



**RESEARCH ARTICLE**

**HEARTS OF GOLD AND HOPEFUL HEARTS: LIVED EXPERIENCE OF PRIMARY CAREGIVERS  
IN TAKING CARE OF INDIVIDUALS WITH DYSTONIA**

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**ABSTRACT**

**Background:** Progressive and involuntary in nature, X-linked Dystonia Parkinsonism (XDP) causes a great impact on the quality of life of the individuals affected. With all these changes involved in XDP, it necessitates the critical participation and support of caregivers in managing and coping with the disease. Published studies about XDP are mainly concerned with the experiences of individuals living with the disease, while the caregiver's perspective is given less attention. **Objective:** This study aimed to explore the lived experience of primary caregivers in taking care of individuals diagnosed with XDP in Panay. **Methods:** A phenomenological research design was used as the strategy of inquiry to provide rich and thick description of the participants lived experience about the phenomenon. A semi-structured, face-to-face, in-depth interview was used to gather data among five purposively chosen participants. Interview transcripts were analyzed and interpreted using the method inspired by Colaizzi. Credibility, dependability, confirmability and transferability were adopted to maintain trustworthiness. **Results:** Six themes emerged: (1) overwhelming odds; (2) seal of care; (3) inescapable reality; (4) dancing under the storm; (5) finding one's feet in; and (6) when hope springs. **Conclusion:** Primary caregivers of individuals with XDP are faced with increasing demands and challenges that are often overlooked. Understanding their experience is fundamental in designing interventions that highlights caring for the carers themselves.

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**INTRODUCTION**

Dystonia is a neurological disorder characterized by uncontrollable, sustained contractions or painful muscle spasms as a result of incorrect signals sent by the brain (Brin *et al.*, 2004; <https://www.dystonia.org.uk/>). The prevalence rate of dystonia based on a meta-analysis study which included 16 studies from different countries found that in every 100,000 persons, 16.43 are affected by the disease (Steeves *et al.*, 2012). In the Philippines, as of February 2010, the estimated prevalence rate of clinically diagnosed dystonia patients is 0.31 % per 100,000 population (cited in Rosales, 2010). X-linked Dystonia Parkinsonism (XDP) affects mostly men with roots from the Philippine Island of Panay (Diestro *et al.*, 2016) with 5.74 % in every 100,000 persons affected. The province of Capiz has the highest rate in Region VI, with an estimated prevalence rate of 23.66 % per 100,000 Capiznons (cited in Rosales, 2010).

The progressive, involuntary nature of the signs and symptoms of dystonia causes great impact on the quality of life as well as on the mental health of these individuals. Affected individuals reported problems in mobility, nutrition, communication, daily activities, self-care and experience of moderate to severe pain, anxiety or depression (Brin *et al.*, 2004; <https://www.dystonia.org.uk/>; Papapetropoulos, 2006). These necessitate the critical and significant participation and support of family members to attain successful care for people living with dystonia. Caregivers assume partially or completely the activities of daily living and functions of another person that requires significant amount of time. In most cases, family members serve as the primary caregivers of people experiencing XDP. This includes the immediate family such as parents, spouses or partners, siblings, adult children and even extends to other relatives such as aunts, nieces/nephews, in-laws, grandchildren, friends and neighbors (<https://www.caregiver.org/caregiving-101-being-caregiver>). Filipinos pride themselves of their close family ties (Nadal, 2011). The close bonding within the family has helped to mold genuine concern for each member. They help each other in times of difficulties like when one family member suffers a

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serious illness, the entire Filipino family unites to aid him or her in any way they are able. Researches about dystonia were mainly concerned on the experiences of the patients themselves and typically employed quantitative research designs. One study found that existing interventional studies in childhood dystonia poorly addressed the main concerns of children with dystonia and carers (Lumsden *et al.*, 2015). A study in Sweden reported that there is a need for health care professionals to encourage physical activity and to question satisfaction with treatment among dystonia patients (Zetterberg *et al.*, 2009). An up-to-date research describing the lived experiences, viewpoints, feelings, challenges, and coping mechanisms of the primary caregivers taking care of individuals with XDP is given a lesser amount of attention, hence this study.

## MATERIALS AND METHODS

A qualitative phenomenological research design was used to describe the participants' lived experience towards the phenomenon. The primary caregivers' verbalizations and descriptions were not altered since the abstracted categories and themes were solely based on the participants' responses, on how they exactly experienced the phenomenon. The participants were chosen using purposive sampling and were identified through referrals and with the aid of a neurologist. The following were the inclusion criteria: a primary caregiver for at least one year to a clinically diagnosed XDP; is currently taking care of a living dystonic individual; must be at least 18 years of age; and a resident on the Island of Panay. There was no preset number of participants. The researchers were able to reach data saturation with only three participants but added two more having a total of five female participants in order to increase the rigour of the study as suggested by Fusch and Ness (2015). For anonymity and confidentiality, the researchers utilized code names that were inspired from the names of Filipina nursing icons who have committed themselves in caring for the delicate and frail.

To commence data gathering, a letter was sent to a neurologist with XDP patients to ask permission to conduct the study and to serve as a gatekeeper between the researchers and the study participants. The researchers contacted the participants through a phone call and those who met the inclusion criteria were recruited and scheduled for interview. On the date that was agreed upon, the researchers met with the participants to conduct a semi-structured, face-to-face in-depth interview with the aid of an interview guide. Informed consent was obtained and the use of audiotapes during the interview was emphasized. The interview started with a grand tour statement, "Can you tell me about your experience in taking care of '*name of the individual with XDP*' when he was diagnosed with dystonia." to encourage participants to open up and ramble on their experiences. One member from the group conducted all the interviews while the other group members listened, observed and wrote field notes. The researchers used probing statements to encourage the participant to continue and delve into the participant's response. The interview ended when the participant was able to provide thick description of their experience. At the end of each interview, the researchers prompted the participants about the need for another interaction with them to make sure that findings of the study reflect the participants' lived experiences. The data gathered were analyzed using the method inspired by Colaizzi's descriptive phenomenological data analysis as described by

Shosha (2012). After every interview with each participant, the audio tape recorded interviews were transcribed in the original language and were then translated to the English language. The non-verbal cues observed by the researchers were also stated in line with the transcribed words. Individually, the researchers read and listened repeatedly, analyzed, and evaluated exhaustively the interview transcripts to fully grasp the sense of the whole content. Any prior knowledge, thoughts, feelings, and ideas about the topic were laid aside. From the transcripts, the researchers extracted significant statements and phrases with the use of a highlighter pen. The statements were encoded on a separate word file and were coded based on transcript, page, and line numbers. After extracting significant statements from the transcripts, the researchers met and compared their outputs within the group until consensus was reached. Initially, there were 146 significant statements and formulated meanings, then 28 clustered themes that were later reduced to six emergent themes and 13 subthemes. Emergent themes and subthemes were then given definition through thorough, thick and vivid descriptions. The researchers sought the help of an English professor to evaluate the translated version of the transcript and to make sure that the thought the participants wanted to convey is retained in the translated version. Trustworthiness in this study was safeguarded following Lincoln and Guba's criteria of credibility, transferability, dependability and confirm ability (Lincoln, 1985). Member checking was done wherein the researchers returned to the participants to discuss and confirm whether the data interpreted by the researchers truly describe their experience. Investigator triangulation was also employed wherein the data transcribed from the recordings were evaluated and analyzed exhaustively by each of the researcher until consensus had been reached. The researchers bracketed all their personal thoughts, preconceptions, biases, and reflections related to the study with the use of a reflexive journal. In addition, qualitative research experts and a registered nurse who had experience in conducting qualitative research functioned as external auditors to examine the scientific soundness of the research protocol, and product of the research study. Transparent detailed descriptions of the research steps undertaken together with thick textual descriptions were likewise provided.

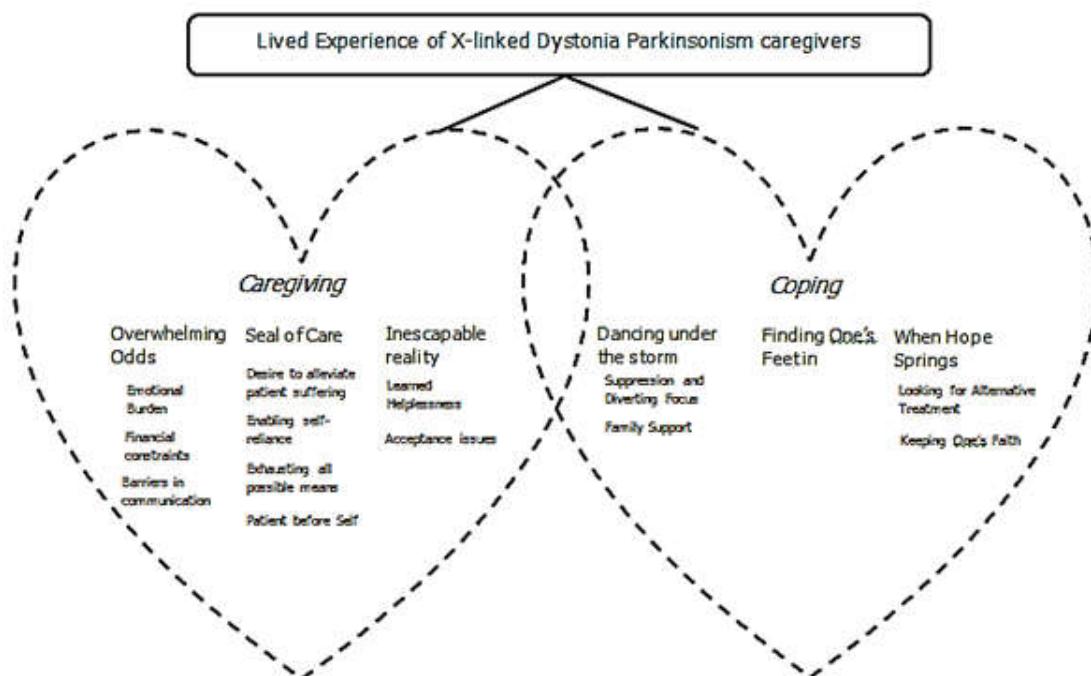
## RESULTS

After arduous data explication process, six main themes and 13 subthemes were developed: (1) overwhelming odds – which pertains to the difficulties experienced by caregivers in caregiving, (2) seal of care – relates to giving care and attention to the dystonic individuals as an utmost priority, (3) inescapable reality – involves the caregivers feelings of being stuck in a situation and not being able to do anything about it, (4) dancing under the storm – refers to how the caregivers were able to cope with the difficult and challenging situations, (5) finding one's feet in – shows how the caregivers were able to adjust and adapt with the repeated exposure of day to day events, and (6) when hope springs – partakes in the idea that the caregivers still had the belief and conviction to hope, no matter what the odds were.

**Theme 1: Overwhelming odds.** This theme pertains to the loads of weight, emotional and fiscal, that is carried by the caregivers. With hindsight, both individuals with dystonia and their caregivers, suffered mainly from the emotional impact of the disease.

**Table 1. Profile of the Participants**

Name	Age	Sex	Occupation	Relationship	Religion	Years of caregiving
Carolina	53 years old	Female	Businesswoman	Wife	Roman Catholic	4 years
Anastacia	66 years old	Female	Housewife	Mother	Roman Catholic	8 years
Carmelita	59 years old	Female	Housewife	Wife	Roman Catholic	7 years
Irma	61 years old	Female	Barangay Health Worker	Wife	Roman Catholic	18 years
Cecilia	22 years old	Female	Nursing Aide	Daughter	Roman Catholic	8 years

**Figure 1. Shows the Thematic Map of the Lived Experience of X-linked Dystonia Parkinsonism primary caregivers**

Various emotions were drawn out from the context as they retold the significant events of their lives. There were barriers identified in terms of their emotions, financial difficulties, and communicating abilities. These primary caregivers retold their living testimonies of the tests of times. A whirlwind of emotions, a handful of thoughts and perplexities were recounted.

**Sub-theme 1.1: Emotional burden:** The study participants were unable to escape the feeling of being emotionally burdened as they witnessed the impact of the disease to their loved ones unfold right before their eyes. As the disorder progressed and continued to disrupt the state of well-being of dystonic individuals, the caregivers were overwhelmed as well with the carousel of emotions riding along with them as they took care of these individuals. Anxiety, pity and sadness were emotions captured in the transcript. As Julita looked back, her eyes gleamed as she said, "*He has already eaten, but then you still worry. Yes, there are times that you would wonder, how is he doing?*" Her eyes widened as she continued, "*That's what I'm thinking. You know, you have questions in your minds. You're scared that it might ... what if we lose our father.*"

**Subtheme 1.2: Financial constraints:** Apart from the emotional burden, one of the hardest issues these caregivers faced was financial difficulties. Most of the individuals with XDP were principal providers of their family, and with dystonia, a debilitating disorder, this forced the caregivers to assume the role as principal providers which they are unaccustomed to.

Being new and inexperienced of the responsibility, the caregivers were overwhelmed by their new responsibilities. They were careworn in making both ends meet as they tried to fulfill the needs of the sick member of the family and other family members. Teresita looked down in disappointment and said, "*We do borrow money. Even my children borrow money from others just to provide for the payments.*" She added, "*That's what really boggles my mind, trying to find a way for me to borrow money.*"

**Sub-theme 1.3: Barriers in communication:** Participants with their story noted how they had difficulties in communicating with one another due to the outcome of the disease. It hinders the individuals with XDP to communicate effectively with their primary caregivers, placing the caregivers in a tight situation in understanding the needs of their sick family member. Carolina recalled, "*We can't understand each other when we talk about something.*" Her voice lowered down as her tears came pouring from her eyes. She added, "*Yes, he also talks, but we can't understand what he is trying to say.*"

**Theme 2: Seal of care:** XDP, being a debilitating disorder, has great impact on the individual's capability of personally meeting his own needs. Due to this incapability, the primary caregiver's role is to act in behalf of these individuals to meet the deficits of self-care. Seal of care pertains to the primary caregiver's experiences of giving care as the utmost priority and the attention is centered towards the sick family member. Despite all the hardships they experienced, these primary caregivers opt to provide all the necessary care in the most

practical means possible. It's either they perform, assist, or compensate for the individual's varying degree of needs.

**Subtheme 2.1: Desire to alleviate patient suffering:** The debilitating effects that come with the disease have major impacts in both the dystonic individual and the caregivers' lives. These primary caregivers voiced out their wishes that they would rather be the one with the disorder rather than seeing their loved ones suffer. Anastacia expressed how, at times, she would want to bear the hardships of her child. She said, "*If it's hard for him, how much more for me? It really hurts me. I would rather bear it instead, than seeing him suffers* (placed both arms on her chest) *let it be me instead.*" Her eyes welled up, as she went on, "*If it is just something to carry, you would want to take turn so that he can also rest.*"

**Subtheme 2.2: Enabling self-reliance:** Caring is focused on promoting self-reliance enabling the individual to perform daily activities to the best of his abilities. This allows him independence with limitations and assistance from his caregiver. Teresita explained how her husband managed his daily activities saying, "*Our water here isn't that good, so he filters it himself with sand. He'd carry it after, and uses it to take a bath*"

**Subtheme 2.3: Exhausting all possible means.** The primary caregivers are willing to do everything, even stepping out of their comfort zones to give the dystonic individuals their everyday necessities. Anastacia vented out her concerns, "*You would borrow in order to buy his medicine. You find means just to buy his medications. You really have to look for a way, even if you need to borrow money first.*"

**Subtheme 2.4: Patient before self.** This subtheme mirrors the experiences of the caregivers' selflessness. It depicts the primary caregivers' willingness to compromise his own well-being in order to cater the dystonic individual's necessities first. Teresita also shared her thoughts, she retold, "*We just let things be. Come what may, and there's always a way, despite all of these, we still manage to eat. What is important is we make sure that we provide his needs first.*"

**Theme 3: Inescapable reality.** The caregivers voiced out their feelings of being stuck in the situation, wherein they are unable to do anything about it. One compared his situation of going into a bottomless abyss and never to return. They also mentioned that they understood that the disease is incurable. Then, they questioned, of all the people, why their loved ones. Despite of the difficulty, they are left with no other choice but to continue to live with what has become an inescapable circumstance.

**Subtheme 3.1: Learned helplessness:** Since the primary caregivers already know that XDP is an incurable and progressive disease, they stressed the feeling of being unable to do anything about the condition of the individual which led them to feel helpless about the situation. Sadness clouded her facial features as Carolina shared, "*Of course, he's probably thinking about it, you can't do anything about it. What else could you do? You can't do anything.*"

**Subtheme 3.2: Acceptance issues:** The primary caregivers had difficulty accepting the situation but they have to bear it all. They often ask the question "why" as to find meaning or purpose for them to accept their fate. Since XDP is a life long

illness, primary caregivers cannot easily accept the diagnosis of a family member. Disbelief overtook Teresita's face as she shared, "*Why does it have to be like this? I wondered why there is this kind of thing. Why is it like that? Sometimes when you find it all to be unbearable, you wonder why.*"

**Theme 4: Dancing under the storm:** It is said that when the going gets tough, the tough gets going. The experiences of these caregivers show how resilient they are in every weather they go through. Ultimately, the question is not how bad the weather was but how one could dance under it, coping with the cards that one has dealt with. Indeed, the hardest struggle is how they were able to cope with the disease and its accompanying difficulties.

**Subtheme 4.1: Suppression and diverting focus:** As the primary caregivers go along with their daily care, they often plunge into other activities to distract themselves from the burdens presented by the disease. They keep themselves busy so they do not dwell in the pains and sorrows that accompany their experiences as caregivers. Shifting her focus to her work is what Carolina opted to do. Her expression hardened as she said, "*Right now, all I think about is my business. I make myself busy.* She added "*Well, you can't let your emotions take over, that's why for me, what I want is just to be able to eat my breakfast and go to work, and then be able to go home and sleep and then wake-up again in the morning.*"

**Subtheme 4.2: Family support:** Primary caregivers tend to struggle with the different tasks that they are confronted with day by day. They reach a point of exhaustion where they cannot physically endure the numerous tasks that are required of them. As their duties and responsibilities increase, they require the aid of others in rendering care to their sick family member. Family members then work together and take turns in taking care of the family member with XDP. Julita shared the responsibilities with her other family members and narrated, "*Mom and I help each other. Example, if I'm the one in the house then I'll be the one responsible of everything. If mom is here in the morning, she'll be the one to prepare the food.*"

**Theme 5: Finding one's feet in:** After years of caring for their significant others, through time and repeated exposure of the day to day events in providing care, the study participants were able to adjust and adapt to the turn of events. They are left with the undeniable reality of taking the role and responsibilities required of them as primary caregivers. Under this theme, acceptance and adjustment were mainly the focus. It was finding ones feet in such terrain, so as to learn the complexities and to flow with the tides. Carolina put in the picture how she was able to adjust to their current state, she said, "*Now that he's suffered for a long time, it's like you already accepted that this is his fate. Of course, whether you like it or not, you have to accept it, little by little because that's the truth. Yes, it's hard. But that's okay.*"

**Theme 6: When hope springs:** It discusses the idea of belief and conviction. Humans as they are, the study participants kept on hoping, no matter what the odds were. Despite all the hardships, the study participants still longed for whatever alternative treatment they could possibly find. As for them, hope was just around the corner. It is their last resort. It was their bedrock of fortitude and found strength in their families and in the Divine Being.

**Subtheme 6.1: Looking for Alternative Treatment:** This subtheme focused on how the caregivers eagerly searched for other treatments possible. The primary caregivers shared how they would much rather find other means of treatment in hopes of better results for their sick family member. They would resort to research from the internet and books that would lead them to the treatment they desire for their sick family member. Despite knowing that XDP is incurable, their hope was never shadowed by the thought rather it has become their motivation. Thus, they strive to search and provide better care to their dystonic member of the family. Carolina's eyes gleamed as she retold how she tried to find other alternatives, "*Of course, if we can afford it then why not. If using marijuana can help him recover then we would probably opt to have that option.*" She said further as her fingers interlaced, "*I really knew about it because I did my research, I knew it already from the very beginning.*"

**Subtheme 6.2: Keeping one's faith:** Amidst the difficulties, the caregivers found strength in consulting the highest source to what is best for their everyday struggles. Faith has been a symbol of hope as they turn to the divine power to aid them with their sufferings. The primary caregivers turn to faith as they pray for the impossible. They pray for help while they provide care to their sick family member and healing that may provide remedy to the incurable disease. As it remains incurable, they still hope that the impossible can be made possible through the miracles and love of the Divine Being. Displaying strong faith, "*I tell him it is okay, as long has he takes his medicines even if his disease is incurable. Nothing is impossible with God*", said Carolina as her voice cracked and her eyes were covered with tears.

## DISCUSSION

As the study participants look back on the important situations they have faced in taking care of an individual diagnosed with XDP, six themes emerged. Through continuous listening to the recorded interviews, re-reading of transcripts, researcher triangulation and consultation with external auditors, two clusters of themes were further appreciated – the care giving experience and coping experience as shown in the thematic map. However, these were not considered as supraordinate themes as the care giving and coping experience does not provide a clear and vivid description of what it means to live as a primary caregiver of individuals with XDP hence, the broken lines outlining the two hearts. The first heart deals with their caregiving experience – The Heart of Gold. Caregivers are special people with a deep purpose in mind of caring for another individual. Like gold, their hearts are rare and precious, when not many would willingly take such responsibility, these individuals did. For like gold, their hearts are strong, firm, and resilient, but behind these exterior signs, it was found that their hearts are truly soft and authentic. They appeared tough and tenacious throughout the struggles and difficulties that they have gone through, but these caregivers are just like any other normal human beings, vulnerable to certain limits, and having an immense amount of passion for kindness above all other. Despite their difficult experiences they remained brave and hopeful for both themselves and for their loved ones. Like gold, their hearts are pure. They have sacrificed so much of their own needs, and their own lives for the sake of maintaining and caring for their loved ones. Despite knowing that this would last a lifetime they still opted to continue giving care to these individuals. They may be

trapped in their current fate, a fate that deprives them of options yet they remained willingly and whole-heartedly by the dystonic individual's side, giving care in any way they can. The second heart deals with the Coping Experience – Hopeful Hearts. Even if faced with various difficulties and situations, the caregivers still found hope in their hearts. The trying times have tested their will. They tried different ways to cope, sought help and support from others to help them carry through. Difficulties had become a day-to-day occurrence but they were able to adapt and cope with them through the help and support of their loved ones. However, despite having coped with the situation, they still hoped that by any chance, or a miracle, that the ones they were taking care of, may be cured or be freed from the disease condition. After finalization of themes, the researchers reviewed related studies to care giving. Previous qualitative studies conducted regarding care giving experience were found to have similarities with the findings of the present study. Caregivers of persons with dementia in Singapore and Hongkong appreciated themes like impact of caregiving, acceptance of destiny, emotional impact and demanding provision of daily care needs (Tuomala *et al.*, 2016; Chan *et al.*, 2010). The lived experience of caregivers of persons with heart failure demonstrated the same significant results such as fear and worry related to the illness, life changes and restrictions and burden due to caregiving (Petruzzo *et al.*, 2017).

Furthermore, studies in other countries regarding the lived experiences of caregivers taking care of different individuals with a variety of illnesses were also found to have shared similar findings to this study. The lived experiences of caregivers providing home care for terminal cancer patients (Mohamed, 2016), family caregivers managing incontinence in stroke survivors (Tseng *et al.*, 2015), African American caregivers caring for adult African American patients with heart failure (Hamilton, 2014), parents taking care of their children with Autism (Hoogsteen, 2013), spousal caregiving for stroke survivors (Coombs, 2007) and spouses of patients with a left ventricular assist device before heart transplantation (Casida, 2005) have shown profound congruency and resonance of the themes and findings to this study on the physical, emotional, social, psychological and financial impact of caregiving. The findings of these studies regarding caregivers of individuals having complex cases showed that similarly caregiving itself poses big impact to their daily lives, and that these caregivers expressed the same feeling of being emotionally affected and having difficulties in coping and maintaining their bonds with their family and friends. It is also prevalent that the participants of the formerly mentioned studies maintained having the sense of hope and faith in the Highest Being as their situations have brought them to a deep uncertainty filled with endless possibilities.

## CONCLUSION

Primary caregivers of individuals with XDP dismiss the misconception that caregiving is purely physical but rather an intricate process encompassing psychological, social, emotional, and financial aspects. As the disease in itself became progressively debilitating, so is the gravity of the impact on the primary caregivers. The needs of individuals with XDP more often became the utmost priority, even if it sometimes means compromising the caregivers own well-being. As time goes by, XDP caregivers are able to understand their roles as family caregivers, are able to handle the

situations they needed to face as caregivers and are able to cope with the demands of caregiving, dancing through whatever storm that came their way, keeping the faith and beating the odds. To add to these XDP primary caregivers have their own needs and concerns, experience strains and pressures and are faced with increasing demands and difficulties that are often left unnoticed. Understanding their experience is crucial in designing interventions that highlights caring for the carers themselves. Hence, putting emphasis on caregivers' well-being and providing support to these carers play important roles to successful care.

**Conflict of Interest Statement:** The authors disclose to have no conflict financial and non-financial interest in the subject matter or materials discussed in this manuscript.

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