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Beyond the disease: Understanding caregivers' perspectives of relatives with tuberculosis in Madang Province, Papua New Guinea

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Research Article

Keywords: caregivers' experiences, families, phenomenology, tuberculosis, Papua New Guinea

Posted Date: June 13th, 2025

DOI: https://doi.org/10.21203/rs.3.rs-6857960/v1

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Additional Declarations: The authors declare no competing interests.

Abstract

Introduction: TB remains a critical public health concern, particularly in low- and middle-income countries. The high burden of TB places an increasing strain on families. Despite substantial support from families for relatives with TB, knowledge about their caregiving experiences is limited, especially in Papua New Guinea. This study examines caregivers' experiences caring for family members with tuberculosis (TB).

Study design and methods: This qualitative study employed hermeneutic techniques to investigate the experiences of fifteen individuals with relatives diagnosed with TB in Madang Province, Papua New Guinea. Participants were selected using a combination of triangulation sampling methods, including convenience and purposive sampling. Data were gathered through recorded, in-depth interviews, observations, and field notes from January to May 2025, and analysed using the Colaizzi data analysis approach.

Results: Key themes emerged regarding the emotional and physical challenges of caregiving, the disruption of family dynamics, and the social stigma associated with TB. Caregivers shared various coping strategies, including spiritual practices, family support, and community involvement, to help them navigate the challenges of caregiving.

Conclusion: The diverse views of families with TB on supporting affected individuals provide valuable insights. Understanding these perspectives is crucial for developing targeted healthcare interventions for caregivers and supporters. In rural areas, this study can guide nurses in equipping families with knowledge about TB to reduce transmission and ensure effective treatment outcomes.

INTRODUCTION

Tuberculosis (TB) continues to be a significant public health challenge worldwide, despite the availability of preventive medications.[1] It infects and causes the deaths of many individuals worldwide, especially in low- and middle-income countries (LMICs). The World Health Organization's 2024 report indicates that over 10 million people are affected by TB, with 4 million deaths attributed to it.[2] Eliminating TB has long been a global health priority; however, the WHO reports that over 80% of infections and fatalities occur in LMICs, highlighting the need for increased efforts to manage and monitor TB in these countries. TB is the second leading cause of morbidity and mortality among infectious diseases, after COVID-19, and disproportionately impacts the impoverished, especially those who are socially and economically disadvantaged.[3,4]

Papua New Guinea (PNG) is one of the top 22 countries with the highest TB burden in low- and middle-income countries (LMICs) and has the highest burden in the Pacific region.[1,2,5] In 2022, the approximate TB incidence was 432 per 100,000 population, with a high mortality rate of 44 per 100,000 among individuals without HIV.[6] The treatment outcome is 70%, falling short of the WHO recommendation. The

emergence of drug-resistant strains of TB poses a significant societal threat, particularly to the predominantly rural population, where over 85% reside in rural and remote areas.[4,6–8] Furthermore, weaknesses in the healthcare system—including insufficient physical infrastructure, sustained shortages of the health workforce, funding limitations, frequent stock-outs of medicine, and insufficient leadership, governance, and accountability—exacerbate the TB epidemic in PNG.[9] Some provinces face treatment delays for TB due to a nearly collapsed healthcare system lacking diagnostic infrastructure. This results in late diagnoses, delayed treatment for suspected patients, ineffective management, and increased default rates.[7,8]

Families play a crucial role in caring for their relatives with TB.[10] Families' attitudes toward TB patients and their understanding of the disease are essential for effective management. This is vital because, according to Sebothoma et al.[10], TB transmission is a complex public health issue influenced by social and environmental factors. A family consists of individuals related by blood, adoption, or marriage who live together for an extended period. [11] Members of the sick patients care for those unable to assist themselves due to TB. Relatives of TB patients receiving home medications are also expected to receive support from their families. Family support practices and care systems have formed the foundation of communities for decades. They play a significant role in managing TB patients and ensuring continuity of care upon discharge from healthcare facilities.[11,12] Family members are responsible for maintaining continuity of care by administering medications, ensuring treatment adherence, providing emotional and physical support, scheduling medical consultations, and feeding their sick relatives after discharge from the hospital.[4]

Research on family caregiving in PNG is limited. Understanding why individuals assume stressful caregiving roles, how they manage these responsibilities, and the implications in low-income settings like PNG is essential, especially where rising TB rates have altered family demographics and social norms, often placing caregiving duties on women and children.[11,13] There are few qualitative studies examining family members' experiences in supporting relatives with TB in PNG, despite the increasing TB burden in the country. This research employs a qualitative descriptive phenomenological approach to investigate families' perceptions of relatives with TB and their management strategies.

STUDY DESIGN AND METHODS

DESIGN

This research employed a qualitative design to explore the daily lives of family members caring for relatives with TB at home after their discharge from healthcare facilities in Madang Province, PNG. The study took place from January to May 2025. The researcher captured the participants' lived experiences using a phenomenological approach experiences.[15–17] This methodology enabled a thorough investigation of caregivers' lived experiences, uncovering the intricacies of their physical, mental, and social contexts while providing deeper insights into the complexities of caregiving.[3]

POPULATION, SAMPLING METHOD, AND SAMPLE SIZE

The study participants included family members of individuals undergoing TB treatment, those who had been cured, and those who had completed the intensive hospital phase in Transgogol, Ambenob region, Madang Province. This area was selected due to the increasing TB trend noted in the local district hospital's TB register. From 2018 to 2024, data indicate that 658 patients received TB treatment.

The researcher used a triangulation sampling technique, including convenience and purposive sampling methods.[18,19] Convenience sampling targeted relatives of TB patients at an adult outpatient clinic and caregivers at the district hospital. The researcher collaborated with the duty nurse to identify family members of TB patients requiring care and inquired about their previous TB diagnoses. This approach was chosen for its accessibility, which reduces both time and costs while ensuring efficacy safety.[20] Additionally, participants with experience caring for TB patients at home and knowledge of the condition were interviewed. A TB register from the district hospital was used to select patients from nearby communities, with assistance from the local health facility's TB program officer, to understand caregivers' experiences. An initial visit was made with 15 families to invite participation, assess eligibility, and arrange a second visit for those who qualified. A participant information sheet informed them about the study's purpose, data collection, and the process of obtaining consent. After the second visit, only 10 participants were eligible, as five did not meet the criteria. The researcher obtained both verbal and written consent from interview participants. Data saturation occurred after the 8th interview, but the researcher continued interviewing the remaining participants to explore any new insights.

DATA COLLECTION

The researcher conducted individual, face-to-face interviews with family members using an interview guide. These informal conversations aimed to generate deeper insights about caregiving experiences. The researcher built rapport by carefully listening and remaining non-judgmental, not interrupting. The researcher posed the following questions to the participants:

i. Can you describe your experiences caring for a relative with tuberculosis?
ii. What challenges do you face when caring for a family member with tuberculosis?
iii. What specific strategies do you employ to care for your sick relative?

Interviews were recorded and transcribed verbatim with consent. Additionally, the researcher took field notes to capture actions, words, and behaviours not included in the interviews, summarising these details to accurately represent the participants' experiences. These notes highlighted the social dimensions of the settings and the challenges faced in caregiving. The interview process reached data saturation with the 10th participant, beyond which no new insights emerged. However, the researcher continued to interview willing participants to gain fresh perspectives. Each interview lasted between 30 and 60 minutes, during which the researcher recorded and analysed the shared lived experiences.

DATA ANALYSIS

The Colaizzi[21] seven-step phenomenological analysis was used to uncover the meanings of participants' experiences through open coding with MAXQDA2018 software.[10] The interviews were transcribed verbatim, and transcripts were read multiple times to gain a deeper understanding of their meanings. Relevant statements were identified, and key statements were formulated, categorising experiences into themes and sub-themes. The results were consolidated into a comprehensive description of caregivers' experiences with relatives who have tuberculosis (TB). Finally, the outcomes were returned to participants for validation.[10]

VALIDITY AND RELIABILITY OF THE DATA

To ensure the validity and reliability of the results from this qualitative research, the researcher employed strategies such as prolonged participant engagement, member checking, and data collection triangulation.[22,23] The researcher maintained interaction with participants by engaging caregivers in in-depth interviews. The transcripts were thoroughly reviewed to identify key themes that supported the credibility of the data. Themes were continually assessed both individually and collectively against the transcripts. Insights from observations and field notes corroborated the findings from the interviews. Member checking was conducted with three respondents at the local health facility to confirm alignment with the initial study outcomes.

ETHICAL CONSIDERATIONS

The Faculty of Medicine and Health Sciences Research Committee at Divine Word University approved the study (Ethical clearance no. FRC 157/25). The researcher obtained permission from the regional office and the Hospital Administration to engage with participants and access the health facility. All individuals signed informed consent forms. The researcher prioritised ethical considerations, respecting human dignity throughout the process. Each participant received equal treatment, and their privacy was assured through the use of pseudonyms such as Participant 001. Interview recordings were kept confidential, password-protected on the researcher's computer, and were accessible only to the researcher. Participants were informed of their voluntary involvement, with the option to withdraw or decline to answer questions without penalties.

RESULTS

PARTICIPANTS DEMOGRAPHIC PROFILES

A total of 10 caregivers from the Ambenob local government in the Madang district were interviewed. As shown in Table 1, most respondents (n = 9/10, 90%) were unemployed women from the villages. All were married and had completed secondary education. The respondents' ages ranged from 28 to 40.

TABLE 1: PARTICIPANTS' DEMOGRAPHIC PROFILES

Participant	Age (years)	Gender	Family composite	Education	Employment	Location or environment
Participant 001	32	Female	Immediate family	Primary	Unemployed	Village
Participant 002	30	Female	Immediate family	Secondary	Unemployed	Village
Participant 003	28	Male	Immediate family	Postgraduate	Employed	Town
Participant 004	34	Female	Immediate family	Primary	Unemployed	Village
Participant 005	38	Female	Immediate family	Secondary	Unemployed	Village
Participant 006	40	Female	Immediate family	Secondary	Unemployed	Village
Participant 007	35	Female	Immediate family	Secondary	Unemployed	Village
Participant 008	32	Female	Immediate family	Primary	Unemployed	Village
Participant 009	39	Female	Immediate family	Secondary	Unemployed	Village
Participant 010	33	Male	Immediate family	Secondary	Unemployed	Village

The data gathered from thorough interviews with family caregivers reveals three primary themes, along with various subcategories: (i) caregiving experiences of family members, (ii) challenging caregiving situations faced by family members, and (iii) support systems and coping strategies of family members. Table 2 summarises the themes and subthemes that emerged from the interviews.

TABLE 2: ESSENTIAL MEANINGS THAT EMERGED FROM CAREGIVERS' EXPERIENCES OF HAVING FAMILY MEMBERS DIAGNOSED WITH TUBERCULOSIS

Themes	Sub-themes
1. **Family members' caregiving experiences**	1.1 Disruption of family dynamics, structures, and norms 1.2 Caregivers' health literacy on tuberculosis 1.3 Demands of caregiving
2. **Family members' caregiving challenging experiences**	2.1 Medical adherence challenges and patient refusal 2.2 Financial challenges 2.3 Accessibility to healthcare services 2.4 Lack of familial support 2.5 Trust in the healthcare system 2.6 Alternative health-seeking behaviour
3. **Family members' support systems and adaptation/coping strategies**	3.1 Faith and spirituality as a source of strength 3.2 Change and adaptation with family dynamics

THEME 1: FAMILY MEMBERS' CAREGIVING EXPERIENCES

Sub-theme 1.1: Disruption of family dynamics, structures and norms

Caregivers shared their profound experiences of how TB has disrupted family dynamics, norms, and basic structures. Several respondents emphasised that since their relative was diagnosed with TB, interactions, including family mediation, have become limited. One caregiver expressed deep emotion, revealing that her husband's illness had entirely dismantled the family's strengths, order, and stability, leaving her feeling powerless and despondent during his battle with TB:

“My husband was seriously ill and could not take care of himself. He was completely bedridden and needed assistance with using the bathroom and eating. During that time, I felt utterly overwhelmed; the family with whom we once shared happiness could no longer support us as our lifeline fell apart. I felt hopeless and helpless since he was the only one providing for us (Participant, 007).

Sub-theme 1.2: Caregivers' health literacy of tuberculosis

All respondents demonstrate a poor understanding of tuberculosis, confusing it with other illnesses like malaria or a mild cough. This misunderstanding drives individuals to seek incorrect treatments, causing sick family members to remain in the village for extended periods without proper diagnosis or care. Many caregivers reported limited knowledge of TB signs and symptoms, leading to delays in diagnosis and treatment. Even some community health workers, who care for ill relatives, have a narrow grasp of TB. Each participant noted caring for their sick relative for several months, often administering anti-malarials and antibiotics instead of the necessary TB treatment:

Initially, when he developed a fever and cough, we assumed it was a mild issue or possibly malaria. As the symptoms persisted, we treated him for malaria and his cough, doubting it could be TB since no one in the family had had TB (Participant, 013).

Sub-theme 1.3: Demands of caregiving

Caregivers shared varying degrees of severity regarding their relative's illness, with the most severe cases requiring additional care. Six caregivers recounted an arduous experience as their relative underwent multiple hospital admissions to a distant facility over several months. Some experienced repeated admissions due to misdiagnoses and insufficient investigations, leading to prolonged hospital stays. These relatives were fragile, needing significant assistance with bathing, eating, and daily chores. Furthermore, participants emphasised overarching health system challenges, such as a lack of anti-TB medications, which extended TB treatment beyond the typical six months and increased the caregivers' responsibilities for over a year.

Caring for our dad was stressful. We visited the hospital multiple times, but the health workers failed to make the correct diagnosis. Initially, they assured us it was not serious, so we returned to the village. A few weeks later, we had to go back because he became very ill and required intensive care, including assistance with feeding and toileting. We spent nearly a year in the hospital (Participant, 007).

THEME 2: FAMILY MEMBERS' CHALLENGING EXPERIENCES

Sub-theme 2.1 Medication adherence challenges and patient refusal

A significant obstacle to effective management and caregiving is ensuring adherence to medical treatments, especially when patients refuse. Many respondents noted the difficulties of administering medications on time. Caregivers often reported that relatives declined their medications, leading to treatment delays and missed doses:

One of my significant challenges is enforcing treatment for my relative. I always remind him to take his medicine on time, but sometimes he refuses and does not take it as scheduled (Participant, 012).

Sub-themes 2.2: Financial challenges

The respondents shared their financial hardships while trying to access healthcare for their family members. Many reported difficulties affording essential items such as food and toiletries. Most participants are unemployed women from the village, facing limited income as they care for their sick relatives. Two respondents described their struggles with the high costs of transferring their loved ones from rural health facilities to tertiary hospitals. They recounted encounters with health workers who required payment before allowing transport to the hospital, despite the urgent pleas from families of critically ill patients needing immediate assistance:

The costs of caring for my relative are rising, particularly for essential items such as food, soap, detergents, and toilet paper. The ambulance fee was very high, and we had to pay it before transportation (Participant, 012).

Sub-theme 2.3: Accessibility to healthcare services

Participants reported limited access to TB care at rural facilities, highlighting the absence of diagnostic and treatment services. This resulted in delays of several months before they sought help. Five participants visited multiple health facilities before being referred to a tertiary hospital, expressing disappointment regarding the delays in diagnoses and the initiation of therapy. Caregivers found this limited access to be mentally and emotionally taxing, and participants experienced financial strain due to the increased costs arising from the prolonged process of accessing care services.

Accessing TB health services in rural areas is often challenging. We took our dad to three different health facilities before he was referred to the general hospital for a more thorough examination. This process also delayed his accurate diagnosis and treatment. Such challenges are a significant concern and cause stress for us in the districts (Participant, 013).

Sub-theme 2.4: Lack of familial support

Caregivers faced significant obstacles due to a lack of family support. Many participants noted that their close relatives neglected them after the sick family member was hospitalised, often failing to visit them at the healthcare facility. Additionally, three participants voiced concerns about contracting TB, which deterred other relatives from visiting. Several caregivers shared their challenges, such as running out of food while juggling caregiving duties and selling groceries at the local market to meet their basic needs.

My family brought us here and has not returned. With no relatives nearby, our food supply has dwindled. The health centre does not provide meals, so we bring our own. Occasionally, I sell items at the market to buy food (Participant, 014). We have been here for months without food and are left alone. No family member has visited us due to the fear of TB infection (Participant, 008).

Sub-theme 2.5: Trust in the healthcare system

Interactions with healthcare providers influence the willingness to seek medical assistance. Experiences at a specific tertiary medical centre have led caregivers to become hesitant to pursue care. Participants noted an increase in deaths among relatives at this facility, resulting in their reluctance to seek treatment for their loved ones. Two participants emphasised that this hesitance has led to harmful health-seeking behaviours and delays in essential medical evaluations and interventions:

We decided against taking my father to the tertiary hospital because we have seen many patients who were admitted and later brought home deceased. We are afraid to seek medical care there. My father also refuses to be admitted to this facility and has requested that we take him to the church-run health facility (Participant, 014).

Sub-theme 2.6: Alternative health-seeking behaviour

Caregivers explored various alternative healthcare options before contacting professionals. Two respondents emphasised their search for conventional TB treatments, such as olive oil and herbs recommended by local bush doctors. Others sought divine assistance through prayer and meditation with clergy. Additionally, two caregivers noted that fostering family harmony facilitated quicker diagnoses and suitable treatments. Many consider family unity essential for achieving accurate diagnoses and often stress the limited availability of TB diagnostics and healthcare services in rural regions as a significant obstacle.

My father had been sick for weeks, so we gave him herbs, olive oil, and prayers, noticing improvement before referring him to the hospital (Participant, 003).

When we learned that our mother was ill, we invited our pastor to pray, provided her with medication, addressed our outstanding issues, and took her to the hospital (Participant, 009).

THEME 3: FAMILY MEMBERS' SUPPORT SYSTEMS AND ADAPTATION/COPING STRATEGIES

Sub-theme 3.1: Faith and spirituality as a source of strength

Caregivers often adopt various coping strategies when relatives have TB. Numerous respondents emphasised the importance of faith and spirituality as pivotal support systems for caring for those infected. Three participants elaborated that people frequently turn to divine intervention through prayer and healing when human support is scarce. They believe this illustrates their hope and recognition of realities beyond human understanding. This nurturing of their religious beliefs provides them with comfort and validation:

Our father has been very ill for weeks without proper treatment, leaving us mentally drained. We invited a pastor from our local church to pray for him because we have faith in God's healing ability (Participant, 014).

Sub-theme 3.2: Change and adaptation with family dynamics

Caregivers reported that having a family member with TB has changed the family's chores. They noted that this illness heightens awareness of prevention and healthy behaviours. Some respondents emphasised that specific challenges arise within the home, including restricted movement, reduced communication with other family members, and shared use of utensils, towels, and other items. This situation has impacted relationships among family members. Several respondents indicated that these conditions have increased anxiety and shame for the affected relative, potentially hindering recovery and treatment:

When our child was first diagnosed with TB, we imposed certain restrictions on eating utensils, playing with other siblings, and sharing utensils and towels. We noticed that this caused our child some

embarrassment. Initially, we found it challenging to manage the situation. However, after starting treatment, we eased the restrictions and allowed him to move around freely (Participant 003).

DISCUSSION

This phenomenological study examined the experiences of family members caring for relatives with TB. Insights from interviews with caregivers reveal their crucial role in managing and controlling TB transmission, at both the proximal and distal levels. Numerous studies have explored the role of caregivers for relatives with tuberculosis.[13,24,25] found data similar to the present study regarding caregivers' experiences, challenges, support systems, and adaptation and coping strategies. Figure 1 illustrates the connections among these themes: Theme 1 examines the lasting effects of caregiving on family dynamics, knowledge, and relationships. Theme 2 reveals the challenges caregivers face, and Theme 3 highlights how caregivers adapt, harness their strengths, and manage by relying on faith and modified family roles.

Family members' caregiving experience

This theme establishes the foundation by emphasising dynamics in the caregiving environment, including family role disruptions, power relations, community involvement, and caregivers' health literacy. TB affected families' daily lives, altering roles and responsibilities and influencing power dynamics. A similar study in South Africa identified TB as a disruptor of family relationships, concluding that families are crucial for TB management, and the destabilisation of family dynamics may reduce home care.[10] This suggests that family members are essential motivators, providing emotional support and encouraging adherence to TB treatment. However, disruptions in family dynamics, norms, and structures, along with limited healthcare literacy, increase patient anxiety and negatively impact their caregiving experiences.[3] In TB care programs, creating family-oriented education sessions can effectively meet caregivers' emotional and informational needs. Furthermore, in public health policy, it is essential to establish psychosocial support services for caregivers and improve community education in order to reduce TB stigma.[13]

Family members' caregiving challenges

This theme sheds light on the obstacles caregivers encounter, such as financial strains, difficulties with medical adherence, inadequate support, and distrust towards healthcare services. Despite facing significant financial challenges and limited family assistance, caregivers remained dedicated, drawing strength from their belief in God and the support of healthcare professionals. This aligns with research on family caregivers of individuals with HIV and TB, highlighting the necessity of fortifying healthcare systems and integrating religion and spirituality to aid caregivers in managing tuberculosis, which is part of the goal to control the disease by 2035.[26] This study presents a theory of resilient commitment in tuberculosis caregiving, illustrating how caregivers sustain their dedication to supporting relatives with TB despite various challenges. They continue to provide care, deriving motivation from two primary

sources: their faith in God and the encouragement of compassionate healthcare workers. Faith acts as a personal source of emotional resilience and significance, while positive engagement with health professionals provides practical advice and moral support.[26] These internal and external motivators enable caregivers to navigate challenges and maintain commitment. Over time, these experiences cultivate personal resilience and a stronger sense of purpose, even when larger systemic support is lacking.

Family members' caregiving support systems and adaptation strategies

This theme explores caregivers' coping strategies, emphasising faith, spirituality, and support from families and communities. Results align with Biru et al[26], highlighting the need for comprehensive healthcare services that address physical, mental, social, and spiritual aspects. Research indicates that when human resources are insufficient, caregivers seek divine support in caring for relatives with TB. Sebothoma et al.[10] affirm that African caregivers turn to divine intervention when healthcare systems fall short. Caring for a TB-affected relative is emotionally and physically taxing, as caregivers face stress, treatment challenges, and nutritional issues, all of which impact their well-being and the patient's recovery. Consequently, familial support is essential for effective TB care management. However, limited support and stigma from family members hinder adequate care efforts.[5] This study presents a coping theory centred on connectedness, aiming to explain how caregivers of relatives with TB navigate the emotional and practical aspects of caregiving challenges.[24] The results indicate that caregivers predominantly utilise coping strategies rooted in faith, spirituality, and social support.[24,27] Spiritual beliefs and faith provide hope, strength, and inner peace, enabling caregivers to navigate the emotional challenges of caring for a sick family member. Furthermore, support from families and communities offers practical assistance, emotional comfort, and a sense of shared responsibility. Together, these elements form a network of spiritual and social connections that protect caregivers from stress and burnout. This theory emphasises that caregivers do not confront their challenges in isolation; instead, they thrive through a web of supportive relationships and deeply held beliefs that collectively enhance their well-being and caregiving skills.

IMPLICATIONS FOR RESEARCH, POLICY AND PRACTICE

The outcomes of this qualitative research will benefit various stakeholders, including nurses, policymakers, and health managers, by providing insights into the care provided to TB patients. Furthermore, healthcare institutions and communities should recognise the challenges faced by caregivers in delivering essential services. Future studies should investigate nurses' views on caring for TB patients, which will aid in identifying suitable interventions to ensure quality care.

STRENGTHS AND LIMITATIONS

A key strength of this study was the substantial number of participants who shared detailed and insightful narratives about their caregiving experiences, reaching theoretical saturation. Consistent with

qualitative research norms, the findings are contextualised to these specific settings and cannot be readily generalised to different contexts.

CONCLUSION

Our research emphasises the need to incorporate insights from family members caring for TB patients into health service planning and TB interventions. By creating solutions that reflect caregivers' perspectives, we can address specific challenges, alleviate caregiver burdens, and minimise TB risks. Understanding caregivers' experiences will inform policy and health service planning for TB, thereby improving safety and meeting the unique needs of patients' caregivers.

Declarations

Participant Consent to Publish Statement

The participants (caregivers) have provided written informed consent for the publication of the individual data presented in Table 1.

DATA AVAILABILITY

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

COMPETING INTEREST

The author declares that there are no conflicts of interest regarding the publication of this paper.

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Figures

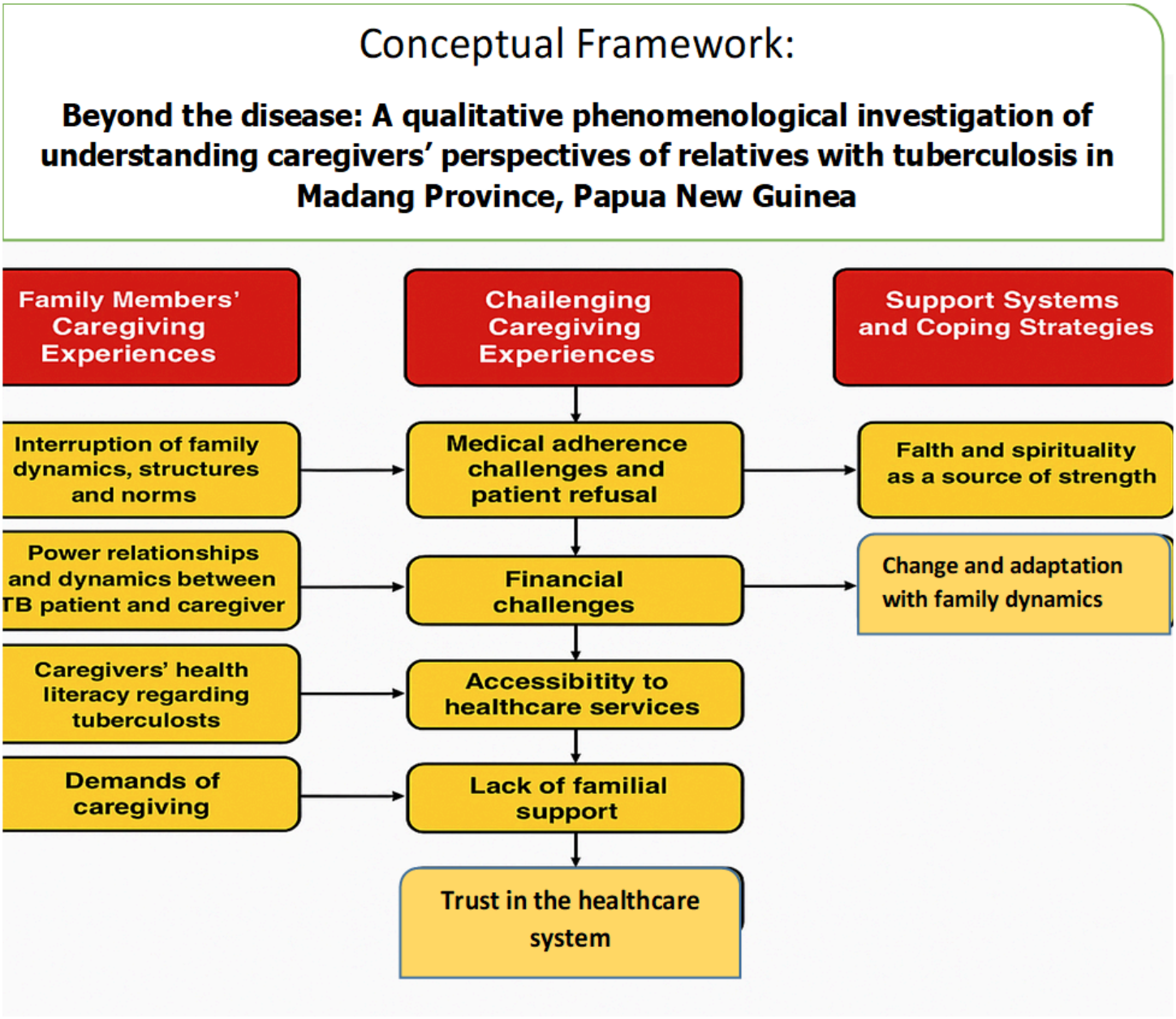


Figure 1: Conceptual Framework: Understanding caregivers' perspectives of relatives with tuberculosis in Madang Province, Papua New Guinea

Figure 1

See image above for figure legend.