



## REVISIONES

### Informal care in times of crisis. Analysis from the nursing perspective

El cuidado informal en tiempos de crisis. Análisis desde la perspectiva enfermera

Manoli Cantillo<sup>1</sup>

Teresa Lleopart<sup>2</sup>

Sandra Ezquerra<sup>3</sup>

<sup>1</sup> Diploma in Nursing, Master in Active and Healthy Aging, Master in Care and Palliative Care. University of Vic-Universitat Central de Catalunya. Spain.

<sup>2</sup> Diploma in Nursing, Degree in Social and Cultural Anthropology, Research Sufficiency in Social Sciences and Health. University of Vic-Universitat Central de Catalunya. Spain.

<sup>3</sup> Graduate in Contemporary History and Social and Cultural Anthropology, Master and PhD in Sociology, University of Vic-Universitat Central de Catalunya. Spain.

E-mail: [manoli.cantillo@uvic.cat](mailto:manoli.cantillo@uvic.cat)

<http://dx.doi.org/10.6018/eglobal.17.2.297211>

Received: 15/06/2017

Accepted: 21/09/2017

#### ABSTRACT:

**Goals:** To quantify and characterize the scientific production in nursing on informal care from 2007 to 2016, to observe the evolution of the theme during this period, to acquire a current perspective on the state of the arts, and to suggest future directions of both research and professional practice.

**Methods:** Bibliographical review undertaken through two strategies: a quantitative strategy and a qualitative one.

**Results:** The most frequent type of published article is quantitative although there is an increase of qualitative publications. Among the most frequent themes are: the study of the caregiver's profile, as well as the impacts of care on their health and on their everyday life; practical professional recommendations to promote care and self-care and to prevent caregivers' overload; and, finally, the use of assessment tools for planning attention of caregivers.

**Conclusions:** While nursing publications rightly identify the centrality of the family and the household in the new care scenario, they do not problematize the current transfer of responsibility for care from public administrations toward the realm of the family. Neither do they problematize the social, economic, and gender inequalities that take place in the context of care. To approach these two themes can contribute to create new research and professional lines in nursing.

**Keywords:** Informal care; Chronicity; Economic crisis; Caregiving crisis.

#### RESUMEN:

**Objetivos:** Cuantificar y caracterizar la producción científica enfermera sobre cuidados informales del período 2007-2016, observar la evolución de la temática durante estos años, adquirir una perspectiva

actual sobre el estado de la cuestión y realizar propuestas sobre futuras líneas de investigación e intervención.

**Metodología:** Revisión bibliográfica llevada a cabo mediante dos estrategias: una cuantitativa, y una segunda estrategia cualitativa.

**Resultados:** El tipo de artículo más publicado es el estudio original cuantitativo, aunque se detecta un crecimiento de las publicaciones con enfoque cualitativo. Los temas más tratados son el perfil de la persona cuidadora, los impactos de la atención en su salud y en otros aspectos de su vida cotidiana, las propuestas de intervenciones profesionales para promover el cuidado personal y para evitar la sobrecarga de las personas cuidadoras y, por último, el uso de herramientas de evaluación para la planificación de la atención a las mismas.

**Conclusiones:** Las publicaciones enfermeras identifican con acierto la centralidad del cuidado informal y el giro asistencial hacia el domicilio y la familia. No problematizan, sin embargo, el actual trasvase de responsabilidades hacia el cuidado desde las administraciones públicas hacia el ámbito familiar, ni analizan en profundidad las desigualdades socioeconómicas y de género reinantes en el actual escenario de cuidados. El abordaje a estos dos elementos puede contribuir a abrir nuevas líneas de investigación e intervención en el campo de la enfermería.

**Palabras clave:** Cuidado informal; cronicidad; crisis económica; crisis de los cuidados.

## INTRODUCTION

In past several years, there has been an increasing presence of analysis about informal long-term care in different knowledge areas, both in the field of the health sciences and the social sciences. However, a systematic approach to the presence and importance of this issue has not been undertaken in the area of nursing yet.

Informal care is defined as the home-based care provision given to people in dependency situation of the family, based on affective relationships with a role assigned to women<sup>(1)</sup>. It is often carried out in the framework of the household, almost 90 % of the total care time received by the older is conducted by family members<sup>(2)</sup>, and it is women who do most of it<sup>(3-5)</sup>.

Care-giving involves a significant amount of energy and time commitment by the caregiver. 95.9 % of the care-givers of people aged 65 or over state providing care from 6 to 7 days a week and 38.9 % dedicates to this task at least 16 hours a day<sup>(4)</sup>. All this has a negative impact on the caregivers' health and their family, professional and social relationships, as well as on their quality of life.

The socio-demographic and cultural changes of the past decades, the variation of women's role through the increase of their presence in the labor market and the changes in family models, have posed new demands and challenges to the Welfare state<sup>(7)</sup>. In 2006, with the law to promote personal autonomy and care for dependent people (LAPAD) in Spain, the government adopted a regulation that unified the basic framework of the individual and subjective rights of the people in a functional dependency situation through the creation of a portfolio of services and benefits<sup>(8)</sup>.

Due to the economic crisis started in 2008 all the state budget lines were affected by cutbacks and all the progress achieved in this sense was lost. Ten years after its birth, the failure of the law is obvious and poses again the question of what answers and solutions need to be given to informal care and the care for dependent adults. As a result of both cutbacks in the welfare system and the increasing situations of chronicity, the welfare system in the coming years will have as a challenge the attention to people with dependency but in a different manner to the existing one up to now.

A new organizational model is proposed; a model that aims at being accessible and able to provide appropriate answers to the emerging needs<sup>(9)</sup>. The design of this new model is built upon the dual premise that the place of residence is the best place where the chronic patient can maintain control over their care<sup>(10)</sup> and community health must be integrated into the care system since it is the basic level of attention that guarantees the totality and the continuity of care<sup>(11,12)</sup>. In this scenario, the nurse has an integral vision that contextualizes the need and the capacity of self-care<sup>(10,13,14)</sup>.

The new scenario will require both a stance and knowledge on the part of nurses in order to transform the challenges into opportunities for impulse, progress and strengthening of community nursing, increasing the competences so that they are focused on the patient, the family and the community's care needs, and encouraging deeper alliances with other care agents<sup>(9)</sup>. The nurse must reflect on the new context as well as on her role in it.

The aim of this systematic review is to identify the features of the scientific production in the field of nursing about informal care from 2007 to 2016 from the point of view of nurses, linking analyses and reflections, highlighting current trends and, with the purpose of suggesting future research lines, identifying possible absences in the studies.

## METHODOLOGY

We have conducted a systematic review of scientific publications about informal care and informal caregivers in Spain.

The search was set during the period from 2007 to 2016 and it was carried out pursuing the following questions: what are the characteristics and the main themes of the publications in nursing scientific journals about informal care in the period from 2007 to 2016? Do these publications reflect the recent changes in the approach to chronicity and informal care? What aspects related to informal care of chronicity receives attention and which ones do not? What are the issues to which the nursing literature pays scant attention and that, therefore, can be fertile and innovative lines of research in the future?

For the bibliographic search, we have used the following keywords: "informal care Spain", "informal caregivers Spain", "family care Spain", "care home Spain", "family caregivers Spain", "care crisis Spain", and "economic crisis Spain" in the main national and international databases: Pubmed, Scopus, Dialnet, Cinahl and Scielo. We have used, in turn, the same terms in Spanish: "cuidados informales", "cuidadores informales", "cuidados familiares", "cuidados en el hogar", "cuidadores familiares", "crisis de los cuidados" and "crisis económica".

We have included all the articles (originals, reviews, briefs and reflections) published in Spanish or in English in nursing journals about informal care and informal caregivers of the elderly in a functional dependency situation in a home environment in Spain.

The articles that were excluded were the ones about informal cares in specific pathologies (dementia, CVA...) or acute situations, the articles about informal care in a hospital or institutionalized context, and the articles about pediatric care.

The selection strategy consisted of the elaboration of a list of all the articles found from the search by keywords. Subsequently, we proceeded to suppress the duplicated articles. Finally, we conducted a review of the titles and located the summaries of the selected articles, discarding those that did not meet the inclusion criteria.

## RESULTS

We obtained 660 articles out of the search. After a first reading of their title and summary, 601 were discarded for not being related to aim of the research. At the end, there were 59 articles which both met the inclusion criteria and were fully accessible. The list of the analyzed articles is presented in Table I.

**Table I:** List of articles analyzed.

Author/s and year	Article	Journal	Methodology	Objectives
Casado-Mejía, R., & Ruiz-Arias, E. (2016)	Factors influencing family care by immigrant women in Spain: a qualitative study	Nursing Research and Education	Qualitative study	Identify and understand the factors that influence relationships in the informal care context provided by immigrant women
Peña-Ibáñez, F., Álvarez-Ramírez, M. A., & Melero-Martín, J. (2016)	"La carga del cuidador en el cuidado informal de los pacientes immobilizados en una zona básica de salud urbana"	Enfermería Global	Quantitative study	Describe the degree of overload and deterioration of the informal caregiver's mental health
Cano, B. G., García, I. A., & Bernal, E. R. M. (2015)	"El sistema informal de cuidados desde la perspectiva de género: Revisión bibliográfica"	Hygia de enfermería: revista científica del colegio	Review article (Qualitative)	Know the socio-demographic changes in Spain which result in new demands on health. Know the informal care system and the inequality from the gender point of view before the new demands on health. Know the profile of people who provide informal care
Martínez-Marcos, M., & la Cuesta-Benjumea, D. (2015)	Women's self-management of chronic illnesses in the context of caregiving: A grounded theory study	Journal of Clinical Nursing	Qualitative study	Discover how informal female caregivers self-manage their own chronic illness
Ferré-Grau, C., Sevilla-Casado, M., Lleixà-Fortuño, M., Aparicio-Casals, M. R., Cid-Buera, D., Rodero-Sánchez, V., & Vives-Relats, C. (2014)	Effectiveness of problems solving technique in caring for family caregivers: a clinical trial study in an urban area of Catalonia (Spain)	Journal of Clinical Nursing	Composite survey	Asses the effectiveness of the problem-solving technique in the reduction of anxiety and depression symptoms among informal caregivers. Describe and asses the process made by nurses to find both strengths in their practice and improvement areas
Ferré-Grau, C., Casado, M. S., Cid-Buera, D., LLeixà-Fortuño, M., Monteso-Curto, P., & Berenguer-Poblet, M. (2014)	Caring for family caregivers: An analysis of a family-centered intervention	Revista da Escola de Enfermagem da USP	Composite survey	Asses the effectiveness of the problem-solving technique (TRP) in informal caregivers by positive levels of anxiety, depression and emotional distress scales. Explore the enabling factors and barriers in their application stemming from nurses' narratives
Del-Pino-Casado, R., Millán-Cobo, M. D., Palomino-Moral, P. A., & Frías-Osuna, A. (2014)	Cultural correlates of burden in primary caregivers of older relatives: A cross sectional study	Journal of Nursing Scholarship	Quantitative study	Analyze the effect of cultural factors in the subjective burden of informal caregivers
Mendoza Sánchez, R. M., Hernández García, E. L., Medina Pérez, M., Gómez Perera, M., Estrada Suárez Pérez, L., Navarro Vázquez, F. J., & Pérez, F. (2014)	"Perfil del cuidador principal en el área de salud de Gran Canaria"	Ene: Revista de Enfermería	Quantitative study	Analyze the profile of the informal caregiver
Rico-Blázquez, M., Gómez, S. S., & Gallego, C. F. (2014)	"El cuidado como elemento transversal en la atención a pacientes crónicos complejos"	Enfermería Clínica	Review article (Qualitative)	Analyze the situation of the assistance of the chronic patient

Rico-Blázquez, M., Escortell-Mayor, E., del-Cura-González, I., Sanz-Cuesta, T., Gallego-Berciano, P., de las Casas-Cámarra, G.,... & Domínguez-Pérez, L. (2014)	CuidaCare: effectiveness of a nursing intervention on the quality of life's caregiver: cluster-randomized clinical trial	BMC Nursing	Quantitative study	Asses the effectiveness of an intervention of care in the primary health care to improve the life quality of informal caregivers
Rodríguez Ruiz, J. C., Archilla Castillo, M. I., & Archilla Castillo, M. (2014)	"La sobrecarga de los cuidadores informales"	Metas de Enfermería	Quantitative study	Analyze the presence of overburden among informal caregivers and identify some variable associated that can affect it
Casado-Mejía, R., & Ruiz-Arias, E. (2013)	"Estrategias de provisión de cuidados familiares a personas mayores dependientes"	Índex de Enfermería	Qualitative study	Explore, identify and typify different strategies of care provision to dependent persons developed by informal caregivers
Cuenca, R. M. A. (2013)	"Historia de una Gran Cuidadora: Cómo gestionar mi vida"	Archivos de la Memoria	Biographical account (Qualitative)	Know the life and experiences of an informal caregiver
Fernández Lao, I., Silvano Arranz, A., & Pino Berenguer, M. D. (2013)	"Percepción del cuidado por parte del cuidador familiar"	Índex de Enfermería	Qualitative study	Determine the meaning of the care for the informal caregiver
Gallart, A., Cruz, F., & Zabalegui, A. (2013).	Factors influencing burden among non professional immigrant caregivers: a case-control study	Journal of advanced nursing	Quantitative study	Identify the factors related with the burden experienced by the untrained immigrant informal caregivers
Gallo Estrada, J., Molina Mula, J., Novajra, A. M., & Taltavull Aparicio, J. M. (2013)	"Estrategias de cuidados de las familias con las personas mayores que viven solas"	Índex de Enfermería	Qualitative study	Know the perception of the family about the care of elderly dependents
García, D. V. (2013)	"Cuidador familiar y profesional de enfermería: dos perspectivas distintas del cuidado"	Archivos de la Memoria	Biographical account (Qualitative)	Describe the informal caregiver's experience, difficulties, feelings and lessons and how this affects her professional life
Guerra Martín, M. D., & Zambrano Domínguez, E. M. (2013)	"Relación entre los problemas de salud de los mayores dependientes y la formación de los cuidadores informales"	Enfermería Global	Quantitative study	Study elderly dependents' health problems and informal caregivers' training
Mata, R. M. A. (2013)	"El cuidado de un familiar anciano dependiente con pluripatología"	Archivos de la Memoria	Qualitative study	Know the impact on an informal caregiver's life and understand the existing differences regarding the care of persons from outside the own family
Matute, A. E. G., Barraso, M. D. C. P., Osuna, M. E., & Jiménez, M. R. (2013)	"El manual de recomendaciones como herramienta de apoyo a la persona cuidadora"	Evidentia: Revista de enfermería basada en la evidencia	Qualitative study	Show the experience in the creation of a handbook developed by informal home-based caregivers that collects recommendations about care
Mejía, R. C., Arias, E. R., Gallego, J. C., Marín, M. J. A., & Sánchez, M. O. (2013)	"Validación y pilotaje de un cuestionario con perspectiva de género para profundizar en el cuidado familiar"	Evidentia: Revista de enfermería basada en la evidencia	Review article (Quantitative)	Design and ratify a survey to know the profile of the informal caregivers, their provision of care strategies, selected institutional arrangements and health effects
Muñoz, M. I. G., Galiano, M. D. C. L., & Muñoz, I. M. G. (2013)	"Cuidar, un hábito familiar. La satisfacción de cuidar a los seres queridos"	Archivos de la Memoria	Biographical account (Qualitative)	Describe the experience as an informal caregiver
Sotto Mayor, M., Sequeira, C., & García, B. (2013)	"Consulta de enfermería dirigida a cuidadores informales: instrumentos de diagnóstico e intervención"	Gerokomos	Quantitative study	Identify the main needs of the informal caregivers who resort to nursing consultations, the methods implemented and the results obtained
Trigueros, A. C., Montes, C. L. L., & Gallego, F. R. (2013)	"Nacida para cuidar. Relato biográfico de una adolescente"	Archivos de la Memoria	Biographical account (Qualitative)	Explore the experiences, attitudes and feelings that a teenager develops when accepting his role of main family caregiver
Álvarez-Tello, M., Casado-Mejía, R., Ortega-Calvo, M., & Ruiz-Arias, E. (2012)	"Sobrecarga sentida en personas cuidadoras informales de pacientes pluripatológicos en una zona urbana"	Enfermería Clínica	Quantitative study	Determine the profile of the informal caregiver, identify factors related to the perceived overburden and evidences of fatigue in order to build predictive models using items of the Caregiver Effort Index

De la Cuesta-Benjumea, C., Donet-Montagut, T., & de Cádiz, M. J. G. G. (2012)	Turning to One's Own World" Escape Mechanisms Employed by Immigrant Caregivers in Spain for Relieving the Burden of Care	Journal of Transcultural Nursing	Qualitative study	Analyze immigrant care givers' strategies to soothe the burden of care
Del-Pino Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Ramón Martínez-Riera, J. (2012)	Gender differences regarding informal caregivers of older people	Journal of Nursing Scholarship	Quantitative study	Examine gender related differences among informal caregivers of persons in dependent situation
Iglesias, L. R. (2012)	"El cuidado familiar: Percepciones, repercusiones y emociones de una persona cuidadora"	Archivos de la Memoria	Biographical account (Qualitative)	Recognize the task of informal caregivers
Martín, M. D. S. M., Rodríguez, A. A., & Serrano, R. R. (2012)	"Una vida dedicada al cuidado. El relato de una cuidadora profesional y familiar"	Archivos de la Memoria	Biographical account (Qualitative)	Show the gender perspective in informal care from the point of view of a nurse
Vázquez-Sánchez, M. Á., Aguilar-Trujillo, M. P., Estébanez-Carvajal, F. M., Casals-Vázquez, C., Casals-Sánchez, J. L., & Heras-Pérez, M. C. (2012)	"Influencia de los pensamientos disfuncionales en la sobrecarga de los cuidadores de personas dependientes"	Enfermería Clínica	Quantitative study	Know the level of dysfunctional thoughts among informal caregivers and their relationship with the overburden in the performance of the caregiver role
Villarejo Aguilar, L., Peña, Z., & Casado Ponce, G. (2012)	"Sobrecarga y dolor percibido en cuidadoras de ancianos dependientes"	Enfermería Global	Quantitative study	Evaluate the subjective overburden and the pain perceived among informal caregivers of dependent persons and determine if the intensity of the pain perceived is linked to the caregiver's overburden
Zambrano-Domínguez, E. M., & Guerra-Martín, M. D. (2012)	"Formación del cuidador informal: relación con el tiempo de cuidado a personas dependientes mayores de 65 años"	Aquichán	Quantitative study	Analyze the training received by informal caregivers of dependent persons in relationship with the care time
Bover, A. (2011)	Economic crisis, austerity discourses and caregiving: how to remain relevant through engagement and social justice	Nursing Inquiry	Article of reflection	Study how the measures implemented to control the cost in public health have affected health and equity inside the public health system
Del-Pino-Casado, R., Frías-Osuna, A., Palomino Moral, PA, y Pancorbo-Hidalgo, PL (2011)	Coping and subjective burden in caregivers of older relatives: a quantitative systematic review	Journal of Advanced Nursing	Review article (Quantitative)	Analyze the effect of coping strategies on subjective burden of informal caregivers
del-Pino-Casado, R., Frías-Osuna, A., & Palomino-Moral, P. A. (2011)	Subjective burden and cultural motives for caregiving in informal caregivers of older people	Journal of Nursing Scholarship	Quantitative study	Research the variables related to the causes of informal/cultural care and analyze their relationship with informal caregivers' subjective burden
Germán Bes, C., Hueso Navarro, F., & Huércanos Esperanza, I. (2011)	"El cuidado en peligro en la sociedad global"	Enfermería Global	Article of reflection	Research the risk of loss of informal, invisible or humanized care, both in society and in the nursing profession
Vives-Relats, C., Ferré-Grau, C., Rodero-Sánchez, V., Cid-Buera, D., & Miembros del Grupo de Investigación: Enfermería Aplicada de la URV. (2011)	"Cuidar a una cuidadora familiar en Atención Primaria a partir de la teoría de la incertidumbre"	Enfermería Clínica	Qualitative study	Address the phenomena informal caregivers experience from the perspective of their experience and anxiety
Crespo, E. M. (2010)	"Valoración del apoyo socio-familiar de las cuidadoras en una zona básica de salud"	Evidencia: Revista de enfermería basada en la evidencia	Quantitative study	Value social and family support of the informal caregivers of dependent persons
Delicado Useros, M. V., Alcarria Rozalén, A., Ortega Martínez, C., Alfaro Espín, A., García Alcaraz, F., & Candel Parra, E.	"Autoestima, apoyo familiar y social en cuidadores familiares de personas dependientes"	Metas de Enfermería	Quantitative study	Describe the profile of informal caregivers, characteristics of care. Identify the support they receive

(2010)				
Rogero-García, J. (2010)	"Las consecuencias del cuidado familiar sobre el cuidador: Una valoración compleja y necesaria"	<i>Índex de Enfermería</i>	Article of reflection	Elaborate a proposal for the classification of the consequences of care on the informal caregiver
Rogero-García, J., & Martín-Coppola, E. (2010)	"Un estudio exploratorio del cuidado provisto por inmigrantes a personas mayores de 64 años en los hogares"	<i>Índex de Enfermería</i>	Quantitative study	Explore the type of care which immigrant informal caregivers provide to the person in a dependence situation at home
Rodríguez, P. H., Sampedro, M. A. Z., & Zamudio, E. F. (2010)	"Sentimientos y emociones en cuidadores informales"	<i>Hygia de enfermería: revista científica del colegio</i>	Qualitative study	Understand the experiences analyzing how the person receives and understands their experiences as an informal caregiver
Alvaro, A. M. B., López, M. C. O., Bustillo, M. G., Fernández, M. Á. G., Gómez, M. B. S., & Climent, G. D. (2009)	"Educación grupal versus educación individual en cuidadores familiares. Revisión Sistemática"	<i>Evidencia: Revista de enfermería basada en la evidencia</i>	Review article (Quantitative)	Find evidence that allows to identify the measuring tools of the informal caregiver's burden
Delgado González, E., González Esteban, M. P., Ballesteros Alvaro, A. M., Pérez-Alonso, J., Mediavilla, M. E., Aragón Posadas, R., ... & Guzmán-Fernández, M. A. (2009)	"¿Existen instrumentos válidos para medir el síndrome del cuidador familiar? Una revisión sistemática de la literatura"	<i>Banco de evidencias de Sacyl</i>	Review article (Quantitative)	Identify the best available evidence about group EPS versus individual among informal caregivers of dependent persons in order to made recommendations to improve the care
González-Pisano, A. C., Granado-Villacé, R., García-Jáñez, E., del Cano-González, C., & Fernández-Fernández, M. I. (2009)	"Calidad de vida relacionada con la salud en cuidadoras de personas dependientes de dos zonas rurales de León"	<i>Enfermería Clínica</i>	Quantitative study	Study the quality of life related to the health and its relationship with social support, family function, and level of burden of the informal caregivers of persons in a situation of dependency
González-Valentín, A., & Gálvez-Romero, C. (2009)	"Características sociodemográficas, de salud y utilización de recursos sanitarios de cuidadores de ancianos atendidos en domicilio"	Gerokomos	Quantitative study	Describe the socio-demographic and health characteristics of informal caregivers in order to establish determining factors of health status and caregivers' use of health resources
López-Casanova, P., Rodríguez-Palma, M., & Herrero-Díaz, M. A. (2009)	"Perfil social de los cuidadores familiares de pacientes dependientes ingresados en el Hospital General Universitario de Elche"	Gerokomos	Quantitative study	Describe the social profile of informal caregivers and know the type of needs that they cover
Bonet, I. Ú., & Roger, M. R. (2008)	"¿Cómo repercute el cuidar en los cuidadores familiares de personas dependientes?"	Nursing (Spanish Edition)	Article of reflection	Analyze the impact care has on informal caregivers of persons in situation of dependence
Cuesta Benjumea, C. D. L. (2008)	"Aliviar el peso del cuidado familiar: Una revisión de la bibliografía"	<i>Índex de Enfermería</i>	Review article (Qualitative)	Analyze the respite programs addressed to informal caregivers
De Cádiz, M. J. G. G., de la Cuesta-Benjumea, C., & Donet-Montagut, T. (2008)	"Cuidadoras inmigrantes: características del cuidado que prestan a la dependencia"	<i>Enfermería Clínica</i>	Review article (Qualitative)	Reflect the characteristics of care conducted by immigrant women
Escuredo Rodríguez, B. (2008)	"Políticas de dependencia. Consecuencias para las familias"	<i>Revista Rol de Enfermería</i>	Qualitative study	Analyze the main policies of care to dependence
Leyva-Moral, J. M., & Mogeda-Marina, N. (2008)	"Necesidades psicosociales del cuidador informal"	<i>Revista Rol de Enfermería</i>	Composite survey	Suggest the use of nursing diagnosis in care planning
Torres Egea, M., Ballesteros Pérez, E., & Sánchez Castillo, P. D. (2008)	"Programas e intervenciones de apoyo a los cuidadores informales en España"	Gerokomos	Review article (Quantitative)	Analyze the scientific publications dealing with different support programs and interventions for informal caregivers
Zabalegui, A., Bover, A., Rodríguez, E., Cabrera, E., Diaz, M., Gallart, A.,... & Pulpón, A. M. (2008)	Informal caregiving: perceived needs	Nursing Science Quarterly	Qualitative study	Know caregiver's profiles and analyze their needs
Camero, M. L. R., Camero, N. R., Hernández, R. A.,	"Mujeres, salud y cuidados familiares. Instituciones económicas desde la"	<i>Índex de Enfermería</i>	Article of reflection	Analyze the economic aspects of care and their relationship with gender

López, A. T., Salvador, M. D. M. R., & Ronda, F. J. M. (2007)	perspectiva antropológica"			
González, M. A. O., Muñiz, R. M. R., & Tinoco, J. P. (2007)	"Atención al cuidador/a principal desde Atención Primaria de salud"	<i>Metas de Enfermería</i>	Composite survey	Answer the quandary of informal caregivers through training workshops
Rodilla, J. M. (2007)	"Cuidar a las personas de apoyo"	<i>Metas de Enfermería</i>	Composite survey	Suggest nursing intervention to informal caregivers
Zabalegui Yarnoz, A., Juandó-Prats, C., Sáenz de Ormijana Hernández, A., Ramírez Llaras, A. M., Pulpón Segura, A., López Rodríguez, L., & Valentín, G. (2007)	"Los cuidadores informales en España: perfil y cuidados prestados"	<i>Revista Rol de Enfermería</i>	Review article (Quantitative)	Analyze the publications about the situation of informal caregivers, their profile, and the type of care they provide
Gutiérrez Valverde, P., & Nieto Jiménez, P. (2007)	"Nuevas cuidadoras. ¿Cómo formarlas?"	<i>Revista Rol de Enfermería</i>	Composite survey	Address informal caregivers' training needs through training workshops

Source: prepared by the authors.

In order to answer the questions posed in this article, we present now the results of the quantitative and qualitative analysis.

The main results of the quantitative analysis, the aim of which was to quantify the scientific production depending on the typology are shown in Table II.

**Table II:** Typology of the published articles.

Type of the article	Year 2007	Year 2008	Year 2009	Year 2010	Year 2011	Year 2012	Year 2013	Year 2014	Year 2015	Year 2016	Total
Original quantitative article			3	3	1	5	4	4		1	21
Original qualitative article		2		1	1	1	4		1	1	11
Original mixed article	3	1						2			6
Quantitative review	1	1	2		1		1				6
Qualitative review article		2							1	1	4
Article of reflection	1	1		1	2						5
Biographical account						2	4				6
<b>TOTAL</b>	<b>5</b>	<b>7</b>	<b>5</b>	<b>5</b>	<b>5</b>	<b>8</b>	<b>13</b>	<b>7</b>	<b>2</b>	<b>2</b>	<b>59</b>

Source: prepared by the authors.

The number of publications related to the research topic was steady during the review period, with a slight increase during the years 2012 and 2013 and, decreasing significantly during the years 2015 and 2016. We detect that the most published type of the article between 2007 and 2016 was the one based on an original quantitative study, with a total of 21 articles edited, followed by the original article based on a qualitative study, with a total of 11. The less recurring article typology was the qualitative review, with 4 articles.

The articles based on quantitative studies provide, above all, descriptive data about the profile of caregivers, tools and measurement scales of the overburden resulting from the care, and assessments of nursing interventions. The fact that this kind of article was the one published more frequently is consistent with the fact that historically nursing has prioritized experimental designs, data collection through surveys and standardized quizzes, and data analysis statistical techniques.

Throughout the analysis, we have observed that biographical accounts and life stories are among the most used techniques in the descriptive qualitative researches of descriptive nature with the aim of collecting first-hand the experiences of caregivers. These stories highlight different issues such as the impact of care, personal satisfaction resulting from meeting family needs, different care burdens between men and women, as well as the need of social and health measures which improve their life's quality. Other qualitative techniques used are focus groups, discussion groups and semi-structured or in-depth interviews. These show the existence of numerous strategies to organize informal care and that the caregivers do not feel supported by the public policies. In this regard, qualitative research has great potential to the nursing profession to identify the subjective needs of care, to offer care on a more individual level and to create new research options.

The aim of the qualitative analysis conducted for this article was to characterize the scientific production according to topics it covers; there are three topics worth shedding light on (Figure 1).

**Figure 1:** Main topics of the publications



Source: prepared by the authors.

The first predominant theme in the analyzed publications is the caregiver's profile and the results of care on her. This is considered important in order to suggest preventive activities. To the study of the caregiver's profile, the publications add the study of the care impact on her, and they classify it as either positive or negative. Positive impacts include the caregiver's development and personal growth and the chance of having a job. The negative impacts, more numerous and frequent, include an important chronic stress which affects both the physical and mental health and the quality of life of the caregiver, as well as economic, labor and social aspects.

A second theme we have detected consists in the intervention to promote care and self-care, and the prevention of overburden resulting from care. The importance of

taking the caregiver into account and identifying the strategies designed for her is argued because these can contribute to her control over her quality of life and her own health. Therefore, the main task of nurses, alongside with caregivers, consists of the training and the counselling that seek to expand their knowledge and abilities in care and self-care.

The third and last theme refers to the use of evaluation tools to plan the care of the caregiver. Suggestions are made to use the standardized nursing language based on the North American Nursing Association criteria (NANDA). The use of nursing diagnoses as a tool to plan objectives and interventions unifies and ensures an understanding between professionals. It is also important to consider the elaboration and use of recommendation handbooks on daily practice with a care methodology that allows a global vision of people's needs and to improve the quality of their care.

## DISCUSSION

The analyzed publications largely reflect the assistance spin in the field of chronicity toward the community and home level announced by the policies and the health plans of different Spanish Autonomic Regions <sup>(10,11,12,14)</sup>. This spin, in turn, provides an increasing importance to informal caregivers in health and care processes <sup>(15-17)</sup>.

A constant in the different strategies of improvement in community care and in the health plans we have reviewed, as well as in the analyzed articles, is the statement that the nurse has the responsibility to incorporate the caregiver as a user with a right to maintain their health <sup>(18)</sup>.

Most of the articles we have analyzed share, either implicitly or explicitly, a more utilitarian view of the caregiver, who is built, presented and treated as a resource, whose health is important to consider in order to warrant that they will be able to continue caring <sup>(19)</sup>. Ultimately, we detect, a latent tension between a preventive approaching to this figure as a future patient, and an interest on the part of the nursing profession, often secondary, toward the caregiver as a mere resource or collaborator.

The analysis of the publications shows that the nursing profession does not pose in a comprehensive way its specific contribution in the frame of new chronicity paradigms neither a new stance before the structural impacts that these have on informal care <sup>(9,20)</sup>. This causes a transfer of responsibility toward care by and from public administrations to the families <sup>(14)</sup>.

To conclude and in order to answer the posed questions:

The publications are focused on studies aimed at knowing the caregiver's profile and how to plan interventions recommending evaluation tools. The studies about informal care, which have a great social impact in the emerging health situation, only add up 8.3 % of the publications in nursing journals.

The changes reflected in the approach to dependency are a comeback to the previous scenario to LAPAD, since the responsibility toward care returns and to the home environment. This is one of the many consequences of the economic crisis and the cutbacks in health, as Rodríguez Cabrero notes <sup>(5)</sup>.

The changes in nursing competencies are aimed at the community and home care taking into account the person who receives care and the caregiver, but teaching and empowering them on disease and self-care<sup>(10,21,22)</sup>.

The publications do not analyze the existing socio-economic inequalities in care. Some of them do mention their economic or labor impacts on the caregiver, but they do not problematize that not all the families are in the same conditions to respond to them or to search alternatives. Social inequalities existing previously to the care experience promote in turn additional health, free time and, among others, labor inequalities among families<sup>(23)</sup>.

If nursing wants to acquire a complex vision of care in order to give effectively answers, it will be necessary to add a specific attention to the social inequalities presents in it. Particularly in times of crisis, as Úbeda & Roca state<sup>(21)</sup>, it becomes essential to consider these aspects to raise awareness among nurses of people's realities, both people who receive care and caregivers.

## CONCLUSION

Nursing publications focus on studies to know the caregiver's profile how to plan the interventions recommending evaluation tools.

They also successfully identify the centrality of informal care in new scenarios and chronicity paradigms, and reflect the assistance spin toward homes and families. The family is considered as the main responsible of care, and within in women are the main providers.

The publications do not problematize, nevertheless, the current transfer of care responsibilities from public administrations toward the family circle. They do not analyze in-depth either the prevailing socio-economic and gender inequalities in the current care scenario. The approach to these two issues can contribute to open new lines of research and intervention in the nursing field.

## REFERENCES

1. García-Calvente, MM. Cuidados de salud, género y desigualdad. Comunidad. 2012; 5: 3-4.
2. Rogero-García J. Distribución en España del cuidado formal e informal a las personas de 65 y más años en situación de dependencia. Rev Esp Salud Pública. 2009; 83:393-405.
3. García-Calvente, MM., Mateo-Rodríguez, I., Maroto-Navarro, G. El impacto de cuidar en la salud y la calidad de vida de las mujeres. Gaceta Sanitaria 2004; 18(II): 83-92.
4. Oliva J, Vilaplana C, Osuna R. El valor social de los cuidados informales provistos a personas mayores en situación de dependencia en España. Gaceta Sanitaria. 2011; 25(S): 108-114.
5. Rodríguez Cabrero G. Políticas sociales de atención a la dependencia en los Regímenes de Bienestar de la Unión Europea. Cuadernos de Relaciones Laborales [Internet]. 2011 [consultado el 15/10/2016]; 29(1): 13-42. Disponible en: <http://revistas.ucm.es/index.php/CRLA/article/view/36184/35063>

6. Calvente M, Del Río M, Marcos JM. Desigualdades de género en el deterioro de la salud como consecuencia del cuidado informal en España. *Gaceta Sanitaria*. 2011; 25: 100-107.
7. Segura, N., Gómez, R., López, R., Gil, E., Saiz, C., Cordero, J. El anciano dependiente y el desgaste físico y psíquico de su cuidador. *Revista Española de Geriatría y Gerontología* 2006; 41(1), 15-20.
8. De Lorenzo R, Rivero A. La futura Ley de Dependencia como pilar fundamental de la protección social en España. *Revista Española del tercer sector*. 2006; (3): 49-80.
9. Contel JC, Muntané B, Camp L. La atención al paciente crónico en situación de complejidad: el reto de construir un escenario de atención integrada. *Atención Primaria*. 2012; 44(2): 107-113.
10. Ferrer C, Orozco D, Román P. Estrategia para el Abordaje de la Cronicidad en el Sistema Nacional de Salud [Internet]. Madrid: Ministerio de Sanidad, Servicios Sociales e Igualdad; 2012 [consultado el 20/06/2016]. Disponible en: [http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/pdf/ESTRATEGIA\\_ABORDAJE\\_CRONICIDAD.pdf](http://www.msssi.gob.es/organizacion/sns/planCalidadSNS/pdf/ESTRATEGIA_ABORDAJE_CRONICIDAD.pdf)
11. Conselleria de Salut. Plan de atención a pacientes con enfermedades crónicas de la Comunidad Valenciana [Internet]. Generalitat Valenciana; 2012 [consultado el 25/09/2016]. Disponible en: <http://iv.congresocronicos.org/documentos/plan-de-atencion-pacientes-cronicos-valencia.pdf>
12. Departamento de Sanidad y Consumo. Estrategia para afrontar el reto de la cronicidad en Euskadi [Internet]. Vitoria: Gobierno Vasco; 2010 [consultado el 24/10/2016]. Disponible en: [https://www.osakidetza.euskadi.eus/r85-skorga01/es/contenidos/informacion/estrategia\\_cronicidad/es\\_cronicos/estrategia\\_cronicidad.html](https://www.osakidetza.euskadi.eus/r85-skorga01/es/contenidos/informacion/estrategia_cronicidad/es_cronicos/estrategia_cronicidad.html)
13. Valderas JM, Starfield B, Sibbald B, Salisbury C, Roland M. Defining comorbidity: Implications for understanding health and health services. *Ann Fam Med*. 2009;7:357-63.
14. Departament de Salut. Pla de Salut de Catalunya 2011-2015 [Internet]. Generalitat de Catalunya; 2011 [consultado el 15/10/2016]. Disponible en: [http://salutweb.gencat.cat/ca/el\\_departament/pla\\_de\\_salut\\_2011\\_2015/](http://salutweb.gencat.cat/ca/el_departament/pla_de_salut_2011_2015/)
15. Rico-Blázquez M, Gómez SS, Gallego CF. El cuidado como elemento transversal en la atención a pacientes crónicos complejos. *Enfermería Clínica*. 2014; 24(1): 44-50.
16. Sánchez-Martín I. Cronicidad y complejidad: nuevos roles en Enfermería. *Enfermeras de Práctica Avanzada y paciente crónico*. *Enfermería Clínica*. 2014; 4(1): 79-89.
17. Rodríguez BE. Políticas de dependencia: consecuencias para las familias. *Revista ROL de enfermería*. 2008; 31(5), 22-32.
18. Escuredo-Rodríguez B. El discurso de las enfermeras ante el cuidado de las personas mayores dependientes y sus cuidadores familiares. *Índex de Enfermería*. 2006; 15(52-53), 45-48.
19. IMSERSO. Cuidados a las Personas Mayores en los Hogares Españoles. El entorno familiar [Internet]. Madrid: Ministerio de Trabajo y Asuntos Sociales. Secretaría de Estado de Servicios Sociales, familias y discapacidad; 2005 [consultado el 30/11/2016]. Disponible en: <http://www.dependencia.imserso.es/InterPresent1/groups/imserso/documents/binario/cuidadosppmhogares.pdf>
20. Departament de Salut. Programa de prevenció i atenció a la cronicitat. Document conceptual. Versió 5.0 del 28.02.2012 [Internet]. Generalitat de Catalunya; 2012

- [consultado el 05/11/2016]. Disponible en:  
[http://salutweb.gencat.cat/web/.content/home/ambits\\_tematicos/linies\\_dactuacio/model\\_assistencial/atencio\\_al\\_malalt\\_cronic/documents/arxius/562conceptual.pdf](http://salutweb.gencat.cat/web/.content/home/ambits_tematicos/linies_dactuacio/model_assistencial/atencio_al_malalt_cronic/documents/arxius/562conceptual.pdf)
21. Úbeda I, Roca M. Los cuidados familiares y las políticas públicas. *Nursing*. 2008; 26(9): 56-58.
22. Germán Bes C, Hueso Navarro F, Huércaños Esparza, I. El cuidado en peligro en la sociedad global. *Enfermería Global* [Internet]. 2011[consultado el 10/05/2016]; 10(23): 221-232. Disponible en: <http://revistas.um.es/eglobal/article/view/125491>
23. Delicado MV. Familia y cuidados de salud: Calidad de vida en cuidadores y repercusiones sociofamiliares de la dependencia [tesis doctoral]. Universidad de Alicante; 2003 [consultado el 12/11/2016]. Disponible en: <http://hdl.handle.net/10045/3410>

ISSN 1695-6141

© COPYRIGHT Servicio de Publicaciones - Universidad de Murcia