Investigación y Educación en Enfermería
ISSN: 0120-5307
revistaiee@gmail.com
Universidad de Antioquia
Colombia

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Investigación y Educación en Enfermería, vol. 32, núm. 3, 2014, pp. 487-497
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Medellín, Colombia

The value of nursing care in the paradigm of chronicity and dependency. New roles and redesigns

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The value of nursing care in the paradigm of chronicity and dependency. New roles and redesigns

The future of Healthcare Systems not only faces financial troubles, but also – perhaps worse, the need to redesign its service offers. It is necessary to work for all the knowledge available to be placed at the service of patients and society, generating much more efficient services and opening to a redesign where nurses lead in new services supported on the strategy of effective care. Additionally, it is hoped that patients assume a responsibility and nurses another: that of accompanying patients during their disease process to become for them a support in their self-care efforts. The new role that must be assumed by community nurses is that of becoming the coaches of chronic patients and of their caregivers so they can reach a situation of equilibrium, between their desires and what they must do, to, thus, assume their responsibility in the self-provision of Basic Care.

Key words: nurses, community health; nursing care; self care; chronic disease; aging; frail elderly.

El valor del cuidado de enfermería en el paradigma de la cronicidad y la dependencia. Nuevos roles y rediseños

El futuro de los Sistemas Sanitarios no solo atraviesa por problemas de financiación, sino, tal vez mucho más, por la necesidad de rediseñar su oferta de servicios. Es necesario trabajar para que todo el conocimiento disponible se ponga al servicio de los pacientes y la sociedad, generando servicios mucho más eficientes y abriéndose a una rediseño en el cual las enfermeras lideren nuevos servicios que se apoyen en la estrategia de un cuidado eficaz. Además, se trata de que los pacientes asuman una responsabilidad y las enfermeras una más importante: la de acompañarlos en su proceso de enfermedad como apoyo en sus esfuerzos de autocuidado. El nuevo rol que deben asumir las enfermeras comunitarias es el de ser las entrenadoras de los pacientes crónicos y de sus cuidadores para que alcancen una

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Article linked to the research: El valor de los profesionales enfermeros en el paradigma de la cronicidad y la dependencia. Nuevos roles y rediseños

Subventions: Ministerio de Sanidad y Consumo de España.

Conflicts of interest: none.

Receipt date: September 3, 2013.

Approval date: February 10, 2014.

How to cite this article: Ferrer-Arnedo C, Santamaría-García JM, Fernández-Batalla M, Salazar-Guerra. The value of nursing care in the paradigm of chronicity and dependency. New roles and redesigns. Invest Educ Enferm. 2014; 32(3): 488-497.

situación de equilibrio entre sus deseos y lo que deben de hacer, para que así puedan asumir responsabilidad en la autoprovisión de Cuidados Básicos.

Palabras clave: enfermeras de salud comunitaria; atención de enfermería; autocuidado; enfermedad crónica; envejecimiento; anciano frágil.

O valor do cuidado da enfermagem no paradigma da cronicidade e a dependência. Novos papéis e redesenho

O futuro dos Sistemas Sanitários não só atravessa por problemas de financiamento, senão talvez bem mais, pela necessidade de redesenhar sua oferta de serviços. É necessário trabalhar para que todo o conhecimento disponível se ponha ao serviço dos pacientes e a sociedade, gerando serviços bem mais eficientes e abrindo-se a um redesenho onde as enfermeiras liderem novos serviços que se apoiem na estratégia de um cuidado eficaz. Ademais se trata que os pacientes assumam uma responsabilidade e as enfermeiras outra: a de acompanhar aos pacientes em seu processo de doença a fim de ser para eles um apoio em seus esforços de autocuidado. O novo papel que deve ser assumido pelas enfermeiras comunitárias é o de ser as treinadoras dos pacientes crônicos e de seus cuidadores para que atinjam uma situação de equilíbrio, entre seus desejos e o que devem de fazer, para que assim possam assumir sua responsabilidade na auto-provisão de Cuidados Básicos

Palavras chave: enfermeiras de saúde comunitária; cuidados de enfermagem; autocuidado; doença crônica; envelhecimento; idoso.

Introduction

In Spain, as in the rest of the countries in our realm, an epidemiological and population transition is underway. Increased life expectancy and improved healthcare services, as well as the adoption of certain life styles, have led people to live more years, but these years also have more disabilities, with greater dependency and in many cases, more years conditioned by chronic disease; this supposes that it is fitting to ponder on the need to propose a new approach in the definition of the offer of health and socio-health services more settled on the co-responsibility of patients and where the practice of nursing care constitutes an opportunity for the sustainability of systems. If we observe the development of Healthcare Systems, as well as the so-called socio-health systems, these have supported development of beneficence strategies for individuals, generating at a given moment lines of service aimed at the search for wellbeing with limits on patient autonomy.

This traditional framework has defined models of service provision based on the idea of work from the figure of the *"Infermus"*, of the patient who has no capacity to decide, as stated by Professor Diego Gracia. The approaches supported on technological development to address health problems, used so often by Healthcare Systems have left along the 20th century in situations of marginality that which is related to care and which of which nurses have been in charge, that is, basic survival and cure care and more has been mentioned of disease than of people with health problems. The medical language, the very technical medical practice, at this time, has been the only element of interest of the health services system. The more comprehensive and more holistic approaches have remained in the hands of nursing professionals, *i.e.*, the system has left it for some groups of nurses to look after these types of approaches, specifically community nurses

that – as denominated by Professor Alberdi:[1] "are the caregiving nurses… being the minority in any of the Support Systems to people". The future panorama, which is now, is changing; it is transforming and is marked by long-lasting diseases, which are buried, what currently supposes the condition of chronicity. These have a series of characteristics among which it can be highlighted that they are of long duration, of slow and disabling progression.

In addition, they lead to limitations in the quality of life of the individuals affected and of their caregivers, causing important economic effects in families, communities, and society and – of course – bring along the necessity that whoever endures them will have to carry out some adjustments in their daily lives, adjustments always related with their daily care and routines, as we already reported in 2008 and, hence, is obligated to develop new strategies, focused – as recommended by international organizations – on generating active patients, strategies based on self-care, which turns out difficult for solitary patients and who require professional support from a healthcare professional who is a nurse, their nurse.[2]

Thus, we know that chronic diseases suppose for the individual some health problem related with their capacity to confront them or to adapt, that is, conditions, that which transcends the concept of falling ill and which affects their daily lives, given that falling ill generates new incidents and different experiences at the individual level. This involves readjustments in daily living. This means that when defining new services that contemplate chronicity and how it affects patients, we keep in mind the individual experience when proposing different approaches to address it. The experience of currently suffering a disease is one of the keys that must be proposed when it is stated that it is necessary to develop strategies that empower patients and which support their capacity for self-care and self-management. Thereby, it may not be overlooked that when we set out to offer services aimed at individuals with health problems related with chronicity it is indispensable to rethink of the importance of providing more personalized service, very individualized, quite oriented to each where the experiences, values, desires, and capacities of each person and which contemplates – upon determining an action plan – these individual conditions in the search of an attainable result for each of the individuals; it is here where the services that can be offered by nurses acquire an essential value.[3]

Analysis of the care environment and chronicity

If we look at a country like Spain, for example, the health status perceived by Spaniards is, in general, positive and shows an intermediate value within the European context. Health, as a service, is the area of greatest interest for Spanish citizens who grant a good score to the public health system: 6.6 over 10. However, 73.1% of Spaniards share the opinion that the Spanish health system functions "rather well" or "well", although it would need some changes.[4] Surely, these changes have to do with: more personalized treatment, comprehensive approaches, less medicalization, and greater agility. That is, approaches where nurses must work hard to support a change or, rather, a transformation capable of responding to necessities in a safe, effective, and efficient manner from a systematized implantation of self-care strategies.

We must not forget; if we set out to promote different strategies to improve the provision of professional care that it becomes necessary to speak of chronicity and of the aging of the population, which translates into decreased functional capacity of the individual that, although it does not intrinsically imply disease, implies greater vulnerability to changes and unfavorable environments. Although longevity is an essential factor in increased chronicity, the elderly are not the only ones affected by chronic disease and, hence, it would not be correct to associate, without the necessary qualification, a person with chronic disease with elderly person. It is estimated that 60% of all the years of disability-adjusted life attributed to chronic diseases occurred in

people younger than 60 years of age, with enough evidence of the increase of chronic conditions in boys, girls, and adolescents since 1960.[5]

When observing how health resources are consumed, some figures are compelling: in 2010, almost 53% of the hospital stays (people/beds/days) were registered in those older than 64 years of age and their mean stay surpassing by nearly two days that obtained by the set of discharges from the National Health System (9.9 days).[6] And, of course, this is important, as is being able to respond sincerely to questions like: Did we improve their quality of life? Did we meet their needs? Did we understand what problems they had and did we offer, as a System, an adequate care response? If the answers are negative, then, we must reflect upon what lessons we have learnt and what we are willing to give up.[7]

On this reflection, on how to provide a proper approach to the previously raised questions, some keys have been defined in the Strategy to Address Chronicity by the Spanish National Health System[5]; Bengoa[8] and the World Health Organization[9] had already expressed their reflections by indicating that it is necessary to propose changes in the health services provision model, where self-care is one of its essential elements. The first model we will discuss is that which is probably the international reference in caring for individuals with chronic disease: the "Model for Chronic Care" in which caring for patients with chronic health problems takes place in three overlapping planes: a) the community with its policies and multiple public and private resources, b) the health system with its providing organizations and assurance schemes, and c) the interaction with the patient in the clinical practice. This framework interestingly identifies six essential elements: the organization of the healthcare system, the close relationships with the community, support to self-care, the design of the care system, support in decision making, and development of clinical information systems.[8-10]

In addition, other proposals of models exist that guide the idea for change. Nevertheless, all of them share some common parts: self-care, proactive patients (more involved), comprehensive systems, and non-fragmentation of intervention, that is, guaranteeing that patients are cared for continuously and comprehensively and, besides, that each patient receives what is necessary when needed and in the most adequate resource and not in function of the offer of medical services available but of their individual necessity. It is important to highlight this idea of proportionality (also understood as vertical equity), assigning to each what they need, given that it is an essential element in change and that it is necessary to delve into better work in health promotion and prevention strategies that are much more active than those carried out until now by Primary Care staff since the 1990s.

Definitely, working with people who are patients, accompanying them, empowering them, and with the population working on prevention are elements in which nurses are experts and, of course, their services are very cost-effective services as long as they are visible to promoters and society.[7] Those previously alluded to models, which would permit addressing the challenges of chronicity would be, among others, the Model of Innovative Care to Chronic Conditions[11] and that of the Kaiser Pyramid,[12] which identifies three intervention levels according to the chronic patient's level of complexity; all are based on essential elements of the nursing practice and, hence, elements that are opportunities for health systems in any part of the world.

Dependency on care within the context of health services

By observing the secondary diagnoses registered in the Minimum Basic Data Set configured by the information source of the necessity profile in the Spanish health system, references are found regarding risk factors and toxic habits. Elements like high blood pressure, diabetes, long-term use of medications or poly-medication are present, respectively, in 25%, 12%, 10%, and 9% of discharges produced in Spanish hospitals.

Regarding the use of resources from the health system, the mean frequency of hospital admissions due to exacerbation of chronic processes is higher than the European mean.[6] Hence, a new panorama opens in health services determined by the aging and chronicity and, furthermore, by individualized attitudes and behaviors in relation to the capacity of caring and caring for oneself.

Consequently, these two phenomena, aging and chronicity, are directly related to necessities of self-care, with dependency, and functional impairment and it becomes necessary to indicate organizational changes, which are difficult because services are rooted into the culture of health organizations evaluated by their highly technical medical practice; very technological aimed at diseases and hardly related to the health problems of individuals or simple practices of self-care.

To generate organizational change it is necessary to consider professional care as service and place nurses in charge of it. This requires a key value, acceptability, that is, that patients, equipment, authorities accept that the care offered by nurses in all its modalities are services. From teaching of self-care to the practice of a specific technique or the evaluation of the degree of pain, all are services with identity, response capacity, possibility of medication and adaptation to new demands. This is thus, because nurses are the professionals recognized for this purpose, given their experience, tradition, and academic formation in the world,[13,14] as well as because they are the players in the system that are competent in providing professional care, designated at the international level as the care profession. It is trivial, and absolutely logical, that when planning redesigns of health and social services with an approach toward care, self-care, or self-responsibility, we speak of nurses as leaders and it is in these professionals where any strategy must pivot to enhance work in care services, in elements that control the different determinants in health, and – above all – to generate prevention of diseases that lead to chronicity.[9]

Professional care in the transformation paradigm

The situations of dependency we observed in the institutions, like hospitals, provide clues on the levels of our current needs and care. One of proposals being forcefully made in Spain is for nurses to assume new roles in light of this panorama, new roles from their former competencies, that is, nurses in healthcare centers and in the hospital setting need to assume the role of training patients and their caregivers in self-care, train people in decision making, teach the population, manage cases and facilitate care continuity. Data in these cases is convincing and the experiences interesting.

In Primary Care, up to 40% of the patients with pluripathology present three or more chronic diseases, 94% is poly-medicated, 34% has a Barthel index below 60, *i.e.*, they have a high degree of dependency, and 37% has cognitive impairment. Simply reviewing, for example, the memoirs published by the Directors of the Guadarrama Hospital in Madrid on care of chronic patients, with mid- and long-term stays, we can note the difference of the situation between patients who are in a sub-acute hospital and chronic patients who require an adequate provision of care. The Guadarrama hospital has European excellence recognition, EFQM + 500 Club. Thus, if we review the 2012 memoirs from said institution,[15] the level of dependency of patients on admission is quite severe, understanding severity with respect to the level of dependency where, in said patients, it is necessary to substitute their self-care. These patients with higher degrees of dependency are admitted to Continuous Care units (79.3%) and to Chronic Re-exacerbated Care units (81.2%), with functional impairment that requires rehabilitation and, thus, require professional care provided by nurses and physical therapists.

If, additionally, we consider some of the problems related with two basic needs like eating and eliminating: two types of problems of care that involve dependency and which require training by

nurses for these to be overcome by the patients, we can have an idea regarding the degree of dependency and the requirements of nurse time each patient needs; thereby, we can see the existence of a situation that can be solved with the assumption of new roles by nurses, with individualized training to improve autonomy in these patients. The care problem in the Guadarrama Hospital is related to incontinence, which can affect up to 64.5% of the patients admitted to a unit for chronic, re-exacerbated patients, and to problems with swallowing in up to 36.8% of admissions, which involves the training nurse to improve swallowing.[15] Of course, these problems are combined with others like alteration of tissue integrity, risk of falling, or lack of adherence presented by many patients.

This set of problems related to dependency requires approaches centered on care. This are problems where the necessity for training in self-care required by people with problems of chronicity or by their caregivers gains its true value, meaning that we are against the need to generate change in the dominance of services and these also visualize the existence of the response capacity of systems with nurses as providers of formal care services; such that have been defined as actions that a professional offers in specialized manner and which go beyond the capacities individuals have to care for themselves or for others, that is, systematized care offered by nurses from Healthcare Systems.[16] An element to bear in mind in defining the new roles is that of meeting the needs of family caregivers or of the immediate environment. It is estimated in Spain that up to 88% of the total time of care required by a dependent person who lives at home and whose care needs to be assumed by the family;[17] thereby, family caregivers should also benefit from this idea of nurses as coaches/trainers of patients and of their caregivers because the need for care is increasingly complex due in great part to chronicity, requiring skills and attitudes that community nurses should be able to fulfill. Due to this, support is required along with the systematization of care professionals that, as stated previously, are the nurses. A systematization of professionals that does not only teach or merely substitute the very person, but rather has them assume the role of trainer for the self-care strategies to permeate the individual when designed individually and continually throughout life.

Our model of caring for chronicity and dependency is supported on work in health centers and in homes with hospital support, whenever necessary, allowing patients to stay in their homes, in their environment with safety and comfort. Home care is a nursing care that needs to be enhanced; it is basically based on the family as a care unit supported by nurses, family physicians, and social support and since the mid 1980s, through health services defined by the Services Section as caring for immobilized and terminal patients. This work has been carried out by essentially teaching caregivers, members of the family unit, making sure they do not falter or become exhausted in the performance of their caregiving role and for them to provide the necessary informal care for the immobilized and terminal patients with support from community nurses and some social municipal resources.[17]

The characteristic profile of the informal caregiver in Spain is that of a woman (83%), from a low cultural level, who dedicates an average of four hours per day, without rest periods and who receives scarce institutional support.[7] According to the 2009 National Health Survey, 33.2% of men and 64.3% of women who live with disabled individuals are in charge of their care.[18] However, this teaching model is not sufficient against the panorama foreseen for the future. We have developed experiences of training caregivers, beyond teaching, for example, with the School of Caregivers at Guadarrama Hospital. This requires working by anticipating with information to make decisions. In this project, caregivers can learn individually and make decisions accompanied by a nurse who is their trainer; this is done safely and in personalized manner to care for a particular patient. Upon observing the data from the 2012 Nursing Direction Memoirs[15] from the Guadarrama Hospital, it was noted that caregivers prior to starting their training felt their health had

been affected (40%), believed they did not have the money to care for their relative (24%), felt incapable of caring for their relative any longer (20%), and wished to have others take charge for caring for their relative (28%).

With this experience, it seems interesting to develop strategies aimed at caregivers, above all, from the community setting and from the hospitals where the mean stay permits this. With respect to the level of dependency on care presented by patients at Guadarrama Hospital, according to the classification made by the SIGNO tool, a notable percentage of all the units have total dependency – Functional Recovery Unit (16.9%), Continuous Care Unit (22.9%), Pneumology Unit or Internal Medicine (19.6%), Palliative Care Unit (33.8%), and the unit for chronic re-exacerbated patients (29.9%), which justifies changing the configuration of the staff to adequately respond to needs of patients.

Where we observe how the volume of patients grows in levels 3 and 4, that is, which require almost total substitution of their self-care, a new factor is proposed that influences on the design of services in the future: increased chronic dependency and progressive tiredness of the caregiver. These data confirm, from our experience in a medium-stay hospital or a Spanish hospital for chronic patients, that patients increasingly require more care, and that it is necessary to design structures where care acquires the rank of service and have an model open to the community where people, family members, can be realistic with their possibilities as caregivers in their homes. A relevant role is required from the Primary Care staff, more specifically the role of community nurses, next to patients and their caregivers generating opportunities and favorable environments to propitiate empowerment of the patients and their relatives; nurses simply accompany, teach, train, or supplement the process through the promotion of self-care support tools.[19]

The role of nurses with caregivers and in self-care against chronicity

If self-care is key, community nurses should play a role as trainers of patients; much more than the mere education that has been practiced within the community environment after the Primary Care reform.[20] This new role, as already indicated, goes beyond the educational and informative concepts in caring; it is accompanying, favoring empowerment, and being with the people. Likewise, we cannot overlook the role caregivers play in providing Basic Care to chronic patients and to the elderly, which is why the training is extended to dependent care of these individuals who are an essential support of the patients.

Evidence exists that permits our paving the way in the design of care services that are to be led by nurses, offered to chronic patients and to their caregivers through helping to generate capacities in patients to manage their disease. Among this evidence, we can highlight the meta-analysis conducted by Chodosh *et al*.,[21] who through 53 clinical trials revealed a statistically and clinically significant reduction in the level of glycated hemoglobin and in systolic blood pressure when self-care programs are developed centered on teaching patients to manage diabetes and high blood pressure.

A basic element in self-care programs is the concept of self-efficacy; this concept is quite close to the proposals of the strategy of nurses as trainers of patients. It tries to instill in patients trust in themselves and security because they will be capable of doing what they set out to do; because they are accompanied by their trainer, their nurse, who is by their side – as posed by Orem[19] in 1973 in her General Theory of Self-care Deficit. This author proposed that every self-care action requires three processes: awareness (which implies the need for cognitive capacity), decision making (which demands motivation), and execution of the action (which needs motor capacity and aptitude). Much later, and equally enriching, we saw the studies by Bandura[22] in 1997, which proposed that an individual has the power to carry out a particular action and seeks to comply with a proposed objective. It is the theory of self-efficacy that indicates that complying with the objectives permits increasing the patients' trust to make changes in daily life, which in the

long run affect how they manage their disease, which will lead to improving their health results.

Both theories set the path to redesign care intervention; it means training patients and their caregivers through support, knowledge, and safety strategies from self-care and self-management. Also, we need to learn to identify the factors impacting on the self-care of a particular person and that the strategy seeks to generate trust in oneself. This is accomplished by being close and accompanying under the paradigm of transformation.[19,23] Certainly, evidence seems to exist that support interventions can help caregivers. It is highlighted that in 2011 Cochrane published two systematic reviews to evaluate the effectiveness of health support interventions of informal caregivers. Candy B. *et al*.,[24] included 11 random controlled trials with 1836 caregivers who received support interventions in caring for dependent individuals, emotional support and/or coping skills. Legg *et al*., [25] included eight clinical trials with a total of 1007 caregivers of dependent patients demonstrating that educational interventions prior to the patient's discharge have greater effect on the caregiver's overload.

An example of these interventions is that of nurses as trainers seen in the Guadarrama Hospital where, in its Services Offer, there is a School of Caregivers which trains individually those caregivers who wish to be trained.[14] This service has a vast practical and scientific foundation, as already discussed; through this exercise we detect realities, where many caregivers wish to be trained to provide daily care, quite related to the substitution of the other and with development of routines, and they can simulate how their daily reality will be and if they can confront it.

Scientific evidence is based on these studies, as well as on those that also identify the transformation to which informal caregivers are subjected and their new and different roles. Reality is stubborn, and if we wish to maintain informal care systems against dependency and chronicity, we must understand the reality of the caregivers and although it is true that many caregivers show weariness without possibilities of taking breaks, as seen in numerous published qualitative studies[26,27] that help us to develop intervention strategy elements supported on the therapeutic closeness offered by the nurse upon being able to listen and understand the different realities, as well as being capable of negotiating individualized care plans, adapted to each reality to achieve the elements of self-management in patients and their caregivers, which will lead to an effective self-care strategy, one of the purposes of governmental strategies to address chronicity.

Due to the aforementioned and as a corolary, the following final considerations are made explicit:

- All models related to chronicity speak of the need to support the Strategy of Approaching Chronicity in Care.

- By examining the models proposed herein, it may be deemed that care is and must be considered an element of value and, thereby, should be part of the core of certain services in Healthcare Systems that should be led from nursing.

- It is important to develop more sound proposals, beyond teaching, because patients need nurses that train them, given that a key issue is involved in an element like self-efficiency, which can help to lead to self-care if we learn to understand people individually from trust with a professional capable of teaching, accompanying, and substituting when lacking in strength, as stated by Herderson.

- Caregivers play a key role; they are much more than executors of care plans, but must develop strategies of caring for themselves. They must receive specific care services, beyond learning in caregiving, and they must work from self-care being able to self-generate "breathing" strategies, within the Spanish context, or "truce" strategies in other contexts, in hand with their training nurse.

- Care must be offered from the hospital setting, from open and proactive systems; the School

of Caregivers at Guadarrama Hospital is a good example of this.

These proposals may be carried out in those systems concerned with the aging and chronicity of their populations, systems willing to transform their model of provision, which have professional nurses and which require of strategies to gain in sustainability for their health systems. For those willing to change, we hope they consider nurses as an opportunity.

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