Needs in palliative care in institutionalized people with advanced dementia

A multidimensional approach

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Summary
Palliative Care is an appropriate typology of care for institutionalized older people with Advanced Dementia. It is necessary to take into account their unique needs and circumstances to guarantee a good quality of life and satisfaction with the health care received. The aim of this study was to identify the needs in Palliative Care associated with institutionalized people with Advanced Dementia. An exploratory two-stage qualitative study was developed. After a narrative literature review, all the phenomena related to the subject were identified as being a possible need in palliative care. This data was discussed and evaluated by two focus group with Portuguese and Spanish experts in the fields of Geriatrics, Psycho-geriatrics, Neurology, Geriatric Nursing, Psychology and Continuity Care. The needs in Palliative Care were identified and categorized into seven dimensions: physical, psychological, social, spiritual, economic, legal and environmental. The identification of these needs is the first step to ensure the provision of Palliative Care with quality and adapted to the particularities of each older person institutionalized.
KEYWORDS: NEEDS; PALLIATIVE CARE; DEMENTIA; INSTITUTIONALIZATION.

Introduction

Dementia is a major challenge for today's global public health. According to the World Alzheimer Report 2014 there are about 44 million people living daily with a dementia. It is expected that this number will double in 2030 and that there are around 7.7 million new cases per year worldwide[1].

Dementia is a syndrome, of a chronic and progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities[2,3]. This disease is a leading cause of disability and dependency among older people[4,5] which may become an overwhelming situation for the patient, their caregivers and families[4].

As dementia progresses and it develops into an advanced stage, cognitive impairment, physical dependence and other symptoms presented by the elderly, as well as their health needs, are similar regardless the type of dementia presented[6].

The advanced stage of dementia, according to the Clinical Dementia Rating (CDR), is characterized by severe memory loss, absent of spatio-temporal orientation, disability in decision making and problem solving and inability to participate in social events outside home; the individual with Advanced Dementia needs help in all activities of daily life and in his personal care; and is often incontinent[7].

Dementia is associated with complex needs[8,9] which include identification, diagnosis and symptom management as well as long-term support. These often challenge the skills and capacity of the health services2. The development of institutionalization units related to the long-term care of the elderly provided permanent and appropriate services to this population[10,11,12]. "Institutional care" stands for institutions and living arrangements where care and accommodation are provided jointly to a group of people residing in the same premises[12].

In developed countries, institutionalization is a relevant typology of care for people with moderate to advanced dementia and is considered to be an appropriate strategy in meeting the needs and care provision of this population[5,13]. In fact, recent studies suggest that around 80% of the

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institutionalized elderly have a diagnosis of dementia or significant memory problems[14].

Providing care to these residents requires knowledge and skills specific to their medical, physical, cognitive and supportive domains[15]. Institutionalized older people with Advanced Dementia have specific care needs, particularly related to palliative care[16-18]. This raises challenges for medical, nursing and other practitioners in terms of dealing with physical and psychological symptoms, spiritual and social needs and other aspects of palliative care[19].

Need

Health care is based on the identification of individual and collective needs that require some type of intervention[20] to achieve the nearest possible state of health as it is defined by the World Health Organization since 1946: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity"[21]. This is evidenced by Culyer, stating that medical care is commonly cited as a service to be distributed according to "need"[22].

Needs represent an imbalance, gap or lack of adjustment between the present situation and a new or changed set of conditions; they may be viewed as the difference between "what is" and "what ought to be"[20]. Green & Kreuter consider that need is everything that is involved in obtaining health and comfort[23]; and it may be defined as the gap between a current and a desired state of being[24]. Doyal & Cough claim that health needs are universal and even a basic human right[25] and to Culyer, need is a prospective concept because it identifies and enhances the interventions that can be done to improve the health status of an individual or population[22].

Currently, a large number of health professionals use the needs assessment as the starting point of their professional activity[26]. According to Leagans, people's needs are identified by finding the actual, the possible, and the valuable through situation's analysis[20].

The concept of need includes some disturbance in the state of health and well-being of an individual and need is defined by phenomena that require health care[27]. In their study, Lawrence and collaborators state that "there is a need to 'dementia proof' end-of-life care for people with dementia. If end-of-life care does not take into account the unique circumstances and needs of people with dementia, it is likely to fail them"[28].

Methods

Frequently, the older person with Advanced Dementia has lost the ability to communicate his needs. This reflects a main problem to the health care team: they don't know the desires, tastes, wills and needs of the recipient of care. If a professional caregiver is not aware of the specific needs in Palliative Care of an older person who is unable to express them, how can he/she implement adequate interventions to that person? It is in this context that was developed the research question of the present study: What are the Palliative Care needs of the institutionalized people with advanced dementia?

In this sense, this investigation aims to identify the needs in Palliative Care associated with institutionalized people with Advanced Dementia.

This article refers to the first stage of an investigation that pretends to identify and describe the needs in Palliative Care of institutionalized people with Advanced Dementia. This first stage refers to a qualitative exploratory study consisted of two phases: a literature review of the phenomena associated with palliative care, advanced dementia and institutional care (phase 1) and the organization, discussion and evaluation of this information through an expert's focus group (phase 2). The present study obtained informed consent of the Ethical Committee of Fundación Matia.

Data collection

A detailed literature review was conducted on Palliative Care, Long-term Care, Institutionalization and Advanced Dementia. It had the purpose of finding all the phenomena related to these topics, including signs, symptoms, diagnosis, treatments, interventions, health care, health objectives and needs. This research involved the use of databases, namely Medline, Elsevier and SciELO. The search was performed using the following keywords (mesh terms): needs, palliative care, dementia and long term care and their translation in Spanish and Portuguese. A resume of the literature review conducted and the included/excluded studies can be found in figure 1.

Additional searches were made through PsycINFO, Google Scholar and health libraries in Oporto (Medical School of the University of Porto) and in San Sebastián (Gipuzkoa Nursing Association). As a result it was obtained a set of phenomena related to the topics mentioned above.

According to the characteristics of each phenomenon found, it was made an initial categorization which included them in one of the dimensions that constitute the human person, in particular the institutionalized older person with Advanced Dementia: physical, psychological, social, spiritual, economic, legal and environmental. This initial list was then evaluated and criticised by Portuguese and Spanish experts in the fields of Geriatrics, Psycho-geriatrics, Neurology, Geriatric Nursing, Psychology, Continuity Care and relatives of institutionalized elderly with Advanced Dementia who work in health care (nurses). All the experts had experience with Palliative Care.

This expert's revision was conducted in two different focus groups due to the number of experts participating. Due to a geographical impossi-

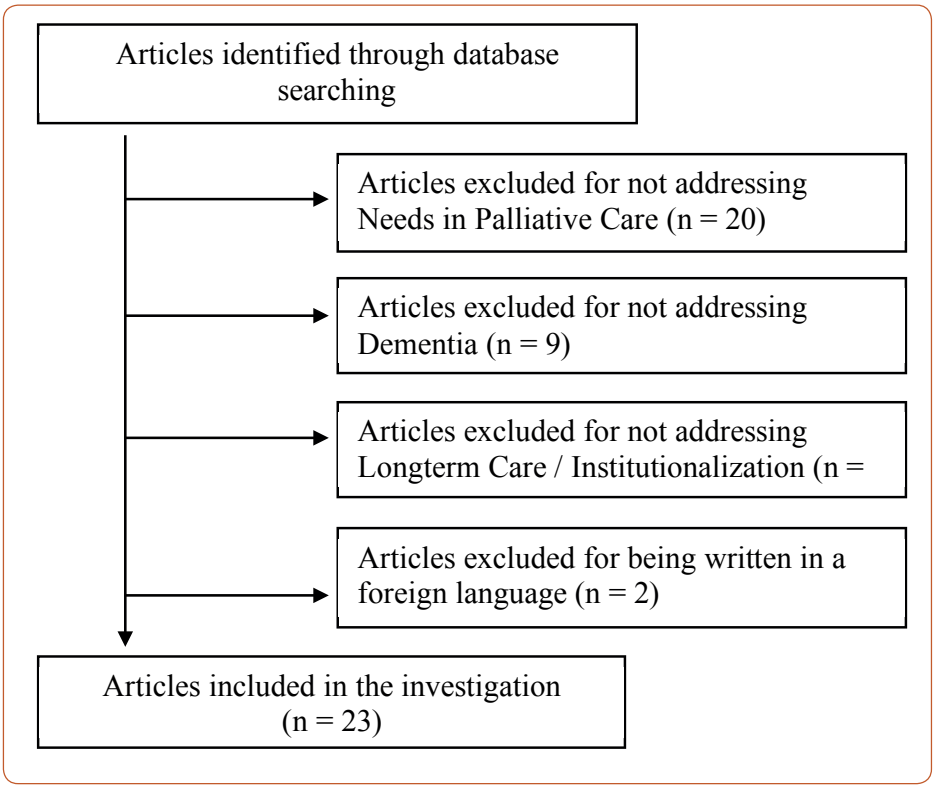

Figure 1. Chart of included and excluded studies

bility to attend and participate in the focus groups, one interview was held and two reports were received by e-mail.

All the analysis, comments and discussions were documented and those who were found to be relevant by the experts were integrated in the list of needs. The objective of the focus groups was not to achieve a high consensus about each need but to include all the relevant items related to needs in Palliative Care.

In the first and second phases of the investigation there were no human subjects involved. The experts who participated in this study were chosen by their professional relation with the Medical School of the University of Porto and Fundación Matia; and they are recognized by their work and experience in the fields described above.

An invitation to participate in the study was sent to all the experts by e-mail. It was explained to them the objective and methodology of the study; they had the opportunity to question the different aspects of the investigation and they could abandon it in any moment. The experts who participated in the investigation have all accepted to do it voluntarily. More information on focus groups and participants can be found in table 1.

Results

Through the literature review, focus groups, interview and reports were identified several needs which were categorized into seven different dimensions: physical, psychological, social, spiritual, economic, legal and environmental. In both focus groups it was decided to put the different needs in alphabetical order in each dimension as a strategy to avoid any kind of judgment about its importance or relation. These needs in Palliative Care are described in table 2.

The physical dimension is characterized by multiple phenomena and in order to facilitate the organization of information it has been carried out a sub-categorization of this dimension in the different body systems. In Focus Group 1 was suggested the integration of hiccups and hiperacusis (by geriatrician, MD and psychogeriatrician, MD) as physical needs, although it has not been found in the literature references to these phenomena. The inclusion of these phenomena was consensual in both focus groups.

Also in the physical dimension was included the domain of Vital Signs as the basis of the initial individual's physical assessment. In geriatric institutions is a common procedure the evaluation of oxygen saturation and blood glucose so these were included as other parameters. The domain of the General Aspects is characterized by phenomena that are often present at the end of life period and which are common to a large number of advanced and terminal pathologies.

In the Psychological Dimension (also differentiated into domains) were included the Basic needs defined by Tom Kitwood[29] that are considered as one of the central aspects in the care of people with dementia. The assessment of cognitive function, a complex task in this population, is facilitated by the identification of three aspects: Comprehension of simple sentences, Cooperation in care and Expression of a message (verbal or non-verbal). Although these aspects are also relevant in the social dimension and communication, it was consensual in both focus groups that they are crucial to the understanding of the cognitive function.

Under the Social Dimension (differentiated into domains), the family member (RN) with whom it was held the interview discussed the capability of a person with Advanced Dementia in establishing a relation with another person: "my mother almost doesn't recognize me, how can she relate with someone new and strange?". Through this testimony, in Focus Group 2 was decided to include the term "interaction" in the domain Social Contact. It may be

FOCUS GROUPS, INTERVIEWS AND RECEIVED REPORTS CHARACTERISTICS 1

		FG 1	I	R	FG 2	Total
Field of Expertise	Geriatrics	1			1	2
	Psycho-geriatrics	1				1
	Neurology	1		1		2
	Geriatric Nursing	2			2	4
	Psychology	1			1	2
	Continuity Care			1		1
	Family relatives		1		1	2
Sex	Male	2		1	1	4
	Female	4	1	1	4	10
Nationality	Portuguese	2		2	2	6
	Spanish	4	1		3	8

FG: focus group; I: interview; R: report.

suitable in more advanced cases of dementia (for example, stage 7 of the Global Deterioration Scale[30]). This discussion raised some discomfort for the experts, and one of Geriatric Nurses (RN) affirmed: "if we consider that an older person is not able to relate with another person, we will be closer to consider her less as a person and aren't we diminishing her dignity? Shouldn't we have a positive attitude and enhance the relationship even if it's difficult to get a feedback?".

The Legal Incapacity of an individual with Advanced Dementia is seen as relevant by health professionals since it identifies a legal guardian and the person who will be a member of the interdisciplinary healthcare team. However, this is not shared by the family member (RN) present in Focus Group 2 who suggested that the legal incapacitation is a secondary process and a formality: "Me and my sister take the decisions in relation to my mother together. It is true that in situations of family conflict or absence of family or caregivers it would be necessary to identify a guardian but in most cases it is simply a legal process and a source of stress for the family".

One of the experts in Continuity Care (RN, MSc, PhD) who sent a report questioned the health objectives of identifying the different needs: "In the different dimensions, domains and systems what is intended? Risk assessment? Monitoring? Prevention? Treatment?" This question was raised in Focus Group 2 and it was consensual that in this phase of the research the objective is to identify the main and general needs in Palliative Care; the determination of an objective would only be appropriate in individuals and specific situations.

Upon completion of the focus groups was consensual that it was achieved a good articulation between dimensions, domains and systems and that these allow a global and comprehensive understanding of the needs in Palliative Care of the institutionalized older person with Advanced Dementia.

Discussion

It is often described in the literature that older people with Advanced Dementia have multiple and complex health needs[2,9,31]. However, it is not common their description and the present study aims to address this subject by identifying and describing the needs in Palliative Care of this population in the context of Institutionalization and Long Term Care.

The categorization of needs according to the several dimensions that constitute the human person allows a good comprehension of these needs[32] and the way in which they influence the living of the person with Advanced Dementia. It is widely recognized that the provision of Palliative Care includes the physical, psychological, social and spiritual dimensions. In the World Health Organization's definition, Palliative Care includes the "assessment and treatment of pain and other physical, psychosocial and spiritual problems"[33].

Several of the described physical needs are often present in the same individual and may constitute a set of morbidities for the older person, a very common situation in Advanced Dementia. Although some of these aspects are not specific to this disease, they are often presented by the population under study.

The psychological dimension is composed with very particular needs of Advanced Dementia: the cognitive deficits and behavioral disorders are intrinsically linked to this disease[34]; they have a great affectation in health care and are one of the main factors leading to institutionalization[14]. The diagnosis and management of these disorders with pharmacological and non-pharmacological interventions requires training and expertise from the interdisciplinary team.

The Person Centred Care Theory developed by Kitwood identifies as common basic needs for people with dementia: Attachment, Comfort, Identity, Inclusion and Occupation[29]. These phenomena can be considered as needs, goals in health care and allow a result's evaluation. This model combines the social dimension (is based on the relationship with other people and on the realization of significant activities), the spiritual dimension (by enhancing the identification with the person itself and by performing activities according to their life history, preferences and culture) and the environmental dimension (to adapt the physical structure into a cosy and familiar atmosphere and by enhancing a close relationship with the health professionals) that also facilitate the intervention in physical and psychological needs.

Reflecting on the discussion related to the person's with Advan-

NEEDS IN PALLIATIVE CARE OF THE INSTITUTIONALIZED PERSON WITH ADVANCED DEMENTIA **2**

	Domain	Needs
Physical Dimension	Vital Signs and additional signs	Blood Pressure. Body Temperature. Heart Rate. Respiratory Rate. Glycemia. Oxygen Saturation.
	General Aspects	Anorexia. Bleeding. Cachexia. Edema. Infectious Process. Inflammation. Odor. Pain.
	Digestive System	Bowel incontinence. Constipation. Diarrhea. Dysphagia. Fecaloma. Hiccups. Nausea/Vomit. Sialorrhea. Xerostomia.
	Integumentary System	Dry/flaky skin. Ecchymosis/Hematoma. Hyperhidrosis. Moisture lesion. Pallor. Pressure ulcer. Pruritus. Wound.
	Nervous System	Daytime sleepiness. Delirium/Acute Confusional State. Dizziness. Hallucination. Paresis. Seizure. Sleep disturbances (Insomnia). Syncope.
	Respiratory System	Airway obstruction/Choking. Aspiration. Cough. Cyanosis. Dyspnea. Sputum/Secretions.
	Skeletal / Muscular System	Immobility. Joint stiffness. Sarcopenia.
	Sensory System	Decreased visual acuity. Hyperacusis. Hypoacusis.
	Urinary System	Oliguria. Urinary Incontinence. Urinary Retention.
	Nutrition	Assessment of Body Mass Index, albumin and hematocrit. Decreased food intake. Dehydration. Hydration. Negativity to feeding. Weight loss.
Psychological Dimension	Basics	Attachment. Comfort. Identity. Inclusion. Occupation.
	Cognitive	Comprehension of simple sentences. Cooperation in care. Expression of a message (verbal or non-verbal).
	Behavioral	Aggression (physical or verbal). Agitation. Anxiety/Nervousness. Calm. Demanding/Calling attention behavior. Interaction with objects. Irritability. Isolation. Negativity to care. Passive involvement. Repetitive behavior. Restlessness. Sadness/Cry. Self-care. Self-injury.
	Emotional	Anger/Rage. Body Language (tense/relaxed posture, repetitive movements, balancing, protect a body part, abnormal posture...). Emission of sounds (moans, cries…). Emotional lability. Facial expression (smiling, closed, tense...). Fear.
	Personal Integrity	Appearance and physical aspect. Inability to ask for help. Security. Support.
Social Dimension	Communication	Empathy. Information/Orientation. Non-verbal communication (posture, gestures / physical movements, tone of voice, expression...). Physical contact. Time spent in the communication. Visual Contact.
	Social Contact	Family conflicts. Recognition of faces/people. Relationship with family, friends and informal carers. Visits from family, friends and informal carers. Interaction with other users. Relationship with other users. Interactions with healthcare professionals. Relationship with health professionals.
	Social Isolation	Knowledge of the reason for the institutionalization. Loss of previous relationships. Separation from close cohabitants.
	Culture	Knowledge of daily habits. Knowledge of the history of life (experiences and memories). Traditions and cultural preferences.
	Vocational	Interests. Leisure activities.
Spiritual Dimension	Beliefs	
	Religion	Rituals associated. Visit from the priest or representative of a religion.
Economical Dimension	Economic Support.	
	Social Support.	
Juridical Dimension	Legal Incapacitation (identification of the legal guardian).	
	Living Will/Declaration of Wills.	
Environmental / Structural Dimension	Adequate environment.	
	Adequate human resources (interdisciplinary team).	
	Adequate physical structure (light, sound, technical equipment and materials).	

ced Dementia capability to maintain a relationship (social dimension) and adding to consideration that an interpersonal relation can be associated to an affective bond between two people[35], it can be affirmed that people with an Advanced Dementia are in fact able to relate with another person. In fact the interpersonal relationships should be enhanced, avoiding the social isolation that occurs with some frequency in dementia patients[36]. As already mentioned Kitwood uses the term Attachment which may be understood as another term to describe this relationship[29]. In very advanced dementia situations, where there is a severe limitation of integration and emission of messages[30], the ability to relate may be diminished and the term interaction, developed in this study, appears to be appropriate. However, there was consensus among the experts that the relationship/interaction and social contact should be enhanced continuously.

In the context of the institutionalized older population, economic and environmental/structural dimensions gain a special emphasis in ensuring the provision of dignified health care and have a great influence on the quality of life experienced by the older person[10,37]. The institutionalization is a form of social support often used in developed countries in cases of Advanced Dementia[5,11,12] due to the physical and cognitive dependence, the occurrence of behavioral disorders and comorbidities and the need for continued care[8,38].

In the case of people with Advanced Dementia, where there is a cognitive incapacity for the decision-making process[30], the legal dimension is also relevant. Situations of total or partial legal incapacity and the presence of legal guardians are quite frequent in this population. However, as observed in the present study, this dimension may be considered as less important by the family members, even though there have been recent developments in this area (the development of the living will legislation in Portugal for example).

The need's description in this study did not followed a theoretical model in particular and wasn't used a specific classified language because it wasn't identified a scientific language or theoretical model valid and accepted by all the disciplines who participated in this research.

The presence of a relatively small number of experts is considered a limitation of the present study. Moreover, with the representation of only two nationalities it is possible that other needs could be identified in different contexts. One of the difficulties faced in the need's categorization consists on the interdependent relation between these needs, which is also relevant for its understanding.

In a later stage of this investigation, the needs identified in the present study will be applied to institutionalized older people with Advanced Dementia in order to confirm the data obtained and the needs in Palliative Care with greater relevance.

Conclusion

Advanced Dementia is associated with complex needs that often challenge the skills and capacity of the workforce and services[2,31].

According to World Health Organization, the main goals for care in dementia are early diagnosis; an optimal physical and cognitive condition; activities and well-being; the identification and treatment of co-morbidities; and the detection and treatment of behavioral/psychological symptoms[4]. The first step to achieve these objectives is the identification of the needs presented by an individual. This will allow an appropriate diagnosis, planning of care and its execution.

A set of needs presented by a specific individual is always unique according to the characteristics of each person. The findings of this study should be considerate as a foundation in the process of identification Palliative Care Needs with Advanced Dementia but don't determine them. It's essential an individualized evaluation and an interdisciplinary approach to guarantee that the needs identified and the care planned and received are suitable for each person.

In a posterior phase of the study these findings were transformed into questionnaires and were applied to an institutionalized population with Advanced Dementia in Spain as a way to explore their incidence and significance.

Bibliography

1. Alzheimer's Disease International. World Alzheimer Report 2014: Dementia and Risk Reduction, an Analysis of Protective and Modifiable Factors. London: Alzheimer's Disease International; 2014.
2. World Health Organization. Dementia: a public health priority. United Kingdom: World Health Organization; 2012.
3. National Collaborating Centre for Mental Health. Dementia: A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care. National Clinical Practice Guideline Number 42. Great Britain: The British Psychological Society and Gaskell; 2007.
4. World Health Organization. Dementia: Fact sheet No 362. [Web site]. 2015 - [cited 2017 Aug 12]. Available at: http://www.who.int/mediacentre/factsheets/f s36 2/en/.
5. International Longevity Center – UK. Non-Communicable Diseases in an Ageing World: A report from the International Longevity Centre UK, HelpAge International and Alzheimer's Disease International lunch debate. London: ILC-UK; 2011.
6. Volicer L. End-of-life care for people with progressive dementias: promoting quality of life. Oral communication presented in: IAGG/ WHO/SFGG Workshop; 2010 Jun 4-5; Toulouse, France.
7. Hughes CP, Berg L, Danziger WL, et al. Clinical Dementia Rating (CDR) Scale. Br J Psychiatry. 1982 Jun;140:566-72.
8. Luppa M, Luck T, Weyerer S, et al. Prediction of institutionalization in the elderly: A systematic review. Age and Ageing. 2010 Jan;39(1):31-8.
9. Beer C, Flicker L, Horner B, et al. Factors Associated with Self and Informant Ratings of the Quality of Life of People with Dementia Living in Care Facilities: A Cross Sectional Study. PloS one. 2010 Dec;5(12):1-5.
10. Alzheimer's Association. Dementia Care Practice: Recommendations for Assisted Living Residences and Nursing Homes. Chicago: Alzheimer's Association; 2009.
11. Governo de Portugal, Segurança Social. Idosos [Web site]. 2016 - [cited 2018 Jul 17]. Available at: http://www4.seg-social.pt/idosos.
12. European Commission. Long-Term Care for the Elderly: Provisions and Providers in 33 European Countries. Luxembourg: Publications Office of the European Union; 2012.
13. Li Q, Zheng NT, Temkin-Greener H. Quality of End-of-Life Care of Long-Term Nursing Home Residents with and without Dementia. J Am Geriatr Soc. 2013 Jul;61(7):1066-73.
14. Alzheimer's Society. Low expectations: Attitudes on choice, care and community for people with dementia in care homes. London, Alzheimer's Society; 2013.
15. Cadigan R, Grabowski D, Givens J, Mitchell S. The Quality of Advanced Dementia Care in the Nursing Home: The Role of Special Care Units. Med Care. 2012 Oct;50(10):856-62.
16. Ngo J, Holroyd-Leduc J. Systematic review of recent dementia practice guidelines. Age Ageing. 2015 Jan;44(1):25-33.
17. Ministerio de Sanidad, Política Social e Igualdad. Estrategia en Cuidados Paliativos del Sistema Nacional de Salud: Actualización 2010-2014. Madrid: Ministerio de Sanidad, Política Social e Igualdad Centro de Publicaciones; 2011.
18. Lorenz KA, Lynn J, Dy SM, et al. Evidence for Improving Palliative Care at the End of Life: A Systematic Review. Ann Intern Med. 2008 Jan;148(2):147-59.
19. Froggatt K, Reitinger E. Palliative Care in Long-Term Care Settings for Older People: EAPC Taskforce 2010-2012. European Association for Palliative Care; 2013.
20. Leagans JP. Concept of Needs. JOE. 1964;11:89-96.
21. World Health Organization. Constitution of the World Health Organization. [Web site]. New York: World Health Organization; 2006, [cited 2018 Jul 18]. Available at: http://www.who.int/governance/eb/who_constitution_en.pdf.
22. Culyer A. Need - is a consensus possible? J Med Ethics. 1998 Apr;24(2):77-80.
23. Green LW, Kreuter MW. Health promotion planning: an educational and environmental approach. 2nd ed. Mountain View: Mayfield Publishing Company; 1991.
24. The Royal College of Physicians and Surgeons of Canada. Defining Societal Health Needs: Royal College Definition and Guide [Web site]. 2012 - [cited 2017 Sep 2]. Available at: http://www.royalcollege.ca/portal/page/portal/rc/common/documents/policy/shn_definition_an d_guide_e.pdf.
25. Doyal L, Gough I. A theory of human need. Hampshire and London: MacMillan Press Ltd; 1992.
26. Wright J, Williams R, Wilkinson J. Development and importance of health needs assessment. BMJ. 1998 Apr;316(7140):1310-3.
27. Acheson R. The definition and identification of need for health care. J Epidemiol Community Health. 1978 Mar;32(1):10-15.
28. Lawrence V, Samsi K, Murray J, et al. Dying well with dementia: qualitative examination of end-of-life care. Br J Psychiatry. 2011 Nov;199(5):417-22.
29. Kitwood, T. The experience of dementia. Aging Ment Health. 1997;1(1):13-22.
30. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry. 1982 Sep;139(9):1136-9.
31. Passos J, Sequeira C, Fernandes L. The Needs of Older People with Mental Health Problems: A Particular Focus on Dementia Patients and Their Carers. Int J Alzheimers Dis. 2012;1:1-7.
32. Hutchison E. Dimensions of Human Behavior: Person and Environment. United States of America: SAGE Publications Inc.; 2011.
33. World Health Organization. WHO Definition of Palliative Care. [Web site]. 2018 - [cited 2018 Jul 12]. Available at: http://www.who.int/cancer/palliative/definition/en/.
34. Burns A, Winblad B. Introduction. In Burns, A., Winblad, B. (eds). Severe Dementia. England: John Wiley & Sons Ltd.; 2006.
35. Heider F. The Psychology of Interpersonal Relations. New Jersey: Lawrence Erlbaum Associates; 1958.
36. Dantas L, Ferreira L, Andrade C, et al. Impactos da institucionalização na saúde mental do idoso. Revista Portal de Divulgação. 2013 Sep;36:35-43.
37. Alzheimer's Disease International. World Alzheimer Report 2013: Journey of Caring an Analysis of Long-term Care for Dementia. London: Alzheimer's Disease International; 2013.
38. Alzheimer's Society. Low expectations: Attitudes on choice, care and community for people with dementia in care homes. London: Alzheimer's Society; 2013.