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Edited by Assoc. Prof. Dr. Yupin Aungsuroch & Dr. Joko Gunawan

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Launched in December 2015, Belitung Nursing Journal (BNJ) is a refereed international publication that provides a venue for the nursing scholarship with an Asian focus and perspectives from the region. We aim to highlight research on nursing science, nursing management, policy, education, and practice in the Asia-Pacific region and Asian communities worldwide to a broad international audience.

BNJ welcomes submissions of original research articles, review articles, concept analysis, perspectives, letter to editors, research methodology papers, study protocol, case studies, and guest editorials on various clinical and professional topics.

We also welcome "negative" results (i.e., studies which do not support a hypothesized difference or association) provided that the design was robust. Discussion papers that elaborate issues and challenges facing health care in one country are welcomed, provided the discussion is grounded in research-based evidence. The authors are addressing a global audience and a local one.

Nurses and midwives write most papers in BNJ, but there are no constraints on authorship as long as articles fit with the expressed aims and scope. BNJ's intended readership includes practicing nurses and midwives in all spheres and at all levels who are committed to advancing practice and professional development based on new knowledge and evidence; managers and senior members of the nursing and midwifery professions; nurse educators and nursing students; and researchers in other disciplines with interest in common issues and inter-disciplinary collaboration.




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# Acceptance Theory of Family Caregiving

Alfredo Feliciano<sup>1,2</sup> , Evelyn Feliciano<sup>1,2\*</sup> , Daisy Palompon<sup>2</sup> ,  
and Ferdinand Gonzales<sup>3</sup> 

<sup>1</sup>College of Nursing, Angeles University Foundation, Angeles City, 2009, Philippines

<sup>2</sup>College of Nursing, Cebu Normal University, Cebu City, 6000, Philippines

<sup>3</sup>Medical-Surgical and Pediatric Nursing Department, College of Nursing, University of Hail, Saudi Arabia



## \*Corresponding author:

Assist. Prof. Evelyn Feliciano

College of Nursing, Angeles University  
Foundation, Angeles City, 2009, Philippines  
Email: [feliciano.evelyn@auf.edu.ph](mailto:feliciano.evelyn@auf.edu.ph)

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## Abstract

Acceptance of roles in the care of older adults by a family caregiver depends on factors emanating from commitment to familial relationships, widespread cultural expectation, and debt of gratitude. This study aims to develop a theory that explains the acceptance of the role of caregiving of the older adults by the family caregiver necessary to predict behavioral adaptation and control caring phenomenon that favors successful meeting of caring expectation across trajectory phases and transitions. A deductive axiomatic approach to theory generation was utilized, resulting in four axioms that served as bases for four propositions. Acceptance Theory of Family Caregiving implies that older adults who expect their children to take care of them as they age have cultural influence and that the acceptance of the role will determine the caregiver's acceptance of consequences in the form of physical, economical, psychological, and spiritual aspects. In terms of preparedness, family members who accept the possibility of the decline of their older adults are more likely to be assume caregiving roles efficaciously. In the process that family members face in this so-called trajectory caregiving process, resources play a significant role. The developed theory suggests that the care of the older adult in the family caregiving process is determined by the acceptance of role assumption by the family caregiver across trajectory phases. This study highlights the vital implication of acceptance of role assumption to the outcomes of the caregiving process with respect to older adult care, prevention of family caregiver burden, and establishment of strong familial and social relationships.

## Keywords

acceptance; adaptation; aged, caregiver burden; family caregiving; nursing

## Introduction

The rapidly aging population has become an urgent global health concern (Sakakibara et al., 2015) because the long-term process of older adult care is faced with limited family and professional caregivers (Harvath et al., 2020). The widespread expectation on families, along with its ubiquity of practice to watch over their older adults, has been aligned with strong intergenerational family solidarity (Paguirigan, 2019). More so, the conception of debt of gratitude has both influenced the responsibility a significant burden. The widespread expectation in terms of family caregiving reveals that 85 to 95% of all older adults receive care from their family members on a global scale (Gaugler et al., 2018). Likewise, the need to balance personal and social roles amidst increasing pressure to provide care to an older adult becomes the caregiver's predicament (Donovan et al., 2011; Thomas et al., 2017). Meanwhile, it gives some an opportunity to reward and fulfill role assumptions (Luichies et al., 2021; Reinhard et al., 2011).

Acceptance of caregiving roles assumption in the care for an older adult can be as sudden or carefully planned to depend

on several factors. Despite the many shared experiences of family caregiving, this process varies in terms of family dynamics, nature of timing, duration, transitions of care, and end of life. Common to this journey is the acceptance of the family members to be able to enter the adjustment process of becoming their "self" in caregiving (Nguyen & Levkoff, 2020). Acceptance of change that requires family decision-making is vital to initiate action (Kristanti et al., 2021; Potter et al., 2017). Caregiving trajectory is the term used to denote the process that family caregivers undergo specifically in phases that generally include role awareness, emerging responsibilities, increasing demands for care, and finally, end of life (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). In the process of caregiving, acceptance and commitment as central aspects of this emerging evidence-based practice are crucial in stress levels and the quality of life of caregivers (Han et al., 2021).

Assignment of the primary caregiver for an older adult in the family is based on several factors that encompass existing relationships, gender, societal norms and expectations, geographical proximity, and moral and expected familial

obligation (Luichies et al., 2021; Nguyen et al., 2021). Evidence suggests that family caregivers do not receive adequate preparation in the assumption of caregiving roles in matters related to problem-solving and communication skills (Robinson et al., 2020). Inadequate preparation and execution caused by an interplay of factors related to poor acceptance of the current condition, inadequate resources, conflict with familial and employment responsibilities and financial difficulties, and new circumstances result in inadequate adaptation to the caregiving role (Ainamani et al., 2020; Hashemi-Ghasemabadi et al., 2016; Nguyen et al., 2021). Moreover, increasing dependence on the caregiver emanates from the older adult's functional decline over time (Ainamani et al., 2020; Pinto et al., 2021), and the caregiving role becomes more intense in the advanced and end-of-life phase (Robinson et al., 2020).

Relevant to understanding the beginning role of caregiving is acceptance of expectation. The Acceptance Theory of Family Caregiving is based on societal and familial expectations endured through several generations (Luichies et al., 2021). In simpler terms, the family caregiver is aware of such a responsibility of looking after the older adult when the time of physical and cognitive decline and dependency emerge while it is also an expectation of the older adult to have someone to look after them when the time comes amidst the possibility of embarrassment or perceived burden on family caregivers (Bekhet & Garnier-Villarreal, 2020; Hickman et al., 2020; Kellner et al., 2017). Therefore, a successful view on adaptation to family caregiving roles prerequisites acceptance.

While cultural expectations on family caregiving hold true, it is vital to determine the degree of family members' acceptance as it is integrated within them. Therefore, this study aims to develop a theory that explains the acceptance of caregiving roles by the family caregiver for the older adults necessary to predict behavioral adaptation and control caring phenomenon that favors successful meeting of caring expectation across trajectory phases and transitions. Developing a working knowledge of acceptance as it vitally influences caring behaviors among family caregivers contributes to older adults' health and well-being. Imperative to this understanding shall be beneficial in relating it with family caregivers' preparedness, self-efficacy, and quality of life secondary to planned behavior of caring.

## Methods

The Acceptance Theory of Family Caregiving utilized a deductive approach. Starting with broad concepts and determining which concepts apply to populations, the top-down approach leads to the formulation of conclusions, known as deductions. For a sound deduction to occur, generalizations must be true because this is where logical consequences can be drawn (Utley et al., 2017). As a premise for deductive argument, an axiom is a logical principle assumed to be true and chosen carefully to avoid inconsistency. Axioms demonstrate consistency, plausibility, and richness to provide a system of logic in the creation of a theory. From a generalized statement that contains abstractions, a theory explains and predicts the interrelationship of variables through its ideas, concepts, and themes (Kivunja, 2018).

With the use of a deductive method to theory development, generalizations about the caregiving process, family psychology, cultural influence of older adult care, and gerontology nursing were determined through rigorous literature reviews. The definition of a family caregiver applies to any relative, partner, friend, or neighbor of the older adult that is based on a significant relationship. Following a literature review, the iterative yet sequential process of searching, screening, and assessing related works proceeded with data extraction and analysis (Paré & Kitsiou, 2017). Data extraction and analysis resulted in the identification of trends and patterns to systematically view the statements that were generally accepted to be true. These non-debatable facts known as axioms were identified, which subsequently became the basis for propositions. An axiomatic approach paved the way for preserving and furthering the growth of the discipline that tackles older adult care through family caregiving. Building the theory through logic and axiomatic systems of the behavior (Levy, 2017) of family caregiving, identification of propositions from the theory, and establishing testable hypotheses are placed at the process.

The proposed Acceptance Theory of Family Caregiving is an example of a mid-range theory that describes, explains, and predicts phenomena of caregiving of older adults by the family members in the practice of gerontology nursing. It also describes how the variables, namely acceptance, the trajectory of caregiving, resources, and cultural influence, relate with each other.

## Results

Consistent with the deductive axiomatic approach to theory generation, literature reviews play a crucial role in the identification and support of the identified axioms and propositions in the buildup of the theory. Table 1 illustrates the extracted four axioms that were derived from literature reviews, and these served as the reference in the formulation of four propositions necessary in the framework of the developed acceptance theory of family caregiving.

The role of a significant relationship between older adults and that of the family caregiver extends beyond influences of blood and marriage through the commitment of various forms explicitly referred on the definition of family caregiver that refers to any relative, partner, friend, or neighbor who provides a broad range of assistance-related activities with a basis of significant relationship to an older adult with chronic and disabling conditions. Therefore, *family relationships are founded based on commitment derived from various forms (Axiom 1)*, which implicates those older adults *who expect their children to take care of them as they age have cultural influence (Proposition 1)*.

Acceptance of the change is crucial to successfully adapt to family dynamics, atmosphere, and role assignments in the presence of older adults that require family caregiving. While it explains that *acceptance pre-requisites successful adaptation to one's environment (Axiom 2)*, the beginning and unfolding responsibilities demand careful family discussion in addressing the older adults' needs along with the caregiver responsibilities that accompany them along with all phases of family caregiving trajectory, thereby suggests that *acceptance*



of the caregiving role is a process (**Axiom 3**). The widespread expectation of pursuing caregiving of the older adults supports the idea that *acceptance of the role will determine the caregiver's acceptance of consequences in the form of physical, economical, psychological, and spiritual aspects* (**Proposition 2**). Furthermore, the acceptance of role is challenged as responsibilities of family caregiving unfold that may present role ambiguity, future uncertainty, and self-efficacy concerns during care provision. This implies that whatever change the older adults present during the term of care provision, the family caregiver is ready to accept the consequences that may accompany role assumption supporting the idea that *family members who accept the possibility of the decline of their older adults are likely to be prepared to assume caregiving roles* (**Proposition 3**).

Following unfolding responsibility in the family caregiving trajectory, increasing care demands lead to surrogacy in terms of healthcare decisions and physical care. This is congruent with the idea that *the family, as a unit, strives for balance and requires resources to sustain it* (**Axiom 4**). Therefore, *the trajectory family caregiving process is influenced by factors such as resources* (**Proposition 4**). Acceptance of the caregiving role also means that end-of-life care terminates the family caregiving trajectory. This requires more intensive caregiving demands, which supports that *acceptance of the role will determine the caregiver's acceptance of consequences in the form of physical, economical, psychological, and spiritual aspects* (**Proposition 2**). This idea is applied not only in the final phase of the family caregiving trajectory but is also evident during unfolding responsibilities and increasing care demands.

**Table 1** Propositions from extracted axioms

Axioms	Propositions	Theory
<b>Axiom 1</b> Family relationships are founded based on commitment derived from various forms.	<b>Proposition 1</b> Older adults who expect their children to take care of them as they age have cultural influence.	Care of the older adult in the family caregiving process is determined by the acceptance of role assumption by the family caregiver across trajectory phases ( <b>Acceptance Theory of Family Caregiving</b> )
<b>Axiom 2</b> Acceptance pre-requisites successful adaptation to one's environment.	<b>Proposition 2</b> Acceptance of the role will determine the caregiver's acceptance of consequences in the form of physical, economical, psychological, and spiritual aspects.	
<b>Axiom 3</b> Acceptance of the caregiving role is a process.	<b>Proposition 3</b> Family members who accept the possibility of the decline of their older adults are more likely to be prepared to assume caregiving roles.	
<b>Axiom 4</b> The family, as a unit, strives for balance and requires resources to sustain it.	<b>Proposition 4</b> The trajectory family caregiving process is influenced by factors such as resources.	

## Discussion

Literature postulates the dynamism of family relationships as crucial to understanding the behavior of its members. Children and parents, for instance, remain closely related across the course of life, and the well-being of these individuals is guaranteed by the quality of intergenerational relationships that they have. These relationships are enduring and consequential, and their behavior is a result of the years they have been together (Schulz et al., 2020; Thomas et al., 2017). The quality of family relationships in the form of support and supervision determines the favorable influence and consequently acceptance among growing children of the responsibility that they hold as their older adults age. Children of the older adults, for instance, assume roles from a personal perspective with the basis of obtaining profound meaning and reward and as a means of giving back the love and care they were given as children along with the idea that central to their well-being is the commitment to favor connection of generations (Reinhard et al., 2011; Thomas et al., 2017).

Shared within the context of familial relationships and rearing, beliefs that underpin the family members' behavior in the care of their older adults encompass culture (Revenson et al., 2016). Who ends up as becoming the primary caregiver is shaped by existing relationships to the older adult in need of care, gender expectations, cultural background, and

geographic proximity (Scheibl et al., 2019; Solomon et al., 2018). Primary caregivers may range from a spouse or any other family members, and this decision is determined by cultural factors (Donovan et al., 2011). Family caregivers often serve as advocates and coordinators of care, and their roles are unfolded within transitions of caregiving trajectory. Assumption of caregiving roles by the family member is directed towards achieving a satisfactory level of acceptance regarding this crucial decision-making process which is highly influenced by widespread cultural expectation (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016; Reinhard et al., 2011). The cultural influence of both the older adults and the caregivers likewise provides direction in the choice of culturally appropriate care that the recipient requires. This likewise connotes that caregiving services become highly individualized for the older adults to receive compared to when they are delivered by service agencies, implicating the cultural relevance of family caregiving societal acceptance (Donovan et al., 2011; Revenson et al., 2016). Endured by generations, the witnessed caring practices have somehow shaped the family members' views of anticipating the care of the older adults in the future. It is also grounded from the influences of internalized debt of gratitude and desire to give back the care they once received, thereby enhancing their motivation to accept family caregiving roles.

Equally important in exploring the cultural and relationship-based nature of the concept of family caregiving is the understanding of the process to denote when it begins, pursues, and terminates. The trajectory of family caregiving begins with the awareness of the family members towards the older adults' behavioral indication or changes in health that may warrant a certain degree of caregiving (Gilbert et al., 2018). Functional impairment, when gradually observed, provides subtle assumption of acceptance of family caregiving as compared with sudden older adult's health decline that proves challenging (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). The Roy Adaptation Model explains the interaction of a person in a changing environment (Ursavas et al., 2014). Given the complexity of family caregiving, preparedness for the responsibility is crucial. Inadequate preparation of the caregivers is what constitutes burnout (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). This denotes the relative importance of acceptance as a requirement for being prepared to assume caregiving roles. While the intensity of required assistance may not be as exhausting in the initial phase of the caregiving trajectory, accepting the role prepares the caregiver for more challenging roles in the future. The psychological well-being of the family caregiver relates to acceptance of the role that positively influences the outcomes of the caregiving (OMalley & Qualls, 2020). Studies pointed out higher anxiety levels and burden caused by longer duration of caregiving, which can be attributed to required duties that range from provision of assistance to direct administration of services to the care recipient, assistance with household activities, self-care measures, ambulation or mobility, emotional and social support provision, advocacy, coordination of required health care and surrogacy (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016; Lou et al., 2015). The need to balance personal and social roles in these trying times can prove to be challenging, specifically with respect to competing pressures of employment, watching over their own children, and older adult care (Donovan et al., 2011; Thomas et al., 2017). The widespread expectation of pursuing caregiving of the older adults provides clear implications that informal caregiving is what families must take as a primary responsibility (Revenson et al., 2016).

The unpredictability of the older adult's condition and poor acceptance of role compromise the process of caregiving, leading to disadvantaged positions for both parties (Camak, 2015; Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). Over time, the older adult's dependency contributes to increasing reliance on the family caregiver to perform required functions (Schulz et al., 2020). Consequently, the caregiver is expected to provide more assistance than usual which compromises resources and work-life balance. Change in caring status and demands results in strengthening coping secondary to required adaptation. While increasing physical dependence leads to more caregiving demands, there is not always a negative consequence as some family caregivers find fulfillment in the

accepted caring roles. Domains of care may include monitoring older adults' condition, medication administration, communication with healthcare professionals, and transition from home to hospital or facility management. This implicates that family caregivers are introduced as partners with healthcare professionals in the integration of a collaborative approach of care with an emphasis on caregiver-friendly policies and flexible arrangements (Bell et al., 2019). On a similar note, better transitional care calls for effective and quality care as the transition from one setting to another proves to be the most vulnerable and traumatic experience of the family caregiving process (Reinhard et al., 2011).

Caregiving roles may change over time and may be highly individualized as older adults tend to go into the transition from one health care setting to the other, changes in the familial, social, and geographical context of care provision. While transitions can be planned as in the case of scheduled older adult's follow up in the hospital or unplanned such as emergency room visit or required re-admission, that certain degree of unpredictability of family caregiving proves that the family members' needs and dynamics must be assessed periodically so that their needs are addressed during transitional periods (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016; Gitlin, 2019). Caregiving responsibilities are considered acute for families if older adults suffer from abruptly appearing conditions such as stroke, dementia, or even mental illness (Gitlin, 2019). These often become troublesome as the older adult's condition becomes complex and their behaviors become severe (Liu et al., 2018; Reinhard et al., 2011). Acceptance of the nature of predictability of the older adult's condition over time makes caregiving roles well-tolerated alongside the idea that family members are more likely equipped to respond to demands when prompted.

The increasing complexity and intensity of older adults' conditions prove to be challenging as they are burdened by their decisions to determine what would be best for their older adults (Jehangir et al., 2019; Reinhard et al., 2011). With respect to the beginning and sustaining family caregiving process, caregivers relied on siblings and other support services to communicate older adults' intensified needs (Gilbert et al., 2018). Monetary resources to pave the way for medication procurement, check-up, and required to follow up are crucial to both the health of the family caregiver and older adult (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). The amount and type of care the family caregivers provide heavily depends on economic resources and the demand for the family caregiver's time and energy (Kaplan & Berkman, 2021; Schulz et al., 2020). Despite challenges, caregivers find meaning and purpose at the end-of-life care phase of family caregiving (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016; O'Malley & Qualls, 2020). The cultural beliefs that underlie the older adults and the family caregivers are crucial to care provision in this process (Revenson et al., 2016).

With an unprecedented demographic imperative of the global population of older adults, specific family caregiving



implications arise (Gitlin, 2019). The concepts related to family caregiving encompass the phenomenon as a process influenced by resources, cultural expectation, and degree of acceptance by caregivers who provide care to an older family member. The development of a theory to fully understand this process is beneficial to certain degrees as it explains the occurrence of practice, predicts based on future empirical evidence, and controls the process that favors both the older adult and the caregiver. This theory can greatly contribute to the practice of gerontology nursing in matters relating to older adults' health and well-being, family structures and relationships, and caregiver self-efficacy and fulfillment. As the family caregivers represent the health care system's partners to ensure older adults' maximal health, understanding this theory from the perspective of both the older adults and their caregivers is essential.

The Acceptance Theory of Family Caregiving aims to explain acceptance as vital in the trajectory phases of caregiving, not only on the older adult but also on the family caregiver to initiate needed actions (Potter et al., 2017). It also aims to predict that inadequate preparation to caregiving role assumption due to poor acceptance of the demanded situation often leads to caregiver burden (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). Therefore, mitigation strategies to address caregiver burden is to allow the family caregivers to realize the change that demands adaptation, and only through acceptance of family caregiving role should adjustment set in (Nguyen & Levkoff, 2020).

Within the bounds of familial relationships and widespread cultural expectation, the care of the older adults translates as a responsibility of the family members endured by several generations (Gaugler et al., 2018). The strong inter-generational solidarity emphasizes that family caregiving, as the name implies, is based on a commitment derived from cultural and familial factors (Paguirigan, 2019). Varying from these influences, the family caregiving process, known as trajectory, involves a series of phases that present several challenges to both older adults and family caregivers (Committee on Family Caregiving for Older Adults; Board on Health Care Services; Health and Medicine Division; National Academies of Sciences, 2016). Requisites to meeting each phase of the process is a degree of acceptance of role assumption by the caregiver that equates to the anticipation of the requirement of resources, role changes, and demands with respect to awareness, unfolding responsibilities, increasing demands, and end of life phases of family caregiving.

### Acceptance Theory of Family Caregiving

Understanding acceptance also intends to communicate it as inherent in family relationships within the context of older adult care (Schulz et al., 2020; Thomas et al., 2017). While it is an expectation for older adults to have someone to care for them when dependency calls for caregiving roles, the crucial role it plays determines the success of the family caregiving process (Luichies et al., 2021). At some point in their lives, older adults require someone to perform for them the activities of daily living owing to increasing physical dependency and cognitive decline. The acceptance of a family member's caregiving role, while a process, is situated in every phase of the family

caregiving trajectory. Associated with motivation, acceptance is a driving mechanism that influences the behavior of the family caregiver in performing roles that are unique in every step of caregiving.

Figure 1 shows the theory's framework as it relates to the essential concepts of family caregiving. Central to the framework is acceptance infused within the overlapping trajectory phases: awareness, unfolding responsibilities, increasing care demands, and end of life. The diagram attempts to communicate that as the phase/s (represented by green circles) move away from acceptance (represented by a yellow circle), it decreases infusion not only with acceptance but successful family caregiving (represented as a large red circle) as well.

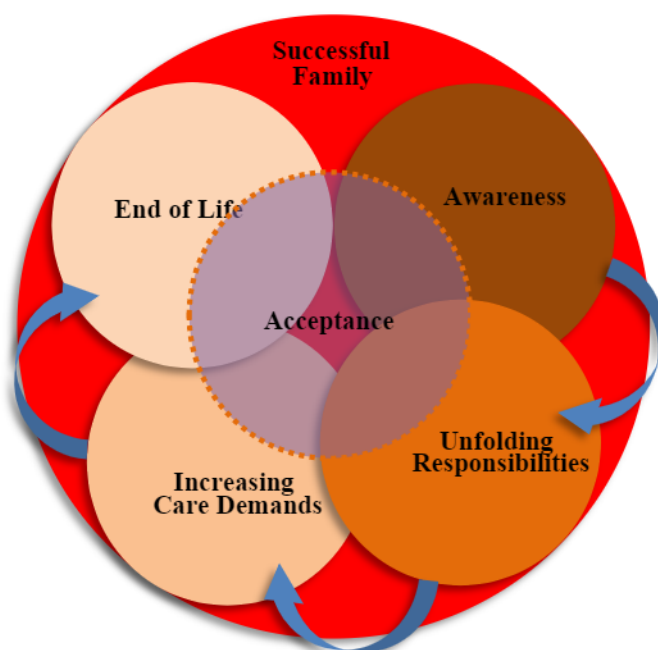


Figure 1 Acceptance Theory of Family Caregiving

The overlapping trajectory phases imply the stages that every family caregiver goes through with respect to the needed assistance of the older adult. As the care can be highly individualized, the demands vary along with other determinants, including resources and self-efficacy. Similarly, there is a variation in terms of the duration by which the family caregiver undergoes, along with the gradual or sudden emergence of care demands. The care of the older adult in the family caregiving process is determined by the acceptance of role assumption by the family caregiver across trajectory phases, crucial in the understanding of successful family caregiving.

The theory is applied among families whose care of older adults is within their domain. It may not be fully applied to families that delegate the care of their older adults in nursing facilities. In addition, the underlying cultural acceptance of family caregiving influences the theory's applicability. Lastly, the definition of the family caregiver in the context of this theory extends beyond the influence of blood and marriage, consistent with related literature and studies. Going through the provided definition minimizes confusion relating to the population scoped within the theory.

## Conclusion

While several challenges await the family caregiver in the assumption of societal and culture-based measures alongside the expectation of older adult care, much concern is concentrated on their health status over the caregiver's situation. The discrepancy of the care recipient and provider focus paved the way for a developed theory that targets acceptance of these challenging roles of the provider as it greatly determines the outcomes of favorable healthcare outcomes of the recipient. The developed theory suggests that the care of the older adult in the family caregiving process is determined by the acceptance of role assumption by the family caregiver across trajectory phases. This study highlights the vital implication of acceptance of role assumption to the outcomes of the caregiving process with respect to older adult care, prevention of family caregiver burden, and establishment of strong familial and social relationships.

## Declaration of Conflicting Interest

All authors declare no potential conflict of interest.

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## Authors' Contributions

AF conceptualized, designed, analyzed, literature searched, and drafted the study. EF contributed to conceptualization, edited, formatted, and prepared the final manuscript draft. DP likewise contributed to conceptualization and analysis, reviewed, and supported concepts with intellectual content and literature search. FG additionally analyzed data with intellectual content and literature search. All authors substantially contributed with equal efforts until approval of the final article and acknowledged that all those entitled to authorship are listed as authors until publication.

## Authors' Biographies

**Alfredo Feliciano, PhD, RN** is an Assistant Professor IV at the College of Nursing, Angeles University Foundation, Angeles City, Philippines and a DScN Gerontology Nursing student at the College of Nursing, Cebu Normal University, Cebu City, 6000, Philippines.

**Evelyn Feliciano, PhD, RN** is an Assistant Professor VI at the College of Nursing, Angeles University Foundation, Angeles City, Philippines and a DScN Gerontology Nursing student at the College of Nursing, Cebu Normal University, Cebu City, 6000, Philippines.

**Daisy Palompon, DScN, PhD, RN** is a Professor VI and Vice-President for Academic Affairs at the College of Nursing, Cebu Normal University, Cebu City, 6000, Philippines.

**Dr. Ferdinand Gonzales** is an Assistant professor at the Medical-Surgical and Pediatric Nursing Department, College of Nursing, University of Hail, Saudi Arabia.

## Data Availability

Not applicable.

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# Quality of life among mothers of preterm newborns in a Malaysian neonatal intensive care unit

Swee Leong Ong<sup>1\*</sup>, Kim Lam Soh<sup>2</sup>, Emni Omar Daw Hussin<sup>3</sup>, Salimah Japar<sup>2</sup>,  
Kim Geok Soh<sup>4</sup>, Ponpun Vorasiha<sup>5</sup>, and Azlina Daud<sup>6</sup>

<sup>1</sup> School of Nursing, Faculty of Medicine, Universiti Sultan Zainal Abidin, Terengganu, Malaysia

<sup>2</sup> Department of Nursing and Rehabilitation, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Serdang, Selangor, Malaysia

<sup>3</sup> Department of Nursing Science, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia

<sup>4</sup> Department of Sports Studies, Faculty of Education, Universiti Putra Malaysia, Serdang, Selangor, Malaysia

<sup>5</sup> College of Nursing and Health, Suan Sunandha Rajabhat University, Dusit, Bangkok, Thailand

<sup>6</sup> Department of Medical Surgical Nursing, International Islamic University Malaysia, Malaysia

## Abstract

**Background:** As Quality of Life (QoL) becomes progressively vital in health care services, its importance in mother and child health is of no exception too. Quality of life among mothers with a premature newborn is an issue that has led to growing concerns in the health care system. Yet, despite the knowledge about mother's QoL being essential to family-centered planning on prematurity integrated healthcare, current evidence has been scant.

**Objective:** To examine factors related to the QoL of mothers having preterm newborns hospitalized in the neonatal critical unit.

**Methods:** A non-probability convenience survey was used in a public hospital in Malaysia, covering 180 mothers whose preterm newborns were hospitalized into level III Neonatal Intensive Care Unit (NICU) through the completion of a 26-questions survey of the World Health Organization Quality of Life (WHOQOL-BREF) and the 26-questions of Parental Stress Scale: Neonatal Intensive Care Unit (PSS: NICU). The data were analyzed using descriptive statistics, bivariate analysis, and Pearson correlation coefficients.

**Result:** The mean scores for mothers' quality of life were ( $M = 3.67$ ,  $SD = 0.73$ ) and maternal stress ( $M = 3.03$ ,  $SD = 0.90$ ) out of 5. A mother's occupation was found to be the only factor associated with the quality of life among mothers who have preterm newborns admitted to the NICU. Furthermore, maternal role change was found to have a moderate negative relationship with the quality of life ( $r = 0.310$ ,  $p = 0.05$ ).

**Conclusion:** The findings of this study revealed that the main factors contributing to the mother's QoL during their preterm newborns' NICU admission were role change-related stress. Thus, to maintain a better QoL among this group of mothers during this traumatic period, a special nursing intervention program must be implemented immediately, right after the preterm newborns' admission, to relieve the mothers' stress which has been proven to have a direct effect on the mothers' QoL. The study results will alert healthcare providers, particularly neonatal nurses, on the need to support mothers psychologically in terms of role change. This is to ensure a better quality of life among mothers whose newborns were admitted to the NICU.

## Keywords

quality of life; mother of preterm newborn; maternal stress; neonatal intensive care unit; nursing; Malaysia

### \*Corresponding author:

Dr. Swee Leong Ong, MSc, BScN, RN  
School of Nursing Science, Faculty of  
Medicine, Universiti Sultan Zainal Abidin,  
Terengganu, Malaysia 21300.  
Telephone: +609 6688509  
Email: [ongsl@unisza.edu.my](mailto:ongsl@unisza.edu.my)

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## Background

Pregnancy and giving birth are usual among women of the reproductive age and are frequently reported to be a joyful moment for nearly all women (Lau, 2013). However, going through the process of pregnancy was always hard. It has been proven that maternal health-associated quality of life for

this period is poorer than for non-pregnant women (Lau, 2013). Some studies also reported that mothers with preterm newborns admitted to the Neonatal Intensive Care Unit (NICU) had lower quality of life compared to mothers of full-term newborns (Eiser et al., 2005; Witt et al., 2012). Hence, it is important for healthcare providers, especially neonate nurses, to study mothers' QoL to plan for a better family-centered, integrative nursing on premature care.



Preterm delivery and the admission of preterm newborns to NICU are considered frightening and stressful life experiences, impacting parental QoL in multiple ways. Adding to the postpartum condition, where the mother is in the process of recovery following labor, this will further worsen the mothers' quality of life (Amorim et al., 2018). The postpartum is known to be a critical point where mothers have to adjust to their body changes, family relationship changes, new responsibilities, the demand for social support, and a financial burden (Huang et al., 2012). Few studies consistently show that the QoL among mothers during postpartum would be compromised by sleep disruptions, exhaustion, anxiety, and mental distraction (Amorim et al., 2018; Huang et al., 2012). However, as of now, there is indeed a limited amount of evidence on these issues associated with QoL among mothers with preterm newborn hospitalization. Are they having the same level of QoL, better QoL, or vice-versa with any other group of mothers? Therefore, there is indeed an urgent need to investigate the wellbeing of mothers within this group. The outcomes will be needed to develop more specified nursing interventions to ensure childcare continuity after the newborn is discharged home.

Ninety-four percent of women had experienced several health problems, i.e., tiredness, backache, and sexual dysfunction in the first six postnatal months (Webb et al., 2008). These health problems have been claimed to negatively affect the postnatal mothers' QoL (Mortazavi et al., 2014). In fact, the mothers' QoL, stress level, and child wellbeing were proven to be strongly interrelated during this period (Eiser et al., 2005; Lee & Kimble, 2009). The negative effects following the process of caring the preterm newborns during this period could significantly affect a women's entire life (Mortazavi et al., 2014). In addition, unexpected preterm delivery and the newborn admission to this critical unit might cause an emotional catastrophe to the mothers throughout the post-delivery period; for example, the stress level is higher than the mothers of full-term newborns (Howe et al., 2014; Kaaresen et al., 2008). The mother's perception of their wellbeing throughout post-delivery influences their quality of life. This experience will potentially persist in affecting the parent nurturing behaviors and produce permanent and continual emotional problems and health modification on their kids (Huang et al., 2012; Williams et al., 2007).

Nevertheless, there is a piece of limited information available regarding mothers' QoL following their preterm newborn hospitalization, especially in NICU, despite QoL having been reported as a vital indicator to determine the results of both treatment and services assessment (Bahrami et al., 2013). Thus, this research seeks to investigate more in detail the level of QoL as perceived by mothers whose preterm newborns have been admitted to the NICU. It also aims to identify the mother QoL and its association with NICU-related maternal stress as well as the maternal and infant characteristics.

## Methods

### Study Design

A cross-sectional study design was employed in this study.

### Participants

Using a non-probability convenience sampling, 180 eligible mothers were included in this study. All the mothers who fulfilled the given criteria were enrolled into the study: i) older than 18-year-olds, willing to give their consent and understand either English or Malay, ii) with preterm newborns between 27-34 weeks' gestation, have an Apgar score of greater than 5, and without other major health problems. Their newborns may be on ventilator care or other medical support (CPAP, intravenous infusion), are clinically stable at the moment of enrolment and are admitted to NICU for the last two weeks. Mothers who have (i) quadruplets or more, (ii) illness or mental problems (psychiatric, drug addiction), (iii) a newborn (any surgical problems and critically ill newborns were not included in this survey.

### Instruments

Three instruments were used in this study:

**Maternal and newborn characteristics.** A demographic data sheet on mothers (age, education, occupation, and total family income) and infants (gender, gestational age, birth weight, and the number of the child) was created to gather data on maternal and newborn characteristics.

**Maternal quality of life.** The World Health Organization QoL (WHOQOL-BREF) was initiated by the World Health Organization quality of life team (The WHOQOL Group, 1998). It comprises 26 questions and a Malay version set; therefore, no translation was needed. The first question is generally regarding the level of quality of life, and the second question evaluates the overall satisfaction in the individual's health. The other 24 questions consist of four components. Namely, (i) physical (PhyC) (seven questions), (ii) psychological (PsyC) (six questions), (iii) social relationship (SRC) (three questions), and (iv) environment (EC) (eight questions). Component scores are ascending scales (higher scores = higher quality of life). The mean score of questions within each component is used to calculate the component score. A pilot study was performed on 40 mothers to check the reliability of WHOQOL-BREF and its components; Cronbach's alpha values were ranged between 0.73-0.89.

**Maternal stress.** The PSS: NICU revised version by Miles et al. (1993) was used to evaluate maternal experiences on the stressors faced in NICU. It consists of 26 questions self-report scale to determine mother's stress associated with three NICU conditions: NICU's Sight & Sound (PSS: SS) (five questions); ii) Newborn Behavior and Look (PSS: NBL) (fourteen questions); and iii) Maternal Role Change (PSS: MRA) (seven questions). A 5-point Likert scale which ranged from (1= not at all stressful) to (5= extremely stressful) and 0 (no experience or not applicable), was used to rate each question. Mothers who claimed to be stressed out were graded (1-5) appropriately, and those who claimed to be no stress were rated as 0 or not applicable (NA). Scoring was shown in a mean score to allow the comparison between studies. In this study, PSS: NICU scores were based on Ong et al. (2018), which rated the level of stress as high-level stress (4-5), moderate level (3-3.99), and low stress (1-2.99).

The Malay version of the PSS-NICU was lately used by the local study in which the construct validity of PSS: NICU had shown that all items were at satisfactory loading factors, which were more than 0.5. The results indicated that the

measurement model fitted the model with  $c2(284) = 579.713$ ,  $p = 0.00$ ,  $c2/DF = 2.041$ ,  $GFI = 0.806$ ;  $CFI = 0.916$ ;  $IFI = 0.917$ ,  $RMSEA = 0.076$  and both convergent and discriminant were met, and results revealed that the Cronbach's Alpha for all subscales and overall was more than 0.90 for PSS-NICU Malay version (Ong et al., 2018).

### Data Collection

This study was carried out from December 2015 to June 2016 at one of the main public hospitals covering the rural state on the East Coast of Peninsular Malaysia. The hospital provides tertiary care with a 1200-bedded and a level-III NICU with a total of 48 ventilator outlets. In this study, all 180 eligible mothers on their first visit were approached within 48 hours of their infants' admission, informed about the study, and a two-week appointment date was given for mothers' QoL data collection. Then, a Parental Stress Scale: Neonatal Intensive Care (PSS: NICU) was used to determine the mothers' stress levels. Again, after two weeks of newborns' hospitalization (appointment date), the mothers were given a set of WHOQOL-BREF questionnaires to measure the mothers' quality of life. The QoL data were collected two weeks later to prevent the possibility of mothers' present or earlier reports on the quality of life. This is because, at the first few days of admission, the mothers are still in the adapting stage and have not been affected by the actual situation (stress following the newborns' hospitalization).

### Data Analysis

The Statistical Package for Social Sciences (SPSS) version 23 was used to analyze the data. The demographic data and questionnaire items were analyzed using descriptive statistics such as frequency, mean, and standard deviation. The relationships between demographic factors and QoL

components as well as total QoL were assessed using bivariate analysis (independent t-test) and one-way analysis of variance (ANOVA). The association between maternal quality of life and maternal stress and its sub-scales was evaluated using Pearson correlation coefficients.  $P$ -value 0.05 was used as the significant threshold.

### Ethical Considerations

Our study protocol for the research project has been approved by the Research Ethics Committee, Ministry of Health, Malaysia (Research ID NMRR-14-179-20048) and conforms to the provisions of the Declaration of Helsinki in 1995. Written informed consent was obtained from the participants when all the explanations were given clearly. Email approvals for the use of the WHOQOL-BREF Malay version and PSS: NICU scales were obtained from the originators. The University Malaysia library was also noted on the similarity index.

## Results

### Maternal and Newborn Characteristics

Newborn gender was relatively evenly distributed according to the frequency and distribution of socio-demographic characteristics. High school education was the most common ( $n = 110$ , or 61.1%) among mothers. Most of the mothers ( $n = 96$ , 53.3%) were housewives with a monthly family income of less than RM 5000 ( $n = 154$ , 85.6%). Nearly half ( $n = 80$ , 44.4%) were first-time mothers. With a mean age of 29.36 ( $SD = 5.99$ ), more than half of the mothers were between the ages of 21 and 30 ( $n = 88$ , 48.9%). The birth weight of more than half of the neonates ( $n = 106$ ; 58.9) was less than 1500g (Table 1).

**Table 1** Maternal and newborn socio-demographic profile, differences in quality of life

	<b>N (%) / Mean±SD</b>	<b>Physical Component</b>	<b>Psychological Component</b>	<b>Social Relation Component Mean±SD</b>	<b>Environment Component</b>	<b>QoL</b>
<b>Age</b>						
≤20	18 (10)	3.71±0.602	3.57±0.790	3.63±0.907	3.60±0.753	3.92±0.733
21-30	88 (48.9)	3.46±0.566	3.63±0.569	3.95±0.653	3.69±0.533	3.67±0.624
>30	74 (41.1)	3.43±0.610	3.56±0.632	3.77±0.717	3.65±0.645	3.71±0.682
<b>Mother Education</b>						
Primary	5 (2.8)	3.31±0.383	3.00±0.425	3.27±1.038	3.13±0.573	3.40±0.548
High School	110 (61.1)	3.45±0.594	3.61±0.639	3.79±0.728	3.61±0.602	3.68±0.719
University Graduate	65 (36.1)	3.54±0.597	3.63±0.574	3.97±0.634	3.80±0.574*	3.78±0.551
<b>Mother Occupation</b>						
Government	44 (24.4)	3.55±0.548	3.82±0.564*	3.95±0.559	3.84±0.498	3.95±0.589*
Private	40 (22.2)	3.41±0.646	3.65±0.648	3.92±0.835	3.67±0.628	3.66±0.803
Housewife	96 (53.3)	3.47±0.588	3.48±0.603	3.76±0.715	3.58±0.623	3.54±0.722
<b>Monthly Income</b>						
<1200	31 (17.2)	3.39±0.463	3.45±0.615	3.75±0.699	3.46±0.578	3.55±0.583
1201-3000	77 (42.8)	3.46±0.601	3.62±0.618	3.82±0.727	3.63±0.646	3.64±0.686
3001-5000	46 (25.6)	3.54±0.581	3.67±0.601	3.98±0.648	3.80±0.526	3.89±0.674
<5000	26 (15.6)	3.51±0.717	3.57±0.650	3.77±0.793	3.76±0.570	3.80±0.584
<b>Birth Order</b>						
First Child	80 (44.4)	3.48±0.585	3.63±0.584	3.91±0.705	3.70±0.582	3.66±0.614
Second Child and Above	100 (55.6)	3.48±0.604	3.57±0.647	3.79±0.719	3.63±0.618	3.69±0.809
<b>Gender</b>						
Boy	99 (55)	3.49±0.614	3.62±0.642	3.82±0.744	3.68±0.605	3.76±0.606
Girl	81 (45)	3.46±0.563	3.57±0.589	3.87±0.674	3.65±0.602	3.65±0.718

Significant level at  $p < 0.05$ ; SD Standard Deviation



## Maternal Stress

The mean score for each of the PSS: NICU subscales is provided in [Table 2](#); the highest mean score was reported for

PSS: MRA ( $M = 3.34$ ,  $SD = 1.07$ ), while the lowest mean score was recorded for PSS: SS ( $M = 2.72$ ,  $SD = 1.00$ ). The entire PSS: NICU mean score was  $M = 3.03$  ( $SD 0.90$ ) out of 5.

**Table 2** Frequency analysis for maternal stress

	Level	n(%)	Mean±SD
Maternal Role Change	High	120(66.7)	3.34±1.07
	Low	60(33.3)	
Newborn Behavior & Look	High	95(52.8)	3.02±1.04
	Low	85(47.2)	
Sights and Sounds	High	90(50.0)	2.72±1.00
	Low	90(50.0)	
Total PSS: NICU			3.03±0.90

## QoL Components and Mothers' Background Variables

The WHOQoL-BREF questionnaire gives a report with scores for the four components and two singles components for overall QoL and health perception. Social relationship component (SRC) ( $M = 3.84$ ,  $SD = 0.91$ ) had the highest mean score of the maternal QoL categories, followed by EC ( $M = 3.66$ ,  $SD = 0.85$ ), PsyC ( $M = 3.61$ ,  $SD = 0.89$ ), and PhyC ( $M = 3.48$ ,  $SD = 0.88$ ). This revealed that all the components had a value more than the scale's median (3), indicating that the various components of QoL were moderate.

[Table 3](#) shows the descriptive statistics on the corresponding questions to these four components. According to these results, the highest mean score among questions related to PhyC was on "The mother's ability to get around" ( $M$

$= 3.60$ ,  $SD = 0.94$ ); and the lowest mean was on "The extent of the physical pain prevents the mother's from doing things" ( $M = 3.34$ ,  $SD = 0.95$ ). The highest mean score for PsyC's on "Mother's level of meaningful in life" ( $M = 3.93$ ,  $SD = 0.87$ ) while the lowest mean score was detected on "Frequency of the mothers felt for negative feelings" ( $M = 3.01$ ,  $SD = 0.98$ ). In SRC, the highest mean score was on "Mother's satisfaction towards support from friends" ( $M = 3.86$ ,  $SD = 0.81$ ) and the lowest mean score was on "Mother's sex life satisfactory" ( $M = 3.83$ ,  $SD = 0.84$ ). In the last component which measured the EC, the highest mean score belonged to "Mother's satisfaction towards her mode of transportation" ( $M = 4.04$ ,  $SD = 0.68$ ), and the lowest mean score was detected on "Mother's physical environment health" ( $M = 3.47$ ,  $SD = 0.76$ ).

**Table 3** Descriptive statistics for question-related to maternal quality of life ( $n = 180$ )

Component	No	Question	Mean	SD
Overall	1	Mother's QoL rating.	3.69	0.80
	2	Mother's satisfaction towards her own health.	3.66	0.81
		Total	3.67	0.73
Physical	3	The extent of the physical pain prevents the mothers from doing things.	3.34	0.95
	4	Amount of medical treatment needed to function normally in daily life.	3.35	1.01
	10	The mother's daily energy level.	3.58	0.84
	15	The mother is moving around capability.	3.60	0.94
	16	The mother's sleep is satisfactory.	3.41	0.84
	17	The mother's level of satisfaction on her ability to perform her daily living activities.	3.44	0.82
	18	The mother's level of satisfaction with her work capacity.	3.51	0.78
		Total	3.48	0.88
Psychology	5	Level of enjoyment in mother's daily life.	3.56	0.91
	6	Mother's level of meaningful in life.	3.93	0.87
	7	The mother's ability to concentrate.	3.60	0.80
	11	The mother's satisfaction towards her own bodily appearance.	3.83	0.94
	19	The mother's satisfaction with herself.	3.72	0.83
	26	Frequency of mother felt for negative emotions.	3.01	0.98
		Total	3.61	0.89
Social Relationship	20	Mother's satisfaction towards personal relationship.	3.84	0.79
	21	Mother's sex life satisfactory.	3.83	0.84
	22	Mother's satisfaction towards support from friends.	3.86	0.81
		Total	3.84	0.81
Environment	8	Mother's satisfaction towards feeling safe.	3.61	0.76
	9	Mother's physical environment health.	3.47	0.78
	12	Mother's financial stability.	3.52	1.08
	13	Mother's knowledge on their need in day-to-day life.	3.63	0.89
	14	Frequency of mother's engagement in leisure activities.	3.22	1.04
	23	Mother's satisfaction towards her own living condition.	3.91	0.77
	24	Mother's satisfaction towards health services accessibility.	3.91	0.79
	25	Mother's satisfaction towards her mode of transportation.	4.04	0.68
		Total	3.66	0.85

[Table 1](#) shows the demographic differences in the four subscales of QoL. Mothers who had completed high school or

college had substantially higher EC scores ( $M = 3.80$ ,  $SD = 0.57$ ) than mothers who had only completed elementary and

secondary school ( $p = 0.05$ ). When compared to those in the private sector and housewives, mothers who work in the government sector had substantially higher PsyC scores ( $M = 3.82$ ,  $SD = 0.56$ ).

### Mothers' Total Quality of Life

The total mean score of maternal quality of life ( $M = 3.67$ ,  $SD = 0.73$ ) suggested that the overall level of maternal quality of life was moderate ( $M = 3.95$ ,  $SD = 0.59$ ) when compared to mothers working in the private sector and housewives ( $p = 0.05$ ). **Table 1** shows the highest QoL ratings among mothers working in the government sector.

### Association between Maternal Stress and Quality of Life

**Table 4** shows the correlations between the three maternal stress subscales and QoL. There were significant ( $p = 0.001$ ) negative weak relationships between QoL and PSS: SS ( $r = -0.252$ ), PSS: NBL ( $r = -0.276$ ), and QoL and PSS: MRA ( $r = -0.310$ ).

**Table 4** Pearson correlation coefficient ( $r$ ) between maternal stress and quality of life

Maternal Stress	Quality of Life
Sights and Sounds	-0.252*
Infant Behavior & Appearance	-0.276*
Maternal Role Change	-0.310*
PSS: NICU	-0.223**

\*Correlation is significant at the  $p 0.05$  level (2-tailed)

## Discussion

The result indicates that overall mothers' QoL and its component were reported at a moderate level, though this cohort of mothers may encounter problems following their preterm newborns' hospitalization and the post-delivery phase. The moderate score of this project result could be related to most of the participants being first-time mothers and were younger (<35 years old). Younger mothers might have a good level of marital life quality as well as a good level of psychological wellbeing (Ismail et al., 2015), which they may perhaps get more attention from the spouses, family, and health professionals. Furthermore, when one individual was absorbed into one of the families from the Malay society, automatically, the individual would participate in every event held by the family, the individual is rarely left alone to deal with any difficulties, including childbearing (Yaacob, 2005). Various studies also have stated similar results (Bahrami et al., 2013; Mortazavi et al., 2014; Rezaei et al., 2016; Zubaran et al., 2009). This similarity could be caused by the mothers' joyful feeling and satisfaction of getting a newborn, which might impinge favorably on the overall idea of QoL and contentment (Wada et al., 2020; Zubaran & Foresti, 2011) or the mother's QoL level had increased even though the premature birth newborns have been considered as a misfortune to the family (Mortazavi et al., 2014).

Furthermore, the social relationship component scored the highest among the four elements in maternal QoL. The finding revealed the actual culture of rural Malays on this issue, which has yet to be studied. Nevertheless, through personal

experiences, the author (A Non-Malay, who was in the Malay community for over 50 years) deeply believes that the highest score documented on SRC may probably cause by Malay's rural culture influences, which demonstrates a solid and powerful social interaction between members in the family, members of extended family, and friends. No matter what, the Malay society is strong and ties up in supporting each other, i.e., sharing confinement information and experiences. This reasoning can relate with the present finding, which showed the mothers' perception on the three questions from SRC, i.e., on what level of satisfaction from the friends' support that the mother scored a moderately high level. The positive social system is thought to bring about a strong influence on the outcomes of each perinatal stage, particularly on the mother's wellbeing (Noy et al., 2015), and women with minimal social assistance are likely to have a lesser level of quality of life and are more prone to fall into depression following the delivery, as compared with those good-supported mothers (Webster et al., 2011).

In the present finding, the PhyC score was the lowest of all the quality of life components, but it was yet at a moderate level. With only a few published research articles on mothers' quality of life, most of the reports claimed that the mothers perceived a lower result on the physical health of quality of life (Lee & Kimble, 2009; Wang et al., 2013). This is probably a consequence of preterm newborn hospitalization; the postnatal mother's physical health was said to be overlooked, either by mothers or the health providers. Mothers said to be disregarded themselves because almost all mothers' time was inhabited with their newborns' admission. Postnatal mothers with premature newborns were significantly less likely to receive direct care from midwives at home and use the provided postnatal facilities (Henderson et al., 2016).

The current finding reported that the mothers' sleeping disturbances and body ache were marked at the lower level of the two questions from the PsyC on the mother's sleep satisfactory and the limitation of mother's daily physical activities due to physical pain as compared to other questions. The contributing factors to the lower level of mother physical QoL were reported due to the physical and hormonal changes following the delivery and mothers' sleep disturbances during the newborn admission to the critical unit (Lee & Kimble, 2009; Webster et al., 2011).

Psychology and maternal environmental quality of life are two other components that scored a moderate level. The scores of mothers' quality of life during postnatal was reported at the moderate level in all the components; however, the PsyC was lower in preterm mothers than normal mothers (Rezaei et al., 2016). This fact is agreed by Hill and Aldag, which stated that the lower score of PsyC was associated with a preterm newborn's unstable condition following the admission (Hill & Aldag, 2007). Studies on the psychology and environment components were scantied. Thus, the conversation was depicted on notable questions in each component.

In the PsyC component of six (6) questions, the lowest score question was on the frequency of having negative feelings. It is a self-explanatory statement, as in the actual situation, the admission of the newborn to the critical care unit made the mother in a stage of stress (Howe et al., 2014; Trombini et al., 2008; Woodward et al., 2014), anxiety (Ali et



al., 2009; Fabiyi et al., 2012), and depression (Gulamani et al., 2013; Sockol & Battle, 2015). In terms of environmental component, the two questions which scored the second-highest were 'mother's satisfaction towards her own living condition' and 'satisfaction towards health services accessibility'. None of the studies revealed specifically on the environmental issue. Nevertheless, these three components are worth to be highlighted because the perception of the mothers from this cohort could reflect the local community situation. For example, the question regarding the 'mother's satisfaction towards her mode of transportation', perhaps linked with the present state scheme on vehicle mortgage, which permits every family to own a car or a motorbike or borrow the vehicles from relatives or friends. Therefore, transportation was not a problem for this cohort of mothers.

Mothers were reported to be very satisfied with questions that are related to the health facilities provided. Satisfaction perceived on the health facilities would probably be due to the mother's current prioritization on the health of the newborns who were in critical condition. They subconsciously disregarded their wellbeing and put their trust, confidence, and positivity on the nurses and team in NICU. This trust and confidence, which had developed right after the newborn admission, added with the conveniences offered by the nurses, particularly on a flexible visiting time, would probably cause the mothers' decision on this perception, which is also supported by a previous study (Mortazavi et al., 2014). Additionally, the mothers working with the government sectors tend to have a better quality of life; this could likely be due to the employment (a longer paid maternal leave), and the majority of Malaysian public employees reported to have a moderate economic status (Mokhtar et al., 2015). Research indicated that financial stability is related to overall health (Franz, 2016).

### Correlation between Maternal Quality of Life and Stress

As far as we know, the correlation between QoL and mothers' stress with preterm newborns in such a critical setting has not been overly studied earlier. Hence, this project aims to determine if the stress is associated with quality of life on a certain quantified amount or whether the NICU-related maternal stress can justify QoL changes between the postnatal mothers and the existence of stressful events (admission of the newborns to the critical unit). The finding indicated that the NICU-related maternal stress was negatively associated with overall maternal QoL. This finding indicates that the mother's overall quality of life is negatively related to NICU-related stress faced by mothers.

The result was parallel with the previous study by Lee and Kimble (2009). This weak and negative relationship could be due to the interaction differences between expectations and experiences among individuals. There are differences between and within individuals according to some universal aspects of life which are relevant to QoL and asserted that the determinants and evaluations of QoL are extremely specific to an individual (Carr & Higginson, 2001). Another possible explanation could be related to the timing of when the data was collected: QoL (at two weeks post-admission) and PSS: NICU (two days after hospitalization), because during this time, which is the beginning of the trial period for mothers, they adapted themselves to the new atmosphere and new

responsibilities. They may not yet be involved in the actual stress situation at which to a certain extent might influence the change of their QoL. The moderate level of stress encountered after the newborn's hospitalization was perceived by the mother as one of the difficulties during motherhood, which might improve mothers' ability to cope and alter their life to be better. Lastly, mothers might reveal about the recent or earlier quality of life as at that particular time mothers were in the altering stages and were not in the actual condition of the stress, and this probably had affected mothers' quality of life in the extended period of time. An extensive adjustment after the delivery, specifically in the case of an unexpected delivery, needs the mother to deal with different and challenging conditions; these stress-managing circumstances may have decreased the mother's quality of life (Noy et al., 2015).

The result also indicates that the PSS: MRA harms the mothers' QoL, which might be related to the majority of mothers studied being first-timers, as they might expect to take part in caring for their infant, which they could not fulfill. This result is in line with many researchers' suggestions that mothers of children with problems may be more susceptible to wellbeing problems and have a lower quality of life (Lee et al., 2009).

### Implications of the Study

The study results serve as a guideline and reference to alert the health care providers, particularly the neonatal nurses, when providing support to mothers psychologically aspect, especially in terms of role change to ensure a better quality of life among the mothers whose newborn was admitted to NICU. The authors were aware of the outdated data; somehow, these findings must be disseminated as baseline data because, to date, there has been no such study done in this setting since 1994.

### Limitations

This study has several limitations; initially, the information was gathered from one setting at a certain time by utilizing a non-probability convenience sampling, which may restrict the generalizability. In addition, the usage of the cross-sectional method significantly restricts more unexpressed and precise data. The addition of qualitative approaches that can foster openness and create personal events would have aided in describing the several Malay postnatal traditional practices and religion, hence would have significantly improved the value of the project.

### Conclusion

In a nutshell, this study has revealed that mothers with hospitalized preterm newborns admitted to the NICU rated their quality of life at a moderate level. Working in government sectors and the PSS: MRA was found to be the most influential factor associated with the mothers' quality of life. This finding resulted in the suggestion that, in dealing with QoL-related issues among mothers with their preterm newborns in NICU, the health care providers, hospital management should give more attention in planning the strategies that can reduce maternal stress, especially on the PSS: MRA rather than tackling direct on the QoL, because with less stress the

mothers would either have a better or maintain the same level of QoL. Effective communication and attention should also be given in improving the QoL for mothers who were housewives and working in the private sector.

## Declaration of Conflicting Interest

No conflict of interest to disclose by the researchers.

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## Authors' Contributions

Study design: OSL, SKL, EH, SJ, PV; Data collection: OSL, SKL, SKG, AZ; Data analysis: OSL, EH, SKL, SJ; Manuscript writing: OSL, SKL, EH, PV, SKG; Critical revisions for important intellectual content: OSL, SKL, EH. All authors agreed with the final version of the article to be published.

## Authors' Biographies

**Dr. Swee Leong Ong, PhD, MSc, BNSc, RN**, Senior Lecturer, School of Nursing Science, Faculty of Medicine, Universiti Sultan Zainal Abidin, Malaysia.

**Professor Dr. Kim Lam Soh, PhD, MHSc, BNSc, RN**, Head of Nursing Department, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Malaysia.

**Dr. Emni Omar Daw Hussin, PhD, BScN, MScN CCN**, Department of Nursing Science, Faculty of Medicine, University of Malaya, Kuala Lumpur, Malaysia.

**Salimah Japar, MSc, BN, RN**, Lecturer, Department of Nursing and Rehabilitation, Faculty of Medicine and Health Sciences, Universiti Putra Malaysia, Serdang, Selangor, Malaysia.

**Professor Dr. Kim Geok Soh, PhD, MSc, B.Sc.**, Department of Sports Studies, Faculty of Education, Universiti Putra Malaysia, Malaysia.

**Dr. Ponpon Varasiha, PhD, BNSc**, Dean, College of Nursing and Health, Suan Sunandha Rajabhat University, Dusit, Bangkok, Thailand.

**Assoc. Prof. Dr. Azlina Daud, PhD, Msc. BNSc**, Senior Lecturer, Department of Medical Surgical Nursing, International Islamic University Malaysia, Malaysia.

## Data Availability

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

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# Prevalence, severity, and self-management of depressive mood among community-dwelling people with spinal cord injury in Nepal

Mandira Baniya<sup>1</sup>, Luppana Kitrungrrote<sup>2\*</sup>, and Jintana Damkliang<sup>2</sup>

<sup>1</sup> Master of Nursing Science Program, Faculty of Nursing, Prince of Songkla University, Songkhla, Thailand

<sup>2</sup> Faculty of Nursing, Prince of Songkla University, Songkhla, Thailand

## Abstract

**Background:** Depression is a common psychological condition after spinal cord injury. There are increased incidences of self-harm, suicidal behavior, and lower quality of life among people with spinal cord injury and depression. However, self-management of depressive symptoms in the community is less explored.

**Objective:** This study aimed to examine the prevalence, severity, and self-management of depressive mood in community-dwelling people with spinal cord injury.

**Methods:** A descriptive study was conducted in 2019 among 115 people with spinal cord injury discharged from three health centers and living in the 13 districts of Bagmati Province. Participants were selected using stratified random sampling. Questionnaires were related to demographics, health and environment, depressive mood, and self-management. Descriptive statistics and quantitative content analysis were used to analyze the data.

**Results:** Ninety-seven (84.3%) people with spinal cord injury had a depressive mood. Of these, 60.8% had moderate to severe depressive moods. They mainly used the internet and social media, shared feelings with family members, and practiced Hindu religious activities for depressive mood management because of the physical barriers to accessing a healthcare facility and easiness to use of non-pharmacological methods. Nearly half of participants who used sharing of feelings felt their depressive mood disappeared when they often used the method.

**Conclusion:** Depressive mood following initial hospitalization is highly prevalent among people with spinal cord injury in Nepal, most of whom live in rural settings. Therefore, nurses and other health professionals should provide psychoeducation for this population and their family members to better address mental health problems. Facilitating pathways for those in rural areas to engage in social activities and timely treatment access may improve depressive mood. Nurses and other rehabilitation professionals can use social media to assess depressive moods and deliver management approaches in the community.

## Keywords

depressive mood; management; prevalence; severity; spinal cord injury; nurses; Nepal

### \*Corresponding author:

Luppana Kitrungrrote, PhD, RN  
Faculty of Nursing, Prince of Songkla University, Songkhla 90110, Thailand  
E-mail: [luppana.k@psu.ac.th](mailto:luppana.k@psu.ac.th)

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## Background

Depression after Spinal Cord Injury (SCI) is the most common psychological condition, and its occurrence is substantially higher than among people with general medical conditions. Based on a meta-analysis, depression is prevalent among one-fourth of the survivors of SCI (Williams & Murray, 2015). Furthermore, although depressive symptoms may occur in the adjustment process after SCI (Dorsett et al., 2017), there are increased reports of self-harm and suicidal behavior among people with depression (Kennedy & Garmon-Jones, 2017). Additionally, depression was associated with lower quality of

life among SCI survivors (Tate et al., 2015). Hence, early identification of depressive symptoms and their management is crucial.

A self-management approach is increasingly becoming popular in chronic health conditions, but it is less explored in depressive symptoms management due to merely focusing on the management of acute symptoms with medications or traditional psychotherapies (Duggal, 2019). Individuals with SCI utilize a wide range of management strategies for depressive moods. It was found that individuals with SCI preferred an exercise program followed by antidepressant medications and counseling programs to reduce depression (Fann et al., 2013). Clinical trials conducted in Australia and

Canada reported the use of cognitive-behavioral therapies (Craig et al., 2017) with no effect in decreasing depressive symptoms. In contrast, specialized yoga sessions (Curtis et al., 2017) and online mindfulness and psychoeducation (Hearn & Finlay, 2018) significantly reduced depressive mood.

Several factors, including personal, health and illness, and environment, influence an individual's perception in symptom experience and management (Dodd et al., 2001). Although previous studies contributed knowledge to the understanding of depressive mood and its management in people with SCI, these studies were conducted primarily in high-income countries (Cadel et al., 2020; Craig et al., 2017; Hearn & Finlay, 2018; Khazaeipour et al., 2015; Tzanos et al., 2018). Gaps of knowledge still exist in low-and middle-income countries like Nepal. Not only does the socioeconomic environment differ, but also striking differences exist within the culture, healthcare services, and physical environment. For instance, Nepal is predominantly a Hindu country, and most Hindus believe in Karma—wrong deeds committed in the past—as a cause of serious illness and suffering in life (Wilson, 2019). In addition, the high cost of medical expenses results in the practice of people seeking traditional methods to manage their health problems. In addition, the large areas of mountainous regions and the lack of wheelchair-accessible transportation are common challenges in Nepal. There is a lack of trained health professionals to provide mental health services in rural areas. Therefore, the previous findings may not be generalizable to the context of depressive mood occurrence and self-management among Nepalese people with SCI.

Specific to Nepal, no study has explored depressive mood self-management among community dwellers with SCI. Therefore, this study aimed to identify depressive mood prevalence and severity and its management strategies among people with SCI living in the community. The results of this study will provide essential information for nurses and healthcare professionals to plan for early identification and management of depressive mood among community-dwelling people with SCI in low-and middle-income countries like Nepal.

## Methods

### Study Design

A descriptive study was employed in this study.

### Participants

The study was conducted in the 13 districts of Bagmati Province of Nepal. The inclusion criteria to select participants were: (1) aged 18 years or older, (2) living in the community for 3-12 months post-discharge from three health centers, and (3) being able to communicate in the Nepali language. The three health centers were: (1) the Tribhuvan University Teaching Hospital (TUTH), (2) the National Trauma Center (NTC), a government-owned trauma hospital, and (3) the Spinal Injury Rehabilitation Center (SIRC), the largest spinal rehabilitation center and a non-government organization.

The sample was drawn from the target population of 490 people with SCI living in the communities in 2018. The estimated sample size was calculated using the proportion

percentage with a level of confidence of 95% and an acceptable margin for random error (Kasiulevicius et al., 2006). From previous studies, the estimated proportion of depression in people with SCI was about 45% (Khazaeipour et al., 2015; Rahnema et al., 2015). Thus, the calculated sample size in this study was 115. The sample was then drawn using a stratified random sampling technique. Hence, the numbers of participants for data collection from the TUTH, NTC, and SIRC facilities were 18, 21, and 76 cases, respectively.

### Instruments

The research instruments consisted of the following questionnaires:

#### **Demographics, Health and Illness, and Environment**

**Data Form.** This questionnaire consisted of closed-ended questions including age, gender, religion, education, employment status, monthly income, duration of injury, type of paralysis, pain intensity, physical complications, place of residence, and functional dependency level.

**Patient Health Questionnaire-9 (PHQ-9).** The PHQ-9, Nepali version (Bhattarai et al., 2018) was used to assess the severity of depressive mood after permission from the original authors. PHQ-9 is widely used among the SCI population (Bombardier et al., 2012; Fann et al., 2013; Tzanos et al., 2018). Each item response in the tool was reported on a 4-point Likert scale of 0 = not at all to 3 = nearly every day. The total score of the PHQ-9 ranges from 0 to 27, where the higher score represents a higher depressive mood. The tool has good reliability, validity, and diagnostic accuracy compared to the DSM-IV MDD criteria (Sun et al., 2020). Internal consistency of this tool demonstrated a Cronbach's alpha of 0.79 in this study.

#### **Depressive Mood Management Questionnaire**

**(DMMQ).** The DMMQ consisted of four questions that were modified from the studies of Dodd et al. (2001) and (Fann et al., 2013). Two open-ended questions were as follows; (i) type of management approach, "what management methods they used to reduce depressive mood" and (ii) reason for using the approach "why did they use those methods". Two closed-ended questions composed of (i) frequency of using the method "how often" which the responses were categorized into three levels, i.e., "rarely", "often", and "always" and (ii) effectiveness of the method "how effective" where the responses were categorized into five levels, i.e., "worsening effect", "no effect", "slightly better", "much better", and "completely resolved". In addition, the participants were asked about the use of depressive mood management approaches within the previous one month. The contents, congruence, and appropriateness of DMMQ were validated by five SCI experts in Nepal, including (1) an orthopedic nurse lecturer, (2) a senior SCI nurse, (3) a rehabilitation physician, (4) a neurosurgeon, and (5) a physiotherapist. The content validity index of DMMQ was 1.00. The DMMQ was then piloted with 15 sample people with SCI in another setting prior to data collection.

### Data Collection

After receiving permission from the ethical committee in each hospital, a list of names and contact numbers were obtained from the medical record departments. The first researcher then contacted possible participants by telephone. Upon meeting



the inclusion criteria, the first researcher set a meeting with participants in person. Willing participants or a designated family member provided written informed consent. Following enrollment, the researcher provided written questionnaires or conducted an interview with participants based on their preferences and literacy. The PHQ-9, Nepali version, and the DMMQ were conducted in the Nepali language by the first author, who was a Nepalese Master's student. The data collection was done from March to May 2019 using multiple methods, including self-report and interview, requiring a time duration of 15-20 minutes. During the data collection, some problems were encountered by the researcher. Since the interviews were conducted at the participant's home, sometimes they were busy with household work, requiring the researcher to wait for long periods. In addition, at many visits, some curious neighbors tried to join the interview process, which distracted the researcher and the participant. The researcher had to stop the interview, counsel participants and neighbors, and start again when this occurred.

### Data Analysis

Descriptive statistics, including frequency, percentage, and mean and standard deviation, were used to present depressive mood. In addition, a quantitative content analysis was done to analyze the data from the open-ended questions of depressive management (White & Marsh, 2006). The steps of quantitative content analysis involve identifying appropriate data, establishing a unit of analysis and coding categories, and coding data. After the coding, the researchers checked coding validity and reliability, analyzed and grouped the coded data, and applied descriptive statistics (i.e., frequency counts and percentages) to present the findings.

### Ethical Considerations

The study received approval from the Institutional Review Board of the Faculty of Nursing, Prince of Songkla University, Thailand (2018 NST-Qn 062) and the Nepal Health Research Council (Ref. No. 2182), Spinal Injury Rehabilitation Center (Ref. No. 88/075/076), Tribhuvan University Teaching Hospital (Ref. No. 21/03/2019), and National Trauma Center (Ref. No. 14/02/2019). Written informed consent was obtained from the participants. For individuals unable to read and write, the researcher read out the participant information sheet to the potential participants, and a written consent form was provided by their family caregiver. Anonymity and confidentiality of the participants were maintained throughout the study.

## Results

### Demographic and Clinical Characteristics

A total of 115 people with SCI were enrolled for data collection from the 13 districts of Bagmati Province. The demographic and clinical characteristics are presented in Table 1. More than half were male ( $n = 67$ , 58.3%), Hindus ( $n = 84$ , 73.0%), and lived in rural areas ( $n = 82$ , 71.3%). The vast majority of individuals had paraplegia ( $n = 92$ , 80.0%) and had physical complications ( $n = 102$ , 88.7%). The pain was experienced by all participants with an average moderate level. The most common level of dependency was moderate ( $n = 46$ , 40.0%).

**Table 1** Demographics and clinical characteristics ( $N = 115$ )

Characteristics	N (%)	Mean (SD)
<b>Age, years</b>		32.5 (9.4)
18–30	58 (50.4)	
31–45	47 (40.9)	
46–57	10 (8.7)	
<b>Gender</b>		
Male	67 (58.3)	
Female	48 (41.7)	
<b>Religion</b>		
Hindu	84 (73.0)	
Others (Buddhist and Christian)	31 (27.0)	
<b>Place of residence</b>		
Urban	33 (28.7)	
Rural	82 (71.3)	
<b>Education, years</b>		8.5 (4.2)
<b>Occupation before SCI</b>		
Unemployed (student, housewife)	33 (28.7)	
Employed	82 (71.3)	
<b>Occupation after SCI</b>		
Unemployed	69 (60.0)	
Employed	46 (40.0)	
<b>Family monthly income, NPR (1 USD = 117 NPR)</b>		
≤30,000	82 (71.3)	
>30,000	33 (28.7)	
<b>Duration of injury, months</b>		12.4 (3.7)
<b>Living in the community, months</b>		
3–6	10 (8.7)	
7–9	53 (46.1)	
10–12	52 (45.2)	
<b>Home medications after hospital discharge</b>		
No	92 (80.0)	
Yes (i.e., Amitriptyline, Imipramine, Escitalopram, Clonazepam)	23 (20.0)	
<b>Type of paralysis</b>		
Paraplegia	92 (80.0)	
Tetraplegia	23 (20.0)	
<b>Pain intensity</b>		5.3 (1.4)
<b>Physical complications</b>		
No	13 (11.3)	
Yes <sup>a</sup> (constipation, pressure ulcer, UTI)	102 (88.7)	
<b>Functional dependency level<sup>b</sup></b>		
Complete (0–24)	11 (9.6)	
High (25–49)	23 (20.0)	
Moderate (50–74)	46 (40.0)	
Minimal (75–90)	32 (27.8)	
Independent (91–100)	3 (2.6)	

Data are presented as  $n$  (%) unless otherwise indicated.

SD: standard deviation; SCI: spinal cord injury; NPR: Nepalese Rupee; UTI: urinary tract infection.

<sup>a</sup>One participant had more than one complication.

<sup>b</sup>Scores were from the tool "Modified Barthel Index"

### Depressive Mood Prevalence and Severity

Ninety-seven cases (84.3%) had a depressive mood. Of these, the mean (SD) score of depressive mood severity was at a moderate level of 11.0 (4.2) (Table 2).

### Self-Management of Depressive Mood

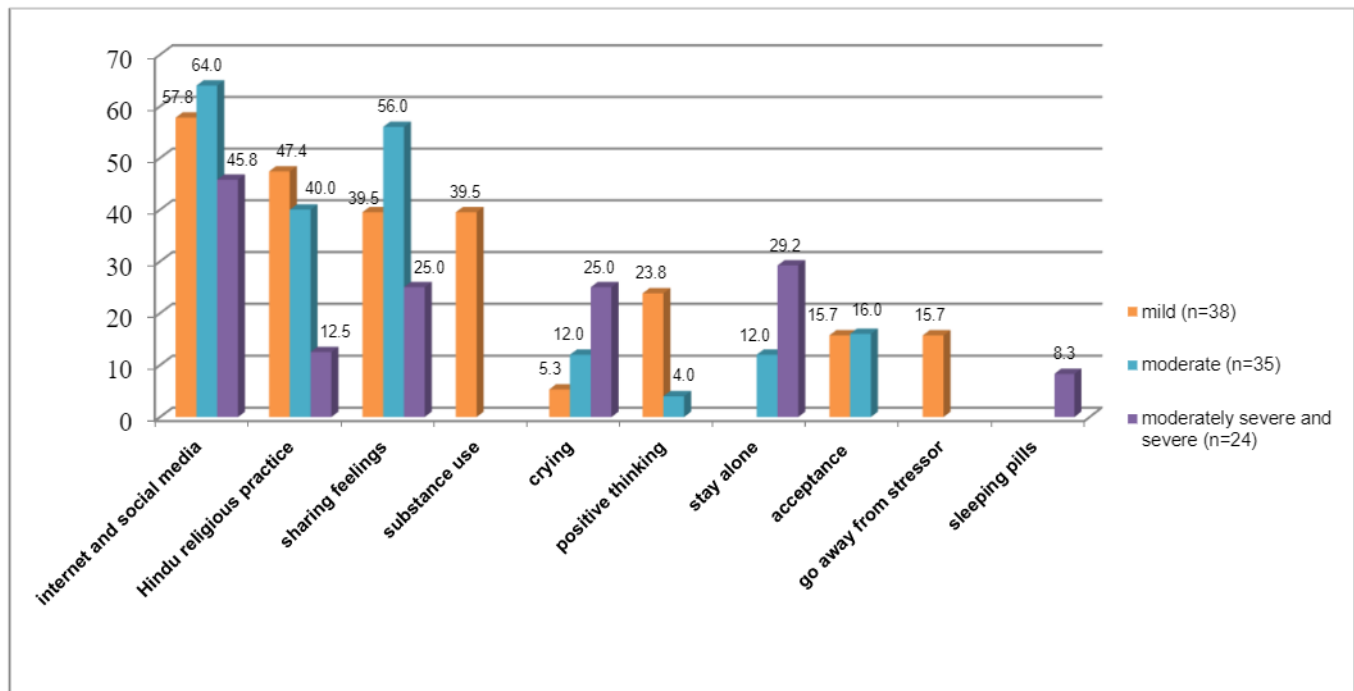
Of the 97 individuals who experienced depressive moods, all of them commonly used non-pharmacological methods for self-management. The five most common methods were: (1) using internet and social media ( $n = 49$ , 50.5%), (2) sharing

feelings (e.g., with family members, friends, and peer group) ( $n = 31$ , 31.9%), (3) Hindu religious practices ( $n = 31$ , 31.9%), (4) substance abuse (e.g., alcohol, cannabis) ( $n = 15$ , 15.5%), and (5) crying ( $n = 11$ , 11.3%). The percentage of depressive mood management methods used by participants was based on the severity of depressive mood (Figure 1).

**Table 2** Severity of depressive mood

The severity of depressive mood (scores)	N = 115	Mean (SD)	Level
None (0–4)	18 (15.7)		
Yes (5–27)	97 (84.3)	11.0 (4.2)	Moderate
Mild (5–9)	38 (39.2)		
Moderate (10–14)	35 (36.1)		
Moderately severe (15–19)	21 (21.6)		
Severe (20–27)	3 (3.1)		

Data are presented as  $n$  (%) unless otherwise indicated.  
SD: standard deviation



**Figure 1** Percentages of depressive mood management methods used by participants based on the severity of depressive mood\* ( $N = 97$ )  
\*One participant used more than one approach

The most common reasons for using the methods of depressive mood management were easy to use and feeling of relaxation (e.g., sharing feelings and internet and social media) (30.9%), peaceful mind and decreased suffering (e.g., religious practice) (20.6%), and find no other ways to provide comfort (e.g., accepting, crying) (20.6%) (Table 3).

In addition, among those who “often” used sharing feelings ( $n = 18$ , 58.1%) to decrease their depressive mood, most individuals reported their depressive mood “completely disappeared” ( $n = 15$ , 48.4%). The effectiveness of internet and social media use and Hindu religious practices were also demonstrated as several participants rated their depressive mood as “much better” ( $n = 26$ , 53.1% and  $n = 13$ , 42.0 %,

respectively) after they “often to always” applied these methods ( $n = 27$ , 55.1% and  $n = 19$ , 61.2 %, respectively) to relieve their symptom (Table 4).

Moreover, the groups of participants with moderately severe to severe depressive mood used self-management that was quite different from other groups to reduce depressive mood. They used the internet and social media ( $n = 11$ , 45.8%), staying alone ( $n = 7$ , 29.2%), crying ( $n = 6$ , 25.0%), sharing feelings ( $n = 6$ , 25.0%), and Hindu religious practice ( $n = 3$ , 12.5%). Few participants ( $n = 2$ , 8.3%) used sleep-inducing medications of unknown names without prescription (Figure 1).

**Table 3** Most common reasons for using the methods of depressive mood management

Reasons for depressive mood management <sup>a</sup>	n (%)
Relaxation and easy to use (e.g., internet and social media, sharing feelings)	30 (30.9)
Reduce depressive mood and suffering and promote peaceful mind (e.g., religious practice)	20 (20.6)
Find no other ways to provide comfort (e.g., accepting, crying, going away from stressors, staying alone)	20 (20.6)
Reduce effects of bad luck and evil eyes (e.g., praying, worshipping)	18 (18.5)
Have multiple effects such as peaceful mind and relaxation (e.g., meditation, substance abuse)	12 (12.4)

<sup>a</sup> One participant gave more than one reason

**Table 4** Frequency of use and effectiveness of depressive mood management approaches (*N* = 97)

Depressive mood management <sup>a</sup>	Frequency of use				Effectiveness			
	Rarely	Often	Always	Worsening Effect	No effect	Slightly better	Much better	Completely resolved
	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)
<b>Pharmacological approach</b> ( <i>n</i> = 2, 2.1%)								
Sleeping pills/name unknown	2 (100.0)	-	-	-	-	2 (100.0)	-	-
<b>Non-pharmacological approaches</b> ( <i>n</i> = 97, 100%)								
Using the internet and social media ( <i>n</i> = 49, 50.5%)	4 (8.2)	18 (36.7)	27 (55.1)	-	-	9 (18.4)	26 (53.1)	14 (28.5)
Share feelings ( <i>n</i> = 31, 31.9%)	3 (9.6)	18 (58.1)	10 (32.3)	-	-	6 (19.3)	10 (32.2)	15 (48.4)
Hindu religious practices (e.g., praying, worshipping 'Puja', 'Graha Shanti', 'Bhakal') ( <i>n</i> = 31, 31.9%)	4 (13.0)	19 (61.2)	8 (25.8)	-	5 (16.0)	9 (29.0)	13 (42.0)	4 (13.0)
Substance abuse ( <i>n</i> = 15, 15.5%)	3 (20.0)	7 (46.7)	5 (33.3)	-	-	2 (13.3)	8 (53.3)	5 (33.3)
Accepting ( <i>n</i> = 12, 12.4%)	-	12 (100.0)	-	-	-	4 (33.3)	6 (50.0)	2 (16.7)
Crying ( <i>n</i> = 11, 11.3%)	-	11 (100.0)	-	2 (18.2)	2 (18.2)	2 (18.2)	5 (45.4)	-
Positive thinking ( <i>n</i> = 10, 10.3%)	-	10 (100.0)	-	-	-	2 (20.0)	8 (80.0)	-
Staying alone ( <i>n</i> = 8, 8.2%)	-	8 (100.0)	-	-	-	4 (50.0)	4 (50.0)	-
Going away from the stressor ( <i>n</i> = 6, 6.2%)	-	6 (100.0)	-	-	-	2 (33.3)	4 (66.7)	-

<sup>a</sup> One participant used more than one depressive mood management

## Discussion

The findings of this study showed that most people with SCI had depressive mood, and its average severity score was at a moderate level, for which they predominantly used non-pharmacological approaches.

The prevalence and severity of depressive mood among Nepalese patients with SCI were higher than reported in previous studies (Al Abbudi et al., 2017; Khazaeipour et al., 2015). These results may be related to physical illness and complications and a lack of self-management skills among people with SCI. In addition, other reasons could be, short duration after SCI (Munce et al., 2016; Tzanos et al., 2018), functional dependence (Khazaeipour et al., 2015), pain and physical complications (Craig et al., 2017; Tzanos et al., 2018), and focusing on non-pharmacological approaches.

Participants in this study predominantly used non-pharmacological measures to manage depressive moods because they are easy to use. Moreover, most of them lived in rural areas, often several hours from roads with vehicle access. At least two people must carry people with SCI in these areas to reach the nearest health facility, which generally occurs only during medical emergencies.

In addition, being a predominately Hindu country, the Nepalese believe that pain or suffering is caused by transgressions of the past, or Karma (Wilson, 2019). This belief can contribute to individuals not accessing medical help for psychological problems. Hence, individuals used mostly a distraction, sharing of feelings, and spiritual/religious belief approaches to manage their depressive mood.

Using the internet as a diversion was commonly used by the participants in this study. This was possible because it is

easy to use as a hobby. Internet use was significantly associated with reduced depression compared to non-users. Specifically, daily internet users had less probability of developing depressive symptoms (Tsai et al., 2014). In addition, people with SCI shared their feelings with their family and peer group and through social media in the form of poems, songs, and maintaining diaries. According to the participants in this study, distraction and sharing feelings with others helped them improve their mood, which could be due to the release of chemicals such as serotonin and endorphins; a similar finding was reported in a previous study (Searle et al., 2011). Likewise, involvement in such pleasurable activities may help to improve psychological functioning.

Individuals in this study regularly used Hindu religious management, including "Puja" and "Graha Shanti" (worshipping God to remove bad luck and evil eyes) and "Bhakal" (promises to God for a special offering). These practices are common because they believe that God gives them strength to deal with difficult situations in life and strengthens their inner power to keep them moving forward in life and provide peace of mind, which was also consistent with past findings (Duggan et al., 2016; Xue et al., 2016). Some believe that their current situation is like an examination or a punishment from a higher power (God). Religious and spiritual approaches are used widely as part of a coping process by individuals living with chronic health conditions (Rahnama et al., 2015). In a developing country like Nepal, where basic health needs are not met, nurses can plan to model spiritual practices and approaches to improve psychological health and assist in the rehabilitation process.

Substance abuse, including drinking alcohol and smoking cannabis, was reported by individuals with mild depressive moods because it was easily available to them from their



friends. In addition, all participants had pain, and many had secondary complications that possibly elevated depressive mood symptoms (Tzanos et al., 2018). Therefore, they reported that drinking alcohol and use of cannabis helped to reduce neuropathic pain (Bourke et al., 2019), improved sleep, and decreased negative feelings and thoughts (Hawley et al., 2018; Kosiba et al., 2019). However, substance abuse is considered a maladaptive coping strategy that can lead to poor emotional control (Heffer & Willoughby, 2017). Hence, health professionals should discourage such practices.

In addition, participants with moderately severe and severe depressive mood symptoms reported crying and staying alone to release their inner feelings of sadness while in a depressive mood. Few participants used unprescribed sleep-inducing medications to forget depressive feelings, which should also be discouraged in any case.

This study was conducted in a single province of Nepal with a limited sample size; therefore, replication of this study with larger sample size and in other settings is necessary.

### Limitation of the Study

Although this study was conducted in many districts of Bagmati province, the findings may not be generalizable to all individuals with SCI living in Nepal.

## Conclusion

Depressive mood was highly prevalent among individuals with SCI living in the community in Nepal during the first year following initial hospitalization. However, most individuals perceived that depressive mood effectively disappeared when sharing feelings with family members as a self-management technique. Therefore, nurses and other health professionals should provide psychoeducation for individuals with SCI and their family members to recognize symptoms of depressed mood and better support mental well-being, either during their stay at the health center or using social media platforms after discharge. Moreover, most individuals with SCI in our study live in rural settings that have transportation barriers to engage in social activities and access healthcare services. Therefore, addressing these barriers is warranted to better identify and treat depressive moods among individuals with SCI.

### Declaration of Conflicting Interest

The authors declare no conflict of interest.

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### Authors' Contributions

MB analyzed the data, wrote and revised the manuscript. LK designed the study, analyzed the data, wrote and revised the manuscript. JD designed the study and wrote the manuscript. All authors agreed with the content of

the manuscript for publication and gave final approval of the version to be published.

### Authors' Biographies

**Mandira Baniya, RN**, is a Master student, Master of Nursing Science Program, Faculty of Nursing, Prince of Songkla University, Songkhla, 90110, Thailand. She is the Head of Department in Spinal Injury Rehabilitation Center, Nepal. She is interested in research and development of rehabilitation nursing.

**Luppana Kitrungrrote, PhD, RN**, is an Assistant Professor, Faculty of Nursing, Prince of Songkla University, Songkhla, 90110, Thailand. She is interested in trauma and surgical nursing.

**Jintana Damkliang, PhD, RN**, is an Assistant Professor, Faculty of Nursing, Prince of Songkla University, Songkhla, 90110, Thailand. She is interested in emergency and trauma nursing.

### Data Availability

The datasets generated and/or analyzed during the current study are not publicly available due to ethical restrictions but are available from the corresponding author on reasonable request.

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# “I can live a normal life”: Exploring adherence to antiretroviral therapy in Indonesian adolescents living with HIV

Nuraidah<sup>1</sup>, Dessie Wanda<sup>1\*</sup>, Happy Hayati<sup>1</sup>, Imami Nur Rachmawati<sup>2</sup>, and Agung Waluyo<sup>3</sup>

<sup>1</sup> Department of Pediatric Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

<sup>2</sup> Department of Maternity Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

<sup>3</sup> Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia, Depok, Indonesia

## Abstract

**Background:** Adherence to antiretroviral therapy (ART) can be challenging since it needs to be continued for a lifetime. At their age, adolescents start to be responsible for their life, and this continued therapy might be a challenge for them.

**Objective:** This study explored the experiences of adherence to ART in adolescents living with HIV in Jakarta, Indonesia.

**Methods:** A qualitative study with an Appreciative Inquiry (AI) approach was employed to explore challenges adolescents face in ART adherence which focused more on positive aspects of the experience. In-depth interviews were conducted with ten adolescents who were selected purposively based on criteria including those aged 13-19 years, having been diagnosed with HIV infection and receiving ART for more than a year, and never having discontinued ART. All participants were registered in the outpatient clinic in one top referral hospital in Jakarta. The data were analyzed using thematic analysis.

**Results:** Five themes were identified from the data: living a normal life, wanting to be healthy, taking medication on time, challenges in undergoing treatment, and there is hope.

**Conclusion:** Adolescents with HIV want to live as normal and healthy as possible, like other adolescents. Even though adolescents face several challenges to comply with ART, they try to take the medication as prescribed. The findings of this study serve as input for nurses to maintain compliance with ARVs in adolescents who have HIV.

## Keywords

adherence; adolescents; antiretroviral therapy; appreciative inquiry; HIV infection; Indonesia; nursing

## \*Corresponding author:

Dessie Wanda, S.Kp., M.N., Ph.D

Faculty of Nursing, Universitas Indonesia

Jl. Prof. Dr. Bahder Djohan, Kampus UI

Depok Jawa Barat 16424, Indonesia

Email: [dessie@ui.ac.id](mailto:dessie@ui.ac.id)

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## Background

Joint United Nations Program on HIV/AIDS (UNAIDS) data in 2019 shows that the number of people who lived with HIV infection across the world was 37.9 million in 2018; of these, 1.7 million (4.48%) were children aged less than 15 years (UNAIDS, 2019). The Indonesian Ministry of Health reported the following percentages of HIV infection cases from April to June 2019 according to specific age groups: 1.9% for children less than four years old, 0.9% for children aged 5–14 years, and 2.7% for adolescents aged 15–19 years old (Direktorat Jendral P2P, 2019). Adolescents in Indonesia are at risk of being infected with HIV due to their developmental characteristics. Adolescents are psychologically immature, extremely curious, and can easily be influenced by their surroundings, particularly related to sexual risk behavior. Often, adolescents have a sexual relationship or other similar

experiences only out of curiosity (Media, 2016), which may lead to HIV infection.

The only treatment for HIV infection is antiretroviral therapy (ART) (Indonesian Ministry of Health, 2019). ART is recommended for patients with HIV infection by disturbing the virus replication and reducing the virus levels, thereby improving immunity and reducing the occurrence of opportunistic infections and the mortality rate (Godfrey et al., 2017; Karyadi, 2017; Mahathir et al., 2021). Consequently, adolescents' quality of life following ART will be improved.

Adherence to HIV treatment is challenging, particularly for adolescents. According to the registrar book from a top referral hospital for infectious disease in Indonesia, 31 adolescents aged 10-19 took ART in March 2018. However, only 51.61% of them complied with the ART, while others were categorized as 'loss to follow up' patients. In the majority, adolescent compliance is less than other children's age. This is because the disease is caused by vertical transmission (92%) in adolescents aged less than 13 years old (Indonesian Ministry

of Health, 2019), and because of that, most of them are not aware of their HIV-positive status (Hornschuh et al., 2017). Denison et al. (2015) stated that if children are not aware of their HIV-positive status until they become teenagers, they may not adhere to ART because they would not know the consequence of nonadherence.

As part of health workers, pediatric nurses must act as a counselor and a facilitator in order to assist adolescents in complying with ARV therapy. Accordingly, their lives become optimal and adapt to their disease conditions requiring children to take ARV for life. As a counselor, a pediatric nurse is responsible for counseling pre-ART, facilitating decisions on who will be the drug assistance for each adolescent, monitoring side effects, regular health teaching on health problems related to ART, and evaluating the effectiveness of ART. Meanwhile, as a facilitator, a pediatric nurse is responsible for facilitating patient access to ART and its availability during certain times to ensure patients' compliance with ART.

Nonadherence to therapy has several negative impacts on patients and increases the healthcare burden. Moreover, adolescents have needs and characteristics very distinct, and they will get different information. The current research exploring adherence ARVs in adolescents with HIV experiences is still low. Therefore, strong evidence is needed to explore and identify problems regarding the experience of adolescents with HIV in undergoing ARV therapy (Chenneville et al., 2017). Nurses as healthcare professionals can apply the self-efficacy theory to identify factors that can boost confidence in adolescents with HIV/AIDS regarding their ability to adhere to ART. In the present qualitative study, the appreciative inquiry (AI) approach was used to explore and identify problems, strengths, and positive aspects to discover new ways to improve adherence to ART in adolescents with HIV infection.

## Methods

### Study Design

This was a qualitative study using the Appreciative Inquiry (AI) approach. In this study, adolescents were interviewed about their experience in adhering to ART. AI aims to explore the positive experiences of participants in order to develop a change in an individual or situation. AI consisted of four phases: discovery, dream, design, and destiny. The researchers described results from the first and second phases in this paper.

### Participants

The participants in this study were adolescents with HIV/AIDS who underwent ARV therapy at a top referral hospital for infectious diseases in Indonesia. The inclusion criteria were as follows: aged 13–19 years, not married, been diagnosed with HIV infection for more than one year, never stopped the medication, aware of their HIV positive status, able to use Bahasa Indonesia, and cognitive-abled. Exclusion criteria were the HIV adolescent that experienced health deterioration during data collection. Participants were recruited using purposive sampling. Nurses in the outpatient clinic assisted in

recruiting the participants. The nurses identified adolescents with HIV/AIDS admitted to the outpatient clinic, and then the researchers met with the adolescents to obtain their consent to be involved in the study. Ten adolescents agreed to be involved in this study. During the data collection period, no participants withdrew from the study.

### Data Collection

The data were collected from May to June 2020 using offline and online in-depth interviews, recorded using a recorder. Data collection was held in the counseling room, cafe, or participant's house. When the interview was conducted, no one else was listening. The interview guidelines (Table 1) and observation sheet were the additional instrument used during the interview process and had been tested beforehand. Interview and observational data were documented in the field note. The interview process lasted 45 – 60 minutes. No repeat interview was performed. Interviews were conducted until no new information was obtained from the participants. The results of the interviews that have become transcripts were stored in a flash disk and printed for further clarification to the participants.

**Table 1** Interview guidelines

No	Questions
1	<b>Discovery Phase</b> Could you describe how did you live with HIV? Could you describe how did you get along with ARV treatment?
2	<b>Dream Phase</b> What do you dream about living with HIV? What do you dream about undergoing ARV treatment?

### Data Analysis

A thematic analysis (Braun & Clarke, 2012) was applied systematically to identify, organize, and facilitate ideas into the meaning in one set of data. This method was chosen to explore the different perspectives among the participants, highlight the similarities and differences and produce unexpected insights. In general, the data analysis process included data recognition, compiling the code, searching for themes, reviewing other potential themes that will appear, defining and naming themes, and writing reports (Nowell et al., 2017). Data analysis was focused on the adolescents' experiences during ARV therapy.

The first analysis process was analyzing the transcript, which was read three to four times, and the experience of each participant was rewritten in a detailed manner. Meaning units were identified from the transcripts and were condensed into key statements. Key statements were sorted into categories which were later formulated into themes (an example of this process is provided in Figure 1). Afterward, the themes of each transcript were compared, and the themes that were relevant to the research question were highlighted. Then the researcher identified the linkages between the themes. The researchers confirmed that the themes possess enough data evidence. After describing and identifying the themes, the researchers validated and confirmed the themes to the participants.

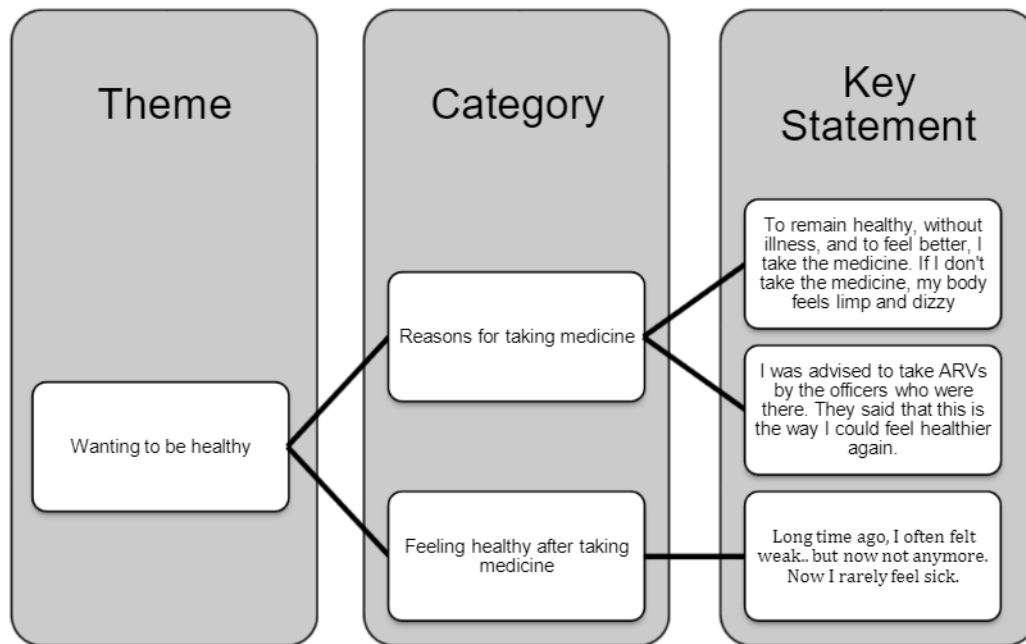


Figure 1 Example of theme formulation

### Trustworthiness/Rigor

The rigor of this study was achieved through several strategies: First, a thick description of the study process, including data analysis, related to transferability. Member checking, the process when the researchers asked for confirmation of the themes from the participants, was also conducted to achieve credibility and confirmability. Finally, to achieve instrument stability, the researchers involved the supervisor as an external reviewer and used literature reviews of the related references.

### Ethical Consideration

This study was approved by the Research Ethics Committee, Faculty of Nursing, Universitas Indonesia (reference: SK-110/UN2.F12.D1.2.1/ETIK.2020). Informed consent was given to adolescents over 18 years old, while for adolescents aged 18 years old or below, the informed consent was given to their mothers.

## Results

Adolescents aged 13–19 years were involved in this study. Out of these, six participants were senior high school graduates. The HIV infection in eight participants was caused by vertical transmission. Four participants lived with their parents at the time of data collection, while the remaining lived with only their father, only their mother, or other family members. Most participants did not join the peer support group. Nine participants were still receiving first-line therapy, i.e., nevirapine and zidovudine, while one participant was receiving second-line therapy, i.e., efavirenz, tenofovir, and lamivudine. The names used in the study are pseudonyms, which are only known to the participants and authors. From this study, five main themes (Figure 2) were obtained closely related to the adolescents' condition when adhering to ART.

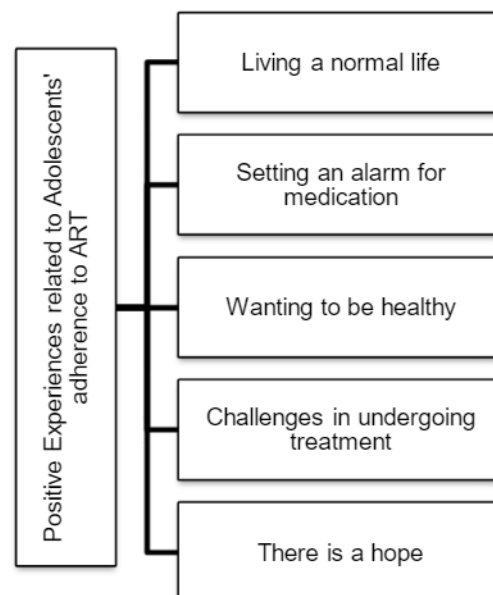


Figure 2 Themes identified related to adolescents who take ART

### Theme 1: Living a normal life

Adolescents in this study reported taking ART every day to live like adolescents without HIV infection. Two of the adolescents said:

*"Yes, helping my mom, eating, sleeping, doing common activities, and surely playing sports... The point is, I have to maintain my immune system so that it is continuously functioning." (Robert)*

*"What I do, staying with my younger sister, playing with my mobile phone, eating, sleeping, watching TV, doing homework, helping my parents." (Juliet)*

Robert and Juliet defined living a normal life as doing everyday activities such as eating, sleeping, and playing. The purpose of doing such daily activities was to keep functioning like other



normal adolescents, even though not quite as normal. This was mentioned by Isabel:

*"... being back to normal life, even though not really like them, just go on, ..., sometimes I play with my friend at home, at work, mingle with them, ..."* (Isabel)

Furthermore, Richard gave another definition of normal:

*"When going home after Asr prayer, I do not directly go home. I play with my schoolmates for a while and play on a mobile phone..."* (Richard)

Richard describes his normal life as spending his time after school with his schoolmates. Those Robert and Richard's definitions of normal life matched with their development characteristics as adolescents, where peer group relationship is important.

## Theme 2: Setting an alarm for medication

Participants mentioned methods used as reminders for taking ART, including phone alarms or alarm watches.

*"Oh yes, I have an alarm before 10 o'clock... I set the alarm for 9.55 am. So, before taking medicine, at 9.55 am, the alarm starts beeping, which means that in 5 more minutes, I have to take medicine, and I prepare accordingly. When the alarm beeps again for the second time at 10.00 am, I take my medicine. So, I set two alarms"* (Robert)

*"I always look at the clock in the living room. I stay at home, not playing with others until I take medicine. When it's already 6 pm, then I take my medicine. That's it. I take my medicine at 6."* (Jessica)

Robert used two alarms to remind him to take ART on time. This strategy was successful in keeping him adhered to taking ARV drugs. In comparison, Jessica used her home clock to remind her when was the time to take medicine. Other adolescents employed people who reminded them to take ART, such as family, friends, and healthcare professionals.

*"My mother keeps the medicine. She asks me to take medicine regularly. No skipping."* (Eric)

*"... and then from the health team, they always support me, even they always remind me to take medicine, they told me when I have to go to the hospital again"* (Jessica)

## Theme 3: Wanting to be healthy

Some reasons that motivated the participants to adhere to ART were their wish to remain healthy after taking the medicines and their belief that they would always be healthy if they adhered to the therapy.

*"To remain healthy, without illness, and even feel better, I take medicine rather than not taking it. If (I) don't take medicine, my body feels limp and dizzy"* (Isabel)

*"Long time ago I often felt weak, but now not anymore. Now I rarely feel sick"* (Mark)

Isabel clearly mentioned that her purpose in taking medicine regularly was to remain healthy. Likewise, Juliet and Jessica said the same reason:

*"My motivation is to be strong, to be healthy... just to be healthy"* (Juliet)

*"To be healthy, so I can grow up, in a healthy condition all the time"* (Jessica)

Juliet and Jessica clearly expressed their motivation relating to ARV adherence, which was to keep them in a healthy condition; consequently, they can grow to adulthood period.

## Theme 4: Challenges in undergoing treatment

Participants felt many challenges must be faced in undergoing ARV treatment. The challenges include feeling the side effects of drugs, forgetting, queuing when taking medication, having to regularly take medication at the same time, being bored of taking medication, and large drug sizes. The participants expressed this in the following statements:

*"I felt dizzy at first, but as time went on, I got used to just feeling dizzy, like people who fly, yes they fly"* (David)

*"My hands often feel numb, when my feet get wet, everything gets wet to the point of sweating like it's hot, but when the water hits the hands, the feet don't get wet"* (Richard)

*"The first time I was nauseous, it was hard to swallow, at first I was often sick, in the past, I used to feel bad every time I took medicine, now I don't feel bad anymore"* (Mark)

## Theme 5: There is a hope

This theme describes participants' hopes for their future life. When they talked about future life, this meant the ART availability and their plan to have a family of their own.

*"It's good that the medicine is there; hopefully, the medicine doesn't run out, it's always available and free. My hope is to get well soon, stay healthy, don't get sick easily."* (Mark)

*"Hopefully, if I get married later, my child won't be affected."* (Kyle)

*"The point is that I have to be obedient to be able to live my future to have a wife to achieve my goals."* (Robert)

The hope is also related to the expectation of being free from stigma as a person with HIV, namely that no one is shunned or demeaned. The participants expressed the following statements:

*"Don't look down on people who have HIV disease; it's not necessarily that HIV is contagious by holding hands"* (Isabel)

*"HIV people don't stay away, don't stay away, stay friends"* (Mark)

## Discussion

Most of these adolescents understood the importance of taking care of their health by adhering to the treatment. The findings of this study showed that the acceptance of their current condition is important in adolescents with HIV infection as a positive coping mechanism. This study is coherent with the previous research that identifies the correlation between self-efficacy and HIV medication adherence. The patients' beliefs in their ability to have self-control in relation to HIV medication are good for them (Aregbesola & Adeoye, 2018). This belief in self-control on HIV treatment impacts the

psychological state. This finding is similar to that of a study conducted by [Rzeszutek et al. \(2016\)](#), who stated that building an adequate psychological condition is an essential aspect of HIV/AIDS medication and treatment. Patients' acceptance of their disease and adherence to therapy is influenced by their views, beliefs, mental health, and social support ([Rzeszutek et al., 2016](#)).

Adolescents with ART can normally live like other adolescents without HIV infection. In this study, all the participants could work, help their parents with work, go to school, play, and mingle. This was in line with the finding of a study conducted by [Madiba and Mokgatle \(2016\)](#), who stated that teenagers want to be healthy and normal like other people. They express positive feelings in their lives, and HIV infection is not necessarily related to bad health. Most of them understand the importance of taking care of their health. Peer support plays an important role in helping people with HIV infection adapt to their normal life ([Martiana et al., 2021](#)).

Adolescents with HIV infection define normal life while using ART to perform activities like other normal adolescents and not have any physical complaints or other diseases ([Kalra & Emmanuel, 2019](#)). Adolescents with HIV infection felt healthier than those who had cancer and diabetes. The participants felt that living a normal life gave them the hope and strength to live their life with HIV infection ([Smith et al., 2016](#)).

Challenge faced by adolescents who managed their medication regarding ART adherence was that they had to remember the time of taking medicine according to the dose daily. In a study conducted by [Hornschuh et al. \(2017\)](#), adolescents forgot to take their ARV medication at times because they forgot to turn on the medication reminder, which affected their treatment adherence. Another study revealed that failing to take medicine was the factor due to which adolescents missed their medication and missed doses; this led to poor adherence to ART and was found to be the main factor associated with treatment nonadherence in adolescents ([Wambugu et al., 2018](#)).

In our study, adolescents mentioned that setting the alarm for medication was the most important factor in ART adherence. Medication reminders were either through a mobile phone alarm or a watch. A study in Cambodia found that the challenge in adhering to ART was the feeling of difficulty in remembering to take medicine ([Chhim et al., 2018](#)). The use of a reminder system has been proven to be effective in improving adherence and success of ART treatment in individuals with HIV infection. In a previous study, the most common reminder used by adolescents was an alarm on their mobile phone; it was an audio reminder or a picture-based reminder that automatically popped up after being set ([Ekop & Okechukwu, 2018](#)).

In addition to a technology-based reminder, a reminder from family, friends, or healthcare professionals is essential. Although an adolescent is an independent person according to their developmental stage, support from family and healthcare workers is required to prevent nonadherence to therapy ([Nabunya et al., 2020](#)). In one study, participants considered using external support to reduce their difficulty remembering the time of taking their medication. Such difficulties can be resolved by having a reminder, receiving information about the importance of not missing a dose, or

being motivated to adhere to the treatment through some support ([Lockwood et al., 2019](#)).

Besides taking medication on time, challenges faced by participants in undergoing ARV treatment were feeling the side effects of drugs, forgetting to take medication, queuing when taking medication, having to regularly take medication at the same hour, getting bored of taking medication, and having large drug sizes. This is in line with research that states that the barriers and challenges to ARV adherence for children/adolescents with HIV include unpleasant drug taste, pill burden, dietary restrictions, acute and long-term side effects, coordination with daily schedules, forgetfulness, and treatment fatigue ([Garvie et al., 2017](#)).

The first challenge in undergoing treatment is the side effects of the drug. Not a few drugs have side effects. The side effects of ARVs are related to each compound as well as to host genetic factors and the patient's lifestyle. In a study by [Godfrey et al. \(2017\)](#), about 94% of patients taking ARV therapy showed side effects. Discomfort caused by various side effects is an important factor that can cause patients to be less compliant or lead to discontinuation of treatment. Ten main symptoms may appear as side effects of ARV treatment, namely diarrhea, nausea or vomiting, stomach problems, dizziness, sleep problems or nightmares, weakness, weight loss, and clinical signs of anxiety ([Natukunda et al., 2017](#)). This is in line with the research of [Gobel \(2019\)](#), which stated that several participants noted that the side effects they often felt while undergoing ARV treatment were dizziness, nausea, vomiting, skin rashes, itching, and even hallucinations. This situation causes them to decide on treatment because they are unable to withstand the side effects that arise.

Participants in this study underwent ARV treatment for at least one year with full hope for the success of ARV treatment for their health and the future that would be achieved. The desire to live longer and healthier is the motivation for adolescents to take ARVs. This is in line with previous research that stated that most adolescents started ARVs after being sick for a long time and required them to take ARVs, so it was a valuable experience for adolescents so that it would not happen again ([Denison et al., 2015](#)). In this study, the participants expressed that their hope to be healthy became their motivation for taking ARV drugs. Based on the self-efficacy theory, patients with HIV/AIDS were found to show higher self-efficacy because they had the belief and felt the benefits of ART, which made them take ARV drugs regularly. Their self-confidence continuously grew and developed through the individual learning process throughout their lives due to performance accomplishments ([Sugiharti et al., 2014](#)). This was in line with the finding of a study conducted by [Madiba and Mokgatle \(2016\)](#) that adolescents took the medicines correctly to prevent illness because they wanted to be healthy and normal. In their research, most adolescents started ART after prolonged illness and felt the effect of the therapy, i.e., improved health status.

In this study, participants had hopes related to stigma, namely that people with HIV would not be shunned and still be accompanied because stigma and rejection seem to remain prominent in the lives of HIV-infected adolescents. HIV infection remains a stigmatized disease and a problem for those living with HIV infection ([Abubakar et al., 2016](#)). Participants also have hopes related to treatment, namely



ARV drugs will always be there for them, and participants' expectations regarding the future are wanting to achieve the desired goals, being able to make parents happy, and being able to build a household where no family member has HIV due to contracting from a person living with HIV. This is in line with research in India that a person with HIV can lead a healthy, normal, and productive life when they practice a positive life. Their positive approach to life, their expectations of treatment outcomes, and hopes for a good future show positive signs of life, which can ultimately lead to a good quality of life (Kalra & Emmanuel, 2019).

The limitation of the study was related to maximum variations of the participants. Most of the participants have HIV from the vertical transmission. This means that they took the medication long ago, and family support is guaranteed. Therefore, different experiences or hope might be different in adolescents who get infected from another transmission.

The implication of this study to the nursing practice is that nurses working with adolescents with HIV should identify challenges and explore adherence experiences to maintain compliance with ARVs. Nurses can also be a counselor for adolescents with HIV who take ART. As counselors, nurses can help adolescents adhere to ART by accompanying them when they get bored with the treatment. This study also provides important insight into the adolescents and their families handling problems during ART.

## Conclusion

This study found that adolescents with their characteristics of not wanting to be controlled and having independent behavior can adhere to ART despite all challenges they face. A specific approach is required in adolescents; therefore, the authors used the AI approach to explore their experience in taking ARV drugs. The data showed that adolescents could live a normal life like other adolescents without HIV infection. This can be possible because of the motivation that they want always to be healthy and maintain their health to fulfill their dream and hope and to make their parents happy. Rewards should be provided for adolescents who have adhered to ART by making them role models for ARV adherence, involving them in providing education to other adolescents with HIV infection, and sharing testimonials of their experience in taking ARV drugs so that they can be proud of their ability.

## Declaration of Conflicting Interest

The authors declare that they have no conflict of interest in this study.

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## Authors' Contributions

NN: conception of the work, acquisition, data analysis, and drafted the manuscript. DW: conception of the work, data analysis, and reviewed draft manuscript. HH: data acquisition and analysis. INR and AW: revised the

manuscript for important intellectual content. All authors provided final approval of the version to be published.

## Authors' Biographies

**Ns. Nuraidah, S.Kep., M.Kep., Sp.Kep.A** is a Pediatric Nurse Specialist working in RSPI Soelianti Soeroro (an infectious disease hospital, including HIV-AIDS). Her research interest is AIDS in children.

**Dessie Wanda, S.Kp., M.N., Ph.D** is an Associate Professor at the Department of Pediatric Nursing, Faculty of Nursing, Universitas Indonesia. Her research interests are infectious disease, clinical education, reflective practice, and qualitative research.

**Ns. Happy Hayati, S.Kp., M.Kep., Sp.Kep.An** is a Pediatric Nurse Specialist and a Lecturer at the Department of Pediatric Nursing, Faculty of Nursing, Universitas Indonesia. She is an expert in qualitative nursing and AIDS in children.

**Dr. Imami Nur Rachmawati, S.Kp., M.Sc.** is an Associate Professor at the Department of Maternity Nursing, Faculty of Nursing, Universitas Indonesia. Her interests are in qualitative research, adolescent reproductive health, and maternal health including women with HIV/AIDS.

**Agung Waluyo, S.Kp., M.Sc., Ph.D** is an Associate Professor at the Department of Medical Surgical Nursing, Faculty of Nursing, Universitas Indonesia. He is an expert in HIV-AIDS in Indonesia. He has several international collaborations and publications related to HIV-AIDS.

## Data Availability

Data from this research is not available publicly; however, readers interested in the data may contact the corresponding author for access.

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