ZIBELINE INTERNATIONAL™ PUBLISHING

ISSN: 2785-8391 (Online)
CODEN: JHDCAZ

Journal of Healthcare in Developing Countries (JHCDC)

DOI: http://doi.org/10.26480/jhcdc.01.2024.27.30

RESEARCH ARTICLE

INVESTIGATING PATIENT PERSPECTIVES AND EXPERIENCES IN CHRONIC ILLNESS MANAGEMENT- A QUALITATIVE INQUIRY

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ARTICLE DETAILS

Article History:

Received 14 January 2024
Revised 18 February 2024
Accepted 22 March 2024
Available online 05 April 2024

ABSTRACT

This qualitative research study delves into the perspectives and experiences of patients regarding chronic illness management. Chronic illnesses present a significant challenge to healthcare systems globally, necessitating a thorough understanding of patient experiences to enhance care delivery. Through semi-structured interviews, this study explores the lived experiences, challenges, coping mechanisms, and suggestions for improvement as voiced by patients. Thematic analysis revealed nuanced insights into the multifaceted nature of chronic illness management from the patient's viewpoint. Findings underscore the importance of patient-centered approaches in healthcare delivery and offer actionable recommendations for enhancing chronic illness management strategies.

KEYWORDS

Chronic illness, patient perspectives, qualitative inquiry, healthcare experiences, thematic analysis.

1. INTRODUCTION

People, families, and healthcare systems all across the globe bear a heavy burden due to chronic illnesses. Conditions such as diabetes, cardiovascular diseases, chronic respiratory diseases, and mental health disorders pose persistent challenges, requiring long-term management strategies. Despite advancements in medical treatments and interventions, chronic illness management remains complex and multifaceted, often involving lifestyle modifications, medication adherence, regular monitoring, and ongoing support from healthcare providers. However, within this landscape, the perspectives and experiences of patients themselves are often overlooked, despite being integral to understanding the effectiveness and impact of healthcare interventions. This study seeks to address this gap by exploring the lived experiences, challenges, and recommendations for improvement as articulated by individuals managing chronic illnesses.

2. LITERATURE REVIEW

Chronic illness management encompasses a wide array of conditions, each presenting unique challenges and considerations. Diabetes, for example, requires meticulous blood sugar monitoring, dietary adjustments, and medication adherence, while cardiovascular diseases necessitate lifestyle modifications and regular check-ups to mitigate risks. Mental health disorders, on the other hand, may require a combination of therapy, medication, and social support for effective management. Within the literature, several key themes emerge regarding patient perspectives and experiences in chronic illness management. Firstly, the concept of patient-centered care is central to understanding the needs and preferences of individuals living with chronic conditions. Patient-centered care emphasizes collaboration between patients and healthcare providers, taking into account the patient's values, preferences, and goals in treatment planning.

Studies have shown that patient-centered approaches lead to improved treatment adherence, better health outcomes, and increased satisfaction with care (Davis et al., 2020). Secondly, the role of social support networks in chronic illness management cannot be overstated. People dealing with long-term health issues greatly benefit from the emotional support, practical help, and information sharing provided by loved ones, support groups, healthcare providers, and healthcare workers themselves. Social support networks can significantly influence treatment adherence, self-management behaviors, and overall quality of life for patients (Zhang et al., 2020; Zhang et al., 2019). Furthermore, the psychological impact of chronic illness must be acknowledged and addressed in healthcare settings.

Many individuals with chronic conditions experience feelings of anxiety, depression, stress, and stigma, which can adversely affect their ability to cope with their illness and engage in self-care activities. Integrating mental health support services into chronic illness management programs is essential for addressing these psychological comorbidities and improving overall patient well-being (Cheung et al., 2019; Heinze et al., 2021). Moreover, the challenges of medication adherence and lifestyle modifications pose significant barriers to effective chronic illness management. Patients often struggle to adhere to complex medication regimens, dietary restrictions, exercise routines, and other lifestyle modifications prescribed by healthcare providers.

Understanding the reasons behind non-adherence and developing tailored interventions to support patients in overcoming these barriers are critical steps in enhancing treatment effectiveness and long-term health outcomes (Fernandez-Lazaro et al., 2019; Stewart et al., 2023). Additionally, disparities in access to healthcare services and resources can exacerbate challenges for individuals managing chronic conditions, particularly those from marginalized or underserved communities. Socioeconomic factors, geographical location, cultural beliefs, and structural barriers can all influence an individual's ability to access timely and appropriate care, leading to disparities in health outcomes. Addressing these disparities requires a multifaceted approach that addresses both individual-level and systemic factors contributing to healthcare inequities (Hughes et al., 2023).

Quick Response Code	Access this article online	
	Website: www.jhcdc.com.my	DOI: 10.26480/jhcdc.01.2024.27.30

Cite The Article: Saleh Ahmed Jalal Siam (2024). Investigating Patient Perspectives and Experiences in Chronic Illness Management- A Qualitative Inquiry. *Journal of Healthcare in Developing Countries, 4(1): 27-30.*

3. Materials and Methods

3.1 Study Design

This qualitative study employed a phenomenological approach to explore the lived experiences and perspectives of patients managing chronic illnesses. Phenomenology aims to understand the essence of human experiences from the perspective of those experiencing them, making it well-suited for investigating subjective phenomena such as illness experiences.

3.2 Participants

Participants were recruited through purposive sampling, aiming for maximum variation to capture a diverse range of experiences. Inclusion criteria included individuals aged 18 or above diagnosed with a chronic illness, able to provide informed consent, and willing to participate in an interview. Efforts were made to ensure representation across various chronic conditions, socioeconomic backgrounds, and demographic characteristics.

3.3 Data Collection

Semi-structured interviews were conducted with participants to explore their experiences, challenges, coping mechanisms, and suggestions for improvement in chronic illness management. Interviews were conducted either in-person or via telecommunication platforms, based on participant preference and feasibility. Each interview lasted approximately 45-60 minutes and was audio-recorded with participant consent.

3.4 Data Analysis

Thematic analysis was employed to analyze the interview data, following six-phase framework (Byrne, 2022). Audio recordings were transcribed verbatim, and transcripts were imported into qualitative analysis software for organization and coding. Initial codes were generated through line-by-line coding, followed by the development of broader themes through iterative coding and constant comparison. Themes were refined through discussion among research team members until consensus was reached.

3.5 Ethical Considerations

Ethical approval was obtained from the Institutional Review Board prior to data collection. Informed consent was obtained from all participants, and measures were taken to ensure confidentiality, privacy, and voluntary participation throughout the study.

4. Results

The analysis revealed several key themes regarding patient perspectives and experiences in chronic illness management, including:

- Navigating Healthcare Systems: Participants discussed challenges with accessing healthcare services, coordinating care between multiple providers, and navigating insurance coverage.
- Impact on Daily Life: Chronic illnesses had profound impacts on various aspects of daily life, including employment, social relationships, and leisure activities.
- Coping Mechanisms: Participants utilized various coping strategies, such as social support, self-care practices, and seeking information online, to manage their illnesses.
- Challenges with Medication Adherence: Many participants struggled with medication adherence due to side effects, cost concerns, and forgetfulness.
- Need for Patient Education: Participants expressed a desire for more comprehensive education and support from healthcare providers regarding their conditions and treatment options.

5. Findings and Discussions

The findings from this qualitative inquiry shed light on the multifaceted nature of chronic illness management from the perspective of patients. Through in-depth interviews, participants revealed their lived experiences, challenges, coping mechanisms, and suggestions for improvement in managing their chronic conditions. The discussions below delve into the key themes identified in the analysis and their broader implications for healthcare practice, policy, and future research.

5.1 Navigating Healthcare Systems

Participants articulated various challenges encountered while navigating healthcare systems in their journey of chronic illness management. Issues such as difficulty accessing specialized care, long wait times for appointments, and complex insurance processes were commonly reported. These challenges often contributed to feelings of frustration, stress, and disillusionment among patients. Furthermore, the fragmentation of care and lack of coordination between healthcare providers exacerbated these difficulties, leading to gaps in care delivery and suboptimal health outcomes.

Table 1: Challenges in Navigating Healthcare Systems

Challenges	Frequency of Mention
Difficulty accessing specialized care	High
Long wait times for appointments	Moderate
Complex insurance processes	High
Fragmentation of care	Moderate
Lack of coordination between healthcare providers	High

The findings underscore the need for healthcare systems to streamline processes, improve access to specialized care, and enhance coordination between providers to better meet the needs of individuals managing chronic illnesses. Efforts to integrate care across healthcare settings, utilize care coordination tools, and implement patient navigation programs could help alleviate the burdens associated with navigating complex healthcare systems (Kokorelias et al., 2021).

5.2 Impact on Daily Life

Chronic illnesses were found to have profound impacts on various aspects of participants' daily lives, including employment, social relationships, and leisure activities. Many participants described struggles with maintaining employment due to health-related limitations, discrimination, or the need for frequent medical appointments. Additionally, managing chronic conditions often required significant time and energy, leading to social isolation, strain on relationships, and disruption of leisure activities. These impacts extended beyond the physical manifestations of the illness, affecting participants' overall well-being and quality of life.

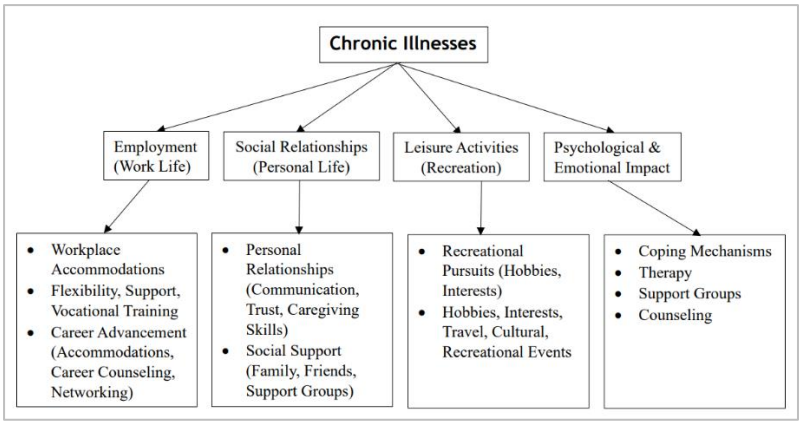

Figure 1: Impacts of Chronic Illnesses on Daily Life

The findings highlight the holistic nature of chronic illness management, emphasizing the importance of addressing not only the medical aspects of the condition but also its broader impacts on patients' lives. Healthcare providers should consider the social, emotional, and practical implications of chronic illnesses when developing treatment plans and support strategies. Interventions aimed at promoting social participation, vocational rehabilitation, and psychosocial support could help mitigate the adverse effects of chronic illnesses on daily functioning and overall quality of life (Yeung et al., 2022).

5.3 Coping Mechanisms

Participants employed various coping strategies to navigate the challenges associated with managing chronic illnesses. Social support from family, friends, and peers emerged as a crucial coping mechanism, providing emotional reassurance, practical assistance, and a sense of belonging. Additionally, participants engaged in self-care practices such as mindfulness, relaxation techniques, and hobbies to alleviate stress and enhance their well-being. Seeking information and support online also played a significant role in empowering participants to take an active role in their care and connect with others facing similar challenges.

Table 2: Coping Mechanisms Reported by Participants

Coping Mechanisms	Frequency of Mention
Social support	High
Self-care practices	Moderate
Seeking information and support online	Moderate

The findings highlight the importance of fostering social support networks and promoting self-care practices in chronic illness management. Healthcare providers can play a vital role in facilitating access to support resources, providing education on coping strategies, and empowering patients to advocate for their needs. Peer support programs, online communities, and self-management interventions tailored to patients' preferences and cultural backgrounds could further enhance coping resources and resilience among individuals managing chronic conditions (Brown et al., 2023).

5.4 Challenges with Medication Adherence

Many participants reported challenges with medication adherence, citing reasons such as side effects, cost concerns, and forgetfulness. Complex medication regimens, polypharmacy, and the perceived lack of efficacy of medications were also identified as barriers to adherence. Non-adherence to prescribed treatments often led to suboptimal health outcomes, exacerbation of symptoms, and increased healthcare utilization.

Table 3: Barriers to Medication Adherence

Barriers to Medication Adherence	Frequency of Mention
Side effects	High
Cost concerns	Moderate
Forgetfulness	High
Complex medication regimens	High
Perceived lack of efficacy of medications	Moderate

The findings underscore the importance of addressing medication adherence barriers in chronic illness management. Healthcare providers should engage in open and non-judgmental discussions with patients about their medication concerns, provide education on the importance of adherence, and explore strategies to overcome barriers. Simplifying medication regimens, utilizing reminder systems, and involving patients in treatment decisions could help improve adherence and optimize treatment outcomes (Singh and Varshney, 2019).

5.5 Need for Patient Education

Participants expressed a desire for more comprehensive education and support from healthcare providers regarding their conditions and treatment options. Many felt overwhelmed by the complexity of their illnesses and lacked sufficient knowledge to effectively manage their health. Participants emphasized the importance of accessible, culturally sensitive, and patient-centered education materials that empower them to make informed decisions about their care.

Table 4: Participants' Perspectives on Patient Education

Perspectives on Patient Education	Frequency of Mention
Desire for comprehensive education	High
Feeling overwhelmed by illness complexity	Moderate
Importance of accessible materials	High
Focus on patient-centeredness.	High

The results stress the importance of patient education in enabling people to be active participants in their own healthcare management. Healthcare providers should prioritize patient education efforts, providing tailored information that addresses patients' information needs, health literacy levels, and cultural preferences. Utilizing multimedia platforms, peer educators, and community-based programs could enhance the reach and effectiveness of patient education initiatives, ultimately improving health outcomes and promoting patient engagement in chronic illness management (Aladin et al., 2023).

5.6 Broader Implications and Future Directions

Overall, the findings of this study have significant implications for healthcare practice, policy, and future research in the field of chronic illness management. By understanding the perspectives and experiences of patients, healthcare providers can develop more patient-centered approaches to care delivery that address the holistic needs of individuals managing chronic conditions. Policymakers can use these insights to inform the development of policies and programs that promote access to comprehensive, coordinated, and culturally competent care for individuals with chronic illnesses.

Future research should continue to explore patient perspectives and preferences to identify effective strategies for enhancing chronic illness management. Longitudinal studies are needed to examine the long-term impact of interventions aimed at addressing the challenges identified in this study on health outcomes, quality of life, and healthcare utilization. Additionally, research exploring the perspectives of healthcare providers, caregivers, and other stakeholders involved in chronic illness management could provide valuable insights into the complexities of care delivery and inform efforts to improve patient outcomes and experiences.

6. Conclusion

In conclusion, this qualitative inquiry offers valuable insights into the lived experiences, challenges, and coping mechanisms of individuals managing chronic illnesses. By recognizing the broader impacts of chronic conditions on patients' lives and addressing their diverse needs, healthcare providers and policymakers can work towards developing more effective and patient-centered approaches to chronic illness management.

References

Aladin, B., Thompson, M., Addison, D., Havens, J., McGowan, J., Nash, D., and Smith, C., 2023. The YGetIt? Program: A Mobile Application, PEEP, and Digital Comic Intervention to Improve HIV Care Outcomes for Young Adults. Health Promotion Practice, 24 (4), Pp. 658–668.

Brown, S.E., Shah, A., Czuber-Dochan, W., Bench, S., and Stayt, L., 2023. Non-pharmacological interventions for self-management of fatigue in adults: An umbrella review of potential interventions to support patients recovering from critical illness. Journal of Critical Care, 75, Pp. 154279.

Byrne, D., 2022. A worked example of Braun and Clarke's approach to reflexive thematic analysis. Quality & Quantity, 56 (3), Pp. 1391–1412.

Cheung, S., Spaeth-Rublee, B., Shalev, D., Li, M., Docherty, M., Levenson, J., and Pincus, H. A., 2019. A model to improve behavioral health integration into serious illness care. Journal of Pain and Symptom Management, 58 (3), Pp. 503–514.

Davis, E.L., Kelly, P.J., Deane, F.P., Baker, A.L., Buckingham, M., Degan, T., and Adams, S., 2020. The relationship between patient-centered care and outcomes in specialist drug and alcohol treatment: A systematic literature review. Substance Abuse, 41 (2), Pp. 216–231.

Fernandez-Lazaro, C.I., Adams, D.P., Fernandez-Lazaro, D., Garcia-González, J.M., Caballero-Garcia, A., and Miron-Canelo, J.A., 2019. Medication adherence and barriers among low-income, uninsured patients with multiple chronic conditions. Research in Social and Administrative Pharmacy, 15 (6), Pp. 744–753.

Heinze, G., Sartorius, N., Guizar Sanchez, D.P., Bernard-Fuentes, N., Cawthorpe, D., Cimino, L., Cohen, D., Lecic-Tosevski, D., Filipcic, I., Lloyd, C., and others. 2021. Integration of mental health comorbidity in medical specialty programs in 20 countries. The International Journal of Psychiatry in Medicine, 56 (4), Pp. 278–293.

Hughes, A.J., Gunn, H., Siengsukon, C., Stearns, M.A., James, E., Donley, T., Grandner, M. A., Thomas, S.J., Hansen, K., and Williams, N.J., 2023. Eliminating sleep health disparities and achieving health equity: Seven areas for action in the behavioral sleep medicine community. Behavioral Sleep Medicine, 21 (5), Pp. 633–645.

Hughes, T.L., Bochicchio, L., Drabble, L., Muntinga, M., Jukema, J.S., Veldhuis, C.B., Bruck, S., and Bos, H., 2023. Health disparities in one of the world's most progressive countries: a scoping review of mental health and substance use among sexual and gender minority people in the Netherlands. BMC Public Health, 23 (1), Pp. 2533.

Kokorelias, K.M., Shiers-Hanley, J.E., Rios, J., Knoepfli, A., and Hitzig, S.L., 2021. Factors influencing the implementation of patient navigation programs for adults with complex needs: a scoping review of the literature. Health Services Insights, 14, Pp. 11786329211033268.

Singh, N., and Varshney, U., 2019. Medication adherence: a method for designing context-aware reminders. International Journal of Medical Informatics, 132, Pp. 103980.

Stewart, S.J.F., Moon, Z., and Horne, R., 2023. Medication nonadherence: health impact, prevalence, correlates and interventions. Psychology & Health, 38 (6), Pp. 726–765.

Yeung, P., Severinsen, C., Good, G., and O'Donoghue, K., 2022. Social environment and quality of life among older people with diabetes and multiple chronic illnesses in New Zealand: Intermediary effects of psychosocial support and constraints. Disability and Rehabilitation, 44 (5), Pp. 768–780.

Zhang, X., Zheng, Y., Qiu, C., Zhao, Y., and Zang, X., 2020. Well-being mediates the effects of social support and family function on self-management in elderly patients with hypertension. Psychology, Health & Medicine, 25 (5), Pp. 559–571.

Zhang, Y., Yan, F., and Jiang, W., 2019. Relationship between self-management behaviors and health-related quality of life among Chinese patients with coronary heart disease: a cross-sectional study. Contemporary Nurse, 55 (6), Pp. 554–564.