

Experiences of the family caregiver of a person undergoing hemodialysis

Abstract

The existing literature on family caregivers recognizes the importance of promoting their well-being, as this immediately influences the care they provide to the patient. Therefore, these informal caregivers are a concern for nurses, from the perspective of caring for the caregiver. With the aim of describing the reality they feel and express, how they perceive their role, their feelings and expectations, and the consequent influence on the care they provide, an exploratory, descriptive, and cross-sectional study was developed, based on the qualitative paradigm and with a phenomenological orientation. It was concluded that the participants' experiences are individual realities that affect various dimensions in the lives of caregivers and consequently the patient. Therefore, nursing interventions should be structured to respond to these family members, partners in caring for the person undergoing hemodialysis, as a way to obtain better care for the patient, but also from a perspective of promoting health and better well-being of the caregiver who cares.

Keywords: caregiver, nursing, family member, hemodialysis, experiences

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Introduction

The perspective of care advocates for the humanization of care not only for the user/patient, but also for their family members^{1,2} With the aging population and the increase in chronic diseases, the involvement of family members as partners in care is increasingly necessary.³ The onset of a disease such as Chronic Kidney Disease (CKD) and the need for hemodialysis in a family member generates an impact on family caregivers that may influence the provision of care.⁴ The existing literature on family caregivers recognizes the importance of promoting their well-being, since this immediately influences the care they provide to the patient. In this way, these informal caregivers present themselves as a concern for nurses, from a perspective of caring for those who care. With the aim of describing the reality as felt and expressed by family caregivers, how they perceive their role, their feelings and expectations, and the consequent influence on the care they provide, an exploratory, descriptive, and cross-sectional study was developed, based on the qualitative paradigm and with a phenomenological orientation. Seven family caregivers of individuals undergoing hemodialysis at a hospital participated. Data collection was carried out through semi-structured interviews, recorded using an audio system, followed by transcription and content analysis according to Bardin. Ethical procedures inherent to the research process were taken into account. Eleven categories emerged, encompassing content such as: reason for being a caregiver, care provided, existence and type of support in caregiving, difficulties and needs presented, feelings expressed, strategies adopted and future perspectives, support provided by nurses, and expectations regarding the role of these professionals. It was concluded that the participants' experiences are individual realities that affect various dimensions of the caregivers' lives and, consequently, the patient's lives. Therefore, nursing interventions should be structured to respond to these family members, partners in caring for the person undergoing hemodialysis, as a way to obtain better care for the patient, but also from a perspective of promoting the health and well-being of the caregiver.

Objectives

To describe the caregiving context and experiences of family caregivers of people undergoing hemodialysis/ To describe the needs of family caregivers inherent in caring for people undergoing hemodialysis/ To describe how family caregivers of people undergoing hemodialysis overcome difficulties/ To describe the expectations of family caregivers of people undergoing hemodialysis regarding the support of nurses.

Methodology

Qualitative research, exploratory, descriptive and cross-sectional study, with a phenomenological orientation and content analysis according to Bardin. The data collection technique used was the semi-structured interview. All ethical procedures were ensured.

Results

The convenience sample obtained sequentially consisted of 7 participants with an average age of 65 years, of which 4 were female and 3 were male; 6 were married and 1 divorced; 3 had completed the first cycle of basic education, 1 the second cycle of basic education, and 3 secondary education; 3 were retired, 3 were employed, and 1 reported having domestic activity; 4 were spouses and 3 were daughters; 4 were non-practicing Catholics, 1 was a practicing Catholic, 1 was an atheist, and 1 belonged to a Christian congregation. The average duration of the caregiver role was 9 years, and the average age of people undergoing hemodialysis was 76 years.

Eleven categories emerged: reason for being a caregiver, care provided, existence and type of support in caregiving, difficulties and needs, feelings expressed, strategies adopted, future perspectives, expectations regarding the role of nurses, with varied and sustained units emerging from these categories.

The results showed that they are caregivers due to:

obligation	"(...) I started taking care of her because I have an obligation to do so. (...)"
reciprocity	"(...) my mother treated us well since we were little (...)"
inevitability	"(...) since I am retired, it's me...I have free time (...)"
financial	"(...) I feel it's cheaper for me (...)"

These family members provide care related to instrumental activities such as:

hygiene	"(...) bathing him...changing his diaper (...)"
feeding	"(...) feeding him...I make food separately...it has to be like that (...)"
comfort	"(...) putting him in bed, taking off his clothes...putting him in bed so he can rest and feel better (...)"
presence	"(...) I'm always permanently, always by his side. Always, always, night and day, night and day (...); (...) And I stay there, tied up, for whatever is needed. If it's needed I'm there, if it's not I'm there too (...)"

They mention some support from other family members:

Household chores	"(...) On Saturdays he goes there and does the little things. He buys the gas bottle...whatever is needed in the house (...)"
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They express difficulties such as:

Diversity of roles	"(...) I...study...work, I go to study...I go to my father's every day...I just wish the day was a little longer (...)"
Physical demands	"(...) she already has a lot of trouble lifting and the weight, I can't lift heavy things anymore either (...)"

They express feelings such as:

revolt	"(...) In the morning I would get up and go out the door...Now I feel trapped, tied up, tied up, tied up...I never thought we would get to this. I am revolted by the situation (...)"
loneliness	"(...) I don't confide in anyone (...)"
resignation	"(...) If it weren't for this treatment, I would have already died...We have to endure it (...)"
satisfaction	"(...) it seems to me that I am still useful for something...that's the gratification I have(...)"
pride in caring	"(...) I think my mother is a strong woman...she doesn't say a word, she doesn't complain...it must be to protect us (...)"

To overcome the situation, they resort to:

life experiences	"(...) it's normal for me to act like this...I always find a solution for everything...As problems arise, I have to solve them (...)"
spiritual support	"(...) I have a lot of faith...HE helps me with everything...so much so that I have strength and I do everything...It's a power that I can't calculate (...)"
psychiatric support	"(...) I have a psychiatrist...she is helping me (...)"

They need:

social support	"(...) so I don't have any friends either (...)"
spiritual support	"(...) I confide in Him...I talk to my Jesus...that church is wonderful there (...)"

They describe their perspectives on the future as follows:

Fear of getting sick	"(...) May God give me health and strength to be alive and take care of her (...)"
Fear of losing a sick family member	"(...) When my mother dies, I know I will fall apart (...)"
Uncertainty	"(...) Dark...Financially, everything. If he dies, what will become of me? I've never worked...And we don't have help from anywhere...I want to help my children and I can't (...)"

How they recognize the care provided:

Good	"(...)“(t“(...) They treat her well and take care of her...I feel that she is being very well cared for.They are good supports (...)"
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They express the desire for:

s u p p o r t ,
a s s i s t a n c e ,
c o m m u n i c a t i o n
a n d i n f o r m a t i o n
f r o m n u r s e s

“(…)“(…) there should be more support... it's good for the family to also be there and supported by the nurses and everything (...)”,“(…) during the time that family members are waiting... to bring them together and talk to them... all family members are experiencing the same thing (...)”

Conclusion

Home care is a challenge that family caregivers must address, as their experiences will determine the care they provide, as well as their own well-being. Given the expressed desire for more attention from nurses, there should be greater investment in the family caregiver-nurse relationship to enhance their capabilities, prevent burnout, and promote their health. This reflects the urgent need for behavioral change, ensuring that caregivers are not left uncared for. Therefore, it is proposed that greater investment be made in the family caregiver-nurse relationship, with more structured and appropriate information, group meetings for sharing experiences and group dynamics that strengthen the caregiver role, and psychotherapeutic interventions to improve well-being (helping relationship, active listening, relaxation).

Acknowledgments

None.

Conflicts of interest

The author declares there is no conflict of interest.

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