



## Emotional and Psychological Experiences of Family Caregivers in Cancer Medication Management: A Phenomenological Study

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### ABSTRACT

Cancer treatment often involves complex medication regimens, which can be physically and emotionally taxing for patients and their families. While much research has focused on the patient's experience, less attention has been paid to the subjective experiences of family members who support them, particularly in managing medication-related challenges. A gap remains in understanding how family caregivers experience and interpret the emotional and psychological burdens of supporting patients through treatment. In this study, we use a phenomenological approach to explore the lived experiences of family members providing support for cancer patients, specifically focusing on medication management and its associated emotional challenges. Data was collected through in-depth interviews with 15 family caregivers, and thematic analysis was conducted to identify key themes. Our findings reveal that family members experience significant emotional distress related to the side effects of cancer medication but emotional support and communication within families were essential to managing these challenges. These findings underscore the importance of healthcare providers offering targeted interventions to alleviate caregiver distress and improve communication strategies. Healthcare providers should consider implementing regular counseling sessions for family caregivers and integrating support systems into the cancer care process. The results contribute to a deeper understanding of caregiving dynamics and offer implications for future research and support strategies for family caregivers.



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## INTRODUCTION

Cancer remains one of the leading causes of morbidity and mortality globally, affecting millions of individuals each year. The treatment of cancer often involves complex medication regimens that include chemotherapy, immunotherapy, and other pharmacological interventions aimed at reducing tumor growth and preventing metastasis (Lacy dkk., 2023). However, these treatments are often accompanied by significant side effects, which can adversely impact not only the physical health of patients but also their emotional, psychological, and social well-being. The experience of managing these side effects and adhering to treatment protocols can be profoundly challenging, particularly for those who are supported by family members.

Family members of cancer patients play a pivotal role in the caregiving process, particularly in managing medication and providing emotional support. This caregiving role, while essential for the patient's treatment adherence, often places significant emotional and psychological strain on the family. The emotional toll, coupled with the challenges of medication management, creates a complex dynamic that is largely shaped by the subjective experiences of the family members. These individuals are often required to navigate the medical complexities of treatment while also managing the social and emotional needs of both the patient and themselves (Lee dkk., 2011). Despite the critical role that families play, there remains a limited understanding of their experiences, particularly in terms of how they perceive the effects of medication and the challenges they face in supporting their loved ones.

The need to explore the subjective experiences of family members in this context is essential. While much of the existing research focuses on the patient's perspective, the family's role in supporting cancer treatment has been less thoroughly investigated. Understanding the emotional and psychological burden that family members endure can shed light on the ways in which their experiences impact both their caregiving roles and their own well-being (Nwankwo dkk., 2021). A phenomenological approach is particularly suited for this purpose, as it allows for an in-depth exploration of the lived experiences of family members, highlighting the personal meanings they assign to their experiences and how these experiences shape their perspectives on caregiving. This research aims to bridge the gap in understanding the intersection of family caregiving and cancer treatment, focusing on the nuanced, subjective experiences of those who are often central to the patient's journey.

Research on the lived experiences of individuals in various phenomena, particularly in caregiving and chronic illness management, has become an increasingly significant area of study. Phenomenological research offers a unique lens through which to explore how people perceive and make sense of their experiences in specific contexts. In the case of family members caring for cancer patients, phenomenological studies have provided insights into the emotional and psychological challenges faced by caregivers, but these studies have often been limited by the scope of inquiry or the methodologies employed. By focusing on the subjective experience, phenomenology allows for a deeper understanding of the meanings individuals assign to their caregiving roles and the impact of those experiences on their well-being.

However, capturing the depth of these experiences is inherently challenging. Traditional quantitative research methods, which often focus on statistical significance and generalization, are not equipped to fully explore the nuances of human experience, particularly in the context of caregiving. The complexity of the emotional and psychological burden faced by family members requires a more nuanced approach that accounts for individual perspectives, feelings, and perceptions (Alazri dkk., 2007). Quantitative methods often fail to capture the richness of the caregiving experience, as they cannot adequately address the subjective dimensions of emotion, meaning, and personal transformation. This highlights a methodological gap, as the true essence of caregiving experiences can only be understood through qualitative approaches that allow for a detailed exploration of individual stories and lived realities.

Thus, while previous studies have explored aspects of caregiving and patient treatment, they often fall short in providing a holistic understanding of the subjective experiences of family members. The limitations of quantitative and traditional qualitative methods underscore the need for a phenomenological approach, which focuses on exploring the deep, personal meanings embedded in these caregiving experiences. This study seeks to address this gap by providing a thorough and meaningful investigation of how family members experience and interpret their roles in supporting cancer patients through medication management.

In addressing the challenges of family caregiving in cancer treatment, existing solutions have often focused on practical, clinical approaches (Azevedo & Payne, 2001). These typically involve providing structured support programs or using standardized assessment tools to gauge caregiver burden or patient adherence. While such strategies have their merits in improving patient outcomes, they often fail to capture the deeper, subjective experiences of family members as they support their loved ones through medication management. These approaches, grounded in more conventional, quantitative research methods, tend to overlook the emotional and psychological complexities of caregiving, leaving the richer dimensions of the family members' lived experiences unexamined.

The limitations of these traditional methods highlight a significant gap in understanding the full spectrum of caregiving experiences. For example, while caregiver burden assessments provide valuable information on the practical aspects of caregiving, they do not offer insights into how family members interpret their roles, the emotional impacts of supporting a cancer patient, or how they make sense of the challenges related to medication side effects. As such, these methods only provide a

partial view of the caregiving experience, missing the intricate nuances that emerge in real-world contexts.

An alternative approach, phenomenology, offers the potential to fill this gap by exploring the essence of these experiences in a more holistic and in-depth manner. By focusing on the lived experiences of family members, phenomenology allows for a deeper exploration of the meanings they attach to their roles and the emotional and psychological impacts of caregiving (Maurer dkk., 2017). This study seeks to address this gap by adopting a phenomenological approach to understand how family members experience and make sense of their involvement in cancer treatment, particularly in managing the side effects of medication. Through this lens, the study aims to uncover the underlying meanings and emotions that shape the caregiving experience, offering a more complete understanding of the phenomenon.

Several studies have explored the experiences of family members in supporting cancer patients, yet there remains a gap in understanding the deeper emotional and psychological aspects of this role. Existing literature often focuses on caregiver burden, providing useful insights into the practical challenges caregivers face. However, few studies examine the subjective meanings attached to caregiving, particularly regarding the management of medication side effects. Previous research on family caregiving in cancer treatment has primarily utilized quantitative methods or structured interviews, which tend to overlook the nuanced, lived experiences of caregivers. This study builds on these foundations but aims to fill the gap by applying a phenomenological approach to better understand the essence of family members' experiences in supporting medication management.

The proposed phenomenological approach was chosen because it allows for a comprehensive exploration of the lived experiences of family members. Phenomenology focuses on capturing the subjective experiences of individuals, seeking to understand how they make sense of their worlds and what meanings they attribute to their experiences (Cho dkk., 2022). This method is particularly effective in addressing the research gap identified in earlier sections, as it enables the study of emotional, psychological, and relational aspects that other methodologies fail to uncover. By delving deeply into the caregivers' personal narratives, this approach offers a richer, more holistic understanding of their experiences and perspectives on supporting cancer treatment. Through in-depth interviews and thematic analysis, this study aims to provide new insights into the role of family members in cancer care.

This article is structured as follows: the introduction provides the context for the study, outlining the relevance of exploring family members' experiences in cancer treatment. The methodological section explains the phenomenological approach used, detailing the data collection process and how themes were identified (de-Graft Aikins dkk., 2010). The results present the findings from the analysis of caregiver experiences, followed by a discussion that situates these findings in the broader context of caregiving literature. Finally, the article concludes by offering insights into the implications for future research and practical applications in cancer care settings.

## **RESEARCH METHODS**

### **Study Design**

A phenomenological approach was adopted for this study to explore the lived experiences of family members supporting cancer patients in medication management. This approach was selected due to its focus on understanding subjective experiences and uncovering the deeper meanings associated with a specific phenomenon (Okano dkk., 2021). Phenomenology allows for an in-depth exploration of how individuals perceive and make sense of their personal experiences. In this study, a descriptive phenomenology approach was used, aiming to capture the essence of the experiences of family members without delving into interpretations or broader generalizations. This design enabled a rich, detailed understanding of the role that family members play in the cancer treatment process and their perceptions of the challenges patients face with medication side effects.

### **Participants**

Participants were selected using purposive sampling to ensure that they had relevant experiences related to the phenomenon under investigation. The study included family members of cancer patients who had been actively involved in the medication management process. Inclusion criteria consisted of individuals aged 18 years or older who had been providing care and support to a cancer patient for at least six months (Herberger dkk., 2011). Exclusion criteria included individuals with a history of severe mental health conditions or those who had not been involved in medication management. A total of 15 participants were included in the study, with an age range from 30 to 65 years, comprising 9 women and 6 men. The participants varied in their relationship to the patient, including spouses, children, and siblings, which provided a diverse range of perspectives on the caregiving experience.

### **Data Collection**

Data was collected through semi-structured in-depth interviews, allowing participants to share their personal experiences in a flexible and open-ended manner. The interviews were conducted in private settings, such as the participants' homes or a quiet meeting room, to ensure a comfortable environment conducive to open dialogue. Each interview lasted between 60 to 90 minutes. A semi-structured interview guide was used, focusing on the participants' experiences and feelings about their role in supporting the patient's medication regimen, the emotional and psychological challenges involved, and their perceptions of the medication's effects on the patient's quality of life (Singh dkk., 2021). The interview guide was adapted from previous research on caregiving in cancer treatment and was modified slightly to fit the context of this study. All interviews were audio-recorded with the participants' consent for accuracy in data transcription.

### **Data Analysis**

Data was analyzed using a thematic analysis approach, in which the main themes and sub-themes were identified through systematic steps. First, the audio-recorded interviews were transcribed verbatim. Then, the transcriptions were read multiple times to gain a comprehensive understanding of the content. Meaning units were extracted from the transcriptions, and these units were grouped into categories based on thematic similarities. The data was then further reduced through thematic reduction to capture the essence of the participants' experiences. Thematic analysis helped identify key patterns and recurring themes, such as the importance of emotional support, the impact of medication side effects, and the role of communication within families. NVivo software was used to organize and assist in the coding of data, ensuring that the analysis remained systematic and consistent.

### **Ethics**

The study was conducted in accordance with ethical standards, ensuring that participants' rights and confidentiality were respected throughout the research process. Ethical approval was obtained from the relevant research ethics committee. All participants provided informed consent, including written consent for audio-recording the interviews. The confidentiality of the participants was maintained by anonymizing their personal information, and all data were stored securely in password-protected files (Mboweni & Risenga, 2023). Participants were informed that they could withdraw from the study at any time without any consequences. The research adhered to ethical guidelines for research involving human subjects, as outlined by international and local standards.

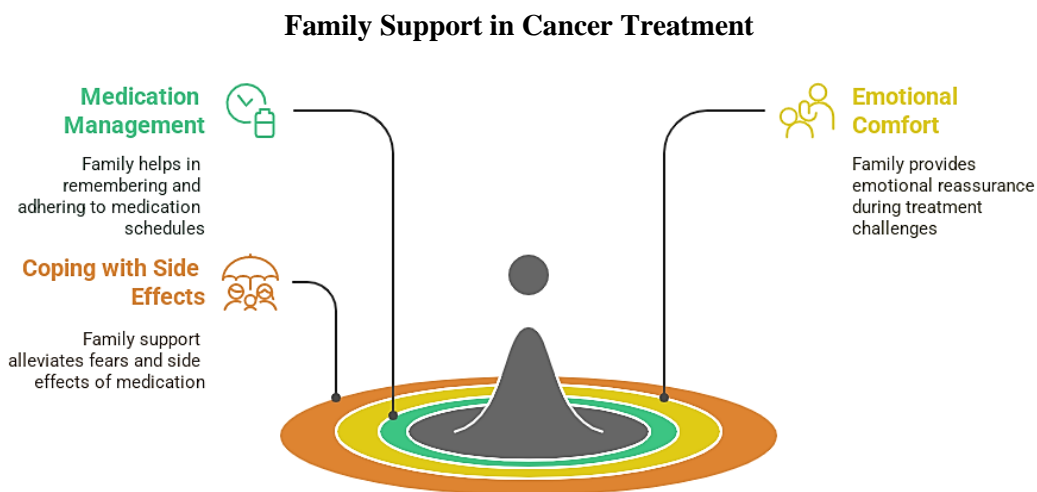
## **RESULTS**

### **Family Support in Medication Management**

The support of family members emerged as a central theme in the participants' experience with cancer treatment. Many participants described the role of their family members as crucial in managing the challenges associated with their medication regimen. A patient shared, "My family is everything. They help me remember when to take my medicine, and they are the ones who stay by me when the side effects get too much to handle." The presence of family members was often associated with a sense of comfort and reassurance, particularly in moments of physical or emotional distress.

For several participants, the emotional support from family members made the experience of enduring the side effects of the medication more bearable.

Participants frequently discussed the emotional toll that the medication had on them, with some describing feelings of helplessness and fear. One participant said, "It's the side effects that scare me the most. But my wife always tells me, 'We'll get through this together.' That makes me feel a little stronger." The ongoing emotional support from family members not only helped participants cope with the daily struggles of their treatment but also facilitated their adherence to the prescribed medication regimen.



### Family's Perception of Medication Side Effects

Another key theme that emerged was the family's perception of the medication's side effects. While patients often focused on the physical symptoms, family members voiced concerns about the emotional and psychological impacts. One family member noted, "It's not just about the nausea or the fatigue. It's how this treatment is changing her mentally, how it affects her spirit." The impact of the side effects was often seen through the eyes of family members who noticed the emotional strain placed on their loved ones.

Participants frequently mentioned that their families were their advocates, ensuring they received the best care and emotional support. However, some participants also expressed feelings of guilt for burdening their families with the emotional toll of their treatment. As one participant described, "I hate that I make my children worry so much about me, but I just don't have the strength to fight alone." This dynamic between patients and their families highlights the complex role that family members play in the medication journey, often balancing between providing care and managing the emotional burden of supporting a loved one through cancer treatment.

### Communication and Understanding within the Family

Communication within the family emerged as a vital factor in providing effective support. Several participants described how open communication helped them understand their medication regimen better, which in turn made it easier to manage their treatment. One participant explained, "We have a routine now. Every time I have to take my medicine, my daughter reminds me, and we talk about how I'm feeling. It helps me feel more in control." In families where communication was open and frequent, patients reported a greater sense of control over their treatment, as they felt more informed and understood.

On the other hand, participants in families where communication was more limited expressed frustration and isolation. One participant stated, "I feel like I'm in this alone. My family just doesn't talk about my treatment. It's like they want to pretend it's not happening." This lack of communication sometimes led to feelings of neglect or misunderstanding, underscoring the importance of family dialogue in the treatment process.

The findings reveal that family support plays a significant role in managing the emotional and psychological challenges of cancer treatment, especially regarding medication. Family members are central in ensuring adherence to medication schedules, providing emotional support, and advocating for the patient's well-being. However, there are challenges, particularly related to communication within families, which can either enhance or hinder the patient's experience. These findings underscore the importance of considering family dynamics in the treatment process, as they significantly influence the patient's ability to cope with the side effects of their medication and their overall quality of life.

## **DISCUSSION**

The main findings of this study highlight the crucial role that family members play in managing cancer patients' medication regimens, emphasizing the emotional and psychological support they provide. Participants described their caregiving experiences as both rewarding and challenging, with a significant emotional toll resulting from the side effects of treatment. The research specifically addressed how these caregiving experiences shape their perceptions of cancer treatment and their personal well-being. These findings shed light on the complexities of caregiving, particularly in relation to the emotional burdens and psychological stress family members experience, which are often overlooked in existing research.

This study contributes to a deeper understanding of the experiences of family members supporting cancer patients, providing insight into the personal meanings they attach to their caregiving roles. It addresses the research gap by demonstrating that family members' emotional and psychological experiences are just as significant as the physical aspects of caregiving. The study found that emotional support and open communication within families are essential to the caregiving process, as they help alleviate some of the distress caused by treatment side effects. These insights offer a more holistic view of caregiving and suggest that cancer care should consider not only the patient's needs but also the needs of their family members, who often act as primary caregivers.

When compared to previous literature, this study aligns with findings that suggest caregiving in cancer treatment is a highly emotional and socially complex experience. Studies by Rahman dkk (2022) have highlighted the psychological and emotional toll that caregivers experience, but this study expands on those findings by focusing on the specific challenges faced by family members managing medication side effects. The study's findings complement the work of Fowler (2008), who emphasized the importance of family support systems in cancer care. However, unlike many previous studies, this research delves deeper into the personal, subjective experiences of caregivers, offering insights into the meanings and emotional impacts of their roles. This contribution is essential for understanding how caregiving experiences can shape family members' perceptions of their loved ones' treatment and the broader context of cancer care.

### **Implications of Findings**

The findings from this study have significant implications both for research and practical application. The emotional and psychological burdens experienced by family members in cancer treatment caregiving are often overlooked, yet they play a critical role in the patient's overall care. By highlighting the importance of emotional support, this research suggests that family members should not only be considered as caregivers but as essential partners in the patient's treatment process. Clinicians and healthcare professionals should be aware of the complex emotional dynamics within caregiving families, and services aimed at supporting cancer patients should also include interventions tailored to family caregivers. These interventions could include counseling or support groups that address the psychological challenges caregivers face. Socially and culturally, these findings emphasize the need for a broader perspective on caregiving in the context of chronic illness, where the family's role extends beyond practical support and encompasses profound emotional involvement.

### **Limitations of the Study**

Despite the valuable insights gained, several limitations must be acknowledged. The sample size, consisting of 15 family members, while sufficient for qualitative research, may limit the generalizability of the findings to larger populations. Additionally, the study's focus on family members within a specific geographical region or cultural context might not fully reflect the experiences of caregivers in different cultural or social settings. The use of in-depth interviews also means that the data is inherently subjective, and participants' reflections may be influenced by personal biases or memory recall. Further research with a larger and more diverse sample, possibly including different regions or countries, would help validate the findings and explore the universality of the themes identified. Additionally, future studies could benefit from longitudinal designs that track the experiences of caregivers over time, which would allow for a deeper understanding of the evolution of caregiving roles and emotional challenges.

### **Prospects for Future Research**

Building on the insights from this study, future research could expand the exploration of the role of family members in cancer treatment by investigating how these caregiving experiences evolve over the course of treatment or across different stages of the cancer journey. Longitudinal studies could provide a more comprehensive view of the changes in family members' emotional and psychological responses as they witness the progression or remission of the disease (Laranjeira dkk., 2022). Additionally, comparing the experiences of caregivers across different cultural or healthcare settings could shed light on how social and cultural factors influence caregiving dynamics. Finally, research could explore the effectiveness of specific interventions or support systems designed to help family caregivers manage the emotional and psychological challenges they face, providing more practical insights into improving the overall caregiving experience.

### **CONCLUSION**

This study explored the subjective experiences of family members who support cancer patients in managing medication regimens, focusing on the emotional and psychological challenges they face. The findings highlight the significant role of family caregivers, emphasizing how emotional support and communication within families are essential in navigating the difficulties associated with treatment side effects. These results address a gap in previous research, which primarily focused on patient outcomes, by providing a deeper understanding of the caregiver's experience and their vital role in the treatment process. The study underscores the importance of integrating family support into cancer care strategies, suggesting that healthcare providers consider the emotional well-being of family caregivers. Further research could examine the long-term emotional impact on caregivers and explore cross-cultural differences in caregiving experiences. This would expand on the current findings and provide a broader perspective on the challenges faced by caregivers in different settings.

### **CONFLICT OF INTEREST**

The authors declare that there is no conflict of interest regarding the publication of this article. The research was conducted with full academic integrity and without any commercial or financial influence that could have affected the study design, data analysis, or interpretation of the results.

### **REFERENCES**

- Alazri, M. H., Heywood, P., Neal, R. D., & Leese, B. (2007). UK GPs' and practice nurses' views of continuity of care for patients with type 2 diabetes. *Family Practice*, 24(2), 128–137. Scopus. <https://doi.org/10.1093/fampra/cmm003>
- Azevedo, K., & Payne, C. K. (2001). The psychosocial economic impact of invisible chronic disease: Examining the experience of patients with interstitial cystitis. *Urology*, 57(6 Suppl 1), 118. Scopus. [https://doi.org/10.1016/s0090-4295\(01\)01065-2](https://doi.org/10.1016/s0090-4295(01)01065-2)

- Cho, Y.-T., Chan, T. C., Lee, C.-H., Chou, W.-Y., Hsiao, P.-F., Chen, Y.-J., Wu, P.-Y., Yang, C.-W., Chiu, T.-M., Chang, Y.-T., Wang, W.-M., Hong, C.-H., Tu, W.-T., Huang, Y.-H., Tsai, T.-F., Lan, C.-C., & Chu, C.-Y. (2022). Taiwanese dermatological association consensus for the definition, classification, diagnosis, and management of urticaria: A 2021 update. *Journal of the Formosan Medical Association*, *121*(7), 1191–1203. Scopus. <https://doi.org/10.1016/j.jfma.2022.02.007>
- de-Graft Aikins, A., Unwin, N., Agyemang, C., Allotey, P., Campbell, C., & Arhinful, D. (2010). Tackling Africa's chronic disease burden: From the local to the global. *Globalization and Health*, *6*. Scopus. <https://doi.org/10.1186/1744-8603-6-5>
- Fowler, J. (2008). Chronic hand eczema: A prevalent and challenging skin condition. *Cutis; cutaneous medicine for the practitioner*, *82*(4 Suppl), 4–8. Scopus.
- Herberger, K., Rustenbach, S. J., Haartje, O., Blome, C., Franzke, N., Schäfer, I., Radtke, M., & Augustin, M. (2011). Quality of life and satisfaction of patients with leg ulcers—Results of a community-based study. *Vasa - Journal of Vascular Diseases*, *40*(2), 131–138. Scopus. <https://doi.org/10.1024/0301-1526/a000083>
- Lacy, B. E., Cangemi, D. J., & Spiegel, B. R. (2023). Virtual Reality: A New Treatment Paradigm for Disorders of Gut-Brain Interaction? *Gastroenterology and Hepatology*, *19*(2), 86–94. Scopus.
- Laranjeira, C., Dixe, M. A., Martinho, R., Rijo, R., & Querido, A. (2022). Building Bridges for “Palliative Care-in-Place”: Development of a mHealth Intervention for Informal Home Care. *Frontiers in Psychology*, *13*. Scopus. <https://doi.org/10.3389/fpsyg.2022.862347>
- Lee, P. T., Kruse, G. R., Chan, B. T., Massaquoi, M. B. F., Panjabi, R. R., Dahn, B. T., & Gwenigale, W. T. (2011). An analysis of Liberia's 2007 national health policy: Lessons for health systems strengthening and chronic disease care in poor, post-conflict countries. *Globalization and Health*, *7*. Scopus. <https://doi.org/10.1186/1744-8603-7-37>
- Maurer, M., Abuzakouk, M., Bérard, F., Canonica, W., Oude Elberink, H., Giménez-Arnau, A., Grattan, C., Hollis, K., Knulst, A., Lacour, J.-P., Lynde, C., Marsland, A., McBride, D., Nakonechna, A., Ortiz de Frutos, J., Proctor, C., Sussman, G., Sweeney, C., Tian, H., ... Balp, M.-M. (2017). The burden of chronic spontaneous urticaria is substantial: Real-world evidence from ASSURE-CSU. *Allergy: European Journal of Allergy and Clinical Immunology*, *72*(12), 2005–2016. Scopus. <https://doi.org/10.1111/all.13209>
- Mboweni, S. H., & Risenga, P. R. (2023). Experiences of patients with chronic diseases during the COVID-19 pandemic in the North West province, South Africa. *South African Family Practice*, *65*(1). Scopus. <https://doi.org/10.4102/safp.v65i1.5643>
- Nwankwo, L., McLaren, K., Donovan, J., Ni, Z., Vidal-Díaz, A., Loebinger, M., Morrissey, A., Igra, A., & Shah, A. (2021). Utilisation of remote capillary blood testing in an outpatient clinic setting to improve shared decision making and patient and clinician experience: A validation and pilot study. *BMJ Open Quality*, *10*(3). Scopus. <https://doi.org/10.1136/bmjopen-2020-001192>
- Okano, M., Kondo, K., Takeuchi, M., Taguchi, Y., & Fujita, H. (2021). SURVEY OF PATIENTS' PERSPECTIVE ON SURGERY FOR CHRONIC RHINOSINUSITIS WITH NASAL POLYPS. *Japanese Journal of Allergology*, *70*(10), 1376–1382. Scopus. <https://doi.org/10.15036/arerugi.70.1376>
- Rahman, N. A., Rajaratnam, V., Burchell, G. L., Peters, R. M. H., & Zweckhorst, M. B. M. (2022). Experiences of living with leprosy: A systematic review and qualitative evidence synthesis. *PLoS Neglected Tropical Diseases*, *16*(10). Scopus. <https://doi.org/10.1371/journal.pntd.0010761>
- Singh, K., Kaushik, A., Johnson, L., Jaganathan, S., Jarhyan, P., Deepa, M., Kong, S., Venkateshmurthy, N. S., Kondal, D., Mohan, S., Anjana, R. M., Ali, M. K., Tandon, N.,

Narayan, K. M. V., Mohan, V., Eggleston, K., & Prabhakaran, D. (2021). Patient experiences and perceptions of chronic disease care during the COVID-19 pandemic in India: A qualitative study. *BMJ Open*, *11*(6). Scopus. <https://doi.org/10.1136/bmjopen-2021-048926>