

**Title:**

Caregiving Burden of the Dyad in Cancer Situations

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**References:**

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**Abstract Summary:**

This research is a development to nursing research in Colombia to validate the functional nursing model with dyads in cancer situation. It is based in nursing paradigm that "Nurses caring to human health experiences."

**Learning Activity:**

LEARNING OBJECTIVES	EXPANDED CONTENT OUTLINE
To analyze the relations of caregiving burden in cancer situations.	Caregiving burden indicators in the bond of a person with cancer-family caregiver dyad.
Research approaches for dyad populations.	Standard dyadic research designs besides canonical correlations in cancer situations.
The concept of caregiving burden in nursing research.	To understand the concept of caregiving burden as a nursing phenomenon.

**Abstract Text:**

According to the World Health Organization (WHO, 2015), cancer is maintained worldwide as the second cause of mortality and morbidity among non-communicable chronic diseases (NCCDs). In Colombia, according to the *Informe del Instituto Nacional de Cancerología* (Pardo *et al.*, 2015), 29,734 new cases of cancer in men and 33,084 in women were reported per year between 2007 and 2011.

This experiences involves an additional demand for care for diseased person, which is transformed during medical treatment and accompanied by a number of psychosocial, economic, and physical changes, understood as *caregiving burden*, emerging concept of nursing.

Researchers from the Universidad Nacional de Colombia, within the framework *Modelo para la disminución de la carga de la Enfermedad Crónica No Transmisible*. This construct asserts that caregiving burden "is the additional effort that involves satisfying the needs of persons with chronic disease, of their family and professional caregivers, of institutions and SGSSS [*Sistema General de Seguridad Social en Salud*], and of society in general" (Sánchez *et al.*2015). Furthermore, it proposes that dyad is a subject of caregiving, visible on the chronicity, which requires to be addressed both individually and as partners. Dyad brings a process with stages of bonding, and has peculiarities on execution of caregiving and manifestation of burden: 1) Limitation and need for support —greater burden in the patient; 2) Step from challenge (or commitment) to achievement —greater burden in the caregiver; and 3) Way to transcend into a "special bond" —dyad burden (Chaparro, 2011).

The main objective of this study was to analyze the relations of caregiving burden of the dyad in cancer situations.

**Design:** Quantitative exploratory correlational study, with a standard dyadic design of reciprocal type (Wittenborn *et al.*, 2013). Due to there are not background of correlational studies with the instruments chosen for this study, an initial sample of 45 dyads was carried out, which enabled to determine the final sample of 76 dyads. Finally, 80 dyads were obtained, which fulfilled the following criteria: over 18 years of age, with a close and family relationship, and to know how to read and write; for persons with a confirmed diagnosis of cancer, the criterion was to have no a vital necessity.

**Instruments:** For characterization, the Characterization Record Card of Caregiver-Person with Chronic Disease Dyad (Chaparro *et al.*, 2014) was used; it has 42 items and three groupings: socio-demographic

characteristics, burden and support perception, and information and communication means. The instrument has facial and content validity. To determine the caregiver's caregiving burden, the Zarit scale for assessing caregiver burden (Zarit *et al.*, 1980; Breinbauer *et al.*, 2009) was used; it has 22 Likert-type questions and three dimensions: *Caregiving Impact*, *Interpersonal Burden*, and *Self-efficacy Expectations*. It has reliability and validity tests for Colombian population (Barreto *et al.*, 2015). To determine the caregiving burden in person with cancer, the instrument Chronic Disease Burden for Patient (Sánchez *et al.*, 2016) was used; it has 50 items distributed in three dimensions: *Psychological and Spiritual Suffering*, *Discomfort and Physical Discomfort*, and *Socio-cultural and Family Alteration*, in which frequency of the event is measured with a Likert-type scale.

The study was endorsed by the *Comité de Ética de la Facultad de Enfermería de la Universidad Nacional de Colombia* and by the institution in Bogotá D.C., where the data were collected. A professional nurse was trained to support the data collection process. The data were collected prior informed consent to sample randomly selected.

An analysis using descriptive statistics and measures of central tendency was carried out, in order to know the participants' profiles. Spearman correlation tests and canonical correlation were used in order to determine the burden relations between members of the dyad. Nonparametric tests (Kruskal-Wallis) were carried out to determine significant dyad burden indicators related to well-being (global quality of life) reported in the characterization (support and burden perception).

**Results: Dyad profile.** Family caregivers: the majority are women—which continues to represent the caring of people in chronicity situations—, with tendency towards better education level, average age of 43,7, prevalence of productive age, medium-low socioeconomic status, originating from interior of the country, residing in urban areas of Bogotá, housewives, with a steady partner and medium-high level of Catholic commitment. Persons with cancer: the majority are women, aged between 18 and over 71 years, predominance of age 51-79 years, low educational level, medium-low socioeconomic status, residing in urban areas, housewives or employees, with a steady partner and medium-high level of Catholic commitment. Dyads relied on a high level of family religious support, but a low level of psychological and economic support. Communication means most used by person with cancer were television and telephone. Caregivers relied on a high-medium level of knowledge and frequency of computer and Internet usage.

Caregivers reported they had no burden. Nevertheless, they reported feelings of fear for the future of the person with cancer and a considerable concern about economic resources. On the other hand, a low score for feelings of anger or shame for the other was obtained.

In persons with cancer, feelings of anguish, despondency, concern, and sadness prevailed. Moreover, they felt nervousness about being economically dependent and having work-related alterations, although they had a positive perception of the family well-being. In physic dimension, symptoms they mostly reported were gastrointestinal disorders, neuropathic effects, and sleep patterns disturbances.

*Correlations between dyad members.* Between total for the person with cancer burden and total for the caregiver burden, a 0.367 was determined, with a  $p$  value = 0.001, which means that there is a relation between both types of burden, significantly different from 0, but with a modest value. Correlation between dimensions of caregiving burden both for the patient and for the family caregiver was not greater than 0,4, which means a weak correlation. In accordance with this result, the feasibility of a correlation with greater value by means of a canonical correlation was explored. For this purpose, the totals for dimensions of caregiver as variables of first group, and the totals for dimensions of person with cancer as variables of second group were considered. The greater canonical correlation coefficient was determined in 0.469, which means that it would be the greater possible value of correlation between variables that synthesize burdens of dyad.

**Additional results:** Taking into account that results showed that some individual characteristics influence the burden of other positively or negatively, an additional test was carried out, in order to delineate those relevant features for dyad burden according to Kruskal-Wallis tests and, thus, to compare the behavior between well-being levels (global quality of life) of person with cancer and caregiver. For person with cancer, an association between the self-efficacy expectation of family caregiver dimension and physical, psycho-emotional, and social well-being of person with cancer was found. Nonetheless, an association between caring impact, interpersonal burden, and general burden and well-being dimensions was not found. In the case of caregiver, only an association between interpersonal burden and physical well-being was found.

**Conclusions:** In respect of disease burden of person with cancer dimensions, it was verified that physical and psycho-emotional well-being are the greater source of burden caregiver in the dyad; the social well-being of person with cancer affects the dyad burden, specifically, due to the influence of cultural factors of the disease. Additionally, for family caregiver, the burden indicators arise from the association between interpersonal burden and physical well-being of caregiver, which means that there is a possibility of increasing desire to devolve the caregiver because of physical well-being of caregiver may be affected, which, at the same time, produces decision-making difficulties. Associations between burden dimensions of person with cancer and burden dimensions of caregiver were not found, which verify the low relations between dimensions.

Dyads are in an individualized coping mediated by a short-time bond, present in early stages of the chronic disease. Nevertheless, this situation shows details that need new researches in order to provide an in-depth analysis of the phenomenon.

In respect of implications for the nursing teaching, it must be considered that dyad is a subject of care, in which care needs were recognized to carry out a nursing intervention in a comprehensive manner, according to stage of disease experience —beginning separately with greater levels of transcendence as a single subject. In respect of implications for the nursing research, other burden indicators with greater cultural sensitivity on family caregiver must be examined, since our study still reports low levels of burden. In respect of implications for the nursing field, it must be focused on the identification of risk factors, which can increase the dyad burden. Moreover, a conceptual framework of caregiving burden in the dyad allowing guiding future nursing research must be drawn up. In respect of clinical care, specific scales for dyads must be considered, in order to integrate the family since cancer diagnosis. In respect of implications for the politics, family caregiver must be recognized as an active subject of care, not merely as an attendant, or as an instrumental tasks performer; likewise, the economic and social contribution to health policies must be regarded.