Enabling People with Dementia to self-report data using digital technologies and methods

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Aims & Objectives

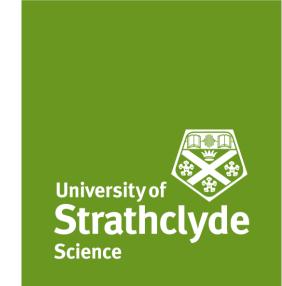To review the current literature on digital technologies, tools and modalities that have been used to collect self-reported data in People with Dementia and to identify barriers and enablers that influence the ability of PwD to self-report successfully.

Intro

Remote collection of digital self-reported data is becoming more prevalent in health care practice as services adopt a more person-centred care approach and deliver more care at a distance (1).

Whilst the benefits of collecting such data using digital technologies is increasingly being recognized (2), This method can be a major barrier to People with Dementia (PwD) who often struggle using electronic devices to self-report.

Factors such as platform design, literacy, language proficiency, and physical/mental capability severely impacting digital self-reported data collection (3) especially if such technologies are not designed with this population (4).

Methods

A narrative review of the literature was conducted using key search terms across 3 scientific databases:

Scopus® PubMed ACM DL DIGITAL LIBRARY

Various MeSH terms for search terms such as dementia, technology and various self-report tools including 'patient reported outcome', diary, and questionnaire

Only studies reporting on PwD using technology for the purpose of self-reporting were included. Articles meeting the inclusion criteria were analysed using Braun and Clarke's thematic analysis (5).

Results

11 out of the 525 studies identified, a total of 11 were eligible for inclusion

Text based modalities were the most common modality used. Visual and voice modalities were rarely used, and when used they were a backup alternative to text and had to be delivered by a researcher.

The most frequently reported tools used were questionnaires including the use of multiple PROMS though these were rarely more than a digital recreation of a paper PROM.

Enablers identified included support from informal carers, appropriate set-up at the start of each intervention and offering multiple alternative methods to self-report. Most studies did not identify any significant barriers.

Discussion

There is a surprisingly sparse body of literature focused on digital approaches to enable self-reporting from PwD.

Identified articles demonstrated a prominence for the use of computers over other types of technologies such as mobile phones or tablets even when the latter were freely available or provided as part of the intervention.

A clear focus for the field has been the reliance on traditional text-based data collection via a computer whereas approaches making use of more interactive modalities or mobile and smart technology were relatively understudied.

As the societal need to deliver person-centred care in dementia will continue to grow, it is critical that future technologies are built and implemented in a manner that combines: the breadth of technological, data and modality possibilities with the founding theories of personhood.

Conclusion

Enabling PwD to self-report data using digital technologies and methods can bring a huge number of benefits to clinicians, general practitioners, pharmacists, and consultants. Such data collection can offer greater insight into PwD quality of life, changing needs, monitoring medication adherence, as well as support shared decision making. Despite the benefits, there currently appears to be a lack of leveraging the full potential of these technologies for the purpose of self-reported data collection.

References

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