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FRAMEWORK FOR DEMENTIA QUALITY OF LIFE ASSESSMENT WITH ASSISTIVE TECHNOLOGY INTERVENTION

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ABSTRACT

This paper proposes a theoretical framework for a Quality of Life (QOL) evaluation tool that is sensitive, flexible, computerized, and specific to assistive technology (AT) for dementia care. Using the appropriate evaluation tool serves to improve methodologies that are used for AT assessment, development and improves the understanding of how health technology outcomes affect overall care. It will largely serve to develop the competence of technology assessments through a more efficient procedure for evaluation. One of the many challenges to assessing QOL is that results are subjective and difficult to analyze in an objective, empirical manner. This paper accentuates that this is not a hindrance to measuring OQL, but could be emphasized and adapted to create a precise measurement tool; the end-user voice must be sought and empowered in determining functional definitions and indicators for QOL. Current QOL measures inspired recommendations for a future assessment tool in order to assist investigators and clinicians in selecting the optimal method for their needs. The proposed framework is evaluated by means of a theoretical analysis focused on future applications, with particular regard to the influx in assistive technologies and their implications as therapeutic interventions for dementia care.

KEY WORDS

Quality of Life, dementia and assessment tools

1. Introduction

Societal attitudes have revolutionized towards an emphasis on active participation by individuals in their health care, which has led to advances in AT in the need to provide health care outside the traditional setting. The development, marketing, and popularity of AT devices for home use has great implications for extended independent living of older adults. The ISISEMD project [1] (Intelligent System for Independent living and Self-Care of seniors with cognitive problems or Mild Dementia) is aimed at addressing successful aging and independent living in Europe through the utilization of AT. At a time when the projected influx of aging adults will globally

overburden social programs, health care, and financial systems, research into aging, housing, and care methods is invaluable.

Dementia can occur in anyone, at any age, resulting from injury or disease, although it is most commonly associated with aging [2]. Dementia is not a specific disorder or disease, but a syndrome (group of symptoms) associated with a progressive loss of memory and other intellectual functions that is serious enough to interfere with performing the tasks of daily life. It is the leading cause of institutionalization of older adults and consists of an overall decline in intellectual function, including difficulties with language, simple calculations, planning, judgment, and motor skills as well as a gradual loss of memory. As there is no cure for dementia, the main focus of treatment and care is to maintain well-being and promote high quality in everyday life.

In the review of new and existing technologies as feasible, successful, and worthwhile therapeutic interventions, only a handful mention computerized assessment tools [3][4][5] and none were specific to dementia or to non-pharmacological interventions. This paper proposes a sensitive, flexible, computerized measurement tool, specific to AT interventions for dementia, in order to advance research trends as well as ensure that developed devices and services are fulfilling intentions. Section 2 explains internal and external parameters influencing QOL, Section 3 highlights the need for development in measurement assessments, Section 4 specifies the proposed structure development, Section 5 conveys the potential impact of such a instrument, and Section 6 presents supplementary considerations for further exploration.

2. Factors Affecting Quality of Life

2.1 Defining Quality of Life

The World Health Organization [6] defines health as “a state of complete physical, mental, and social well-being, not merely the absence of disease” and QOL as one’s perception about their current status in the perspective of their culture, mores, and concerning their aspirations,

opportunities, and interests [2]. Activities of Daily Living (ADLs) [7] and Instrumental Activities of Daily Living (IADLs) [8] have a strong correlation to the need for long-term care and QOL. ADLs include bathing, dressing, hygiene, transferring, continence, and feeding, while IADLs include meal preparation, finance management, shopping, housework, transportation, medication management, and use of communication. The most common thread connecting measurements of quality of life with dementia is that they are modeled after Lawton's constructs [9]. Lawton stresses that QOL has temporal dimensions, including reflection on the past and expectation of the future, as well as appraisal of the present and the need for cues to reinforce identity. These factors are interpreted as defining features of QOL, predictors of QOL, or indicators of QOL [10]. From a multidisciplinary point of view, and with intentions of using AT in the home to increase life quality, this protocol recognizes QOL as the overall result of total health, involving physical health, psychological status, environmental factors, social relationships, level of independence, and individual convictions.

2.2 Assistive Technology

QOL is a broad, multidimensional construct, yet all of these domains can be influenced by technologies in the home. Virtual environments, mobile communication, and sensors have contributed to significant advances in home care technologies [11]. These fields, merging together and with others, have created new platforms for assistive technology: enhancements in an environment that are sensitive enough to adapt and respond to users' needs and behaviors. Robust, ad-hoc networks are formed through the use of mobile devices and wireless systems that are embedded, context aware, personalized, adaptive, and anticipatory [11]. AT emphasizes user experiences, which allows for feedback based on user interactions to anticipate and create adjustments in the environment. Through a user-centered design, devices serve as support for daily activities and tasks in an unobtrusive, natural way, enhancing functional capabilities while minimizing limitations. When appropriately integrated, context aware systems can improve the quality of life of persons using them by means of a direct impact on users' ADLs and domains of QOL. Other potential benefits for a home setting intervention include privacy, security, efficiency, convenience, and support for the end user, informal caregivers, and formal caregivers.

2.3 Aging in Place

Independent living, thus independent caring, can be regarded as a means by which services are brought to persons in a setting that offers autonomy, social connectedness, comfort, safety, effectiveness, and low sacrifice [12]. Being able to stay in one's home into old age is called *aging in place*. Aging in place realizes a continuum of care, increasing as functional status

declines, to allow a person to live safely and comfortably in one location [13]. Aging in place is about proactively participating in the creation of one's own life while seeking to connect to others and acknowledging the influence of the quality of one's own life and the lives of others in the community.

Living in the community defers or delays the need for public funds and reduces the need for institutionalization. Through home care, the dependence on clinical medical care, such as long-term care or hospitalization, is moderated. Extended clinical treatment often results in depersonalizing effects, immobility, and physical, psychological, and financial suffering [14]. The benefits of remaining in the community are apparent to anyone who has spent a significant amount of time in the clinical setting. Community living is frequently less excessive, more affordable, and allows for individuals to support themselves [12]. The positive psychological, sociological, and physiological effects of aging in place strengthen independence despite functional dependence [13]. With one of the largest aging populations, the United States Institute of Medicine Staff praises and supports developments in home care as an advancement of signal importance [14].

3. Demand for State of the Art

Current QOL assessments for dementia do not allow for technological interventions as a direct influence on parameters, nor has there been an assessment tool developed specifically to evaluate the QOL outcomes with AT. This demonstrates a significant gap in the verification between how AT is used and where high-quality evidence supports it. Although FLAIR 1 and FLAIR 2 [2][3][4] are computerized assessments, they are not designed for dementia nor specific to technological intervention. They only assess ADL functioning status as an indicator of QOL, but have laid the groundwork for future investigative endeavors. Further advances in dementia research and care methods warrant appropriate evaluation methods. In this respect, the assessor can more accurately gauge whether or not a therapeutic intervention, such as utilizing telehealth technologies, has succeeded in its purpose. Additionally, the proposed assessment has implications for further development for use in longitudinal studies. When an AT system is installed in the home for supported care for dementia, it would be extremely beneficial to regularly assess QOL to adjust technological interventions, non-pharmacological and medical therapies, and take a proactive role in bettering the individual life quality.

4. Proposed Protocol Development

4.1 Considerations for Target Population and Environmental Influences

Figure 1 depicts the global focus areas and their interconnected influence on QOL outcomes.



Figure 1. Factors Affecting Quality of Life

When assessing reported QOL, two perspectives come into play:

- the first is the subjective experience by the individual to be assessed;
- the second is the subjective perception by the proxy individual (usually a caregiver or physician).

Because *quality* is a subjective term and different people perceive different levels of quality on the same subject, the problematic nature of measuring QOL becomes even more confounded when dealing with cognitive impairments. Interestingly, research is now verifying that the subjective opinion of the person with dementia is not only accessible even into later stages of dementia [15][16], but is often more of an accurate result than proxy opinions [16][17] and could be empowered in future applications [17][18]. Studies in which the persons with dementia themselves have been interviewed to determine life domains most important to them [16-18] will be most beneficial in developing this assessment tool as data clearly demonstrates that proxy reports consistently rate patient QOL lower than patients do [16-19]. The self-reported domains of QOL, ISISEMD interventions, and desired outcomes are represented in Table 1.

Table 1. Quality of Life domains and outcomes of assistive technology

Self-Reported Domains [16-18]	Technological Intervention (ISISEMD) [1]	Desired Outcome
Affect	Videophone; Functions monitoring; Lighting/Ambience control	Positive impact on life; support feelings of independence; maintain emotional balance; fosters expression of happiness, agitation, depression, etc.
Self-Esteem/Image	Electronic calendar; Reminders/Alerts; GPS tracking with mobile phone; Intelligent dosing system; Access control; Function monitoring	Support for the self-image of being a person with abilities; strengthened coping abilities
Social Contact	Electronic calendar; GPS tracking with mobile phone; Videophone; Access control	Developing and maintaining social relationships; developing care relationship with caregivers; interactions with family, friends, society
Attachment	Electronic calendar; Reminder/Alerts; GPS tracking with mobile phone; Videophone; Access control	Feeling of imbeddedness in surroundings; friendship and kinship bonds; participation in local community and networks
Physical and Mental Health	Electronic calendar; Alarms; Reminders/Alerts; GPS tracking with mobile phone; Intelligent dosing system; Access control; Function monitoring; Home equipment control; Lighting/Ambience control; Access to patient records	Not feel as a person with disabilities; freedom from barriers; documented behavioural and psychiatric symptoms; satisfaction with health care; promotes self-care abilities
Enjoyment of Activities	Electronic calendar; Reminder/Alerts; GPS tracking with mobile phone; Videophone; Intelligent dosing; Access control; Home equipment control; Lighting/Ambience control	Support the user in making choices; empower a person with a notoriously dehumanizing disease
Sense of Aesthetics	Electronic calendar; Videophone; Lighting/Ambience control	Remind user of previously familiar situations; promote comfortable atmosphere conducive to reducing anxiety, agitation, etc.; stimulating qualities
Security/Personal Privacy	Electronic calendar; Alarms; Reminders/Alerts; GPS tracking with mobile phone; Videophone; Access control; Function monitoring; Home equipment control	Peace of mind that one does not need to worry about locked doors, fire hazards, etc.
Being Useful	Electronic calendar; GPS tracking with mobile phone; Intelligent dosing system; Function monitoring; Home equipment control	Support for skills retained, de-emphasis on lost skills

As the target population is aging adults in early to moderate advances of dementia who are utilizing technological interventions in the home setting, it is imperative to allow for environmental influences to affect QOL. Does an electronic calendar really increase satisfaction in the social contact domain? Does an intelligent dosing system affect subjective feelings of being useful? Does a specific intervention influence clinical and therapeutic outcomes that would not be so if the intervention were not implemented? Determining the best course of action and selecting appropriate therapy management influences patient outcomes which allows for further assessment of societal and economic benefits. Health care interventions (and their evaluations) must address these defining points specific to an individual situation while remaining flexible enough to be applied to broader populations. Additionally, for these devices to be widely accepted and used, they must possess attributes in order to make the relationship between the diagnostic test and health outcomes unambiguous, shown in Figure 2.

The method used for eliciting information (e.g. level of satisfaction versus need for improvement) and the number of response options are also important factors in instrument design. Concerning the time frame of the inquiry [19], if a snapshot of the QOL is desired, such as for research, then a short time frame can be used; however, if feedback is to be used to improve a specific domain of QOL, such as with AT interventions, a longer time frame will be required in order to grasp the experience.

4.2 Format Description

First and foremost, the computerized assessment tool must allow for guiding the user through suitable use, require limited demands on the user, present itself in an aesthetically pleasing way, incorporate habitual patterns of the individual, and not impose that the user adjust to AT. This new assessment tool will also have a user friendly interface to accommodate inexperienced computer users, produce faster and more accurate results, be easy to access (and to access previously stored data), and personalized for end users. The multimedia QOL assessment will be fundamentally individual and known as iQOL.

iQOL will be web-based to facilitate portability and apply multimedia graphics and sound to determine QOL penchants, accruing information on individual influences and outcomes of QOL. The program will base proceeding questions on preceding answers, narrowing in on the specific constructs important to the individual's QOL. This also serves as a framework for longitudinal studies, as the reported answers will allow for a truly individual evaluation and results which can be assessed as a timeline of QOL.

Various elements of complex decision analytic models will be applied to evaluate therapeutic outcomes by typifying how optional interventions influence QOL [12]. By further incorporating elements of Standard Gamble

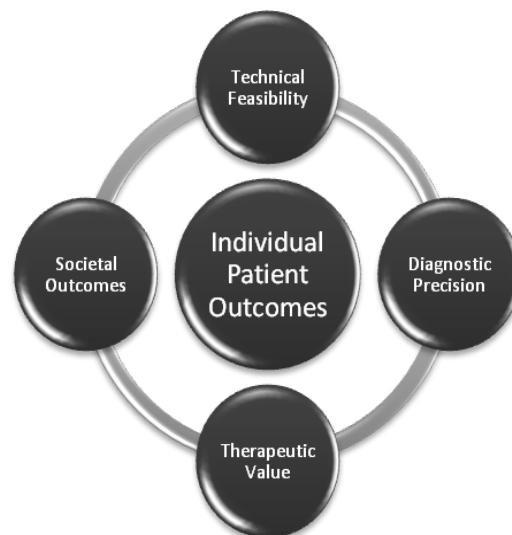


Figure 2. Attributes determining therapeutic course of action

(SG) techniques [4], individuals will rate their current status by stating the highest risk they would be willing to accept to obtain an ideal health condition (with “health” being a comprehensive state and “ideal” understood as a clearly subjective concept). iQOL will provide multimedia illustrations and explanations for each state of ADL dependency (randomized to reduce ordering influence), asking the user to identify their present functional status of independence or dependence. This allocates a standardized classification of ADLs and data collection on performance levels. The standardizing and performance evaluation will also be carried out on IADLs. It is seen as critical to include IADLs in the assessment, as instruments sensitive to IADL fluctuations can detect changes in status that would otherwise be overlooked. iQOL will then display illustrations of QOL domains to identify their current status of fulfilled or not. For instance, in the domain of attachment, iQOL could inquire if the individual experiences being involved in the environment and events around them. Once a basis is established, questions can be specified to the AT environment, e.g. does the user attain increased attachment through the support of videophone communications. The individual will be shown QOL illustrations and asked to express the highest risk they would accept in order to be fully functional and satisfied within that domain, e.g. would the individual be willing to chance 50% possibility of death to feel included and contributive in social occasions.

Measuring preferences is indispensable for evaluating care interventions designed to improve life quality. A computerized assessment provides immediate results, allowing caregivers to notice changes in the individual's QOL, care personnel to adjust therapeutic services accordingly, technology administrators to evaluate their system, and researchers to proficiently exploit data with faster dissemination of results.

5. Discussion and Implications

The fundamental purpose of care technologies is to improve patient well-being and the quality of care; therefore, the goals of this and analogous future research studies are to:

- promote the development and application of AT assessments,
- evaluate the appropriate use of assistive technologies, and
- improve the application of AT through the utilization of evaluation criteria.

Furthermore, assessments will need to take into consideration whether or not the end user uses the technology and why. If it is found that the individual does not use the AT anymore, exploring non use will be informative and beneficial. It could mean that the end user cannot perform a particular task, even when utilizing AT, that the end user has found an alternative method to carry out task performance without AT, that a new device or service has replaced the AT, or simply that the individual does not use the AT service. Correspondingly, the assistive technologies will be considered and evaluated as potentially supportive and hindering, varying according to the individual circumstances.

Empowering the individuals to supervise their own well-being greatly improves the success of health management [14]. Shifting societal views make it more desirable and beneficial to age in place in one's own home, and this can be accomplished quite successfully even with chronic, degenerative disease processes [13][14]. As Lawton's constructs are so broad, they cover nearly every facet of human living and most factors affecting them. Future assessments will continue to expand on them, as they serve as a resilient structure for QOL measurement; however, to assess individual QOL perceptions, it is strongly recommended to incorporate and emphasize the individual attributes to each person's view of their quality in daily life [16-20]. iQOL, by design, also allows for variability in user performance and functioning status, with the option to add or remove parameters measured based on intra individual fluctuations in domain value and new developments in technology. This approach enables researchers, practitioners, end users, and lay people to understand the context in which new technologies would be used, the reasons why AT might be adopted, and the impact of technology on the quality of everyday life. To be specific, iQOL, as a computerized assessment of QOL with AT for dementia, sanctions a comparison of the projected advantages of AT to acceptable risks. The attributes and results of iQOL are particularly valuable for gauging the appropriateness of AT, and for application in policy decisions on health and social care and assistive technologies. However, obtaining the data alone does not assure optimum decision making, nor does it necessarily direct improved health or greater individual satisfaction; using high quality data simply enhances the probability of desired outcomes through a better understanding of the interconnectedness of the situation.

6. Conclusion and Future Research

Technology is very fluid and its development is shaped by many external factors, especially in regards to assistive and multimedia technologies, which can be vast and eclectic. The coevolution of technology and society needs to be structured by research frameworks that focus on political, economic social and psychological influences of and on technology in addition to its use, infrastructures, standards, and development trends. Further advancements in AT applications for dementia and for home care will also shape how social, health, and scientific fields address the needs and outcomes of future populations.

When measuring life quality, it is of vital importance to seek the desires of the persons being assessed. Continual studies into domains of life are required to change with cultural, social and technological trends, as well as with intraindividual changes as disease processes progress. Future targeted research will supplement comprehension of how, where, and why to best integrate AT in health and social care. Important considerations include:

1. *Does AT result in diagnostic decisions and implications that would not otherwise be achieved?*
2. *Does AT result in significant outcomes for QOL?*
3. *Does the use of AT enhance access to care?*

The care for the aged, as for everyone else, should be appropriate. The key to success in health care for older adults is to take a comprehensive view of their total situation for the careful matching of therapeutic interventions with the care needed. This involves the preservation of function, maintenance of autonomy, effective therapy at a reasonable cost, and resorting to institutional care only when all else fails. Accordingly, we cannot consider health care independent of the social services required for support when individual capabilities begin to decline; only by respecting the comprehensive individual and their situation as interdisciplinary and interconnected can we achieve the many objectives that we pursue in health and social care success.

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References

- [1] ISISEMD Intelligent System for Independent Living and Self-Care of Seniors with Cognitive Problems or Mild Dementia. <http://www.isisemd.eu/>, 2009-2012.

- [2] World Health Organization, Division of Mental Health, *WHO-QOL Report No. 100*, 1995.
- [3] Leslie A. Lenert & John C. Hornberger, Computer-Assisted Quality of Life Assessment for Clinical Trials, *American Medical Informatics Association Annual Symposium Proceedings*, 1996, 992-996.
- [4] T.L. Sims, A.M. Garber, D.E. Miller, P.T. Mahlow, D.M. Bravata, & M.K. Goldstein, Multimedia Quality of Life Assessment: Advances with FLAIR, *American Medical Informatics Association Annual Symposium Proceedings*, 2005, 694-698.
- [5] M.D. Goldstein, D. Michelson, A.E. Clarke, & L.A. Lenert, A Multimedia Preference-Assessment Tool for Functional Outcomes, *Annual Symposium on Computer Applications in Medical Care*, 1993, 844-8.
- [6] World Health Organization (WHO). 12 June 2009. <http://www.who.int>.
- [7] S. Katz, Assessing self maintenance: Activities of daily living, mobility and instrumental activities of daily living, *Journal of the American Geriatrics Society*, 31(12), 1983, 721-726.
- [8] M.P. Lawton, & E.M. Brody, Assessment of older people: selfmonitoring and instrumental activities of daily living, *The Gerontologist*, 9, 1969, 179-186.
- [9] M.P. Lawton, K.S. VanHaitisma, M. Perkison, & K. Ruckdeschel, Observed Affect and Quality of Life in Dementia: Further Affirmations and Problems, *Journal of Mental Health and Aging*, 1999.
- [10] Rebecca E. Ready, & Brian R. Ott, Quality of Life Measures for Dementia, *Health Quality of Life Outcomes*, 1(11), 2003.
- [11] Giuseppe Riva, Pierpaolo Loreti, Massimiliano Lunghi, Francesco Vatalaro, & Fabrizio Davide, *Presence 2010: The Emergence of Ambient Intelligence*, (Amsterdam, IOS Press, 2003).
- [12] Independent Living Institute, Accessed 4 June 2009, <http://www.independentliving.org/indexen.html>, 2003.
- [13] National Aging in Place Council, Accessed 12 June 2009, <http://www.naipc.org/NAIPCHome/tabid/36/Default.aspx>, 2008.
- [14] Institute of Medicine Staff, Care of the Elderly Patient: Policy Issues and Research Opportunities, *National Academies Press*, Washington, DC, 1989.
- [15] Rebecca G. Logsdon, Laura E. Gibbons, Susan M. McCurry, & Linda Teri, Assessing Quality of Life in Older Adults with Cognitive Impairment, *Psychosomatic Medicine*, 64, 2002, 510-519.
- [16] Schölzel-Dorenbos, et al., Evaluating the Outcome of Interventions on Quality of Life in Dementia: Selection of the Appropriate Scale, *International Journal of Geriatric Psychiatry*, 22, 2007, 511-519.
- [17] Susanne Cahill, et al., 'I Know Where This is Going and I Know it Won't Go Back,' Hearing the Individual's Voice in Dementia Quality of Life Assessments, *Dementia*, 3(3), 2004, 313-330.
- [18] Rose-Marie Dröes, et al., Quality of Life in Dementia in Perspective, *Dementia*, 5(4), 2006, 533-558.
- [19] J.L. Novella, et al., Evaluation of the Quality of Life in Dementia with a Generic Quality of Life Questionnaire: The Duke Health Profile, *Dementia and Geriatric Cognitive Disorders*, 12, 2001, 158-166.
- [20] Robert Costanza, et al., An Integrative Approach to Quality of Life Measurement, Research, and Policy, *Sapiens Journal*, 2008, 17-21.