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OPEN PEER REVIEW

Exploring the Lived Experiences of Family Caregivers Who Provided End-of-Life Care to Hemodialysis Patients: A Phenomenological Study in Iran

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About this report

This open peer review (OPR) report shows the public comments made on this article during peer review, by the reviewers, the associate editor and the editor-in-chief, for every revision round, together with the authors' replies. Comments appear only with the consent of the people who wrote them. Reviewers who chose to sign their report are named; the others are shown as "Referee". Comments are edited for language only, and confidential remarks to the editors are not included.

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1 Original submission

4 comments · 14 Jun 2024 – 16 Aug 2024

Zahra Gorjian Reviewer

MINOR REVISION 14 Jun 2024

Thank you for your valuable work. Some comments are provided to improve it.
1. In the methods section of the abstract, it is not necessary to mention the name of the city.

2. Please check your keywords with MeSH.

3. You need a better-structured introduction. I think you should start your introduction with hemodialysis and then present statistics on patients undergoing hemodialysis worldwide and in Iran. Then write about why these patients need care from their families.
At this stage, you can add your other content about caregivers.

4. In the methods section, you did not mention what software you used to analyze the interviews.

5. Before the conclusion, you need to write about the limitations of your study.
Your study has serious limitations that could change the results of the study.
Among other things, nothing was asked about the income level or economic status of the families. This issue can have significant effects on the experiences and the way patients are cared for.
Also, as seen in table number one, caregivers all have a low literacy level. Education can influence people's ability to care.

6. Reference number 4 should be rewritten based on the format of the journal.

Referee 1 Reviewer

MINOR REVISION 15 Aug 2024

1. What steps did you take to ensure rigor?
2. How was agreement on themes and codes reached?
3. In Table 2, the duration of each participant's interview should be mentioned.
4. In the themes and sub-themes, "challenge" should be removed and replaced with a more appropriate term. For example, use “complex care” instead of “care challenge”. Sub-themes should also be replaced by the appropriate term.

Associate Editor

MINOR REVISION 16 Aug 2024

Dear Author,
Thank you for submitting your manuscript to JJCDC. Based on our reviewers' comments, your article needs some revisions throughout. Please use previously published related articles in your references. I recommend you revise the manuscript and resubmit it as soon as possible.
With regards

Editor-in-Chief

MINOR REVISION 16 Aug 2024

Dear Author,
Thank you for submitting your manuscript to JJCDC. Based on our reviewers' comments, your article needs

some revisions in all sections. Please use previously published related articles in your references. I recommend you revise the manuscript and resubmit it as soon as possible.
With regards.

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Revision 1

AUTHORS' RESPONSE TO REVIEWERS

Authors' reply to reviewers

The next pages contain the authors' point-by-point reply to the comments of this revision round, as submitted with the revised manuscript. It is published as the authors wrote it.

Response to Reviewers

Journal: *Jundishapur Journal of Chronic Disease Care*

Manuscript ID: *149105*

Manuscript Title: *Exploring the lived experiences of family caregivers who provided end-of-life care to hemodialysis patients: A phenomenological study in Iran*

Dear Editor-in-Chief,

Thank you for your and reviewers' great efforts in evaluating and providing valuable suggestions to advance this article as best as possible. Our research team has reviewed the reviewers' comments and discussed them separately in the following tables. It is worth mentioning that every change made in response to the comments is highlighted in the revised manuscript.

Sincerely Yours

Response to Reviewer #1:

Reviewer #1	
COMMENTS	**AUTHORS' RESPONSE**
- Please check your Keywords with the MeSH database. It seems that the keywords need some revisions.	* The keywords were revised according to the MeSH database.
- The result of the abstract is poor. There should be more explanation about your findings in the results.	* Details regarding participants' demographic characteristics were included in the results section of the abstract.
- Please explain more about the necessities of your study in the introduction	* Further explanation on the necessity of the study was provided at the end of the introduction, as outlined below: "*The rise in life expectancy among chronic patients, advancements in science and technology, and significant limitations in kidney transplantation have contributed to the growing number of hemodialysis patients. This group's heavy reliance on family caregivers places a substantial burden on those providing care. To enhance caregivers' quality of life and address their daily challenges, it is crucial to thoroughly examine their experiences during the demanding process of caring for dying hemodialysis patients. While previous studies have primarily used quantitative methods with predefined questions, the deep emotions and experiences of individuals in such difficult situations can only be fully understood by investing time and immersing in their stories.*"
- In the last paragraph of the introduction, you cited reference 5 twice in two-sentence follow each other you should cite one time after the second sentence.	* The suggested change was made.
- Design of the study has not been explained clearly.	* Explanation on the design of the study was provided in the Study Design section, as outlined below: *"A qualitative descriptive-phenomenology research design, also referred to as Husserlian or transcendental phenomenology, was used to explore the lived experiences of family caregivers providing care for hemodialysis patients at the end of life . Descriptive-phenomenology research design*

	illustrates individuals' everyday life experiences, as well as the values of these experiences, as explained by those who live them (21)."
- You should explain the method section by section.	* The suggested change was made, as outlined below: *"After obtaining the necessary permissions from the relevant authorities, the researchers referred to the study settings. Eligible participants were selected through purposive sampling, with snowball sampling used if needed. Participants were then informed about the research objectives and methodology, and asked to sign the informed consent form.* *Data were collected through individual in-depth and semi-structured interviews conducted by an interviewer with a Ph.D. in critical care nursing. These interviews began with gathering participants' demographic information and then proceeded with a series of questions, including: "Tell me about your daily experiences caring for your patient", "In the form of a story, describe how you care for your patient at home and how you feel about it", and "In your opinion, what is the meaning of care in such circumstances?". To delve deeper, several probing questions such as "Can you give me an example?", "Do you mean that …?", and "How …?" were asked to explore participants' experiences further. At the end of each interview, participants were invited to share any additional thoughts or topics they wished to discuss.* *An interview was considered complete once participants had fully described their experiences and no further clarification was required. If necessary, a second interview was conducted to resolve any remaining ambiguities. After conducting 14 interviews, no new information, descriptions, or explanations emerged from the participants' responses. This lack of novel insights indicated that data saturation had been reached, leading to the conclusion of the data collection process.*

	It is worth noting that the interviews followed a predetermined protocol, which outlined guidelines for the interview process, the interview space, and the duration of the interviews, etc. This protocol ensured that all relevant topics were covered. Appointments were scheduled with participants a week in advance, and the interviews were conducted in person in a calm and stress-free environment within the hemodialysis centers. Each interview lasted between 30 and 45 minutes, was digitally recorded, and then transcribed verbatim for analysis."
- Your qualitative method analysis should be written step by step.	* The suggested change was made, as outlined below: *"1) Listing & Grouping: Our team began by thoroughly examining the interview transcripts, listing every significant expression related to the caregivers' experiences. In this step, we ensured that each statement was considered equally valuable.* *2) Reduction & elimination: We then applied rigorous criteria to evaluate the listed statements, eliminating those that were irrelevant, repetitive, or overlapping. We focused on retaining only the statements that were essential for understanding the phenomenon and that could be clearly and distinctly categorized.* *3) Clustering of Invariant Constituents: The remaining significant statements were grouped into themes, reflecting the core, invariant aspects of the caregivers' lived experiences. This step allowed us to organize the data into meaningful clusters that encapsulated key themes.* *4) Final Identification of Invariant Constituents: To ensure the accuracy of the identified themes, we verified their connection to the original data by cross-referencing each theme with the participants' actual responses. This process confirmed that our thematic analysis was grounded in the participants' authentic experiences.* *5) Construction of an Individual Textural Description: For each participant, we*

	developed a detailed textural description that captured "what" they experienced while providing end-of-life care. This description focused on the participants' perceptions, emotions, and interactions with the patients. *6) Construction of an Individual Structural Description: Next, we explored "how" the caregivers' experiences unfolded by examining the underlying context, such as the social, familial, and environmental conditions. This allowed us to understand the structural dynamics that shaped their caregiving roles.* *7) Synthesis of Composite Description: Finally, we synthesized the individual textural and structural descriptions into a comprehensive, composite description that reflected the shared essence of the caregivers' experiences. This synthesis allowed us to present a holistic view of the commonalities and differences across all participants (23).”*
- What was saturation in your sampling strategy; What are your inclusion criteria?	* Saturation was achieved, as outlined below” *“An interview was considered complete once participants had fully described their experiences and no further clarification was required. If necessary, a second interview was conducted to resolve any remaining ambiguities. After conducting 14 interviews, no new information, descriptions, or explanations emerged from the participants' responses. This lack of novel insights indicated that data saturation had been reached, leading to the conclusion of the data collection process.”* * The inclusion criteria, as outlined in the revised manuscript, were: *being at least 18 years old, expressing willingness to participate, being directly responsible for the care of a patient at the end of life, and having verbal communication skills.*
- How do you control the confidentiality of participants especially?	* As stated in the revised manuscript, to ensure the confidentiality of participants, they were told that their data would be used solely for academic purposes and that their identities would remain confidential. To ensure this, the researcher employed codes to present the data.
- What approach that the researcher use for the	* As stated in the revised manuscript, in this

qualitative study? Is it an In-depth interview or a focus group discussion? What protocol that the researcher follow for an in-depth interview for example (I suggest looking into the following paper: Ryan, F., Coughlan, M., & Cronin, P. (2009). Interviewing in qualitative research: The one-to-one interview. International Journal of Therapy and Rehabilitation, 16(6), 309-314. doi:10.12968/ijtr.2009.16.6.42433).	study, data were collected through individual in-depth and semi-structured interviews conducted by an interviewer with a Ph.D. in critical care nursing. * The interviews followed a predetermined protocol, which outlined guidelines for the interview process, the interview space, and the duration of the interviews, etc. This protocol ensured that all relevant topics were covered. Appointments were scheduled with participants a week in advance, and the interviews were conducted in person in a calm and stress-free environment within the hemodialysis centers. Each interview lasted between 30 and 45 minutes, was digitally recorded, and then transcribed verbatim for analysis.
- How did the researcher conduct the interview? Online? If yes, using what platform? Have you communicated with the link (e.g., WhatsApp, email)? Or did you conduct the physical face-to-face interview? If yes, then how do you arrange the appointment? Where did you conduct the interview (at the participant's home, at the researcher's institution)? What are the safety precautions measures available?	* As stated in the revised manuscript, in this study, interviews were conducted in person, and in a calm and stress-free environment within the hemodialysis centers. Appointments were scheduled with participants a week in advance. * During various phases of the study, several precautionary measures were implemented, as detailed in different sections. For instance, participants were notified about their appointments a week in advance, and the interviews were held in person at hemodialysis centers, ensuring a calm and stress-free environment.
- Why didn't you maximum vibration in your participants?	* In response to this question regarding the maximum variation in participant selection, efforts were made to ensure diversity by selecting participants from two major referral hemodialysis centers in Qazvin city—Velayat and Booali Sina hospitals. These centers serve a broad patient population, and we aimed to include participants from different demographic and socio-economic backgrounds. However, the participant pool was ultimately limited by the availability of family caregivers who met the study's specific inclusion criteria.
- You mentioned about credibility and reliability of the data however you just briefly	* As stated in the revised manuscript, To establish the reliability and validity, the

told (e.g. two faculty members to receive their opinions, expanding the size). Please be explicit. Please refer to the following reading material: Korstjens, I., & Moser, A. (2018). Series: Practical guidance to qualitative research. Part 4: Trustworthiness and publishing. European Journal of General Practice, 24(1), 120-124. doi:10.1080/13814788.2017.1375092.	Lincoln & Guba's criteria, including credibility, dependability, confirmability, transferability, and reflexivity, were used (23). Credibility was achieved through prolonged engagement with the participants, and peer debriefing. Dependability was achieved through writing a quick copy, considering colleagues' opinions, and re-reading the whole data. Confirmability was achieved through time combination and a variety of sampling in participants. Transferability was supported by detailed descriptions of context and participants' experiences. Reflexivity was ensured by accurately reflecting participants' lived experiences and presenting diverse perspectives (24).
- There are some spelling and grammatical errors in the text. Please correct them.	* The suggested change was made.
- Please mention the limitations and strong points of your study.	* The suggested change was made, as outlined below: *“One of the primary strengths of this study is its in-depth qualitative approach, which offers a comprehensive understanding of the complex challenges faced by family caregivers. By conducting detailed, phenomenological interviews, the researchers were able to immerse themselves in the caregivers’ experiences, providing rich, nuanced insights that go beyond what is typically captured through quantitative studies with predefined questions. This methodological approach allows for a deeper exploration of the challenges faced by caregivers, offering valuable perspectives that contribute to a more complete understanding of end-of-life care.* *A notable limitation of this study is that some participants may not have fully expressed their experiences due to personal reasons, despite the researcher’s efforts to build trust and communicate effectively. Additionally, the study had a lower representation of male participants compared to female participants, which may affect the generalizability of the findings. Future research should aim to include a more balanced representation of*

	both genders. Another limitation is the lower educational level of many participants, which may influence their caregiving abilities and perceptions. Future studies could explore how educational interventions might impact caregiving practices and experiences."
- Is there any novelty in your study? Please describe it in the discussion.	* The suggested change was made, as outlined below: *"Its novelty lies in its in-depth exploration of the lived experiences of family caregivers providing end-of-life care to hemodialysis patients in Iran. This study offers fresh insights into the challenges faced by caregivers, which have not been extensively documented in the existing literature. By capturing these real-life experiences through a phenomenological lens, the research provides a deeper understanding of the unique needs and struggles of caregivers. These findings can directly inform the development of targeted educational and psychological support programs, filling a critical gap in current end-of-life care strategies and enhancing the effectiveness of interventions tailored to the specific context of home caregiving in Iran."*

Response to Reviewer #2:

Reviewer #2	
COMMENTS	**AUTHORS' RESPONSE**
- In the method of abstract, it is not necessary to mention the name of the city.	* The name of the city was omitted.
Please check your keywords with Mesh.	* The keywords were revised according to the MeSH database.
- You need a better structured introduction. I think you should start your introduction with hemodialysis and then go to the statistics of patients undergoing hemodialysis in the world and Iran. Then write about why these patients need the care of their family? At this stage, you can add your other content about caregivers.	* The suggested change was made.
- In method, you did not mention what software you used to analyze the interviews.	* As outlined in the revised manuscript, given the study involved a total of 14 interviews, and all stages of the interviews, implementation, and analysis were conducted by the main researchers, there was no need for auxiliary software for data analysis; the analysis was performed manually. The research team held frequent meetings to discuss and analyze the written texts and interview content, ensuring a shared understanding and accurate extraction of codes and main themes. Through this thorough process, 184 key statements were identified and analyzed.
- Before conclusion, you need to write about limitations of your study. Your study has serious limitations that could change the results of the study. - Also, as seen in table number one, caregivers all have a low literacy level. Education can influence people's ability to care.	* The suggested change was made, as outlined below: *"A notable limitation of this study is that some participants may not have fully expressed their experiences due to personal reasons, despite the researcher's efforts to build trust and communicate effectively. Additionally, the study had a lower representation of male participants compared to female participants, which may affect the generalizability of the findings. Future research should aim to include a more balanced representation of both genders. Another limitation is the lower educational level of many participants, which may influence their caregiving abilities and perceptions. Future studies could explore how educational interventions might impact*

- Among other things, nothing was asked about the income level or economic status of the families. This issue can have significant effects on the experiences and the way patients are cared for.	*caregiving practices and experiences."* * In response to the comment about not inquiring into the income level or economic status of families, we intentionally chose not to include these questions in our study. Based on our extensive experience with hemodialysis patients and caregivers, we found that individuals often either underestimate or overestimate their socioeconomic status, which can result in inaccurate or misleading data. Instead, we focused on capturing the lived experiences of caregivers without the potential bias that socioeconomic self-reporting might introduce. Nonetheless, we acknowledge the potential influence of economic factors and recommend future studies to explore this aspect using more objective measures.
- Reference number 4 should be rewritten based on the format of the journal.	* Since the introduction was revised, the mentioned reference was omitted.

Response to Reviewer #3:

Reviewer #3	
COMMENTS	**AUTHORS' RESPONSE**
- What steps did you take for rigor?	* As stated in the revised manuscript, To establish the reliability and validity, the Lincoln & Guba's criteria, including credibility, dependability, confirmability, transferability, and reflexivity, were used (23). Credibility was achieved through prolonged engagement with the participants, and peer debriefing. Dependability was achieved through writing a quick copy, considering colleagues' opinions, and re-reading the whole data. Confirmability was achieved through time combination and a variety of sampling in participants. Transferability was supported by detailed descriptions of context and participants' experiences. Reflexivity was ensured by accurately reflecting participants' lived experiences and presenting diverse perspectives (24).
- How was the agreement about themes and codes made?	* As outlined in the revised manuscript, the research team held frequent meetings to discuss and analyze the written texts and interview content, ensuring a shared understanding and accurate extraction of codes and main themes. Through this thorough process, 184 key statements were identified and analyzed.
In Table 2, the duration of the interview of each participant should be mentioned.	* The suggested change was made.
In themes and sub-themes, "challenge" should be removed and replaced with a more appropriate term. For example, use "complex care" instead of "care challenge". Sub-themes should also be replaced by the appropriate term.	* The suggested change was made.

2 Revision 1

3 comments · 18 Sep 2024 – 18 Sep 2024

Referee 2 Reviewer

ACCEPT 18 Sep 2024

Dear Author,
All comments have been made, and the current version of this manuscript is acceptable for publication.
Thank you

Associate Editor

ACCEPT 18 Sep 2024

Dear Author,
All corrections are acceptable.
Thanks

Editor-in-Chief

ACCEPT 18 Sep 2024

Dear Author,
This manuscript is acceptable.
Thank you