

'The point is family involvement on caring cardiac patient' lived experience nurses and family caregivers on collaboration in Indonesian Hospital Care: A phenomenology study

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Abstract

Background: Chronic diseases including heart disease have a significant impact due to demographic shifting, especially in low-mid income countries like Indonesia. Nurses have vital roles on chronic disease management, such as prevention, early detection, and effective treatment. However, the global nurse's shortage poses a challenge for healthcare collaboration nowadays.

Purpose: To explore the experience of collaboration between nurses and family caregivers in disease patients in an Indonesian hospital.

Methods: A phenomenological approach in qualitative study was applied in this study. The data collection involved eight semi-structured interviews with PKU Muhammadiyah Gamping hospital nurses in Yogyakarta, Indonesia. Data was analysed thematically, using six steps from Braun and Clarke and Atlas.ti software.

Results: Data analysis revealed four themes: (1) Nurse's role and tasks; (2) Family caregiver roles & tasks; (3) Positive impacts collaboration with family; and (4) Negative impacts collaboration with family.

Conclusion: The family caregiver's role during patient hospitalization primarily involves assisting with activities of daily living (ADL) and participating in family-focused education for discharge planning. Nurses highlight the significance of family engagement in monitoring fluid balance, supported by guidance on recording intake and output. Although errors may occur, caregivers believe that their involvement results in improved patient outcomes, such as enhanced calmness and adherence to treatment.

Keywords: family integrated care; family engagement; healthcare collaboration; collaboration on nurse-family caregiver

Introduction

Globally, aging population is very rapidly when compared to the younger group where significant growth is in individuals aged 65 and above, which is projected to increase faster from 10% in 2022 to 16% by 2050 (United Nations Department of Economic and Social Affairs Population Division, 2022). Ageing causes progressive tissue damage that negatively impacts on vital organs, making it a significant risk factors for chronic diseases, particularly ischemic heart disease (Guo et al., 2022; World Health Organization, 2020a). In the upcoming decades, hospital employees will have more workload due to an aging population and a rise in chronic illness.

World Health Organization Global Status Report that chronic disease are on the rise and their impact is uneven, especially countries with low- and middle-incomes, where almost 75% of chronic disease-related global deaths (World Health Organization, 2025). Significant demographic and

epidemiological changes have occurred in Indonesia in recent decades, making it the third most populous low-mid income country after China and India. It is estimated that a quarter will be 65 of age and older by 2070, potentially increasing the threat of chronic disease (Marthias et al., 2021).

Early detection, screening, efficient treatment and preserving access to palliative care are all essential components of management chronic diseases (World Health Organization, 2025). In a patient-centered healthcare system, nurses are crucial in play assisting people in changing their lifestyle to live long, happy and healthy life. However, they present significant obstacles due to nurses shortage globally, which hinders collaborative and inhibits efforts in disease to prevention and health promotion (International Council of Nurses, 2024). The differences in nursing duties between nations highlight how crucial it is to modify healthcare planning in order to maximize nurses' contributions to population health objectives (World Health Organization, 2020b).

The Netherlands is addressing the shortage of nurses by involving families in patient care. The Bachelor of Nursing 2030 framework highlights the importance of collaborative care and family engagement (van Merode et al., 2024). However, a research reveals that family involvement in patient files research is still limited (Hagedoorn et al., 2021). Another study shows that Dutch focus more on involving families in information gathering and discharge preparation, as well as emphasizing the role in the care process, but they are less involving in providing active care (Woldring et al., 2023). These findings suggest that the role and support of family in hospital care in the Netherlands is less reflected in the behavior of nurses, in contrast to Eastern countries where family involvement is more integrated in care practices (Park et al., 2022).

Gotong Royong, an Indonesian cultural principle that dates back to 117-45 B.C, emphasizes mutual help among community members, as well as reflecting cohesion, solidarity and togetherness (Nelson, 2024; Simarmata et al., 2020). The ethos of care in Indonesia includes volunteering in caring for sick families and communities, both at the home and in hospitals, in contract to Western countries where such care is not always expected (Widayanti et al., 2020). Families, including caregivers, have an important role to play in supporting stroke survivors in Java, where Javanese proverbs are very influential (Purdani & Rungreangkulkij, 2024).

Considering that family engagement is a cultural standard and value in Indonesia, and there are limitations in documentation of family involvement in patient files as well, this research seeks to explore the collaboration between family members and professional caregivers (nurses) within the healthcare process on the cardiac units in Indonesian hospitals.

Materials and Methods

Design

The study uses phenomenological approach to explore the various personal experiences of nurses. Qualitative design was chosen due to allow for an in-depth dive into participants' individual experiences, arguments, and motives (Verhoeven, 2022).

Participants and Setting

The research focused on nurses in the cardiac unit at PKU Muhammadiyah Gamping hospital in Yogyakarta, Indonesia selected for their roles due to the high fatality of ischemic heart disease and their frequent interactions with family caregivers. No relationship between the researchers and participants.

Recruitment

Theoretical sampling was determined in advance. The number of participants was determined based on data saturation to ensure comprehensive exploration and understanding of the phenomenon. Data saturation refers to the point in qualitative research where new data ceases to provide additional insights or information relevant to the research question (Verhoeven, 2022). Data saturation was chosen, because it provides the researchers with a complete set of data that can be analyzed to draw necessary conclusions (Saunders et al., 2018). After eight interviews from one hospital, data saturation on the major subjects was reached, and no further insights could be found.

Inclusion and exclusion criteria

This study's inclusion criteria were focused on nurses regularly employed at a cardiac unit, as their experiences are most relevant and specific. Flex workers from other departments were excluded to avoid incorporating unrelated experiences. To improve outcome reliability, nurses with less than a year of experience on the cardiac unit were excluded from the study since they require support during their transition period to a new work environment. This criterion ensures that participants have sufficient experience as professional nurse.

Data collection instrument

The researchers are the tool used in qualitative research. Semi-structured interviews guidance was used to gather data. Beside this, the researcher also provide field note to capture participants behaviour in the natural contexts. It is promoting participant input while permitting flexibility with predetermined questions. The researchers, an Indonesian interpreter, and a participant attended each interview, which focused on how nurses and family caregivers divided up the workload. The main ideas discussed were cooperative roles and patient problems. This study additionally explored the reasons behind of current role divisions, emphasizing the issues, unfulfilled needs, and

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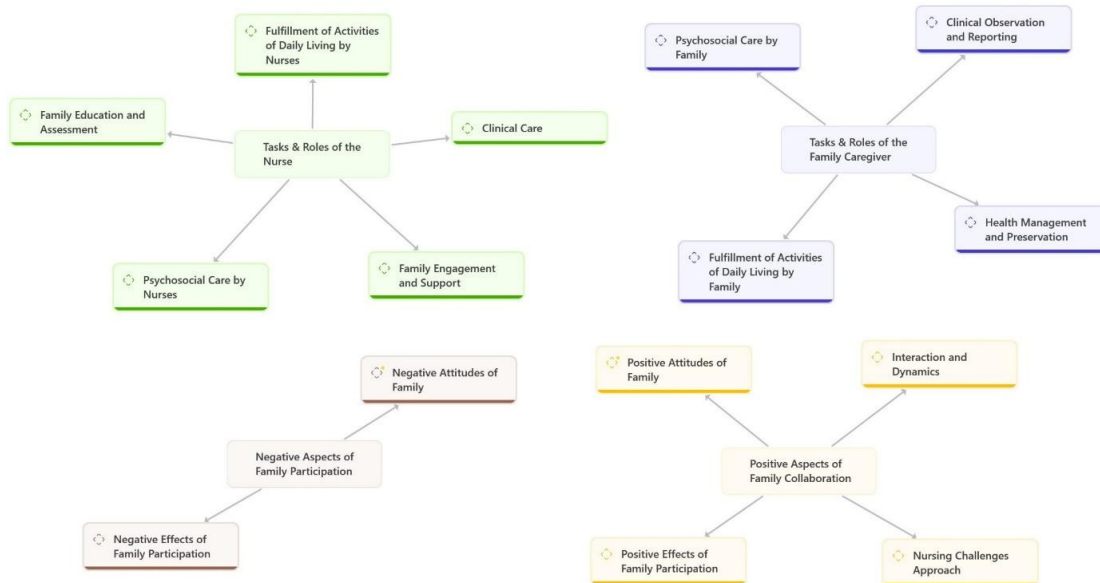


Figure 1. Thematic analysis process

expectations of nurses, as well as their interactions with patients and the surrounding environment.

Collecting the data

Within a period of two and a half weeks, both researchers conducted interviews concurrently. The data collection involved Indonesian interviewer with the qualification of professional nurses who experience in clinical area and qualitative research with PhD degree and fluent in English. In order to reduce the possibility of misunderstandings and lost meanings during translation, the interviewer has a role as an interpreter due to most of the participants speak in Indonesian language. The interviews took place in a quiet, private area in the hospital and lasted between 45 to 60 minutes. Minor disturbances during interview such as the adhān (Islamic calls to prayer) and participant's phone ringing. After the eighth participant, data has reached saturation.

Translation Processes

The researcher conducted meeting to make same perception with Indonesian interviewer. Furthermore, the English interview guideline was translated into Indonesian language then it was tested into two nurses for gain the understanding of the list of questions, deepen of the question, and developing the probing. After the interview guideline revision, data collection was applied to all the participants using Indonesian language. The researchers individually recorded and transcribed in English. Since numerous participants statements were incompletely mentioned during the interviews, the interpreter was supplied the audio recordings for additional translations.

Data analysis

The interviews were subjected to a six-step process

(Braun & Clarke, 2022) for thematic analysis in order to interpret the results and address the research question: (1) familiarization with data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) writing the report. Researchers initially familiarized themselves with the data by reviewing interview transcripts to identify key details. During the second step, Atlas.ti software was used to generate initial codes. In the third step, significant patterns were collated to identify broader themes. Fourth step is the reviewing of themes entailed eliminating unrelated ones and conforming their credibility. Four main themes and 15 subthemes were ultimately defined and named in the step fifth. Lastly, the process concluded with writing a report that emphasizes meaningful data interpretation and connects findings to existing literature while ensuring methodological transparency.

Trustworthiness

In this study, criteria for ensuring trustworthiness known as rigor recently that included reliability/dependability, validity/credibility, and generalizability/transferability (Kakar et al., 2023). Validity was ensured through observation of facial expression, member-checking with participants and peer the briefing with the supervisors. Generalizability was ensured through detailed descriptions of study settings, methods and participants. Reliability was enhanced through member-checking and using Atlas.ti's software for storage and manage the data. Lastly, conformability was ensured using double devices for audio recording through mobile phone and recorder. The researchers followed COREQ (Consolidated Criteria for Reporting Qualitative) study (Tong et al., 2007).

Ethical consideration

The PKU Muhammadiyah Gamping Hospital review board has granted ethical approval for this study (No. 087/KEP-PKU/IV/2024). All participants provide written consent prior to data collection and can withdraw at any time if they feel uncomfortable. The confidentiality and anonymity of data collection were also explained to the participants. Participants are required to sign an consent from prior to the interview, which includes the purpose, the rights of participants, how personal data is used, and other conditions that must be agreed.

Results

Finding analysis broke down the nurses' perspectives on collaborating with family caregivers in cardiac unit care into four main themes and 15 subthemes (Figure 1).

Theme 1: Nurse's role & tasks

Subtheme 1.1 Nurses' completion of activities of daily living

Participants shared diverse views on their daily ward tasks, noting that the integration of Activities of Daily Living (ADL) into nursing varies by department, patient type, and family involvement. Family members often assist with ADL when available, while nurses assume full care responsibilities for VIP admissions, ICCU patients, and those requiring total care.

Subtheme 1.2 Clinical care

Participants indicated that clinical care mainly consists of preparing and administering oral and injectable medications in the morning, including teaching families to self-administer insulin. Pain management incorporates relaxation techniques, while other responsibilities involve interventions and assessments related to cardiac disease, such as performing ECGs and monitoring vital signs.

Subtheme 1.3 Family education and assessment

Participants emphasize their educational roles while engaging in patient-centered activities, dedicating time to teach family caregivers, particularly focusing on older patients. Education includes a variety of instructional activities relevant to daily living, mobilization, and monitoring fluid charts, with the goal of enhancing self-reliance after discharge and minimizing readmission risks. Participants also gather insights about the patient's home environment to offer tailored advice for ongoing care at home, addressing essential aspects like lifestyle changes, disease management, and caregiving practices.

"At this time, perhaps we really have to make patients and families independent, so when the patient is able to carry out activities and the family can also help. I think the family and patient can coordinate to do that. So, not all nurses, but we

educate how families and patients can do that." – Participant 2

Subtheme 1.4 Family engagement and support

Participants highlight the importance of collaborating with family caregivers and involving the family in care, focusing on post-discharge self-reliance. Nurses often ask patients which family member they prefer for care, leading to trust training for both the patient and the selected family member. Additionally, some participants take on a mediating role during conflicts between patients and caregivers.

"I think it's (family involvement) important, because when we take care of the patient, it's not just about the patient. We take care of the family. The family can take care of the patient when the patient forgets about the medication, the food, the life. So, besides in the hospital, the family is very important when at home, it's a very important role." – Participant 2.

Subtheme 1.5 Psychosocial care by nurses

Participants highlight the use of psycho social care in various situations, especially for recovering patients who may experience frustration due to limitations, such as restrictions on straining. Caregivers focus on calming these patients, as they tend to express frustration towards family caregivers. This calming approach is also applied in cases of pain and discomfort. Furthermore, RS PKU Gamping provides spiritual care, allowing patients to pray according to their own beliefs, regardless of the hospital's Islamic affiliation.

Theme 2: Family caregiver roles & tasks

Subtheme 2.1 Family's completion of activities of daily living

Family caregivers play an essential role in assisting patients with activities of daily living (ADL), particularly when patients are not bedridden. They often take on responsibilities such as bathing, feeding, and mobilizing patients. Some patients express a preference for receiving care from family members over nurses. Additionally, family caregivers may also administer oral medications prescribed by nurses and verify medication administration.

Subtheme 2.2 Clinical observation and reporting

Participants reported that the family caregiver was given guidance to maintain fluid balance and the nurse explained fluid intake limits for patients. In addition to monitoring intake and discharge, fluids, families also monitored the status of intravenous infusions, just as one participant had reported. Two participants reported their observations to the nursing staff in both different scenarios.

Subtheme 2.3 Psychosocial care by family

Family caregivers play a crucial role in patient care, helping to calm patients during pain or discomfort and enhancing their independence in managing

complications. The absence of sufficient nursing staff and overwhelming workloads accentuates the importance of family caregivers in supporting patient care.

"The point is that if there is a family involved, he will be calmer about his readiness. Like that. It's different if they don't get involved, for example if they have chest pain, you'll (the patient) definitely be scared." – Participant 4.

Subtheme 2.4 Health management and preservation

As mentioned earlier, significant time is dedicated to preparing family caregivers for post-discharge care, which includes supervising the patient's lifestyle, medication, and safety. Caregivers are also guided to limit harmful behaviors. Participants observed that patients with family support have fewer readmissions, attributed to factors like intrinsic motivation and medication adherence. Thus, family members not only supervise but also provide crucial encouragement. Forgetfulness and other age-related ailments also contribute to the importance of family participation.

"There are some patients whose families care so much that the medicine is packaged in small pieces, given a date, given the time, and it is confirmed whether the medicine will be taken or not. While being reminded, at this time it's time to eat, it's time for snacks." – Participant 5

Theme 3: Positive impacts of collaboration with family

Subtheme 3.1 Interaction and dynamics

Participants noted that families play a crucial role in bridging communication gaps for elderly patients in the cardiac ward, who may show signs of senility. These patients tend to comply more with family members than with nursing staff and prefer family involvement in their care.

"That's where we start to play our role in how to include the family. Sometimes we ask the family to convey it to the patient, uh... in family language." – Participant 1

Subtheme 3.2 Nursing challenges approach

The participants underline how important family engagement is because the heavy workload makes it impossible to give patients the care and attention they require. They determined that the main causes of this heavy workload were the scarcity of nurses, the numerous responsibilities they have to perform because there isn't enough administrative staff, and the excessive volume of paperwork. The participants stated that without family engagement, handling the matter would become a "hassle".

"Taking care of patients who will be going home, entering visits, we document them in the EMR, visiting doctors sometimes 3 at the same time, so it's like... It seems like we have to divide ourselves, face everything." – Participant 5

Subtheme 3.3 Positive attitudes of family

The positive attitude of the family caregiver that has been conveyed by the participants focuses on the motivation to take care of the sick member. One participant noted that caregivers are allowed to take on assignments if they are willing. In addition, other participants also revealed that nurses feel happy when providing family-applied nursing education. In addition, other participants also said that caregivers also often help other patients even though they do not know the patient in situations where the patient has no family relatives to take care of them.

"For VIP, usually most of the nurses do the action, but for class 3, 'I'll just do it' because they have been given education or given an example." – Participant 6

Subtheme 3.4 Positive effects of family participation

Family presence significantly supports patient recovery, as participants noted that patients retain their autonomy despite family involvement. Participants expressed positive views on this involvement, stating it aids nurses and contributes to a calmer environment. The lack of family caregivers negatively impacts outcomes, leading to slower recovery and higher readmission risks.

"When an elderly patient has family, he will use good medicine, and for other things he is good, so re-hospitalization usually rarely happens." – Participant 2

"If we can collaborate with the family, InsyaAllah (God willing – Islamic terms) it will be easier." – Participant 4

Theme 4: Negative impacts of collaboration with family

Subtheme 4.1 Negative attitude of family

Some participants observed that family members may occasionally refuse to assist in patient care, believing it to be the nurses' responsibility or due to a lack of awareness about the patient's condition. Nurses often try to encourage family involvement, but frustration can arise when family members, especially distant relatives, feel detached from the responsibility of care. This reluctance is notably prevalent among families of VIP patients. Furthermore, impatience from family members can lead to demands for immediate medical action, such as questioning why a patient remains in pain despite medication administration.

"If you do good to your parents, insyaAllah, your children will do good to you" – Participant 4

"In terms of feelings, sometimes there are feelings of anger, annoyance, but sometimes it's human. Well, then, it disappears. At least 'nggondok' (holding back anger – Javanese) in the pantry, right?" – Participant 4

Subtheme 4.2 Negative Effects of Family Participation

Family participation in patient care can negatively impact treatment due to errors made by relatives, such as feeding patients post-surgery against protocol or failing to monitor fluid balances. Family members may withhold information from nurses and suggest alternative remedies that conflict with standard treatments. Some relatives also lack motivation to assist in care, believing it is the nurses' responsibility. This lack of engagement is often more prominent among distant relatives of VIP patients. Additionally, families can exhibit impatience, pressuring healthcare staff for care updates even when treatment is ongoing.

A negative impact on nurses is that family members overhear their conversations, hindering open communication. This is tied to the department's layout. Furthermore, nurses' privacy is compromised when family members take photos during procedures, causing discomfort. The presence of family members may also infringe on patient privacy.

"Sometimes not all patient families are honest about what their illness is, sometimes the family says 'don't tell them that'." – Participant 7

Discussion

The study focused on understanding the duties and responsibilities of caregivers and family caregivers, with findings that are in line with other studies on the function of the family caregivers. Study findings align with those of the other study, particularly in terms of the roles undertaken by family caregivers (Park et al., 2022). The main difference from two studies lies in the perception of education, with this study emphasizing the importance of family caregiver education, which contributes to a decrease in readmissions. The Park et al. study was conducted in a district level hospital, whereas PKU Muhammadiyah is a provincial hospital, hence differences at the hospital level may account for the discrepancy in this finding. In addition, although it involved nurses and family caregivers, Park et al.'s study focused only on caregivers, so a lack of input from family caregivers could lead to bias in outcomes.

Important findings suggest that the engagement of family members in monitoring the fluid balance of heart patients is crucial. Participants indicated that family support helped maintain the accuracy of fluid balance graphs, given the challenges nurses faced in this task, which was supported by the Leinum et al. study (Leinum et al., 2023). A systematic review revealed the quality of fluid balance monitoring in medical, surgical, and intensive care units, found that the personnel, time, and training shortages frequently result in incomplete mapping data. Half of the studies showed less than 50% of fluid balance graphs were completed accurately, presenting challenges in fluid balance documentation. Correct documentation is critical to clinical decisions and

patient safety, while poor documentation can result in incorrect conclusions. Causes of inadequate mapping underscore the importance of engaging family caregivers

However, research indicates that using visual evaluation to estimate fluid volume can be incorrect (Leinum et al., 2023). If nurses wrongly estimate quantities based on their visual assessment while having training and expertise in fluid balance monitoring, one could ask if family members might do the same even more. The quality of patient care may be adversely affected by these disparities as well as the sporadic failure of family members to record fluid intake or output. Based on the study, it might be hazardous and counterproductive to interpret fluid balance charts incorrectly. These errors may result in either an excessive or insufficient prescription of fluids, which could have detrimental effects on patient outcomes. Long hospital stays, greater rate of morbidity rates, and higher rates of mortality may follow from this (Leinum et al., 2023). As long as the graph is appropriately completed, involving families in fluid balance monitoring can assist overcome nurses' time constraints. Family members' participation in this process is enhanced by the nurse's absence from the patient.

The statement that family involvement improves patient outcomes is supported by the literature, including the impact of family caregivers on the self-care of heart failure patients associated with the risk of hospital hospitalization (Bloemberg et al., 2026). A study in Lebanon, with a collectivist culture similar to Indonesia, compared family education interventions with a control group for 30 days. The findings showed significant reductions in readmission, better maintenance and confidence, as well as a reduction in major vascular events and healthcare use in the intervention group. It emphasizes the success of family involvement in the self-care of heart failure patients

A randomized controlled trial study showed that patients with caregivers who received educational interventions experienced longer time to cardiac resuscitation compared to patients without intervention, supporting the view that family involvement can improve patient outcomes (Clements et al., 2023).

Conclusions

Nurses perceive family caregivers' roles for taking care Cardiac patients—such as assistance with activities of daily living, supervision, and discharge tasks. Nurses are responsible for educating caregivers to enhance post-discharge self-reliance and reduce readmissions. Also, nurses perceive their education efforts positively. The findings provide insights that could inform further research and contribute to developing a more systematic approach to integrating families into care. The study recommends including family caregivers' perspectives in future research to validate findings

^aThe point is family involvement on caring cardiac

and improve understanding of the educational dynamics in caregiver collaboration.

Declaration of Interest

Each authors affirms that they have no conflicts of interest.

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Data Availability

The corresponding author can provide derived data supporting the study's upon request.

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