



## Review Article

# Patient-Caregiver Dyad: A Systematic Review Informing a Concept Analysis

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**Citation:** Jacops R, Hopkins CS, Fasolino T (2022) Patient-Caregiver Dyad: A Systematic Review Informing a Concept Analysis. Int J Nurs Health Care Res 5: 1298. DOI: 10.29011/2688-9501.101298

**Received Date:** 09 May, 2022; **Accepted Date:** 16 May, 2022; **Published Date:** 20 May, 2022

### Abstract

The patient-caregiver dyad is becoming more prevalent in literature, but a clear definition of this concept is lacking. This study aimed to clarify the concept within disease-related conditions, either acute with a planned recovery trajectory or chronic with terminal characteristics. Using a systematic review and Rodgers and Knafl's concept analysis process, 28 articles referring to patient-caregiver dyads informed our results. Attributes included the type of caregiver, selecting a caregiver, reaching an agreement, burden of caregiving, and emotions toward the diagnosis. Antecedents were the presence of an acute illness with planned recovery or chronic illness with terminal characteristics and the availability of caregivers. Consequences included patient-caregiver dyads are key to disease management and a directional benefit from the caregiver to the patient. Results of this analysis will assist clinicians and researchers when investigating the synergistic relationship of the patient-caregiver dyad for future theory development and interventional design studies.

**Keywords:** Caregivers; Patient; Dyad; Concept analysis

### Introduction

An estimated 133 million Americans (40%) are affected by a chronic illness requiring some form of informal caregiving [1]. To support those with chronic illnesses, nearly 66 million Americans serve as informal caregivers [2]. These staggering figures also represent a significant financial impact on the United States economy. Nearly 90% of the \$3.8 trillion in annual health care expenses are associated with chronic illnesses [3]. With informal caregivers being the primary source of care, the annual estimated loss of income is \$522 million, and replacing these with unskilled paid care at minimum wage would cost \$221 billion a year [4]. The expanding role of the patient-caregiver dyad in the management of chronic illness calls for a detailed appraisal of this complex concept. Investigating aspects of patient-caregiver dyads and describing their unique characteristics will enhance healthcare providers' understanding of this critical component of care management.

### Defining Patient-Caregiver Dyads

The designation of 'patient' implies some type of illness or health issue requiring services by experts and informal caregivers. In the role of a patient, he/she/they may be viewed as passive and could experience an unequal relationship between healthcare provider and at times, informal caregivers. However, patients are considered an essential part of the healthcare team and empowered to direct their own care. In fact, in the Institute of Medicine's landmark report, *Crossing the Quality Chasm*, patient-centered care focuses on culture, preferences, social support and lifestyle and is one of the six domains of quality care [5].

An 'Informal caregiver' is defined as a relative, possibly spouse or partner, friend or neighbour who supports the broad range of needs of the patient [6]. Typically, the informal caregiver provides physical needs and emotional support for someone who can no longer care for himself or herself due to illness, injury, or disability. Physical needs might include assistance with activities of daily living, such as toileting, feeding, and bathing. The care may often include support with financial aspects as well as legal affairs [7].

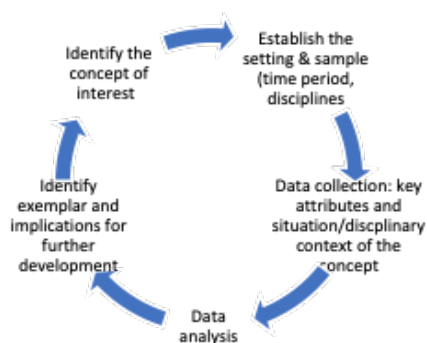
Healthcare teams rely heavily on informal caregivers for management of the needs of patients, particularly those with chronic illnesses. Prior research suggests the role of the patient and informal caregiver are discrete entities with directional influence flowing from the caregiver to the patient [8]. More recently though, emphasis is being placed on the coactive relationship of the patient and their informal caregivers. Thus, the creation of a 'dyad' indicates a synergistic relationship that is dynamic and mutually beneficial [9].

## Purpose

The purpose of this systematic review and concept analysis is to define and clarify the patient-caregiver dyad within disease-related conditions, either from an acute illness with planned recovery or a chronic condition associated with terminal characteristics.

## Method

The Rodgers and Knafl [10] evolutionary view of concept analysis considers a concept as contextual and dynamic with variability based upon circumstances. This approach counters the fixed, essentialist view of concepts as unchanging phenomena. For example, in patients with disease-related conditions of terminal characteristics, the patient-caregiver dyad concept begins at diagnosis and evolves over some time with ever-changing needs. Rodgers and Knafl [10] outline specific steps for clarifying concepts using a model of concept analysis, which includes a fluid and cyclical process that occur simultaneously, rather than a linear approach (Figure 1 Evolutionary concept analysis process). The attributes, antecedents, and consequences included the current concept analysis were determined and agreed upon collectively by the investigators.



**Figure 1:** Evolutionary concept analysis process.

## Search Method

Based upon Rodgers and Knafl [10] process, surrogate terms must be identified before data collection to enable appropriate data sampling. Based on our clinical experience and prior literature review, the following surrogate terms were identified: 'patient-caregiver dyad', 'caregiver dyad', 'patient-partner dyad', 'survivor-caregiver dyad', and 'patient-family caregiver dyad'. These terms were used to search for publications matching inclusion criteria. Nursing, medicine, psychology, and social science databases, including CINAHL, PubMed, MEDLINE, and Ovid, were searched to identify relevant studies published between 2008 and 2020. Based upon the evolutionary view, the setting is reflective of the time period examined and the types of literature included in the analysis. A period of 12 years was selected, based upon the prominence of patient-caregiver dyad research in the literature during this time.

## Screening and Eligibility

The following inclusion criteria were applied: English language; nursing, medicine, and health science disciplines; and patient-caregiver dyads involved with acute or chronic disease-related conditions. The initial search yielded 504 records. Once duplicates were removed, 286 records remained. The titles and abstracts were screened to ensure the articles were relevant to the topic and were representative of original research. We excluded review papers, scale development, and those not specially addressing the patient-caregiver dyad. After the first screening, 69 records remained. Records were then thoroughly screened on methods and outcomes to ensure the research adequately examined and addressed the dyad interaction. During the second screening, six records focused on acute health-related issues. We chose to exclude these records because the nature of the dyad differed from the majority of the records. The remaining records addressed diseases inclusive of cancer, cerebrovascular accident, heart failure, major depressive disorders and anxiety. Another 35 records were excluded because the methods were not intentionally measuring aspects of the patient-caregiver dyad. Thus, the second screening yielded the exclusion of 41 records. 28 records were included in the review, representing a comprehensive view of the antecedents, attributes, consequences, and surrogate/related terms. A PRISMA flow diagram depicting the record selection process is presented in Figure 2 [11] (Table 1).

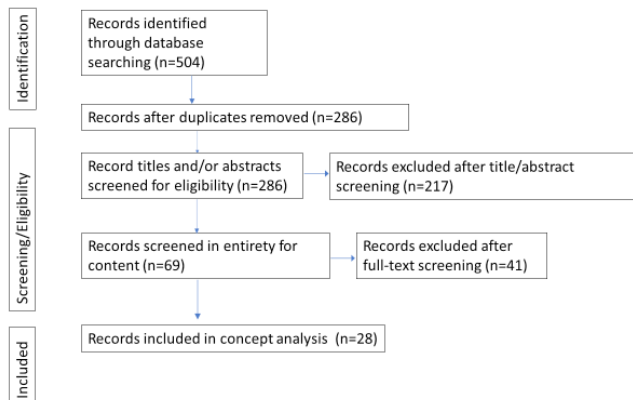
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First Author (Year)	Topic	Disease/Illness	Study design	Population	N	Country
Bergstrom (2011)	Life satisfaction and effects of the dyad on cognitive function	Stroke	Cross-sectional	Patient/caregiver dyad	81	Sweden
Bidwell (2015)	Patient/caregiver heart failure maintenance and quality of life	Heart failure	Secondary analysis	Patient/caregiver dyad	364	Italy
Boyer (2017)	Impact of emotional intelligence on quality of life	Depression	Cross-sectional	Patient/caregiver dyad	79	France
Buck (2018)	Effects of decision making on heart failure self-care	Heart failure	Cross-sectional	Patient/caregiver dyad	27	USA
Bucki (2019)	Mutual trust and harmony effects on quality of life	Stroke	Secondary analysis	Patient/caregiver dyad	56	France
Dellafore (2019)	Effect of mutuality among the dyad on depression and anxiety	Heart failure	Interdependence Model Analysis	Patient/caregiver dyad	366	Italy
El Masry (2013)	Dyads go through changes in quality of life together due to their constant change of tension and closeness	Australia	Interviews	Patient/caregiver dyad	20 caregivers, 10 stroke patients	Australia
Goldsmith (2016)	Patterns and characteristics of family caregiver communication	Cancer	Interviews	Patient/caregiver dyad	24	USA
Hamidou (2017)	Effect of coping, time perspective, and personality on quality of life	Cancer	Cross-sectional	Patient/caregiver dyad	156	France
Hendriksen (2015)	Shared anxiety	Lung cancer	Interviews	Patient/caregiver dyad	21	USA
Hooker (2018)	Quality of patient/caregiver relationship (mutuality), caregiver burden and patient self-care	Heart failure	Cross sectional	Patient/caregiver dyad	99	USA
Kemp (2017)	Relationship between supportive care needs and perceived burden	Breast cancer	Cross sectional survey	Group of survivors and group of caregivers	99	Australia
Kim (2020)	Patient attitudes and knowledge about advanced directives and completion of AD	Hematologic malignancy	Cross sectional survey	Patient/caregiver dyad	44	South Korea
Kitko (2015)	Incongruence between patient and caregiver and health care management and EOL decision making	Heart failure	Interviews	Patient/caregiver dyad	100	USA

Kroemeke (2019)	Effect of provided and received support on caregivers and patients receiving hematopoietic stem cell transplantation	Cancer	Diary assessments	Patient/caregiver dyad	200	Poland
Li (2018)	Depression, anxiety, and quality of life	Cancer	Secondary analysis of cross sectional survey	Patient/caregiver dyad	641	China
Lin (2020)	Mutual impact and moderating factors of quality of life between patients and caregivers	Cancer	Secondary analysis of cross sectional survey	Patient/caregiver dyad	641	China
Molassiotis (2010)	Symptom burdens with patients	Cancer	Longitudinal study	Patient/caregiver dyad	238	United Kingdom
Nie (2016)	Quality of life, perceived stress, and poor-prognosis disclosure preferences of dyads	Cancer	Cross-sectional survey	Patient/caregiver dyad	549	China
Nightingale (2014)	Effects of early-stage disease progression on quality of life	Head and neck cancer	Prospective pilot study	Patient/caregiver dyad	10	USA
Pasek (2017)	Acceptance and response of illness depending on coherence and social support	Cancer	Cross-sectional study	Patient/caregiver dyad	80	Poland
Powe (2013)	Effect of caregiver strain on quality of life within the dyad	Cancer	Correlational study	Patient/caregiver dyad	68	USA
Retrum (2013)	Congruence and incongruence effects on emotional wellbeing	Heart failure	Secondary analysis/ interviews	Patient/caregiver dyad	17	USA
Secinti (2019)	Examination of loneliness on positive and negative relationship qualities	Gastrointestinal cancer	Structural equation modeling	Patient/caregiver dyad	56	Germany
Shin (2013)	Understanding the effect of family members on cancer treatment decisions	Cancer	Cross-sectional	Patient/caregiver dyad	24	United Kingdom
Vellone (2018)	Effects of dyad mutuality on patient self-care and caregivers assist in self-care	Heart failure	Cross-sectional	Patient/caregiver dyad	266	USA
Woolridge (2019)	Examining communal coping among dyads managing HF	Heart failure	Secondary analysis		34	USA
Zhang (2020)	Difference of opinions among dyads in regard to treatment and care decisions of lung cancer	Lung cancer	Cross-sectional		184	USA

**Table 1:** Summary of Articles.

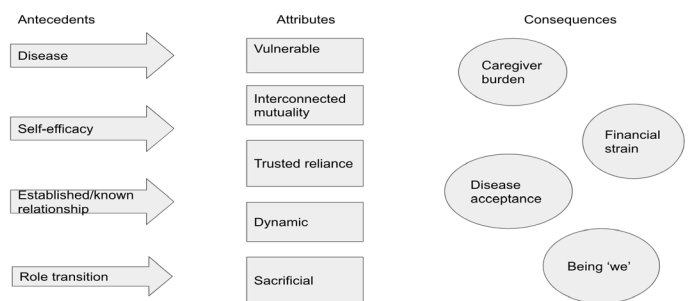
Finally, the findings were further interpreted and combined into a model representing the concept of patient-caregiver dyads, which included five attributes (interconnected mutuality; trusted reliance; sacrificial; vulnerable; and dynamic), antecedents (disease; self-efficacy; established/known relationship; and role transition), and consequences (caregiver burden; financial strain; disease acceptance; isolation; and loss of independence).



**Figure 2:** Record selection process.

## Results

Attributes of patient-caregiver dyad were extracted from the selected articles by identifying descriptions of the dyad from each publication. Attributes are the unique characteristics of a concept that differentiate it from others. After discussion of the attributes identified in the analysis, the antecedents and consequences are presented. Antecedents are events that must occur or be in place before the existence of the concept, while consequences are events that occur as a result of the concept. A patient-caregiver dyad was conceptually defined as a synergistic relationship between an individual requiring physical, emotional, psychological, and financial assistance with a self-selected individual that could be biologically, legally, or no relationship but willing to assume the role of a caregiver in health disease states, with a common goal of assisting in disease states. The relationships between the attributes, antecedents and consequences are depicted in Figure 3.



**Figure 3:** Relationship between attributes, antecedents, and consequences.

### Attributes

**Interconnected mutuality.** The strongest attribute identified in this analysis was the interconnected mutuality of the patient-caregiver dyad. The dyad is formed to manage the needs associated with activities of daily living, address symptoms, design management strategies, and pursue shared goals of care typical of disease states [12,13]. Patients and caregivers may or may not live together, but the dyad consists of two individuals with varying levels of life satisfaction [14]. The dyad experience daily life together and follow a trajectory together throughout the course of the disease [15]. This interconnection leads to collective emotions and coping resulting in self-confidence and self-efficacy, independently and mutually [15]. They transition into a ‘we-disease’ state, relying on each other for socialization and support, sharing in celebrations as well as frustrations related to the disease [16-18]. They weave so tightly together that they complete each other’s sentences, or thoughts [19].

### Trusted reliance

The dyad develops from within the patient’s closest network of individuals, and are often partners or family members [20]. A relationship typically exists prior to the diagnosis of a disease and continues through the course, whether be curative or chronic in nature. They have established reciprocal trust with reliance (confidence), which is often seen as a prerequisite to trust [21]. The amount of reliance plays a central role in the overall functioning of the dyad. For example, cancer patients depend upon caregivers



to help manage their needs, which places a strain on the caregiver [19]. Caregivers provide primary and informal support for the patient emotionally, and in other practical ways [7,18,22].

### **Sacrificial**

Caregivers often place the patient's needs ahead of their own, continuously giving of their time and energy to care for the patient [7]. They often place the patient's needs ahead of their own, even to their own personal health demise. Ultimately, the caregiver and patient experience burden and make sacrifices [17]. Caregiver burden and sacrifice, often found within health system encounters, management of complex medical regimens, and assisting the patient with activities of daily living, can take up to ten hours daily of the caregivers' time [16]. Cultural influences may impact the degree of self-sacrifice that is expected of the caregiver [7].

### **Vulnerable**

Patients with a disease or debilitating illness experience physical and emotional well-being decline, leading to vulnerability and reduced quality of life [23]. Increased levels of stress, decreased social support, and decreased spirituality contributes to poor quality of life [24]. The patient yields to interdependence and increasing reliance on their caregiver [25]. In situations where the dyad has incongruence, the vulnerable patient may experience fear and loss of control [20,26,27]. Conversely, the caregiver experiences vulnerability due to uncertainty when maintaining complex needs, identifying coping strategies, and navigating the various paths of disease trajectory [28,24].

### **Dynamic**

Patient-caregiver dyads undergo constant change and adaptation throughout the disease process [24]. These adjustments take place at the individual level as well as simultaneously, which further contributes to interconnected mutuality of the relationship. As time lapses, the quality of life of individuals within the dyad are impacted. For example, how the individual processes and interprets memories, life events, and views of future, contribute to the dyadic relationship [15]. Social interactions within the dyad change over time during the disease progression, both negatively and positively [27].

### **Antecedents**

Rodgers and Knafl [10] defined antecedents as precursory causes associated with the concept being explored. In this analysis, we explored the major antecedents to patient-caregiver dyad in the presence of an acute illness associated with a planned recovery trajectory or chronic illness with terminal characteristics.

### **Disease**

Each article outlined the occurrence of illnesses that would require the intimate involvement of a caregiver to either

regain stability of health and well-being or require emotional and physical support with a debilitating chronic illness or life-limiting diagnosis. For example, Lazzarotte et al. [29] posited that patient-caregiver dyads are particularly helpful in age-related hearing loss due to the alterations in communication, impaired physical and social functioning. Most of the articles focused on a type of cancer illnesses and the importance of strong caregiving relationships to successfully navigate the management and treatment [7,8,19,20,23]. Kim et al. explored end-of-life care decision-making amongst cancer patient-caregiver dyads using a Korean advance directive.

### **Self-efficacy**

Each publication indirectly assumed a caregiver was readily available and able to assume the role of caregiver and participate in the dyad relationship. After being presented with the patient's diagnosis and need for assistance, the caregiver would have been faced with a dichotomous decision to accept or refuse the role. There would have been little time for an individual to reflect on the roles and responsibilities subsumed under the title 'caregiver'. In the event of a chronic illness as described by Li et al. [7], explaining the impact on the physical, emotional, and psychological aspects of caregiving was explored.

### **Established/known relationship**

Many dyads had a pre-existing relationship prior to the disease diagnosis with intimate knowledge of the patient's wishes and views on medical decisions. Typically, the selected caregiver was the person most involved in the patient's life [23]. Caregivers included, but not limited to, spouses, biological and non-biological children, siblings, friends, and even neighbours. Other patients did not have a caregiver that was readily available to provide the necessary care. Interestingly, spouses and children did not always have the same views on decision-making prior to caring for the patient.

### **Role transition**

Throughout the treatment of the illness, relationships evolved, both positively and negatively for several reasons, including the stress of decision-making. The acceptance of illness and sense of coherence within the dyad altered the relationship between the caregiver and patient [30]. Before the formation of the dyad, patients did not require a caregiver. The designated caregivers did not provide formal care prior to the dyad either. The transition to becoming a full-time caregiver and patient can put a strain on one's well-being. Many caregivers were forced to give up their job and extracurricular activities to provide full-time care for the patient. On the other hand, patients lost independence and relied on the caregiver to help manage the disease. The change in social life and support from family members led to greater distress for dyad members [25]. Overall, the transition from an ordinary

life to a strict dyad is life-changing and bound to alter disease management outcome.

### Consequences

In this concept analysis, consequences are defined as situations following the occurrence of the concept of interest [10]. The result of the analysis showed patient-caregiver dyads are key to disease management, either a positive or negative impact. In most studies, the caregiver's role was to be supportive and provide some type of assistance with physical needs.

*Being 'we'.* Within the dyad, various factors contribute to the nature and health of the relationship. Wooldridge et al. [13] recognized transition from individuals to 'we' in forming the dyad and noted the enhanced relational satisfaction when the dyad was collaborative and like-minded when appraising the disease. While caregivers and patients did not always agree on treatment and management of the disease, the dyad still consisted of 'we' in terms of decision-making and collaboration.

### Caregiver burden

The burden of caregiving has been substantiated with emerging evidence countering this position. The patient-caregiver dyad results in a developing relationship. Very few studies investigated the impact of the caregiver role on the well-being of the caregiver. Li et al. [7] did examine the quality of life for both roles, considering the emotional well-being individually and collectively for the dyad. Additionally, [16] considered mutual anxiety in the patient-family dyads. The majority of the studies considered the dyad as a directional one-way benefit to the patient. This assertion is well documented throughout literature and discussed by providers in a practice setting.

Financial strain. The time commitment associated with caregiving forced many caregivers to give up their job to care for the patient. According to an interdependence analysis on depression, over 32% of patients and over 19% of caregivers reported financial difficulties as a result of the dyad [15]. The drastic and sudden change in lifestyle did not give patients and caregivers time to deal with important financial decisions. Regardless of the onset and progression of the disease, the dyad faced finances they did not expect to be responsible for prior to the dyad. Almost all patients and caregivers identified finances as a focus of their anxiety [16].

### Disease acceptance

Disease acceptance is an important consequence that resulted from the dyad. Prior to the dyad, many patients and caregivers did not expect the diagnosis and change in lifestyle. As the dyad progressed, the relationship between the patient and caregiver changed in terms of openness, topics discussed and details shared [31]. The process of disease acceptance is inevitably difficult, and the route that patients and caregivers take in this process contributes

to the outcome of the disease treatment and management.

### Surrogate terms/related concepts

Surrogate terms were defined as an expression that was used interchangeably with the patient-caregiver dyad literature. Rodgers and Knafl [10] support searching for related concepts which bear some resemblance to the concept of interest but not sharing the same attributes, to clarify concepts further [32-35]. "Patient-family caregiver" was a term identified in two of the international studies with minimal explanation for what qualifies an individual as 'family' [7]. The use of 'family' within the dyad may be linked to the cultural aspects of these particular countries [36]. Furthermore, 'patient-partner dyad' was used by Sherman et al. [8] defining the partner as an individual having "skills required by a given task" (p. E185).

### Exemplar

Rodgers and Knafl (2000) [10] proposed that general exemplars should be identified as universal illustrations of concepts in the literature or clinical practice, only if appropriate and not constructed to prevent bias and ensure neutrality. In this analysis, patient-caregiver dyads in the presence of disease illness (either acute or chronic) were used as a generic term and applied to a wide range of contexts [38-40]. Therefore, identifying an exemplar would be of minimal benefit to researchers. Moreover, examples matching the patient-caregiver dyad attributes are currently absent from the literature; therefore, ascertaining an exemplar was omitted from the analytical process.

### Discussion

Overall, the dynamic of the patient-caregiver relationship greatly affects patient care. After analyzing 28 studies, we attempted to further understand the meaning of a patient-caregiver dyad and how the relationship affects the overall treatment of chronic illnesses [41-43]. Caregivers provide emotional, physical, and financial support for the patient. For the relationship to persevere, the patient and caregiver must reach mutual agreements and respect the other's opinion. Many factors can affect the relationship of the dyad, including the type of caregiver, how the caregiver is selected, the emotions towards the illness, and the financial situation of both the patient and caregiver. The combination of these factors shapes the overall patient-caregiver dyad and dictates how the patient will respond to the treatment of the disease. Support and flexibility from both the patient and the caregiver yield more effective care.

We systematically reviewed the literature and used the findings to inform a concept analysis of the patient-caregiver dyad [44]. By describing the attributes, antecedents, and consequences of the patient-caregiver dyad we found the multifaceted relationship to be central to the trajectory of disease management. Additionally, the health and functionality of the patient-caregiver

dyad as a collective unit impacts the health-related outcomes of the individuals involved.

The dyad encompasses the ever-evolving roles of both patient and caregiver within the context of chronic illness over time and how those roles intersect at any given point on the continuum. Further research is needed to explore and define the patient-caregiver dyad in varying contexts within the field of nursing and healthcare. Nursing professionals would benefit from research elucidating how dyads are formed and dissolved, how to measure the effectiveness of a dyad with regard to health outcomes, and what internal and external factors are most significant to the effectiveness of the patient-caregiver dyad. Within the scope of chronic disease management, the patient-caregiver dyad will always exist and will affect how care is delivered and received [45]. The importance of the dyad will continue to increase as our population ages and as rates of chronic disease grow. Our analysis of the patient-caregiver dyad as a concept provides a foundation on which to build the science surrounding this important synergistic relationship.

Using the Rodgers and Knafl [10] evolutionary view of concept analysis, we conducted a concept analysis and literature review on patient-caregiver dyads in disease-related conditions. The patient-caregiver dyad is a complex relationship that contributes to the outcome of disease treatment and management. After understanding the factors that contributed to the outcome before the dyad was established, the attributes, or unique characteristics that contributed to the functioning of the dyad, became clearer. Following the attributes, we were able to better understand the consequences, or outcomes, of the dyad to better understand the effect of patient-caregiver dyads on disease management and decision-making. Overall, the results concluded from this analysis and review will assist clinicians and researchers in future theory development related to patient-caregiver dyads.

Consideration of patient-caregiver dyads in states requires a clear reflection of the benefits and drawbacks of each role, particularly in chronic illnesses where the roles have extended periods. The two portions of the whole can create a turbulent or supportive dyad. Nursing professionals could make a lasting contribution by focusing on the synergistic relationship and investigating the various aspects of the patient-caregiver dyad. Nursing research studies examining the process of selecting a caregiver would benefit the overall well-being of both portions of the dyad to create harmony amongst the challenges associated with disease management.

Researchers are bound by ethics to follow good scientific guidelines and procedures. These ethical mandates have been applied to this process to ensure quality and compliance with the standards. This review was completed according to responsible ethical conduct with transparency and rigor of the research process.

The data obtained from the original papers have been represented accurately and truthfully by the authors through a thorough inspection. Care was taken to ensure information was not distorted in any way and the original data were reviewed critically. Since this was a review student based upon literature, formal ethical approval was not sought. All authors who participated in this study gave their informed consent. There are no existing conflicts of interest related to this article.

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