

Assessing quality of life of the lived experience in elderly with dementia

Anand P. Ambali

Professor, Dept. of Medicine, BLDE (Deemed to be University), Geriatric Clinic, Shri B M Patil Medical College Hospital and Research Centre, Vijayapura, Karnataka, India

***Corresponding Author:**

Email: anandambali@yahoo.com

Abstract

The seniors in India now constitute 9% of total population, and the prevalence of dementia is also rising. There is very less research happening in people with dementia. The approach to research quality of life in people with dementia especially their lived experiences, differs from general population. Involving the people with dementia itself is a challenging task. The main objectives of doing the research will be to know the person living with dementia, secondly their lived experiences and thirdly its impact on their quality of life.

The multidimensional approach using interview method will be suitable especially in early stage of dementia. In developing countries, factors like illiteracy, superstition and low awareness about research hampers research work in people with dementia. The various approaches in understanding the persons lived experiences requires skills and patience in researcher.

This review is an attempt to share the issues that are to be faced while doing research on people with dementia especially those living in developing countries and that too in rural areas. The challenges are the ethical, communication, understanding local factors that influence quality of life and involving person with dementia along with family members. Various studies which have overcome these challenges has been mentioned here so that it will assist in research process.

Keywords: Research, developing country, experiences, person with dementia.

Introduction

Quality of Life (QOL) is multidimensional. It has different meaning to different individuals in different countries. Also in same country, it will be different among people residing in urban and rural areas. Quality of Life is mostly objective, hence subjective indicators to measure Quality of Life may at times underestimate or overestimate Quality of Life. The researcher should be aware that merely a person being diagnosed having dementia, the basic structure of Quality of Life will not change.

It is important to know the perspectives from people with dementia in early stage and that too by direct communication. Because they are the one who will be utilizing the services and policies when applied. Barnett 2000; Goldsmith 1996 and Cahill et al 2004, showed that the person with dementia when interviewed can provide accurate appraisal of their life.

The definition of quality of life expects individuals to make assessment of their quality of life. The issues are is the person with dementia capable to participate and how valid the answers can be? In the same way if proxy is involved, then the very basics of definition is lost. Dementia in early stages may challenge one's QOL. The people with dementia struggle to the changes that are occurring in body during early phase of dementia and adapt certain features to fulfil their life (Harman G 2006).

The another important aspect is to assess quality of life in various domains and not as a single entity. The domains can be co morbid conditions, social interactions, and self esteem activities. The common co morbid conditions that is seen in old age along with

dementia is depression. This is due to factors like osteoarthritis limiting physical activities, stroke producing physical disability and bereavement. In research of QOL these issues needs to be addressed. Such individuals where dementia is associated with depression, the QOL shall be very low.

People with dementia are the "hard to reach population" for research. (Shaghghi et al. 2011). The difficulties lie here are identifying them, counselling their family members and meeting them periodically. When the people with dementia are involved in research it leads to a better fit between health care and people with dementia, which leads to better QOL, autonomy, empowerment for them (Van Baalen et al. 2010) and makes it positive experience for them (Higgins 2013). One of the approach to measure of QOL is subjective evaluation. It means a good life being one that is experienced as such. (Brock D 1993).

I, support the QOL measure should be broad rather than disease specific, hence share this literature review regarding how to assess lived experience in terms of health and social issues by interview method. The benefit of the research should be owed to the people with dementia as they are the end users. This discussion should benefit the researcher in developing countries.

History of QOL

The initial description of QOL was given by Aristotle (Hays RD 2000). The concept then was good life is not only something to live for but also something to live by.

Definition of QOL

It is “an individual’s perception of their position in life, in the context of the culture and value systems in which they live, and in relations to their goals, expectations, standards and concerns” (WHOQOL Group 1995)

Why there is need to assess QOL?

1. The use of Quality of Life measure will help physician to know the feelings of the patient
2. For the physician, Quality of Life assessment helps in patient management.
3. It helps policy makers to develop supporting policies

What is already known on QOL from perspectives of people with dementia according to study by O’Rourke (2015b) are four major factors that have influence on QOL. The factors are 1) whether they are living together or alone, 2) what is the purpose in life, 3) whether illness is present, and 4) are they well located. This study has interviewed 345 participants with dementia and has shown that there are factors which are to be known from the person with dementia himself and are modifiable to attain good QOL.

The unidimensional models of Quality of Life are of not much use both for patients and clinicians. This is because the people with dementia may not have any problem with the disease process but will have problems in other aspects like social and emotional aspects which cannot be assessed using unidimensional model. The tool to measure QOL need to be multidimensional. This will ensure the clinician to know which aspect is bothersome for QOL. For example, In a person with stroke, he might have retained good QOL on some dimension, even if this illness detracts from others.

Aims and methods of research should be

1. To identify the elements that are meaningful and that have impact on self and identity in the person with dementia.
2. To identify the factors that promote good and bad quality of life
3. To identify accurate knowledge of what are their experiences in early stage and how they cope up with these changes.
4. To understand the health and social needs of the participants which are likely to enhance quality of life in them and involve them in policy making.
5. To find ways in which services will contribute to wellbeing of person with dementia.

Involving people with dementia in research

Research in dementia itself is a challenging area. Many authors have framed scales, tools, methods to assess quality of life in people with dementia. Equally many authors have brought out studies on this issue and have discussed challenges and solutions they faced while doing assessment of QOL in person with dementia. Still

I feel there is lack of holistic approach while using scales.

What is clear so far regarding involvement of people with dementia in research is that, the person with early dementia can be involved in research (Murphy 2007), we should hear the voice through direct communication at least in early stages (Barnett 2000; Goldsmith 1996 and Cahill et al 2004), allow them to speak which helps to know them better, people with dementia in early stages are more active to participate and they too can be part of suggestions to policy makers. And the most important thing noted is that, the proxy rating the QOL is lower than the people with dementia (Sheehan et al.2012, Moyle et al., 2012.). According to Hulko 2009, the QOL in person with dementia improves when they are able to do the things and contribute to their households’ chores and community. To make a policy or a program which improve QOL in person with dementia, the participation of person with dementia is vital. The research should focus on the health and social domains of life of person with dementia, which have impact on QOL.

To enable the person with dementia in research, participation ladder described by Binkhorst 2009 is worth mentioning here. It has five steps and are as follows.

1. Information – the person with dementia is informed about research
2. Consultation – the researcher wish to know the opinion of the client
3. Advice -the researcher listens to ideas of the person with dementia
4. Partnership – the collaboration is based on equality
5. The person with dementia determines priorities in the research.

Approach to the research

Knowing QOL from people with dementia was studied by O’Rourke et al (2015) using interview method and focus group discussion. The challenges described so far are cultural background, ethnicity, economic status, consent, reliability of the proxy and gender differences. In India, apart from above mentioned challenges we come across illiteracy, superstition and noncompliance in research. As a clinician, I feel communication with older people is more challenging. Apart from having cognitive decline, they can have decreased vision and hearing, and speech defects which a researcher needs to overcome.

It need to emphasize how a person live with a disease and how he perceives various aspects of the disease that affects. Browne et al 1994 is of view that only focussing on health status may not describe QOL completely. Dabbs 1999, is of opinion that aspects of life like social, emotional and intergenerational relations along with health are more important in defining QOL. Hence the lived experience of the person with dementia will be complete only when we assess multiple dimensions.

While involving people with dementia in research, following steps needs to be followed:

1. To take informed consent
2. To communicate in a better way
3. To provide comfort and keep the person involved throughout research process
4. Follow guidelines while interviewing the person.
5. And overcome miscellaneous issues

1. Informed consent

To begin with first meet the family members initially and appraise them about the concepts in research and take their permission to access the person. Once the permission is granted, the person with dementia is appraised about the research, method of research and confidentiality that will be maintained. If the person with dementia does not give consent, he is not included in the study. Even if the participant wish to dissent during the process, it should be respected. Then signature of the person and family members should be taken on a suitable consent form.

2. Communication

While discussing with person with dementia address his problem as 'Memory problem' rather than dementia. This will help them feel more positive. Try to meet the person once or twice before the actual research process begins. This will help us know the nature of the person, what time he will be active and what are the hobbies carried out.

The schedule timing for the interview should be before lunch hours preferably, because at this time they are more alert. During conversation, one need to look at nonverbal cues and facial expression.

The questions asked will be short, read clearly and loudly. And for the reply we should have patience. One can print the questionnaire in large format preferably font of 14, so that if the participants wish to read, it should be easy to read. Always will use common words in the questions and avoid the words that gives double messages. There will be flexibility in the schedule, the order in which questions to be asked and content of the questions. The most important feature of the communication will be 'to listen'.

3. Keeping them comfort and involved

Keep the duration of interview short and will space at short intervals. Try to develop good relationship and trust. The open end questions will be used to assess the life style and daily routine schedule of the participants. Always end the conversation with a positive subject. The length of the interview will depend up on the ability of concentration of the participants.

4. Interview process

The interview will be conducted in familiar surrounding with less noise. The care giver or the gate keeper will be involved to support the participant and for

context information. It is vital to record answers given by participants as exactly as possible. The researcher shall thank the participant at end of the interview.

5. Address cultural issues

The cultural issue is the central and integral part of concept of QOL as mentioned in definition by World Health organisation. In my place, the dementia in older people is considered as part of old age and it has stigma associated with it. There is less awareness about dementia and most of the families avoid talking about it.

To address cultural issues, I feel merely translating the tool in local language will not make it culturally viable. It needs to address local issues prevalent in that locality. Few changes like adding local words to suit local meaning, measures used locally for good QOL should be included in measuring QOL will make the research culturally viable.

The people in my village spends time in watching stage drama, visiting temple, chanting mantras, participating in melas and festivals which has positive impact on QOL. Hence these cultural issues need to be considered to define QOL in older people with dementia.

6. Gender Issues

Gender is important determinant of Quality of life. It is found that men have better QOL than female counter part. The very important aspect of research in gender differentiation lies in that the women are more experienced and have maturity developed towards life after being through various experiences, feelings and emotions. The women also under go transition in identity from being very active to being dependent, from carer to being cared for, very literate to not understandable. These transitions affect QOL as mentioned by Borley et al 2016. It is worth mentioning the quote by Reinharz 1992, "*females are worth examining as individuals and as people whose experience is interwoven with other women*".

7. Overcome miscellaneous issues

To overcome superstition among mind set of people with dementia, involve the priest of that village and arrange to meet the person with dementia to convince the person to be part of research. Also the care givers and friends will be requested to share their advice with the person with dementia.

Approach to lived experiences

There are various approaches mentioned in literature regarding approach to the lived experiences of person with dementia. One of the project worth mentioning here is "Good Life" project. This project was carried out in university of Stirling has identified what components make a good QOL. The researcher has framed questions by working with thirty older people of five different communities. This study has a advantage that it has worked with people with dementia is person –

centre based. (Patton 2002). This study has also laid emphasis on participation and citizenship (Barlett and O'Connor 2007).

The another advantage of involving people and knowing their lived experiences is that there is a two way exchange occurring on an ongoing basis which also has impact on cultural shifts (Morgan 2014).

The older people here have high acceptance rate of good and bad happening with them. Even when they are abused, they feel it is their fate and have to accept it as there is no alternative, and if voice is raised they will not be taken care. On social front, many older people are restricted from attending marriages and cultural events to avoid embarrassment as dementia here is considered as mad disease. In such situation it shall be wise to involve people with dementia and stake holders in framing questions and try to understand effect of abuse and social isolation on QOL.

I being from medical background, I wish to add following factors concerned as health indicators of QOL. The health factors are: a) good appetite, b) moving around in home, c) less episodes of agitation, d) having control over bladder and bowel habits, and e) sound sleep. If these factors are in order, the person with dementia is leading good QOL atleast from health point of view. Authors like Akdag et al 2013, Leon-Salas et al 2015, have explained the relationship between QOL and physical health, mobility and pain.

As far as social involvement is concerned, the two important aspects that are considered important here in my place for being social active is to attend marriages and visit temples. Questions on these social issues will be framed in the research. This will add to QOL from social angle. Another important issue that affects QOL is being abused. The older people with dementia are more prone for being abused. This will have negative impact on QOL. Hence it is important to know about abuse and even identify the signs, if it is happening.

Another issue which needs to concentrate is, the struggle of the person of dementia with the changes happening in them. The struggle needs to be valued. Steeman 2013, proposed being valued is more central in lived experiences of older people with early stage of dementia.

Strengths of interview method based study are:

1. This will help researcher to know the person with dementia in detail.
2. Variety of questions can be framed with keeping case research in view.
3. It will create open atmosphere which encourages participants to answer.
4. It will be more flexible, questions can be rearranged to suit the understanding of the person and can be conducted according to time convenience of person with dementia.
5. It helps clarify misunderstandings and tackle complex issues.

6. It gives first hand information of the issues related to person with dementia. The aim here remains is what factors determine the measure of QOL in them and most importantly the results of the research will be applied on participants itself. So the information gained during research will be 'for the people' of dementia by involving people with dementia.
7. The validity of the research model is increased when lived experience of the people with dementia are involved in development of conceptual frameworks. (Harrison et al. 2016)
8. There will be diversity of persons involved in the research.

The Limitations of interview based study

1. The limitations of such interview based research is Bias, which has been mentioned by various authors. It has been found that bias is seen in all types of interview and group based studies.
2. Another concern will be data management, analysis and interpretation. The validity of different stand points is usually questioned. However the sole objective of such research is to identify the perspectives of QOL in a given person with dementia in research than generalisation. I feel flexibility in questions will help overcome such issues.
3. It is also said that such research method need considerable skill and more time. Since our aim is to identify the factors that contribute to QOL, from perspectives of person with dementia, one can overcome by developing skills.
4. The direction of research may alter and the dementia progress to moderate form over period of time. So, the research process should be completed in short possible time.

Role of person with dementia in policy making

The research should highlight various factors that affect QOL of older people with dementia. The issues which are multidimensional like health and social aspects needs to be addressed. The very involvement of person with dementia in research and knowing their lived experiences has the advantage that there is accurate appraisal of their lives (Cahill et al 2004). Involving care givers, General practitioners and service providers while making policy will be an added advantage. In a study by McCabe and Bradley 2012, they found that many topics that were missed or misunderstood in research were rectified and also added in prioritising recommendations. The other method can be used is Focus group which has helped to enhance participation of people with dementia and define service dimensions of QOL (Bamford and Bruce 2000). The ethical issues with research in involving people with dementia can be overcome to certain extent by involving them as advisors in the research process.

After care

After completion of the research activity, the researcher shall meet the family members, care givers and person with dementia and appraise them the positive findings found in brief. During such small meetings one can share experiences in lighter ways. The recommendations for improvement in QOL will be made to policy makers.

Conclusion

Quality of life when assessed the lived experience of person with dementia will help know the person in all aspects of his life and is more than simply being participants. It enhances feel good effect on them. The sharing of their lived experience itself may improve their QOL. The research will identify the modifiable factors that contribute towards QOL which the policy makers can take a note of it. They are thus contributing to formation of services towards betterment of care services. The assessment of spiritual, personal beliefs and sexual life on QOL remains less explored. There is a definitive positive experience on QOL of person with dementia when they are involved in the research process. The outcome of the research should benefit to the well being in order to support dignity and autonomy of person with dementia and should be looked up on as a valuable person.

Conflict of Interest: Nil

Funding: Nil

References

- Akdag, B., Telci, E.A. and Cavlak, U. (2013) Factors affecting cognitive function in older adults: a Turkish sample. *International Journal of Gerontology*, 7 (3), pp.137-41.
- Barnett, E. (2000). *Including the person with dementia in designing and delivering care*. London: Jessica Kingsley.
- Binkhorst, P. & Lobenstein, 2009. Patienten betrekken bij de zorg in het ziekenhuis. Een handboek. Kwaliteitsinstituut Voor de gezondheidszorg CBO.
- Browne, J.P., O'Boyle, C.A., McGee, H.M., Joyce, C.R.B., McDonald, N.J., O'Malley, K. and Hiltbrunner, B. (1994) Individual quality of life in the healthy elderly. *Quality of Life Research*, 3 (4), pp. 235-44.
- Brock D (1993) Quality of life in health care and medical ethics. In Nussbaum M, Sen A (eds) *The Quality of Life*. Oxford: Clarendon Press, 95-132.
- Bartlett, R. and O'Connor, D. (2007) from personhood to citizenship: broadening the lens for dementia practice and research. *Journal of Aging Studies*, 21 (2), pp. 107- 18.
- Borley, G., Sixsmith, J. and Church, S. (2016) How does a woman with Alzheimer's disease make sense of becoming cared for? *Dementia*, 15 (6), pp. 1405-21.
- Cahill, S., Beglet, E., Topo, P., Saarikalle, K., Macijauskienė, J., Budraitienė, A., Hagen, I., Holthe, T. and Jones, K. (2004) "I know where this is going and I know it won't go back": hearing the individual's voice in dementia quality of life assessments. *Dementia*, 3 (3), pp. 313-30.
- Dabbs, C. (1999) What do people with dementia most value in life? *Journal of Dementia Care*, 7 (4), pp. 16-19.
- Goldsmith, M. (1996) *Hearing the voice of people with dementia: opportunities and obstacles*. London: Jessica Kingsley.
- Hays RD, Woolley JM (2000). The concept of clinically meaningful health -related Quality-of-life research. How meaningful is it? *Pharmacoeconomics*, 18, 419-23.
- Harrison, J.K., Noel-Storr, A.H., Demeyere, N., Reynish, E.L. and Quinn, T.J. (2016) Outcomes measures in a decade of dementia and mild cognitive impairment trials. *Alzheimer's Research and Therapy*, 8(48).
- Higgins, P. (2013) Involving people with dementia in research. *Nursing Times*, 109 (28), pp.20-3.
- Hulko, W. (2009). From 'not a big deal' to 'hellish': experiences of older people with dementia. *Journal of Aging Studies*, 23, 131-44.
- Harman G, Clare L 2006. Illness Representations and Lived Experience in Early-Stage Dementia. *Qualitative Health Research*. Vol 16 No. 4, April 2006 484-502.
- León-Salas, B., Ayala, A., Blaya-Nováková, V., Avila-Villanueva, M., Rodríguez-Blázquez, C., Rojo-Pérez, F., Fernández-Mayoralas, G., Martínez-Martin, P. and Forjaz, M.J., on behalf of the Spanish Research Group on Quality of Life and Aging (2015) Quality of life across three groups of older adults differing in cognitive status and place of residence. *Geriatrics Gerontology International*, 15 (5), pp. 627-35.
- McCabe, L. and Bradley, B.E. (2012) Supporting user participation in local policy development: the five dementia strategy. *Social Policy and Society*, 11 (2), pp. 157-69.
- Moyle W., Murfield, J.E., Griffiths S.G. & Venturato L. (2012). Assessing the quality of life of older people with dementia :a comparison of quantitative self-report and proxy accounts. *Journal of Advanced Nursing* 68(10), 2237-46.
- Moniz-Cook, E., Vernooij-Dassen, M., Woods, R., Verhey, F., Chattat, R., De Vugt, M., Mountain, G., O'Connell, M., Harrison, J., Vasse, E., Droes, R. M., Orrell, M. for the INTERDEM group. (2008) A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging and Mental Health*, 12 (1), pp. 14-29.
- O'Rourke, H.M., Duggleby, W., Fraser, K.D. and Jerke, L. (2015b) Factors that affect quality of life from the perspective of people with dementia: a metasynthesis. *Journal of the American Geriatrics Society*, 63 (1), pp. 24-38.
- Patton, M.Q. (2002) *Qualitative research and evaluation methods*. London: Sage. (Chapters 4, 6, 7 and 8).
- Reinharz, S. (1992) *Feminist methods in social research*. Oxford: Oxford University Press.
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray & K. Chamberlain (Eds.), *Qualitative health psychology: Theories and methods* (pp. 218-240). London: Sage.
- Steehan 2013. The lived experience of older people living with early-stage dementia. Academic centre of nursing and midwifery Gerontology and Geriatrics. <https://lirias.kuleuven.be>.
- Sheehan, B. (2012) Assessment scales in dementia. *Therapeutic Advances in Neurological Disorders*, 5 (6), pp. 349-358.
- Shaghghi, A., Bhopal, R. S. and Sheikh, A. (2011) Approaches to recruiting 'hard-to-reach' populations into research: a review of the literature. *Health Promotion Perspectives*, 1 (2), pp. 86-94.
- Thorgrimsen, L., Selwood, A., Spector, A., Royan, L., de Madariaga Lopez, M., Woods, R. T. and Orrell, M.

- (2003) Whose quality of life is it anyway? The validity and reliability of the Quality of Life-Alzheimer's Disease (QoL-AD) scale. *Alzheimer's Disease and Associated Disorders*, 17 (4), pp. 201-8.
28. The WHOQOL Group (1995). The World Health Organisation Quality of life Assessment (WHOQOL): position paper from World Health Organisation. *Soc Sci Med* 41(10):1403-9.
29. Van Baalen., Vingerhoets,J.J.M., Sixma, .J. & Lange,J.(2010). How to evaluate quality of care from the perspective of people with dementia: An overview of the literature. *Dementia*:10(1).