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Family caregiving experiences in X-linked Dystonia-Parkinsonism: A transcendental phenomenological study in New Washington, Aklan

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Abstract

Aim: This study explored the lived experiences of family members caring for individuals with X-Linked Dystonia-Parkinsonism (XDP), focusing on their caregiving challenges, observations of patients' physical, psychological, and social struggles, and coping strategies in managing the progressive condition.

Methodology: The study employed a Husserlian Transcendental Descriptive Phenomenological approach. Data were gathered from six (6) family caregivers of individuals with X-Linked Dystonia-Parkinsonism residing in Barangay Candelaria, New Washington, Aklan, through in-depth interviews and focus group discussions and were analyzed thematically to understand their experiences, perceptions, and coping practices.

Results: Findings revealed that family caregivers experienced hereditary anxiety, emotional distress, financial difficulties, and uncertainty about the future. They also witnessed the progressive physical deterioration, psychological struggles, and social isolation of their affected relatives. To manage these challenges, families employed adaptive caregiving practices, sought healthcare and institutional support, and relied on spiritual faith, patience, and family resilience.

Conclusion: X-Linked Dystonia-Parkinsonism affects not only individuals diagnosed with the condition but also their families, who experience substantial psychological, social, and economic burdens. The findings highlight the importance of strengthening family-centered healthcare services, accessible psychosocial support, and socioeconomic assistance to improve the well-being and resilience of affected households.

Keywords: *X-Linked Dystonia-Parkinsonism (XDP), lubag, family caregivers, lived experiences, caregiving burden, coping strategies*

INTRODUCTION

X-Linked Dystonia-Parkinsonism (XDP), locally known as *Lubag*, is a rare, inherited neurodegenerative movement disorder predominantly affecting males of Filipino descent, particularly those with ancestry tracing back to Panay Island in the Philippines. Clinically, XDP is characterized by progressive dystonia, which manifests as involuntary muscle contractions that cause abnormal postures and repetitive movements (Pozojevic et al., 2021). As the condition advances, patients frequently develop parkinsonian symptoms including tremors, rigidity, and bradykinesia, resulting in severe impairment in daily functioning. Because of its progressive and debilitating trajectory, XDP eventually leads to profound physical disability and heavy dependence on caregivers, altering the daily lives of both the diagnosed individual and their immediate household.

Beyond its overt motor manifestations, the burden of XDP passes the broader physical, emotional, and social dimensions of a patient's life. Santiano and Rosales (2021) emphasized that individuals living with XDP routinely endure chronic pain, persistent fatigue, sleep disturbances, and severe limitations in performing basic activities of daily living. As physical autonomy steadily declines, patients become increasingly reliant on their relatives for continuous care and daily assistance. This protracted deterioration places an immense, long-term demand on the

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family unit, transforming relatives from passive observers into primary caregivers who must navigate the complex realities of a degenerative illness.

At the family systems level, inherited X-linked conditions introduce profound emotional and psychosocial strain. Stuhlreyer (2025) found that families navigating X-linked genetic disorders contend with persistent uncertainty regarding disease progression, anxieties surrounding genetic inheritance, and difficulties in communicating hereditary risks among relatives. These pressures strain interpersonal relationships and diminish overall family well-being, particularly as many family members feel inadequately prepared to manage the complex emotional and informational demands of the condition. Consequently, there is a critical need for stronger educational and psychosocial support mechanisms tailored to affected households.

Despite existing clinical and genetic studies on XDP, a significant gap remains in the qualitative literature regarding the lived, day-to-day caregiving realities of the families behind the patients. Specifically, there is limited documentation capturing the granular, daily caregiving routines of relatives, the emotional toll of witnessing a loved one progressively deteriorate, and the specific ways family members observe and facilitate the patient's coping mechanisms. Addressing this gap is vital, as family caregivers serve as the primary pillar of support in resource-limited settings. Therefore, this study sought to explore the lived experiences of family members caring for a relative with XDP, alongside their observations of the patient's struggles and coping strategies, offering the broader community and healthcare sector a deeper understanding of how these families bear and navigate the burden of the disease.

Review of Related Literature and Studies

Clinical Progression and Multidimensional Burden of XDP

X-Linked Dystonia-Parkinsonism (XDP) imposes a severe, multidimensional burden on diagnosed individuals that begins even before classic motor symptoms appear. Padilla et al. (2024) established that gene-positive individuals commonly experience non-motor manifestations including memory impairment, urinary disturbances, pain, sleep dysfunction, depression, and anxiety, prior to the onset of overt motor decline. As the disease progresses, Acuna et al. (2023) demonstrated that patients undergo steady deterioration in motor function, speech, swallowing, feeding, dressing, and personal hygiene, accompanied by significant weight loss and increasing physical disability. Compounding these physiological and cognitive losses, Cataniag et al. (2026) emphasized that patients also endure profound emotional and social struggles, marked by heightened anxiety, depression, social stigma, and isolation. Taken together, these studies map a continuous trajectory from premotor vulnerability to severe functional dependency and psychosocial distress; however, because they focus predominantly on patient-level clinical outcomes, they leave open how family members absorb and adapt to these escalating losses in real time within the household.

Clinical Care, Neurological Management, and Rehabilitation

Reviewing X-linked parkinsonian disorders, Di Lazzaro et al. (2021) reported that medical management relies primarily on dopaminergic therapy, botulinum toxin injections, baclofen, and deep brain stimulation (DBS), noting that treatment strategies must be individualized according to disease phenotype and underlying genetic etiology alongside formal genetic counseling. Expanding on longitudinal care models for progressive movement disorders, Hickman et al. (2026) underscored the necessity of multidisciplinary care, individualized pharmacological regimens, structured rehabilitation, and continuous long-term follow-up in early-onset Parkinson's disease. Similar cross-specialty coordination is advocated in other rare, progressive neurogenetic conditions; for instance, Garcia-Moreno et al. (2023) emphasized that patients with Xeroderma Pigmentosum require integrated management spanning neurology, neuropsychology, clinical genetics, specialized nursing, and patient support groups regardless of genetic subtype. Furthermore, a systematic review by Barros-Ferreira and Reis-Pina (2025) demonstrated that integrating multidisciplinary palliative care into Parkinson's disease and related disorders significantly improves symptom management, patient quality of life, and caregiver outcomes. While these studies collectively establish multidisciplinary, continuous care as the clinical gold standard, they also highlight a sharp contrast with the realities of XDP care in endemic settings, where specialized follow-up is often fragmented and households remain heavily reliant on invasive surgical interventions such as DBS (Cataniag et al., 2026).

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Nursing Practice and Caregiver Preparedness

Translating complex neurological management into daily home care places substantial technical demands on nurses and family caregivers, particularly as patients lose the ability to perform basic activities of daily living (Acuna et al., 2023). Within multidisciplinary neurogenetic frameworks, specialized nursing plays a critical role in bridging clinical recommendations and household execution (Garcia-Moreno et al., 2023).

Public Health Implications and Healthcare Delivery Systems

Beyond the clinical and household levels, hereditary neurological disorders carry major public health and health-system implications, particularly in geographically isolated or underserved regions. Tan et al. (2024) argued that low health literacy regarding genetics, combined with prevailing cultural beliefs, stigma, and misconceptions, frequently impedes the acceptance and utilization of genetic counseling and testing services in underserved communities. These sociocultural barriers are often compounded by structural limitations within local healthcare delivery systems.

Family Caregiver Burden and Sociocultural Coping Mechanisms

Because XDP steadily erodes a patient's independence amidst these clinical and systemic constraints, its impact extends deeply into the lives of relatives who assume long-term caregiving roles. In a scoping review, Ramos et al. (2026) found that family caregivers experience substantial psychological, social, and economic strain as they continuously adapt to the escalating demands of the illness. Cataniag et al. (2026) corroborated this multidimensional burden, revealing that the extensive time and physical effort required for daily care contribute to heightened psychological stress, anxiety, and depression, leaving a considerable proportion of caregivers at high risk for or already experiencing severe strain. Moreover, Cataniag et al. (2026) observed that the social stigma surrounding XDP frequently spills over onto relatives, prompting families to withdraw from social interactions or conceal the condition to protect themselves and the patient from discrimination.

Despite these pervasive stressors, affected individuals and their families mobilize a combination of clinical, familial, and sociocultural mechanisms to endure the disease. At the immediate household level, Cataniag et al. (2026) noted that families navigate daily challenges through medical interventions such as DBS paired with heavy reliance on internal family caregiving labor. Beyond the home, broader psychosocial and spiritual resources serve as vital buffers that foster resilience. Both Alcachupas et al. (2022) and Cheah (2017) highlighted that patients and caregivers frequently draw upon religious faith, peer networks, and community support to cope with the physical, emotional, and social toll of the disorder. Echoing these findings, Ramos et al. (2026) identified faith, peer support, and informal social networks as primary coping resources among Filipino families, underscoring the need for culturally appropriate psychosocial interventions. Notably, comparing these studies reveals an important tension in the caregiving experience: while affiliate stigma drives many families toward secrecy and social withdrawal (Cataniag et al., 2026), informal community and peer networks simultaneously function as primary sources of resilience (Alcachupas et al., 2022; Ramos et al., 2026), leaving unanswered how families negotiate this paradox in their everyday lives.

Synthesis

Existing literature establishes a clear clinical and psychosocial profile of X-Linked Dystonia-Parkinsonism (XDP), mapping its progression from premotor mood and cognitive symptoms to severe motor decline, dysphagia, and total functional dependency. Without a cure, individualized symptom management such as pharmacotherapy and deep brain stimulation paired with multidisciplinary, nursing, and palliative support represents the clinical gold standard. However, public health and psychosocial studies reveal that low genetic literacy, structural barriers in underserved areas, and severe physical, emotional, and economic strain heavily burden family caregivers, who rely on faith and informal networks even as affiliate stigma drives them toward social isolation.

Because prior research primarily measures disease progression, systemic barriers, and caregiver strain as isolated, quantifiable variables, little is known about how families holistically navigate these intersecting realities in everyday life, specifically how they manage complex care without formal training or reconcile stigma with help-seeking. This phenomenological study addresses that gap by capturing the lived, subjective experiences of family members, generating grounded insights to inform family-centered nursing education, culturally responsive psychosocial support, and community-based healthcare delivery.

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Theoretical Framework

This study was grounded in Transcendental Descriptive Phenomenology, a philosophical tradition founded by Edmund Husserl (2012) and operationalized for qualitative research by Moustakas (1994). Husserl argued that knowledge of a phenomenon emerges through the careful examination of how individuals consciously experience it within their everyday world or lifeworld *(Lebenswelt)*. Rather than seeking causal explanations or clinical interpretations, transcendental phenomenology focuses on describing the meanings participants assign to their lived experiences.

Central to Husserl's philosophy is the concept of intentionality, which posits that consciousness is always directed toward an object, event, or lived reality. In the present study, intentionality guided the inquiry toward understanding how family caregivers consciously experience and make meaning of caring for a relative living with X-Linked Dystonia-Parkinsonism (XDP). Through open-ended interviews, participants were encouraged to describe their caregiving realities, observations of patient struggles, and experiences supporting coping strategies as they were directly lived and perceived within the context of daily family life.

Another fundamental principle is epoché or bracketing, through which researchers intentionally suspend prior assumptions, clinical knowledge, personal beliefs, and theoretical expectations regarding XDP and caregiving. Prior to data collection, the researchers engaged in reflexive self-examination by documenting their existing knowledge and assumptions about XDP, family caregiving, and disease burden. Throughout the interviews, participants were allowed to narrate their experiences freely using non-leading, open-ended questions. During data analysis, reflexive notes and analytic memos were maintained to continuously monitor potential researcher biases and ensure that themes emerged from participant narratives rather than from preconceived interpretations. During interpretation, findings were reviewed repeatedly against the original transcripts to preserve fidelity to the participants' descriptions and meanings.

The concept of lifeworld (*Lebenswelt*) informed both data collection and interpretation by directing attention to the everyday realities of family caregivers. Rather than focusing on biomedical symptoms alone, the study examined how caregivers experienced the social, emotional, economic, and relational consequences of living with a family member affected by XDP. Participants were therefore invited to describe ordinary situations, daily caregiving activities, household adjustments, emotional responses, and interactions with healthcare systems that constituted their lived reality.

Through transcendental reduction, the researchers systematically examined participants' narratives to identify recurring meanings and experiential structures shared across accounts. This process allowed the study to move beyond individual stories and reveal the essential characteristics of family caregiving in the context of XDP while remaining grounded in participant descriptions.

The three dimensions explored in this study emerged directly from this phenomenological orientation. First, participants described their own lived experiences as family caregivers, reflecting their immediate consciousness of caregiving responsibilities. Second, caregivers described the struggles of their relatives with XDP as these struggles appeared within their lived awareness through daily observation and interaction. Third, participants narrated how they observed and facilitated coping strategies, revealing the intersubjective and relational aspects of caregiving. These dimensions were not constructed as clinical variables or intervention domains; instead, they represent interconnected experiential dimensions through which family caregivers understood and made sense of their caregiving lifeworld.

Accordingly, the theoretical framework served not as a nursing or intervention model but as a philosophical guide for understanding the essence of caregiving experiences associated with XDP. By illuminating how families experience, interpret, and respond to the challenges posed by a rare neurodegenerative disorder, the study contributes to clinical and population health scholarship by providing evidence that can inform family-centered care, culturally responsive psychosocial support, community-based health programs, genetic counseling services, and caregiver assistance initiatives.

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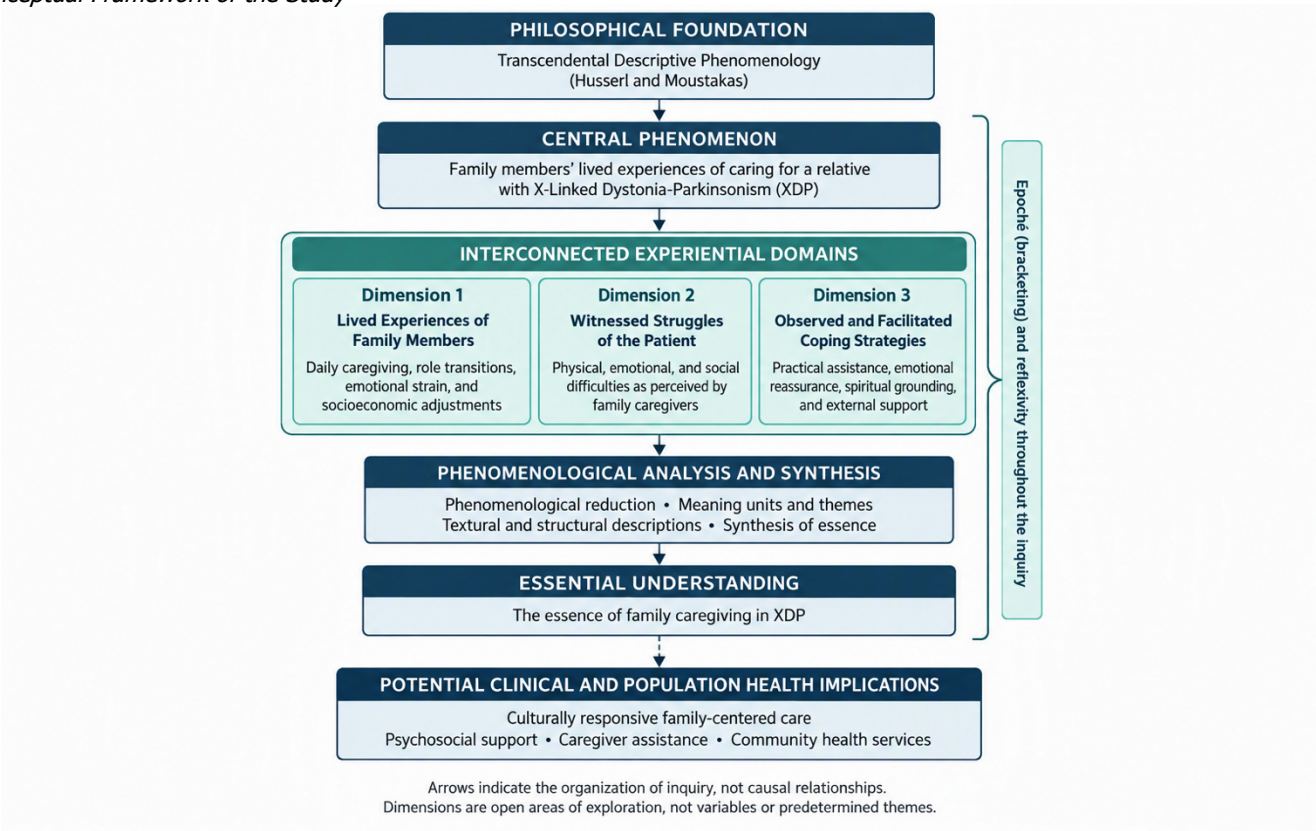
Conceptual Framework

Figure 1
Conceptual Framework of the Study



The conceptual framework of this study was grounded in Transcendental Descriptive Phenomenology as articulated by Edmund Husserl and operationalized by Moustakas (1994). Consistent with phenomenological inquiry, the framework does not propose causal, predictive, or correlational relationships among variables. Instead, it served as an organizing structure for understanding the multiple dimensions through which family members experience the phenomenon of caring for a relative diagnosed with X-Linked Dystonia-Parkinsonism (XDP).

At the center of the framework is the lived experience of family caregiving in XDP, which constitutes the phenomenon under investigation. This phenomenon was explored through three interrelated experiential dimensions that emerged from the study's research questions and are examined through participants' narratives:

1. Lived Experiences of Family Members – encompassing caregiving responsibilities, emotional responses, role transitions, and socioeconomic adjustments;
2. Witnessed Struggles of the Patient – referring to caregivers' observations of physical decline, emotional challenges, social limitations, and disease progression;
3. Observed and Facilitated Coping Strategies – involving practical, emotional, spiritual, familial, and community-based approaches used to manage caregiving demands and support individuals living with XDP.

These dimensions are not conceptualized as independent or dependent variables. Rather, they represent interconnected aspects of caregivers' lifeworld through which the central phenomenon is experienced, interpreted, and understood. The dimensions collectively inform the phenomenological analysis process, which employs epoché, bracketing, transcendental reduction, and thematic synthesis to arrive at an essential understanding of family caregiving in the context of XDP.

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The framework ultimately supports the development of knowledge relevant to family-centered healthcare, psychosocial support systems, caregiver assistance programs, and culturally responsive clinical and community health interventions for families affected by XDP.

Statement of the Problem

Although X-Linked Dystonia-Parkinsonism (XDP), locally known as Lubag, has been investigated through biomedical, genetic, and clinical perspectives, existing literature has largely focused on the disease's neuropathology, symptom progression, and therapeutic management of affected individuals. Comparatively, limited qualitative research has examined the lived experiences of family members who assume primary caregiving responsibilities and navigate the physical, emotional, psychological, and socioeconomic challenges associated with caring for a relative with this progressive neurological disorder.

This gap is particularly important in rural communities in Aklan, Philippines, where affected families may experience difficulties accessing specialized neurological services, genetic counseling, psychosocial support, and other essential healthcare resources. The progressive nature of XDP places considerable demands on family caregivers, who must adapt to changes in household responsibilities, witness the physical and psychological deterioration of their loved ones, and develop practical and emotional coping strategies to manage the continuing challenges of the condition. These experiences have important implications for family-centered healthcare, caregiver education, community health services, and psychosocial support interventions.

Despite the growing recognition of the importance of family involvement in managing progressive neurological disorders, insufficient attention has been given to understanding how family members personally experience their caregiving responsibilities, interpret the physical, emotional, and social struggles of affected relatives, and observe and facilitate their coping strategies within the household. A deeper understanding of these experiences is necessary to inform culturally responsive and family-centered healthcare support for households affected by XDP.

In response to this research gap, the present study sought to explore the lived experiences of family members caring for a relative diagnosed with X-Linked Dystonia-Parkinsonism in Barangay Candelaria, New Washington, Aklan. Specifically, it examines their caregiving experiences, their observations of the physical, emotional, and social struggles of their affected relatives, and the coping strategies they observe and facilitate in managing the challenges associated with the disease

General Objective

The study sought to explore the lived experiences of family members caring for a relative diagnosed with X-Linked Dystonia-Parkinsonism (XDP), particularly their caregiving experiences, observations of the patient's struggles, and coping strategies.

Specific Objectives

Specifically, this study aimed to:

1. Describe the lived experiences of family members caring for a relative diagnosed with X-Linked Dystonia-Parkinsonism;
2. Examine how family members witness and describe the physical, emotional, and social struggles of their relative living with X-Linked Dystonia-Parkinsonism; and
3. Explore how family members observe and facilitate the coping strategies employed by their relative in facing X-Linked Dystonia-Parkinsonism.

Research Questions

This study sought to answer the following questions:

1. How do family members describe their lived experiences of caring for a relative diagnosed with X-Linked Dystonia-Parkinsonism?
2. How do family members witness and describe the physical, emotional, and social struggles of their relative living with X-Linked Dystonia-Parkinsonism?
3. How do family members observe and facilitate the coping strategies employed by their relative in facing X-Linked Dystonia-Parkinsonism?

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METHODOLOGY

Research Design

This study employed a transcendental descriptive phenomenological research design to explore and describe the lived experiences of family caregivers of persons living with X-linked Dystonia-Parkinsonism (XDP). Transcendental phenomenology, rooted in the philosophical works of Husserl, seeks to understand how individuals perceive and make meaning of a phenomenon as it is consciously experienced, free from preconceived assumptions and interpretations. The primary objective is to arrive at a rich description of the essence of lived experience from the perspective of those who have directly encountered the phenomenon.

Consistent with Husserlian phenomenology, the researcher engaged in epoché or bracketing, a process of consciously setting aside personal beliefs, assumptions, and prior knowledge to approach participants' experiences as openly as possible. This process enabled the researcher to focus on the meanings participants attributed to their caregiving experiences and to capture these experiences as they were lived and perceived.

The use of transcendental descriptive phenomenology was deemed appropriate because the study sought to understand the subjective realities of family caregivers of persons with XDP, including the emotional, social, physical, and caregiving challenges inherent in their everyday caregiving experiences. By eliciting detailed descriptions of these experiences, the study aimed to reveal the common meanings and essential structures that characterize caregiving in the context of XDP.

Guided by the methodological principles advanced by Moustakas (1994), this design provided a rigorous framework for describing and understanding the essence of caregivers' lived experiences while remaining faithful to participants' perspectives and voices.

Participants and Sampling

The participants of this study consisted of family members caring for individuals clinically diagnosed with X-Linked Dystonia-Parkinsonism (XDP) residing in Barangay Candelaria, New Washington, Aklan. Purposive sampling was employed to recruit participants who possessed direct, firsthand, and substantial caregiving experiences relevant to the phenomenon under investigation. This sampling strategy was deemed appropriate for transcendental descriptive phenomenology because it enabled the selection of individuals who had personally experienced the caregiving realities associated with XDP and could provide rich descriptions of those experiences.

A total of 6 family caregivers participated in the study. Participants met the following inclusion criteria: (1) they were biological or legally recognized family members of an individual clinically diagnosed with XDP; (2) they were actively involved in providing physical, emotional, financial, or daily caregiving assistance; and (3) they resided with the affected individual or maintained regular and substantial contact with the patient. Family members who had limited interaction with the patient or were not directly involved in caregiving responsibilities were excluded from participation.

Participant recruitment continued until data saturation was achieved. Consistent with qualitative phenomenological research, saturation was determined when additional interviews no longer yielded substantially new descriptions, meanings, or experiential insights regarding family caregiving in XDP. Following the analysis of the 6th interview, recurring patterns and themes had become consistently evident across participants' narratives. To verify saturation, 1 focus group discussion was conducted; however, no new meaning units, thematic categories, or significant experiential variations emerged. Consequently, data collection was concluded, as sufficient depth and richness had been attained to describe the essence of family caregiving experiences among families affected by XDP in Barangay Candelaria, New Washington, Aklan.

Research Instrument

The primary data-gathering instrument utilized in this study was a researcher-made, open-ended interview guide designed to elicit rich, comprehensive descriptions of the participants lived experiences. In alignment with Transcendental Descriptive Phenomenology, an open-ended format was selected because it provides an open, flexible conversational structure that encourages family members to narrate their caregiving lifeworld (*Lebenswelt*) in their own words while ensuring consistency across interviews.

The interview guide was systematically constructed and directly aligned with the study's three core research questions. Specifically, the instrument was organized into four main parts:

1. Demographic and Caregiving Profile — gathered essential background context, such as the participant's age, relationship to the diagnosed relative, duration of caregiving, and living arrangement.

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2. Lived Experiences of Family Members — consisted of broad, open-ended prompts exploring the day-to-day caregiving realities, shifting household roles, and emotional or socioeconomic impacts of having a relative diagnosed with X-Linked Dystonia-Parkinsonism (XDP).
3. Witnessed Struggles of the Relative with XDP — focused on how the family members perceive, observe, and describe the physical, emotional, and social challenges experienced by their loved one in daily life.
4. Observed and Facilitated Coping Strategies — explored the practical, emotional, spiritual, and external coping mechanisms utilized by the affected relative, as well as how the family members actively support and co-facilitate these strategies.

To ensure linguistic accessibility, cultural resonance, and clarity during the interviews, the questions were originally formulated in English and subsequently translated into Akeanon, the local vernacular spoken by the participants. Translating the instrument into the participants' native language minimized comprehension barriers and allowed them to articulate subtle emotional nuances, household dynamics, and culturally embedded experiences of XDP (*Lubag*) with greater authenticity and ease.

Prior to data collection, the semi-structured interview guide underwent rigorous content and face validation by a panel of three experts:

1. A licensed healthcare professional, who evaluated the clinical accuracy, sensitivity, and appropriateness of the questions concerning XDP symptoms, patient care, and health-related struggles;
2. A language expert examined the grammatical precision, semantic equivalence, and cultural appropriateness between the English version and its Akeanon translation; and
3. A qualitative research expert holding a Doctorate degree, who assessed the methodological alignment of the interview prompts with the principles of Husserlian descriptive phenomenology, ensuring that the questions were non-leading, open-ended, and free from researcher assumptions (*epoché*).

The comments, suggestions, and revisions recommended by the three validators were thoroughly incorporated into the final version of the instrument prior to its administration.

Data Collection Procedure

Data were collected from December 2025 to February 2026 in Barangay Candelaria, New Washington, Aklan. Following the acquisition of the necessary institutional and community permissions, eligible family caregivers were identified through purposive sampling.

The researchers explained the study's objectives, procedures, potential risks, and participants' rights before obtaining written informed consent. Individual in-depth interviews were conducted in private settings, primarily within participants' homes, to encourage open discussion of their caregiving experiences.

A total of 6 individual interviews were conducted, each lasting approximately 1 hour. Subsequently, 1 focus group discussion, involving the same participants was conducted at their residence to further explore shared experiences and coping practices. The discussion lasted approximately 3 hours.

The validated interview guide was administered in English or Akeanon, depending on participants' language preferences. With their explicit consent, all sessions were audio-recorded. Recordings were transcribed verbatim in Akeanon and subsequently translated into English. The translated transcripts were reviewed to preserve the original meanings and cultural nuances of participants' accounts.

Treatment of Data

The qualitative dataset obtained from the six (6) individual in-depth interviews and the one (1) focus group discussion (FGD) was analyzed using a combined framework integrating Braun and Clarke's (2006) six-phase thematic analysis and Moustakas's (1994) transcendental phenomenological procedures. Consistent with the study's data collection design—in which the FGD was conducted with the same six participants following the individual interviews to verify data saturation and explore shared caregiving perspectives—both the individual interview transcripts and the FGD transcript were incorporated as a single, integrated corpus throughout all stages of analysis.

Analysis began with the verbatim transcription of all six individual in-depth interviews and the FGD session, followed by translation from Akeanon into English and repeated reading of the entire dataset to achieve holistic familiarization. Throughout familiarization and analysis, the researchers practiced *epoché* (bracketing) by consciously setting aside personal assumptions, prior clinical knowledge, and preconceptions regarding caregiving and X-Linked Dystonia-Parkinsonism (XDP) to remain faithful to participants' lived descriptions.

During initial coding, significant statements relevant to the research questions were extracted systematically across both the individual interview transcripts and the FGD transcript. Rather than treating the FGD solely as a

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separate validation check, both data sources were coded and analyzed concurrently within a unified coding framework. Individual interview transcripts captured granular, personal, and household-specific nuances, whereas the FGD transcript captured collective consensus, interactive elaboration, and shared meanings across caregivers. Comparable codes from both sources were clustered into meaning units and synthesized into overarching themes, which were subsequently reviewed, refined, and defined against the complete combined dataset to ensure internal coherence and accuracy.

Following Moustakas's (1994) phenomenological procedures, the researchers then constructed textural descriptions (what participants experienced) and structural descriptions (how these experiences unfolded within their domestic, socioeconomic, and rural healthcare contexts) drawing upon evidence from both individual interviews and the FGD. Finally, these textural and structural descriptions were integrated into a composite synthesis representing the essential structure of family caregiving in XDP. Incorporating both data sources into a unified analytical process ensured that the final themes reflected both intimate individual realities and shared collective experiences while confirming thematic saturation across the dataset.

Ethical Considerations

At the time this study was conducted, the institution did not have an established Research Ethics Committee (REC) or Institutional Review Board (IRB) authorized to review research involving human participants. Consequently, the study was not subjected to formal ethics review, and no ethics approval reference number was issued. The study was therefore conducted without formal REC/IRB review due to the absence of an available institutional ethics review mechanism during the study period.

Despite the absence of a formal ethics review board, the researchers adhered to recognized ethical principles governing research involving human participants. Prior to data collection, permission to conduct the study was obtained from the appropriate institutional and community authorities. All participants were informed of the purpose of the study, data collection procedures, potential risks and benefits, and their rights as research participants. Written informed consent was secured from all participants prior to their involvement in the study.

Participation was entirely voluntary, and participants were informed of their right to refuse participation or withdraw from the study at any stage without penalty or adverse consequences. To ensure privacy, anonymity, and confidentiality, pseudonyms were assigned to participants, and all identifying information was removed from interview transcripts and research reports. Audio recordings and transcripts were stored in encrypted, access-restricted digital files. Only the researchers are allowed to access the said files. The researchers also observed the requirements of the Philippine Data Privacy Act of 2012 (Republic Act No. 10173).

Emotional sensitivity was maintained throughout data collection. Participants who experienced distress were given the opportunity to pause, discontinue, or reschedule their interviews. The researchers also committed to sharing an accessible summary of the findings with participating families and relevant community stakeholders.

PHENOMENOLOGICAL FINDINGS AND INTERPRETATIONS

Consistent with the transcendental descriptive phenomenological design of the study (Husserl, 2012; Moustakas, 1994) and the six-phase thematic analysis framework of Braun and Clarke (2006), the findings presented in this section reflect the participating family caregivers' direct descriptions, perceptions, and lived consciousness of caring for a relative diagnosed with X-Linked Dystonia-Parkinsonism (XDP). Through the rigorous observance of *epoché*, these thematic meaning structures should not be interpreted as formal clinical diagnoses, biomedical verifications, or objective causal relationships. Rather, they represent how family members personally experienced, witnessed, and attributed meaning to their caregiving realities, their loved one's physical, emotional, and social struggles, and the coping strategies enacted within their domestic and rural community context in Barangay Candelaria, New Washington, Aklan.

Lived Experiences of Family Members

Fear of passing down the illness. Within the family members' lifeworld, living with X-Linked Dystonia Parkinsonism (XDP) is defined not only by present caregiving demands, but also by the persistent apprehension surrounding its X-linked hereditary transmission. Participants expressed their understanding that XDP may be transmitted through maternal family lines. Some participants believed that male offspring may have a higher likelihood of developing the condition and that female descendants may carry the gene. These statements reflect

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participants' perceptions and understanding of hereditary transmission rather than independently verified genetic information.

> *"May una ngani anda nganing lolo sa side ni mother na. Kase ro masakit nga makaroyun carrier kara ay si mama na halin pa sa anang lolo kapag mag-asawa, kapag mag unga, halimbawa mag asawa kami mag-unga it bayi may possibility nga kung mag unga it eaki igtu ta matapik."*
> (Yes, his grandfather on their mother's side. The carrier of this illness is his mother. It came from his grandfather. If someone gets married and has children, for example if we have a daughter, there is a possibility that it will be passed on.) (Participant 2)
> *"Pero sa mga unga nga eaki 50 percent pa ro ano karun, ru masakit nga dystonia depende pa sa genes nga halin kay mama na."*
> (But for male children, it's still a 50 percent chance. The painful reality is that dystonia still depends on the genes inherited from his mother.) (Participant 2)

These accounts illustrate that for XDP-affected families, the burden of illness is temporally extended, stretching backward through ancestral lineage and forward into unborn generations. Rather than experiencing XDP as an isolated medical event affecting a single relative, family members internalize a sense of generational vulnerability. Even when relatives expressed what they believed to be an understanding of inheritance patterns, their perceptions of heredity did not alleviate their distress; instead, these beliefs were accompanied by reproductive uncertainty and ongoing worry about future generations and family planning. These findings represent participants' perceptions and interpretations of familial disease transmission. The study did not assess the accuracy of participants' genetic knowledge nor investigate genetic mechanisms of inheritance.

Exhausting all treatments without a cure. Participants described a relentless, multi-avenue pursuit of relief, turning simultaneously and sequentially to traditional faith healers (*albularyo*), local hospitals, and specialized medical foundations. Despite exhaustive personal, financial, and logistical efforts, family members perceived little to no substantial improvement in their relatives' progressive symptoms. Repeated encounters with limited symptom relief were experienced as deep helplessness and resignation, as families confront the stark reality that current interventions offer only limited symptomatic management rather than a definitive cure or restoration of their loved one's baseline health.

> *"May una ron ay sariling sikap nag pa albularyo, nag pa ospital, nag pa doctor sa Roxas City sa sangka foundation, inubra man do tanan hay uwa gid ga mayad."*
> (Yes, that is personal effort. Went to a faith healer, went to the hospital, received treatment at a foundation in Roxas City, did everything, but it really didn't get better.) (Participant 1)
> *"Uwa pa gida it bueong."*
> (There's no medicine yet.) (Participant 2)

These narratives reveal an exhausting cycle of medical pluralism and therapeutic disillusionment within XDP-affected households. Driven by deep familial obligation (*sariling sikap*), caregivers navigate both indigenous healing frameworks and biomedical institutions in hopes of reversing the disease trajectory. However, when neither spiritual intervention nor specialized neurological care arrests the physical decline, families experience a feeling of helplessness. Recognizing that there is 'no medicine yet' was described as shifting their caregiving outlook from hoping for recovery to enduring ongoing decline.

Shifting breadwinner roles and financial hardship. Participants reported that as XDP progressed and their affected male relative could no longer work, traditional household economic roles shifted, leaving spouses and relatives to assume primary breadwinning responsibilities. Spouses and relatives must abruptly assume sole breadwinning responsibilities while simultaneously managing escalating daily caregiving demands. One participant described acute financial strain following her husband's loss of employment, expressing distress over plunging rural households into severe financial hardship and participants' reported experiences of food insecurity and concerns

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regarding child malnutrition. Another participant emphasized the critical need for proactive financial preparation prior to symptom onset, recognizing that the progressive loss of livelihood is an inevitable consequence of the condition.

> *"Madali imaw ma-stress, syempre kalisod sa owa imaw it ubra. Ako ga-trabaho ron para ron may makaon ang mga unga ngarang mga malnourished."*
> (He gets stressed easily. Of course, it's hard because he has no work. I'm the one working so my children, who are malnourished, have food to eat.) (Participant 3)
> *"Dapat habang sayod man abi nga magkaroon na sya it makaroyun dapat pinaghandaan para indi baga malisdan sa makaraya euta indi eun kapangita."*
> (You should know that if something happens in the future, you need to be prepared so that you won't struggle when it comes. You might not be able to work.) (Participant 2)

These accounts illustrate how participants experienced severe socioeconomic strain across the household when a primary earner could no longer work. Caregivers described taking on sole financial responsibility alongside daily caregiving duties, reporting worries over food availability, child malnutrition, and household expenses. Furthermore, their emphasis on advance financial preparation reflects their personal view that anticipating future care demands could help families cope with economic vulnerability, rather than an objective measure of household income or clinical nutritional status.

Constant worry over sudden health crises. Caregivers reported experiencing intense emotional distress, fear of sudden medical crises, and heightened vigilance while caring for a relative with a progressive neurological condition. The narratives reveal an acute dread of sudden mortality compounded when underlying comorbidities such as heart disease, diabetes, and high cholesterol intersect with dystonic crises. Moreover, periods of solitude trigger severe psychological distress and feelings of spectral isolation (*"feeling like a ghost"*), requiring continuous digital or physical monitoring between family members to ensure safety.

> *"Huo. Madali maw ma stress. Ga litik anang ueo. Ga chat imaw kakon kong owa imaw it kaibahan iya.*
> (Yes. He gets stressed easily. His mind is confused. He chats with me when he has no one with him here.) (Participant 2)

The findings reveal an overarching lifeworld defined by intergenerational dread, therapeutic helplessness, socioeconomic upheaval, and constant existential vigilance, aligning with broader literature on the multidimensional toll of caregiving. As highlighted in the scoping review by Ramos et al. (2026), family caregivers experience substantial psychological, social, and economic challenges as they continuously adapt to the escalating demands of the illness.

In the present study, caregivers described living with persistent anxiety surrounding their belief in maternal transmission and perceived risks to future offspring, which casts persistent fear over family planning and parenthood. This genetic burden is compounded by the exhausting futility of pluralistic health-seeking, spanning traditional folk healers (*albularyo*), local hospitals, and specialized neurology clinics only to confront the harsh reality that no definitive cure exists.

Simultaneously, participants reported taking on sudden breadwinning roles and experiencing financial strain, worries about food insecurity and child malnutrition, and ongoing emotional distress as they balanced household survival with daily care. Ultimately, living alongside a progressive neurodegenerative disorder traps families in a state of chronic emotional distress and hypervigilance, marked by profound isolation and an ever-present fear of sudden mortality when dystonic crises intersect with underlying health comorbidities. These lived experiences are further corroborated by Cataniag et al. (2026), who revealed that the extensive time and effort required for daily care contribute to heightened psychological stress, anxiety, and depression, leaving a considerable proportion of caregivers either at risk for or already experiencing severe caregiver strain.

Witnessed Struggles of the Relative with XDP

Involuntary spasms, difficulty swallowing, and shortness of breath. Family members bear witness to a relentless, multi-systemic physical deterioration in their affected relatives. Rather than remaining static symptoms

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evolve from focal cranial and facial abnormalities such as excessive blinking and involuntary facial grimacing (*kiwit-kiwit*), into severe cervical dystonia and life-threatening bulbar and respiratory complications. Participants described extreme neck stiffness accompanied by visible vascular strain, alongside alarming episodes of shortness of breath (*hapo*) that clinicians attributed directly to dystonic progression rather than primary pulmonary pathology. Participants also observed increasing swallowing difficulties, which prompted them to prepare liquid or broth-based meals (sabaw) that they perceived as easier for their relatives to swallow.

> *"Gabaeakod ro liog, mingko sasabog do ugat. Anang napinunggan hay ro pag ngisi."*
> (The neck stiffens, it feels like the vein here is going to burst. He only tries to stop the involuntary grinning.) (Participant 1)
> *"Habang ga buhay hay galala, iba-iba nga sintomas nga guwa makara hay hapo euman dayang hapo ngara hay daea eon sa Dystonia uwa man imaw it sakit sa ano ay uwa man it tama anang baga. Daya hay daea eota sa dystonia do hapo duyon man do hambae it doctors."*
> (As time goes by, it gets worse. Different symptoms are appearing now, like 'hapo,' which is caused by dystonia. He doesn't have any illnesses in his lungs, they're fine. The 'hapo' is caused by dystonia, that's what the doctors said.) (Participant 1)
> *"Kung owa't sabaw 'di imaw kalunok haeos kaya kinahangean hay may sabaw permi."*
> (If there's no soup, he can't swallow well, so he always needs soup.) (Participant 2)

These accounts capture the instinctive, everyday terror of watching a loved one's body progressively turn against its own vital functions. For family caregivers, symptom progression is not an abstract clinical staging process; it is experienced intimately at the dinner table and the bedside, through the visible physical agony of neck spasms, the constant vigilance caregivers described during meals because they were concerned about choking or swallowing difficulties, and the panic induced by sudden respiratory distress. Caregivers' accounts of physicians explaining dystonia-related shortness of breath (hapo) illustrate how families drew upon medical explanations to make sense of frightening episodes, while relying on practical home adjustments—such as consistently serving broth—based on their everyday observations of feeding comfort.

Loss of strength and inability to work. Caregivers observe the progressive stripping away of their loved one's bodily agency, muscular strength, and physical stamina. Tasks that once anchored their daily routines and social identity such as lifting heavy objects, engaging in manual labor, exercising, or sharing casual social activities, gradually become physically impossible. Consequently, the affected relative's spatial and social world contracts into a monotonous, sedentary cycle confined to the immediate perimeter of the home: lying down, sleeping, taking brief, slow steps outside, and sitting.

> *"Makaruyon malang dun ga eubog matueog maguwa mag tikang tikang ruyon mapungko dayun malang ron ana."*
> (That's all he does—lies down, sleeps, goes outside, walks around, then sits. That's all he usually does every day.) (Participant 2)
> *"Indi eun nana maubra anang mga ueobrahon dati, indi eun imaw katrabaho ag ka inom."*
> (He can no longer do the things he used to do. He can't work or drink anymore.) (Participant 5)

These narratives reflect caregivers' observations of how declining physical strength narrowed their relatives' daily routines to resting, sitting, and walking briefly near the home. In their accounts, losing the ability to perform physical labor and join everyday social activities such as sharing drinks with peers was perceived as a major loss of independence and social participation.

Irritability, stress, and hopelessness. While motor symptoms progressively ravage the body, family members observe that their relative's cognitive awareness remains fully intact, which caregivers perceived as deeply distressing for their relatives. Caregivers witness heightened emotional volatility, marked by short-temperedness (*mainiton da ueo*) and rapid stress responses triggered by physical helplessness, communication barriers, and the loss of livelihood. Furthermore, caregivers describe the emotional toll of witnessing extreme symptom fluctuations: while

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some days feel manageable, severe episodes of involuntary spasms (*kiwit-kiwit*) and acute shortness of breath plunge the affected relative into profound existential despair, leaving them feeling on the brink of death.

> *"Mainiton da ueo."*
> (Has a short temper.) (Participant 2)
> *"Tiniis ron kung alin ga abot sa adlaw ngara, atakihon imaw it kiwit-kiwit or indi makahinga may adlaw man ngaron nga medyo normal ta ag magaan do anang pamatyag, may adlaw gita nga malisod gita, madya mapaalam eon kuno imaw sa mundo."*
> (He endures whatever each day brings. Some days, he gets attacked by shortness of breath and uncontrollable movement. But there are also days when he feels somewhat normal and lighter. Still, there are days when everything feels like difficult days that makes him feel like he might already leave this world.) (Participant 1)

These accounts highlight the caregivers perceived substantial emotional distress among their relatives, where an intact, observant mind remains trapped inside an increasingly unresponsive and spasmodic body. For caregivers, irritability and anger (*mainiton da ueo*) are understood not merely as personality flaws, but as visceral expressions of frustration, grief, and loss of autonomy. Moreover, caregivers reported feeling chronically watchful and emotionally strained as they navigated fluctuations between calmer days and severe spasm or breathing episodes.

Embarrassment and social withdrawal. In the social sphere, family members observed that visible involuntary movements and speech difficulties were accompanied by embarrassment (nahuya) and reluctance to join neighborhood gatherings, which caregivers perceived as deepening their relative's social isolation and limiting community interaction.

> *"Indi eon ngani imaw makipag-halubilo hay nahuya imaw hay gakiwi-kiwit imaw."*
> (He no longer socializes because he feels embarrassed due to his uncontrolled movements.) (Participant 2)
> *"Nalisdan imaw maghambae."*
> (He has difficulty in speaking.) (Participant 3)

These accounts illuminate the relational and symbolic cost of visible motor and bulbar symptoms in XDP. In tightly knit rural communities where face-to-face sociability and verbal exchange form the fabric of daily belonging, involuntary facial grimacing and slurred or strained speech become hyper-visible markers of bodily loss of control. The experience of *nahuya* (deep shame or embarrassment) acts as a powerful internal barrier: rather than enduring pity, curiosity, or social awkwardness, affected individuals choose self-exile within the home. For family caregivers, this withdrawal compounds their burden—not only must they witness their loved one's reduced social participation and increasing social withdrawal, but the household becomes increasingly insulated from informal neighborhood solidarity and mutual aid.

Family members observe a holistic, multi-dimensional decline encompassing severe physical deterioration, emotional distress, and social withdrawal. While Padilla et al. (2024) found that gene-positive individuals commonly experience non-motor manifestations such as memory impairment, urinary disturbances, pain, sleep dysfunction, depression, and anxiety, prior to the onset of motor decline, caregivers in the present study predominantly detailed the overt progression of somatic and functional impairments. Physically, family members witness the escalation of focal motor symptoms such as blinking, facial grimacing (*kiwit-kiwit*), and intense neck rigidity into swallowing difficulties and dystonia-induced shortness of breath (*hapo*), accompanied by a progressive loss of strength and work capacity that confines the affected relative to a sedentary routine of resting, sitting, and brief indoor or yard movement. This trajectory aligns with Acuna et al. (2023), who established that as the disease progresses, patients undergo steady deterioration in motor function, speech, swallowing, feeding, dressing, and hygiene, accompanied by significant weight loss and increasing disability.

Beyond these physical impairments, Cataniag et al. (2026) emphasized that patients endure profound emotional and social struggles, including heightened anxiety, depression, social stigma, and isolation. These clinical observations are strongly reflected in the lived realities described by families: emotionally, caregivers observed heightened irritability (mainiton da ueo), stress, and expressions of despair as their relatives remained aware of their

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physical limitations and inability to work. Socially, participants reported that visible involuntary movements and speech difficulties (nalisdan maghambae) were associated with embarrassment (nahuya) and withdrawal from social gatherings.

Observed and Facilitated Coping Strategies

Adjusting diet and prioritizing rest. Caregivers reported making daily dietary and activity adjustments—such as preparing softer foods including soup and broth (*sabaw*), limiting hard, fried, or sugary foods when diabetes was also present, and encouraging rest, television, or mobile phone use. Participants perceived these routines as easier for their relatives to manage and felt they helped ease choking worries and fatigue, though these accounts reflect caregiver practices rather than clinically verified prevention or nutritional outcomes.

> *"Kung owa't sabaw 'di imaw kalunok haeos kaya kinahangean hay may sabaw permi. 'Di imaw ka-mukbang eon, indi eon imaw kaagaw it mga lechon, prito, indi eon imaw ka soft drinks hay diabetic."*
> (If there's no soup, he can't swallow well, so he always needs soup. He can't do mukbang anymore, can't grab lechon or fried food, and can't drink soft drinks because of diabetes.) (Participant 2)
> *"Indi imaw mag pinamug-at mag pahuway eang imaw... Pahuway lang imaw run, magsenelpon ag mantaw it tv."*
> (Don't do anything heavy and he just rests... For now, he just rests, uses his phone, and watches TV.) (Participants 3 & 5)

These accounts illustrate how family caregiving evolves into adaptive domestic stewardship, wherein the household environment and daily rhythms are systematically reorganized around bodily preservation. Rather than passively surrendering to symptom progression, caregivers and patients collaboratively construct protective routines that balance physiological safety with emotional comfort. Eliminating festive or indulgent foods (*lechon*, fried dishes) and physical labor represents a tangible loss of everyday pleasures, yet substituting structured rest and accessible digital entertainment (television and mobile phones) preserves a modest sphere of normalcy and peaceful engagement within the home. Notably, navigating XDP alongside metabolic comorbidities like diabetes demonstrates the heightened vigilance required of family caregivers, who must harmonize neurological dysphagia precautions with broader chronic disease management.

Relying on medical check-ups and foundation support. Participants reported that assistance provided by the Sunshine Care Foundation helped them access medications, consultations, and other forms of support that they perceived as beneficial in managing caregiving demands and reducing some financial burdens associated with the condition.

> *"Sunshine care foundation sa Roxas nga ano it centrums. Pag member ka eon igto sa may free, pag nakakaagto ka igto makaka refund ka sa pamasahe tapos libre eon do pagkaon nanda igto tapos pag kung may reseta nga bueong kung may igto sanda stock libre eon man to."*
> (Sunshine Care Foundation in Roxas, which is for these centrums. If you become a member there, you can get free assistance. When you go there, you can get a refund for your transportation fare, and the food there is also free. If you have a prescription, and they have the medicine in stock, it will be free as well.) (Participant 2)
> *"Ga provide sanda it mga bueong, check-up ag botox nga gina injection."*
> (They provide medicines, check-ups, and Botox injections.) (Participant 3)

These accounts illustrate how caregivers viewed ongoing membership and follow-up visits at the Sunshine Care Foundation as helpful in accessing check-ups, medications, botulinum toxin injections, meals, and transportation refunds, which they perceived as easing practical and financial burdens. These findings reflect caregivers' reported experiences of support rather than measured clinical effectiveness or economic outcomes. These observations reflect

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caregivers' experiences and perceptions of support. The present study did not evaluate clinical outcomes, treatment effectiveness, or the extent of economic burden reduction.

Holding on through faith, patience, and preparation. caregivers described drawing emotional strength from prayer (*pangamuyo*) and patience (*tyaga*), shifting their focus toward day-to-day living (*pangabuhi*) rather than paid work (*hanapbuhay*), and preparing practically based on past emergencies. These narratives reflect how participants made sense of uncertainty and sustained hope in their daily lives, without establishing measured psychological or clinical outcomes.

> *"Tyaga-tyaga ron pangamuyo eang sa Diyos... Pangamuyo ag kapit eang."*
> (For now, we just must keep going and continue praying to God... Just keep praying and hold on, don't lose hope.) (Participants 1 & 2)
> *"Magpangabuhi ron indi eon kahanapbuhay."*
> (For now, he just focuses on living, because he can no longer work.) (Participant 1)
> *"Malisod mag ano e kaya lesson learned ngani ginahandaan gid run kung alin du ga abot nga sitwasyon."*
> (It's hard to do things, which is why it's a lesson learned to always prepare for whatever situation may come.) (Participant 2)

These accounts illuminate a profound *existential reorientation and active spiritual resilience* within XDP-affected households. In the absence of a biomedical cure, faith (*pangamuyo*) and patience (*tyaga*) function not as passive resignation, but as vital cognitive anchors that prevent despair and sustain emotional steadiness amidst chronic uncertainty. The linguistic and philosophical shift from *hanapbuhay* (making a living) to *pangabuhi* (simply living) captures a transformative redefinition of human worth: when economic labor is stripped away by progressive disability, survival, presence, and relational continuity become sufficient grounds for meaning. Coupled with experiential learning from prior crises, this spiritual grounding empowers families to face future deterioration with heightened composure and practical readiness.

Overall, the findings suggest that family caregivers in this study navigated the daily demands of XDP through practical home adjustments, external support from a specialized foundation, and spiritual and experiential coping. Specifically, participants reported preparing softer foods such as broth (*sabaw*), restricting certain foods considering comorbid diabetes, encouraging rest, and utilizing check-ups, medications, botulinum toxin injections, meals, and fare refunds from the Sunshine Care Foundation. Alongside these practical measures, caregivers described relying on prayer (*pangamuyo*), patience (*tyaga*), a focus on daily living (*pangabuhi*), and preparation informed by past crises. Consistent with prior literature on Filipino families living with XDP (Alcachupas et al., 2022; Ramos et al., 2026), these accounts highlight the role of faith and support networks in caregivers lived experiences, without implying clinically verified treatment efficacy or causal improvements in quality of life.

Conclusions

Based on the lived experiences and observations shared by family members caring for individuals diagnosed with X-Linked Dystonia-Parkinsonism (XDP) in Barangay Candelaria, New Washington, Aklan, the following conclusions were drawn:

1. Family members experienced substantial emotional and psychological challenges associated with caring for a relative with XDP. These included anxiety regarding the hereditary nature of the condition, uncertainty about future generations, concerns about disease progression, and distress arising from their relatives' continuing health difficulties.
2. The caregiving experience involved considerable socioeconomic adjustments. Participants described changes in household responsibilities, the assumption of additional breadwinning roles, and financial difficulties associated with the affected relative's reduced capacity to work. These experiences highlight the economic vulnerabilities that may confront households managing progressive neurological conditions.
3. Family members observed various physical, emotional, and social difficulties among their affected relatives. These included involuntary movements, difficulties with swallowing and speaking, reduced physical activity, irritability, embarrassment, and withdrawal from social interactions. These findings reflect the caregivers' observations and do not constitute independent clinical assessments of the patients.
4. Family members described several coping practices, including dietary adjustments, prioritization of rest, seeking healthcare and institutional assistance, maintaining spiritual faith, practicing patience, and preparing

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for anticipated caregiving challenges. These practices represented their efforts to manage everyday difficulties and sustain family resilience amid the progressive nature of the condition.

5. The findings demonstrate that XDP affects family life beyond the diagnosed individual, creating interconnected caregiving, psychological, social, and economic concerns. The experiences documented in this study highlight the importance of accessible neurological services, family-centered nursing support, genetic counseling, caregiver education, and community-based psychosocial and socioeconomic assistance.

Recommendations

Based on the findings and conclusions of the study, the following recommendations are proposed:

1. Local Government Units and Social Welfare Offices may consider identifying and assessing households affected by XDP for appropriate disability assistance, nutritional screening, social welfare support, and livelihood opportunities, particularly when the affected individual can no longer participate in income-generating activities.
2. Rural Health Units and Partner Healthcare Institutions may explore providing accessible genetic counseling through qualified professionals, regular neurological consultations, and referral arrangements with specialized healthcare facilities. Telehealth services and transportation assistance may also be considered to address geographical and financial barriers to healthcare access.
3. Healthcare Professionals and Community Health Workers may provide appropriate caregiver education on daily care, nutrition, swallowing difficulties, recognition of warning signs, and timely referral for clinical assessment. Training on feeding and swallowing management may be conducted under the guidance of qualified healthcare professionals.
4. Mental Health Professionals and Community Organizations may develop culturally responsive psychosocial support activities and caregiver peer groups that recognize the emotional difficulties experienced by affected families. Partnerships with local faith-based organizations may also be explored, respecting the participants expressed reliance on prayer, patience, and spiritual resilience.
5. Future Researchers may conduct additional qualitative and quantitative investigations involving larger and more diverse populations to further examine caregiver burden, healthcare accessibility, nutritional concerns, genetic counseling needs, and the psychosocial experiences of households affected by XDP. Future studies may also explore the perspectives of patients and healthcare professionals to complement the family caregivers' accounts.

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