



Design and technology for enhancement of quality of life of person with dementia: New care pathways

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Abstract

This piece of writing argues that the experience of the person with dementia should frame the perspective brought to build the design and the philosophy of care. In essence, 'looking out from the inside'. Shifting the emphasis from condition to experience encourages the paradigm shift needed to create environments that allow the person with dementia to be an active participant in everyday life rather than a passive recipient of care. How consideration of the living experiences provides a way to focus thinking for design of the built in potential environment to practically support the person with dementia, thereby addressing the wider spectrum of issues in creating a dementia friendly physical, social and technological environment from the perspective of the person with dementia is what is highlighted here. The assistive technology helped the person and the carer to maintain a quality life and reduce the challenges of caring. This paper also addresses the impact of technology in dementia care in a wider range as well as the negative influence regarding man and machine.

Keywords: person with dementia technology, quality of life

Introduction

The increasing numbers of people with dementia has led to an increasing need for professional care services providing high quality care. However, care providers often find it difficult to obtain advice about what is involved in designing, setting up and maintaining a good dementia care service.

As recently as 2002, the relatively low priority accorded to dementia services by national policy makers was seen as contributing to the social exclusion of older people with dementia (Innes 2002). Since then, predictions about the likely rise in numbers of people with dementia, coupled with official concerns about the quality of care being provided, have led to the publication of national strategies (Audit Commission 2000, National Audit Office 2007^[1, 14]; Mental Welfare Commission/Care Commission in Scotland 2009, Department of Health 2009; Scottish Government 2009).

Quality of life

The definition of quality of life is relevant here to understand. According to Gregory, Derek, *et al* (June 2009) the term quality of life is used to evaluate the general well-being of individuals and societies. The term is used in a wide range of contexts, including the fields of international development, healthcare, and politics. Quality of life should not be confused with the concept of standard of living, which is based primarily on income. Instead, standard indicators of the quality of life include not only wealth and employment, but also the built environment, physical and mental health, education, recreation and leisure time, and social belonging. Bamford and Bruce (2000)^[2] review a wide range of literature about views on service quality and outcomes and compare them to measures commonly used to assess quality of life of people with dementia. At that time, few studies had explored

the views of people with dementia on this topic. Those studies involving users emphasised that desired outcomes would relate to an individual's needs, circumstances and personality. Key themes which emerged included maximising choice and control, respecting dignity, maintaining social contact and the process of service delivery. They identified a number of desired outcomes falling within two basic themes: quality of life and service processes

Assistive technology always influences the quality of life of the individual positively & negatively through the interaction of the individual in relation to the technological environment. The determinants of a good quality of life in old age vary from person to person.

Glendinning *et al* (2008)^[9] reviewed the wider literature on social care outcomes for older people and identified three main clusters of desired outcomes: changes in physical, mental or emotional wellbeing; maintenance of quality of life and the process of seeking and receiving services. They found little evidence on the outcomes valued by particular groups of older people such as people with dementia.

Assistive technology

Assistive technology was first defined in the Technology Related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407) as "any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities."

Assistive technology is the term used to describe devices used by people with disabilities that help compensate for functional limitations and increase learning, independence, mobility, communication, environmental control and choice. This term also refers to direct services that assist individuals in selecting,

acquiring or using such devices. Assistive technology can help people with dementia in overcoming challenges towards independence and inclusion. Technology can compensate for a person's functional limitations.

People with dementia should be introduced to assistive technology as early as possible. Transitions from one device to another should be made as smooth as possible by building on and integrating previously learned skills. Technology solutions should be flexible and customized to accommodate the unique abilities of each person with dementia

Use of assistive technology

Communication

Historically, communication is probably the most widely discussed area in the fields of dementia and assistive technology. Sometimes we may miss what the person is saying, or trying to say. Just about anyone who has supported a person with dementia has asked herself: "What is he trying to tell me with this behavior?" Those who work with persons who do not use typical spoken communication often try to find an alternate or additional technique for communication.

When a successful technique (or device) is found for the person who has dementia but does not speak, it is an enormous breakthrough. However, despite good intentions, sometimes we forget that communication is something that happens all the time, day and night. Frustration and accompanying expressions of frustration are almost inevitable if we fail to facilitate the use of the technique or device in all communication settings.

Environmental Controls

Devices to control the environment are important to people with severe or multiple physical disabilities and / or cognitive disabilities, who have limited ability to move about in their environment or control electrical appliances. Technology allows a person to control electrical appliances, audio / video equipment such as home entertainment systems or to do something as basic as locking and unlocking doors.

Mobility

Simple manual to sophisticated computer-controlled wheelchairs and mobility aids are available for a person who cannot walk.

Education

The computer can be a tool for improved literacy, language development, mathematical, organizational and social skill development. Alternative ways to access computers are available for people who cannot operate a keyboard. Software can be regulated so it runs at a slower pace if a person needs this type of modification. This draws upon the experience of different types of provider organisations with different financial strata. In so doing, it aims to show how much providers can achieve when they are committed to translating the principles of good dementia care into the realities of everyday life in a care home.

Assistive Technology and quality of life of the person with dementia

There are various dimensions of quality of life of person with dementia. These are quality of life of the person with dementia, the quality of life of the carers and the quality of life of the total family involved. Using the technological advancement in dementia care, the quality of these three dimensions will improve as well as improving the total social system improves

The affected individual may not be aware of the quality of life, but he or she can feel the positive changes in their own daily life. There are physical, psychological, emotional changes has been occurring with the quality of life. Simply say that considering the activities of daily living of the person with dementia have limiting the barriers and increases the mobility in all aspects due to the use assistive technology. It is actually providing a life from dependency to the world of independency of the affected person, than promoting an environment around the person. Dependency leads to the absence of quality of life gradually, but a journey from dependency to independency give rebirth of the person with dementia.

The quality of life of the carer

Carer may be a hidden patient because of the stress arising situations in the home or the care center. According as reducing the dependency of the person with dementia, the carer also getting relief from the stress and strain. Increasing the emotional and psychological health of the carer will positively influence the care and then develop quality of life. Good design and assistive technology creates an environment of positive energy for growth.

There are many contributing factor are in the health of the carer due to the implementation of assistive technology. Main factors are getting more time for the carer, reduce physical strain as well as fatigue, reflect the feeling of happiness of the person with dementia in the carer too, chance to avoid risk creating stimulus, feel more confident etc.,

Assistive technology may also help to support and reassure carers of person with dementia. Caring for an individual with dementia can be challenging and, at times, overwhelming. Frustration is a normal and applicable emotional reaction to many of the complications of being a caregiver. While some frustration may be part of everyday life as a caregiver, feeling tremendous frustration can have serious consequences for the carer.

Frustration and stress may negatively impact physical health or cause physically or verbally aggressive behavior towards loved one. If care giving circumstance is causing extreme frustration or anger it is advisable to practice assistive technology for reducing the stress on other negative emotions.

Many ways AT helps in caring

- It provide some time for personal care of the carer
- It reduces physical work regarding the activities of the person with dementia

- According as the mood changes from negative to positive of the person with dementia by the use of assistive technology, the carer also gets some positive attitude with respect to the mood of the person with dementia
- Care giver can also enjoy with the person with dementia (for example music therapy)

The quality of life of the total family

Increasing the quality of life of each individual has an indicator for the improvement of the total quality of life of the total family. These may provide more time for the family rituals, improving family get together, improving a sense of 'we' feeling and confidence as well as self-satisfaction.

Marshall (2000) ^[13] summarises three models of dementia. The medical model, the disability (social) model and the citizenship model and highlights how different models will lead to different uses of design and technology. Good design creates a homely feeling and that leads to positive change in the person with dementia as well as carers. Assistive technologies are used for minimising the risk and maximising independence in their own home. Usually older people may have fears about the role of technology in their lives. But gradually they can accommodate a few of the assistive technologies. It has real potential to change and improve the lives of people with dementia.

Bill Gates (2005) ^[3] notes that cochlear implants, which use digital signals the brain interprets as sound, can help profoundly deaf people hear. He remarks that these types of technologies will continue to be improved and expanded, especially in areas where they would "be correcting deficiencies." "We will have those capabilities...and computer human links would become mainstream, though probably not for several generations."

The use of technology to enhance quality of life is an effective approach for many individuals with dementia. It can increase a person's self-reliance and sense of independence. It offers powerful tools to persons with dementia by providing compensatory support in the home and other stay places like respite center, dementia care centers etc. Considering assistive technology in any situation, the focus should be on what the device does for a person, not on the device or technology itself. Assistive technology is merely the support to "get the job done" more independently. It can reduce a person's reliance on carers, family members, friends, and helping the transition into a quality life and fostering self-esteem and reduce anxiety.

For critically analysing the topic, the definition of AT is narrowed to define any technology or product that offers a person with dementia using compensatory techniques. Equally important in the process of identifying and selecting appropriate assistive technology is the element of "assistive technology service", defined as any service that directly assists an individual with dementia in the selection, acquisition, or use of an assistive technology device. The forces of "equal access", "non-discrimination", and "reasonable accommodations" have created an environment which encourages the use of technology designed to help those with dementia. Every use of AT should be to improve functional capabilities. Because every person with dementia has a unique profile of strengths, weakness, interests and

experiences, not all the technologies discussed will be appropriate for all people who have dementia.

Myths About AT

There are many myths relating to AT devices and services for individuals with disabilities. These misconceptions may affect attitudes and become invisible barriers to an individual's independence and productivity. Common misconceptions are:

AT device is a luxury

For someone with a disability who relies on AT to perform a critical function or achieve a desired goal in life, AT is very much a necessity in some cases. A computer is a necessary piece of equipment for anyone doing data entry even though it could be done with a pencil and paper. Just because a device makes a task easier or more convenient to do, does not make it a luxury.

Assistive Technology and elitism

Some people believe that AT is a part of elitism and this is not approachable to common people.

Design

When a person with dementia moves to a center or a home, they are moving into a new environment. Each will be different in some way, whether in its design, its population characteristics, or the way in which it is run. Brawley (2001, p.77) ^[4] suggest that "Good design directly impacts quality of life, and it is likely that the way in which an extra care scheme is designed will have an effect on quality of life through its effect on social aspects".

Case study

Alzheimer's and Related Disorders Society of India, Kottayam chapter; Mobile Geriatric clinic

Alzheimer's and Related Disorders Society of India Kottayam chapter is working in the field of Alzheimer's and dementia care for the last 15 years in a few districts of Kerala State. They have a mobile geriatric clinic with a geriatrician, psychologist, social worker and nurse. This is a service that provides family-centred care packages and diagnosis services to individuals and family members with dementia within Kottayam town. Viju Mathew, a social worker, working within the ARDSI team and involved in the assessment and implementation of low and high 'tech' assistive technology. He has provided the following examples to demonstrate some of the benefits and challenges that occur with the implementation of assistive technology and highlight the need for comprehensive assessment and evaluation.

Case study

Background

Joseph (79) was an elderly gentleman with a clinical diagnosis of dementia. His wife was no more. There were a number of reports from the neighbours that Joseph was found outside during the day time in his pyjamas, disorientated and making verbal abuse at neighbours loudly. His son, who works outside Kottayam town, was living with him and he had to go to work every day except Sunday and his wife is working abroad. He was very depressed because of his father's behaviour.

Assistive technology installed

Initially, a tape recorder was placed on the back of the front door and played music cassettes of Malayalam songs that Joseph was very fond of earlier. Joseph was happy to hear the music and almost always he seemed to be very calm, happy and ready to spend time near the music system in the home. Following assessment it was apparent that his condition did not distress Joseph who responded with a smile on each occasion the song was activated.

The worry was whether the player caused any health hazard to Joseph. His son was able to check this on a daily basis and ensure it did not cause any detriment to Joseph's health.

Outcomes

Over the following weeks there were no reports from the neighbours that Joseph had been seen wandering outside with loud voice and this reduced anxiety levels for Joseph's son and daughter. This piece of technology has been effective in the short term. However it will need reviewing at regular intervals to ensure that it is still meeting Joseph's needs.

Technology and dementia

Criticism

Although there has been a tremendous rise in using and developing technology in dementia care, the ethical issues also have to be discussed. This observation offers a series of reflections on technology, dementia and ethics in an attempt to widen the debate and generate new ways of thinking about the issues involved in the development and application of technology in the field of dementia care.

Dementia as disability

Many people focus on the medical model of treatment of dementia than the social model. Kitwood (1997) challenged this model, arguing that dementia is not solely a medical condition but a composite of bio-social-psychological factors, uniquely constellated in an individual's life. For Kitwood (1997) people with dementia are not only disadvantaged by the environment but also by the attitudes and actions of those around them. These disadvantages well understood in the field of disability.

Technology, dementia and ethics

Today as the moral crisis deepens, the need for ethical life style is realised more and more. As humans acquire enormous power due to the revolutionary growth of science and technology, it is also experiencing calamity due to falling ethical standards. Ethics are the survival need of the hour.

The major ethical issue is related to the relationship between machine and man. Technology reduces the human touch in caring and there may be a tendency of over dependency on technology that decreases the quality of human care.

Relationship in different levels should consider:

- The relationship between technology and society,
- Technology and technological thinking and the person,
- Technology and our form of life and
- Technology and the lived environment.

Technology, however, is not without its cost, not only in financial terms, but also in terms of our relationships, our

physical environment and our sense of self but also our ethical thinking and environment. There has been considerable interest shown in the development of technology with regard to cognitive decline and/or dementia

Values and technology

Technology is not, as some would claim and as is widely assumed, value neutral and that value judgments only enter into the debate when discussing the application of technology. The ethical framework we use to evaluate and analyze technology will determine the sorts of questions that can be asked of that technology and the boundaries within which ethical reflection can legitimately take place. Much work is required to explore the differing landscapes carved out by bioethics, feminist ethics, narrative ethics, and virtue ethics, to name but a few of the potential frameworks for ethical analysis.

Ethics and technology

Ethics and technology relate to each other in complex and dynamic ways. It is not a case of simply applying ethical standards upon the design and application of technology but also reflecting upon how the technological environment we live in influences and contributes to the nature of ethical reflection itself. North Lanarkshire council (2005) suggests that Assisted Living Technology has the potential to be very intrusive in people's lives, assessors and care managers. Therefore it must be also ensure that individual dignity and privacy are respected and not abused, by its use. Wherever practicable assessors should consult and respect service user's wishes

There are a few things to remember in the use of technology in dementia care, these are; 1) The technology must have new direction, new purpose and humanistic approach, 2) The craze for technology in the name of saving labour, comfort and time should not lead to unemployment 3) Small technological machines rather than expensive machines create work and wealth for many people than expensive machines.4)the motive for the use of machinery should not be greed.5) The individual should be the supreme consideration

Conclusion

As suggested by Wey, S., (2007) Assistive technology is often thought about in relation to risk but in fact it is any technology that helps people to do things that are beyond their reach on their own. This can also include being able to maintain relationships or keep in contact with loved ones, or being able to remember events, or being able to carry out a task.

- So try and think about how technology could be used to help a person achieve things they are finding harder to do. Or how it can raise their quality of life and the quality of their relationships.
- Safety is of course of great importance but it may be that they are compromising their safety in order to meet a need. For example they may be going out at night because they are looking for social contact or something to do. In this situation a technology like a door sensor may keep them safe but it will not meet that need and in the long run that might just make their need feel more urgent. Maybe that need can be met another way?

In conclusion, there are many positive impacts of design and technology in the quality of life of persons with dementia as well as negative effects. Compared to positive elements negative elements are much less.

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