ORIGINAL RESEARCH ARTICLE

Implementation of Respect for Autonomy in Hospital Services Within the Indonesia National Health Insurance System

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ABSTRACT

The principle of patient autonomy forms the foundation of medical ethics. However, its exploration within the context of national health insurance systems in developing countries remains under-researched. This study aimed to evaluate respect for patient autonomy within Indonesia's National Health Insurance (NHI/JKN) system. The study using a qualitative research interview analyzed thematically. Conducted in Depok, West Java, the study involved in-depth semi-structured interviews with 18 participants, encompassing patients from first-level health facilities (FLHF), general practitioners at FLHF, specialist doctors, and management of referral hospital (RH) officers, and staff members of the JKN. The data were transcribed and analyzed using a thematic approach. The study revealed substantial underutilization of respecting patient autonomy within medical contexts under the JKN. Five themes emerged: challenges in the referral system, knowledge and information dissemination, decision-making and autonomy, quality of healthcare services, and systemic constraints and impact. These themes highlight the lack of patient awareness, restricted medical choices, the dominant role of paternalism (a system in which the government or a person in a position of authority makes decisions for other people) in healthcare decisions, and improper informed consent process. The findings suggest that the principles of beneficence and paternalism often overshadow respect for patient autonomy in the JKN system. This raises concerns about the ethical aspect of patient treatment, particularly the need for greater focus on patient autonomy and shared decision-making to align more closely with global medical ethics practices. This study contributes to understanding autonomy in national health insurance systems in developing countries. It highlights the need for systemic reforms to enhance healthcare efficiency and effectiveness while respecting patient autonomy.

Keywords: patient autonomy, hospital, informed consent, national health insurance, paternalism, ethics

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INTRODUCTION

In global healthcare, respect for autonomy is one of the four medical ethical principles foundational in guiding healthcare practices and policies worldwide.[1] It is defined as 'respect for autonomy', acknowledging individuals' rights to their beliefs and choices and emphasizing active engagement in social relations. Respect for autonomy involves more than non-interference in patients' decisions; it includes supporting their capacity for autonomous actions when they have intent but lack ability. Moser et al.[2] connect respect for autonomy with the concepts of negative freedom (freedom from interference) and positive freedom (control over one's life). Respect for autonomy in healthcare is, thus, about respecting patient intentions, aiding their autonomy capacity, and minimizing physical or knowledge limitations that restrict choices.

Respect for autonomy itself intersects with the other principles of ethics: beneficence, non-maleficence, and justice. While autonomy emphasizes respecting patient choices, beneficence aligns them with the patient's best interests. Non-maleficence involves protecting patients from harm and making decisions that minimize harm while respecting their autonomy. Justice ensures fairness and equality in healthcare, balancing individual choices (autonomy) with equitable access to healthcare resources and services. These principles collectively ensure ethical and patient-centered care.[3]

Respect for autonomy significantly impacts healthcare delivery. When healthcare providers acknowledge and support patients' autonomous decisions, they cultivate patient satisfaction and trust.[4,5] This, in turn, enhances the therapeutic relationship, leading to improved adherence to treatment plans and better overall health outcomes. In environments where autonomy is respected, patients are more likely to feel valued and understood, contributing to their psychological and emotional well-being, which is a critical aspect of comprehensive healthcare.[6]

However, in certain healthcare systems, such as Indonesia's National Health Insurance (NHI)/Jaminan Kesehatan Nasional (JKN), managed by the Social Security Agency for Health (BPJS), this principle is challenged, especially by paternalistic attitudes influenced by sociocultural factors. JKN was implemented in 2014, increasing accessibility and equity in healthcare services.[7] It was structured to integrate first-level health facilities (FLHF) and referral hospitals (RH). In such a healthcare system, paternalism, where health workers guide treatment decisions based on their belief of what is best for the patient, often conflicts with the ethos of respect for autonomy. This paternalistic approach can be viewed as a carryover from traditional societal attitudes, where it is not considered inappropriate for physicians to overlook patient requests.[8] This perspective contradicts contemporary medical ethics, which shift from paternalistic to prioritizing patient autonomy as essential for effective care and protecting patient rights.[9,10]

As discussed by Molyneux[11] and Darwall[12], the importance of autonomy involves both welfare and non-welfare considerations and extends autonomy beyond personal authority to include a moral right to make demands. However, in Indonesia's JKN system, financial sustainability and resource constraints may hinder respect for patient autonomy. Similar challenges have been observed in other countries, such as Taiwan[13] and Ghana[14], where concerns about care quality, financial viability, and ethical considerations may affect healthcare efficiency and ethical violations. In the JKN system, these limitations can potentially violate respect for patient autonomy, as patients might not receive full comprehensive information or choices about their treatment due to these systemic limitations. This can potentially damage the clinician-patient relationship, reduce trust in the healthcare system, and lead to patients receiving unwanted treatment, causing potential physical and emotional harm. This violation also poses legal and ethical risks, highlighting the crucial need for healthcare professionals to respect patient autonomy for effective care and rights protection.[6] A prior study in in the Middle East and North Africa (MENA) region[9] highlights the need for culturally sensitive approaches to providing informed consent, which is closely linked to the autonomy principle. Another study[15] found differences in privacy and autonomy practices between China and the United States arising from cultural, religious, and legislative perspectives.

Although there is extensive empirical research on patient autonomy in developed countries, few studies have been conducted in developing countries. For instance, Ebrahimi et al[16] research in Iranian teaching hospitals identified key factors, such as intrapersonal aspects, health status, family support, communication styles, and organizational constraints, as crucial areas for improving patient autonomy. Rahmani, et al[17] revealed differing perspectives of nurses and patients with respect to patient autonomy. However, these studies did not address specific aspects of health insurance systems, which can present unique challenges.[18] In Indonesia, research on medical ethics within the JKN system primarily focuses on general medical ethics, as viewed from the perspective of medical professionals (e.g., doctors, nurses, and pharmacists).[19–21] To date, there appears to be a gap in the research exploring respect for autonomy from the viewpoint of patients, doctors, and nurses, particularly in the context of a national health insurance system with limited options and resources.

This study aimed to evaluate the implementation of respect for patient autonomy in the Hospital service under the Indonesian NHI (JKN) system. By exploring patient perspectives, this study aimed to bridge the gap in understanding respect for autonomy in developing countries' healthcare systems, especially in the context of Indonesia's unique challenges. The findings will provide valuable insights into patient experiences and expectations, contributing to developing more patient-centered care and influencing healthcare policy and practice within Indonesia and similar global healthcare systems.

To provide a visual overview of the key concepts discussed, Figure 1 illustrates the foundational principles of patient autonomy, the specific challenges within Indonesia's National Health Insurance System (JKN), and comparisons with global research, which emphasizes the critical importance of autonomy in healthcare and identifying existing research gaps.

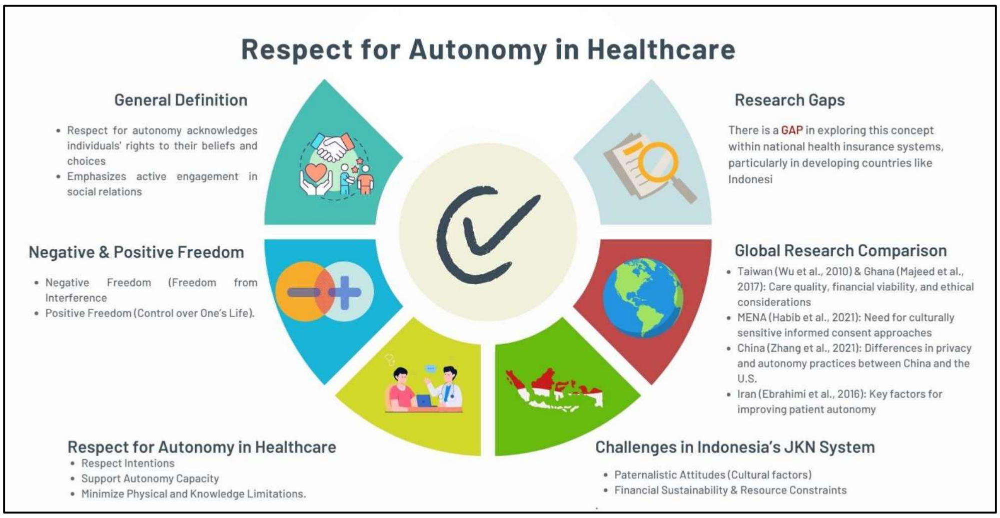

Figure 1: The Foundation of Ethical Healthcare: Understanding and Respecting Patient Autonomy in Indonesia's JKN System

METHODOLOGY

This study employed a qualitative research design, employing thematic analysis of interviews, to evaluate the extent to which patient autonomy is respected within the JKN system in Indonesia. The thematic analysis approach of this study is particularly suited for understanding the complexities and nuances of how patient autonomy is respected under the JKN system. By focusing on real experiences in specific, varied contexts, this study aimed to uncover deep insights into the challenges and successes of implementing patient autonomy in a developing country's national health insurance framework.

Our study sample consisted of 18 participants, ranging in age from 21 to 60 years, with a mean age of 35. The gender distribution was 72.22% female and 27.78% male. All participants were of Asian (Indonesian) ethnicity. Regarding education, 83.3% had completed a bachelor's degree, while 16.7% held a high school diploma or equivalent. The study was conducted in a community health center (*Puskesmas*) and a Type C referral hospital located in Depok, West Java, Indonesia. In Indonesia, health facilities are categorized into two levels based on the size and scope of their medical services: first-level health facilities (FLHF) or primary care providers, and Referral Hospitals (RH) or secondary care providers. FLHFs include clinics, *Puskesmas*, and Class D hospitals, whereas RHs include hospitals ranging from Class A to Class C, with Class A being the highest tier offering the broadest range of health services.[22] To provide context for the study, Figure 2 illustrates the referral system within Indonesia's National Health Insurance (JKN) framework, which supports the patient flow between FLHF and RH. This system is central to understanding the challenges discussed in the interviews conducted at the community health center and Type C hospital in Depok, West Java. Data collection spanned three weeks, from mid-February to early March 2023.

Purposive sampling was used to recruit the participants. The inclusion criteria for participants were as follows: 1) patients receiving care at both outpatient and inpatient clinics referred from FLHF; 2) general practitioners serving at FLHF; 3) specialist doctors employed at the Type C hospital (RH); 4) management staff of RH; 5) staff members of JKN or JKN in Depok; and 6) nurses working inward and outpatient at RH. Exclusion criteria were set to omit participants who could not provide coherent explanations of their medical conditions to ensure the reliability and representativeness of the data in reflecting the experiences of those who could articulate their interactions with the JKN system effectively. Table 1 shows the basic characteristics of informants.

Data were collected through in-depth consent interviews with selected participants, utilizing a set of self-developed questions detailed in the supplementary file. These interviews aimed to probe the participants' personal experiences, perceptions, and views regarding respect for autonomy in the JKN system.

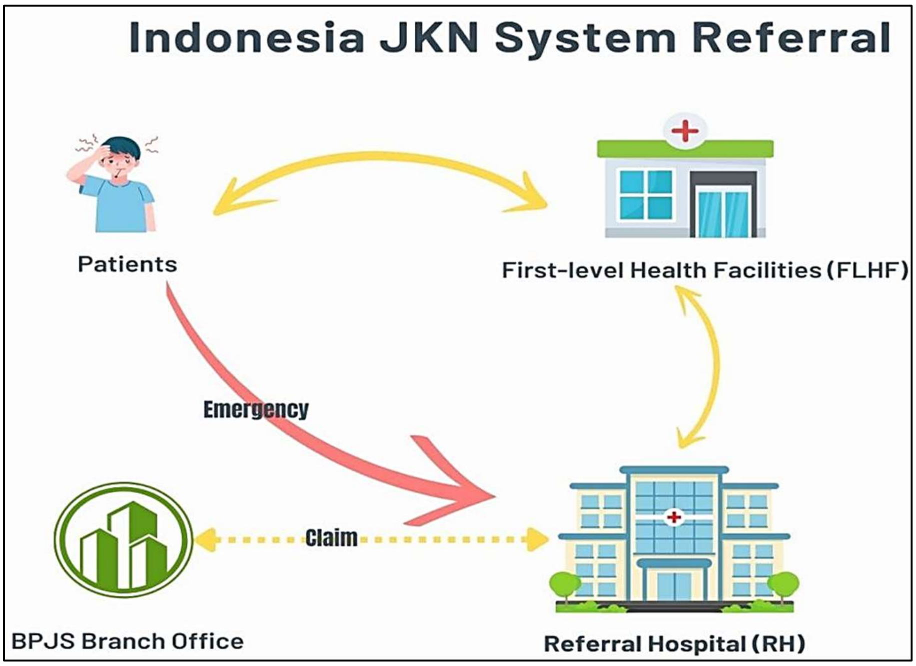

Figure 2: Flowchart of the Referral Process in Indonesia's National Health Insurance (JKN) System

Table 1: Basic characteristics of informants

Characteristics	Total
Gender	
Male	5
Female	13
Age (years)	
< 40	12
> 40	6
Profession	
Patient (Housewife)	3
Patient (Employee)	1
Nurse	4
General Practitioner at FLHF	4
JKN staffs	2
Hospital Management staff (Medical Service)	1
Hospital Management staff (Committee Ethics)	1
Specialist Doctor (Orthopedic)	1
Specialist Doctor (Pediatrics)	1
Working Experience (years)	
<10	4
>10	11
Not working	3

To ensure impartiality and consistency, the interviews were conducted by trained interviewers who were not directly involved in the research. The interview structure was deliberately designed to encourage participants to express their experiences and viewpoints in their own words, thereby emphasizing the tangible impact of the JKN system on patient autonomy. All data collected, including dates, times, and any issues encountered, were meticulously recorded to facilitate tracking and verify data integrity. Moreover, we periodically reviewed our data collection processes and adjusted to address any problems or inconsistencies.

Data analysis was carried out after the results of the in-depth interviews were transcribed manually because this is qualitative research. Each transcript was thoroughly read to ensure that there were no missing data. Manual coding was chosen for this analysis to allow for deeper engagement with the data, providing flexibility in categorizing informants' statements according to their profession and focusing on their experiences with RH. Given the manageable sample size, this approach was efficient and aligned with the researcher's expertise. This approach also ensured that context-specific nuances were thoroughly understood. Researchers then explored themes relevant to the research questions and developed initial thematic maps supported by appropriate quotations from the informants. This process led to defining and naming the final themes related to shared concerns between patients and health professionals. Additionally, information from nurses was utilized for validation and data triangulation, a process integrated into the overall analysis and interpretation. However, we acknowledge that the use of specific qualitative data analysis software could have provided additional benefits, such as more systematic coding processes.

The study protocol was approved by the Human Research Ethics Committee of the FKKMK Universitas Gadjah Mada University (KE/FK/0157/EC/2023). Participation in this study was voluntary, and all participants provided written informed consent.

Our study is the first study conducted in Indonesia, and it aims to evaluate the implementation of respect for patient autonomy in hospital services under the Indonesian National Health Insurance (JKN) system. By exploring patient perspectives, this study aimed to bridge the gap in understanding respect for autonomy in healthcare systems in developing countries, especially in the context of Indonesia's unique challenges.

RESULTS

Figure 2 shows a visual overview of the JKN referral process, highlighting areas where patients often face challenges that can affect their ability to make healthcare decisions. Our initial analysis revealed ten issues from patients, six from healthcare professionals, three from hospital management staff, and one from JKN staff, as shown in Table 2. Subsequently, we identified several gaps or inconsistencies and shared concerns between the patients and healthcare professionals. These key observations were grouped into five main themes visually represented in Figure 3. We will now discuss each of these themes further.

Table 3: Summary of Initial Issues Identified by All Participant Groups

Patients	Healthcare Professionals	Hospital Management Staffs	JKN Staff
• Difficulty in getting a referral • Autonomy to choose referral hospital FKTL • Knowledge of medical treatment and procedural services available in • The quality of medical staff's service • Adequate information about medical treatments and procedures and filling the informed consent • The doctor or nurse asked for consent for the actions and treatments to be undertaken. feel obligated to adhere to the decisions made by medical professionals • Autonomy in selecting and deciding on their medical treatments and procedures. • Role and influence of family members in a patient's decision-making process regarding medical treatments and procedures • Knowledge of the healthcare service regulations of BPJS • Opinion on the medical treatment facilities and medical actions covered by BPJS	• Role in treating BPJS/JKN patients • Healthcare provided is patient-centric, focusing on the importance of the patient's needs and interests in medical decision-making and care. • The decision-making process in medical treatments inquires whether patient input, such as their suggestions or opinions, is considered or if decisions are made solely based on the patient's medical condition without their input. • Process or criteria used by a healthcare professional to evaluate a patient's condition and how they determine the appropriate course of action or medical treatment based on that assessment • Providing education, specifically regarding the patient's health condition and the details of the medical treatments and procedures they will undergo. • Knowledge concerning the range of medical treatments and procedures that are covered under BPJS	• Knowledge concerning hospital management's role in educating about BPJS procedures • Providing medical facilities and treatments • Involvement in the operational aspects of medical treatment and procedures for efficiency in healthcare services.	• Role in treating BPJS patients

Challenges in the Referral System

This theme highlights significant gaps and shared concerns between patients and healthcare professionals in Indonesia's JKN system. On the patient side, experiences of obtaining referrals to RH are varied and often troubled with challenges. One patient explained it vividly:

> *"I experienced difficulties obtaining a referral to the RH. I had to visit multiple times, even as my symptoms worsened, to the point where I had to bang the table and get angry"*

Another patient shared the following frustration:

> *"I explained that my medical history is with Hospital X, but the nurses and doctors at the clinic insisted that I should be referred to the nearest hospital from the FLHF. I didn't have the power to change their decision, so I had no choice but to accept the situation as it was."*

These accounts reveal the common issues patients face: repeated visits, delays, and limited choices in selecting referral hospitals. One patient mentioned:

> *"I preferred being treated at this hospital since it's close to my home, but the doctor and nurse suggested referring me to a type A hospital, citing the seriousness of my illness and the need for extensive, long-term treatment."*

Healthcare professionals also recognize these challenges from a different perspective. The GP at the FLHF highlighted the systemic constraints:

Patients Autonomy in Indonesia's JKN System

01 Challenges in the Referral System

- ·Lack of patient awareness about JKN services.
- ·Challenges in educating patients effectively.
- ·Insufficient information compromises informed decision-making.
- ·Need for better communication and educational mechanisms.

02 Knowledge & Information Dissemination

- Lack of patient awareness about JKN services.
- Challenges in educating patients effectively.
- Insufficient information compromises informed decision-making.
- Need for better communication and educational mechanisms.

03 Decision-Making & Autonomy

- Limited treatment options for patients.
- Inadequate informed consent process.
- Systemic constraints overshadow patient participation.
- Challenges with literacy and informed consent in developing countries

Quality of Health Service 04

- Inconsistent care affects patient trust and autonomy.
- Poor quality leads to mistrust and hinders decision-making.
- High-quality care fosters patient involvement in decisions

Systemic Constraints & Impact 05

- Budget limitations and policy inconsistencies
- Suboptimal treatment plans due to systemic issues.
- Paternalism overshadows respect for patient autonomy.
- Need for a shift toward patient-centered approaches and shared decision-making.

Figure 3: Thematic Overview of Patient Autonomy in Indonesia's National Health Insurance System (JKN)

> *"JKN imposes strict limitations on the number of referrals from FLHF to RH, presenting significant challenges for those who work at FLHF in terms of making referrals. We often find ourselves have to repeatedly explain and educate patients until they understand the situation. Occasionally, patients become frustrated or angry when they do not receive a referral letter to the RH. Moreover, JKN doesn't permit us to create a list of diseases that are not covered, so we at FLHF are also tasked with educating patients and managing their discontent when they are unable to obtain a hospital referral."*

Healthcare professionals also observe instances in which patients seek referrals that may not be medically necessary. For example, GP stated:

> *“However, there are cases where some patients request a referral to RH right from their first visit to FLHF, even though their conditions could still be effectively managed at our FLHF level."*

This situation suggests a fundamental misunderstanding or miscommunication about how the referral system works and what conditions necessitate referral to a higher-level facility. Both patients and healthcare professionals acknowledge systemic issues in the referral process, such as delays and restrictions, as determined by JKN guidelines.

Knowledge and Information Dissemination

This theme highlights the critical gaps in the knowledge and information dissemination experienced by patients and healthcare professionals within Indonesia's JKN system. From the patients' perspective, a significant lack of understanding regarding the facilities and procedures of the JKN is evident. This lack of awareness adversely affects their ability to meaningfully participate in healthcare decisions. Several patient reports illustrate this challenge.

> *"I agreed to all the procedures and treatments, even though I didn't fully understand them, because I want to get better."*

Another patient expressed confusion about what to ask their healthcare provider.

> *"If I try to ask questions, I often find myself unsure of what exactly to ask. Usually, I end up inquiring whether I will receive treatment, need surgery, or require hospitalization. Even then, my questions are mostly limited to what documents I need to prepare."*

On the other hand, healthcare professionals face obstacles in educating patients. High patient volumes make it challenging to provide detailed and individualized information. Uncertainty regarding JKN coverage further complicates this task. A GP stated:

> *"Due to JKN's lack of transparency about which medical treatments and actions are not covered, I often find it overwhelming to explain this to patients. This challenge is particularly pronounced when there is a high load of patients at FLHF, making it is impossible for me to provide detailed education to each patient."*

One nurse resonated with this sentiment.

> *"I frequently find myself overwhelmed when trying to explain treatment coverage to patients, primarily due to JKN's lack of transparency regarding which medical treatments and actions are not covered."*

Furthermore, healthcare professionals, such as specialist doctors, noted the challenges of providing quick yet informative communication:

> *"I offer concise communication, information, and education (KIE) due to the limited time available. The decisions I make are always based on the consent of the patients or their families. Despite my best efforts, there are occasions when patients refuse the proposed treatment. Conversely, they sometimes request additional interventions that I do not recommend."*

This situation reflects a systemic issue in which both patients and healthcare providers acknowledge significant gaps in information dissemination and understanding of JKN services, leading to confusion and a lack of awareness.

Decision-Making and Autonomy

This theme explores the tension between patients' perceptions of compromised autonomy and healthcare professionals' efforts in Indonesia's JKN system. Patients often feel that their autonomy is undermined because of limited treatment options and insufficient involvement in the informed consent process. Many express frustrations over being unable to choose their preferred treatments or not fully understand the treatments they receive. Patient quotations illustrate these concerns. One patient shared their experiences with the medication changes.

> *"The doctor and nurse told me that I couldn't select my medication, even though I normally take a specific medicine regularly. They instructed me to stop my usual medication and only take what the hospital provided. As a result, I've been experiencing body aches and dizziness."*

Another patient discussed the consequences of not complying with the medical advice.

> *"I didn't ask if the medication provided by the hospital had the same components as my usual medication. I was concerned that if I did not comply with the doctors' and nurses' decisions, I might be left untreated. They warned me, saying, 'If you don't agree to the operation, then we cannot continue your treatment here. It's your choice, but remember, you'll be responsible for the consequences and the progression of your illness."*

One patient preferred local treatment.

> *"I preferred being treated at this hospital since it's close to my home, but the doctor and nurse suggested referring me to a type A hospital, citing the seriousness of my illness and the need for extensive, long-term treatment."*

The issue of trust and satisfaction with the healthcare system is further exacerbated when patients' choices conflict with their medical recommendations. This is evident in the patient's hesitation to undergo surgery.

> *"When I was informed that I needed surgery, my mother objected. She suggested trying medication first, if possible, as she was deeply affected by a traumatic past incident where a relative suffered from post-surgical bleeding and sadly passed away."*

Moreover, the approach to obtaining informed consent varies significantly between the FLHF and RH. At the FLHF level, consent for medical procedures such as minor surgical wound stitching and inhalation treatments is typically given verbally, without the use of written forms. A GP clarified this practice.

> *"For medical action such as handling minor surgical wound stitching and administering inhalation treatments, I give informed consent verbally and do not use a written form."*

By contrast, at RH, the process is more structured and formalized. Patients were provided with detailed educational materials and were required to fill out and sign informed consent forms. This procedure is particularly evident in inpatient care settings, as explained by the nurse.

> *"In the context of hospital inpatient care, we ensured that informed consent was obtained for any medical action, but only after comprehensive education was provided. If a patient disagrees with the proposed treatment, we then offer a letter of refusal to document their decision."*

However, healthcare professionals at both FLHF and RH face several challenges. Time constraints and the difficulty of effectively communicating complex medical information within limited interactions have been recurrently mentioned, as previously highlighted in the themes of Knowledge and Information Dissemination. This disparity in practice and understanding between patients and healthcare providers indicates a significant gap affecting the effective implementation of patient autonomy within the JKN system.

Quality of Healthcare Service

Patients in Indonesia's JKN system frequently express dissatisfaction with the quality of healthcare services, particularly in inpatient settings. Their frustrations resulted from experiences of delays, inadequate care, and unavailability of essential treatments or facilities. One patient vividly described:

> *"The nurses always seem busy. There have been times when my infusion ran out, and it has not been replaced for hours. Even after calling for a nurse, I had to wait a long time for someone to arrive. Additionally, the doctor's visit times are unpredictable, and they don't come every day."*

Another patient shared their experience with medication shortages.

> *"I once had to wait in a long queue only to be informed that the medication was out of stock. I was compelled to purchase it externally at my own expense. This medication, which I need to take daily, is expensive. Without it, my asthma tends to flare up again."*

In contrast, healthcare professionals, particularly doctors, express confidence in their medical expertise, but acknowledge the limitations of the system. A specialist doctor remarked:

> *"One thing is certain: I have full confidence in the abilities of Indonesian doctors to manage diseases within their area of expertise. However, it's the constraints of the system that often undermine their capability and knowledge."*

Nurses, often at the forefront of patient care, face challenges related to prioritizing certain patient groups due to institutional directives, as explained by one nurse:

> *"...but honestly, I have an additional obligation to pay extra attention to patients who are members of the police force. This is because our RH hospital is owned by the police institution, and as such, we adhere to the directives and rules set by the National Police Headquarters."*

This dual perspective of patients and healthcare providers underscores a broader challenge within the healthcare system. The struggles to meet patient needs and expectations, influenced by JKN regulations and systemic priorities, highlight significant inconsistencies in service quality and indicate underlying issues within the healthcare infrastructure.

The acknowledgment of inconsistencies in service quality by both patients and healthcare providers paints a picture of a healthcare system struggling to meet the needs and expectations of patients. Influenced heavily by JKN regulations and systemic priorities, these inconsistencies reflect a deeper issue within healthcare infrastructure. The role of hospital management staffs, including Medical Service and Ethics Committee personnel, are educating patients about JKN procedures encompasses informing patients about JKN service flow, such as referral reception, registration, examinations, medication, and support services, providing medical facilities and treatments that comply with JKN regulations, managing the limitations of Type C hospitals, and referring patients to larger hospitals for treatments that are not covered or more advanced than their capabilities, communicating about treatments not covered by JKN and the associated challenges in processing these requests without directly intervening in the treatment plans for efficient healthcare services.

The role of JKN staff in patient referral and treatment management, which aligned with the hospital management staff's perspectives, also seemed normative. Their responsibilities include managing staged health services to ensure effective and efficient transitions from FLHF to higher-level facilities, including provision for emergencies and specific health conditions. administer the Refer Back Program to patients with stable chronic diseases, requiring specialist certification for referrals back to FLHF, focused on ensuring adequate treatment facilities at FLHF and RH in compliance with the Presidential Regulation on Health Insurance. Educational outreach on referral procedures and ensuring compliance with JKN regulations, although limited resources, are also crucial components of their role. Hospitals' efforts to provide healthcare services according to JKN regulations and accept referrals based on the FLHF zoning guidelines. However, the extent of their application in practical settings has not yet been fully covered.

Systemic Constraints and Impact

Similar to the previous theme, patient dissatisfaction was largely due to the limited range of treatment options available to them under the JKN system. This dissatisfaction is further exacerbated by additional financial burdens arising from budget limitations and policy inconsistencies in the JKN system. A nurse from FLHF highlighted the following challenges:

> *" However, we sometimes encounter obstacles owing to the inadequate facilities provided by JKN, as well as the regulations set by JKN. These limitations often lead to patient dissatisfaction with the services we offer at FLHF."*

Healthcare professionals, while acknowledging these systemic limitations, often feel constrained and powerless to effect change. The restrictions imposed by the JKN system considerably limit its capacity to offer diverse treatment options. A GP from the LFHF shared the following experiences:

> *"I provide a range of services, from curative care and examining sick patients to treating them according to clinic rules and making referrals when necessary. Additionally, I conducted health promotion activities twice a month, such as educating people about chronic diseases. However, there are numerous challenges, including limited availability of medicine. At FLHF, we're also constrained by rules that limit the number of patients we can refer, which is tough to explain, but those are the guidelines we must follow."*

Orthopedics further illustrates these systemic issues.

> *"I manage JKN patients at the orthopaedics clinic and provide consultations for emergency room referrals. However, I cannot address all cases due to inadequate surgical facilities and the unavailability of certain operations and diagnostic tests under JKN coverage. Consequently, I often have to refer patients to larger hospitals, even though I am capable of performing the required procedures."*

These challenges highlight a broader issue in the health care system. Healthcare professionals often struggle to offer clear guidance and effective treatment due to policy inconsistencies and confusion about coverage under the JKN. This complex scenario can lead to difficult decisions in which respect for patient autonomy may not be fully realized.

DISCUSSION

This study explores how the principle of respect for autonomy is implemented within Indonesia's NIH and JKN. It focuses on obtaining insights from patients to better understand how respect for autonomy is practiced in developing countries' healthcare systems.

As expected, this study revealed significant limitations of the current JKN system, particularly in its underutilization of respect for patient autonomy. Specific instances where patient autonomy is not respected include scenarios such as medical paternalism, where healthcare professionals make decisions for patients without adequate involvement; issues with informed consent, either due to healthcare providers not properly obtaining consent or patients lacking an understanding of the medical intervention; and treatment refusal, where patients decline treatments considered beneficial by physicians but face pressure from family or healthcare staff.

From the perspectives of both patients and healthcare professionals, the study identified five key themes: challenges in the referral system, knowledge and information dissemination, decision making and autonomy, quality of healthcare service, and systemic constraints and impact. These themes provide a comprehensive overview of the various factors affecting the implementation of patient autonomy and other principles of ethics in Indonesia's health care system.

Knowledge and Information Dissemination are closely linked to the principle of respect for patient autonomy. This theme highlights the issue of patients lacking awareness and information about JKN services and the difficulties healthcare professionals encounter in effectively educating them, resonating with Darwall's focus on informed choice.[12] Inadequate information compromises patients' ability to make informed and voluntary healthcare decisions. Without sufficient knowledge, patients cannot make decisions beneficial to their welfare. They may choose fewer effective treatments or misunderstand the consequences of their healthcare choices. This information gap also limits their ability to use their right to make informed decisions independently, thus affecting the non-welfare aspect of autonomy.[11] This situation emphasizes the necessity for more effective and accessible communication and educational mechanisms within the JKN system to empower patients to make better-informed healthcare decisions while simultaneously enabling healthcare professionals to offer more effective guidance and support.

Furthermore, the theme of Decision-Making and Autonomy deals with the limited treatment options available to patients and their involvement in the informed consent process, making respect for autonomy the central ethics. The systemic limitations of the JKN system often overshadow patients' desires and rights to be active participants in their healthcare decisions. While sympathetic to patient needs, healthcare professionals find themselves constrained by the same system that is supposed to facilitate patient care. This situation contrasts with Darwall's view of autonomy as a moral right to make claims[12] and Molyneux's integration of welfare and non-welfare considerations[11], acknowledging the intrinsic value of autonomy. This theme also highlights the issue of obtaining proper informed consent, which aligns with Koita's findings.[23] In developing countries, community leaders often initiate decision-making, and literacy challenges can impact the effectiveness of informed consent, reducing the relevance of written documents and signatures. This issue is exacerbated by the fact that those most at risk of disease often have limited literacy, experience with Western medicine, and an understanding of scientific research.[23,24]

Moreover, the high patient volume and healthcare provider workload under the JKN system often result in rushed consultations, hindering comprehensive discussions essential for informed consent. This situation can impede the development of in-depth relationships between clinicians and patients, which are critical for understanding patient values and preferences.[25,26] Therefore, effective consent strategies in developed countries may not be as suitable in developing countries with such diverse and challenging settings.

Conversely, the theme of Challenges in the Referral System is primarily concerned with issues such as the accessibility of healthcare services and equitable distribution of healthcare resources, reflecting the principle of justice due to concerns about fairness and equity in resource allocation. In line with this, Handayani et al[27] identified significant inefficiencies and rigidities in the referral process in Indonesia's JKN system. They observed that online healthcare referral systems did not effectively ensure compliance with referrals or regional guidelines. The study reported an alarming waiting time of up to 55 days for health referrals in cases of malignant disease. This finding suggests the urgent need for a comprehensive review and reform of healthcare referral policies, particularly in relation to capitation funding for primary care providers and tiered referral mechanisms based on hospital classes. However, this theme is still closely linked to the principles of autonomy. The referral system has a direct impact on patient access to healthcare services. Difficulties in obtaining referrals or delays compromise the patient's ability to make timely and informed healthcare decisions. Autonomy is not just about making choices but also about being able to access the necessary services to act upon these choices. Therefore, inefficiencies in the referral system can indirectly limit patients' autonomy by restricting access to the full range of available medical options.[27,28]

Similarly, the Quality of Healthcare Services theme connects to patient autonomy. The quality of healthcare services has a significant impact on patients' trust and confidence in the healthcare system. Inconsistent or poor quality of care can lead to mistrust, which might discourage patients from actively participating in their healthcare decisions. Furthermore, if the quality-of-service leads to incorrect or delayed diagnoses, it impedes the patient's ability to make informed decisions, thereby affecting their autonomy. On the other hand, high-quality healthcare, provides a foundation for patients to feel secure in the care they receive and more willing to involve in autonomous decision-making.[4,5]

Finally, the Systemic Constraints and Impact on Patient Autonomy theme addresses issues such as budget limitations, policy inconsistencies, and limited coverage of treatments, all of which directly limit patient options. These systemic issues often force patients to either accept suboptimal treatment plans or incur additional costs. Consequently, patients' autonomy is compromised, as their choices are no longer driven solely by personal preference or optimal medical advice, but are influenced by external systemic factors. Perceptions of illness and other beliefs may have a beneficial or bad impact on an individual's actions, health, and medicine use.[29] Our findings indicate that in the context of Indonesia's JKN system, the principles of beneficence and paternalism tend to overshadow respect for patient autonomy, a key aspect of medical ethics.[1,9,10] It highlights the dominant role of paternalism in healthcare, where health workers often guide patient treatment actions based on the belief that doctors generally know what is best for their patients.

Paternalistic decision-making in healthcare is generally considered acceptable in cases of 'true paternalism,' where individuals are incapable of making informed decisions due to incapacity.[10] However, this raises ethical concerns when it involves competent individuals who are capable of making their own healthcare decisions, as this can affect their autonomy. While exceptions are recognized in emergency situations or specific public health contexts requiring prompt decisions, this study finds that paternalism often occurs in patients who are neither weak nor vulnerable patients. The issue lies not in their competence, but in a lack of understanding of treatments, procedures, and insufficient involvement in the consent process. Additionally, patients may feel overwhelmed in hospital settings or unsure about the questions to ask, particularly if healthcare professionals do not actively encourage dialogue. This leads to a doctor-patient dynamic in which the doctor's judgment often takes precedence, a practice increasingly criticized for diminishing patient autonomy.[10]

While developed countries have experienced a significant shift from paternalistic practices to patient-centered approaches and shared decision-making[26], such a transition remains challenging in developing nations such as Indonesia. A similar phenomenon was observed in the Middle East North Africa (MENA) regions. In these regions, cultural, religious, and legislative influences pose significant hurdles to implementing informed consent, especially in emergencies. In such scenarios, the norm of informed consent often gives way to a more paternalistic approach by physicians that prioritizes life-saving actions over patient values.[9] These findings emphasize the need for greater emphasis on patient autonomy and shared decision-making in Indonesia's healthcare system, aligning it with modern medical ethical practices globally.

IMPLICATIONS

Under the current JKN system in Indonesia, respecting patient autonomy with limited resources and diverse patient education levels is challenging. Healthcare providers and policy workers must work synergistically to improve healthcare efficiency and effectiveness while enhancing patient involvement and autonomy addressed with a multifaceted approach.

These include:

1. Simplifying and streamlining the referral process to reduce delays and complexities and possibly integrating digital solutions to facilitate easier access and tracking[27] suggested an innovative approach in which referrals are determined based on the healthcare facility's competency rather than hospital classification, potentially addressing the system's deficit issues.

2. Launch comprehensive awareness campaigns and educational programs about the JKN system, focusing on healthcare rights, treatment options, and effective navigation of healthcare procedures, along with community outreach initiatives, such as schools, religious institutions, and community centers. By conducting these sessions in familiar communities, the programs become more accessible and likely to have higher attendance, ensuring that information reaches and benefits a wider audience.

3. Provide education tailored to individual understanding levels using visual aids and simple explanations with clear and accessible language. In some cases, alternative methods of obtaining consent, such as witnessing oral consent or using videos to present the study and record consent, may be more appropriate, especially in developing countries.[30]

4. The integration of new technologies and artificial intelligence should be explored to enhance these methods, aiming to present information in a more personalized, engaging, and accessible manner.[31]

5. Providing training for healthcare providers in communication, ethical decision-making, and cultural competency to navigate resource limitations and patient diversity.

6. Develop guidelines and tools to support shared decision-making that respects patient preferences while considering JKN constraints. This approach can lead to increased patient satisfaction, improved adherence to treatment plans, and improved health outcomes. Therefore, developing trust in patients is

crucial in a JKN system with limited options. This includes open communication, empathetic listening, respect for privacy and confidentiality, and encouraging feedback on patients' experiences and suggestions for improvement.[26]

7. Review and revise JKN policies to address coverage inconsistencies and financial limitations, including funding, reevaluating the list of covered treatments and medications, and improving resource allocation.

8. Support healthcare professionals by reducing the burden on staff, particularly in high-demand facilities.

LIMITATIONS

This study has certain limitations that must be acknowledged. First, its scope and impact were constrained by its nature as a pilot study. Conducted with a relatively small group of participants, the conclusions might only partially represent the broader attitudes and experiences within the country. A notable concern in this study is the potential influence of the close relationships between some participants, specifically healthcare professionals and researchers. This proximity could have affected the objectivity of the findings. Furthermore, this study faces the challenge of a social desirability bias. Patients may withhold complete information because of concerns about receiving proper treatment. Similarly, the information provided by the JKN and hospital staff might appear normative, with the JKN staff consistently answering questions and referring to JKN guidelines without providing further clarification, lacking a critical perspective on the limitations of the JKN system and hospital services. Another critical aspect is the study's focus on a type C hospital, which may encounter different challenges from larger hospitals, such as types A and B. However, these limitations do not diminish the study's contribution to understanding autonomy issues in the context of a universal coverage health system in a developing country.

CONCLUSION

This study examined the implementation of respect for autonomy within Indonesia's National Health Insurance (JKN) system, focusing on patient insights to understand its application in healthcare systems in developing countries. This research found a significant underutilization of respecting patient autonomy within JKN, identifying issues such as lack of patients' knowledge, pressured treatment acceptance, medical paternalism, and inadequate informed consent processes. The study revealed five themes: challenges in the referral system, knowledge and information dissemination, decision-making and autonomy, quality of healthcare services, and systemic constraints and impact. These themes collectively present various factors that influence patient autonomy in Indonesia's healthcare sector. In particular, the themes of Knowledge and Information Dissemination and Decision-Making and Autonomy were found to directly affect patient autonomy, highlighting issues such as inadequate patient awareness and restricted medical choices. The study also noted a dominant paternalistic approach in healthcare, often overriding patient autonomy, especially in cases where patients are capable yet uninformed or not fully involved in decision-making. This study suggests the need for greater emphasis on patient autonomy and shared decision-making, aligning Indonesia's healthcare system with global medical ethics practices. Multifaceted strategies are required to improve healthcare efficiency and effectiveness while respecting patient autonomy. Recommendations include streamlining the referral process, launching comprehensive educational programs, providing tailored patient education, training healthcare providers in communication and ethical decision-making, and revising JKN policies to address systemic limitations. Despite its limitations, this study significantly contributes to understanding autonomy in the context of the national health insurance system in a developing country.

ABBREVIATIONS

NHI: National Health Insurance; JKN: Jaminan Kesehatan Nasional; FLFH: First Level Health Facilities, MENA: Middle East and North Africa, RH: Referral Hospital

AVAILABILITY OF DATA AND MATERIALS

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

AUTHORS' CONTRIBUTIONS

DD conceptualized the study, designed the methodology, conducted the investigation, analysed and interpreted the data, and drafted the original draft. SM conceptualized the study, participated in the method design, supervised the study, administered the project, and reviewed and edited the manuscript. DAP conceptualized the study, participated in the method design supervised the study, and reviewed the manuscript. All authors have read and approved the final version of manuscript.

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