

Balance of Family Caring in Families with Chronically Ill Children: A Concept Analysis

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Abstract

The concept of balance of family caring was expected to emerge as a vital issue in families with chronically ill children. However, it was unclear to clarify understanding about the scope of this concept. This study aimed to identify the balance of family caring in families with chronically ill children. Walker and Avant's eight-step method was employed to conduct this study comprising selecting a concept, determining the purposes, uses of the concept, defining attributes, identification of a model, borderline, related and contrary cases, antecedents and consequences, the definition of empirical referents. The search was performed in September 2018. Five databases were included: CIHAHL, MEDLINE, PsycINFO, Academic Search Premier, and EBSCO Host. Ten articles were used for analysis. The actual attributes were composed of the balances between working outside and providing home-based care, potential hope and despair, caring for a sick child and practicing self-care, and balancing caring style. The antecedents, namely family characteristics, family stress, and family coping skills were identified in this study. The consequences composed of effective family functioning, improved family well-being, and children's quality of life. In conclusion, this concept can be applied for developing effective care for children with chronic illnesses.

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Keywords : concept analysis, balance, family caring, chronically ill child.

Current advances in medical technology have helped extend the average life expectancy of people in the world, including children with chronic illnesses. Most chronic illnesses do not fix themselves and are generally not cured. The progression of chronic illness may be rapidly or slowly progressive, depending on several factors. The generally-accepted characteristics of chronic illness include permanent change, disability, irreversible pathology, need for respite, and long-term or permanent need for continuous care.^{1,2} The global chronic illness situation reveals 10-15% of children aged under 16 years have been diagnosed with a chronic illness that leads to increasing numbers of children with chronic illness (asthma, type 1 or type 2 diabetes mellitus, obesity, heart disease, cancer, thalassemia, hemophilia, nephrotic syndrome, etc.) with more than 1,000 million people in the United States (U.S.)³ Moreover, about 80-90% of chronically ill children caused by diabetes mellitus, kidney disease, or heart disease will have an increased average life expectancy until they are 20 years old with proper care.⁴ These findings reflect the increase of chronically ill children that requires continuous care provided by family caregivers who have a key role in providing quality care for their children.⁵

According to the illness trajectory of chronic illness, chronically ill children and their families have to encounter uncertain situations due to constantly changing circumstances based on the illness trajectory of chronic illness that differs in each child.⁶⁻⁸ In this regard, they are sometimes inconstant, acute, relapsing, or crisis phases, all of which can occur with the children and their families.⁹ Since the children have many limitations in taking care of themselves with limited capability caused by developmental and chronic conditions, family caring is a challenging role for the entire family to provide quality care for children with chronic illness.^{5,10}

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The literature review found that families faced with the burden of caring for their child bear endless responsibility, even though the family also needs to maintain other responsibilities. Many studies have stated that families feel uncomfortable, stressed, guilty, exhausted, despair, isolated from social activities and neglectful of self-care, etc.^{1,2,6,7,11,12} These findings reflect the problem of imbalance in family life due to the provision of care for children with chronic illness potentially affecting both the quality of care for their child and family well-being as well.¹³⁻¹⁵ The effect on the quality of care for chronically ill children due to the family tension caused by economic or family relationship problems may prevent the family from adhering to treatment regimens or result in neglect in caring for the sick child, etc.¹⁶ Due to the effects on family satisfaction or well-being, the family may spend more time taking care of the sick child, while neglecting other parts of the whole family. As a result, healthy siblings are ignored and there are disharmony in family relationships.¹⁷⁻¹⁹ These are the main factors that potentially disrupt family functioning and well-being in such circumstances. The issue of balance in family caring focusing on the balance between working outside and providing home-based care, potential hope and despair, caring for a sick child and practicing self-care, and balance of caring styles, therefore, is a vital issue that can enhance deeper understanding and create tailored interventions to promote the balance of family caring in families with chronically ill children.

Based on the previously mentioned highlight, the balance of family caring is expected to emerge as an issue in families with chronically ill children. Unfortunately, many words are interchangeably used to communicate the understanding of the balance of family caring such as good family adaptation, harmony, well-being, homeostasis, and resilience.^{20,21} In addition, the balance concept has been found to be used in a wide range of areas concerned with maintaining the balance of family life.²²⁻²⁷

The purpose of this study, thus, was to determine the antecedents, attributes, and consequences of the balance of family caring as proper for the phenomenon of families were living with chronically ill children. Also, to clarify understanding and encourage communication about the scope of this concept as a means of facilitating the ways to measure the concept for further research.

Method

The Walker and Avant²⁸ method was employed to conduct the concept analysis. Studies were identified through a comprehensive electronic search using the following databases: CIHAHL, MEDLINE, PsycINFO, Academic Search Premier and EBSCO Host. The search was performed in September 2018. Then, ScienceDirect, and Google TM Scholar databases were employed for additional searches. These searches were conducted between January 2010 and September 2018. The literature search used combinations of the following key terms: family caring balance, the balance of

the family caring, the family balance, the caring balance, chronically ill child, and families with chronically ill children. The inclusion criteria for selecting eligible articles for the review were as follows:

1. Full text.
2. English and Thai language, as the researcher can translate from Thai to English.
3. Primary research.
4. Chronically ill child in the family.
5. Qualitative and quantitative research methods.

The exclusion criteria were as follows:

1. Editorials.
2. Commentaries.
3. Discussion papers.
4. Conference abstracts.

The author reviewed the titles of all articles that were displayed by the searches and dismissed those articles that did not match the inclusion criteria. The reference lists of the eligible articles were examined to identify additional articles. Finally, ten studies were included for analysis in this review. The following eight steps by Walker and Avant²⁸ are illustrated below.

Step 1: Select a Concept

The phenomena contributing to the balance of family caring in families with chronically ill children are important, since the concept of balance of family caring in families with chronically ill children remains unclear.²⁰⁻²⁷ As a consequence, nursing knowledge for promoting deeper understanding can be applied to the creation of tailored interventions promoting the balance of family caring in families with chronically ill children.

Step 2: Determine the Purposes of the Analysis

This study aimed to identify antecedents, attributes, and consequences of the balance of family caring in families with chronically ill children that will lead to providing effective care for children with chronic illnesses.

Step 3: Identify All Uses of the Concept

The term "balance" is generally used in broad areas such as sports, daily life, medication, and work. In sports, this word is used in reference to a person's special ability to maintain the balance of their body on any object.²⁹ Medically, this word is used to help in the assessment of abnormalities of the central nervous system (CNS), which can result in the inability to remain upright.³⁰ In work, the term is used to determine a person's work ability in terms of confidence while performing daily tasks with or without assistance.³¹ In daily life, the term is used in reference to daily life activities such as time management of career work, relaxation, exercise, maintaining contact with friends or other people in society, staying involved with family activities, and personal development, etc. The goal of

the above mentioned definitions of balance is to promote satisfaction or quality of life commonly expected for everyone.

In nursing, the concept of balance of family caring is emphasized in adult and elderly care^{22,23,25-27} since aging basically relies on caring for family members with physical impairment from either illness or age-related degeneration.³² This finding corresponds with the definition of the balance of family caring in aging, which is the balance between caregiving and work because most family caregivers need to work outside the home.²⁷ This limitation contributes to the quality of care for the elderly in which caregivers may experience stress, strain, and work-family conflict. Therefore, if the family can cope with the conflict between the balance between both roles, or if they have personal resources and social support, or support from employers, then family members can maintain the work-family balance.

In end-of-life care, the concept of balance in family caring has emerged to help family caregivers cope with the grieving process caused by the death of a loved one.³³ Also the study by Walker & Sque²⁵ found that the balance of family caring facilitated the family in discovering a trajectory of hope and despair in terms of organ and tissue donations seemed to give meaning to the life and death of deceased persons and was relieving to families in their grief.

In a family situation with chronic illness, a study by Teunissen et al.,²² found that families faced with troubled situations due to chronic illness are subject to psychological distress such as tension, anxiety, insecurity in life, unsafe conditions and so on. These problems can cause life imbalance for couples and families. However, families can use the balance of family caring to maintain couple and families lives through balancing love and care under pressure situations.

In children with chronic illness, the balance of family caring is reflected through helping the needs of children diagnosed with chronic illness. These children perceive the parents' caring style in which they are treated differently from their siblings in areas such as communication patterns, activity restrictions, parental hypervigilance, and parental overprotection. Children in this group have reported being bothered by parents' need for supervision, and further perceived hostility from parents differed from other siblings.³⁴

The balance of family caring, therefore, is the family caring process in terms of effort to properly maintain the balance of family caring when the family encounters imbalanced situations caused by the inability of a family member to care for themselves as a result of illness or immature age. Family caring is proceeded by feelings of shared love in the effort to maintain balance in all aspects of human life, namely physical, mental and emotional dimensions affecting abnormal situations and being capable of eventually returning to normalcy. If the family can obtain the attributes of balance in family caring, children's quality of care and family well-being can be achieved. In this study, the balance of family caring

comprises the balance of work outside the home and home-based care, possible hope and despair, responsibility to care for a sick child and a practice of self-care, and caring style.

Step 4: Determine Defining Attributes

The author performed a synthesis of empirical literature from the systematic data search to identify the attributes that are essential components to the concept of balance in family caring in families with chronically ill children. The four attributes are identified and described below.

Balance between Working Outside and Providing Home-based Care: Chronic illness has tremendous impact on the family burden. The family is forced to reorganize all parts of family life, which can result in role conflict, overload, strain,³⁵ because chronic illness requires intensive and continuous care from family caregivers in response to the high demands the sick child.⁵ Importantly, the economic burden is a challenging problem in families with chronic illness. In this regard, families need to pay for the added expenses of treatment, while family income is decreased caused by some of the family members quitting their jobs to spend more time caring for the sick child. On the other hand, other family members may devote more time to career work; (working overtime, or doing extra work) in response to the increasing expenses incurred in caring for children with chronic illness.³⁶ As highlighted above, having a child with chronic illness potentially impacts families by preventing them from providing appropriate care for their child, which will lessen the quality of care received. Therefore, although working is a necessary activity in order to maintain the economic status of the family, it is a challenging issue for families to maintain balance between working outside and caring a sick child at home. In addition, healthcare policymakers should legislate relevant laws to facilitate families in taking more time to care for sick children in addition to finding solutions to decrease the economic problems of those families. This issue requires good cooperation from employers and other parties involved in order to improve the quality of care for children and increase family well-being as well.

Balance between Potential Hope and Despair: Due to the incurable nature of the chronic conditions, its progression tends to worsen feelings of despair for both children and families. Despair is a psychopathological response that reflects the failure of the family caring adaptation. However, the data synthesis found that families should maintain the balance between hope and despair, even during bad events since doing so will enable the family to cope with the grief process from anticipated loss caused due to a chronic condition. In this regard, hope is one part of a spiritual need that helps both children and their families to savor positive aspects in the present. Therefore, hope seems to be a miracle power source providing a positive force to help children with chronic illnesses and their family to be able to overcome any suffering.²⁵

Balance between Caring for a Sick Child and Practicing Self-Care: Family caregivers are accepted as the people who have the main role in providing the enduring responsibility of promoting quality of care for chronically ill children, regardless of the impact of this responsibility on their personal lives. The empirical synthesis found that family caregivers reflect the negative impact of taking care of their children (sleep problems, fatigue, lack of exercise, lack of leisure time to do personal activities, lack of social activities etc.) that lead to the family caregiver's physio-psycho-social problems.³⁶ Therefore, the balance between caring for a sick child and practicing self-care is essential to promoting both quality of care for the well-being of children and families as well.^{15,37} This balance can be identified by the family having time to exercise, participate in community activities, get involved with other family activities, taking care of other family members, engaging in religious practice, interests and hobbies etc.

Balance of Caring Styles: Numerous physical limitations are caused by chronic conditions faced by children and families resulting in sick children being imposed greater restrictions and parental overprotection than healthy siblings.⁶ We can say that the family caregivers' constant focus on the disease can frustrate them and lead to strained relationships and disagreements between the chronically ill children and their families.⁷ More stringent restrictions or over-focusing on the disease not only affects the psycho-emotional impacts on chronically ill children, but can lead to negative impacts on health care outcomes such as failure to adhere to the children's treatment regimens, because they are tired of having so many restrictions.³⁷ Therefore, families should be promoted in maintaining balance in caring styles for chronically ill children such as adopting more open parenting care styles, including discussions, trusting relationships, less control, no hyper-vigilance, and more responsibility for children to potentially administer medicine and making decisions about the disease and dietary requirements by themselves.

Step 5: Identification of a Model Case

Identifying a model case of the concept involves finding a sample of using the concept to present functional status based on the real life of a family living with a chronically ill child. The author used this method to assess the balance of family caring. The following is a model case in which all attributes have been included:

In one nuclear family, an 11-year-old daughter had thalassemia. The mother was the main caregiver for the child both at home and in hospital. The family followed the medical regimens prescribed, because they believed the sick child might get better or might avoid greater severity if the sick child received proper treatment. However, the family perceived thalassemia as an incurable disease. Sometimes when the progression of the disease worsened worse, the family felt hopeless. The family always went to the temple to make merit with hope to reduce their suffering. When the child was

admitted to the pediatric ward, the father would visit and stay with the child and mother after work. The older sister helped do housework, caring for another young child and rotating with her mother in taking care of the sick child to let her mother have some leisure time to relax by doing her personal activities and taking care of other family members. Importantly, the family gave the sick child more responsibilities congruent with her developmental stages such as taking medicine, monitoring signs and symptoms, and selecting disease-appropriate foods to promote the sick child's potential ability to take care of herself.

Step 6: Identification of Borderline, Related and Contrary Cases

Borderline Case

This borderline case violates the attributes of the concept of balance in family caring in families with chronically ill children.²⁸ As the mother of the children with asthma tried to enforce strict caring in terms of hyper-vigilance, it was recognized that, although this caring pattern might not have been a problem when the sick child was young, it might no longer be suitable as the sick child transitioned to older childhood. This reflects imbalance in family caring in terms of the caring style.

In one nuclear family, a 13-year-old child was diagnosed with asthma. The mother is the main caregiver for taking care of the child. The older sister reminds the sick child to take their medicine. Sometimes, the sick child feels uncomfortable and imposed upon with even more control from the mother's caring style. The sick child usually has been prohibited to play with their friend due to the mother anxiousness that the sick child may have an asthmatic attack at that time. All these lead to occurrence of family relationship problems and the sick child is left feeling bored with the illness and its treatment.

Related Case

A related case has a close relation to some attributes in this concept, however, it does not meet all of the defining attributes. The family satisfaction is illustrated in the following presentation of a related case.

A nuclear family had three children. The youngest child was a school-aged boy who had been diagnosed with thalassemia. The entire family pitied him because he had to face invasive treatment and tremendous suffering from the disease and the side effects of treatment. Thus, everyone tried to appease him too much to compensate for his circumstances. This act helped the parent suppress their feelings of guilt and helped the family feel greater satisfaction.

Contrary Case

The contrary case is obviously not an example of the concept under analysis, since it does not include all attributes of the concept of balance in family caring.³⁸

In this case, a nuclear family had three children. The youngest child was a school-aged boy who had been diagnosed with thalassemia. The entire family was faced with huge suffering in the adaptation process. The mother had been laid off from her work, because she frequently took time off work to take the sick child to hospital. Consequently, the father was overloaded with burden and felt stressed due to added expenses, while the family income had decreased. The father needed to do extra work to earn more money. The family was rarely able to do family activities together. The mother did not have time to relax or do other activities and the healthy siblings were largely ignored by the parents. At the same time, the sick child usually bought fried chicken livers and sticky rice to eat after school, which made his prognosis worse. This reflects an imbalance in family caring in the context of a family member's illness, disrupted family functioning, and left the family faced with feelings of hopelessness.

Step 7: Identification of Antecedents and Consequences

Antecedents

There is widespread recognition that the presence of children with chronic illness can be a source of increasing stress and distress among the whole family.³⁵ An antecedent of the concept of balance in family caring has three antecedents, namely family characteristics, family stress, and family coping skills.

Family characteristics are defined as marital status and socioeconomic status. In terms of marital status, many studies have found that being a single parent is a risk factor for poorer family functioning.¹⁵ According to the literature review, socioeconomic status has been found to be the greatest emerging problem, especially among families in the lower socio-economic groups, since chronic disease requires prolonged care and treatment with frequent hospitalization. Financial problems seem to be a universal cause of suffering in families living with chronically ill children.³⁶

Family stress is defined as a source of the huge distress of the whole family that can lead to family disruption. It is those changes in a family's situation above the tolerable limit composed of imbalance in the family caring between sick children and healthy children, imbalance in caring for a sick child between caring and restrictions, failure of family coping, altered family financial status, failure to envision family hope and altered family relationships.^{6,7,11,39}

Family coping skills are defined as family coping patterns in the following three areas: (a) family integration, cooperation, and definition of the situation; (b) maintaining social support, self-esteem, and psychological stability; and (c) understanding the health care situation through communication and consultation.⁴⁰

Consequences

Balance in family caring is a family caring process that is triggered by changes in family situations above the tolerable limit caused by a family member having a chronic illness leading to imbalance in family caring. This challenging event triggers the adaptation of the whole family to meet the increased demands and sophisticated needs of chronically ill children.^{36,41} Fortunately, if the family can meet all of the criteria or attributes of balance in family caring, the family will obtain the consequences of balance in family caring, namely, effective family functioning, improved family well-being, and the child's quality of life.^{15,37}

Family functioning is an important mechanism in driving family tasks in terms of promoting children's adaptation to their illness and allowing them to achieve their developmental tasks as much as possible.⁴¹ Family functioning involves the competency of the whole family to keep their function as a whole, resulting in the family being able to manage the care for chronically ill children, and being capable of assimilating chronic conditions into their daily lives.^{37,41}

Achieving a high level of family functioning will lead to higher family well-being which refers to the degree to which a family is adjusted in terms of concerns about health, tension, cheerfulness, anger, fear, sadness, and general concerns.⁴²

Ultimately, the family will be able to provide the best care for chronically ill children resulting in a better quality of life for the children. This is congruent with a study by Yang et al.,⁴³ which found that there was a significant relationship between family functioning and health-related quality of life in chronically ill children.

Step 8: Definition of Empirical Referents

Since the characteristics of the balance of family caring are subjective viewpoints, and because the circumstances of families with chronically ill children are constantly subject to change, a quantitative instrument alone may not prove sufficient. Therefore, multiple methods including both quantitative and qualitative methods are required to measure balance in family caring such as observation, interviews, self-reports and questionnaires. These can be determined to properly assess balance in family caring.

Conclusion

This concept analysis offers greater insight and understanding about the definition, antecedents, attributes, consequences, and examples of various cases to clarify understanding about the balance of family caring concept analysis in families with chronically ill children. This body of knowledge on this concept can contribute to the construction of measurement and identification of appropriate ways to measure the concept being studied. In this regard, all-important attributes of this concept will be applied to develop an instrument,

for example, questionnaires, self-report assessment, interview method, and observation technique. This is a challenge for the healthcare professional. This study suggests that healthcare providers can address effective care to promote balance in the family caring by manipulating the attributes of balance in family caring. Importantly, a deep understanding of this concept can be used to promote the health literacy of the family living with chronically ill children resulting in quality of family caring that ultimately contributes to a child's quality of life. For instance, nursing care can promote the balance of family caring in terms of potential hope based on the religious

beliefs respected by individual families in addition to promoting the balance of caring styles through family empowerment programs, etc.

Finally, although this study presents current literature on the balance of family caring, further research needs to identify how the family caring trajectory and balance can change over time. Moreover, the perceptions derived from the different areas of nursing should be examined to establish and expand the understanding of balance in family caring.

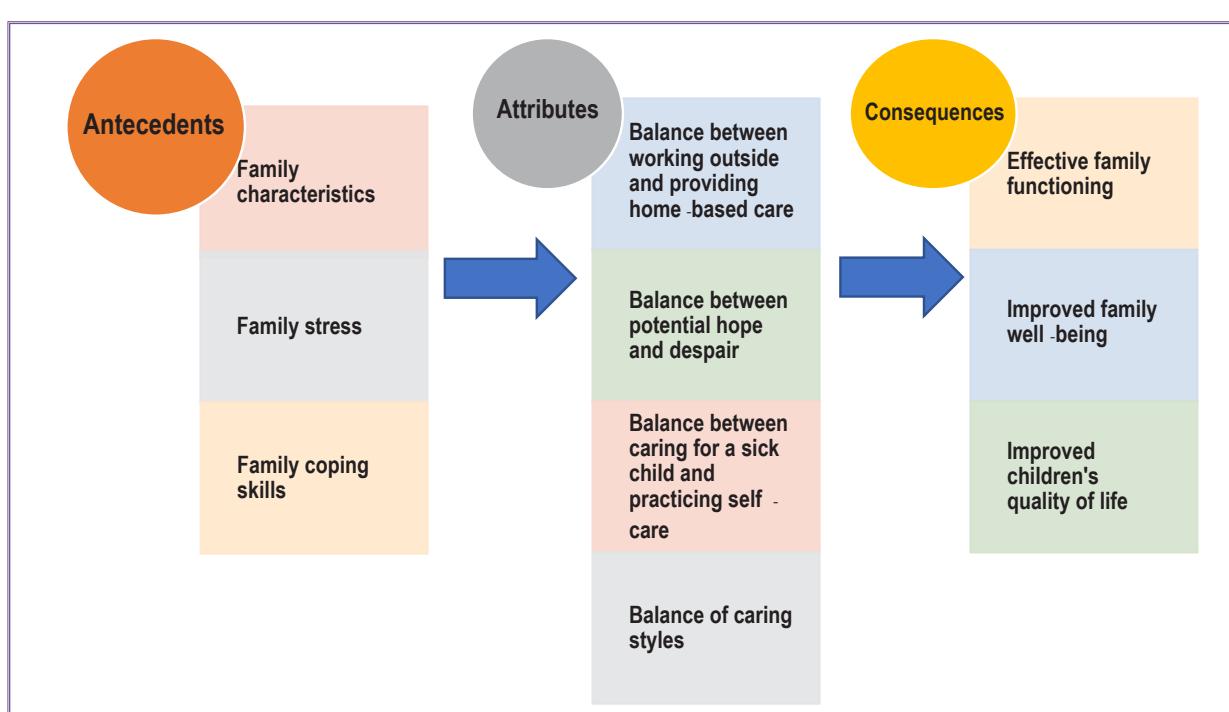


Figure 1: Relationships among antecedents, attributes, and consequences of the concept of balance in family caring.

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