ENGAGING PATIENTS FOR PATIENT SAFETY: A QUALITATIVE STUDY ON HEALTHCARE RECIPIENTS’ PERSPECTIVES

Pelibatan Pasien untuk Keselamatan Pasien: Studi Kualitatif terhadap Perspektif Penerima Layanan Kesehatan

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Abstract

Background: Patient safety (PS) is a global priority for achieving quality healthcare. Although patient engagement (PE) is a crucial risk-reduction strategy, research on this subject in Indonesia is scarce.

Aim: This study aims to explore healthcare recipients’ (HCRs’) perspectives and their potential role in PS.

Methods: Exploratory qualitative research was conducted with in-depth interviews (IDIs). This study purposively selected fourteen patients and fifteen caretakers in chronic wards. Content analysis was subjected to the IDIs data that has been transcribed verbatim.

Results: HCRs showed inadequate knowledge, perception, and willingness to engage in patient safety. Four themes were identified from data analysis: (1) complexity barriers to PE Implementation; (2) enabling factors for PE; (3) HCRs’ expectations; and (4) existing and potential HCRs’ roles in PS. HCRs’ roles were still limited to communication, positive attitude and behavior, aided healthcare process, and error prevention.

Conclusion: The limited roles of HCRs resulted from their unreadiness to participate more in PS. For patients to be engaged in safety measures, it was essential to improve the ability of patients and caregivers and eliminate obstacles encountered by healthcare professionals and the broader health system.

Keywords: patient engagement, patient safety, quality healthcare

Abstrak

Latar belakang: Keselamatan pasien (patient safety/ PS) merupakan prioritas global untuk mencapai pelayanan kesehatan yang berkualitas. Meskipun keterlibatan pasien/ patient engagement (PE) adalah strategi pengurangan risiko yang penting, penelitian tentang hal ini di Indonesia masih terbatas.

Tujuan: Penelitian ini bertujuan untuk mengeksplorasi perspektif penerima layanan kesehatan (pasien dan keluarga) dan peran potensial mereka dalam PS.

Metode: Penelitian kualitatif eksploratif dilakukan dengan wawancara mendalam. Empat belas pasien dan lima belas keluarga pasien bangsal penyakit kronis dipilih secara purposive. Analisis konten dilakukan terhadap data wawancara yang telah ditranskrip secara verbatim.

Hasil: Pasien dan keluarga menunjukkan pengetahuan, persepsi, dan kemauan yang tidak memadai untuk terlibat dalam PS. Empat tema teridentifikasi meliputi: (1) hambatan kompleksitas implementasi PE; (2) faktor pemicu PE; (3) ekspektasi pasien dan keluarga; dan (4) peran pasien dan keluarga saat dalam PS. Peran penerima layanan kesehatan dalam PS masih terbatas pada komunikasi, sikap dan perilaku positif, membantu proses kesehatan, dan pencegahan kesalahan.

Kesimpulan: Terbatasnya peran pasien dan keluarga diakibatkan oleh ketidaksyapan untuk lebih berpartisipasi dalam PS. Agar pasien terlibat dalam upaya PS, penting untuk meningkatkan kemampuan mereka serta mengatasi hambatan yang dihadapi oleh profesional pemberi layanan kesehatan dan sistem kesehatan yang lebih luas.

Kata kunci: keterlibatan pasien, kualitas layanan kesehatan, keselamatan pasien
**Introduction**

Patient safety (PS) is a fundamental aspect of healthcare worldwide. This aspect becomes more critical since the evidence for unsafe care is apparent. PS incidents are one of the 10 top leading causes of mortality globally (WHO, 2018; Committee on Improving the Quality of Health Care Globally et al., 2018). Every year, 2.6 million deaths occur due to unsafe care in low and middle-income countries (LMICs), including Indonesia. According to a systematic review, drug management incidents (25%, 95% CI 16%-34%) and other treatment-related incidents (24%) caused the most preventable harm to patients, following surgical procedure events (23%), healthcare associated infections (16%) and diagnosis (16%). PS incidents are also higher in advanced specialties (intensive care or surgery) than in general hospitals (from where most data came) (Panagioti et al., 2019). It implies that trillions of dollars are spent globally and have significant social consequences (Auraaen, Slawomirski and Klazinga, 2018).

Most PS incidents are preventable (up to 83%) (Committee on Improving the Quality of Health Care Globally et al., 2018). Numerous complex efforts have been undertaken and strongly suggested by international health organizations for lowering these incidences (WHO, 2008; WHO, 2017; Glasper, 2019). In most practices, such efforts are limited to policy, administrative procedures, patients' education, improving healthcare professionals' (HCPs') awareness and capacity, and technology application. Specific initiatives for patient participation in risk reduction remain an unresolved issue, as shown in the majority of research that patient engagement (PE) levels were generally low (Trier et al., 2015; Kim et al., 2018; Glasper, 2019; Hammoud et al., 2020). Hospitals frequently still emphasize lowering these incidences (WHO, 2008; WHO, 2017; Glasper, 2019). In most practices, such efforts are limited to policy, administrative procedures, patients' education, improving healthcare professionals' (HCPs') awareness and capacity, and technology application. Specific initiatives for patient participation in risk reduction remain an unresolved issue, as shown in the majority of research that patient engagement (PE) levels were generally low (Trier et al., 2015; Kim et al., 2018; Glasper, 2019; Hammoud et al., 2020). Hospitals frequently still emphasize lowering these incidences (WHO, 2008; WHO, 2017; Glasper, 2019). In most practices, such efforts are limited to policy, administrative procedures, patients' education, improving healthcare professionals' (HCPs') awareness and capacity, and technology application. Specific initiatives for patient participation in risk reduction remain an unresolved issue, as shown in the majority of research that patient engagement (PE) levels were generally low (Trier et al., 2015; Kim et al., 2018; Glasper, 2019; Hammoud et al., 2020). Hospitals frequently still emphasize

In Indonesia, patient-family-centered care has been introduced as the basis for the involvement of HCRsi in health services and safety (Utarini, 2020; Choi, Kim and Kim, 2021). Although the patient-centered care (PCC) aspect has become a focus of national hospital accreditation, the practice of patient involvement for PS has not been institutionalized (KARS, 2020). Research that supports this is still limited (Kaharuddin, 2014; Darmayanti, Simatupang and Rudito, 2019). Compared to Indonesia, many studies have proven that patient engagement encouragement could improve PS practices in developed countries (Berger et al., 2014), (Trier et al., 2015), (Sharma et al., 2018). The impact of patient involvement includes increasing medication safety (Ritzert, 2015; Khan et al., 2018; Kim et al., 2018), improving communication (Khan et al., 2018); preventing patient falls (Dykes et al., 2020); preventing infection (Hart, 2012; Sharma et al., 2018); and activating rapid response systems and care transitions (Ray et al., 2009; Gerdik et al., 2010). Hence, this study aims to explore patients' and caretakers' perspectives and their potential roles as the foundation for developing patient engagement programs for patient safety in Indonesia.

**Method**

An exploratory qualitative study was conducted in a faith-affiliated private hospital in Sleman District, Yogyakarta Special Region, Indonesia, in June-July 2021. This fully accredited type B hospital has 15 specialist and subspecialist field services and covers 216 beds. The scope of this research was limited to chronic care inpatient services. Fourteen patients and fifteen family/caretakers (Table 1) who received inpatient care were selected purposively from the patient registry list. Those who were conscious, communicative, and did not have severe mental illness could be involved as informants of this research. A chronic ward nurse was appointed to approach the patients and caretakers who meet the inclusion criteria above. The nurse explained that an interviewer would ask
questions for research before the interview began.

We used an interview guide to aid the information exploration. The questions conveyed HCRs’ knowledge about PS, their experience in the inpatient ward related to hospital quality and safety, and how to improve PS in hospitals. This guide was previously tested on a patient and a caretaker and revised accordingly. All interviews were conducted in Bahasa Indonesia and audio recorded. The data collection was stopped after saturation was reached. We used criteria of data saturation based on the definition by Sounders et al., (2018).

Table 1. Informants’ Characteristics

<table>
<thead>
<tr>
<th>Informant Code</th>
<th>Age (year)</th>
<th>Gender*</th>
<th>Education</th>
<th>Employment</th>
<th>Inpatient frequency</th>
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<tbody>
<tr>
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<td></td>
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<tr>
<td>P1</td>
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<td>Undergraduate</td>
<td>Unemployed</td>
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<tr>
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<td>Merchant</td>
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<tr>
<td>P5</td>
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<td>F</td>
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<td>&gt;4x</td>
</tr>
<tr>
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<td>M</td>
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<td>Entrepreneur</td>
<td>2–4x</td>
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<tr>
<td>P7</td>
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<td>&gt;4x</td>
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<tr>
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<td>M</td>
<td>Elementary school</td>
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<tr>
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<td>2–4x</td>
</tr>
<tr>
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<td>56</td>
<td>M</td>
<td>Undergraduate</td>
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<td>2–4x</td>
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<tr>
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<tr>
<td>K5</td>
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<td>Unemployed</td>
<td>2–4x</td>
</tr>
<tr>
<td>K6</td>
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<td>Student</td>
<td>&lt;2x</td>
</tr>
<tr>
<td>K7</td>
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<td>F</td>
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<td>Unemployed</td>
<td>2–4x</td>
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<tr>
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<tr>
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<tr>
<td>K10</td>
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<td>F</td>
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<tr>
<td>K12</td>
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<tr>
<td>K13</td>
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<td>F</td>
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<tr>
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<td>Private sector employee</td>
<td>&gt;4x</td>
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</table>

* F = Female, M = Male
A series of processes were meticulously carried out in the analysis of data. Interview recordings were transcribed verbatim by two research assistants. EL and MA then analyze the data under the supervision of ACS, AA, and AB using a content analysis approach.

**Trustworthiness**

We maintained research rigor by applying four dimensions of criteria: credibility, transferability, dependability, and confirmability (Forero et al., 2018). In terms of data credibility, data sources triangulation was conducted among HCPs informant groups in the different steps of this research. Before and during coding, data credibility was double-checked. We also conducted peer debriefing from the preparation of data collection until the research report writing. We provided a thick description of the study to improve transferability, including detailed descriptions of the participants, setting, and methods. Throughout the study, we prepared detailed drafts of the study protocol and tested the interview guide to ensure dependability. We also kept a detailed record of the data collection process by taking field notes and keeping a daily journal. To perform confirmability, we implemented weekly researcher team meetings. NVivo 12+ for data management and field notes also contributed to the study's dependability and confirmability.

**Result and Discussion**

This research included 14 patients and 15 caregivers (Table 1). These caregivers were not necessarily the patient's partner or family members. Most respondents worked in the informal sector.
and were female. The majority of HCRs have been hospitalized more than twice.

Four themes emerged from in-depth interviews with patient and caretaker informants (Figure 1). The themes include (1) complexity barriers to PE Implementation, (2) enabling factors for PE, (3) HCRs' expectations, and (4) existing and potential HCRs' roles in PS.

**Theme 1: Complex barriers to PE implementation**

Obstacles to PE implementation were identified as healthcare recipient-related barriers, HCPs-related barriers, and complex health systems. Patient and caretaker informants showed low health literacy, a lack of knowledge about PS and how to get involved. Low health literacy is evidenced by the statements of informants that they have inadequate self-care abilities, lack of knowledge about health in general and about the illness they are suffering from, and the inability to be involved in making decisions regarding themselves or their family's health condition. Moreover, the changing shift of caretakers without adequate information transfer also worsened this condition due to unequal knowledge. These conditions also described in the following interview excerpts from the HCRs informant:

“... the family plays a big role but when it comes to safety, what kind of family should be I don't know... because usually the family just takes care for example don't let the patient fall. At least that's as far as I know. The rest, I don't really understand.” (K2)

“... it was decided by the doctor, not me. The doctor decided for catheterization and I just agreed.” (P13)

On the other hand, HCRs mentioned varying levels of willingness to participate in PS efforts. Fear, shyness, worry about offending, resignation, thinking that the HCPs were smarter than them, fear of being considered stupid/nagging, and the presumption of being disappointed with the HCPs' answer were among the submissive attitudes and behaviors mentioned by informants who were hesitant to participate in PS. The quote below represents an example of disappointment that caused informants to be reluctant to ask HCPs.

“We never ask. Yes, it has to be the same. We are not going to be satisfied. We will not get a clear answer. You will be labeled as chatty if you ask too many questions.” (K1)

Aside from the factors mentioned earlier, the HCRs' characteristics and the patient's burden appeared to have influenced them to participate in PS efforts during hospitalization. The informants highlighted characteristics of patients such as passivity, cooperation, communicativeness, activeness, and elderly companions. The severity of the patient's clinical condition, including change of the level of consciousness, emergencies, complicated procedures, psychological burden, polypharmacy, experience with safety incidents, and drug side effects, were all crucial issues in how they can participate in PS. These quotes might illustrate these situations.

“My old mother sought advice from the officers, but she was unable to comprehend.” (K12)

“This depends on the patient, as he is the one who is ill. There are those who are uninterested in conversing, some people do not speak much, but I am a talker.” (P1)

“Yes, because this is an emergency condition. At that time, I fainted and was intubated. So, okay, I immediately signed the medical procedures agreement.” (K2)

Our study found that HCRs often experience physical and psych burdens that hinder them in PE. The previous study also showed PE barriers related to the patient (illness severity, extended hospitalization, invasive procedures) and family burden (socio-economic problems, depressive symptoms) (Burns et al.,...
2018). The patient burden could impede them from getting the health services they need (Arini, Ahmad and Utarini, 2020).

In our study, HCRs’ unwillingness to be involved was influenced by factors of inadequate health literacy, which contributed to varying perceptions and indisposition. The submissive attitude might closely relate to Javanese culture, in which the research setting was conducted, and also appeared as a barrier that hindered the proactive roles of HCRs in healthcare procedures. This finding is also consistent with previous studies on health literacy and specific ethnic and cultural backgrounds could affect patients’ willingness to speak up or be involved in general healthcare (Nurjanah and Mubarokah, 2019; Chegini et al., 2020).

HCPs-related barriers

Furthermore, our research findings in the category of HCPs-related barriers included information delivery barriers, communication styles, and working conditions. The HCPs’ assumption that the patient already knew about the limited knowledge of nurses and HCPs only providing explanations when asked were all barriers to communicating information to patients. The HCPs’ explanation style was quite varied. The informants highlighted that some HCPs were less communicative, less friendly, and had inadequate responses. The work conditions such as night shift, tiredness, or negligence affected how HCPs communicated with HCRs.

“I asked (to the nurse). Their ability to respond may be limited due to the doctor’s decision.” (K2)

“The nurse is not always in a good situation. As a result, they are not always friendly.” (P2)

In the HCPs’ barriers aspects, our exploration results were also in line with the findings of another study about the negative attitudes HCPs towards PE, ineffective communication, and the reluctance of physicians (Chegini et al., 2020). These HCPs related-barriers are generally thought to be caused by the inadequate curriculum for HCPs and ineffective retraining programs. Hence, it requires HCPs to be prepared during their formal education. Hospital management should ensure continuing education while working (Ruben, Blanch-Hartigan and Hall, 2020).

Complex health system

Informants shared their experiences while being treated in the hospital, which indicated barriers to PE implementation from health system aspects. Time constraints, complicated health procedures, a lack of information disclosure, difficulty in identifying HCPs’ identities, and the COVID-19 pandemic were all service delivery barriers that impacted patient involvement in safety initiatives. The limited number of HCPs implies that HCRs had less time and fewer opportunities to ask questions. On the other hand, the limited service at night, the performance of other units, and the fact that families might not accompany the patients during the intervention also contributed to these barriers.

“We, the patients, are dissatisfied with our conversations with physicians.” (P13)

“I am not sure how good services are. The medical community is not exactly transparent.” (K6)

Our findings in health organization management showed existing problems on the inadequate resources, in terms of HCPs workload and ineffective procedures execution. These conditions were in line with research in some Low-Middle Income Countries such as Iran (Chegini et al., 2020) and China (Wong et al., 2017). On the contrary, a study in Boston showed that patient partnership intervention did not change HCPs’ workload (Weingart et al., 2004). Hence, to respond to the complex barriers of PE, high-level commitment and multifaceted improvement programs require the roles of the government, community,
healthcare facilities, HCPs, and HCRs simultaneously (Burns et al., 2018).

Theme 2: Enabling factors of PE

A good relationship between HCPs and HCRs is one of the supporting factors for involving patients in PS. Based on interviews, this relationship was built by patients being frequently hospitalized, having the same affiliation with religious organizations, and mutual respect in a family-like atmosphere. HCRs with good prior knowledge and perception might facilitate their involvement in safety.

"... but in my second hospitalization, they already knew me. So, they tend to communicate with me" (laugh). (P1)

Meanwhile, positive attitudes and behaviors among HCRs, on the other hand, also supported this implementation. HCRs' positive attitudes appeared in their cooperativeness, independence, curiosity, communicativeness, and gratitude.

"(Patient safety is) shared responsibility. The nurses and doctors are also responsible, so they must inform the patients' families (what to do) because they are the ones who are caring for patients." (K3)

The HCP's positive attitude and behavior also aided in developing interactions with the patient. Caring, patience, friendliness, and communication are some of these characteristics. HCPs also kept patients calm, motivated them, responded to their needs, and respected their privacy, as shown below.

"You have to be passionate and healthy," they said." (P2)
"Oh yea, they knock the door first, then ask permission" (K8)

As per our study, HCRs' communication ability and willingness were also essential to improving PS. Without ignoring other equally important roles, HCPs and healthcare facilities must encourage HCRs willingness to communicate. HCRs highlighted the need for attempts to promote HCRs willingness to communicate. HCRs must be able to speak up or communicate their need was influenced by the ability to recognize the critical clinical condition, self-monitoring ability, confidence and trust, and culture (Rainey et al., 2015). Furthermore, the responsibility to make HCRs willing to communicate could not ignore the need for the community's role and general formal education to improve the public's health literacy (Danis and Solomon, 2013; McCormack et al., 2017; Nutbeam, McGill, and Premkumar, 2018; Chegini et al., 2020).

The hospital quality culture mentioned by the informants regarding implementing PE included the opportunity to submit complaints and the availability of educational media. In general, informants expressed trust and satisfaction with the services they received. They stated about feeling safe and comfortable during treatment, receiving prompt service, experiencing a clean environment, and having a simple service flow. As an external factor, although the pandemic resulted in barriers, the informant stated that it also increased HCPs' and HCRs' behavior in safety efforts, particularly infection prevention programs.

"Their kindness is... they said that if anything happens, I am supposed to report it." (P3)
"Given the current pandemic situation, there are many
Our significant finding was the close relationship between HCRs and HCPs and hospital quality culture as an enabler of PE implementation. This relationship was strengthened by frequent interactions and a family atmosphere of mutual respect. However, these results were inconsistent with some previous research that the relationship between patients and staff was treated to become ineffective due to healthcare delivery systems issues such as HCPs' workload and complicated service flow. Furthermore, cultural background and communication barriers were identified as threatening factors in previous research (Rainey et al., 2015; Schildmeijer et al., 2018; Chegini et al., 2020). Although a positive relationship was found to be an enabler for PE implementation, patients' fear that their active role would negatively impact their care and relationship with HCPs, similar to Doherty and Stavropoulou (2012). Moreover, future research is recommended to develop specific instruments that help HCPs engage HCRs in healthcare activities.

Theme 3: HCRs' expectations
The informants expressed some expectations related to the health services they got. Informants expected that the HCPs especially nurses and physicians would improve interaction with patients, routinely monitor, and be more thorough in carrying out their duties. Existing expectations occur due to the gap between practice and what they desire. As per the informant, they received IEC (information, education, and communication) from HCPs. However, the informants pointed out the lack of PS orientation at the beginning of the hospitalization. There was still a scarcity of information about the role of caregivers and patients in aspects of patient medication, treatment plans, diet, and general care. The following is what the informants stated.

“There was no mention about safety. We only get a brochure about the patient's rights and obligations, as well as a brochure about prayer.” (K1)
“Yes, nurses should be forthcoming with patients' families. They have to inform if the patient has to do something. They also could inform the family for anticipating and reminding the patients.” (K7)

Our study found that HCRs' perceptions of PS cannot be separated from their views on the quality of health services in general. Although the informants were generally satisfied with the hospital service, their experiences with delayed and unclear administrative services, service flow, issues of equity, continuity of care and collaboration between units, and patient-centered care raised concerns. Since patients experienced variation in how HCPs applied PS, their competencies and attitudes were also highlighted. These excerpts inform about these situations.

“The services provided in class 1 ward are quite extensive. Except for that, nurse explanations are thorough. However, this has not happened here (class 3).” (K1)
“I have never seen they check this (identity bracelet).” (K3)

It is interesting to note that communication becomes an essential issue in engaging patients for PS. Previous research revealed that clear, encouraging, multimodal communication has the most significant potential to increase patients' engagement in their safety (Walters and Duthie, 2017), (Burns et al., 2018). As IEC is required in almost all healthcare activities, the need for good HCPs' communication skills goes in hand with the competencies or general skills requirements they have (Elwyn et al., 2012; Hashim, 2017). These findings
Theme 4: Existing & Potential HCRs’ roles in PS

The fourth theme is informants’ reflections on their roles in healthcare process to achieve PS. Patient roles identified included effective communication, preventive efforts, and aspects of patient attitudes and behavior. The communication aspect included their role in initiating communication, communicate complaints or problems, providing accurate information, and actively asking questions. Their potential role in injury prevention was identified in preventing falls and checking medicine accuracy. Aspects of the patient's attitude and behavior included awareness of their rights and obligations, compliance to hospital rules, cooperativeness, and obedience on the advice of health workers.

"The one who can feel short of breath until I faint is me. So, I think the patient himself should be able to communicate to the nurse." (P1)

"As a patient, you have to follow the hospital's regulations. If not, it is the patient's fault (laughs)." (P9)

The caretakers’ roles were similar to the patient in caretaker-HCPs communication, preventive efforts, and patient assistance. They played significant roles in communication by reporting the patient’s condition or complaints, calling nurses, and actively asking questions. Caretakers are responsible for assisting patients in all activities, reminding them, and managing diet according to the doctor's advice. In prevention action for safety, the patients' guardian's identified functions included assuring patient hygiene, fall prevention, and medication management.

The following interview excerpts describe these roles.

“We administered the medication on time and continued to feed her with the hospital-supplied food. Then, I ask my mother when she gets bathed at the ICCU. I also enquired about patient care with the doctor." (K3)

“We reminded them that the bedside rail needed to be raised again." (Informant K1)

Even though our study had a strength in the diverse variety of HCRs informants' characteristics, it has several limitations. First, this research was only conducted in one hospital in Indonesia and might not reflect a broader Indonesian perspective. Hence, generalization and transferability must be approached with caution. Second, all HCRs who participated in this study had
received chronic inpatient care. As a result, their experiences might differ from other patient populations.

Conclusion

The findings indicated that patients and caretakers had varying levels of knowledge, perception, and willingness to engage in PS. HCRs' comprehension and attitude about PS and what they must do to involve in PS are still lacking. Our health system had complicated barriers to PE implementation due to HCRs, HCPs, and health organization-related factors. These factors contributed to HCRs' unreadiness to engage and their existing roles in safety that were limited to administrative roles, communication, injury prevention, and assisting the healthcare process.

Although some enabling factors regarding the HCRs' and HCPs' attitudes, behavior, relationship, pandemic situation, and quality culture of the hospitals, there is still a long way to go to implement PE in healthcare services. Since safety could not be separated from quality as patients expected, both of them should go in hand to be improved with multifaceted and continuing programs, especially in improving HCRs' and HCPs' capacities. Our study implies that high-level commitment and multiparty roles are crucial for ensuring that PE implementation runs effectively in healthcare facilities. Empowerment is needed since educational institutions, community roles, and supportive health policies are prerequisites for HCRs' ability to engage.

Abbreviations

HCP: healthcare professional; HCR: healthcare recipients; ICCU: intensive cardiology care unit; PCC: patient-centered care; PE: patient engagement; PS: patient safety. IEC: information, education, communication;

Declarations

Ethics Approval and Consent Participant

Ethical approval for this study was obtained from the Health Research Committee of the Faculty of Medicine and Health Sciences, Universitas Indonesia (No: Ket-584/UN2.F10.D11/PPM.00.02/2020). Before data collection, written consent was obtained. The confidentiality of the informants was ensured by replacing all personal identifiers.

Conflict of Interest

The authors declared no conflict of interest to be disclosed.

Availability of Data and Materials

The availability of data and materials were based on demand from journals and readers

Authors' Contribution

EL conceived the study. EL and MA were involved in developing the research manuscript, preparing interview guidelines, obtaining ethical approval, recruiting informants, and analyzing data. ACS, AA, and AB, contributed to critically revised articles for important intellectual content. All authors reviewed and approved the final version of the manuscript.

Funding Source

This research was supported by The Muhammadiyah Research Grant, Research and Development Board of Higher Education, Muhammadiyah Central Executive.

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