

Digital Wellbeing Assessments for People Affected by Dementia

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Abstract. Currently there is a lack of digital tools for assessing the Wellbeing of those affected by dementia in a home environment. This paper presents an alternative to existing assessment modalities in order to facilitate large scale collection and analysis of data. This development will allow those affected to be assessed from the comfort of their own home, potentially reducing time costs and personal discomfort associated with assessment. Existing Wellbeing measures were evaluated against inclusion criteria and four tools were considered appropriate to develop into a digital application. An additional tool was also developed for quick assessment. Issues surrounding the use of technological devices for those affected by dementia are also considered. In light of these considerations an Android application was developed for Wellbeing self-assessment. Finally, the methods and approaches for user-evaluations of such technologies are explored.

Keywords: Human-centered Design · User-centered Design · Service design · Telehealth · Dementia care · Assessment · Wellbeing

1 Introduction

Assessing the Wellbeing of those affected by dementia is a research area that is becoming increasingly popular. However, there are many potential problems that need to be addressed if one is to consider seriously the possibility of developing a practical self-assessment solution. Paper-based evaluations are often time consuming and require specialists to administrate them. They are often implemented to serve as a single use evaluation and therefore cannot easily identify change over time.

1.1 Current Practices

The importance of an effective response to dementia was highlighted by health ministers in the G8 Health summit of December 2013, who state that; “We need to provide better and more concrete measures for improving services and support for people with dementia and their carers, to improve their quality of life and wellbeing” [1]. In the UK, the needs of those who may require additional support are assessed using a Community Care Assessment which is often both time-consuming and costly. It should also be noted that Community Care Assessments vary between regions and are not designed for the purposes of continuous monitoring. Whilst there remains a great deal of optimism over current policy, there is a more general concern that those most in need may find it difficult to gain access to the relevant support [2]. Using traditional methods such as interview or pen-and-paper based approaches will become increasingly infeasible as the number of people living with dementia increases. An automated system which is able to store and automatically process such large data sets appears to be a much more preferable alternative.

It seems appropriate therefore, to develop digital tools to assess the Wellbeing of people living with dementia and their carers in order to facilitate prompt intervention for the most vulnerable. There is a general agreement on the need for people to maintain their independence and stay in their preferred home environment for as long as is possible [3], yet without adequate Wellbeing assessment it is difficult to know how people are coping and how support services could be most efficiently allocated. Developing self-assessment measures to monitor Wellbeing may prove crucial for ensuring appropriate support is provided in a timely manner and may help to promote independent living.

1.2 Defining Wellbeing

Wellbeing is an often ill-defined and ambiguous term, frequently considered synonymous with Quality of Life [4]. It is usually defined as the internal and subjective aspects of how well somebody is dealing with life in general, as opposed to Quality of Life (QoL) which also includes external and objective aspects such as housing and finance which are often beyond the immediate control of the individual. Not everyone draws such a distinction and some of the research discussed here will also include QoL studies and trials due to its pervasive reference within the literature.

Much of the research in this area is based on the work of Lawton [5] who considers QoL to be the difference between positive and negative affect as well as the congruence between desired and attained goals. Some definitions of Wellbeing include broader constructs, for instance cognitive functioning and daily living [6]. Others consider more psychological aspects such as autonomy, independence and control [7]. The most common view of Wellbeing is that it is a measure of psychological and affective states rather than cognitive capacities. However, upon examining Kitwood’s definition it is clear that these aspects are not always easily delineated [7]. He suggests that the five main psychological needs that constitute Wellbeing are; comfort, attachment, inclusion, occupation and identity. Whilst these aspects may seem almost entirely non-cognitive in

nature, ultimately they depend upon a certain level of linguistic, attentive, and memorial capabilities. Consider for example the concept of identity, which Kitwood suggests is continuity of the self over time. This is dependent upon being able to recall past events and trace those events forward in time to the present moment. It is unlikely that such an important psychological need would easily be satisfied by an individual with severe memory impairment. Hence, despite the fact we may want to reduce the extent to which Wellbeing assessment overlaps with cognitive assessment, it is impossible even in principle to completely isolate these two distinct yet related factors.

1.3 Evaluating Wellbeing

Despite the lack of a formal consensus on a clear definition of Wellbeing there are a number of instruments available to both researcher and clinician for evaluating the Wellbeing of those affected by dementia. These instruments have been developed over the course of decades by numerous researchers and implement a variety of approaches. The most common of these are highlighted by Ready and Ott [6] and include direct measurement, proxy assessment and observational analysis. Due to the varying definitions and approaches, there are a considerable number of Wellbeing assessments. Detailed below are examples of a few popular and widely used approaches.

Dementia Care Mapping (DCM) [8] is a popular approach that is often used to assess Wellbeing and quality of life that uses a structured observational analysis. An assessor uses a six-point ordinal response format which ranges over twenty-four activity categories, and also considers staff attitude towards the service user. It is therefore most appropriate for use with moderately to severely impaired patients living away from home. Some questionnaires such as the QUALID [9] require that the main caregiver acts as a proxy rater and answers questions relating to care recipient's behaviour and mood. Each response is given a numerical value and the total assessment score is calculated by summing of all responses. It should be stated that this method is designed for individuals with severe dementia where the patient is considered unable to assess their own QoL. The QUALID questionnaire is an example of an Activity and Affect approach highlighted by Ready & Ott [6]. These are indirect ways of assessing the Wellbeing which use a proxy to rate the frequency of certain behaviors and moods exhibited by their care recipient. This approach is considered useful for assessing many people living with broad range of dementia severity. However, it should be noted that Wellbeing is by definition subjective, and therefore proxy Wellbeing assessments suffer a methodological shortfall in a way that other proxy assessments (such as Health-Related QoL) may not. It is also evidenced that carers often rate their care recipients' QoL as being lower the person in question [10].

Contrastingly, some measurements do rely on direct assessment. Usually these involve a person living with dementia being asked about various aspects of their Wellbeing in a structured interview. This method seems uniquely positioned to assess the "subjective evaluation of one's own quality of life" (pp. 356 [4]), in a way in which the other approaches do not. The BASQID is one such approach [11] and acknowledges that people with dementia are very often capable of reporting on their own experiences, unlike proxy or observational approaches which fail to take into account

the views and opinions of those being assessed. Unfortunately, self-assessment measures are not appropriate for all people and no existing measure could be found that was recommended for a person with a Mini Mental-State Exam score below twelve.

2 Inclusion Criteria for Digital Assessment

In order to develop a fit for purpose, standardised digital assessment suitable for home use, it was decided that existing and well-established Wellbeing assessment tools should be integrated into a single software application as opposed to developing a completely new set of tools *ex nihilo*. In some circumstances it has been shown that computational assessment measures yield results indistinguishable from their paper based counterparts [12]. Further validation should be undertaken to ensure that this is the case and that the digital versions have comparable reliability and robustness.

Inclusion criteria were developed in order to decide which existing measures would be the most appropriate to digitise. The inclusion criteria are:

- Reliability
- Validity
- Brevity
- Automatability
- Simplicity

Perales et al. [13] examine methods of establishing various types of validity and reliability in relation to QoL assessments for people with dementia by collating multiple reviews of QoL instruments. They concede however, that data was not always available or consistent enough to perform a more rigorous analysis. Nevertheless, they examine various methods in which various QoL measures have been evaluated and their findings have been considered here. The validity of Wellbeing assessments is often difficult to establish. One cannot conclude with certainty that a particular assessment tool is adequately measuring Wellbeing and not a related construct. In this case, construct validity can only be approximated by comparing the assessment's items to a generally agreed upon definition of Wellbeing. Concurrent validity is also hard to establish due to the fact that there is no current Wellbeing assessment measure that is considered to be the 'Gold Standard'. Difficulties aside, Perales et al. do highlight important methods for establishing the suitability, reliability and validity of QoL scales.

Studies involving the completion rates of questionnaires were also examined order to identify which factors contribute to higher completion rates and higher quality of data. Unsurprisingly, shorter questionnaires yield higher rates of completion [14]. It has also been shown that open ended questions are less likely to be completed and would be likely to make a potential assessment much more difficult to automate. Therefore these types of assessments can be excluded for failing to meet the inclusion criteria.

Two existing carer Wellbeing assessments were included for digitisation; the Satisfaction with Life Scale [15] and the Zarit Burden Interview [16]. The Satisfaction with Life Scale is a five item assessment which is designed to assess a person's global evaluation of their current life according to their own standards. It was chosen due to its short length, proven reliability, *prima facie* simplicity and high construct validity.

In addition, the Zarit Burden Interview was also considered appropriate to assess the Wellbeing of carers in order to evaluate how well they are coping in their role as a carer. Using two measures of Wellbeing is likely to capture a much more rounded view of how the person is coping both generally and specifically in their role as a carer.

In order to ascertain a detailed understanding of the Wellbeing of the person living with dementia, two assessments were chosen from the literature and an additional assessment was also developed.

The BASQID satisfied the inclusion criteria and was considered appropriate for inclusion in the digital toolkit. This is a direct assessment for people with dementia which aims to use brief, simple, questions in order to reduce cognitive burden. The BASQID has been validated for use with patients living with mild to moderate dementia (MMSE score 12 or above) and therefore would apply to all but the most severe cases where detailed self-assessment would not be possible.

However, it is acknowledged that some of the most afflicted would be unable to complete this assessment, especially via an Android application. For this reason a proxy assessment was also included. The QUALID instrument which seeks to discover Wellbeing through assessing the behaviours of the sufferer was chosen because it also fared well against the inclusion criteria. However, due to the concern that proxy ratings do not constitute a truly subjective evaluation, an additional tool was also developed to be used in conjunction with the QUALID. This was designed to be as simple to use as possible and consists of only one item. This is a pictorial based rating scale which simply asks the user to choose from a selection of cartoon faces which best represent their mood. It has been shown that pictorial based rating scales can produce comparable results to their text based counterparts [17]. Using a dual approach should help to mitigate some of the concerns about each individual method of operationalization.

3 Design Considerations

Developing user-interfaces for people affected by dementia presents unique design considerations. Whilst many existing and widely recognised user-interface guidelines are appropriate [18, 19] additional factors need to be considered when designing for people with cognitive impairment. Tamanini et al. highlight the importance of reducing cognitive burden for those with dementia in the design of graphical user interfaces [20]. They also suggest implementing dual user-interfaces to cater for the differing needs of people living with dementia and their carers. Other research in this area includes the work of Granata et al., who outline associated usability and accessibility problems of this population [21]. These include; scrolling, insufficient contrast, moving content and cascading navigation menus. It is thought that the layout for the application should be as clear as possible and only those elements essential to the assessment should be present. It is also thought that a high contrast colour scheme should be implemented to assist users that may have age-related visual impairments or other difficulties. Additionally questions and responses should have the option to be read aloud by the application in order to further assist in this respect and also to reinforce the questions/responses for those with attentional deficits.

The possibility of using voice recognition as an input method was also considered. It is thought that this may help increase the accessibility of the delivery system as many people living with dementia also experience poor eyesight and limited dexterity. Unfortunately, current speech recognition software is not always accurate and some of the end-users may experience problems with speech production either as a result of their dementia or other health problems. Conceivably, the speech recognition software may fail to properly comprehend their speech and thus register an incorrect response. This may not only result in a faulty or incorrect measure of Wellbeing but also cause undue stress to the user and ultimately reduce completion rates.

4 Development of a Digital Toolkit

As part of an iterative design process an Android application was developed allowing carers, clinicians and those living with dementia to easily administer and analyse the results from these five tests. With guidance from domain experts, this was developed with the Eclipse IDE using Java for Android with XML layouts for the graphics. The application contains digitised versions of the aforementioned assessment instruments, as well as home screens and a graphical representation of the assessment data. The application utilizes a high contrast colour scheme, provides appropriate cues and feedback and allows for the possibility of easily correcting errors. The home screens for each user type vary slightly in terms of the complexity and amount of data being represented and available assessments. Upon clicking a test, all users are directed to an instruction screen, which displays instructions that were taken directly from the administration manuals provided with each assessment where available.

The instructions and assessment questions are read aloud by the text-to-speech engine, and when the user makes a response it is also read aloud. Upon clicking the “submit” button their response is stored and they are taken to the next question. Haptic feedback is provided after each action to denote that the touchscreen has been pressed. After completing each assessment, users are taken to a results screen that displays their assessment score and the corresponding advice before all assessment scores are sent to a server using http post and the JSON protocol for storage and analysis.

The carer and care recipient are presented with slightly different home screens to accommodate their different user needs. The carer’s screen has access to the assessment results of both themselves and the person that they care for. It also presents more detailed information of their results over a longer time scale. On the other hand, the home screen designed for the user living with dementia shows less information and presents fewer options in order to reduce the complexity. The direct assessments for the person living with dementia are both five item response formats. The ‘Quick Assessment’, simply asks the user to “Click on the face that best represents how you have felt today”, and presents five cartoon faces representing different moods with corresponding text underneath face. Once clicked, the application reads their response aloud using the Android text-to-speech engine and the user is given a choice to change their response before it is automatically sent to a server. The digital version of the BASQID implements the same interface with the addition of a progress bar to demonstrate progression and length of the assessment (see Fig. 1). The addition of a progress bar

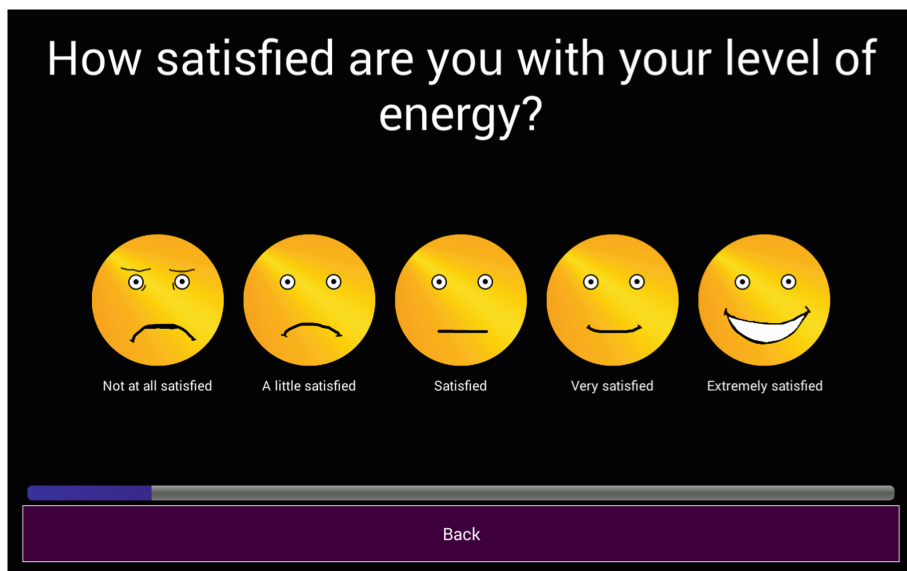


Fig. 1. Digital version of the BASQID

has been shown to significantly increase questionnaire completion rates [14]. The text underneath each face corresponds with the responses given in the BASQID.

The carer can complete a total of three questionnaires. One of these is the QUALID; a proxy rating of their care recipient. The other two evaluate their own Wellbeing; the Satisfaction with Life Scale and the Zarit Burden Interview. Both of the digital self-assessments implement a slider bar in order to show agreement or disagreement with a statement. Upon releasing the slider bar, their current response is shown on the screen and also read aloud by the text-to-speech engine. The screen also has one button to confirm their current response and another to go back to the previous question (see Fig. 2).

Unfortunately, it was not possible to implement a slider-bar interface to the digital version of the QUALID tool without significantly compromising the assessment. Instead, the QUALID interface presents users with a particular statement and shows the possible responses with large buttons.

After the completion of each assessment users are taken to a results screen which details their score, provides a bar graph representation of their results and a small description. It also suggests possible intervention methods which might be recommended for a person with that particular score.

5 Evaluating the Prototype

Currently, the prototype is undergoing an evaluation which consists of a series of focus groups constituted by carers, clinicians, researchers and other stakeholders. Initially the focus group participants are presented with the application and then asked a series of

Do you wish you could leave the care of this person to someone else?

Sometimes

Never Sometimes Nearly Always

Back Submit

Progress bar: approximately 75% complete

Fig. 2. Digital version of the Zarit burden interview

open ended questions pertaining to usability and appropriateness of both the assessment tools and the user interface. Once the findings of the focus groups have been analysed these insights will be taken into consideration to in order to further improve the application. Finally, it is hoped that a longitudinal study will be undertaken using people diagnosed with dementia and their carers as participants. The digital assessments could be taken in conjunction with the original assessments in order to establish the validity and reliability of the new methods. Such a study would also allow data about completion rates to be evaluated in order to further improve the application.

6 The Future of Wellbeing Monitoring

Eventually, it is thought that unobtrusive monitoring methods will one day replace digitised versions of paper and interview based assessments. Developments within this area have already been trialed regarding the early prediction of mood changes within people with bipolar disorder by detecting subtle changes in broad features and properties of speech [22]. The monitoring occurs via a smart phone application which records phone conversations. The privacy of each user is protected and the researchers only have access to the results of the computational feature extraction. Whilst this work is still in the research stage of development, initial results look promising. Results are benchmarked against standardised weekly assessments which are used to correlate the acoustic features of speech with mood. This is a major development in unobtrusive healthcare technology, and it is likely that other measures will eventually be implemented in the not too distant future. An advantage to this type of analysis is that individual differences could be taken into account using machine learning methods.

Perhaps one day these unobtrusive assessments will become more reliable, more accurate and far easier to implement than current methods. Measures such as these completely negate response bias, which is largely inescapable using any type of questionnaire or interview methods [23]. These methods could also be used to analyse a whole host of other behavioural, affective and cognitive issues facing people affected by dementia such as wandering and aggression.

7 Conclusion

Wellbeing of both the carer and care recipient, are highly correlated with the breakdown of familial care and subsequent institutionalisation [24]. There is a general agreement on the need for people with dementia to maintain their independence and stay in a home environment for as long as is possible, yet without a standardised assessment for those affected it is difficult to know when and where to administer interventions. Developing digital alternatives holds the promise of facilitating more timely and appropriate intervention, potentially increasing the quality of life of those affected and simultaneously optimising the allocation of health and community care resources. Digital assessments such as these are not the *deus ex machina* of healthcare solutions but must instead provide a platform for all involved to monitor and communicate the needs of vulnerable people in a much more efficient and effective way.

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