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What are the factors that influence the engagement of people with Cystic Fibrosis (pwCF) with web-based self-care management (SCM) strategies

A Systematic Review

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Background Adherence to treatment regimens in CF is poor resulting in increased morbidity and health care utilisation^{1,2}, the factors underlying this are multiple and complex^{3,4,5}. Self-care management (SCM) offers a way forward in terms of increasing engagement of people with CF to improve health and longevity. Current approaches to supporting SCM in people with CF draw on principles of self-regulation theory combined with those of Motivational Interviewing (MI)⁶. Delivery of SCM utilising these principles through electronic health (eHealth) and mobile health (mHealth) technologies⁷ is on the rise, however, engagement particularly long term, with eHealth and mHealth is low⁸. In order to understand factors that influence engagement with web-based SCM strategies, a systematic review of current literature was undertaken.

Aims

The aims of the systematic review were to:

- identify factors that are influential in the engagement of people with CF with web-based self-care management strategies

Methods

The Joanna Briggs methodology for meta-aggregative systematic reviews was used. 6 databases were electronically and hand searched (dates: 2000-2018).

Inclusion Criteria

Studies were included if they explored the use of web-based strategies in supporting self-care management in pwCF. All ages and languages were included in the review.

Search Strategy

Key words:

- Cystic Fibrosis, CF
- Web-based, online, cyberspace, World Wide Web, www., web, information technology, computer-based
- Self-management, self-support, self-care

Methodology

One reviewer conducted searches. Two independent reviewers, using the standardised critical appraisal instruments from, the Joanna Briggs Institute (JBI), the Critical Appraisal Skills Programme (CASP) and the Appraisal of Cross-sectional Studies (AXIS), carried out title, abstract and subsequent quality review of papers identified from the search. Any disagreement between reviewers was resolved through discussion including a third reviewer. Please see figure 1 for the review flowchart. Two reviewers using a modified and piloted version of the JBI data extraction tool then extracted data independently. The process of meta-aggregation was used to identify initial findings, develop categories and synthesize these findings; each stage was discussed and agreed by the two reviewers.

Results

432 studies were identified, reviews resulted in eight papers being identified for the final review figure 1. Study designs included qualitative research (n=3), mixed methods (n=2), cross-sectional survey (n=1) and text and opinion pieces (n=2). Five key themes were identified from the papers.

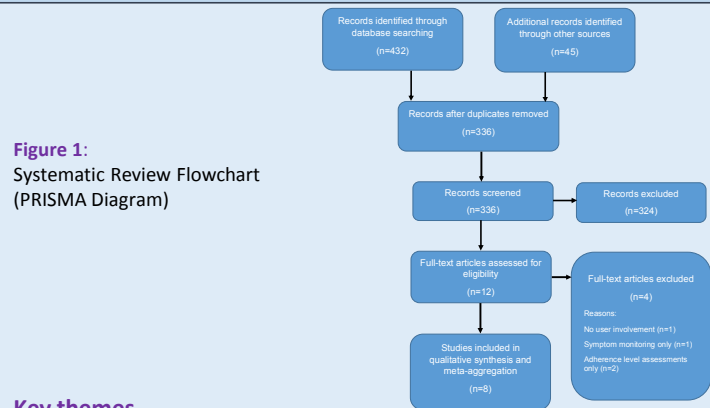


Figure 1:
Systematic Review Flowchart
(PRISMA Diagram)

Key themes

1. **Habit formation:** People with CF would like tailored development of habits around SCM to be commenced and practiced repeatedly early in life through the support of the CF team and their social support networks.
2. **CF Team:** People with CF expressed benefit through having mutual respect, trust and understanding with their CF Team through skilful communication. They desired shared decision-making that is patient-led, preferring honest feedback, team motivation and clinicians skilled in treatments and strategies to promote SCM.
3. **Individualised approach:** People with CF want recognition of the unique nature of CF and for approaches to management to be individually tailored to the variability of individuals. They would like help to develop problem-solving skills and support to use them to negotiate management plans, outcome measures and therapy choices.
4. **Low level of burden:** People with CF expressed preferences for web-based SCM strategies to be simple and easy to use, through automated and integrated functions, instant information and good internet access.
5. **Technology preferences:** People with CF would like technology developments to be easy to access, be relevant to the unique nature of CF, have graphical displays of data, use a variety of data capture technology and functions, provide adequate security and confidentiality, be financially viable and have training available for its use.

Conclusion

These synthesized findings have strong associations with evidence from other LTCs, yet in CF the research is scarce and of low quality. Taken tentatively, these findings can be used as guidance for clinicians in promotion of engagement with web-based SCM strategies in CF. However, meta-aggregation aims to develop guidance for future practice and policy and to achieve this, further studies are needed to strengthen the evidence-base. These studies must be of high quality and specific to the CF population. Additionally, an understanding of how to engage individuals with the lowest motivation and engagement was not identified, this is needed if future research is to provide evidence-based guidance for the most vulnerable members of the CF community.

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