blame" subthemes.
- Within the role-function domain, the theme of "adaptation to the caregiving role" included the "thinking no one else can give similar care" subtheme. The subthemes of "fear of failing to cope with emergency situations," "failing to fulfill roles and responsibilities," and "economic inadequacy" were determined under the "non-adaptation to the caregiving role" theme.
- The subthemes of "loneliness," "inadequacy of healthcare services," and "not being understood" were elicited under the theme of "lack of support" and the subthemes of "the support of healthcare professionals" and "the support of family members" were elicited under the theme of "receiving support," which were evaluated under the domain of interdependence.

It is thought that the results of this study, which were carried out following the conceptual framework of the RAM, will contribute to understanding the adaptation of individuals who provide care for an individual on MV at home during the care process and to developing strategies to handle such situations in the future. Based on the study results, it is recommended to organize education plans for the entire care process for informal caregivers, at regular intervals, in their home environment. It is also recommended that individuals who use and monitor a complex device such as MV at home be monitored more closely. Since individuals providing home care have to accompany their patients 24 hours a day, it is seen that they need a professional whom they can trust and leave their patients with to meet their needs. It is recommended that those who provide care for an individual on MV at home be supported psychosocially for psychological and social changes. In addition, it may be recommended to conduct studies on the evaluation of caregivers' loneliness. It would be especially useful to activate and strengthen social support systems to increase their psychological and spiritual well-being.

## ETHICAL APPROVAL

Before starting the study, approval was taken from the Faculty of Medicine Ethics Committee, Ondokuz Mayıs University, Samsun,

Turkey (B.30.2.ODM.0.20.08/1942). The required legal permissions were taken from the Public Health Directorate of the province where the study was conducted to carry out the study. The participants were explained about the purpose of the study and the volunteering participants were included in the study. Since one of the participants who were contacted at the time of research was out of town on the date the study was conducted, he was not interviewed.

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