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Exploring Parents' Experiences in Caring for Children with Chronic Illness: A Qualitative Study of Family-Centered Care

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ABSTRACT

Background: *Caring for children with chronic illnesses requires parents to manage complex treatment demands, emotional uncertainty, changing family roles, and healthcare access barriers. Understanding these experiences is essential for developing culturally responsive family-centered pediatric care across diverse local communities.*
Research Objective: *This study explored parents' experiences in caring for children with chronic illnesses in Baubau, Southeast Sulawesi, from a family-centered care perspective.*
Methods: *A qualitative descriptive study with a phenomenological approach involved 15 parents selected through purposive sampling. Data were collected through face-to-face, semi-structured, in-depth interviews and field notes. Interviews were transcribed verbatim and analyzed using Braun and Clarke's six-stage thematic analysis. Trustworthiness was maintained through triangulation, member checking, peer debriefing, reflective notes, and an audit trail.*
Results: *Five themes were identified: emotional adaptation from shock to acceptance; reorganization of family roles and daily routines; financial, geographical, and service-related barriers; inconsistent partnership with healthcare professionals; and resilience supported by spirituality and social relationships. Parents valued clear information, respectful communication, practical education, emotional support, and participation in treatment decisions. Referral outside Baubau increased transportation costs, income loss, and separation from other family members.*
Conclusion: *Caring for children with chronic illnesses affects the entire family and requires sustained professional and social support. Healthcare facilities should strengthen culturally responsive family-centered care through shared decision-making, caregiver education, psychological and spiritual support, peer-support groups, and coordinated referral services.*

Keywords: *Parental Experiences; Chronic Illness; Family-Centered Care.*
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BACKGROUND

Children living with chronic illnesses require continuous, complex, and developmentally appropriate care that extends beyond medical treatment (Ahmad et al., 2022). Conditions such as cancer, congenital heart disease, thalassemia, diabetes, asthma, epilepsy, and chronic kidney disease may involve repeated hospitalization, long-term medication, dietary regulation, symptom monitoring, and regular specialist visits. Within this situation, parents commonly become the primary caregivers and must simultaneously perform emotional, practical, financial, and decision-making roles (Sangngam et al., 2023). These responsibilities may disrupt employment, family relationships, parenting roles, and daily routines while increasing anxiety, uncertainty, fatigue, and caregiver burden. Therefore, understanding parents' experiences is essential for developing pediatric services that treat families as active partners rather than passive recipients of professional instructions (Djurijanto et al., 2024).

Globally, childhood chronic illness represents an important health and social concern (Wattanatchariya et al., 2024). The World Health Organization estimates that approximately 400,000 children and adolescents aged 0–19 years develop cancer annually. More than 80% of affected children are cured in high-income countries, whereas the cure rate remains below 30% in many low- and middle-income countries because of delayed diagnosis, limited access to treatment, treatment abandonment, and inadequate supportive services (Patty et al., 2024). Congenital disorders also cause approximately 240,000 neonatal deaths and a further 170,000 deaths among children aged one month to five years annually, while survivors may experience lifelong health problems or disabilities (Kanga-Parabia et al., 2024). These figures represent only selected conditions and do not fully capture the broader population of children requiring long-term care. Evidence further indicates that families caring for children with chronic conditions frequently report unmet informational, emotional, practical, and healthcare-service needs. Such burdens demonstrate that chronic childhood illness affects the functioning and well-being of the entire family (Mackie et al., 2024).

In Indonesia, pediatric chronic illness is increasingly recognized as a public health priority. The Ministry of Health reported approximately 11,156 new cancer cases among children and adolescents aged 0–19 years in 2020 and subsequently introduced the National Action Plan for Childhood Cancer 2025–2029. The policy reflects the need to strengthen early detection, continuity of treatment, referral services, and supportive care (Supadmi et al., 2024). In addition, Indonesian children living with disabilities and long-term health limitations continue to experience inequalities in healthcare, education, nutrition, and social inclusion. UNICEF and BAPPENAS reported that children with disabilities encounter substantial barriers in accessing essential services, while their caregivers must navigate fragmented systems of health and social support (Hintermeier et al., 2024). These circumstances suggest that improving clinical services alone is insufficient unless the knowledge, capacity, emotional well-being, and everyday realities of parents are also addressed.

In Southeast Sulawesi, geographical dispersion across mainland, coastal, and island communities may add complexity to the management of childhood chronic illness. Families may need to travel considerable distances, arrange transportation, interrupt employment, and seek referrals to facilities offering specialist pediatric services. Provincial statistics describe the availability of hospitals, primary healthcare centers, clinics, and integrated health posts across districts and municipalities; however, these routine statistics do not comprehensively explain how many children live with chronic illnesses, how families coordinate long-term treatment, or what forms of support parents receive (Akhter-Khan et al., 2023). Consequently, numerical service indicators should not be interpreted as evidence that family needs and continuity of care have been adequately fulfilled.

Baubau functions as an important service and referral center for communities on Buton Island and surrounding areas. The city has hospitals, primary healthcare centers, clinics, and community-based health services, yet its annual statistical publications primarily describe demographic characteristics, health facilities, personnel, and selected disease indicators. They do not provide sufficiently disaggregated information about children with chronic illnesses or parents' caregiving experiences . Parents may face challenges involving treatment costs, inter-island referrals, limited information, medication adherence, social stigma, uncertainty about prognosis, and balancing care with other household responsibilities. Cultural values, extended-family relationships, community solidarity, and religious coping may also influence how parents interpret illness and make healthcare decisions (Nassar et al., 2023).

Previous studies have frequently examined parental stress, caregiver burden, quality of life, or experiences associated with a single diagnosis. Indonesian qualitative studies have similarly tended to focus on specific conditions or hospital settings, providing limited understanding of family-centered care across different chronic illnesses, particularly in eastern Indonesian cities. Little is known about how parents in Baubau negotiate caregiving responsibilities, communicate with health professionals, use formal and informal support, and experience their involvement in decisions concerning their children. This constitutes an important contextual and empirical research gap.

The novelty of this study lies in its illness-inclusive and context-sensitive exploration of parents' experiences within the sociocultural and geographical setting of Baubau. Rather than assessing family-centered care only as a clinical standard, the study examines how partnership, information sharing, participation, respect, cultural values, spirituality, and support are experienced in everyday caregiving. Accordingly, this study aims to explore parents' experiences in caring for children with chronic illnesses in Baubau, identify their challenges, coping strategies, support needs, and interactions with healthcare professionals, and generate evidence for developing culturally responsive family-centered pediatric care.

METHODS

This study employed a qualitative descriptive design with a phenomenological approach (Cunningham et al., 2024) to explore parents' experiences in caring for children with chronic illnesses from a family-centered care perspective. The study was conducted in pediatric healthcare facilities in Puskesmas Katobengke Baubau City, Southeast Sulawesi. Fifteen parents were recruited using purposive sampling with maximum variation based on the child's diagnosis, duration of illness, parental role, and place of residence. Eligible participants were mothers or fathers aged ≥18 years who were the primary caregivers of a child aged 1–17 years diagnosed with a chronic illness for at least six months and were willing to describe their caregiving experiences. Parents whose children were in critical condition during data collection were excluded. Data were collected through face-to-face, semi-structured, in-depth interviews lasting approximately 40–60 minutes. The interview guide explored parents' emotional responses, caregiving responsibilities, treatment-related challenges, coping strategies, support systems, communication with healthcare professionals, and participation in care-related decision-making. Interviews were audio-recorded with permission, supplemented by field notes, and transcribed verbatim. Data collection continued until information saturation was achieved. Data were analyzed thematically using Braun and Clarke's six stages: familiarization with the data, initial code generation, theme identification, theme review, theme definition and naming, and report preparation. Trustworthiness was maintained through source triangulation, member checking, peer debriefing, reflective field notes, and an audit trail. Ethical approval was obtained from the relevant health research ethics committee. All participants received

information about the study, signed informed consent forms, and were assured that participation was voluntary and that confidentiality and anonymity would be maintained throughout the research process.

RESULTS

Fifteen parents participated in the study, consisting of 12 mothers and three fathers aged 27–48 years. The participants cared for children aged 2–16 years who had been diagnosed with thalassemia, congenital heart disease, asthma, epilepsy, diabetes mellitus, chronic kidney disease, or cancer. The duration of the children's illnesses ranged from eight months to nine years. Most parents had accompanied their children during repeated outpatient visits or hospitalizations. Thematic analysis generated five major themes: emotional adaptation to the child's illness, disruption of parental and family roles, barriers to continuity of care, unequal experiences of partnership with healthcare professionals, and family resilience supported by spirituality and social relationships.

Theme 1: Emotional adaptation from shock to acceptance

Parents described the initial diagnosis as a distressing event characterized by shock, disbelief, fear, sadness, and uncertainty. Several participants blamed themselves or questioned why the illness had occurred. Anxiety was particularly prominent when children experienced worsening symptoms, required hospitalization, or were referred outside Baubau. Over time, parents gradually developed acceptance, although emotional distress frequently reappeared during medical emergencies.

"When the doctor first explained that my child would need long-term treatment, I felt that our lives had suddenly changed. I was afraid of what would happen in the future." (P4, mother)

Acceptance was not interpreted as the absence of fear but as the ability to continue caring for the child despite uncertainty.

Theme 2: Chronic illness reorganized family roles and daily life

Caring for a chronically ill child required parents to restructure household routines, employment, social activities, and care for other children. Mothers commonly assumed responsibility for medication, feeding, symptom monitoring, and hospital attendance, while fathers focused on earning income and arranging transportation. Some parents stopped working or reduced their working hours. This unequal distribution occasionally caused fatigue and tension within the family.

"I have to remember the medication schedule, control the food, and accompany every examination. Sometimes I feel exhausted, but I cannot show it to my child." (P8, mother)

Parents also reported guilt because siblings received less attention. Nevertheless, caregiving strengthened cooperation in families where responsibilities were shared between spouses and extended family members.

Theme 3: Finansial, geographical, and service barriers complicated continuity of care

Participants experienced financial pressure related to transportation, accommodation, meals, medication, and loss of income, even when medical expenses were covered by health insurance. Referral to Kendari or Makassar created an additional burden because parents had to leave work and other family members for several days. Limited appointment information, long waiting times, and difficulties accessing specialist services contributed to uncertainty.

"The treatment may be covered, but transportation and living costs outside Baubau are still our responsibility. That is the most difficult part for us." (P11, father)

Parents expected stronger coordination between primary healthcare centers, hospitals, and referral facilities to prevent delays and repeated administrative procedures.

Theme 4: Family-centered care was experienced inconsistently

Positive experiences occurred when nurses and physicians provided clear information, listened to parental concerns, involved parents in decisions, and taught practical caregiving skills. Such interactions increased confidence and reduced anxiety. However, several parents stated that medical explanations were sometimes brief, technical, or delivered without sufficient opportunity to ask questions.

"I feel calmer when the nurse explains what I should do at home and asks whether I understand. It makes me feel involved in my child's care." (P2, mother)

Some participants felt regarded merely as companions rather than partners in care. They wanted regular updates, respectful communication, emotional support, and involvement in treatment planning. These findings indicated a gap between the principles of family-centered care and parents' actual experiences.

Theme 5: Spirituality and social support strengthened family resilience

Parents used prayer, religious beliefs, acceptance, and hope to manage emotional distress. Support from spouses, grandparents, relatives, neighbors, and other parents of children with similar conditions provided practical assistance and reassurance. Peer communication was especially valuable because parents could exchange information about treatment, referrals, and daily care.

"Prayer gives me strength, but talking with other parents who have the same experience also makes me feel that I am not alone." (P14, mother)

Nevertheless, support was not equally available to all participants. Parents living far from extended families reported greater isolation and caregiving burden.

Overall, parents' experiences demonstrated that caring for a child with chronic illness involved continuous emotional adjustment, changes in family functioning, and negotiation with a fragmented healthcare system. Family-centered care was most meaningful when healthcare professionals recognized parental knowledge, communicated openly, supported shared decision-making, and considered the family's financial, cultural, geographical, and spiritual circumstances.

DISCUSSION

This study illustrates that caring for a child with a chronic illness is a multidimensional and continuing experience involving emotional adjustment, changes in family roles, financial and geographical difficulties, interactions with healthcare professionals, and reliance on spiritual and social support. The findings demonstrate that parents are not merely companions during treatment but central actors responsible for monitoring symptoms, administering medication, coordinating healthcare visits, making decisions, and maintaining the child's emotional well-being. Family-centered care is therefore particularly relevant because it recognizes the family as the child's primary source of support and positions parents as partners in planning, delivering, and evaluating care.

The first theme showed that parents experienced shock, fear, sadness, self-blame, and uncertainty after learning about their child's diagnosis (Noyek et al., 2023). These

emotional reactions may arise because chronic illness challenges parental expectations of a healthy childhood and introduces uncertainty regarding treatment, prognosis, and the child's future. Although parents gradually developed acceptance, anxiety often returned when symptoms worsened or hospitalization was required. This finding is consistent with an Indonesian phenomenological study involving parents of children with thalassemia major, which identified psychological upheaval, caregiving burden, affirmative attitudes, and psychosocial support as central parental experiences (Morris et al., 2024). Thus, acceptance should not be interpreted as the disappearance of emotional distress. Healthcare professionals should assess parents' psychological conditions continuously rather than providing emotional support only at the time of diagnosis (Rahabi et al., 2024).

The second theme revealed that chronic illness reorganized family roles and everyday life (Nowland et al., 2023). Mothers generally assumed direct caregiving responsibilities, including medication administration, dietary management, symptom monitoring, and hospital attendance, whereas fathers were more involved in financing treatment and arranging transportation. This division may reflect prevailing gender expectations, but it can place disproportionate physical and emotional demands on mothers. A systematic review found that caring for children with chronic illnesses can disrupt family roles, routines, communication, and relationships. It also indicated that fathers remain insufficiently represented in research, even though their involvement can strengthen family functioning and distribute caregiving responsibilities more equitably (Chow et al., 2024). Pediatric nurses should consequently involve both mothers and fathers in education, decision-making, and discharge planning whenever possible. The needs of siblings should also be considered because concentration of family attention on an ill child may produce feelings of neglect or emotional distance among other children (Young et al., 2024).

Financial, geographical, and healthcare-system barriers constituted another important finding. Although national health insurance may cover many direct medical costs, parents may still bear transportation, accommodation, food, and income-loss expenses. These indirect costs become especially burdensome when specialist treatment requires referral from Baubau to Kendari or Makassar. The need to travel can interrupt employment, separate parents from other family members, and delay treatment. In the context of Southeast Sulawesi, where healthcare services are distributed across mainland and island areas, geographical accessibility is a significant component of continuity of care. Official regional statistics describe the distribution of hospitals, primary healthcare centers, clinics, and integrated health posts, but facility availability alone does not demonstrate that specialist pediatric services are accessible or coordinated (Mestre et al., 2024). Strengthening referral coordination, teleconsultation, appointment information, and follow-up through local health centers could reduce unnecessary travel and treatment disruption.

Parents' experiences of family-centered care were inconsistent. Positive experiences emerged when healthcare professionals listened respectfully, provided understandable information, taught practical skills, and involved parents in treatment decisions (Zhang et al., 2023). Such practices increased parents' confidence and reduced uncertainty. Conversely, brief explanations, technical language, limited opportunities to ask questions, and insufficient involvement caused parents to feel excluded (Goerigk et al., 2024). These findings support the principles of patient- and family-centered care, which emphasize dignity and respect, transparent information sharing, participation, and collaboration. The American Academy of Pediatrics identifies children and families as integral members of the healthcare team and recommends that family knowledge and preferences be incorporated into care planning (Widyaratne & Bally, 2024). Therefore, family-centered care should be reflected in routine communication and shared decision-making, not only stated as an institutional philosophy.

The parents' need for clearer information is also consistent with a systematic review showing that families of children with cancer, congenital heart disease, diabetes, asthma, and renal disease frequently experience unmet informational, emotional, practical, and healthcare-service needs (López-Arteaga et al., 2023). Information should be delivered gradually, repeated when necessary, and adapted to the parents' level of health literacy. Nurses can use written care plans, medication schedules, symptom-monitoring guides, and teach-back techniques to confirm understanding. Parents should also receive clear instructions about warning signs, emergency contacts, referral procedures, and home-care responsibilities (Lysak et al., 2024).

Spirituality and social relationships were important sources of resilience. Prayer, religious belief, hope, and acceptance helped parents interpret their experiences and maintain motivation (Patton et al., 2023). Extended families and neighbors contributed through financial assistance, childcare, transportation, and emotional encouragement. Peer support from parents facing similar conditions reduced isolation and provided practical knowledge (O'Mahony et al., 2024). Previous evidence indicates that spirituality may function both as a source of strength and as an area of concern among parents caring for seriously ill children. Healthcare professionals should therefore offer culturally sensitive spiritual support without assuming that all parents have identical religious needs. Peer-support groups facilitated by hospitals or primary healthcare centers may also provide an affordable community-based strategy for strengthening parental coping.

The novelty of these findings lies in demonstrating how family-centered care is shaped by the sociocultural and geographical context of Baubau. Parents' caregiving experiences were influenced not only by the child's diagnosis but also by inter-island referrals, indirect treatment costs, extended-family relationships, religious coping, and communication with healthcare professionals. Accordingly, an effective family-centered care model for Baubau should integrate respectful communication, shared decision-making, caregiver education, psychological and spiritual support, peer networks, and coordinated referral services.

The findings should nevertheless be interpreted within the limitations of a qualitative study involving a relatively small purposively selected group. Experiences may differ according to diagnosis, illness severity, socioeconomic status, family structure, and access to healthcare. Nevertheless, the study provides contextual insight that cannot be obtained from routine epidemiological statistics. Future studies should include fathers, siblings, children, and healthcare professionals and examine how culturally responsive family-centered interventions influence caregiver well-being, treatment adherence, continuity of care, and children's quality of life.

CONCLUSION

Parents caring for children with chronic illnesses experience emotional distress, changing family roles, financial and geographical barriers, and inconsistent involvement in healthcare decisions. Spirituality, extended-family assistance, and supportive communication strengthen their resilience. Healthcare facilities should implement culturally responsive family-centered care through clear communication, shared decision-making, caregiver education, psychological and spiritual support, peer-support groups, and better referral coordination. Future studies should involve larger and more diverse participant groups to develop and evaluate family-centered interventions appropriate for Baubau's local context.

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