Healthcare Access Inequities Experienced by Patients Supported by Cancer Patient Navigators (NAPAK)

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ABSTRACT
Cancer patients in Indonesia continue to experience substantial inequalities in accessing healthcare services, driven by structural, geographical, financial, and informational barriers. These disparities often result in delayed diagnosis, fragmented care, and adverse health outcomes. This study aimed to explore the lived experiences of cancer patients receiving navigation services from Cancer Patient Navigators (NAPAK) and to examine how these experiences reflect broader patterns of healthcare access inequality. A qualitative descriptive phenomenological design was employed, involving ten purposively selected participants who met the inclusion criteria. Data were collected through in-depth interviews and analyzed using thematic analysis supported by NVivo 14 software. Four major themes emerged from the analysis: (1) various healthcare access inequalities, including saturated schedules, complex administrative procedures, geographical distance, financial constraints, and appointment difficulties; (2) the primary role of cancer patient navigators, who provided essential informational, procedural, emotional, and advocacy support throughout the care continuum; (3) transportation and access disparities, highlighting both accessible and severely limited mobility conditions across regions; and (4) the impact of healthcare access disparities on health, reflected in heightened anxiety, psychological distress, physical exhaustion, and emotional burden. Participants also expressed expectations for improved navigation services, enhanced facilities, clearer information systems, and stronger governmental support for insurance programs. The study concludes that healthcare access inequality significantly shapes cancer patients' physical and psychological well-being. Strengthening communication between healthcare providers and patients, improving navigation services, and enhancing policy support are critical to reducing disparities and promoting equitable cancer care.
Keywords: cancer patient navigation; healthcare access inequality; transportation barriers; patient experience

INTRODUCTION
Cancer remains a major public health burden in Indonesia [1], with an estimated prevalence of approximately 1.4 million cases nationwide. Mortality rates remain high, largely due to delays in diagnosis and treatment initiation. Data from the Ministry of Health indicate that nearly 30% of cancer patients experience diagnostic delays, commonly arising from barriers in accessing adequate healthcare facilities. Among the most prominent obstacles are treatment costs and limitations in health insurance coverage, particularly affecting socioeconomically vulnerable populations [2]. The introduction of Cancer Patient Navigators (NAPAK) is expected to mitigate these barriers by providing structured assistance throughout the care continuum. Financial constraints constitute the most significant impediment, with 40% of access-related issues stemming from complexities in health insurance or assurance systems, especially among vulnerable groups seeking essential cancer care services [2].

Socioeconomic disparities, geographical challenges, and cultural differences further exacerbate inequities in cancer care access [3]. Patients from low-income households, those residing in remote or rural areas, and individuals belonging to minority groups frequently encounter diagnostic delays, limited treatment access, and poorer clinical outcomes compared to other demographic groups [4]. In response to these inequities, cancer patient navigation has emerged as a promising intervention model. Cancer patient navigators are trained healthcare professionals who assist patients and their families in navigating the healthcare system from initial screening and diagnosis through treatment and follow-up care [5]. They serve as critical intermediaries between patients and healthcare providers, ensuring timely, coordinated, and integrated access to services.

Healthcare access inequality among cancer patients in Indonesia is shaped by multiple interconnected structural factors. First, geographical distribution plays a pivotal role. Approximately 58% of Indonesia's population resides in urban areas, while 42% live in rural regions, resulting in substantial disparities in access to healthcare facilities [6]. Only 30% of hospitals are located in remote areas, whereas 70% are concentrated in urban centers, creating significant geographic barriers to care [7]. Second, the distribution of human resources in the health sector remains uneven. The ratio of general practitioners to the population is 1:1,000, while the ratio for specialist physicians; including oncologists is approximately 1:20,000, reflecting a severe shortage of specialized cancer care providers [8].

Economic constraints further intensify these challenges. Around 25% of the Indonesian population lives below the poverty line, limiting their ability to access quality healthcare services [9]. Only 60% of cancer patients registered under the National Health Insurance (JKN) program can fully utilize cancer care services, indicating persistent gaps in coverage and service availability [10]. Third, public education and awareness significantly influence healthcare access. Merely 30% of the population possesses adequate knowledge regarding cancer and the importance of early detection [7], while 40% of cancer patients delay seeking treatment due to limited understanding of cancer symptoms and associated risks. Regions with high poverty levels often lack sufficient support systems, further exacerbating disparities in access to care [11].

Transportation barriers also contribute substantially to access inequality. Only 30% of villages in Indonesia have adequate public transportation infrastructure [12]. Additionally, 20% of rural residents spend more than 10% of their income on transportation costs to reach healthcare facilities, creating a substantial financial burden [9]. Social and cultural factors further shape care-seeking behaviors. Approximately 35% of individuals in certain regions prefer traditional medicine over conventional medical treatment [13]. Family and community support; critical for patients undergoing cancer treatment is often insufficient in specific areas, compounding the challenges faced by patients [14]. Collectively, these structural, economic, social, and cultural inequalities present complex obstacles to improving healthcare access and quality for cancer patients in Indonesia.

Patient navigation programs were first established in New York in 1990 and were subsequently introduced in Indonesia in 2022. Navigators play a central role in addressing barriers related to information and education, care coordination, psychosocial and social support, resource access, and patient advocacy [15]. The emergence of this model is closely linked to persistent delays in diagnosis and treatment, driven by financial constraints, socioeconomic disparities, geographical limitations, cultural barriers, and low public awareness regarding the importance of cancer screening, all of which stem from inequitable access to healthcare services [16].

A study by Gondhowiardjo and colleagues reported high rates of treatment delays among cancer patients, attributable to both patient-related and healthcare system factors. These delays are commonly associated with low public awareness of early cancer symptoms, prolonged waiting times for diagnostic examinations, logistical challenges in accessing healthcare facilities, and the absence of an organized referral system [17]. Evidence indicates that patient navigation interventions are effective in accelerating diagnostic timelines, reducing financial barriers, improving patient satisfaction, and enhancing overall quality of life [18,19].

Hildegard Peplau's nursing theory underscores the importance of interpersonal relationships between nurses and patients, emphasizing trust-building and emotional support as essential components of care. Within this theoretical framework, it is envisioned that all patients, regardless of socioeconomic status or geographical location can obtain high-quality, affordable, and equitable care, ultimately contributing to improved treatment outcomes and enhanced quality of life for cancer patients [20]. This study aims to explore the lived experiences of cancer patients receiving navigation services from Cancer Patient Navigators (NAPAK) and examine how these experiences relate to healthcare access inequality. A distinctive contribution of this research lies in its ability to identify the long-term implications of access inequality on the quality of life of cancer patients, thereby providing critical evidence for future improvements in navigation services. Preliminary findings from observations and in-depth interviews conducted at the Cancer Patient Navigator Polyclinic (NAPAK) at Dharmais Cancer Hospital in September 2024 revealed that five out of ten respondents reported financial barriers, beyond geographical distance as the most significant obstacles to accessing healthcare services.

METHODS

Research design

This study adopts a qualitative research design grounded in a descriptive phenomenological approach [21]. This methodological orientation is intended to capture the intricate and multifaceted nature of patients' lived experiences, thereby providing a clear and authentic representation of the phenomenon under investigation. Through this approach, the researcher engages directly and intensively with participants to explore, analyze, and describe the essence of their experiences. Descriptive phenomenology enables a holistic examination of individuals' subjective realities, offering profound insights into their behaviors, motivations, actions, and perceptions as expressed through their own narratives and linguistic frameworks [22,23]. By prioritizing the voices of participants, this design facilitates a deeper understanding of how healthcare access inequality is experienced and interpreted within the context of cancer navigation services.

Participant selection

A purposive sampling strategy was employed to recruit participants who met the predefined inclusion criteria and were capable of providing rich, relevant, and meaningful information aligned with the study's objectives [24]. The sampling process was intentionally structured to achieve maximum variation across key demographic and experiential characteristics, including age, marital status, gender, employment status, cancer type, educational attainment, urban or rural domicile, ethnicity, duration of engagement with navigation services, economic access, and health insurance coverage. This diversity was essential for capturing a wide spectrum of experiences related to healthcare access inequality.

The inclusion criteria comprised: (1) cancer patients actively receiving services from a Cancer Patient Navigator (NAPAK); (2) individuals aged 20 years or older; (3) participants willing to share their experiences regarding healthcare access; and (4) proficiency in Bahasa Indonesia. Exclusion criteria included: (1) uncooperative patients; (2) patients who had not completed the navigation service program; (3) individuals unwilling to participate; (4) patients in emergency medical conditions; and (5) patients unable to communicate verbally.

To identify eligible participants, the researchers collaborated with hospitals and polyclinics offering NAPAK services. Potential participants were provided with detailed information regarding the study's purpose, anticipated benefits, interview procedures, and confidentiality measures. This recruitment strategy ensured the deliberate selection of individuals whose experiences were most relevant to the phenomenon under study [25]. Consistent with qualitative research standards, the final sample size was determined by data saturation [22]. In alignment with established phenomenological research, which typically involves 3 to 10 participants [26], data saturation in this study was achieved with 10 participants, at which point additional interviews no longer yielded new or meaningful insights.

Data analysis

Following data collection, the researchers conducted a systematic and rigorous analysis of significant statements, organizing them into clusters and subsequently synthesizing them into overarching themes [22]. The analytic process comprised the following steps:

1) Repeated listening and reading: Interview transcripts were reviewed multiple times to develop a comprehensive understanding of each participant's narrative.
2) Identifying significant statements: Meaningful excerpts were highlighted and coded using distinct colors or visual markers.
3) Formulating categories: Significant statements were synthesized into preliminary categories reflecting core experiential elements.
4) Thematic clustering: Categories were integrated into broader thematic structures, with original transcripts revisited to ensure accuracy and consistency.
5) Constructing descriptions: Themes were woven together to produce a rich, descriptive account of participants' experiences related to healthcare access inequality.
6) Narrative synthesis: Findings were articulated in a coherent narrative that preserved the clarity and authenticity of participants' voices.
7) Validation: The accuracy of the findings was confirmed through participant validation, ensuring that interpretations faithfully reflected their experiences.

NVivo 14 software facilitated the thematic analysis by supporting the organization, management, and visualization of qualitative data. Ten interview transcripts were imported into the software, followed by systematic coding and thematic categorization. During the validation phase, participants confirmed the accuracy of the findings through in-person meetings, digital communication, or telephone interviews.

Trustworthiness

Ensuring trustworthiness is essential for establishing the credibility and authenticity of qualitative findings, particularly when exploring sensitive patient experiences [22]. This study adhered to the four established criteria of trustworthiness:

1) Credibility: Achieved through prolonged engagement with participants, meticulous field notes, accurate verbatim transcription, regular peer debriefing with supervisors, and triangulation of data sources.

2) Transferability: Strengthened by selecting a diverse participant pool, enabling the findings to be applicable to broader contexts with similar characteristics.
3) Dependability: Maintained through continuous consultation with supervisors throughout the research process, ensuring methodological consistency and reducing researcher bias.
4) Confirmability: Enhanced through transparent thematic analysis procedures and collaborative audits with supervisors, ensuring that interpretations were grounded in the data and free from undue researcher influence.

RESULTS

Participant characteristics

This study involved 10 participants who had experienced various forms of healthcare access inequality. The participants' ages ranged from 31 to 68 years, comprising 7 females and 3 males. Their educational backgrounds were diverse, spanning from primary school to bachelor's degrees. Professionally, the group included 4 housewives, 4 employees, 1 junk collector, and 1 entrepreneur. Regarding healthcare financing, all participants utilized the National Health Insurance (JKN), categorized by provider type: 4 company-sponsored, 4 government-sponsored, and 2 independent members. The duration of their experiences with healthcare access inequality while receiving services from a Cancer Patient Navigator (NAPAK) ranged from 1 day to 11 months.

Themes

All participants shared their lived experiences regarding healthcare access inequality during their interaction with the NAPAK service. Thematic analysis of the data from the 10 participants yielded four pivotal themes: 1) various healthcare access inequalities; 2) the primary role of cancer patient navigators; 3) transportation and access disparities; and 4) impact of healthcare access disparities on health. These interconnected themes reveal significant insights into the experiences of cancer patients.

Theme 1: Various healthcare access inequalities

This theme explores the manifestations of unequal access encountered by patients receiving navigation services. The majority of participants identified significant barriers, including saturated schedules, complex administrative procedures, geographical distance, financial constraints, and appointment difficulties, all of which impeded their access to essential services.

"When the treatment quota is full, I have to wait again, which of course wastes time and energy; sometimes it's quite frustrating." (P1, Serang Banten)

"Obtaining healthcare services is quite difficult, especially with long doctor queues and a high volume of patients, which consumes a lot of time." (P2, Batam)

"It's a bit difficult, especially if you lack adequate information; you feel confused, not to mention the procedures that feel complicated." (P4, Bali)

In contrast, some participants perceived healthcare access as relatively manageable without substantial barriers, frequently highlighting the critical support provided by navigators:

"...I feel that I haven't experienced severe difficulties in accessing healthcare services so far; I can still have check-ups even if the doctor is on leave." (P3, Bogor)

"Access to healthcare services isn't really that difficult; it's easy. If I want to get treatment, I use my own car; I'll travel from Lampung to Jakarta because we want to recover, right?" (P10, South Lampung).

Theme 2: The primary role of cancer patient navigators

This theme delineates the functions and responsibilities of NAPAK in delivering navigation services. Navigators offer comprehensive support, ranging from technical information and procedural guidance to vital emotional support throughout the treatment continuum.

"I see navigators helping cancer patients receive the proper treatment they deserve... they convey our needs, especially to the doctors." (P2, Batam).

"...so, we don't miss seeing the doctor." (P8, South Lampung)

"...the navigator helps with information about the documents to prepare and ensures the information is complete before treatment starts." (P9, Tangerang)

Overall, participants considered the role of NAPAK highly effective in providing information and supporting patients throughout their entire care journey.

"...NAPAK is very effective; they provide guidance on treatment, registration processes, and information about halfway house facilities." (P2, Batam)

"Effective... I am very much helped by NAPAK; consultations are more relaxed compared to when I was with the doctor, where I felt tense and scared." (P3, Bogor)

"...NAPAK is very effective, especially for patients accessing cancer treatment for the first time." (P4, Bali).

Theme 3: Transportation and access disparities

Unequal access and transportation issues present formidable challenges within the healthcare system, particularly for cancer patients requiring regular care. While some participants found reaching facilities relatively easy, others faced systemic logistical barriers.

"Generally, transportation is quite easy in my area. The roads are good and there's plenty of public transport to get to the hospital, like taxis and online ride-hailing services." (P2, Batam)

"Access from Lampung to Jakarta is quite good, taking around 6 hours by private car... in my area, getting to healthcare facilities is easy... because I have a private car." (P10, South Lampung)

However, several participants experienced acute transportation difficulties related to geographical distance, remote locations, or inadequate infrastructure:

"...transportation in my area is quite difficult, especially at night... public transportation is rare... I have no choice but to wait for my husband to pick me up at the terminal." (P1, Serang Banten)

"Transportation in my area is very challenging. To get to a large hospital, I first have to take water transport, riding a ferry to cross to another area, then travel by land using public cars. You have to leave very early to avoid traffic, and the cost is quite high." (P7, Ambon-Maluku).

Theme 4: Impact of healthcare access disparities on health

This theme illustrates the physical and psychological toll of access inequality, specifically highlighting anxiety and distress.

"...living in Jakarta for treatment impacts my mental health... I feel anxious, worried about leaving my child in Batam, having no friends here, and feeling exhausted." (P2, Batam)

"I'm stressed and worried about having to seek treatment far from home in another city, but family support gives me the spirit to fight." (P10, South Lampung)

"This makes me feel stressed and tired, which impacts my physical health; sometimes I just feel exhausted." (P1, Serang Banten)

Participant expectations and hopes

Participants expressed a desire for more responsive and concrete actions from navigators to address their immediate needs, particularly regarding facilities and information transparency.

"I hope NAPAK services can be better in the future; little people like me can be helped, especially with daily living costs in the halfway house." (P5, Karawang)

"NAPAK services should be further improved, and facilities for ordinary people should be enhanced, especially since we're far from home and family." (P8, East Belitung)

"The BPJS program is good, but it still has shortcomings... make the program easier for ordinary people... so that online registration isn't difficult." (P5, Karawang)

DISCUSSION

The findings of this study are organized into four interconnected themes: (1) Various Healthcare Access Inequalities, (2) The Primary Role of Cancer Patient Navigators, (3) Transportation and Access Disparities, and (4) The Impact of Healthcare Access Disparities on Health. Collectively, these themes illustrate the multifaceted barriers that cancer patients face when seeking timely and equitable healthcare services. The results highlight how structural, geographical, financial, and informational challenges can negatively affect access to care and ultimately influence health outcomes. Across all themes, cancer patient navigators emerged as key facilitators who help patients overcome these barriers by providing guidance, coordinating services, addressing transportation and logistical challenges, and ensuring that patients receive appropriate information and support throughout the cancer care continuum. Their role is therefore essential in reducing healthcare disparities and promoting more equitable access to cancer care.

This research reveals that many patients encounter significant barriers in accessing healthcare services, which directly impacts the quality of care they receive. The majority of participants reported substantial difficulties, including saturated schedules, bureaucratic procedures, and high costs. Furthermore, many felt that appointment scheduling often hindered their access to necessary services, creating a disparity where some patients lack equitable access to health information [27]. Research by Alberto et al. (2023) emphasizes that these perceptions are significantly influenced by prior experiences and the quality of information received, further exacerbating inequalities in cancer diagnostic services [28].

The utilization of healthcare services, including patient satisfaction and long-term health outcomes, is crucial for evaluating the effectiveness of the healthcare system. Evidence suggests that superior access correlates with improved health outcomes, yet many patients still face formidable constraints [27]. Conversely, some participants perceived healthcare access as relatively manageable. They noted that an optimistic attitude and robust social support helped them navigate obstacles, highlighting the variation in healthcare experiences among cancer patients and indicating that not all patients encounter identical difficulties [29]. Research by Cahya et al. (2023) underscores that geographical barriers, such as distance and travel time, remain primary factors affecting healthcare utilization. To mitigate these issues, several strategies can be implemented: 1) Utilizing Geographic Information Systems (GIS) to identify underserved areas and plan service distribution; 2) Providing mobile health facilities to deliver services directly to remote communities; and 3) Expanding telemedicine to facilitate follow-up treatments and consultations without geographical constraints [30].

Effective navigation ensures that patients receive clear and accurate information throughout their treatment. Navigators do not merely guide patients through registration; they also serve as advocates, championing the patient's right to appropriate care. They foster trust and comfort by communicating patients' needs and concerns to clinicians [31]. Patient navigation is a vital component of oncology that bridges gaps for underserved populations, though it requires stronger policy support for sustainability. Studies indicate that navigation improves screening adherence, reduces diagnostic timelines, and enhances patient satisfaction [32]. Furthermore, navigators collaborate with the multidisciplinary medical team; including doctors and nurses to bridge communication gaps and ensure effective care execution [33]. As educators, they explain complex procedures, helping patients feel more prepared and informed. They also provide practical advice on self-care, demonstrating a commitment to the patient's holistic well-being [29]. By managing consultation schedules and ensuring documentation is complete, navigators reduce administrative burdens, allowing patients to focus on recovery [34,35]. Participants in this study regarded the role of NAPAK as highly effective, valuing the continuous support provided from the beginning to the end of the treatment journey [35]. The performance of NAPAK services is reflected in improved patient satisfaction and therapy adherence. The presence of navigators reduces stress levels and increases the delivery timeliness of service, contributing to better clinical outcomes [34]. Consequently, continuous development of training programs for navigators is essential to ensure they perform their duties effectively. Further research is also needed to better understand the long-term impact of navigators on patient experiences [33,31].

Regarding transportation, while some participants found access to facilities relatively easy; contributing to a positive patient experience [33] others faced significant logistical hardships. Limited transportation options, long distances, and inadequate public infrastructure represent major barriers to receiving necessary care [36]. For these individuals, traveling involved land and water routes, often in crowded and uncomfortable conditions, which added an immense burden to those already struggling with illness [37]. Evidence confirms that reliable transportation access is critical for health outcomes, as the inability to reach services results in dangerous treatment delays [33].

Social Mobility Theory emphasizes that limited transportation access acts as a significant barrier; specifically, as distance increases, the difficulty in obtaining healthcare services intensifies [38]. The experience of inequality significantly impacts participants' health, primarily through heightened anxiety and distress. This disparity profoundly affects emotional well-being, with many reporting prolonged stress and exhaustion. Therefore, addressing unequal access must be a central focus of healthcare reform [33]. Additionally, navigators play a crucial role in providing

informational support to help patients overcome financial and procedural challenges [29], while patients hope for clearer information accessibility, particularly through digital systems [37].

Finally, policy and government support are essential for enhancing healthcare programs. Participants felt that government involvement in insurance programs, such as JKN or BPJS, is vital for cancer patients [31, 34]. Despite the benefits of existing policies, there is a clear need for improvements in socialization, systemic efficiency, nutrition education, and guidance on service access to ensure all cancer patients in Indonesia receive effective and efficient care [33].

Research limitations

The small sample size in this study may limit the generalizability of the findings to a broader population. Additionally, as the research was conducted in a single specific location, the results may not be applicable to different regional contexts. There is also a potential for subjective bias in data collection due to the reliance on participants lived experiences. Furthermore, the limited timeframe of the study may have affected the depth of the analysis regarding the phenomena investigated.

CONCLUSION

This research successfully explored patients lived experiences in accessing healthcare services, effectively addressing the predetermined research objectives. The findings demonstrate that factors such as service satisfaction and systemic access barriers significantly influence the overall patient experience. Addressing these disparities is essential for ensuring equitable cancer care. Enhanced communication between healthcare providers and patients is paramount to ensuring the delivery of clear and accurate information. Strengthening this interpersonal bridge can significantly mitigate patient confusion and enhance overall satisfaction with the care process.

Enhanced communication between healthcare providers and patients is paramount to ensuring the delivery of clear and accurate information. Strengthening this interpersonal bridge can significantly mitigate patient confusion and enhance overall satisfaction with the care process. Future studies should employ larger sample sizes and encompass diverse geographical locations to strengthen the generalizability and validity of the findings. Longitudinal research would also be beneficial in understanding the evolving nature of patient experiences more comprehensively.

Professional training programs for healthcare providers should rigorously incorporate components of advanced communication and empathy. This will empower clinicians to better understand and proactively meet the multifaceted needs of cancer patients. Healthcare administrators and management should systematically integrate patient feedback into strategic service planning and development. Prioritizing patient voices is key to enhancing the quality, responsiveness, and accessibility of oncology services.

Ethical consideration, competing interest and source of funding

-Ethical integrity served as the cornerstone of this study, which received formal approval from the Research Ethics Committee of Dharmais Cancer Center Hospital (No: D.04.03/11.10/037/2025). The research rigorously applied the following ethical principles: confidentiality, through participant coding and secure data storage; anonymity, by omitting identifying details; informed consent, by providing comprehensive study disclosures; non-maleficence, by prioritizing participant comfort; autonomy, by respecting the right to withdraw; and justice, by ensuring fair and non-discriminatory treatment of all participants.
-There is no conflict of interest.
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