Quality of Life in Dementia

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Abstract

Dementia is a complex neurological syndrome which is characterized by the deterioration of cognitive functions. Elderly people are highly susceptible to this type of disease. Despite of the great variety of approaches to treat patients with dementia, quality of life is the primary and most important indicator that applies to them. The present paper examines how quality of life (QoL) is perceived by patients with dementia treated in different settings and their caregivers, factors that shape QoL, and approaches that increase QoL in the given category of patients.

Quality of Life in Dementia

A. Kada, S. (2013). Quality of life of nursing home residents: A comparative study of persons with and without dementia in regular units, and persons with dementia in different care settings. *Journal of Gerontology & Geriatric Research*, 02(03),1-5.

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| **Background/Introduction** | The increase in the prevalence of dementia in society suggests that more attention should be paid to quality of life for people living with the disease. |
| **Review of the Literature** | Kada’s (2013) relies on 24 peer-reviewed studies published within the last 17 years. |
| **Discussion of the Methodology** | The study relied on a mixed method research approach. The scientist used survey method to collect quantitative data. Qualitative data were collected through interviews with nursing home residents. |
| **Data Analysis** | Kada (2013) used Cronbach’s alpha to assess the internal consistency reliability of the adapted quality of life (QoL) questionnaire. |
| **Researcher’s Conclusion** | 1. There is no significant difference between QoL-AD score between residents with and without dementia in regular units.  2. There is no significant difference between QoL-AD score between residents with dementia in different care settings.  3. There is a significant difference between QoL-AD score between residents with different marital status. |

Research of Kada (2013) aimed at identifying whether residents of the regular units with dementia had lower QoL when compared to those without dementia, and whether residents of the special care unit with dementia had higher quality of life compared to individuals with the same condition hosted at a regular unit. This would give supportive evidence for the hypothesis that quality of life of residents in special care units was better compared those in the regular units. However, results of the study showed no significant difference between the perceived QoL in the studied groups. Evidently, perceived QoL depends on factors other than settings where patients with dementia receive treatment.

The findings suggested by Kada (2013) need further verification given a number of limitations involved in the research design. Firstly, the non-randomised one-time survey did not consider the duration of stay in the nursing home or the presence of concomitant diseases, factors that are considered to shape the perception of QoL in patients with dementia. Secondly, the collected sample is small to make reliable conclusions about the perceived QoL in patients treated in different types of settings. Thirdly, the questionnaire was not validated for people with dementia.

Research of neurological and behavioral disturbances in people can be challenging, since an ethical study involves obtaining informed consent from the participants. Although Kaad (2003) managed to obtain an approval from the Regional Ethical Committee for Medical Research and the Norwegian Social Science Data Services and an informed consent from caregivers participating in the study, he did not obtain it from patients. It is attributed to the fact that it is complicated to explain the research procedure to patients with dementia, and the author of the study can only take measures to ensure that participation in it does not disturb wellbeing of patients with dementia.

In order to collect evidence, Kaad (2013) utilizes mixed methods research framework. Quantitative data is collected through surveying patients with dementia and their caregivers. Qualitative data is obtained through interviews with residents of nursing homes. While using mixed method research Kaad (2013) aims to benefit both quantitative and qualitative approaches. Qualitative data collection enables Kaad (2013) to collect in-depth information to answer particular research questions, while quantitative methods provide numerical information for other research questions.

QoL in patients with dementia can also be addressed through using only qualitative or quantitative data collection tools. Such approach though involves a challenge of establishing a balance between strengths and limitations that are involved in a specific approach. Quantitative data collection tools may for example provide an objective vision of the research problem, but it is very complicated to obtain informed consent to participate in the study from dementia patients. In turn, qualitative data collection methods provide in-depth information on and valuable insights into specific research questions, but they involve a high probability of subjectivity, so the validity of research findings can be questioned.

B. Annotated Bibliography

1. Conde-Sala, J., Garre-Olmo, J., Turró-Garriga, O., López-Pousa, S., & Vilalta-Franch, J. (2009). Factors related to perceived quality of life in patients with Alzheimer's disease: the patient's perception compared with that of caregivers. *International Journal of Geriatric Psychiatry*, 24(6), 585-594. –The discrepancy between how AD patients perceive QoL and how it is assessed by their caregivers impacts the efficiency of treatment. The study conducted by Conde-Sala *et al* verifies this assertion thorugh comparing between perceptions of quality of life in patients with Alzheimer disease by care recipients and caregivers.

The findings though need further verification given the researchers focus on AD as one of the many types of dementia. Despite this limitation, the findings are of interest for caregivers, as they facilitate establishing the balance between their own perception with that of care recipients. Establishing this balance is important as Conde-Sala *et al* suggest that there is a disparity between AD patients’ perception of QoL, who view it more favorably, and their own. A favorable perception of QoL is an important precondition to effective treatment of patients with dementia.

1. Crespo, M., Hornillos, C. and de Quirós, M. (2012). Factors associated with quality of life in dementia patients in long-term care. *International Psychogeriatrics*, 25(04), pp.577-585. – QoL is a multifaceted concept. In their study, Crespo *et al* seek to identify factors that are associated with QoL as perceived by patients with dementia living in nursing homes and as viewed by their caregivers.

Knowledge about factors that are associated with QoL can be used to improve the efficiency of treating patients with dementia. The findings presented by Crespo *et al* need further verification given survey forms were not adapted for people with dementia. Notwithstanding this limitation, the findings are improtant not only for nursing researchers, but also for those who care for those living with dementia. While providing care, they are expected to consider that emotional state is the most important factor of QoL in patients with dementia. This finding contributes to better understanding of dementia and factors that influence the course of the condition.

1. Gallrach, F., Kirk, R., Hornblow, A. and Croucher, M. (2009). Quality of life in dementia: Money matters. *Alzheimer's & Dementia*, 5(4), 91. – Few studies adopt multivariate approach to analyze QoL dementia. In their research, Gallrach *et al* aim to measure QoL in persons with dementia and to suggest interventions to increase it.

Unlike previously analysed researches, the study of Gallrach *et al* offers strategies to increase QoL in patients with dementia. These strategies can be adopted, though with some reservations, given the study was conducted in a fairly specific context. The findings presented by Gallrach *et al* are of interest for nursing researchers, given the multivariate nature of the study, as well as for caregivers who are suggested practical steps to increase QoL in patients with dementia. In addition to the already mentioned factors, Gallrach *et al* name financial well-being as a precondition to high QoL in patients with dementia. The conclusions suggested by Gallrach *et al* provide a wide field for reflection on QoL in dementia.

1. Hoe, J., Hancock, G., Livingston, G., Woods, B., Challis, D. and Orrell, M. (2009). Changes in the quality of life of people with dementia living in care homes. *Alzheimer Disease & Associated Disorders*, 23(3), 285-290. – QoL is strongly influenced by the person with dementia’s mood. In their study, Hoe *et al* aim to identify the most significant changes that occur in QoL once a person is diagnosed with dementia.

The study contributes to understanding the relationship between dementia and QoL. Despite a fairly narrow research context, the findings allow concluding there is a relationship between dementia and QoL that is most often modified by an individual’s dementia mood. This finding is important both for nursing researchers who seek to understand changes taking place in dementia and caregivers who incorporate this knowledge to ensure an effective treatment. While summing up survey and interview findings, Hoe *et al* conclude that QoL is often preconditioned by a mood of an individual diagnosed with dementia. Similar findings was made by Conde-Sala *et al*, which encourages to approach strategies in which the mood of patients diagnosed with dementia can be controlled.

1. Inouye, K., Pedrazzani, E., Pavarini, S. and Toyoda, C. (2010). Quality of life of elderly with Alzheimer’s disease: A comparative study between the patients and the caregiver’s report*. Revista Latino-Americana de Enfermagem*, 18(1), 26-32. – QoL is perceived differently by patients with dementia and their caregivers. This conclusion was made by Inouye *et al* after comparing between the reports of the former and the latter.

Finding consistency between how patients with dementia and caregivers percept QoL has become an important breakthrough. The existing consistency provides insights into establishing efficient treatment; however the findings should be accepted with some reservations given the subjective nature of self-reports. The conclusions presented by Inouye *et al* will be of particular interest for nursing researchers and practitioners who seek to explain the nature of and bridge the perception of the major stakeholders of the treatment process. The findings suggest that there is a high level of consistency between the relatives’ and patients’ perception of QoL. Although this finding is contrary to the previously discussed, the methodology suggested by Inouye *et al* does not challenge its veracity.

1. Kada, S. (2013). Quality of life of nursing home residents: A comparative study of persons with and without dementia in regular units, and persons with dementia in different care settings. *Journal of Gerontology & Geriatric Research*, 02(03), 1-5. - The increase in the number of elderly people and the increase in the prevalence of dementia in society suggest that more attention should be paid to quality of life for people living with the disease. In his study, Kada aims to compare QoL between persons with and without dementia in regular nursing home units, and to compare between the QoL between persons with dementia in different care settings.

The findings are important, as they suggest that QoL is not preconditioned by the type of care setting. However, a small sample and negligence of a number of important factors question the validity of Kada’s conclusions. If the findings are verified, they will be of particular interest for caregivers who realize that quality of their services is preconditioned by multiple factors, but hardly by the type of care settings. The patient’s marital status is a more important factor shaping QoL in dementia. This is quite a bold statement that was though verified in previous research.

1. Marventano, S., Prieto-Flores, M., Sanz-Barbero, B., Martín-García, S., Fernandez-Mayoralas, G., Rojo-Perez, F., Martinez-Martin, P. and Forjaz, M. (2014). Quality of life in older people with dementia: A multilevel study of individual attributes and residential care center characteristics. *Geriatrics & Gerontology International*, 15(1), 104-110. – The individuality of a patient with dementia shapes his or her QoL. This conclusion was made by Marvetano *et al* when comparing between the characteristics of institutionalized people with dementia.

The research adopts a completely new approach as previously conducted studies tend to focus on external factors shaping QoL in patients with dementia. Although the study has a very accurate methodology, one may question the validity of findings, as there is no control group. Meanwhile, the conclusions are of interest for nursing researchers who take a look at one more factor shaping QoL in dementia and caregivers who incorporate knowledge about it in the treatment process. Marvetano *et al* suggest that such individual characteristics as functional independence, health status, and openness to dialogue increase QoL in patients with dementia. While written in a plain language and with an accurate methodology, the study provides a comprehensive and insightful picture of QoL in dimentia.

1. Maslow, K. and Heck, E. (2005). Dementia care and quality of life in assisted living and nursing homes: Perspectives of the Alzheimer's Association. *The Gerontologist*, 45(Supplement 1), 8-10. – Measuring QoL in patients is dementia is a frequently overlooked issue. While summarizing the experience of Alzheimer’s Association, Maslow & Heck identify its major components and provide recommendations to increase QoL in dementia.

The findings presented by Maslow & Heck are very important, as the researchers incorporate professional experience in what was former viewed as *terra incognita* of health care. However, the majority of presented findings are evidence-based, rather than empirical, which makes some experts wonder the accuracy of conclusions that are presented by Maslow & Heck. Despite the possible limitations, the study will be of particular interest for health care practitioners and families that care for individuals with dementia. From it, they will learn about the relationship between dementia and QoL and the key factors that shape the latter, for example patient’s perception, caregiver’s attitude, and health care provider’s competence. Written in a plain language and a coherent manner, the article by Maslow & Heck provides valuable insights into delivering quality care to patients with dementia.

1. Missotten, P., Thomas, P., Squelard, G., Di Notte, D., Fontaine, O., Paquay, L., De Lepeleire, J., Buntinx, F. and Ylieff, M. (2009). Impact of place of residence on relationship between quality of life and cognitive decline in dementia. *Alzheimer Disease & Associated Disorders*, 23(4), 395-400. – The attempts to identify the relationship between the perception of QoL in dementia patients and their place of residence have already been made by Kada (2013) and other experts. Missotten *et al* though suggest a different approach to the issue through comparing between cognitive decline and LoQ for institutionalized dementia patients and dementia individuals living at home.

The findings are very important, as they put an end to the protracted debate on whether dementia patients should be placed in special institutions, or whether their families should take care of them. While providing some very interesting conclusions, Missotten *et al* though do not explain the nature of the relationship between QoL and place of residence. In general, caregivers learn that institutionalized dementia patients show better scores for QoL when compared to non-institutionalized patients. This finding allows concluding that institutionalizing patients with dementia is a better in terms of QoL option when compared to entrusting care to relatives. Despite the finding is contrary to the common belief that family interactions are very important for dementia patients, the accurate methodology and consideration of ethical issues leave no doubt in its validity.

1. Orgeta, V., Orrell, M., Hounsome, B. and Woods, B. (2014). Self and carer perspectives of quality of life in dementia using the QoL-AD. *Int J Geriatr Psychiatry*, 30(1), pp.97-104. – QoL is an important indicator of an effective treatment of patients with dementia. The stufy conducted by Orgeta *et al* aimed to compare self and carer ratings of QoL in PwD.

Although the comparison between the patient’s and the carer’s perception can be seen in previous study, Orgeta *et al* provide information about the factors that influence it. The information about these factors though should be considered with some reservations given the subjective nature of self-reporting. The verified findings would be of particular interest for nursing researchers who seek to explain the discrepancy between the perception of QoL in dementia patients and carers; and it will be useful for carers who incorporate understanding of this discrepancy in their practice to deliver better care. While approaching the study, it can be concluded that understanding the discrepancy between perceptions is the most important precondition to quality treatment. Orgeta *et al* contribute to this understanding through identifying factors that shape it.

The collected evidence is adequate to make a recommendation for a practice change. The analysis of ten research studies allows identifying that the perceived QoL does not depend on the type of setting where patients with dementia receive care, but is preconditioned by a number of other factors, including a patient’s health status, functional independence, and ability to maintain social contacts. The retrieved information is considered to be important for three main reasons. Firstly, it confirms that there is a relationship between dementia and perceived QoL. In individuals with dementia, perceived QoL is lower when compared to individuals without dementia. Understanding this relationship encourages carers to pay closer attention to conditions in which patients with dementia live. Secondly, the examined studies suggest that there is a difference between how patients with dementia perceive QoL and how their carers perceive it. Understanding this difference provides insights into bridging the gap between the perceptions to ensure an effective cooperation between patients with dementia and their carers. Thirdly, the analysed studies identify factors that shape the perception of QoL in patients with dementia. Knowing these factors helps carers to organize treatment so that it best meets patients’ needs.

Treatment of people with dementia is interrelated with increasing the perceived QoL that is preconditioned by different factors. This conclusion was reached after summarizing ten research studies. The studies were selected according to two criteria. Firstly, the research topic is relevant to QoL in patients with dementia. Secondly, the study is recent (published with the last 5-7 years). The received knowledge is summarized below.

Dementia is a chronic degenerative disease, and it cannot be completely cured. Therefore people with this condition require life-long care. The outcomes of their treatment are mainly viewed from the point of quality of life and ability to perform everyday activities. Moreover, dementia affects mainly elderly people, and the burden of taking care often has a negative impact on normal life of their family members. The question of specialized care vs. family care for people with dementia is widely discussed in scientific literature. Still there is no unanimous opinion on this question. Thus, Juanita Hoe et al. (2009) in their research assessed the QoL of people with dementia, who stayed in the nursing homes in the UK. They have found that the reduced quality of life of people with dementia was largely influenced by expressed depression and anxiety symptoms, while improvement of cognition and mood resulted in increased quality of life (Juanita Hoe et al., 2009). Similar results were obtained in another research conducted by Vasiliki Orgeta et al. (2014). They have reported an association between patient’s level of depression and ability to perform everyday activities and the estimated level of QoL (Vasiliki Orgeta et al., 2014). Consistent results were obtained in several other researches performed by Conde-Sala et al. (2009), Franziska Gallrach et al. (2009) and Stefano Marventano et al. (2014). Taking into account the abovementioned, it can be concluded that the most important factors that predict patient’s perception of their quality of life include level of depression (patient’s mood) and ability to perform activities of the daily living. Another interesting direction of these researches was comparison of patient’s and care givers estimates on the QoL scale. It was made in order to evaluate the level of consistency between two estimates and reveal good sensitivity of the care givers to the needs and states of the person with dementia. Interestingly, that greater functional autonomy was associated with a better perception of the QoL-AD in patients and even more so in caregivers (Conde-Sala et al., 2009). It was also worth mentioning, that caregivers tended to overestimate dimensions such as family, marriage and housing, as some of them were family members who lived in the same house and considered themselves as good to their elderly family members (Inouye K. et al., 2010). Interestingly, that the QoL scores of both patients and caregivers were higher when a carer was a spouse than when the carer was a son or daughter (Conde-Sala et al., 2009). The use of such evaluations might have beneficial effect on patient’s state and its application in regular practice could contribute to better understanding between the person with dementia and the care giver.

In addition, several researches were focused on comparing of quality of life of residents in different nursing homes with those who received home-based care. Despite of the results of multilevel analysis, which showed that the 16.4% of the differencesin QoL was related to residence factors (Marventano S. et al., 2014), there were no consistent data on which type of nursing home is better. In example, Missotten P. et al. in their research concluded that there is no direct relationship between cognitive declineand QoL, and QoL does not seem to be better at home comparedwith the institution (Missotten P. et al., 2009). While Maslow K. et al. reported that change in qualityof life was better in facilities that used a specializedworker approach, trained more staff, and encouraged activityparticipation (Maslow K. et al., 2005). Kada S. et al. and Crespo M. et al. in their turn suggested that facility features and family and staff members’ personal features donot affect QoL ratings (Kada S. et al., 2013; Crespo M. et al., 2010).

With regards to the available information, it could be advised to pay much attention to the psychological state of people with dementia. Pharmacological treatment can improve symptoms of depression and help to recover the ability to perform everyday activities, which in it turn can have a positive effect on the overall quality of life. However, there is a wide variety of non-pharmacological methods that showed their efficacy in treatingf dementia. There are no strong evidences of better results in case of home-based care, or regular units compared to the specialized care centers. Still using the QoL-AD questioner is promising in evaluating the state of the patient. All the above mentioned researches used this type of scale in their assessment. standard scale includes 13 items: 1) physical health, 2) energy, 3) mood, 4) living situation, 5) memory, 6) family, 7) marriage or significant other, 8) friends, 9) self as a whole, 10) ability to do chores around the house, 11) things for fun, 12) money, 13) life as a whole. The person interviewed (whether the patient or his/her relative or care giver) should rate these parameters depending on their perception of the wellbeing. After completion of the questioner the overall score is calculated. This value gives an opportunity to evaluate the patient’s quality of life and determine which aspects have greater importance and which aspects need to be corrected. This questioner is convenient to use and could be applied in different researches. As psychological comfort is one of the most important targets in treatment of people with dementia the QoL estimate can be quite representative in evaluating the treatment results. However, this method has some limitations. First and the most important is that the mood of the patient influences the results of the evaluation. As patients with dementia often have depression and agitation, which can change with the periods of wellbeing, the results of this methods therefore can greatly vary. This scale is based on subjective perception of QoL by patient and only indirectly reflects the actual improvement in mental and physiological state. Moreover, this scale should be always validated before conducting the trial, to assure its applicability to specific needs and peculiarities of the condition.

Another tool used in the observed researches was Mini Mental State Examination (MMSE). This test is widely used to determine cognitive impairment, especially in people with dementia. It is a sensitive and reliable measurement of the current cognitive state of the person. It helps to examine such cognitive functions as language, attention and calculation, registration, recall, ability to follow commands and orientation. Though it is not very effective in determining mild mental disorders and in distinguishing different types of conditions as well as the areas affected, it was not necessary in the observed studies. MMSE estimate can serve as a reliable evidence of the patient’s mental state and can be used to observe the effectiveness of treatment, when repeated within some period of time.

While the review was aimed at determining the key factors affecting the quality of life of people with dementia the QoL-AD questioner was the only and the most important measurement taken. Among the items evaluated by this scale mood and physical health were the most important in determining overall quality of life. It was found that improvement in cognitive functions did not result in increase in QoL perception. The ability to perform everyday activities was associated with higher scores on QoL scale. Despite of the fact that results on the benefits from treatment in specialized care units was inconsistent, still there were evidences that positive attitude of the care givers and good relations in the working team have a positive impact on patient’s quality of life.

Nowadays there are many methods aimed at the involvement of people with dementia in different creative activities, such as music, theater, and drawing (Gerdner, L.et al., 2012). These activities help patients with dementia maintain social contacts, thus have a better perception of QoL (Marventano et al., 2014). Nurses play an important role in involving people with dementia in recreational activities. They not only take an active part in organizing social clubs (for example, clubs for avid readers or yoga classes), but also motivate patients are members of their families to participate in them.

Person-centered dementia care has a beneficial effect in the treatment of such conditions. Quality of care of people with dementia needs radical improvement (Kontos P., 2010). This improvement can be achieved by changing the ethic aspects of care in residential and nursing homes. People with dementia require special attention and attitude. Despite of the deterioration of the cognitive and physical activity, they can still participate in different type of activities, which can make them feel a part of the community and help in overcoming depression symptoms. Such improvements were shown in researches of Hattori H at al. (Hattori H at al., 2011). Nurses ensure quality care of patients with dementia through introducing and putting into practice rules of ethical treatment of dementia patients. They also ensure quality treatment while acting as a linking chain between a patient and a physician, and a patient and his or her family.

Involving people with dementia in research can be challenging as well as choosing the appropriate method to evaluate and fulfill the determined goal. Ethical aspects should always be considered before enrolment of patients. It is required to receive an informed consent, while in case of people with dementia, who have cognitive decline, it can be difficult to determine whether the person understands the terms and conditions of the study or not. The researches should try their best explaining the essentials of the study and what the person is expected to do. Another problem may occur in case of accidental disclosure of diagnosis, as patients sometimes are not aware of their diagnosis or simply can forget about it. However, such researches have a great importance. Earlier, only care givers, relatives and family members were involved in dementia studies. But this could not reflect the actual situation (Core principles for involving people with dementia in research, 2014). Nowadays, it is admitted that special trainings and educational tools should be used to prepare personnel and members of the family not only to take care of physical state of the patient with dementia, but also to use tools which will improve the psychological state of the person. From this point of view researches using QoL-AD questioner for people with dementia is a great step over. Understanding the needs and preferences of people with dementia will contribute to finding better treatment strategies. However, another option for research of people with dementia can include theoretical model. Theoretical model for nursing research can help to summarize the available knowledge and create a framework for further implementation into the healthcare practice. Conceptualization and search of evidences in literature can serve as a background for new approaches. Therefore, it is important to use both conceptual and theoretical frameworks as well as empirical results to improve the state of art in nursing practice. Nurses ensure that using dementia patients for research is ethical. This objective is achieved through advocating for patients’ rights and acting as a mediator between a patient and a researcher, and between the researcher and the patient’s family.

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