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The Journal of Geriatric Care and Research (ISSN 2397-5628) is a multidisciplinary, peer-reviewed, international journal covering all areas related to the care of the elderly. It is affiliated to Geriatric Care and Research Organisation (GeriCaRe). It publishes articles from all fields relevant to old age such as geriatric medicine, psychiatry, neurology, nursing, end of life care, public health and related fields like gerontology, sociology, psychology, culture and law. Besides the professionals, the journal intends to reach older persons and their carers as its readers. The key feature of the articles is their contribution towards the care of elderly through reporting, discussing and debating current issues of importance.

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Editorial

Creating age friendly health systems in India: challenges and opportunities

Palanimuthu T Sivakumar, Vijaykumar Harbishettar, Sojan Antony, A Thirumoorthy

Abstract

Increase in the percentage of elderly population in India poses challenges to existing health systems and opens opportunities for health care policymakers and professionals. Affordable quality health care is the right of the elderly population. Current health care system needs to invest resources to cater this requirement and to establish a comprehensive health system for elderly. Economic and social marginalization of the elderly population due to the cognitive decline and non-communicable diseases demand scientific planning to facilitate comprehensive geriatric care that is affordable and accessible particularly to indigent senior citizens in India. Further, the primary health care system has to be prepared to provide preventive, curative and rehabilitative services at community level.

Key words

aged, delivery of health care, health care facilities, manpower, and services, health services for the aged

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Population ageing and related health issues are emerging as a challenge for health systems globally, particularly in the developed countries with high proportion of elderly.[1] The proportion of the elderly population (aged 60 years and over) in India is around 9% currently and it is projected to increase rapidly in future. The projected proportion of elderly by the year 2050 is estimated to be around 20% in India,[2] thereby increasing the demand on healthcare delivery. World Health Organization (WHO) has proposed the development of age-friendly community and age-friendly health system to ensure the well-being of the elderly population.[3] Globally many other governmental and non-governmental organizations have also contributed to the development of the concept of age-friendly health systems.[4]

Some of the critical issues related to health care of elderly are the need for person-centered care, caregiver satisfaction, accessibility of a complete range of services required for geriatric care, shortage of trained health professionals and burden of cost for the health care providers as well as users. In addition to these, developing countries like India are facing the dual burden of non-communicable diseases related to population ageing as well as issues related to infectious diseases. In terms of the magnitude of the problem, the elderly population in India has already crossed 100 million. Globalization, industrialization, urbanization, migration and associated social changes have affected the structure of the families that were once considered as a reliable primary social support system for elderly compared to the developed countries.[5] Rising economy, increased life expectancy and decreased the size of the family demand the need for comprehensive health care system in India for the elderly population.

Health care service delivery in India consists of public and private health systems. The health system has predominantly been focusing on providing acute medical care.[5] Care for the chronic diseases such as non-communicable diseases has gained some importance recently. Specialty clinical services for elderly are possibly in its initial stages in India. This facility is provided through isolated tertiary care hospitals or institutions. These institutions offer training, trying to expand their services within their limited budget allocation. Awareness programs are being held to sensitize public and state authorities, to divert attention towards the healthcare need of elderly.

The important aspects of age-friendly healthcare system are preventive health, access to treatment for chronic medical conditions and rehabilitation. Preventive health care in elderly aims at delaying the onset of illness and prevent untimely or premature deaths.[6] WHO has focused on health promotion activities targeting the older adults.[7] The elderly people are likely to suffer from social isolation or loneliness. Golinowska et al suggest maintaining self-care, improving functional capacity and stimulating social network as part of health promotion activities.[7] The burden of care for chronic medical conditions is huge. As a step towards the achieving the universal health coverage, Patel et al studied the need for care towards cardiovascular diseases, diabetes, cancer and mental health disorders and advocated the need for care to the poor and rural populations.[8] The rehabilitation for elderly involves promoting independence, advocating to make their needs a national priority and organizing services, which occurs mainly in urban areas.[9]

In addition to the accessibility of care for elderly, the other key issues to be considered in health care delivery are the user-friendly environment and affordability, as most of the health insurance schemes do not cover the care of chronic illness. The health insurance schemes are run by both government and private organisations. The insurance would mostly cover the cost of acute medical inpatient care, but not for long-term management of chronic diseases. Therefore, there is a gap in the system in terms of affordability. Also, delivery of care requires motivated staff with appropriate training and sensitiveness towards the needs of elderly. The Indian National Program of Health Care for Elderly of 2011 aims to create healthy and active ageing and to create the architecture of ageing.[10] The implementation of measures to create age-friendly health-care systems and achievement of this objective is remaining as an unfulfilled wish even in most of the developed countries across the world. Advocacy from different agencies is required to ensure that care of the elderly gets the attention it deserves.

As per recommendations of WHO to ensure care access, Government of India has announced Universal Health Coverage by 2022, which is expected to involve the care of the elderly. There is a need to address the gap in senior citizen friendly infrastructure, knowledge, skills and trained manpower for delivering the quality health services to the ageing population. Public-Private Partnership and investments would be the solution to meet the challenging health needs of this population. Within the flagship programme of Skill Development by the Prime Minister of India, geriatric health care skills may be included; and youth population may be trained to take this as a career option. Promoting physical activity and social engagement among senior citizens would reduce physical and psychological morbidity and disability-adjusted life years among this population. Large-scale reforms in the healthcare sector at the government level, as well as the collective effort and advocacy from senior citizens, family members and other relevant governmental and non-governmental organizations, are required urgently to initiate work towards achieving 'age-friendly health system'.

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References

1. World Health Organisation. Global Health and Ageing. [Internet] Geneva: World Health Organisation. 2011. [cited 2018 May 31]. Available from: http://www.who.int/ageing/publications/global_health.pdf
2. Department of Economic and Social Affairs, World Population. [Internet] United Nations Report 2017. [cited 2018 May 31] Available from Aginghttp://www.un.org/en/development/desa/population/publications/pdf/ageing/WPA2017_Report.pdf
3. World Health Organisation. Towards an Age-friendly World. [Internet] [cited 2018 May 31] Available from http://www.who.int/ageing/age-friendly-world/en/
4. Fulmer T. The Rosalie Wolf Memorial Lecture: Abuse-free care in a world of age-friendly health systems. Journal of Elder Abuse & Neglect. 2018; 30(3):167-75.
5. Dey S, Nambiar D, Lakshmi JK, Sheikh K, Reddy KS. Health of the elderly in India: Challenges of access and affordability. In: Smith P, Majmundar M, editors. Aging in Asia: Findings from new and emerging data initiatives. Washington, DC: National Academies Press; 2012. p.371-86.
6. Mangin D, Sweeney K, Heath I. Preventive health care in elderly people needs rethinking. BMJ. 2007; 335(7614):285.
7. Golinowska S, Groot W, Baji P, Pavlova M. Health promotion targeting older people. BMC Health Serv Res. 2016; 16(5):345.
8. Patel V, Chatterji S, Chisholm D, Ebrahim S, Gopalakrishna G, Mathers C, Mohan V, Prabhakaran D, Ravindran RD, Reddy KS. Chronic diseases and injuries in India. The Lancet. 2011; 377(9763):413-28.
9. Shah N, Tank P. Rehabilitation and residential care needs of the elderly. [Internet] Clinical Practice Guidelines, Indian Psychiatric Society, 2007; p:259-288. [cited 2018 May 31] Available from http://www.indianjpsychiatry.org/cpg/cpg2007/CPG-GtiPsy_16.pdf
10. Verma R, Khanna P. National Program of Health-Care for the Elderly in India: A Hope for Healthy Ageing. Int J Prev Med. 2013; 4(10):1103-1107.

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Short report

Recovering Quality of Life (ReQoL) – Kannada version: a report of translation project

Chethan Basavarajappa, Nilamadhab Kar

Abstract

Recovering Quality of Life (ReQoL) developed at the University of Sheffield is a brief instrument to assess the quality of life of persons with mental illness. It is available in two versions: a 10-item and a 20-item measure, ReQoL-10 and ReQoL-20 respectively. An attempt was made to translate ReQoL-10 to Kannada, a widely spoken language in South India. The translation followed the procedure suggested by Oxford University Innovation Translation and Linguistic Validation Process. Difference of opinions during the translation process and its resolution; description of patient population and results of pilot testing are reported here. The Kannada version of ReQoL was found to be linguistically equivalent to the original version of English. It was simple to use and comprehensible for the Kannada speaking people with mental illness. Validation of the measure to establish its psychometric properties in Kannada is recommended.

Key words

Kannada, quality of life, ReQoL, scale, translation

Introduction

Recovering Quality of Life (ReQoL) developed at the University of Sheffield is a brief instrument to assess the quality of life of persons with mental illness (PMI) focussing on recovery process. It was commissioned and funded by the Department of Health Policy Research Programme in England for use in the National Health Service (NHS).[1]

It is available in two versions: a 10-item and a 20-item measure, ReQoL-10 and ReQoL-20 respectively. It is a brief, simple and generic (across all mental illnesses, except dementia and learning disabilities) measure. The initial validation is completed with good internal reliability, test-retest reliability, good construct validity and sensitivity to change. It is currently available in English.[1,2]

There is a dearth of quality of life scales in Indian languages especially for patients with mental illness and this was an opportunity to translate ReQoL-10 into Kannada. Kannada is a widely spoken language in South India with about 38 million native speakers and about 50 million non-native speakers. It is also the official and administrative language of the state of Karnataka and has been recognized as a classical language in India.[3]

Method

The translation from English to Kannada was carried out following the standard procedure as suggested by Oxford University Innovation.

Translation

The measure was translated independently from English to Kannada by three forward translators; this was then reconciled by the in-country investigator. This reconciled version was back translated independently to English by two translators. This was reviewed by both the in-country and the chief investigator and was found to represent the original measure. This was formatted into the approved layout matching the original ReQoL-10. All the five translators were bilingual.

Pilot testing

Five PMI were included in the pilot test after obtaining a written informed consent. They were provided with the Kannada version of the ReQoL-10 for completion of the measure and discussion. All the five participants could read and write in Kannada. The results of the same are shown in the results section. The comments made by the PMI were discussed by the investigators and the measure was modified accordingly.

Proof reading and finalizing

The modified measure was proof-read by the in-country investigator and an independent translator (bilingual) not involved in the earlier translation process. The finalized copy was submitted to the research team of ReQoL at the University of Sheffield.

Results

Translation

During back translations, in the item-5 “I felt happy”, it was observed that *“nanage santhoshavaayitu”* could mean “I felt happy” and also “I was happy”. As this was easily comprehensible, carried similar meaning and is commonly used in Kannada as such, no further modification was considered.

Pilot testing

There were three female and two male participants. The average age of the patients was 42 years. Three participants were diagnosed with bipolar affective disorder, two with paranoid schizophrenia. Two had co-morbid substance dependence, and two had co-morbid physical illnesses (obesity and diabetes mellitus). All of them could read and speak Kannada and English. They took 3 minutes 24 seconds in an average to complete the measure, least being 2 minutes and maximum being 6 minutes.

During the pilot testing, most of the participants felt that they could understand the meaning and could respond to the items of the scale. One of them expressed that he could not understand item-3 *“nanage nibhaayisalu saadhyavilla endu bhaaviside”* as he wanted to know *“what to cope with, which could be a situation or life or an event?”* It was decided with consensus that the item could be explained to those who ask for elaboration, that it could be anything that they feel that they are not able to cope with.

In the last item on physical health, the words used to describe “mobility” and “caring for yourself”, *“chalanasheelate”* and *“nimmannu neeve kaalaji maadikollalu tondaregalu”* were also found difficult to understand by the participants. They were changed to include *“chalanasheelate / attitta nadedaaduvudu” and “nimmannu neeve kaalaji maadikollalu / nodikollalu tondaregalu”.*

The average scores of each items is shown in Table 1. The highest average score (3.4) was for item-6 i.e., “I thought my life was not worth living” and the lowest score (2.2) was for item-2 i.e., “I felt able to trust others”. The total score in the measure ranges from 0 to 40. In this pilot, it was found to be 28. Longitudinal evaluation may be helpful in tracking the change over time.

Table 1: Individual item scores

Item	Average score
1	2.4
2	2.2
3	3.0
4	2.8
5	2.8
6	3.4
7	2.6
8	3.0
9	3.2
10	2.6
Total score (1-10)	**28.0**
Physical health	2.8

Discussion

Translation of the ReQoL in Kannada language was a useful experience for all the translators and participants. The process was stepwise and allowed discussion to develop a consensus on various points of linguistic dilemmas. Feedback from the participating PMI was helpful to improve the understandability of the final version in Kannada language. Although the participants in the pilot stage were able to read and speak in Kannada and English, it is evident that the scale will be primarily applicable to monolinguals in Kannada.

As it does not take long to administer the scale, it can be easily used even in busy clinical settings. Longitudinal repeat assessments can provide the change in score indicating progress and it has been reported that the score is responsive (sensitive to change) in quality of life.[4] It is expected that like other Indian language versions of ReQoL,[5,6,7] this version will be able to cater to the needs of Kannada speaking PMI expressing quality of life in their first language.

Conclusion

The Kannada version of ReQoL was found to be linguistically equivalent to the original version of English. It was simple to use and understand for Kannada speaking persons with mental illness. Future studies are needed to establish the psychometric properties of ReQoL in Kannada.

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References

1. Recovering Quality of Life (ReQoL) for users of mental health services [Internet] The University of Sheffield. [cited 2018 April 8] Available at http://www.reqol.org.uk/p/overview.html.
2. Keetharuth A, Brazier J, Connell J, Carlton J, Taylor Buck E, Ricketts T, & Barkham M. Development and Validation of the Recovering Quality of Life (ReQoL) Outcome Measures. 2017. Policy Research Unit in Economic Evaluation of Health and Care Interventions. Universities of Sheffield and York. EEPRU Research Report 050. Available at http://www.eepru.org.uk/wp-content/uploads/2017/11/eepru-report-development-and-validation-of-reqol-mar-2017-050.pdf Accessed 10 April 2018.
3. Kannada [Internet] Wikipedia. [cited 2018 April 10] Available at https://en.wikipedia.org/wiki/Kannada.
4. Keetharuth AD, Brazier J, Connell J, Bjorner JB, Carlton J, Buck ET, et al. Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties. The British Journal of Psychiatry. 2018 Jan;212(1):42–9.
5. Tharoor H, Gopal S, Kar N. English to Tamil translation and linguistic validation of Recovering Quality of Life scale (ReQoL). J Geriatr Care Res. 2017;4(2):55–7.
6. Sethi S, Punia V, Khurana H, Kar N. Translation of Recovering Quality of Life (ReQoL) to Hindi: addressing linguistic issues. J Geriatr Care Res. 2018;5(1):3–5.
7. Kar N, Patra S. Recovering Quality of Life (ReQoL) scale: translation and linguistic validation in Odia. J Geriatr Care Res 2018, 5(1): 9-11.

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Viewpoint

Physician assisted death in the UK: decision making on a debatable issue

Ayesha Bangash, Farooq Khan, Qusai Bharmal

Abstract

The majority of the British public support medically assisted suicide. However, it remains illegal under British criminal law despite several attempts to legalize it. The uncertainty of medical opinion has impacted on this; studies on the subject have revealed polarized views of doctors affected by religious beliefs, ethnicity and medical specialty as well as concerns about safeguarding the vulnerable. This article discusses how doctors in the UK can utilize evidence collected worldwide to aid in decision-making on this controversial issue, how to improve upon unclear aspects of the world's evidence base and whether there is actually a need to change the law.

Key words

assisted suicide, euthanasia, physician assisted suicide, voluntary euthanasia

Introduction

Legalizing physician assisted death (or medically assisted death) is a current topic of debate in many countries including the UK. Euthanasia and physician assisted suicide (PAS) are different forms of physician-assisted death. Euthanasia is the administration of lethal drugs by a physician to end a patient's life on the patient's explicit request. In PAS, the patient self-administers medication to end his or her life that was prescribed for this purpose by a physician. Passive euthanasia, whereby medical treatment is stopped and nature is allowed to take its course, is not considered to be illegal in the UK and worldwide.[1,2]

Physician assisted death is currently illegal in the UK. Most earlier polls find that majority of general public support euthanasia, while regular church goers, ethnic minorities, non-UK nationals, disabled people and those with less formal education are more likely to be opposed.[3] More recently as the public support for the choice of assisted dying for terminally ill adults remains consistent, opinion of other groups seems to changing with 86% of people with a disability supporting a change to the law and 79% of religious people supporting an assisted dying law.[4]

The legal position of physician assisted death in the UK

There have been various unsuccessful attempts to change the legal situation regarding assisted suicide and euthanasia in the UK. The first attempt to reform the law in England was in 1936 by Lord Arthur Ponsonby, former leader of the Labour party. Between 1969 and 2006, 4 Bills that were introduced into the House of Lords were rejected. An assisted dying bill was introduced to the House of Lords by Lord Falconer of Thoroton in 2015, but was turned down as in previous years.[5]

In 1994, 424 general practitioners (GPs) and hospital consultants in one area of England were asked by questionnaire whether they thought physician assisted dying should be made lawful. 47% supported a change in the law, 33% opposed any change and 20% were undecided. In 1998, 322 UK and Irish psychiatrists were surveyed to get their views on the legalization of assisted suicide; 44% percent opposed a change in the law, 18% were neutral and 38% supported it. In 1999, a survey was undertaken on 742 members of the British Geriatrics Society and 820 members of the Intensive Care Society. It was observed that 80% of geriatricians and 52% of intensive care doctors were not in favour of changing the law.[6,7,8]

In 2004, a Royal College of Physicians survey showed that 73% of physicians did not want PAS to be legalised including 94% of palliative medicine consultants. At the annual general meeting of the British Medical Association (BMA) in 2005, a proposal that the BMA should lobby in favour of assisted dying was rejected by 58% to 42%. In 2006, 1202 GPs in Wales were surveyed; 62% opposed a change in the law to allow PAS. Around this time, the House of Lords Select Committee requested more deliberative research of doctors' views on assisted dying. In 2007, a survey of 1000 consultants and GPs showed that 39% were in favour of a change to the law to allow assisted suicide, 49% opposed a change and 12% neither agreed nor disagreed.[7,8,9]

The Royal College of Nursing abandoned its opposition to physician assisted death in 2009 after a consultation with its members found that 49% supported assisted suicide. The college now has a neutral stance. During the same year, the House of Lords rejected a proposal to remove the threat of prosecution from those who go abroad to support an assisted suicide. However, some months later, the Law Lords ruled that the Director of Public Prosecutions must clarify the factors taken into account when deciding whether to prosecute relatives who help a loved one to die; prosecution would be more likely if the person assisting had malicious motives. Despite these developments, there is no immediate prospect of UK law permitting physician assisted dying; and healthcare professionals face up to 14 years in prison if convicted of PAS. Depending on the circumstances, euthanasia is regarded as either manslaughter or murder. The maximum penalty is life imprisonment.[5,6]

In 2011, the level of agreement among 1000 consultants and GPs on the possibility of rational suicide, the taking of one's own life based upon logical decision-making, was investigated. Majority (72%) of doctors agreed with the possibility of rational suicide, 17% disagreed and 11% were neutral. Doctors who identified themselves as being more religious were more likely to disagree. Some doctors who disagreed with legalization of assisted dying nevertheless agreed with the concept of rational suicide. The views of the doctors had no association with their specialty.[10]

Physician assisted death across the world

Internationally, different factors may determine the debate focusing on medically assisted suicide such as legislation, culture and tradition. As of 2017, human euthanasia is legal in Belgium, Colombia, Luxembourg and Canada. PAS is legal in Switzerland and the US states of Washington, Oregon, Colorado, Vermont, Montana, Washington DC and California. The Netherlands is the only country where legislation covers both euthanasia and PAS. Apart from the voluntary, well-considered request being needed, the patient-related criteria vary across countries. The legislation is restricted to those with terminal illnesses in the US, Luxembourg, Columbia and Canada whereas physician assisted death for people who are not terminally ill but experiencing unbearable physical or mental suffering that cannot be alleviated is legal in Belgium and the Netherlands. Swiss non-profit organizations dedicated to PAS may require that a terminal illness has been diagnosed. In 2017, Victoria (Australia's second-most populous state) legalized PAS. The law will go into effect in 2019 and will allow terminally ill patients to undergo PAS.[11,12,13,14]

Most doctors working in countries where assisted dying is legalized state that the decision to go ahead with it is neither easy nor straightforward. The freedom to refuse requests for physician assisted death is valued by physicians where it is legalized. If a physician is not willing to fulfill the request although the criteria for due care can be met and normal palliative care does not suffice, the patient can be referred to a colleague who may be willing to perform assisted death.[2,15]

In countries where physician assisted death is permissible, physicians grant or refuse such requests based on personal, ethical and psychological arguments, while taking the legal boundaries into account. The majority of physicians accept requests from patients with cancer or another physical disease whereas fewer accept requests from patients suffering from mental illnesses or being tired of living due to doubts about whether all treatment options had been exhausted and whether the suffering was unbearable and hopeless.[2]

Switzerland is the only country which offers assistance to die to foreign nationals. Two organizations, Dignitas and Lifecircle provide PAS. In 2013, the first Briton ended his life at Dignitas. Forty-seven Britons ended their lives at Dignitas in 2016. According to 2017 research undertaken by Dignity in Dying, a British organization campaigning for providing terminally ill adults with the option of an assisted death, only 25% of people would be able to afford to have an assisted death in Switzerland.[16,17,18]

Physician assisted death in older people

It has often been stated that if euthanasia and PAS were legalised, they would represent dangers for vulnerable groups of society, especially the elderly. It has been feared that once the practice of physician assisted death in competent patients is allowed, this may lead to a practice of euthanasia/PAS with incompetent patients; the road to assisted dying would turn into ‘a slippery slope’. However, the suggestion of the danger of ‘a slippery slope’ is not supported by currently available evidence; in the Netherlands, the age distribution of physician assisted death shows no signs of older age being a relevant factor. Physician assisted death is considered to be rare in nursing homes. The administration of medication with life-shortening effects seems generally to be practiced less often among the elderly patients compared to younger patients, while decisions that include the withdrawal or withholding of treatments seem to be more common in older people.[19,20]

Physician assisted death in patients with dementia

It remains a topic of debate whether euthanasia in patients with advanced dementia is acceptable. Physicians acknowledge difficulties in the assessment of the voluntariness of the request. Direct communication with the patient is essential for this assessment which tends to be compromised in patients with advanced dementia. Legally, an advanced physician assisted death directive could replace direct communication with the patient when making decisions about euthanasia or PAS. An advanced directive contains a request that was expressed in the past when the patient was still competent, and provides no information about the patient’s actual suffering. Research showed that many geriatricians felt that it was impossible to determine whether an incompetent person experiences dementia as unbearable and hopeless suffering and that it was also impossible to determine at what moment an advanced directive in dementia is to be carried out. Studies show that many people with Alzheimer's disease actually tend to rate their quality of life as high. However, this would probably not be the case from an outsider's point of view. Studies suggest that, in actual practice, physicians would rarely act upon an advance euthanasia directive in the case of advanced dementia.[11]

Double suicide

A suicide pact is a mutual agreement between two people who resolve to die at the same time and, nearly always, at the same place. This type of suicide is sometimes referred to as spousal suicide, joint suicide, or double suicide. People who do not meet the criteria for assisted dying can choose this method of ending their lives. Despite the fact that suicide pacts involving older people are rare, they attract extensive media attention, probably out of all proportion to their frequency. They are often framed as an expression of romantic attachment: as the thought of being separated - by the relocation or death of one of the two - seems unbearable, the couple choose to end life the way they lived it; together as partners in life and death.[21]

The first systematic study on suicide pacts was published in 1961; 65 double suicides were described. A number of case reports have since appeared, mostly from a clinical or psychiatric perspective. However, participants in suicide pacts suffer less frequently from mental disorders than those who commit suicide alone. The limited research on the subject suggests that individuals involved in joint suicides had capacity make decisions to end their lives. It appears that people who die in a suicide pact are more likely to be older, married, ill, and from a higher social class. Other motives include the negative impact of ageing, ill health, and constant mental suffering caused by grave illness. When an intimate bond is threatened, couples start balancing the pros and cons of a mutual suicide pact. Most couples seem to live an isolated life which inhibits them from discussing their ideas with others. In most pacts, the initiator seems to have been the man. Some studies associate pacts with coercion on the part of the initiator. Some studies, however, challenge this claim as they found no evidence for coercion. In 2016, the first study to investigate the process prior to a spousal self-euthanasia by describing the subjective experiences of an elderly couple planning a spousal self-euthanasia was published.[21,22]

Depression

It is well known that suicide rates increase progressively with age, with the highest rates occurring in men aged 65 and older. In addition, physical illness plays a very important role in suicide risk, particularly for those who are aged. Studies that systematically assess depression in terminally ill individuals provide robust evidence that depression plays a role in the desire for a hastened death. It is greatly under-recognized in terminally ill patients and increases the risk of the inappropriate use of physician assisted death. Depression can affect one's capacity to make decisions regarding assisted dying.[23,24]

Depression is the most frequently studied factor in relation to death wishes in elderly people. Many studies indicate that suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety and depressive feelings might not be related to pathology but rather to normal aging. On the other hand, depression among the elderly can be under-recognized in that both the person and family may view depressive symptoms and suicidal ideation as a normal aspect of aging. Older people may be hesitant or unable to report psychiatric symptoms, even when asked. Primary care physicians may not be trained to elicit or recognize symptoms of depression or be able to treat it adequately.[21]

Problems with legalizing physician assisted death in the UK

The surveys of UK's doctors have contributed to uncertainty about their views on medically assisted suicide. Doctors are divided over assisted dying legislation, with the majority opposed to changing the law to permit this practice. The reasons for conflicting views are not fully understood. GPs were less opposed than doctors in hospital specialties. Doctors with more experience of caring for people (such as geriatricians and palliative care doctors) with terminal illness were more opposed. A high level of knowledge about palliative care did not seem to influence attitude towards performing physician assisted death. Religious physicians were less likely to find it conceivable that they would perform assisted death than non-religious physicians.[3,10,25]

In 2009, the House of Lords requested more comprehensive research of doctor's views on medically assisted dying. Empirical data on the effect of euthanasia and PAS may be hard to obtain for a number of reasons. Few countries have legalized assisted dying. It can take time before legal changes have effect on a societal level. Research may be consciously or unconsciously biased by ethical presuppositions. Surveys appear to have been responded to more by older doctors and by doctors who thought that replying was only relevant if they were involved in terminal care. Surveys tend to have low response rates and use non-randomization techniques.[3,8,15,26]

Improving the evidence base on euthanasia and PAS

UK doctors have access to a large body of research undertaken worldwide to inform themselves, the government and the public of the clinical repercussions of legalizing assisted dying. However, further examination of some unclear aspects of the evidence base can help better inform decision-making by UK's doctors.[23]

Understanding the views of UK's health professionals, patients and the public

Despite areas of conflict in the surveys, there was common ground. Doctors generally wanted to reduce the suffering of patients, respect their rights, preserve patient autonomy, and protect the vulnerable from coercion. Future research could look into a possible consensus focusing on these areas. Further work needs to have a large enough sample size to be able to extrapolate the views to all doctors and help reach a democratic agreement. This could be done by a quantitative survey that would ensure true representation of views.[8]

The attitudes of medical professionals towards physician assisted dying have been widely discussed. Less explored is the level of agreement among physicians on the possibility of rational suicide. Most doctors who were opposed to physician assisted suicide believed that rational suicide was possible. One explanation for opposing assisted dying may be that it would be impossible to select only those people who rationally wish for suicide, while ensuring vulnerable people receive the protection they need. More strongly held religious beliefs were associated with opposition to rational suicide, although levels of opposition were not high. Further research is needed to investigate the reasons for medical opposition to assisted dying in light of this. Qualitative research could assist the development of questionnaires and could also allow a deeper understanding of doctor's views on the morality of suicide.[10]

It is likely that the final assistance in preparing the drugs to be used in physician assisted death will be carried out by a nurse. Few articles in the British nursing literature offer an objective overview of the practical, legal, ethical and educational implications for nurses. One problem with researching physician assisted death is that, since it has never been legal in the UK, discussions on its implications for healthcare staff are often based on hypothetical situations. Studies of attitudes to euthanasia and PAS among professionals, patients and the wider public as well as studies of their experiences of these issues may inform the wider debate. Many published studies, however, suffer from methodological weaknesses raising doubts about the evidence base. A more coordinated approach to these studies is needed. Care has to be taken that studies are of good quality and high generalizability.[6,26,27]

Strengthening the evidence base of older people

Given the fact that the elderly are often dependent on their families, it might be difficult to determine whether a request actually came from a competent autonomous patient or was the result of subtle pressure of the family on the patient. A permissive climate with regard to assisted dying might induce older people to make such a request because they do not wish to become a burden for their families. No research has yet been conducted to investigate these arguments. Although ill-health can precipitate suicidal ideation, there are few studies of a single cohort of completed suicides among the elderly. Studies about death wishes are virtually non-existent. Suicidal ideation in old age often does not meet the criteria for clinical disorders such as depression or anxiety and suggest that depressive feelings might not be related to pathology but rather to normal aging. Further research on this topic is thus recommended.[20,21]

More research is needed on joint suicide. Most studies focus on examining characteristics and motives, based on data gathered from police files, coroners' records, medical reports, and interviews with friends/relatives. There is little research that addresses the experiences and motivations of participants to a suicide pact themselves, other than the suicide notes of the deceased. Many questions remain unanswered, including: How do agreements to commit suicide develop? What is the background and what are the considerations underlying a suicide pact? What about the degree of mutual influence? To what extent are pacts based on voluntariness or coercion? To what extent are joint suicides in elderly people related to depression? The limited research on this topic suggests that those involved in suicide pacts had capacity to make decisions to end their lives. Should doctors accept the ultimate decisions of couples or intervene?[21]

Improving research on psychiatric patients requesting assisted dying

Studies are needed on physicians' opinions on physician assisted death in psychiatric patients as little is known about them. Among the problems seen in countries that have legalized assisted death for mental disorders are difficulties in assessing the disorder's intractability and the patient's decisional competence, and the disproportionate involvement of patients with social isolation and personality disorders. Legitimate concern exists that assisted death could serve as a substitute for creating adequate systems of mental health treatment and social support.[28,29]

Understanding the discrepancy between attitudes and practices related to assisted dying

In the US and the Netherlands, there appears to be a possible conflict between attitudes and probable practices related to euthanasia and PAS. Patients with pain do not seem to view assisted suicide as the appropriate response to poor pain management. Indeed, oncology patients in pain may be suspicious that if euthanasia or PAS are legalised, the medical care system may not focus sufficient resources on provision of pain relief and palliative care. The discordance between attitudes and likely practices warrants a re-examination of the purpose and probable use of assisted suicide.[30]

A few studies suggest that while most doctors are willing to perform physician assisted death in patients with advanced cancer, fewer are willing to do so in a patient with advanced dementia or in the absence of severe disease. More research is needed on the relationship between the cause of suffering and physicians' willingness to perform physician assisted death.[2]

Palliative sedation

Should euthanasia/PAS be legalized, there may be fear of the possibility of forgoing analgesia or other symptom relief. Though evidence of this is not apparent where physician assisted death is permitted, the impact should continue to be evaluated. Palliative sedation is the practice of relieving distress in a terminally ill person in the last hours or days of a dying patient's life, usually by means of a continuous intravenous or subcutaneous infusion of a sedative drug, or by means of a specialized catheter designed to provide administration of ongoing medications via the rectal route. The definition of palliative sedation has been the focus of much debate worldwide. It is potentially indicated for patients with intolerable distress due to physical symptoms, when there is a lack of other methods for palliation. According to the European Association for Palliative Care, palliative sedation must be distinguished from assisted dying and it should never have the intention to shorten life. Studies suggest that practitioners working in countries where euthanasia has been legalized have differing views on this topic including that of palliative sedation being a possible alternative to assisted dying. This needs further attention in future research. Some systematic reviews clarified that palliative sedation does not shorten survival in terminally ill cancer patients. In fact, effective pain relief can actually prolong life by ensuring that patients do not die from the exhaustion associated with uncontrolled pain.[26,31]

Does effective palliative care in the UK prevent the need for assisted dying?

Some doctors who were surveyed said that the topic of assisted dying would not be brought up if palliative care was better developed and widespread. Some studies suggest that even if palliative care is delivered with the utmost quality, this will not prevent patients from requesting medically assisted dying. A concern is that allowing assisted dying will stunt the development of palliative care culture and resources. However, research has shown that this has not been the case in the Netherlands, Belgium and Luxembourg. Rather, there have been improvements in palliative care provision in the Netherlands over time. Researchers suggest that, in order to ensure patients do not request assisted dying for lack of adequate palliative care, it is essential that nations considering legalizing assisted dying enhance palliative care services at the same time.[25,26,32]

In 2015 The Economist ranked the UK number one in the world in a comprehensive study on the quality and availability of palliative care. The UK is considered to be the cradle of palliative care with the longest tradition of advocacy and provision. Many who chose to die at DIGNITAS said their decision had not come about through poor care or absence of care and in fact praised the quality of palliative care in the UK. Of 2265 doctors from a range of specialties responding to an online doctors.net.uk poll in 2005, 68.8% stated legal change was unnecessary in view of advances in palliative care.[9,17,25,32]

Possibly avoiding the need for physician assisted death

The use of euthanasia or PAS has an inherent danger of misinterpreting the patient’s preferences by failing to acknowledge the possible ambivalence or changing priorities of the patients. A few surveys of terminally ill patients have shown that many patients requesting physician assisting dying had changed their minds many months later. In clinical practice, patients often show major ambivalence, with the wish for hastened death on one hand, and the will to live, on the other.[26]

A request for assisted dying should lead to an exploration with the patient of the experiences that are underlying the question. In Germany, patients explained that the intention to address their wish for hastened death to palliative care staff was associated with the need for reassurance and the perception of staff competence in symptom control.[26]

Delirium can affect mental capacity and decision stability. Delirium can be present in up to 85% of patients in the final stages of cancer, yet is often misdiagnosed or unrecognized by non-psychiatric doctors. Like depression, delirium should be ruled out in those making requests for assisted dying.[23]

Advance physician assisted dying directives may strengthen the autonomy of the patient and alleviate anxiety; they could replace direct communication with the patient when making decisions about assisted dying. However, a legal framework for such directives is not yet provided in all European countries. The applicability of advanced directives in advanced dementia seems limited, which explains the very low number of cases worldwide. People who write such directives are often unaware of this. Respectful communication between all involved remains important for the prevention of expectations that cannot be met.[11]

Conclusion

The lack of clarity about UK medical opinion and how it may compare with public opinion in the UK has contributed to uncertainty about the stance of the British medical profession when legislation is proposed. Majority support, or at least neutrality, from the medical profession has been an important factor in enabling the passing of permissive legislation in other countries. Given periodic attempts to pass similar legislation in Britain, a better understanding of the opinions of UK doctors is therefore long overdue. Before legislatures can contemplate doctors supplying lethal drugs to their patients, they need clear evidence that the existing law is unsuitable and, should that be the case, what would be put in its place would be better. In Britain, Parliament has not been persuaded that such evidence exists.[3,33]

Given the support for assisted dying by groups such as Dignity in Dying, and the state of public opinion, it is likely that a further Bill will be presented to Parliament in the future. UK doctors have access to an adequate body of research and clinical expertise to inform themselves, government and the public of the clinical repercussions of legalizing assisted dying in the UK. It is necessary for doctors to clarify their position on this subject and to decide whether providing assisted dying to the few who would qualify in legal terms, truly outweighs their responsibility to advocate for the protection of other patients who would be placed at risk by its legalization.[7,23]

It is recognized that within Europe several approaches to euthanasia and PAS are emerging and open and respectful debate surrounding this is to be encouraged. This debate should contribute to an understanding of the areas of consensus and dissent on medically assisted dying in Europe and inform the social, spiritual, ethical and legal implications of the different approaches, both for patients and for the healthcare professionals.[26]

As an open and free society, every viewpoint should be deliberated upon. Assisted dying is a sensitive and contentious issue. It needs to be given due consideration to ensure that in a democracy the wishes of all segments of the population are represented.

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References

1. Politics.co.uk (London). Euthanasia [internet]. London: Politics. co.uk; [cited 2018 Apr 2]. Available from: http://www.politics.co.uk/reference/euthanasia.
2. Bolt EE, Snijdewind MS, Willems DL, van der Heide A, Onwuteaka-Philipsen BD. Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? J Med Ethics 2015; 41:592–598.
3. Seale C. Legalisation of euthanasia or physician-assisted suicide: survey of doctors’ attitudes. Palliat Medicine 2009; 23: 205-212.
4. Dignity in Dying (London). Public opinion [internet]. London: Dignity in Dying; [cited 2018 Jan 2]. Available from: https://www.dignityindying.org.uk/assisted-dying/public-opinion/
5. CARE (Christian Action, Research & Education). Euthanasia: the History [internet]. London: CARE (Christian Action, Research & Education); [cited 2018 Jan 3]. Available from: https://www.care.org.uk/our-causes/sanctity-life/euthanasia-history
6. Trowell F. Exploring the nursing implications of physician-assisted suicide in the UK. Nurs Times 2009; 105(30): 31–33.
7. Lee W, Price A, Rayner L, Hotopf M. Survey of doctors' opinions of the legalisation of physician assisted suicide. BMC Medical Ethics 2009; 10 (2): 1-10.
8. Hussain T, White P. GPs' views on the practice of physician-assisted suicide and their role in proposed UK legalisation: a qualitative study. Br J Gen Pract 2009; 59 (568): 844-849.
9. Pasterfield D, Wilkinson C, Finlay IG, Neal RD, Hulbert NJ. GPs' views on changing the law on physician-assisted suicide and euthanasia, and willingness to prescribe or inject lethal drugs: a survey from Wales. Br J Gen Pract 2006, 56 (527): 450-452.
10. Ginn S, Price A, Rayner L. Senior doctors' opinions of rational suicide. J Med Ethics 2011; 37 (12); 723-726.
11. Kouwenhoven PSC, Raijmakers NJH, van Delden JJM, Rietjens JAC, van Tol DG, van de Vathorst S, et al. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. BMC medical ethics 2015; 16:7
12. SBS (Special Broadcasting Service). Euthanasia: where does the rest of the world stand? [internet]. Australia: SBS (Special Broadcasting Service); 2017 Oct 20 [cited 2018 Jan 4]. Available from: https://www.sbs.com.au/news/euthanasia-where-does-the-rest-of-the-world-stand
13. Smith P. State of Victoria will allow voluntary euthanasia from mid 2019. BMJ 2017;359: j5571.
14. Petrillo LA, Dzeng E, Harrison KL, Forbes L, Scribner B, Koenig BA. How California prepared for implementation of physician-assisted death: a primer. Am J Public Health 2017; 107: 883–888.
15. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe. JAMA 2016; 5;316(1):79-90.
16. DIGNITAS. Frequently asked questions [internet]. Switzerland: DIGNITAS; 2018 Jan 31 [cited 2018 Feb 1]. Available from: http://www.dignitas.ch/index.php?option=com_content&view=article&id=69&Itemid=136&lang=en
17. Dignity in Dying. The true cost: how the UK outsources death to Dignitas [internet]. London: Dignity in Dying; 2017 Nov [cited 2018 Jan 3]. Available from: https://www.dignityindying.org.uk/wp-content/uploads/DiD_True_Cost_report_FINAL_WEB.pdf
18. Dyer C. Dignitas accepts the first case of suicide for dementia from the UK. BMJ 2013; 346: f3595.
19. Rietjens JAC, Deschepper R, Pasman R, Deliens L. Medical end-of-life decisions: Does its use differ in vulnerable

patient groups? A systematic review and meta-analysis. Soc Sci Med 2012; 74: 1282-1287.

20. Muller MT, Kimsma GK, van der Wal G. Euthanasia and assisted suicide: facts, figures and fancies with special regard to old age. Drugs & Aging 1998; 13(3): 185-191.
21. van Wijngaarden EJ, Leget CJW, Goossensen A. Till death do us part: the lived experience of an elderly couple who chose to end their lives by spousal self-euthanasia. Gerontologist 2016; 56 (6): 1062–1071.
22. Brown M, Barraclough B. Epidemiology of suicide pacts in England and Wales, 1988-92. BMJ 1997; 315(7103): 286-287.
23. Hicks M H-R. Physician-assisted suicide: a review of the literature concerning practical and clinical implications for UK doctors. BMC Fam Pract 2006; 7(39): 1-17.
24. Weinberger LE, Sreenivasan S, Garrick T. End-of-life mental health assessments for older aged, medically ill persons with expressed desire to die. J Am Acad Psychiatry Law 2014; 42:350–361.
25. Dickinson GE, Lancaster CJ, Ahmedzai SH, Noble W. UK physicians' attitudes toward active voluntary euthanasia and physician-assisted suicide. Death stud 2002; 26 (6); 479-490.
26. Radbruch L, Leget C, Bahr P, Muller-Busch C, Ellershaw J, de Conno F, et al. Euthanasia and physician-assisted suicide: A white paper from the European Association for Palliative Care. Palliat Med 2016;30(2):104-16.
27. Mullock A. The Assisted Dying Bill and the role of the physician. J Med Ethics 2015;41: 621-624.
28. Dierickz S, Deliens L, Coen J, Chambaere K. Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases. BMC Psychiatry 2017; 17(203): 1-9
29. Appelbaum PS. Should mental disorders be a basis for physician-assisted death? Psychiatr Serv 2017; 68 (4): 315-317.
30. Emanuel EK, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide. Lancet 1996; 347(9018): 1805.
31. Seymour J, Rietjens J, Bruinsma S, Deliens L, Sterckx S, Mortier F et al. Using continuous sedation until death for cancer patients: a qualitative interview study of physicians' and nurses' practice in three European countries. Palliat Med 2015; 29(1): 48–59.
32. Chambaere K, Bernheim JL. Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience. J Med Ethics 2015;41: 657–660.
33. Preston R. Physician-assisted suicide—a clean bill of health? Br Med Bull 2017; 123 (1); 69-77.

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Review

Edentulism in elderly: a review of current clinical concerns in India

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Abstract

Background: Edentulism is one of the public health burdens for elderly people; as about 30% of the elderly population aged over 65 years is edentulous across the globe. There is a significant rise in the demographic growth rate of elderly in India from 5.6% (1961) to 8.6% (2011). **Aims:** The objective of the review is to explore current Indian scenario about edentulism in older persons, especially the extent of the problem, the clinical and aesthetic concerns and its impact of quality of life. **Method:** Available current literature from electronic and print resources was reviewed. **Results:** Complete tooth loss in different cross-sectional studies has been recorded up to 75%. Reasons attributed to the cross-sectional studies for complete edentulism are periodontal diseases (65.8%), dental caries (33.7%) and trauma (0.5%). Elderly edentulous people are generally malnourished due to poor mastication and selective food habit. The reduced facial height and impaired phonetics significantly affect their socialization as well as self-esteem. There is a lack of oral health awareness in general. While the options of treatment are available including dentures and dental prosthesis, inability to afford and unavailability of services locally especially in the rural areas or smaller towns have been major hindrances. **Conclusions:** Improving awareness about edentulism and availability of treatment among the people is urgently needed. Effective intervention of edentulism is expected to improve the quality of life of the elderly.

Key words

dental prosthetics, edentulism, elderly, India, oral health, rehabilitation

Introduction

Edentulism or toothlessness is defined as the state of life without permanent natural teeth in the dental arches. The degree of edentulism may be partial or complete. A person with all the natural teeth is known as dentate being. Ageing is an inevitable biological phenomenon in life which is associated with tooth loss. Tooth loss process among the older population is a progressive phenomenon on each added year leading to complete edentulism if it is not addressed suitably. Edentulism is one of the important community health burdens which affect the quality of life in the elderly population. According to World Health Organization (WHO) about 30% elderly people over 65 year's age, across the globe have no natural teeth.[1]

Facial trauma due to falls, road traffic accidents, violence, and sports also contribute to the tooth loss.[2] It is also established that poor oral health condition promotes dental caries and periodontal diseases which in turn leads to tooth loss and ultimately to the edentulous phase of life.[3,4]

Edentulous phase is a debilitating and irreversible state of oral health, which remarkably affects the nutrition and well-being. Several studies have revealed the negative impact of edentulism on the nutrient intake. Partial or complete loss of functional teeth is associated with reduced intake of macro and micronutrient including dietary fibers.[5,6] It is due to selective dietary intake of only soft food to overcome the mastication difficulties.[7]

Complete or major tooth loss leads to reduced facial height, shrunken cheek and impaired phonetics. Above orofacial changes result in impaired communication skill, poor self-esteem and limit socialization; which bring mental agony and distress among elderly individuals.[8,9] So complete natural teeth or dentures are essential to restoring the facial expression, speech quality and smile as well.

In the Indian context, age over 60 years is defined as elderly where people are considered as senior citizens of the country. According to the current demographic picture, there is a remarkable increase in the elderly population from 5.6% in 1961 to 8.6% in 2011 in India. Two-third of this population lives in rural areas.[10] Among the rural elders over 50% are of poor socioeconomic status, many of them live alone and are vulnerable.[11] With increased life expectancy a large number of senior citizens retain few natural non-functional teeth which need enough restoration treatment and prosthetic support to make them functional.

Lack of dental rehabilitation awareness, poor accessibility of dental care centers and unaffordability for paid treatment etc. are some of the challenges for alleviating edentulism from the country.[12] Geriatric oral health treatment and dental rehabilitation programme in India is not at a satisfactory level compared with developed countries. This sector is neglected due to lack of adequate funding, public-private partnership and government policies.[13] The morbidity and mortality associated with edentulism are yet to be assessed in the country. Except for a few sporadic reports, India has no database or detailed study on edentulism and its impact on elderly wellbeing.[14, 15]

This review aimed at exploring current Indian scenario about edentulism in older persons, especially the extent of the problem, the clinical and aesthetic concerns and its impact of quality of life. It also intended to put together and discuss various challenges associated with edentulism mitigation. It is expected that this review may improve awareness among elderly and their carers along with professionals on clinical concerns for edentulism.

Methods

Indian demographic information was collected from the census data of last six decades using google based search engines. The literature on the risk indicators associated with tooth loss and edentulism among the elderly population was searched electronically (PubMed and Google engine). Some articles of relevance from Indian journals which are not indexed by PubMed were referred manually. Various keywords and their combinations were used for literature searches like Indian elderly, oral health, dental care, edentulism, dental conservation, dental prosthetics and rehabilitation. Articles within last 10 years were included.

Results

The most prevalent oral infectious diseases in India are dental caries and periodontal diseases,[15] which if left untreated may lead to tooth loss.[16,17] People in India especially in rural areas are more vulnerable considering lack of awareness and appropriate services for dental diseases. Street dentistry, the unauthorized as well as unethical practices by quacks are still highly prevalent in the remote parts. Quacks prefer extraction of the diseased tooth than the conservative treatment due to lack of clinical knowledge and skill.[18] The assessment of the dental prosthetic need for edentulous and their dental rehabilitation at an affordable cost is not possible at the community health centers.[15] Based on the referred articles, etiology, epidemiology and treatment options of edentulism are summarized below.

Dental carries

Karia and Dabral in a cross-sectional study in India mentioned dental caries as one of the major factor (33.7%) leading the edentulism.[15] Normal morphological changes of teeth due to the reduced thickness of dentin as well as enamel are evident in the ageing process. Scuff and erosion of the crown are not uncommon among the elderly population. Many a time the erosion process is augmented by tobacco chewing, smoking and malocclusion.[16] The cementum which covers the root is increased over the age and found substantially thickened in the elderly population. The gingival recession in adult phase of life increases the possibility of multiple root caries on one or more teeth. Incidences of root caries are relatively less in young adults but progressively increase in old age.[19] Oral hygiene measures and endodontic procedures extend the life of natural teeth and delay the edentulous process.

Periodontal diseases

Indian adults are highly susceptible to various periodontal diseases. Prevalence of periodontitis in India has been recorded as high as 80%, among the age group 65-74, causing the tooth loss.[20] Several other cross-sectional studies attributed periodontal diseases as the major factor which leads to partial and complete edentulism.[14,15] In periodontitis, gums recede down from the teeth and form spaces which are named as pockets. These pockets accumulate calculus, plaque and debris. Chronic periodontitis deteriorates the periodontium that support the teeth. If left untreated, the teeth may eventually become loose. The teeth in motion become un-functional and have to be removed. According to WHO, more than 3 mm probing depth is pathogenic and more than 6 mm is severe. High prevalence of severe loss of attachment is recorded in the 65-74 age groups in Maharashtra, Odisha, Delhi, Rajasthan, undivided Utter Pradesh and Puducherry. The highest occurrence was in Maharashtra (96 %) followed by Odisha (90%) in the survey sample.[20] It is suggested that the prevalence of edentulism can be considerably reduced by preventing periodontal diseases.[16]

Epidemiology of edentulism in India

In a recent study, Kailembo *et al.* reported the prevalence of edentulism among adult and elderly Indians as 15.3%,[21] which was comparable to 16.3% reported by Peltzer *et al.*[4] Complete edentulism is a challenge for elderly Indians. In a cross-sectional study, Nayar *et al.* reported the prevalence of complete and partial edentulism among elderly Indian over 60 years as 8.1% and 10.2% respectively.[17] They also mentioned the major cause of edentulism as trauma (15.2%), caries (44.1%) and periodontitis (26.6%). In a hospital-based cross-sectional study, Chabra *et al.* reported 75% complete edentulism and 25% partial edentulism among 412 edentulous subjects over 60 years age groups.[14] Complete edentulousness is more prevalent in rural India, which is the common findings of several reports, with varied proportions in different genders.[15,16,17]

Fluoridated drinking water in some rural population also contributes negatively for early edentulism. Vandana *et al.* in a cross-sectional study reported 27% prevalence of periodontitis among fluorosis-affected patients.[22]

India is one among three countries in the world with largest number elderly diabetic subjects. These subjects are more prone to periodontal disease, with a higher rate of bone loss and gum infection leading edentulism.[23]

The institutionalized geriatric patients and disabled persons are other vulnerable group for edentulism.[12]

Effect of edentulism on oral and general health

Edentulous condition impairs the functional stability of the stomatognathic system. The epithelium and connective tissue of oral mucosa may reduce the functional sensitivity and loses its elasticity. The tissue regeneration process is also affected in this phase of life.[3]

This diminishing quality and quantity of the bone or ridge after the removal of teeth is termed as residual ridge resorption. Generally, residual ridge resorption is more common in women than men. It is seen that during the first year following extraction, residual ridge resorption is ranged 2-3 mm in the maxilla and 4-5 mm in mandible but this intensity of reduction of residual height increases over the year.[24] Reduction of sulcus width and depth, displacement of oral musculature from its original position, reduction of lower face height, shifting of mental foramen to a higher level than its actual position are some of the severe consequences of residual ridge resorption.[3]

The efficiency of masticator muscles is reduced in this phase of life which reduces the biting force. There are considerable changes in the movement pattern and size of the tongue in edentulous phase of the life. Completely edentulous patients are found to be at higher risk for poor nutrition, with multiple systemic disorders like chronic pulmonary disease, diabetes, and cardiovascular diseases.[5,24] Edentulous individuals have inappropriate mastication of hard and fibrous food. They prefer soft, creamy and sized food. Many a times this food habit leads to nutritional deficiency and systemic disease among elders.[5,25]

In a hospital-based cross-sectional study in India, Pillai *et al*. reported 48% of geriatric edentulous are at risk of malnutrion.[6] Edentulous condition also acts as one of the critical predisposing factors for obstructive sleep apnea syndrome (OSAS) where sleep is disturbed for elderly people.[3]

Effect of edentulism on quality of life

When the comfort of eating, speaking, smiling and sleeping is affected it has a considerable impact on the quality of life. Retention of limited functional teeth or complete edentulous condition limits the day to day functioning. It is established that the systemic health and quality of life are compromised during the edentulous phase of life.[15] Speech of an individual is altered due to altered phonetics in edentulous, which affects the socialization of elderly.[9]

The facial appearance changes to a great extent in edentulous condition. Self-consciousness to the changed facial appearance may affect the person negatively. The oro-facial esthetic value is well reflected on the psychological condition and socialization of an individual due to embarrassment.[3,8]

Although quality life is a relative term, it is the self-perception of physical and mental wellbeing in society. Geriatric oral health assessment index (GOHAI) is a recommended tool to assess the oral health-related quality of life (OHrQoL). A study at All India Institute of Medical Sciences revealed that GOHAI score was high in the patients who need the prosthetics; and OHrQoL decreased with an increased degree of the edentulous condition.[6]

Treatment options

Nayar *et al.* in an epidemiological study indicated that awareness about edentulism and its appropriate treatment is less among Indians.[17] This is mainly due to poor understanding of the patients and lack of guidance by dental professionals. It is relevant here to mention some of the treatment options for edentulous people. The treatment option for partial edentulism is to conserve the existing teeth if they are not severely defunct.[3] Endodontic approaches like root canal treatment and tooth filling increase the life of existing teeth. The root canals of the teeth are treated not only to save endodontically involved teeth but also to use them as abutments for bridges and partial dentures. Of course, the success in endodontic treatment depends on the factors like the anatomy of root, existing crown or root fractures if any, grade of root resorption and periodontal status of teeth. Periodontal treatments like flap surgery and scaling can prevent a gingival recession.[20] Similarly bridging and prosthesis in the partial phase of edentulism can improve the occlusal relationships in the tooth lost oral condition.

Prosthetic treatment

It is reported that many of the elderly edentulous are not aware of the various type of dental prosthesis and its usage.[9] Shrivastav *et al.* in a cross-sectional study in four old age homes reported that 65% elderly edentulous subjects did not have any dental prosthesis.[26] An elderly edentulous can opt either fixed denture, removable denture or dental implant according to the suitability and affordability. Each of these options has its merits and demerits. Any prosthesis that replaces some teeth in a partially dentate arch, which can be removed from the mouth and replaced at patient’s will, is known as removable partial denture (RPD). It is often recommended in senior elderly due to obvious systemic and oral pathologies that contraindicate the tooth preparation for a fixed prosthesis. In case of edentulism in distal extension, RPD is the only option next to dental implant. When abutment is under uncertain prognosis, the preferred recommendation is the RPD in the form of transitional prosthesis.

Fixed partial denture (FPD) is the replacement or restoration of teeth by artificial substitutes that are not readily removed from the mouth by the patient. Short edentulous spaces with healthy abutment teeth and supporting tissue are indicative of FPD. In a denture wearing awareness study, 61% of the edentulous preferred fixed prosthesis.[17] Mentally and physically challenged patients are only prescribed to go for FPD. Complete denture (CD) is recommended to the older adult with the full arch of missing teeth, dental implants that have deemed inappropriate or in the case of intraoral cancers that has caused a loss of gross intraoral tissues resulting in an edentulous dental arch.

Dental implants

Very few edentulous elderly in India are aware of about dental implants especially in rural areas. In a cross-sectional study, Nayar *et al.* found that only 19% of subjects had the information about implants.[17] Implants are alloplastic materials incorporated into the oral tissue beneath the mucosal or periosteal layer for supporting removable or fixed dental appliances. A dental implant is used for single tooth replacement, distal extension cases, utterly edentulous state, and long edentulous spans. It is not recommended to the older adult with high dose irradiation, haematological disorders, psychosis and dysmorphobia.

Discussion

Several reviews concluded that tooth loss prevalence is higher among vegetarians compared with people with mixed diet, especially those are having nutrient deficient diet.[5,16,27] India recorded the second highest number of road traffic accident fatalities, where head injury and dental trauma is common place.[28,2] Fluorosis is endemic in at least 25 countries around the world with India being one of the countries where the higher prevalence rates are seen (UNICEF).[29] Dental fluorosis eventually leads to early tooth loss in adult and edentulism in elders.[21] Lifestyle risk factors like smoking and tobacco chewing are also the indicators for partial and complete tooth loss in elderly adults.[30] Gotfredsen and Walls suggested ten pairs of contacting functional teeth in upper and lower jaws are essential for efficient mastication of food in the oral cavity.[31] WHO projected to retain at least 20 functional teeth or denture of each elderly adult by 2020 as a global mission. Gambhir and Gupta reported that the DMFT (decayed missing filled teeth) value in elderly Indians is somewhere between 25-32,[13] which suggests achieving the global mission for functional teeth is a distant target. It is known that a higher number of missing teeth instances are negatively correlated with general health status and well-being.

The primary health concern of edentulous elders is poor masticatory performance which limits dietary intake and leads to the poor nutritional status.[16] As mastication process stimulates the salivary secretion the possibility of salivary gland atrophy and xerostomia cannot be ruled out in edentulous elders.[5]

Several cross-sectional studies across India attributes the poor socioeconomic status and low educational level as two significant factors that impede to minimize the edentulism among the elderly population.[30,31] Unwillingness to receive the dental rehabilitation or treatment and fear about intervention are also contributing factors.[12] Bharti *et al*. described fear and anxiety as one of the critical barrier of edentulous patients among elderly Indians to opt for dental treatment or prosthesis.[32] Chabra *et al.* in a hospital-based cross-sectional study at New Delhi reported that 75% of the elderly population over sixty years were utterly edentulous, where they added the poor accessibility to the dental health service as an indicator.[14]

Fixed or removable denture wearing are the only options to restore the facial aesthetics and masticatory activities in edentulism. Shrivastav *et al.* in a study conducted in Bhopal reported only 4.2% of edentulous elderly had complete denture.[26] Generally edentulous elderly are found more comfortable with fixed prosthetics than the removable ones. In a case study Nayer *et al.* reported that 61% of the subjects preferred fixed denture as the best treatment option to replace the missing teeth, which gave more natural look as they expressed.[17] Reddy *et al.* also made similar observation on the preference matrix.[33] Removable complete denture is the option for elderly edentulous those who do not retain any natural tooth or implant. It is not recommended to the patient those who are allergic to the acrylic materials, which is used to fabricate denture.[26] The patient having severely resorbed ridges may affect the retention.[27,34] Incidences of complete edentulism are more among rural adults in India.[16,27] It is established that complete denture brings compatibility with surrounding oral environment,[36] restores the mastication,[25,36] harmonizes the functions of speech, respiration and deglutition.[31,34] It also helps the aesthetics preservation of remaining oral tissues.[16]

Box: 1 Guidelines for elderly with denture

A. Denture should be cleaned every day to remove biofilm with suitable cleansers.

B. The cleansers should only be applied on the denture outside the mouth.

C. Periodical (maybe annually once) disinfection of the denture with ultrasonic cleansers is advised.

D. Denture should not be kept in boiling water for disinfection.

E. Denture should not be kept more than 10 minutes in the cleanser containing sodium hypochlorite for bleaching.

F. The wearer should not use any zinc-based denture adhesive which is cytotoxic and may have some adverse systemic effect.

G. Denture wearer should not use the denture for all the twenty-four hours in a day which may lead to stomatitis

H. Denture should be kept immerged in water while it is removed from the mouth.

I. A denture wearer should see a dentist at least once in a year to rectify and certify the denture fitness.

Based on the suggestion of American College of Prosthodontists[24]

Like natural teeth, complete denture also accumulates food debris and form calculi. When the denture is not cleaned properly the biofilm which is formed on the surface of denture often cause the denture stomatitis and may lead to some serious systemic diseases like endocarditis, aspiration pneumonia and chronic obstructive pulmonary diseases.[37] The prevalence of infection is found more in case of institutionalized or dependent elderly.[38,39] The taskforce formed by American College of Prosthodontists recommended few guidelines for care and maintenance of the denture,[24] and have suggested few evidence-based practices for complete denture wearer and carer (Box1).

It is precisely understood that tooth loss in elderly is the growing phenomenon due to the cumulative effect of chronic dental diseases, lack of accessibility and affordability for treatment as well as a prosthesis.[10,13] In addition, due to inadequate fund allocation and lack of specific oral health policy by the government the edentulous alleviation mission at present is a distant dream in India.[40,41] At this juncture support regarding public-private partnership would be one of the better alternatives for edentulism mitigation.

Conclusion

Edentulism have a tremendous impact on general health and wellbeing of the elderly population. Factors like low literacy level, poor socio-economic status, unhealthy lifestyle, lack of awareness regarding different prothesis, lack of dental care services etc. contribute to the higher prevalence of edentulism among elderly adults. Improving awareness among all the stakeholders along with availability of appropriate services are essential to deal with edentulism.

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References

1. World Health Organization. Oral Health. Fact sheets no 318. [cited 20 march 2018], 2012. Available at: www.who.int/mediacentre/factsheets/fs318/en/index.htm
2. Pagadala S, Tadikonda DC. An overview of classification of dental trauma. International Archives of Integrated Medicine, 2015; 2(9): 157-164.
3. Elham E, Raphael FS, Marla K, Jocelyne SF. The Impact of edentulism on oral and general health. International J Dent. 2013; 1: 1-7.
4. Peltzer K, Hewlett S, Yawson A, Moynihan P, Preet R, Wu F, Guo G, Arokiasamy P, Snodgrass JJ, Chatterji S, Engelstad ME, Paul K. Prevalence of loss of all teeth (Edentulism) and associated factors in older adults in China, Ghana, India, Mexico, Russia and South Africa. Int. J Environ Res Public Health. 2014; 11 (11): 11308-11324.
5. Kazemi S, Savabi G, Khazaei S, Savabi O, Esmaillzadeh A, Keshteli AH, Adibi P. Association between food intake and oral health in elderly: SEPAHAN systematic review no. 8. Dent Res J (Isfahan). 2011; 8: 15-20.
6. Pillai RS, Mathur V P, Jain V, Shah N, Karla S, Kumar P, Dey AB. Association between dental prosthesis need, nutritional status and quality of life of elderly subjects. Quality of Life Research 2015; 24(12): 2863-2871.
7. Kshetrimayum N, Reddy CVK, Siddhana S, Manjunath M, Rudraswamy S, Sulavai S. Oral health-related quality of life and nutritional status of institutionalized elderly population aged 60 years and above in Mysore City, India. Gerentology. 2013; 30(2): 119-125.
8. Rodrigues SM, Oliveira ACB, Vargas AMD, Moreira AN, Ferreira EFE. Implications of edentulism on quality of life among elderly. International J Environ Res Public Health; 2012; 91: 100-109.
9. Cano-Gutiérrez C, Borda MG, Arciniegas AJ, Borda CX. Edentulism and dental prostheses in the elderly: impact on quality of life measured with euroqol – visual analog scale (EQ-VAS). Acta Odontol Lathinoam. 2015; 28(2): 149-155.
10. Rath AA. Clinical concerns of oral health in old age: an Indian perspective. J Geriatr Care Res. 2017; 4(1): 17-21.
11. Registrar General and Census Commissioner, Census of India 2011. [Internet] Rural Urban distribution of population. New Delhi: Government of India. 2011. [Cited 20 Feb 2018]. Available from http://censusindia.gov.in
12. Panchbhai AS. Oral health care needs in the dependent elderly in India. Indian J Palliat Care. 2012; 18(1): 19-26.
13. Gambhir RS and Gupta T. Need for oral health policy in India. Ann Med Health Sci Res. 2016; 6(1): 50-55.
14. Chhabra A, Chhabra N, Kabi D, Jain A. Understanding dental status and treatment need of geriatric patients: oral health trends in an Indian population. J Oral Health and Dent Manag. 2013; 2(4): 213-216.
15. Kaira LS, Dabral E. Prevalence of complete edentulism among Udaipur population of India. Saudi J Dent Res 2014; 5(2): 139-145.
16. Jalee, BF, Nagrarajapa R, Mohapatra AK, Ramesh G. Risk indicators associated with tooth loss among Indian adults. Oral health Dent Manag. 2014; 13: 170-178.

17. Nayar S, Bhuminathan S, Nisha JS, Ramesh G Sujitha K. Edentulism and public awareness- an epidemiological study. Biomed & Pharmacol J. 2013; 6: 77-81.

18. Sandesh N, Mohapatra AK. Street dentistry: Time to tackle quackery. Indian J Dent Res. 2009; 20: 1-2.

19. Gonsalves WCA, Stevens W, Robert GH. Common oral conditions in older persons. American Family Physician 2008; 78(7): 845-852.

20. Shaju JP, Zade RM, Das M. Prevalence of periodontitis in the Indian population: A literature review. J Indian Soc Periodontol. 2011; 15(1): 29-34.

21. Kailembo A, Preet R Williams JS. Common risk factors and edentulism in adults, aged 50 years and over, in China, Ghana, India and South Africa: Results from the WHO Study on global ageing and adult health (SAGE). BMC Oral Health. 2017; 17(29): 1-16.

22. Vandana KL, Reddy SM. Assessment of periodontal status in dental fluorosis subjects using community periodontal index of treatment needs. Indian J Dent Res. 2007; 18: 67-71.

23. Tiwari B, Ladha, K. Type 2 diabetes and edentulism as chronic co-morbid factors affecting Indian elderly: An overview. J Indian Prosthodont Soc. 2013; 13(4): 406–412.

24. Felton D, Cooper L, Duqum I. Evidence-based guidelines for the care and maintenance of complete dentures: a publication of the American College of Prosthodontists, J American Dent Association. 2011; 142(1): 1-20.

25. Prakash N, Kalavathy N, Sridevi J, Premnath K. Nutritional status assessment in complete denture wearers. Gerodontology 2012; 29: 224-230.

26. Shrivastav A, Bhambal A, Reddy V, Jain M. Dental prosthetic status and needs of the residents of geriatric homes in Madhya Pradesh, India. J International Oral Health. 2011; 4: 9-14.

27. Shah N, Prakash H, Sundaram KR. Edentulousness, denture wear and denture needs of Indian elderly – a community based study. J Oral Rehabilitation. 2004; 31: 467-476.

28. Road accident in India [Internet] 2015. [Cited 10.03.2018] Available from: http://www.mapsofindia.com

29. UNICEF. [Internet] Official Position on Water Fluoridation 2017. [Cited 10.03.2018]. Available from: http://www.nofluoride.com/Unicef_fluor.cfm

30. Parmar G, Sangwan P, Vashi P, Kulkarni P, Kumar S. Effect of chewing a mixture of areca nut and tobacco on periodontal tissues and oral hygiene status. J Oral Sci. 2008; 50: 57-62.

31. Gotfredsen K, Walls AW. What dentition assures oral function? Clin Oral Implants Res. 2007; 18: 34-45.

32. Bartti R, Chanrdra A, Tikku AP, Arya D Gupta R. Oral care needs, barriers and challenges among elderly in India. J Indian Prosthodont Soc 2015; 15(1): 17-22.

33. Reddy NS, Reddy NA, Narendra R, Reddy SD. Epidemiological survey on edentulousness. J Contemp Dent Pract. 2012; 13: 562-570.

34. Bilhan H, Geckili O, Ergin S, Erdogan O, Ates G. Evaluation of satisfaction and complications in patients with existing complete dentures. Journal of Oral Science. 2013; 55: 29-37.

35. Kandelman D, Petersen PE, Ueda H. Oral health, general health, and quality of life in older people. Special Care in Dentistry. 2008; 28 (6): 224-236.

36. Liedberg B, Stoltze K, Norlen P, Owall B. Inadequate dietary habits and mastication in elderly men. Gerodontology 2007; 24: 41-46.

37. Coulthwaite L, Verran J. Potential pathogenic aspect of denture plaque. Br J Biomed Sci. 2007; 64(4): 180-189.

38. Jainkittivong A, Aneksuk V, Langlais RP. Oral mucosal lesions in denture wearers. Gerodontology. 2010; 27(1): 26-32.

39. Sumi Y, Miura H, Michiwaki Y, Sakagami N. Colonisation of dental plaque by respiratory pathogens in dependent elderly. Arch. Gerontol Geriatr. 2007; 44 (2): 119-124.

40. Singh A, Purohit BM. Addressing geriatric oral health concerns through national oral health policy in India. Int J Health Policy Manag. 2015; 4(1): 39-42.

41. Reddy KV, Moon NJ, Reddy KE, Chandrakala S. Time to implement national oral health policy in India. Indian J Public Health. 2014; 58: 267-69.

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Research article

The barriers determining the use of the carer support subsidy in the Northland region of New Zealand - A qualitative study

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Abstract

Background: Unpaid care-giving once seen as a personal family matter, has now become a major social, economic and policy concern worldwide. This qualitative study aims to look at the barriers determining the use of carer support subsidy for informal carers. **Methods:** Purposive sampling was done to identify the participants for relevant information. Eight participants were encouraged to talk freely about their experiences. All interviews were audio recorded. Data analysis was done concurrently with data collection to understand the different emerging themes. **Results:** Themes emerged included inadequate delivery of information, poor understanding of the information provided, poor retention of information, reliance on self, unwillingness to seek help, feelings of self-sufficiency as main components. Themes on service and support systems were that people wanted to use but had difficulty in organising relief care, issues around claiming money and poor communication. **Conclusion:** The study revealed several barriers in the usage of subsidy. Study provides recommendations to encourage and assist carers, which include improving information delivery, providing easy access to support, clear and transparent processes and improved understanding by health care professionals of carers' needs. It is expected that these suggestions may help government agencies as well in this regard.

Key words

Barriers; Carers; Informal carers; support subsidy.

Introduction

Evidence suggests that care-giving is a stressful, non-paid responsibility which impacts on day-to-day life. Studies in Australia and New Zealand on the impact of caring roles on family carers showed that it is mostly invisible to other people outside the home. Many issues were identified in areas including mental and physical health, employment, financial hardship, relationships and support networks, having multiple responsibilities and spending hours in caring activities, inappropriate support and lack of information. There were high risks for negative mental health outcomes including depression, relationship costs and also considerable financial burdens involved along with huge emotional hardships.[1-3]

Multinational momentum in supporting carers

Unpaid care-giving was once seen as a personal family matter; but it has now become one of the major social, economic and policy concerns worldwide. Carers' organizations estimated 434 million carers worldwide.[4] Several organizations, forums and global programs like the International Alliance of Carer Organisations (IACO), work together to determine how to improve support for carers. Globally many countries including Australia, US, UK, Sweden, Finland, Ireland and Austria have supporting measures.[5-9] Table 1 gives details support measures available in various countries.

Issues affecting carers

Many carers get huge personal satisfaction from care-giving and would like to continue in their carer roles. However, there is evidence to show that care-giving is a stressful, non-paid responsibility which impacts on day-to-day life. In the UK, Elderly Parent Responsibility Stress Syndrome (EPRSS) is a phrase used to describe the issues faced by carers.[10] Most carers need to work for a living and care for someone at the same time causing huge amount of stress and result in EPRSS. Carers not having adequate break is considered to be one of the biggest issues and respite care and carer support subsidies seem to be important in helping carers avoid burn-out. To be effective, these services need to be of a high standard, flexible, reliable, accessible, culturally appropriate, and not constrained by financial support needs.[11] A consultation document prepared to help the development of a carers' strategy for New Zealand, called Caring for New Zealand Carers[12] found that carers experience several barriers to full involvement in work, education and family life because of their caring role. Even the attitudes of other people and lack of understanding about the responsibilities of a carer can themselves be a huge barrier. The publication notes that "the so-called gateways end up becoming gatekeepers."

Table 1 Support measures available for carers in various countries

Country	Support Agency	Type of support	Context of use
Australia	Government Department of health	Respite care	Support older people and carers
	Government Department of human services	Carer payment, Carer allowance, carer supplement	Carers of disabled people, frail and old people
	Government Carer gateway	Information and support to carers	Explain carer payments; where to get support.
	Centre link	Counselling Other psychological support	Support for older people and carers
	Government 'Carers Australia'	Unpaid care and support for family members	Disability, mental illness, chronic condition, terminal illness, drug use
United States	Administration of aging Private agencies	Locating agencies including respite Counselling Training services to manage stress	
United Kingdom	"Carer's assessments" Local council The Carers UK	Cover for carers Support carer holistically Respite care Day care programmes Provide vouchers Financial support	
Sweden	Local municipalities	"24 hour instant relief" Relief carer	
Finland	Government	Respite for carers	
Austria	Government	Allowance	Pay for respite
Ireland	Government	Annual grant	Fund respite care
New Zealand	Government/NASC	Carer support subsidy	Day activity programmes and camps

NASC: Needs Assessment and Service Coordination

In New Zealand (NZ) one in ten New Zealanders are carers;[12] and this number is predicted to increase over time with the expected increase in the ageing population. The care needed for a disabled person is mostly provided by their family, relatives or friends rather than by formal types of support, called as informal carers.[11] However, they are not supported financially by government and that is what separates them from being formal carers.

The carer support subsidy is intended to help carers by enabling them to take a break from their caring role; so understanding the issues related to use of the subsidy will enable those caring for our older population to use it effectively and consequently it will help older people in our community to receive better care. The 'carer support subsidy' is available to unpaid full-time carers of disabled persons. The Needs Assessment and Service Coordination (NASC) team at the Northland District Health Board (NDHB), Whangarei or in some situations a general practitioner (GP) or social worker can assess the client's need and allocate carer support. There is a subsidy provision for relief carers as well. This subsidy can also be used for day activity programmes and camps so that the patient is in a safe and stimulating environment while the carer is away. Studies related to carers' experiences in using the carer support subsidy in New Zealand are needed which may help to put supporting in place and to improve the use of available assistance. This qualitative study aimed to look at the barriers determining the use of carer support subsidy in the Northland region of New Zealand. The study specifically explored the experiences of carers of older people to determine the factors affecting the use of carer support subsidy.

Methods

Data was collected by face-to-face semi-structured interviews. Participants' details were obtained from the records of the NASC service at Northland District Health Board Whangarei hospital. Purposive sampling was done to identify the participants in this study to get relevant information.

Participants

The inclusion criteria for the participants in the study were: age 18 years or more, sound cognitive status, being located in Northland, English language literacy and willingness to participate in the study. Participants needed to be carers looking after an older person (age 65 or more), currently eligible for carer support subsidy, which may or may not have been used at the time of interview. We excluded carers looking after dementia or any other cognitively impaired patients, as the issues these carers face may be different from other carers. Carers for palliative care or end-of-life patients were also excluded from this study.

Recruitment

Participants in the NDHB, Whangarei area who met the criteria were selected and confirmed that they were currently allocated a carer support subsidy. Carers who were currently eligible for the carer support subsidy were identified and a letter of introduction signed by the manager of the Health of Older People team at the NDHB was then sent out to eligible carers to invite them to participate in the study. In addition carers were contacted by phone once they had received the invitation letters, to determine their willingness to participate in the study and obtain verbal consent to proceed.

A participant information sheet was provided to each individual participant to inform them about the study in detail and gave an explanation of the carer support subsidy. Over six months, 22 invitations were sent out and follow-up calls were made. In total, nine people were willing to participate.

Ethical approval

Consent and approval was gained from the NDHB Ethics Committee. Approval was also obtained from the University of Auckland Human Participants Ethics Committee (UAHPEC).

Study settings and interview

The settings for the interviews were selected by the interview subjects; in most cases it was their own home. Participants were encouraged to talk freely about their experiences, explained that they could stop the interview at any time. All interviews were audio recorded. One of the researchers reviewed the tapes and selected quotes as needed. Each interview was assigned an identifying code.

Data analysis

Data analysis was done concurrently with data collection to understand the different emerging themes. Data collection continued until a saturation point was reached where no new themes emerged. A sample size of eight was sufficient to get good quality data in depth interview. The audio-taped interviews were then transcribed verbatim by one of the researchers. A qualitative interpretive design in conjunction with general inductive analysis was used in this study. One of the researchers read the transcribed interview scripts repeatedly in order to be familiar with the words and ideas coming up in each interview. Illustrative statements were extracted. The isolated ideas were carefully gathered and scrutinised, making conscious judgements using bracketing. Similar codes were clustered to form themes. All the themes located during the analysis were summarised and a validity check was carried out by peer checking. Themes were discussed and checked by another researcher to make sure they were valid. The significant categories were then encoded to larger themes which reflected the experiences of carers using the carer support subsidy.

Results

A total of eight participants, four males and four females, were interviewed and their ages ranged from 55 to 85 years. Seven of these interviews were conducted in the participants' own homes and one was conducted in a hospital office room. Four interviews were conducted with the carers alone. The other four interviewees didn't want to leave their care recipient alone or wanted their support for the interview, so these interviews were conducted in the presence of the care receiver but the questions were only directed to the carer. Six participants were New Zealand Europeans and two were NZ Māori.

Barriers experienced by the carers of older people in using the carer support subsidy

Figure 1 illustrates the barriers experienced by the carers of older people in using the carer support subsidy.

Information

Information was a major theme emerged. Participants made several comments about the importance of timely and adequate delivery of information.

Inadequate delivery of information

Inadequate delivery of information was one of the main categories of barriers for carers. The codes included: poor clarity about the process; inadequate or inappropriate timing of initial explanation about the services; not knowing that the subsidy could be used to pay family or friends; needing things laid out more simply; and not knowing how many days' support were currently allocated. On participant's understanding of how the subsidy worked, who did the allocation and when, *"Well... the lady who came to interview mum, the lady at the hospital gave me some books to read and I might have got something in the mail about it."* Most participants had poor clarity about the whole process, especially in the initial stages and some failed to ask further help to access better information.

Poor understanding of the information provided

Understanding the process of allocation of days, expiry of days, renewal and utilisation was confusing for some participants. One carer commented about the difficulty of understanding the process: "*It's like all paper work. If things are laid out simple... Now I have to go through the booklet and start getting, work it all out and that is how we go about these things; that is the thing that probably I thought about too."*

Figure 1 : Codes and themes about the barriers for carers in utilising carer support subsidy

Code	Category	Theme
Poor clarity about the process Inadequate or inappropriate timing of initial explanation about the services Didn't know this could be used to pay family or friends "If things are laid out simple" Doesn't know how many days currently has allocated	Inadequate delivery of information	Information
Doesn't remember how to claim money Difficulty in remembering the process Didn't remember that if not used, days will expire." I hate using it up".	Poor retention of information	
Thinking that it can only be used in rest homes. Confusing carer support with respite care Confusing carer support with the personal care support they are receiving.	Poor understanding of the information provided	
Male carers are not using the subsidy as much as female carers Seeing caring as moral responsibility Don't want to burden someone else "We manage alright" Prefer other resources like family or friends. Stress about help seeking or the source of help itself	Unwillingness to seek help	Reliance on self
Never used before so doesn't think it's needed. Busy organising regular life and manages without. No perceived need for accepting support.	Feeling of Self-sufficiency	
Patient not agreeing to go to residential care for carer support Not enough to pay agency staff Not being able to find relief carer "I don't have a great source family".	Wanting to utilise, but difficulty in organising relief care.	Service and support systems
I don't like forms Claim forms are confusing Claim forms have complex wording Loading of allocation takes ages Assessors need to show how to fill in the form Takes a long time to reimburse Process is too hard Some people don't want to give their bank account details	Issues around claiming money	

Her understanding about the process was such that she didn't know she could use this money to pay a friend or family member who was relieving her to let her have a break. Another person's comment was "*If I don't use them, that will expire, so that was another hiccup. But I know for next time.*"

Poor retention of information

Retaining information provided was a major factor affecting utilisation. Some carers forgot what was explained or mistook it for something else, such as personal care hours. *"Well, the only thing that I can remember was they would be sending someone here, I don't need it. I can wash myself, dry myself and you know I'm pretty independent."* It shows poor retention of information that carer thinks it's about him. Another carer was hesitant to use it, saying *"we sort of try to save it for over Christmas time."* One participant was confused by the name 'carer support subsidy'. He calls these days respite days. He said *"at the moment, my respite...on these days my leisure is going to RSA."*

Reliance on self

Reliance on self was the second major theme that emerged in the study. Two categories stood out: unwillingness to seek help and feelings of self-sufficiency.

Unwillingness to seek help

Unwillingness to seek help stood out as a major reason for lack of use of the subsidy. When one participant was asked whether he had heard about the carer support subsidy, he replied *"I haven't needed it, I heard about it and I know it is there."* He had been in his caring role for the last 10-12 years and had been allocated carer support for the last five years but had never used it. When asked why he hadn't used it his comment was *"No, because I think it is my moral responsibility to look after my wife and not had any real reason to use it."* Another participant hadn't used the support subsidy yet. She mentioned *"Maybe... I will. Yeah when it perhaps gets a bit difficult, in between perhaps, transitions or something."*

Feeling of self sufficiency

Feelings of self-sufficiency formed a major component in the self-reliance category. Some participants conveyed that they were managing by themselves and did not need to seek help. One participant said, "*Well, only when I had to go to hospital, other than that I never really get out."* As he hadn't used it before he didn't think that he really needed it.

Service and support systems

The third major theme that emerged was service and support systems. Most of the codes developed under this umbrella fall into three different categories: wanting to use but having difficulty in organising relief care; issues around claiming money; and poor lines of communication.

Wanted to use but had difficulty in organising relief care

Few participants reported that they like the carer support subsidy and want to use it but find it difficult to arrange relief care. When asked about finding a relief, carer said, *"I think it's one of the difficulties. Family is really important and I don't have a big source of family, myself. Because my mother will only go to a certain few, it's really difficult. Won't go in residential care, so that's really difficult."* This comment showed another barrier: that of not having enough family or other resources as relieving carers. She said *"I can see why people don't use it. It is really difficult especially if you don't have family or friends around that could support you. It would be great for short periods of break for hours or something like that."* One carer mentioned that the money you can claim for a day is not enough to pay private agency relief carers.

Issues around claiming money

On issues around claiming money, the codes were: some carers don't like to deal with forms; claim forms are difficult and confusing; allowances for days claimed take a lot of time to be reimbursed; NASC could not help with any changes with the forms; the process is too hard; and some people did not want to give their bank account details. *"If there is a counter even and you just have the paper to go see someone and hand it over then it is easy. So if you had a piece of paper like this, name....address and dates when you would like the care and you know a form like that you could just fill out and take it to the office and say this is for my mum and I'm just wondering if there is any places"* which showed that the claim forms were not worded in a simple way; and no-one was available to provide face-to-face help with the forms. On claim forms, response were *"Oh they are very confusing, really confusing. But I just don't like forms."*; "*I'm not very good on forms*" *One carer* said "*Another thing is some people doesn't like to give their bank accounts, because you need a bank account..."* This was another barrier as carers may not want to provide bank account details, which is mandatory to receive reimbursement.

Poor lines of communication

Poor line of communication to assist with the use of the carer support subsidy was another theme. *"It would be more helpful if they could show how to fill in the form"*. She commented that GPs don't allocate carer support and stressed the importance of why they should be doing it. *"You see your doctor before you see a needs assessor. Plus you have a review from your doctor at least 6-monthly"*. She stressed the importance of NASC assessors carrying the form and demonstrating to carers how to fill in the form instead of just giving out brochures. Another carer was concerned about not having an office, a counter or a person to talk to face-to-face to assist with the processes involved in using the subsidy. Some participants had their daughters or other family members assisting them with this process so they didn't have any personal concerns about this aspect of using the subsidy.

Discussion

Sample size

In this study saturation was obtained when we interviewed eight clients as the expressed experiences were repetitive and emerged themes were similar. Semi-structured interviewing is the best method of choice when the researcher gets only one chance to interview the participants.[14] Developing an interview guide helped to organise the questions or topics that needed to be covered in the interview. This ensured comparable and reliable information, bearing in mind that in a semi-structured interview, the researcher has the freedom to stray away from the guide when it feels appropriate to do so. A qualitative interpretive design in conjunction with general inductive analysis was used in this study as this method is helpful to condense raw text into a more summarised version. The general inductive method helped to establish the connection between the objectives and findings that are derived from the raw data.

Limitations

Our sample size was small, which limited in-depth exploration of carers' experiences. We used purposive sampling which may cause selection bias and this may have affected the final results. Those who declined the invitation may have had different views about their experiences as carers or they may have been too busy in their caring roles so their views have not been registered.

Barriers

Lack of information as a barrier to access support was a major issue that stood out in this study. A report to national health committee in New Zealand[11] and in another study of 'whānau'(family) caregivers training programme in Waikato showed the role adequate information plays in carers' lives in past.[14] Our study corroborates lack of evidence as a barrier in accessing support. Many participants raised concerns about the poor clarity of information provided about the carer support subsidy, which is a key element in effective communication. Arksey and Hirst in their review on unpaid carers' access to and use of primary care services mentioned poor clarity of information, failure to fully understand or retain the information as barriers.[15] Information about the carer support subsidy should be primarily provided by the family GP, practice nurse, NASC or local hospital staff. Many carers in this study stated that either they didn't know how this subsidy worked, or that they learned about it over the years. These findings are supported by many studies.[16-17]

On self-reliance, which comprises two main categories, unwillingness to ask for help and feelings of self-sufficiency, Carduff et al found that the informal carers do not understand or identify themselves as carers, instead of spouse, child or parent.[18] Identifying as carers is a gradual process. Our study also confirmed unwillingness to ask for help or feeling of self-sufficiency. This study is consistent with the findings of other studies as the innate traits and societal influences impact on the willingness of carers to access carer support subsidy. These barriers to access services have been described by Arksey et al.[19] The current study enquires whether the relationship between the carer and the care recipient impacts on health-seeking behaviour. A study by Brodaty and Donkin explains the issues usually faced by the spouse carers of dementia patients.[20] At present it is unclear whether being a spouse makes it harder for the carer to leave their partner to someone else's care when they go away for a break. This whole issue could be an area to look at in future research. There are several factors that directly link to carers' inclination to seek help. Hesitance to ask for help, care recipients' choices or dislikes, Carers may feel guilty if they send their loved ones to residential care. Studies have also suggested that the carers' feelings – guilt, pain, fear, loss, duty, resignation – involved in their caring can directly link to their inclination to seek help.[15, 21] The current study illustrates the impact of gender on use of the subsidy and the potential effect of male carers not seeking assistance. In our study, most male carers felt that they could manage by themselves. This is supported by a study by the Department of Family and Community services, New South Wales (NSW).[22]

Our study identified number of systemic issues that impacted on accessing the carer support subsidy which included difficulty in finding relief carers, poor communication between service providers and receivers, difficulty in completing paperwork and issues around claiming reimbursement. Arksey et al noted that service organisations, GPs and their delivery methods were a major barrier for carers.[19] Adequate communication between GPs, practice staff and carers could improve the accessibility of support and services. Many studies proved the close link between GPs and carers' service use;[23-25] and many carers felt that their GPs understood them better than any other healthcare professionals.[26] Our study raises concern about the poor communication lines between support providers or agencies. The National Health Committee[27] found that informal carers face many barriers related to accessing and using the supports and services available. Claiming process, how it could be made easier and how all the services could be better linked were also important issues.

Most of the participants in this study were themselves older people. Their difficulties should be taken in to consideration when support is offered to them in their carer role. The current study showed that another barrier limiting carers' ability to access services might be health care professionals' failure to understand the carers' issues and to recognise them as carers, so supports are not meeting actual needs and carers are not being given adequate information relevant to their situation. Participants also raised the issue of the difficulty in finding a relief carer.

Conclusion

Carers' experiences in relation to the carer support subsidy were explored and a number of recommendations are proposed to improve subsidy usage. Recommendations to encourage and assist carers are: being able to identify themselves as carers; accessing adequate information; understanding the importance of taking breaks; and getting help in finding relief carers and completing claim forms. Recommendations for health professionals and service systems include improving information delivery; providing easy access to support; clear and transparent processes; and improved understanding by health care professionals of carers' needs. The study helps agencies including government to understand the major issues carers face and take action to improve the level of satisfaction amongst informal carers. This is the only study investigating into the use of the carer support subsidy in New Zealand. Future studies with more participants could reveal more about different types of carers. Further investigations could also focus carer burnout, the relationship between carer burnout and admission of the elderly to long-term residential facilities.

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References

1. Edwards B, Higgins J, Gray M, Zmijewski N, & Kingston M. The nature and impact of caring for family members with a disability in Australia. AIFS Research Report No. 16. [Internet]. Melbourne: Australian Institute of Family Studies; 2008. [Cited 2017 Dec15] Available from http://www.aifs.gov.au/institute/pubs/resreport16/main.html
2. Deakin University and Carers Australia [Internet]. Australian Unity Wellbeing Index: Survey 17.1 Report 17.1, Melbourne; 2007. [Cited 2017 Dec 15]Available from http://www.carersaustralia.com.au/storage/Wellbeing-Index-Special-Report-October-2007.pdf
3. Jorgensen D, Arksey H, Parsons M, & Jacobs S. Caregiver assessment of support need, reaction to care, and assessment of depression. Home Health Care Services Quarterly. 2009; 28(4): 130-150.
4. Greene R. Family caregiving is global, not local [Internet]. Biotech Now 2015. [Cited 2017 Dec21]. Available from http://www.biotech-now.org/health/2015/12/family-care giving-is-global-not-local
5. Carers Australia [Internet]. About carers; 2016.[Cited 2017 Dec 21] Available from http://www.carersaustralia.com.au /about-carers/statistics/
6. My Aged Care [Internet]. Help at home; 2016. [Cited 2017 Dec 21]. Available from http://www.myagedcare.gov.au/ help-home
7. U.S. Department of Health & Human Services [Internet]. Administration for community living; 2015. [Cited 2017 Dec 21] Available from http://www.acl.gov/
8. Carers UK. Help & advice 2015.[Internet]. [Cited 2017 Dec 2] Available from https://www.carersuk.org/help-and-advice
9. Johansson L. Services for supporting family carers of elderly people in Europe: Characteristics, coverage and usage. National Background report for Sweden. Report submitted to EUROFAMCARE consortium. Hamburg, Germany: EUROFAMCARE. 2004
10. Myagingparent.com [Internet]; 2015. [Cited 2017 Dec 21] https://myageingparent.com/life/coping-life/issues-facing-family-carers-of-elderly/
11. Goodhead A & McDonald J. Informal care givers literature review: a report prepared for the National Health Committee [Internet]. Wellington, New Zealand: National Health Committee; 2007. [Cited 2017 Dec 22] Available from http://www.moh.govt.nz/notebook/nbbooks.nsf/0/fb327285c9043995cc25734500069193/$FILE/informal-care givers-literature-review.pdf
12. Ministry of Social Development [Internet]. Caring for New Zealand carers. 2007 [Cited 2017 Dec22] Available from http://www.ccdhb.org.nz/meetings/DSACpapers/2007_08_14/Caring_For_Carers_Strategy.pdf

13. Cohen D & Crabtree B. Qualitative research guidelines project. 2006 [Cited 2018 Jan 5] Available from http://www.qualres.org/HomeSemi-3629.html

14. Ashwell A, Ridley F & Thompson K. Evaluation of the Whānau Caregivers Training Programme delivered by LIFE Unlimited. Hamilton, New Zealand: Maori and Psychology Research Unit, University of Waikato. 2004.

15. Arksey H & Hirst M. Unpaid caregivers' access to and use of primary care services. Primary Health Care Research and Development, 2005; 6(2): 101-116.

16. Walters K, Lliffe S. & Orrell M. An exploration of help-seeking behaviour in older people with unmet needs. Family Practice, 2001; 18(3): 277-282.

17. Neufield A, Harrison M, Stewart M, Hughes K & Spitzer D. Immigrant women: Making connections to community resources for support in family caregiving. Qualitative Health Research, 2002; 12(6): 751-768.

18. Carduff E, Finucane A, Kendall M, Jarvis A, Harrison N, Greenacre J & Murray S. Understanding the barriers to identifying carers of people with advanced illness in primary care: triangulating three data sources. BMC Family Practice, 2014; 15: 48.

19. Arksey H, Jackson K., Wallace A, Baldwin S, Golder S, Newbronner E, & Hare P. Access to health care for carers: barriers and interventions. London, UK: NHS NCCSDO.2003.

20. Brodaty H. & Donkin, M. Family caregivers of people with dementia. Dialogues in Clinical Neuroscience, 2009; 11(2): 217-228.

21. Sisk R. Caregiver burden and health promotion. International Journal of Nursing Studies, 2000; 37(1), 37-43.

22. Department of Family and Community Services NSW. Older men and HACC services: Barriers to access and effective models of care. (Version 1.0) [Internet]. Sydney, NSW, Australia: University of Western Sydney. 2012. [Cited 2018 Jan 21] Available from https://www.adhc.nsw.gov.au/__data/assets/file/0006/236328/22_older_men_and_hacc_services_report.pdf

23. Katbamna S, Bhakta P, Ahmad W, Baker R & Parker G. Supporting South Asian carers and those they care for: The role of the primary health care team. British Journal of General Practice 2002; 52(477): 300-305.

24. Simon C. Informal carers and the primary care team. British Journal of General Practice, 2001; 51(472): 920-923.

25. Simon C & Kendrick T. Informal carers – the role of general practitioners and district nurses. British Journal of General Practice, 2001; 51(469): 655-657.

26. Keeley B & Clarke M. Carers speak out project: Report on findings and recommendations. London, UK: Princess Royal Trust for Carers 2002.

27. National Health Committee. Meeting the needs of people with chronic conditions, [Internet] 2006. [Cited 2018 Jan 21] Available from https://www.health.govt.nz/system/files/documents/publications/meeting-needs-chronic-conditions-feb07.pdf

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Short report

Translation of Recovering Quality of Life (ReQoL) to Hindi: addressing linguistic issues

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Abstract

The linguistic validation process of the Recovering Quality of Life (ReQoL) scale to Hindi, the national language of India, was undertaken by a team of mental health professionals at Post Graduate Institute of Medical Sciences, Rohtak, India. The standard process of translation and review was followed. The translated Hindi version of ReQoL was considered acceptable. The process of translation and the linguistic issues encountered during the process are discussed.

Key words

English, Hindi, issue, quality of life, ReQoL, translation

Introduction

There is paucity of patient rated Quality of Life (QoL) measures in Indian languages.[1,2] Recovering Quality of Life (ReQoL) scale developed in the UK, is a brief patient-rated scale to assess the quality of life of people with mental illness, aged 16 and above. ReQoL is available in two versions, i.e., a brief 10- item measure and a 20-item measure.[3,4]

Around 258 million people in India (25% of the population) consider Hindi to be their native language. However, when other Hindi dialects are included this figure becomes around 422 million Hindi speakers (41% of the population).[5] In addition, Hindi is spoken by the large majority of Indian diaspora worldwide.

Generic version of a QoL scale is available in Hindi WHOQoL and WHOQoL-BREF;[6,7] however there is no specific brief scale for mentally ill people. We undertook the translation and linguistic validation process of the brief 10-item ReQoL to Hindi language.

Methodology

The translation from English to Hindi was carried out following the standard procedure (Translation and Linguistic Validation Process) suggested by Oxford University Innovation.[8] The translation team included in-country investigator, co-investigator, four independent translators and a proofreader based at Post Graduate Institute of Medical Sciences, Rohtak, India. All the members were bilingual (Hindi /English). Five patients participated in the pilot-testing phase. All the patients in pilot were monolinguals, versed with Hindi only. The translators were requested to focus on conceptual equivalence, neutral wording and phraseology that incorporated cultural nuances.

Results

We present here the translation process and various issues encountered during the various steps of the translation.

Step 1: Forward translation

Forward translation into Hindi was done independently by two translators and there was no difficulty. The items describing the theme of 'Quality of Life' are commonly understood in the Hindi speaking population.

Step 2: Forward translation reconciliation process

Reconciliation process following forward translation showed that literal translation of item 2 (I felt able to trust others) and item 3 (I felt unable to cope) somehow diluted the essence of the questions. The original questions put the onus on the patient. It is the patient who could or could not trust or cope. Translation turned it around to the inability to control the circumstances making the patient unable to trust or cope. Following discussion, in the reconciled version the focus was reestablished to the patient.

Specifically for item 3, it was felt 'I was unable to cope' did need a specifier e.g. 'not able to cope what'. It was decided to provide a specifier '*haalat*' (situation) to make it more comprehensible and clear.

Step 3: Back translation of reconciled version

Translators had following difficulties in various items of the questionnaire. In the item 1, it was difficult to understand and conceptualise the phrase "to get started"; in the sense 'what was difficult to start'. This difficulty was overcome by adding words "daily activities".

The item 2 was translated as “I trust others” rather than “felt able to trust others”. After discussion the item from reconciled version was kept as such. This problem seemed to be a colloquial rather than conceptual. There was a similar issue with item 7. The item was translated as “Whatever I did, I enjoyed” rather than ‘I enjoyed what I did’. To tackle this issue word “bhi” was added. Addition of "bhi" does change the meaning of 'what' to 'whatever' but this was the colloquial way to put emphasis on the fact that "I enjoyed what I did" rather than losing the essence of the original question which was getting translated as “I did what I enjoy”.

In the item 3: The word “cope” when translated literally lost its meaning. The translation conveyed that the patient found it difficult dealing with problems. This difficulty was circumvented by replacing “*dealing with problems*” with the word *haalaat* (circumstances). Other items were translated back exactly as the original one.

Step 4: Pilot testing

During pilot testing with 5 patients, they found most of the items easy to understand and were able to complete the scale in about 4-5 minutes. However they had difficulty understanding the meaning of certain words or concept behind items.

Step 5: Review after pilot testing

In the opening statement the Hindi word for “feelings” (*bhabanaaon*) needed to be replaced by the word ‘man’. Though the latter literally translated into “mind” but the former word conveys the colloquial meaning of word “feelings”.

In item 1 the word ‘*rojmarra*’ (everyday) was replaced with ‘roj’ (everyday) as the former was difficult to understand and it did not change the meaning.

Patients also felt that options given were too overlapping and confusing to make clear distinction. The same difficulty was also noticed by other Indian investigators.[9]

It was suggested that word “problem” (*dikkat*) should be added to each option for the last question about the physical health. This addition was relevant and did not alter any meaning of the questions, so it was added.

Step 6: Proof reading

Following the review the translated Hindi version of ReQoL was considered acceptable. It was proof-read by a Hindi language scholar.

Conclusion

The process of translation was a meaningful and fruitful exercise in achieving an acceptable ReQoL scale for Hindi speaking patients with mental illness. Difficulties encountered were minor and reflected the semantic and colloquial differences of two languages rather than conceptual problems. This shows the cultural/linguistic neutrality of the scale. Further work of validating the translated version in a larger sample of psychiatric patients with different diagnostic profile is recommended.

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References

1. Kar N, Swain SP, Patra S, Kar B. The WHOQOL-BREF: Translation and validation of the odia version in a sample of patients with mental illness. Indian J Soc Psychiatry 2017; 33:269-73.

2. Tripathy S, Hansda U, Seth N, Rath S, Rao PB, Mishra TS, Subba SH, Das R, Nayak S, Kar N. Validation of the EuroQol five-dimensions - three-level quality of life instrument in a classical Indian language (Odia) and its use to assess quality of life and health status of cancer patients in Eastern India. Indian J Palliat Care 2015; 21:282-8.

3. Keetharuth A, Brazier J, Connell J, Carlton J, Taylor Buck E, Ricketts T, & Barkham M. Development and Validation of the Recovering Quality of Life (ReQoL) Outcome Measures. 2017. Policy Research Unit in Economic Evaluation of Health and Care Interventions. Universities of Sheffield and York. Available at http://www.eepru.org.uk/wp-content/uploads/2017/11/eepru-report-main-report-v3.pdf Accessed 29 November 2017

4. Recovering Quality of Life (ReQoL) for users of mental health services [Internet] The University of Sheffield. [cited 2017 November 22] Available at http://www.reqol .org.uk/p/overview.html.

5. Hindi Belt [Internet] [cited 2018 January 10] Available from https://en.wikipedia.org/wiki/Hindi_Belt.

6. Saxena S, Chandiramani K, Bhargava R. WHOQoL-Hindi: a questionnaire for assessing quality of life in health care settings in India. World Health Organization Quality of Life. Natl Med J India. 1998; 11(4):160-5.

7. Meena UK, Sen RK, Behera P, Tripathy SK, Aggrawal S, Rajoli SR. WHOQoL-BREF Hindi questionnaire: Quality of life assessment in acetabular fracture patients. *Indian Journal of Orthopaedics*. 2015; 49(3):323-328.

8. Oxford University. 2013. Translation and Linguistic Validation Process. Oxford University Innovation Limited, Oxford, UK.

9. Tharoor H, Gopal S, Kar N. English to Tamil translation and linguistic validation of Recovering Quality of Life scale (ReQoL). Journal of Geriatric Care and Research 2017, 4(2): 55-57.

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Short report

Recovering Quality of Life (ReQoL) scale: linguistic validation in Malayalam, an Indian language

Aloka Joy, Vasudevan V T Namboodiri, Manoj Therayil Kumar, Nilamadhab Kar

Abstract

Recovering Quality of Life (ReQoL) is a self-reported measure of quality of life of people with mental illness, with a potential for use as a patient rated outcome measure. ReQoL in English has been designed and validated in United Kingdom. This paper describes the process of translation and validation of ReQoL in Malayalam, a language of predominant South Indian usage, especially in the state of Kerala. This was done by a team of mental health professionals at the Institute for Mind and Brain, in Kerala. The process involved translation, back-translation and piloting with patients. The Malayalam version is considered to be a valid translation of the original scale in English.

Key words

Malayalam, mental illness, quality of life, recovery, scale, translation

Introduction

Health-related Quality of Life is a growing concept in the area of health care. It assesses the short and long-term impact of a health condition on individual well-being and can be one of the measures of effectiveness of the interventions. Measuring quality of life (QOL) in mental illness is methodologically challenging. Most of the generic measures used in determining the Quality of Life of mentally ill patients fail to cover the concept entirely. The commonly used generic scales (WHO-QOL BREF, SF- 36, EQ- 5D) may appear nonspecific on occasions for mental illnesses.

Under these circumstances, there was a perceived need for a more specific scale for patients with mental illness. Researchers at The University of Sheffield have developed a new outcome measure called Recovering Quality of Life (ReQoL) for mentally ill patients. It is a psychometrically validated tool for clinicians to monitor treatment outcome and it would aid decision making in recovery-oriented services. ReQoL has 2 versions - a 10 item version, ReQoL-10 and a 20 item version, ReQoL-20. ReQoL-10 can be used regularly for monitoring progress while ReQoL-20 can help in clinical decision making and research.[1] It is suitable for mentally ill patients aged 16 and over. Items in ReQoL cover areas of QOL such as meaningful activity, belonging and relationships, control and autonomy, hope, self-perception, well-being and physical health. It is designed for the breadth of mental health problems from common mental health problems at one end to the severe forms at the other.[2]

ReQoL was constructed as a PROM (Patient Reported Outcome Measure) commissioned by the Department of Health for use in NHS, England. The developmental process progressed through the stages of forming the theoretical basis, generation of candidate items, content validation, psychometric evaluation and final item selection by combining the qualitative and quantitative evidence.[1] The scale was originally developed in the English language. ReQoL has been translated to many Indian languages like Hindi, Tamil, Kannada, and Odia.[3,4,5,6] In this article, we are describing the translation of ReQoL from English to Malayalam. Malayalam is a classical Indian language spoken across the state of Kerala and neighbouring South Indian states, by around 38 million people.[7]

Methodology

The translation work started in May 2017. The translation was carried out according to the procedure recommended by ‘Clinical Outcomes at Oxford University Innovation’.[8] The team included two forward translators, two back translators, a proof-reader (all of them were independent of each other), an in-country investigator and a co-investigator. All the team members were bilingual.

The translation work progressed through the following phases.

Phase 1 – Forward translation

- The two forward translators independently converted the English version into Malayalam versions. The translators were advised to remain faithful to the concepts, rather than words or literal equivalence.

- Thereafter the two forward translations were reconciled into a single Malayalam version by the in-country investigator.

Phase 2 – Back translation

- Two translators created independent back translations of the Malayalam version to English. They had no access to the original English version.

- The original version and the re-created English version were diligently compared to ensure there was no loss or misrepresentation.

Phase 3- Pilot testing

- The Malayalam version thus created was formatted into the layout of the original English version. This was pilot tested on five patients recruited from the out-patient unit of Institute for Mind and Brain, (Inmind Hospital) a mental health establishment in Thrissur, Kerala. All these five patients were native speakers of Malayalam language.

- The time taken to complete the questionnaire, the comments on response options, any difficulties with wordings used and any suggestions for modification of wordings were recorded verbatim from each patient and translated into English.

- A pilot testing report was prepared summarizing the five patients' responses and their suggestions.

- The need for any change was discussed among the translation team members to create the final Malayalam version.

Phase 4- Proofreading

- Proofreading was done initially by the investigators and later by an independent translator.

Results

The translation issues and difficulties encountered during each phase of the translation work are described below.

Forward translation

The conceptual translations for the response options 'occasionally', 'sometimes' and 'often' were described to be hard; however, the translators and the person who reconciled the forward translations were satisfied with the translations. These gradations are used with a lack of precision by native speakers of Malayalam; however, we wonder if this imprecision extends beyond Malayalam to English. Translation of 'feeling happy', 'feeling able to trust others' etc. was not easy. Words like '*Thonni*' and '*Anubhavappettu*' in Malayalam were reflecting the concept well though these words in isolation may have different notions. '*Thonni*' would translate literally as 'thought' and '*anubhavappettu*' as 'experienced (passively)' to English. Conceptual translation was considered primary, rather than literal translation of words, phrases or even sentences. The final version appeared conceptually reflective of the original version.

Backward translation

The backward translations mostly reflected the original ReQoL. Notable was the lack of precision of the gradients between the response options 'occasionally', 'sometimes' and 'often'. This lack of precision appears to be common to English and Malayalam. No further modification was warranted of the reconciled version of forward translation of ReQoL to Malayalam after this review.

Pilot study

The Malayalam version of the ReQol was formatted into the layout of the original English Version. The Malayalam version of ReQoL was given to five patients attending the mental health outpatient clinic at Inmind Hospital, Thrissur, in the state of Kerala, India. Three of them had anxiety spectrum disorders. The other two had bipolar disorder and psychosis, both in remission. The age of the patients varied from 20 to 65. Three patients took less than three minutes to complete the questionnaire. The rest took up to ten minutes. One patient felt the 5th question confusing. The word '*santhosham*' used in 5th question was perceived as extraordinary happiness, rather than just happiness. Another respondent indicated the response options were overlapping from one to another. She commented that 'Yes or No' options would have been simpler.

These responses were discussed amongst the research team. More discrete response options were considered unrealistic and beyond the scope of the work of translation. The unexpected response towards the fifth question by a respondent was not considered to be an imperfect translation, but it reflected the patient's learned response to questions about his mood.

Proofreading

The Malayalam version was proof-read by the investigators initially and later by an independent translator. This process did not generate any amendments.

Discussion

It is always helpful to have assessment scales in the language used by patients. There was a need for QOL scales in Malayalam for patients with mental illness. ReQoL in Malayalam will help in bridging this gap. Considering that it is available in other Indian languages and English,[2-6] it will be easy to compare the findings related to QOL status of patients in similar studies conducted in different places.

Conclusion

The translation team was satisfied that the Malayalam version reflects the parent questionnaire (ReQoL) in its entirety and meaningfulness. It is hoped that further community based validation and ongoing use will strengthen its base further.

Acknowledgement

We thank all the patients at Inmind Hospital, Thrissur, Kerala, who participated and provided their suggestions during the piloting stage.

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References

1. Recovering Quality of Life (ReQoL) for users of mental health services [Internet]. The University of Sheffield. [cited 2018 May 17]. Available at http://www.reqol.org.uk /p/overview.html
2. Keetharuth AD, Brazier J, ConnellJ, Bjomer JB, Carlton J, Buck ET, et al. Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties. Br J Psych 2018; 212(1):42-9.
3. Tharoor H, Gopal S, Kar N. English to Tamil translation and Linguistic validation of Recovering Quality of Life Scale (ReQoL). J Geriatr Care Res 2017; 4(2):55-57.
4. Sethi S, Punia V, Khurana H, Kar N. Translation of Recovering Quality of Life Scale (ReQoL) to Hindi: addressing linguistic issues. J Geriatr Care Res 2018; 5(1):3-5.
5. Kar N, Patra S. Recovering Quality of Life (ReQoL) Scale: translation and linguistic validation in Odia. J Geriatr Care Res 2018; 5(1):9-11.
6. Basavarajappa C, Kar N. Recovering Quality of life (ReQoL)-Kannada version: A report of translation Project. J Geriatr Care Res 2018; 5(1):12-14.
7. Malayalam. [Internet]. Wikipedia [cited 2018 May 27] Available at https://en.wikipedia.org/wiki/Malayalam
8. Oxford University. Translation and linguistic validation process. Oxford University innovation Limited. Oxford, UK; 2013.

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Health Information Capsule

Preventing falls in old age

The risk and frequency of a fall increase with age, so the elderly population are particularly vulnerable.[1,2] A fall can have serious consequences like fractures of bones especially with individuals with osteoporosis, head injury and concussion which may lead to disabilities. These can impact upon a person's confidence and independence for activities of daily life. Therefore, the prevention of falls is extremely important; given below are several methods to reduce the risk of having one.

History of fall

- Having a fall can increase the chances of having another fall in the future.[3]
- Knowing details of where, when and under what circumstances a fall occurred can help prevent a fall from repeating in the future.

Physical illnesses

- Certain physical illnesses can increase the risk of fall, e.g. poor vision, ear disorders affecting balance, osteoarthritis, muscle weakness, neurological conditions. These need to be appropriately treated to reduce the risk of fall.

Medication side effects

- Certain medications can cause dizziness or fainting and may affect balance. Medicines for high blood pressure, heart diseases, diuretics, muscle relaxants or sleep medications may be linked to falls.
- Remaining aware of the side effects of medications is important.
- Doctors can review long-term medications and may recommend changes to reduce the risk of fall.

Hazards at home

- There may be many hazards in and around the home which can cause a fall.
- Identify potential dangers and the individual's use of the home then accommodate changes to reduce risks.

Exercise and activity

- With age, muscles weaken and balance reduces, which may increase the risk of fall.
- Exercise and training will strengthen muscles and balance.
- There are specific balance exercises which may help.[4]

Support bone health

- Bones become more brittle and fragile with age so are more likely to break.
- Strong bones will lessen injury related to a fall.
- Eating calcium-rich foods, taking vitamin D and doing weight-bearing exercises can increase bone strength.

Assistive devices

- These include walking canes, walkers, hand rails, non-slip treads on shoes, raised toilet seats, armrests and grab bars in the bathroom etc.
- Assistive devices stabilise a person and keep them steady when moving, sitting down and standing up.

Other tips for preventing falls in the home

- Remove trip-hazards: e.g. newspapers, trailing wires, cords and frayed carpet.
- Clean spilled liquid, food and avoid wet floors.
- Use non-slip mats and carpets.
- Use a rubber bath mat in the shower or bathtub.
- Using bright light bulbs to see clearly.
- Use a night light.
- Keep your hands free as much as possible during activities.
- Minimise climbing, stretching and bending.
- Store clothing, dishes, food and other necessities within easy reach.
- Be aware of stairs and changes in levels of the floor when entering and leaving rooms.
- Avoid walking in socks on slippery floors.
- Avoid wearing loose-fitting, trailing clothes that might cause a trip.
- Wear well-fitting shoes that are in good condition and support the ankle.
- Get help to safely do things.

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References

1. https://www.nhs.uk/conditions/falls/prevention/ [cited 2018 June17]
2. https://www.ageuk.org.uk/information-advice/health-wellbeing/fitness/falls-prevention/ [cited 2018 June17]
3. https://www.mayoclinic.org/healthy-lifestyle/healthy-aging/in-depth/fall-prevention/art-20047358?p=1 [cited 2018 June17]
4. https://www.bones.nih.gov/health-info/bone/osteoporosis/fracture/preventing-falls-and-related-fractures [cited 2018 June17]

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Creative Expressions

Jhoti – an artistic tradition

Sabita Manjari Dash

Jhoti is a traditional Odia art created with a religious fervour, mostly by women in Odisha, India. It is painted by rice paste using bare fingers. Holding on to creative traditions is meaningful for older persons. Sabita Manjari Dash creates these Jhoti paintings with immense interest and finds the process not only devotional but a source of contentment.

Traditional arts can certainly help older persons reinventing their creative potentials and give them a sense of wellbeing while sharing these with the younger generations. It can be used as a tool in occupational therapy for older persons in appropriate cultural settings.

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Case report

Primary progressive aphasia: a case report on diagnostic issues

Prince Nwaubani, Ejaz Nazir

Abstract

Primary progressive aphasia (PPA), a neurodegenerative condition of insidious onset which has language impairment as the most salient and significant initial feature may provide diagnostic challenges due to obstacles in confirming normal functioning in other cognitive domains. PPA is listed by the office of rare diseases (National Institute of Health) as a rare condition affecting less than 200,000 people in the entire United States population. The close similarities with the clinical signs of Alzheimer's disease and the behavioural variant of frontotemporal dementia in the later years, may also allow for a missed or false diagnosis if not recognised early enough. This case report describes a 63-year-old Caucasian female diagnosed with PPA and elaborates on the clinical presentation, the role of neuropsychology in arriving at a potential diagnosis and highlights a management approach.

Key words

neurodegenerative disorder, primary progressive aphasia, neuropsychological assessment, logopenic variant type

Introduction

With the increasing trend in life expectancy, it is no longer uncommon knowledge that neurodegenerative conditions are on the increase. The rarer sub-classes of dementias are now being seen more often in clinical practice, more disturbingly, in the younger age groups. The ability of clinical specialists to adequately recognise and diagnose these conditions remains imperative as this usually underpins the manner of support and therapy such patients receive.

According to the National Aphasia Association in the United States and seemingly defined by Mesulam,[1] Primary progressive aphasia (PPA) can be described as a syndrome spanning approximately 2 years, which comprises a progressive disorder of language function, with sparing of higher mental functions and general activities of daily living (ADL). Occasionally acknowledged as a diagnosis of exclusion in practice, PPA could be confirmed after assessment of clinical presentation, imaging, and linguistic testing.[2] This case report describes a 63-year-old White British female who was given a formal diagnosis of PPA after exclusion of other probable organic aetiological causes. Contribution of neuropsychological assessments to the diagnostic process is described.

Case history

A 63-year-old Caucasian female presented with a progressive cognitive decline, markedly in speech and language, of over 18 months duration, with notable difficulties in word finding, naming, spelling and comprehension. Some short-term memory deficits were also notable. There was no apparent change in general level of functioning as regards to the use of electronic devices, managing of finances, shopping, driving, maintaining personal hygiene and activities of daily living. There were also no changes in mood and no evidence of psychosis.

Two months after first presentation, patient was reviewed, and still presented with sustained language impairment with gradual progressive decline in word finding and comprehension. There were no changes to short term memory.

Assessments

Clinical assessment and investigation

Past medical history mentioned anxiety episodes in the previous year and benign breast cyst more than a decade back. Physical examination and haematological investigations were uneventful. She was on atorvastatin 20mg daily.

Results of MRI scan of head showed no evidence of ischaemia or haemorrhage. The midline structures appeared normal. There were involutional changes, although generalised and these appeared most marked around the left temporal lobe; no other abnormalities were noted.

Addenbrooke's Cognitive Examination III score was 67/100, which was below the cut-off score of 82. Difficulties were noted across several domains such as attention, memory, verbal fluency and language.

Neuropsychological assessment

Profile validity testing showed that subject was above cut-off on relevant scales. Intellectual functioning was within average range. Wechsler Adult Intelligence Scale (WAIS-IV) revealed a borderline IQ, with a score of 70. Wechsler Memory Scales, Forth Edition (WMS-IV) revealed that her deficits in memory were resultant from difficulties in the comprehension of language rather than secondary to memory impairment. Application of the Delis Kaplan Executive Function System (DKEFS), also further strengthened this observation. The test showed that executive function was intact, but seemed impaired due to significant word finding difficulties.

Assessment related to speech therapy also reported that the subject's problems arose from difficulty in language comprehension. In this regard, paucity in the use of verbs in subject's expressive speech as well as marked difficulties in word retrieval were noted, which were ultimately leading to a breakdown in communication.

Management

The patient was given a potential diagnosis of PPA. Though there is no known pharmacological agent with proven efficacy for PPA, the acetyl-cholinesterase inhibitor was tried on off-label medication basis. The patient was commenced on donepezil 5mg, which was increased after a month to 10mg. Patient continued to function at a high level, without any observable changes in personality or behaviour at the time, as is seen in most variants of PPA.

An extensive information pack from Alzheimer's research UK on understanding the condition and means of accessing help and support was offered to the patient.[4] A key worker was assigned and information on accessing PPA support groups was also provided. Speech and language therapist also remained involved. Duration of follow up and observations was for a period of around one year.

Discussion

Using a diagnostic criteria for PPA suggested by Mesulam,[1] we sought to further establish and confirm a potential diagnosis in our patient (table 1).

An article published by Gorno-Tempini,[3] elaborates on a proposed working classification of PPA and its variants. The article describes three possible variants: a nonfluent/agrammatic type, a semantic type and a logopenic type. The article further describes a potential diagnosis of PPA in terms of three aspects:

- ■ Clinical presentation based on specific speech and language characteristics

- ■ Supported by imaging, where there is known specific patterns notable on the scan

- ■ A definite pathology when there is available genetic data.

The progressive deterioration in speech abilities in the reported patient, coupled with the subsequent neuropsychological assessment and speech therapy reports suggested a possible logopenic variant type of PPA.

For purposes of research, further genetic analysis may have provided definitive pathological diagnosis and the significance. According to the literature, pathologic mutations in certain faulty genes (MAPT, Progranulin, C9ORF72) have been isolated.[5]

Conclusion

Based on the inclusion and exclusion criteria suggested by Mesulam, the reported case fulfilled the criteria deemed necessary for a potential diagnosis of PPA. This was also supported by generalized temporal lobe changes on the reported MRI scan. The neuropsychologial assessment findings were helpful in the diagnostic process.

This case report contributes to the literature base of one of the rare forms of dementia and may improve further awareness. Appropriate use of suggested criteria and neuropsychological assessments may prevent the risk of misdiagnosis and may help the patient in receiving appropriate supportive measures early.

Table 1: Characteristics in the reported case compared to the criteria adapted from Mesulam[1]

Criteria suggested by Mesulam[1]	**Findings in the reported case**
Inclusion criteria	
Language difficulty	Positive
Deficits in language should be the primary cause of any impaired activities of daily living	Positive
At onset aphasia should be the most prominent deficit.	Positive
Exclusion criteria	
Other medical disorders could better account for patterns of deficit	Negative
A psychiatric diagnosis could better account for cognitive disturbance	Negative
Prominent initial episodic, visual or visuospatial memory impairments	Negative
Marked prior behavioural disturbance	Negative

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References

1. Mesulam M, Primary progressive aphasia. Annals of Neurology 2001; 49(4):425-432.
2. Hong FS, Sinnappu RN, Lim WK. Primary progressive aphasia: a case report. Age Ageing 2007; 36(6):700-702.
3. Gorno-Tempini ML, Hillis AE, Weintraub S, Kertesz A, Mendez M, Cappa SF, et al. Classification of primary progressive aphasia and its variants. Neurology 2011; 76(11):1006-1014.
4. Alzheimer's Research UK. What is primary progressive aphasia (PPA)? [Internet] United Kingdom, 2017. [Cited 2018 March 11] Available at https://www.alzheimersresearchuk.org/wp-content/uploads/2017/07/PPA-0517-0519-What-is-PPA_WEB-1.pdf
5. Léger GC, Johnson N. A review on primary progressive aphasia. Neuropsychiatric disease and treatment 2007; 3(6):745-752.

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Short report

Recovering Quality of Life (ReQoL) scale: translation and linguistic validation in Odia

Nilamadhab Kar, Suravi Patra

Abstract

The article describes the process of translation and linguistic validation of Recovering Quality of Life (ReQoL) scale in Odia an eastern Indian language. While there are a few generic quality of life measures for use in health related subjects, there is none specific for mental health available in Odia. ReQoL is translated to Odia to bridge this gap. The translation and linguistic validation process was guided by the suggested methodology for translation of scales which involved forward and back-translation, pilot-testing involving patients, review and reconciliation steps. There were no major concerns in the translation process; the translated scale in Odia was observed to be easily comprehensible by the patients and useful in the clinical scenario.

Key words

English, Odia, quality of life, ReQoL, translation, validation

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Introduction

Quality of life (QOL) is an important outcome measure in health related research and there are many generic and specific scales to assess it in various conditions. However there is still a need for scales to be available in different languages and specific conditions.

Odia, one of the six classical languages in India, is spoken mostly by people in Odisha and neighboring states of eastern India and by a vast Odia diaspora around the world.[1] There are a few validated generic QOL scales such as WHOQOL-BREF[2] and The EuroQol five-dimensions-3-level (EQ-5D) [3] available in Odia language. However, there is need for specific QOL scale for use in the clinical psychiatry. It was intended to translate the Recovering Quality of Life (ReQoL) scale (10-item version) in Odia to bridge this gap. It may be highlighted that ReQoL has been translated in different Indian languages.[4,5]

ReQoL scale is a self-rated scale for quality of life which has been validated for patients attending mental health services in the UK.[4] There are 10 and 20 item versions. ReQoL has been reported to be easy to complete, score and interpret.[5] The psychometric properties of both versions of ReQoL were reported to be better than Short Warwick-Edinburgh Mental Well-being Scale and the EQ-5D.[6]

Methodology

Translation of ReQoL to Odia followed the suggested methodology from the Oxford University Translation and Linguistic Validation Process.[8] It involved various stages: forward translation by two independent translators, reconciliation of forward translations to an agreed version, back translation of the reconciled version to English by two independent translators, review of back translations and adjusting the reconciled Odia version to an agreed version. The emphasis of the translation process was on comprehensibility and ease of usability by individuals with primary level of education.

Following that the agreed version was piloted on 7 patients attending psychiatric outpatient department of All India Institute of Medical Sciences, Bhubaneswar, Odisha. Their feedback was taken into account to finer adjustment in the translated version. The version was proof read by experts in Odia language and agreed by the consensus of all in the translation team.

Result

During the forward translation, it was observed that many descriptors were used to explain the item 3 which was ‘I felt to unable to cope’. In Odia it was not becoming clear or complete with just the words describing ‘unable to cope’ and it was needed to clarify with the terms describing what the person was unable to cope, such as ‘situations’. ‘Unable to cope’ was also translated in many ways such as ‘*sahya karipaaru nathili*’, ‘*sambhaali paru nathili*’ or ‘*sahibaaku kashta laaguthilaa*’. It was decided with consensus to provide a generic word to describe what the person was not able to cope. So the word ‘*paristhitiku*’ (with the situation) was added within bracket to improved comprehension and to have equivalence in the meaning. For the ‘unable to cope’ ‘*sambhaali paru nathili*’ was considered following deliberation and consensus.

Other items needed minor changes between the two forward translations and the reconciled version was agreed.

We changed the translation from literal terms to words that are commonly used and more comprehensible to people with lower range of education. This way it can be easily adapted to people in any situation and higher level of education. Some examples were: in item 2: '*biswaas karibaare sakhyam thili*' to '*biswas karipaaruthili*'; item 5: '*mun khusi anubhav karuthili*' was changed to '*mote khusi laaguthila*'; and in the physical health item: '*bibarani diantu*' was changed to '*bishayare kuhantu*' for 'describe'.

Following back translation, the response words were further simplified to use more colloquial and commonly used terms. This improved the ease of understanding the responses and their gradations.

The diagnoses of the participating patients were paranoid schizophrenia, unspecified psychosis, depressive episodes, generalized anxiety disorder, adjustment disorder, dissociative disorder and non-organic insomnia. Their education level ranged from primary school to post-graduation. All the seven patients found the Odia version to be easy to comprehend and responded the items. One of the patients however reported some difficulty in understanding item 3 'I felt unable to cope' and item 10 'I felt confident in myself'. She could understand the meaning and essence of the questions following brief explanation. Another participant stated that it was nice to see that this assessment reflected what he was undergoing and how he felt.

Discussion

The translation process of ReQoL to Odia adopted the process as suggested in the Translation and Linguistic Validation document from Oxford University Innovation.[8] It was structured, stepwise process which was useful in arriving at a final acceptable Odia version.

The patients who participated in the pilot study expressed their satisfaction in the questionnaire. All the participants were of the opinion that the questionnaire was helpful in assessing various areas relevant to their health and it was quite easy to complete. It appeared that there was no major concern in the Odia version of the ReQoL. It was comprehensible, conveyed the meaning and carried the essence of the English version. Similar observations have been reported for Tamil and Hindi versions of the ReQoL.[4,5]

As there are no QOL scale specific to mental health in Odia, ReQoL in Odia will be really helpful to provide a structured and standardized instrument for clinical use, measuring current level and progress. It would help Odia speaking patients to report their well-being in their first language. Being a generic scale on QOL for people experiencing mental health difficulties,[6] it may be expected that it can be used in various mental health set ups and diagnostic categories.

Conclusion

Odia version of ReQoL was accepted as a comprehensible instrument, linguistically equivalent to the original English version of the scale. It conveyed the meaning of the items appropriately. It was felt that it can be easily used by Odia speaking patients in the mental health settings. Further studies to establish psychometric properties of the ReQoL in Odia would be needed involving a larger clinical population.

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References

1. Odia language. In: Wikipedia [Internet]. 2018. [Cited 31 Mar 2018] Available from: https://en.wikipedia.org/w/index.php?title=Odia_language&oldid=832947756

2. Kar N, Swain SP, Patra S, Kar B. The WHOQOL-BREF: Translation and validation of the Odia version in a sample of patients with mental illness. Indian Journal of Social Psychiatry. 2017 Jul 1;33(3):269–73.

3. Tripathy S, Hansda U, Seth N, Rath S, Rao P, Mishra T, et al. Validation of the euroqol five-dimensions - three-level quality of life instrument in a classical Indian language

(Odia) and its use to assess quality of life and health status of cancer patients in Eastern India. Indian Journal of Palliative Care. 2015;21(3):282–8.

4. Tharoor H, Gopal S, Kar N. English to Tamil translation and linguistic validation of Recovering Quality of Life scale (ReQoL). J Geriatr Care Res. 2017;4(2):55–7.
5. Sethi S, Punia V, Khurana H, Kar N. Translation of Recovering Quality of Life (ReQoL) to Hindi: addressing linguistic issues. J Geriatr Care Res. 2018;5(1):3–5.
6. Keetharuth AD, Brazier J, Connell J, Bjorner JB, Carlton J, Buck ET, et al. Recovering Quality of Life (ReQoL): a new generic self-reported outcome measure for use with people experiencing mental health difficulties. The British Journal of Psychiatry. 2018 Jan;212(1):42–9.
7. Recovering Quality of Life (ReQoL) Questionnaire [Internet]. Oxford University Innovation. [cited 2018 Mar 30]. Available from: https://innovation.ox.ac.uk/outcome-measures/recovering-quality-life-reqol-questionnaire/
8. Oxford University. Translation and Linguistic Validation Process. Oxford University Innovation Limited, Oxford, UK.; 2013.

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Instructions for authors

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2. Murray PR, Rosenthal KS, Kobayashi GS, Pfaller MA. Medical microbiology. 4th ed. St. Louis: Mosby; 2002.

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4. Foley KM, Gelband H, editors. Improving palliative care for cancer [Internet]. Washington: National Academy Press; 2001 [cited 2002 Jul 9]. Available from: http://www.nap.edu/books/0309074029/html/.

5. Cancer-Pain.org [Internet]. New York: Association of Cancer Online Resources, Inc.; c2000-01 [updated 2002 May 16; cited 2002 Jul 9]. Available from: http://www.cancer-pain.org/.

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