Original Article

Families' Experiences of End-of-Life Care at Home for Iranian Older Adults: A Qualitative Study

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Abstract

Aim: While the care of dying elderly patients at home is very complex and ambiguous, it has not been studied in Iran so far. Hence, this study aimed to explore the experience of a representative sample of the Iranian family caregivers from the end-of-life (EOL) care for their elderly relatives. **Methods:** The present study was conducted using a qualitative content analysis method. Twelve family caregivers caring for the chronically ill dying elderly were selected using purposeful sampling. The purposive sampling method was applied with an extreme variation in sampling, and data gathering was pursued until data saturation was achieved. Semi-structured interviews were utilized for data collection. Interviews were recorded and instantly transcribed verbatim. Inductive content analysis was used to analyze the data. **Results:** Four core themes and 13 subthemes emerged from the experiences of family's caregiver as fallow: (1) Committed to care: This is related to encounter with the end of stage disease of the relative, accepting the care role and priority of care, (2) challenges of Care: Caregivers, despite their efforts, provided ineffective care, so they sought to empower themselves and at the same time provide compassionate care, (3) the crisis of care including the complexity of care, fear, and wandering, helplessness, devastating tension, and vacuum of supporting, and (4) conditions after death that family members involved with a sense of loss and Tension control. **Conclusion:** When families had to take care of their elderly patients at home, although their wish to give the best care, they are completely powerless to provide care, and in an atmosphere of the vacuum of supporting, they encounter severe challenges and crisis. It is vital that palliative care centers in the society are arranged to care for EOL elderly with comprehensive insurance services.

Keywords: Caregiving experience, elderly, end-of-life care, family caregiver, qualitative research

INTRODUCTION

The elderly people is highly susceptible to chronic and life-threatening diseases.[1] Up to 80% of the population over 65 years have at least one or two chronic diseases which finally endanger their life, and necessitate implementation of end-of-life (EOL) care to them.[2,3] EOL care is part of palliative care that concentrates on patients with life-threatening diseases and with a life expectancy of 6–12 months.[4] It helps patients to die in clam, and solemity.[5]

About 20.4 million of population globally need of EOL care, and it is estimated that by 2040, up to 88% of patients at EOL stage could benefit from palliative care.[4]

According to the Iranian census in 2015, the mortality rate of the elderly population over 60 years accounted for 65.6% of all deaths.[6] Therefore, the most of elderly population have severe chronic disease which lead them to experience EOL care prior to death.[2]

Although most of these patients require EOL care,[3] their special care needs are ignored in many societies,[5] and most of them die in unfavorable conditions. Until, EOL care needs have been slightly provided only by elderly family members.[7]

In Iran, the health-care system does not provide any formal EOL care for patients and there are only a limited number of

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palliative care centers scattered across several major cities.[8,9] When these patients are admitted to the hospitals, the services provided them is limited and inefficient which restricted only to the routine basic cares.[10,11] Furthermore, EOL care mainly provided by family members without any social, governmental, and health-care providers support.[11,12]

EOL care of the dying elderly could be a very complex and often long-lasting phenomena, which require complicated and varied professional care tasks.[13] EOL caregivers encounter with many challenges during care giving that are beyond of their ability which leads to a deficient care and frustration of caregivers.[13,14]

Surveying the family caregiver experiences could be crucial to understand EOL care challenges,[15] and important knowledge for determining different services and a useful tool for optimizing existing resources.[12,15]

Researching on the experience of family members related to provided EOL care to the terminally ill elderly has been conducted largely in Asian countries except Iran.[16-18] Since EOL care could highly be culturally dependent, it is essential that all nations should survey EOL care separately. Hence, the present study was conducted with the aim of acquiring a deep perception of the experiences of families who care for the elderly with the chronically end-stage disease at homes. To achieve a whole knowledge of families' experiences of giving EOL care, this study used qualitative research.

METHODS

Design

This qualitative study was conducted using content analysis method in Tabriz, Iran, in 2018. The research environment was patients' homes, home care institutions, palliative care centers, and hospitals of Imam Reza, Shahid Madani, and Gaghi Tabatabai in Tabriz.

Participants

Study participants were selected through purposeful sampling method from family caregivers involved in-home care. To maximize diversity, participants were invited to participate from different socioeconomic levels with different family relativity, as well as possible, the elderly patients with different age, gender, and diseases were selected, too. Sampling was continued until data saturation.

The inclusion criteria of caregivers were: Being over 18 years, having cared for an elderly relative with EOL stage at home during the past 2 years, having the most responsibility of care in the family, and having the willingness to participate in the study. The caregivers who were physicians or nurses were excluded. To access the participants, the researcher first referred to different home care and palliative care centers, due to the low number of eligible family caregivers and possibility of their lack willingness to participate in the study, the researchers identified more family caregivers across hospitals of Imam Reza, Shahid Madani, and Ghazi Tabatabai in Tabriz. After identifying eligible participants, the consent form was signed on the day of the interview after the participants were given a face-to-face explanation of the study goals and their cell-phone numbers were obtained to coordinate the interview time and location. In all cases, the researcher called with participants before interviewing.

Data collection

Data were collected through in-depth and face-to-face interviews with semi-structured questions between June and September 2017 utilizing an interview guide in the quiet rooms. Each interview started with questions about the patient's medical history and continued with open-ended questions about the participant's care experience with lasting of 60–90 min. With the open-ended questions, the participants were given an opportunity to share their experiences of caring for the elderly with EOL care needs. In-depth interviews with participants were asked to elaborate on their experiences in more detail. Totally, 15 interviews were conducted with 12 family caregivers. The nine caregivers were taking care of the patient at the interview time and the three ones had previous care experience, whose elderly relatives have died. The two caregivers were interviewed twice; first, during their care time and second, a few months after their patient's death.

Ten interviews were conducted with prior coordination at home, and five were conducted at the approved place of the participants, including at the workplace of the participants, at the workplace of the researcher, and at parks. With the exception of two interviews that the caregivers were disagreed to use a voice recorder, other interviews were digitally audio recorded. All recorded data transcribed manually verbatim.

Ethical considerations

The ethical approval was achieved from the Ethics Committee of the University of Social Welfare and Rehabilitation Science (USWR), Tehran, Iran (The ethics Code: IR.USWR.REC.1396.265). The participants were convinced that their contribution would be completely voluntary and confidential. Prior to the interview, the study objects were explained to the participants, and they were told that they could withdraw from the study, or refuse to participate at any time, and would have right to ask any questions. Each informant was recognized by a research code. Written informed consent was obtained from all those who agreed to participate in the study.

Data analysis

The interviews were transcribed verbatim in Persian during data gathering. The transcripts were read several times to get a deep understand of all the statements. Data analyzed using qualitative content analysis.[19] The analytic steps consisted of: (a) comprehensively reading the transcripts; (b) separating the interviews into content areas according to the interview queries; (c) extracting and condensing meaning units; (d) abstracting and labeling a code; (e) grouping the codes into categories; and (f) creating subthemes/themes.[19] Data analysis was accomplished using MAXQDA software after typing the interview.

Trustworthiness

The credibility, transferability, dependability, and conformability of data were assessed using Lincoln and Guba's four evaluative criteria[20] to determine the validity and reliability of our findings.

RESULTS

Of the total 12 informants, six participants were women. The time of the interview was as fallow: six participants only caring time, three at the caring time and after patient's death, and three only after patient's death. The length of times of care was varied from 3 to 18 months. Most of the caregivers were a householder with a level of education from illiterate to a bachelor. In terms of marital status, most of them were married. The participant's relationships with the chronically ill elderly were as fallow: Two wives, three sons, three daughters, and three daughters-in-law. More detailed information presented in the Table 1.

End-of-life care at Iranian homes

Four main themes and 13 associated subthemes emerged from experiences of caregivers [Table 2]. When family encountered with EOL stage of their elderly, although they tried to provide the best care as much as possible, but they completely were unable to provide and meet needed professional cares, so while struggling to strengthen themselves to could provide better cares, they would have suffered from many challenges that associated with a perception of a vacuum of support from the other family members and the community. As the condition worsened, family caregivers enter in a state of crisis and helplessness that inevitably the had wish for a comfortable death for their patient. Finally, they experienced the death of their patient which leads them to have a sense of loss after death and their trying to control tension.

Committed to care

Encounter

In most cases, although families are aware of their elderly chronic disease, they do not anticipate that it would reach the terminal stage soon. So for many families, this was a sudden news and shock. The main family reaction was anger. Their anger was usually directed at the doctors. They blamed the doctors for failing to diagnose and treat the disease early.

Her doctor hadn't diagnosed my mom diseases, so her condition had been worsened, if her doctor had diagnosed her early enough, she wouldn't be like that now (P1).

Some families were unable to accept and were inquiring for a way to cure their patients, which led them to numerous referring to various doctors that were without effective results. Some participants stated that striving to save the patient had an emotional relief to them.

Repeatedly we were going to the hospital to take scan and lab tests, we took a few more doctors, but all of them told us that no more need to more try (P2).

Accepting the role of care

Often, a caregiver was a person who lives with the patient and has a financial subscription with him/her. The caregiver was often a young child of the family member and other family members had usually a supportive role. Family members were highly motivated to take care of the patient because they saw patient care as the last opportunity that they could be with him. Most participants mentioned a fear of remorse and torment of conscience as their motivation to give care.

I don't want to regret and suffer later for a lifetime, to say I could gave better care (P8).

However, in some cases, family members were reluctant to accept care and the primary caregiver has to take a caring role alone and which made the care more challenging.

Table 1: Characteristics of participants (n=12)

Patients	Gender of patients	Age of patients	Type of disease	Gender of participants	Caring time (months)	Caregiver job	Caregiver education	Marital status of caregivers	Informant's relationship to patients
1	Female	62	Leukemia	Female	5	Housekeeper	Diploma	Married	Daughter-in-law
2	Male	65	Lung cancer	Female	3	Housekeeper	Illiterate	Married	Spouse
3	Male	76	Heart failure	Male	5	Employee	Bachelor	Married	Son
4	Female	72	Gastric cancer	Female	4	Housekeeper	Diploma	Single	Daughter
5	Male	84	Pulmonary fibrosis	Female	8	Housekeeper	Illiterate	Married	Spouse
6	Male	85	Prostate Cancer	Female	7	Housekeeper	Diploma	Married	Daughter-in-law
7	Female	74	Heart failure	Female	4	Carpet weaver	High school education	Single	Daughter
8	Female	75	Liver failure	Female	5	Employee	Bachelor	Married	Daughter-in-law
9	Male	86	COPD	Female	7	Housekeeper	Bachelor	Married	Daughter-in-law
10	Male	75	Brain tumor	Male	18	Freelance job	Master's degree	Single	Son
11	Female	68	Pancreatic cancer	Female	6	Housekeeper	Associate degree	Single	Daughter
12	Female	79	Heart failure	Male	13	Teacher	Bachelor	Married	Son

COPD: Chronic obstructive pulmonary disease

Table 2: Main themes and subthemes

Themes	Subthemes
Committed to care	Encounter
	Accepting the role of care
	Priority of care
Challenges of care	Inefficient care
	Struggle for empowerment
	Compassionate care
Crisis of care	Complexity of care
	Fear and wandering
	Helplessness
	Abrasive tension
	Lack of social and governmental support
Postdeath conditions	A sense of loss after the death
	Tension control

Her children rarely come, my husband and I do all of his work. he cries in the bathroom and curses her children. He gets anguished by taking a bath by me (his daughter-in-law) instead of his sons (P9).

Priority of care

After accepting the caring role, the patient becomes the only concern of the families. Patient care took priority over other matters and costs for the patient over other costs.

I can care and serve my husband and baby later, but not for my Mother-in-law (P1).

We may Suffer from starvation, but not let our father starve, for example, we couldn't eat vegetable oil ourselves but use olive oil for father's gavage (P12).

Sometimes, the patient's primary caregiver was forced to give up his or her life's priorities, abandon his/her education, stayed away from his/her family to could stay with the patient for 24 h to could be in constant attendance and give optimal care.

I left my family and my job in Karaj and came to my father home, he needed to stay there for 24 h, I couldn't leave him alone (P3).

Challenges of care

Inefficient care

Often, the family had very little knowledge and skills in patient care and care equipment. Family members felt seriously insufficient and confused about their patient care needs. This situation led them to fear of caring for and imposing serious stress and inflicting torture on the patient.

We didn't know how to care for her, we didn't know anything, we were very stressed out and scared to even touch her oxygen machine (P7).

Struggle for empowerment

The family felt the need to develop their care information when they saw the patient's suffering and their inability to care for him, but there was no adequate and accessible source of information. Hence, they grabbed whatever resources they felt could help them. Mostly, the source was nonprofessional individuals.

She had a lot of problems, no one was telling me how to how could I care for her, her doctor didn't even say anything. I had to ask this and that, from the relatives or neighbors (P4).

Families used a variety of strategies to develop caregiving skills, including observing the nurse's performance while in hospital and the main strategy for families to develop caregiving skills was the repeated trial and error.

The hospital, where the father was embedded, was a training center, where I could watch and learned as the students were trained, and I did them several times at home with caution and could learne more (P3).

Compassionate care

The most focus of the family was on patient physical care such as carrying out of him/her daily activities, preventive and convenience proceedings. The patient comfort was the most important in the family. Major family comfort activities included massage, daily bathing, breathing exercises, opium use, and herbal remedies to relieve symptoms.

Father's convenience was most important, although we were annoyed very much, we did everything for his convenience (P10).

In addition to physical support, emotional supports were provided by other family members because of the primary caregiver's involvement in physical care. The greatest, the emotional need of the elderly relative was the need for the presence of him/her children. Most of the family's emotional support for the elderly included being with him, hoping to heal him/her, the happiness of his/her family, encouraging his/her to talk more and listen, and paying attention to him/her spiritual needs.

When kids were with my dad, he was in good spirits, slept comfortably, but when the kids weren't, he just was whining. Because of this, everyone was trying to be with him (P6).

Crisis of care

Complexity of care

As the patient's condition declines, he or she may experience multiple physical, psychological, and cognitive complications. The patient's condition worse frequently and it needs to transfer him/her to the medical centers.

When Mom went worse, we obliged to sleep her in a blanket and lift her up to put on the emergency medical stretcher (P8).

Some participants stated that at that such conditions, the patient would reject them and would not allow caregivers to care and it gets worse the situation. Over time, other family members needed to be more involved with inpatient care.

She yelled at me to not be and touch her. I told her I was your daughter, my dear, let's stay the girl's mother, but she wouldn't let me do it anymore (P7).

Fear and wandering

The family caregivers were extremely frightened because of the possibility of additional problems for the patient and inability of them to control it, and they felt extremely insecure and hopeless, as they said they experienced death several times a day.

Repeatedly, she was feeling bad and got worse. That day suddenly became very bad, we were just cried and scared. Our neighbor came and tokes her to the hospital. We didn't know what to do. We couldn't sleep at night (P2).

After transferring the patient to the hospital, due to him/her incurable nature of the disease, the treatment team was reluctant to keep the patient in the hospital and with a brief reliving of symptoms, they would discharge him/her, which caused frequent patient and family wandering between the home and the hospital.

They wouldn't keep her in the hospital, after a couple of days of embedding, they would tell us to take our patient to home, sometimes we begged them that our patient be hospitalized more time. We were tired, we were just wandering (P4).

After being discharged, because of seizure recurrence, we were scared to go home, by ordering of an acquaintance, we were admitted to a teaching hospital, but there, our patient so annoyed that I said it is better to go home (P10).

Helplessness

The patient's pain and symptoms were progressive and the prescribed medication was not effective totally. Eventually, the family caregivers were unable to do anything to their patients, which lead them to feel intensely incapability.

No matter how much we took the doctor, it made no difference, we were disappointed with the doctor, the more we get to the doctor, the more it gets worse, my mother was just suffering (P6).

As the situation gets worse, the family's caregivers were frustrated with keeping care and paying costs, caregivers were exhausted and frustrated by the futile care.

Both she and we were tired and tormented. We didn't longer know what we should do (P11).

The frustration caused by the patient's incurability and his/her suffering, made the family found death, as the only way to save the patient from the pain and suffering despite being unsatisfactory.

I begged God that my Mom wouldn't suffer pain too much from now on and have an easy death soon (P8).

Abrasive tension

With complicating of care, anticipating the imminent death of the patient and the loneliness of the family in providing care, that led caregivers to endure severe psychological, emotional, and physical stress. The major stresses mentioned by the participants were from the emotional suffering of predicting sudden patient death and deterioration of the patient's condition daily.

It is very painful to see your loved one be in a situation like this, it was absolutely agonizing to see that she was getting worse and worse and not going to well (P11).

Anger caused by severe fatigue and stress due to the inability to manage the patient's condition has been repeatedly reported by family caregivers.

I was nervous because I was so tired, I was always fighting the kids, I was screaming at my husband, sometimes he was getting nervous (P9).

Lack of social and governmental support

Almost all participants stated that despite their caring for elderly patients imposed physical, mental, emotional strain to them, they also suffered from high financial burden, too.

The long nature of the disease and its constant recurrence made us spend our total earnings on our father, which left nothing for us (P6).

There is government and social support for such families in other countries, while we don't have any financial support here, and we spend all our income on treatment (P10).

Postdeath conditions

Sense of loss

The participant reported a sense of vacuum and loss after their elderly death. The time after death was represented as a time with many loneliness, which contributed to the difficulty of keeping of life, sadness, isolation, difficulty in attention with unbelieving of death.

After her death, I felt a great loss. The house was quiet all the time and I couldn't believe he had gone to God and could never go back (p4).

After my dear death, I didn't want even to keep living, and I often denied it (p3).

Stress control

Families' caregivers have tried in various ways to control stress and maintain balance. They tried to control their stress by using strategies such as crying and self-consolation, relaxation exercises, and diversion of mind.

Most participants said that mostly God helped them to endure the difficulties of postdeath conditions and worship including praying and reading the Quran were the best way to control stress.

I was only talked to God, there was no one besides God that could help me, sometimes I was very upset and frustrated. I read the Quran and wept, I talked to God and got relaxed (P9).

DISCUSSION

This study documented the emotional and practical experiences of family caregivers of caring for their elderly relative with end-stage disease. These experiences were reported in the term of 4 categories and 13 subcategories. However, until now, EOL care has been associated with many weaknesses in providing high-quality health services in homes or hospitals.[21-25] The findings of our study also showed that caring for the relative with the end-stage disease at home was associated with the main strain and many challenges for family caregivers which indicate forgetting such an important phenomenon in our society.

Our findings are in line with other similar studies which indicated that providing EOL care to the elderly relative has a significant negative impact on the physical and emotional health of caregivers and family members.[21,26,27]

The first concept of our findings was committed to caring for the elderly relative with end-stage disease. Our findings showed that family caregivers were initially unable to admit it when faced with the late stage of their elderly disease and believed that their patients could get better.

Denying the late stage of the elderly person's disease caused more pain to the elderly patient because they turned to many diagnostic and therapeutic approaches to treatment that did not were effective. Wong and Chan (2007) showed that the family's main reaction to the diagnosis of the last stage of their elderly disease was angary, and most families' anger was directed at physicians because families initially believed that physicians initially failed to make the right diagnosis.[28]

Morasso *et al*. reported that family members suffer from psychological distress after being informed of the terminal stages of disease that makes them susceptible to depression.[26]

Our findings showed that families took care of the elderly relative, despite numerous challenges, such as the burden of caring for one caregiver and the lack of adequate support from other family members, which reflects the culture of the Iranian families when their loved one is going to die. Other studies also indicated that at the time of end-stage disease of an elderly, family devoted their days as giving care and recognizing it as an opportunity to be moreover with their elderly.[18,28] Findings from other similar studies also show that high levels of responsibility and sense of guilt in caregivers roused them to accept of caregiving role.[26,29,30]

Our participants reported that EOL care for elderly patients is typically imposed on a person in the family and other members handle their own affairs, which increases the burden of care. Morasso *et al*. concluded that the lack of support of other family members increases the physical and emotional burden of caring on one individual as a caregiver.[26,31] Another study revealed that some caregivers were tormented by the family members' disregard for the patient and were strained with care alone.[18]

We found that the caregivers leave all their time to care and put their work and education in the second priority. A study showed that participants spent most of their time caring and had to sacrifice their time and income on EOL care for the elderly relative because they had to take care of their patients all day long. Our study indicated that family caregivers could not get involved in economic activities and were under great financial pressure. Such difficulties in everyday life could exacerbate the strain of caring.[18]

The next concept extracted was the giving of care, which consisted of the subcategories of inefficient care, struggle for self-empowerment, and supporting. Concerning inefficient care, our findings showed that caregivers were lacked sufficient information and skills of caring, and thus, they felt disappointed in their care, which is similar to other studies.[26,32-34] Caregivers sought to empower themselves to cope with inefficient care by empowering themselves through trial and error, learning from professionals or nonprofessionals. A similar study showed that caregivers were committed to caring for their relatives and were eager to learn more about how to care perfectly.[18,26,28] With being and interacting with the patient, the family sought to provide more emotional and physical support to could meet the care needs of the patient which was consistent with other studies.[18,26]

As the severity of the disease worsened and complications developed, EOL care for the elderly became more difficult and complex, and family caregivers established more efforts to improve the patient's condition by transferring the patient to medical centers. However, because of the incurable nature of the disease, hospitalization was not very helpful for the patient's condition. As the patient's condition became more complex at the end stage of the disease, prescribing medications had no effect on relieving patient pain, so doctors were not prescribing medication more.

Caregivers became more anxious with increasing patient suffering, and despite efforts to ameliorate the patient's condition, the state continued to deteriorate.[21,26] As the caregivers saw the patient's growing suffering, families realized the treatment team's inability to relieve their elderly. As the situation worsens, they desperately wished for a comfortable death for the patient.

Other studies suggest that in such conditions, the situation is very difficult for both the patient and the caregiver. Therefore, from a family perspective, a comfortable death was the only possible way for the patient to be free from suffering, although they did not show such emotion to their patient.[21]

The findings of our study showed that caregivers were confusing, wandering, and helplessness as the patient's condition worsened which is in line with other studies. One study found that families were constantly frightened when their patient was going to die and many felt tired and guilty.[27] According to the findings of our study, participants in such conditions were in great need of support, while they were deprived of it. A study reported that caregivers and family members were fully instructed by the treatment team to could control such conditions. Communicating with caregivers about what to do before and after death is essential for caregivers.[35] An honest and formative relationship between the treatment team and the caregivers and family members could make family prepare for such situations,[35] Because families accept that there is no cure and therefore do not insist on improving the condition of the patient, they want their patient to experience only one comfortable death. The created challenges were stressful for caregivers. Previous researchers reported that caregivers had less attention to themselves and had a higher chance of developing insomnia, depression, and chronic disorders.[36] They wanted to be away from home for even a moment so could have some rest.[21,29,35-37]

The last subcategory of this concept was the perception of a supportive gap. The findings of our study showed that in our country, home care services, especially for patients at EOL have not been formally defined, implemented and covered by insurance, which in turn increases the burden on family caregivers. While in developed countries, caregivers benefit from home care services, they appreciated the nurses' inexpensive role in caring for their patients at home and found trust in the treatment team.[15] In those countries with social support for patients at the EOL, family caregivers have fewer burdens of caring.[38] One study found that families who received adequate support viewed care as a positive and meaningful experience.[33]

The last concept was the postdeath situation. That included the feeling of losing and unbelieving of the death with strain control.

The findings of our study showed that family members experienced a feeling of loss after their elderly death, which is in line with another similar study.[10,17] The feeling of loss happens to most families, especially the deceased's partner and it could be determined by interacting and not leaving family members alone.[26,33]

Our participants tried to control their stress through solutions such as crying and self-consolation and remembrance of God. Findings from other studies showed that participants with religion believed that God would relieve their pain and suffering and that they would be comforted by the belief that their patients would be returned to the embrace of God.[15] Participants felt comforted when they found that did their best to take care of their patients, and some participants were proud of giving their care, which gives some comfort.[18]

CONCLUSION

This study showed the values, attitudes, and beliefs of Iranian family's culture in caring for their relatives and families consider caring for a dear loved one as their moral duty. However, the lack of scientific and clinical skills needed for family care, community support networks, policies to promote nursing home care from dying patients, and insurance coverage for home care services have made it very challenging for family members to carry out home care. Therefore, given the growing population of elderly people with chronic diseases, there is a great and urgent need to develop strategies for assessing and enhancing the quality of EOL care of patients and decreasing the burden of stress and strain on their families.

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Conflicts of interest

There are no conflicts of interest.

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