

Patients' experiences of eHealth in palliative care: an integrative review.

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Abstract

Background: With a growing world population, a longer life expectancy, and more deaths due to chronic diseases, the need for palliative care is increasing. E-Health involves the use of information and communication technology to provide care, and also to transmit health information through the Internet and related technologies. E-Health can be an effective way of supporting communication between patient and healthcare providers, but it is unclear to how patients regard information and communication technology (ICT) within palliative care

Methods: The aim of this study was to describe patients' experiences of eHealth in palliative care. An integrative review with a systematic literature search of six databases: Cinahl Complete; MEDLINE with Full Text; PubMed; Psychology and Behavioral Sciences Collection; Nursing and Allied Health; and PsycINFO generated 12 scientific articles. The articles were evaluated, data extracted, analyzed and synthesized, according to the aim.

Results: The results are presented in the main theme: *E-health applications – promoting communication on patients' and families' terms*, and three sub- themes: usability and feasibility of eHealth applications; symptom control and individualized care promoted through eHealth applications; and use of eHealth applications increased sense of security and patient safety. Patients described ease of use, usability and feasibility of eHealth applications. Equal and individualized care, security, better symptom management, participation through increased accessibility and increased patient safety were described.

Conclusions: E-Health applications promoted equal, individualized care, and may be a tool to promote accessibility and patient participation in palliative care settings. Furthermore, care transparency increased with eHealth communication when patients and families received more information, and experiences were that patient safety and feelings of security also were promoted. At organizational and societal levels, eHealth may contribute to sustainable development and more efficient use of resources in palliative care.

Background

With a growing world population, a longer life expectancy, and more deaths due to chronic diseases, the need for palliative care is increasing (1, 2). Palliative care is described with the aim of alleviating suffering and promoting the quality of life for patients with progressive, incurable disease or injury, taking physical, psychological, social and existential needs into account (3, 4), and further to provide family support (5). Combining healthcare professionals in a team approach to care is intended to offer support and to allow meeting complex needs (6), and for patients to continue living as they prefer until death. Communication is a key concept in palliative care (7), and an important dimension of patients' experiences of care (8). Perceptions of care quality and patients' well-being are affected by the possibilities for inclusive communication (9, 10). With global access to palliative care varying greatly (2, 11), and to facilitate patients' being heard and cared for, exploring alternative approaches for patients to communicate their needs and preferences to healthcare professionals is crucial (12).

E-Health involves the use of information and communication technology (ICT) to provide care, and to transmit health information through the Internet and related technologies (9, 13), without being concerned about distance. Other commonly used words are telemedicine and telehealth (14, 15). Ideally, eHealth promotes patient involvement and participation in care, improves quality of care, and increases access to care while maintaining cost effectiveness (1, 13), especially in remote locations (16). Other benefits are convenience, reduced travel time and reduced risk of infections. In a qualitative study, healthcare professionals express concerns regarding eHealth use in palliative care, both regarding technological issues and possibilities for creating a caring relation from a distance (17), concluding that eHealth may be useful as a complement to regular face-to-face care. Using eHealth would also mean handling patient data and confidential information remotely, which highlights issues regarding storing and protecting confidential information (16). In another study, healthcare professionals expressed fear that eHealth would replace human contact and interaction (18). Identified barriers to eHealth in Africa are access to technology, like modern mobile phones, and infrastructure surrounding internet and digital applications. In a literature review highlighting eHealth technologies in palliative care, applications for eHealth were charted, including analysis of strengths, weaknesses, opportunities and threats of the technology (19). Findings indicate that eHealth is an emerging field with potential to improve comfort and quality of life,

however, the validity of applications is rarely discussed and respecting patient preferences for forms of care requires further attention.

The Technology Acceptance Model (TAM) explains how a user accepts the use of technology (20), and has been used in studies regarding eHealth application (21–23). The goal of TAM is to gain an understanding and explanation of the user's behavior and use of technology, where usability and ease of use indicate the user's acceptance of the technology, see Fig. 1.

Other important factors are the utility and quality of the technique (20, 24), and that technology is adapted and meets needs (23). There is interest in using quality-of-life instruments within eHealth in palliative care, as a foundation for reinforcing person-centered and participatory care (25, 26), however, a challenge remains in adapting ICT to patients' individual resources and needs (12).

The United Nations (UN) Sustainable Development Agenda (27) emphasizes modern and effective care for all, and promotes development to create conditions for all people to attain their fundamental rights to health and well-being. Innovation and technological advances are crucial to finding sustainable solutions to both economic and environmental challenges, that in turn can contribute to efficient and equitable use of resources. Healthcare services and ideals are shifting towards a view of patients as proactive, well-informed, collaborative partners in healthcare provision (28), and this seems to align with patient preferences (5, 29). Effectiveness increases if patients are involved in the process of their own care (1). E-Health can be an effective way of supporting communication between patient and healthcare providers, and the technology to do so exists (19), but it is unclear to how patients regard use of ICT within palliative care (9).

Methods

The aim of the study was to describe patients' experiences of eHealth in palliative care.

Design

An integrative review was chosen to allow inclusion of both experimental and non-experimental research, aiming to provide broad view of the phenomenon of eHealth, and to investigate the available evidence (30). The study was informed by the outlined steps of Whittmore and Knafl (30), namely problem identification (presented in the background), literature search, data evaluation, data analysis and presentation.

Literature search

Systematic searches were performed in the following databases: CINAHL Complete, MEDLINE (full text), Nursing and Allied Health database, PsycINFO, Psychology and Behavioral Science Collection, and PubMed using the key words *telemedicine, patients and palliative care*. The inclusion criteria were peer-reviewed original studies describing patients' experiences of eHealth, with the words telemedicine, patients and palliative care in either title or abstract, and with explicit ethical considerations. Exclusion criteria were studies published before 2014, participants under age 18, literature reviews and studies in languages other than English or Swedish.

Data evaluation

All included articles were evaluated according to the Critical Appraisal Skills Program (CASP) depending on method used. Articles were not excluded if quality was found lacking, in line with Whittmore and Knafl's recommendations (30), however, reflection on valid inferences aligned with scientific quality were performed throughout the research process. For details and results of the CASP evaluation, see Table 1.

Data analysis

A core in the integrative review, as described by Whittmore and Knafl (30), is the qualitative, iterative nature. As suggested in the data reduction and data display phases, primary data were analyzed and arranged, coded, categorized and summarized in a matrix. Next, the data comparison phase, entailed noting patterns and commonalities, performing clustering and contrasting, to

creatively question plausibility and allow critical analysis of data. A thorough and impartial interpretation of data, promotes innovative synthesis of evidence (30), one goal of the data analysis step. This process resulted in the creation of a main theme: *E-health applications – promoting communication on patients’ and families’ terms*, and three sub-themes.

Results

This integrative literature review included 12 empirical studies, with a total of 397 patients. The qualitative studies comprised 187 patients and the quantitative studies 225 patients. Two studies used mixed methods, and the 15 participating patients were counted once even though they were part of two data collections. The patients' ages ranged from 18 years to 91 years, and studies were from Australia, Brazil, Italy, Canada, the Netherlands, Portugal, Switzerland, Germany and the United States, see Appendix 1 for details on the included studies. The study inclusion/exclusion process is outlined according to the PRISMA structure as described by Moher (31), see Figure 2.

The results are presented in the main theme: *E-health applications – promoting communication on patients’ and families’ terms*, and through three sub- themes: (1) usability and feasibility of eHealth applications; (2) symptom control and individualized care promoted through eHealth applications; (3) use of eHealth applications increased sense of security and patient safety.

E-health applications - promoting communication on patients’ and families’ terms

Throughout the literature review, findings were that eHealth applications generated multiple arenas for communication on patients’ and families’ own terms, and in their own time. In all the included studies, patients' experiences were predominantly positive for eHealth applications and communication (32-43). Eleven studies described patients' practical experiences of using various technological tools to communicate digitally with their caregivers (32, 33, 35-43). In the twelfth study, patients described wanting technical communication aids both to receive and to provide information digitally, and thus facilitate communication with healthcare professionals (34).

Usability and feasibility of eHealth applications

Through technology, new opportunities and arenas for meetings were made possible, as an addition to the more common traditional face to face care meetings or conferences. Several studies described that patients perceived various technical communication aids as user-friendly and feasible (32, 33, 35-43). An example of user flexibility, was an app that could be used in the way individual patients or families wanted, either on a mobile phone, a computer or a tablet (33, 35, 39-41). Communicating via video link also worked well and was found convenient (33, 35-39, 42). Patients experienced benefits of videoconferencing as compared to telephone consultations, since the added visual dimension provided information about body language and emotions (35, 36, 40). The majority of participants in two studies were very satisfied with video meetings, and even preferred them before physical meetings (38, 40). Another advantage of videoconferencing, compared to telephone consultation, was that how patients were feeling quickly became apparent, which was found convenient by patients since they did not need to explain themselves (42). The added visual information was desired and considered useful (34). However, contradictory findings were found in two studies; one where patients favored the personal encounter and found that a deeper personal connection could not be achieved through eHealth technology (33), and in another study, some patients and families felt that they were satisfied with telephone calls and information by letter, since they found new technology difficult (34).

One important factor for adopting ehealth applications was the attitude and enthusiasm of the healthcare professionals (HCPs) (40, 41). If the HCPs were not excited and motivated to use the new technology, neither was it used by patients or families. None of the studies indicated the use of eHealth technology was restricted by high age, and a mix of ages used eHealth technology in the included studies (32-43). Older people were able to manage the technology well, but sometimes needed additional support at the start (32, 33, 40). In case of technical problems, these were solved through support from HCPs or through help from family members (35, 36, 41).

Symptom control and individualized care promoted through eHealth

Various eHealth applications enabled patients to participate in and govern their own care, for example by self-reporting symptoms and needs (32-37, 39-41, 43). The possibility of sending text messages to HCPs, for example to give notice that medication needed refilling, was perceived by patients as a well-functioning alternative for communication. Information from validated instruments describing physical, mental, social and existential symptoms, as well as quality of life, was sent to HCPs using eHealth technology, and was subsequently used for making care and treatment decisions (32-37, 39, 40, 43). Participants experienced a high degree of satisfaction when videoconferencing was conducted to address concerns raised by previously submitted information (38, 42). Patients found that communication was improved through eHealth applications, since instant feedback and help were provided as a result of the submitted, self-reported symptoms (32-34, 36, 40). This enabled individualized care according to patients' and families' needs. Patients wanted to register and monitor symptoms over time since it was found valuable method to be able to manage their symptoms themselves (34, 41), and patients were highly motivated to be involved in their own care (32, 38, 43). Studies also showed that automatic reminders to take their medication could be of benefit to the patient (32-34, 39). Improved symptom control empowered patients to remain in their homes until the end of life (36). However, in one study, some patients experienced increased symptoms, but the placebo effect could not be rejected (37).

Care was perceived as more accessible and patients described increased access to care (32, 33, 36, 38-43). Communication and consultation with HCPs through eHealth applications aligned with patients' daily lives, since it enabled patients to determine the time of contact themselves (32, 39, 42). Another finding was that using digital consultations could condense health care meetings and make them more efficient (33, 36, 38, 40, 42). eHealth application could be tailored to patients' needs, thus enabling individualized care (33, 35, 38, 39, 41-43).

Through eHealth technology, patients were able to maintain their social relationships and contacts in everyday life, since they were able to be cared for at home (35, 36, 38, 42). With the help of eHealth, patients could continue to participate in social activities like before the illness (35, 38). Despite long distances, it was possible for patients to receive care through eHealth applications, in a convenient manner, without spending time nor funds for travelling (36, 38). During treatments that resulted in a low immune response, eHealth was a good way to meet, participate and interact with peers to feel support (38). Being able to participate in both private and social contexts, as well as in caring and supportive situations, despite troublesome symptoms and severe illness, was perceived as positive and provided a sense of connection to life and living (32, 35, 36, 38, 41).

Use of eHealth applications increased patient safety and sense of security

Several studies described how patients felt that information, guidance and advice could be transmitted safely through various eHealth applications (32-34, 36, 37, 39-41, 43). An application enabled the healthcare staff to see the text in their language even though the patient wrote it in another language (33). Patients stated that they received a guarantee that the information was forwarded to the intended recipient, and further that they experienced a faster response (33, 42). Patients also expressed that they did not want to interfere, and therefore found eHealth applications less intrusive since HCPs monitor them at their own convenience (34). Thus, patients did not hesitate to contact HCPs through the application. Patients admitted to palliative care also described how difficult it was to remember and understand all the information provided about diagnosis, treatment and potential symptoms and how easy it was to forget the information (34). Patients described how they relied on the family members and therefore wished to share information with health care professionals, friends and family through the eHealth application (34, 35, 38). E-health consultation provided a sense of security, relief and accessibility; for example, reminders to take medication (32-34, 39), facilitating renewal of prescriptions (33), increased access to care and prolonged care meetings (33, 36, 39), feeling better involved in own care (36), quicker response time to queries (33, 41), and that information, advice, and guidance could be safely delivered due to eHealth applications (33, 43).

Patients described how the eHealth applications provided increased opportunities and circumstances to feel secure (33, 35, 36, 38-43). In a study where patients had not tried the technology, patients anticipated that use of eHealth applications could mean feeling safe at home, since call for help and a follow-up visit was facilitated through the technology (34). Increased access to care resulted in increased confidence in the care, which led to reduced emergency hospital admissions (36, 42). Patients using different eHealth applications experienced security and increased well-being, as well as peace of mind and feeling at ease (33,

35, 36, 39, 41-43). A negative finding was that the integrity of the patient could be jeopardized since other persons unannounced could enter a room during an ongoing meeting (40, 42). This resulted in patients experiencing a sense of intrusion.

Discussion

The results of this integrative review highlight that patients' experiences were that eHealth applications promoted and improved communication with healthcare professionals in palliative care. Through eHealth applications, patients had access to a convenient information- and contact channel on their own terms, and furthermore, felt empowered to participate and govern their own care, which resulted in experiences of security. In the twelve studies in this review, most patients found the eHealth applications easy to use and helpful in managing their daily lives with life-threatening illness.

Ability and willingness to accept new ICT, ease of use, and usefulness has been explored using the TAM model (20). The model has been widely used to predict and explain users' reactions to new information technology, and has become a gold standard (44). An early idea with using the model was to encourage use of ICT and to think of ways to increase modern advances (20), including healthcare settings. However, technology and palliative care may seem as polar opposites since technology lacks human touch. Palliative care is described as inherently built on communication and interaction between patients, families and healthcare professionals (7, 19), and as such demands sensitivity and flexibility to promote understanding of experiences and goals of care in alignment with patients' wishes (45, 46). Contrary to this, the results of this review indicate that use of eHealth applications in palliative care may provide feasible alternatives without violating palliative care standards. Some patients even found that eHealth improved communication and connectivity with the healthcare providers.

The benefits of eHealth can be increased access to care, increased convenience, reduced travel time and reduced risk of infections (47, 48). These aspects are reflected in the results of this review, and in line with previous findings from Pinto et al (19). Communication between patient, close relatives and team members was facilitated through eHealth, and patients' experienced increased access to care since physical distance was not an issue. Patients found that the use of video consultation, strengthened communication since visual features are included, also described in other studies (48, 49). Another benefit found in our review was that despite life-threatening illness and being close to the end of life, patients could take an active role and govern their own care if they want to, thus promoting individualized care. The use of technology can increase access to healthcare and can provide savings (48). Allsop et al (12) describe that patients in palliative care are willing to try new technologies as part of their care. In our review, benefits of technology mentioned were that it could be used for language translations, response time could be quicker, and it was perceived as less intrusive than a home visit. These benefits align with dimensions of usefulness as described in the TAM model (50).

The result indicate that eHealth applications may promote participation, security and safe care. One way to participate was self-reporting symptoms through mobile phones, tablets or internet, which also has been described by Cooley et al. (51); and facilitating symptom reporting in this manner consequently resulted in faster access to care (51, 52). For nurses, using validated questionnaires in combination with eHealth applications, may be one way forward to enhance quality of care on the terms of the individual patient. This approach also promoted patients' motivation and adherence to monitoring symptoms and governing their own care. Video meetings have had positive effects on patients' knowledge and provided social support for people with chronic illness (49), which agrees with the results of this study. However, safeguarding the integrity of patients in the context of video meetings is crucial to maintain a sense of security. Also, it is imperative that registered nurses keep in mind those who do not have or use eHealth applications, to ensure that patients have access to equal care and treatment, where needs are met, and strive to counteract exclusion (53), since everyone will not want or be able to use eHealth applications. There also seems to be a risk that when submitting data for interpretation by health care professionals, the act in itself may generate a sense of security, which unfortunately may result in ignoring warning signals and waiting for an intervention. In a time of change and implementation of new technology, it is imperative that responsibilities surrounding self-monitoring are specified and that there is a clear plan for how to respond to 'red flags' in the system. With this taken into account, using eHealth applications within palliative care, seems highly relevant considering the philosophy of a holistic view of patients (4) where security, participation and patient safety are pivotal (54). This also seems reasonable considering that the technology is easily available in our time.

According to Nelson et al. (55), health care systems can be understood on multiple levels. The microsystem is the immediate vicinity around the patient, and in this system values are created for the patient. Depending on patient's needs, the structure of the microsystem changes over time. The goal of the microsystem is to create the best possible value in care, relative to needs, for the patient. The mesosystem, or community level, describes interactions between units, while the macro system (society), provides support and structure to facilitate the work of the micro systems (Nelson et al., 2008). The findings of this review may be regarded in a health systems perspective, see Figure 3.

When patient values, like participation and security, are established at the micro level, this may be understood at meso- and macro levels as well. At meso levels, eHealth provides improved chances to make care available when and where patients want or need it, and at macro levels, societies have opportunities to generate and provide infrastructure, including resources to implement eHealth applications. Developing and implementing eHealth applications for patients may also be a feasible way to promote the UN Agenda 2030 (27) sustainability goal 3, *good health and well-being*, and goal 9, *industry, innovation and infrastructure*, to reduce inequalities for a better and more sustainable future for all. Or as the case may be in palliative care, meeting physical, psychological, social and existential needs when time is limited and death is near (7).

Finally, it is our belief that eHealth should be seen as a complement to the face-to-face meetings and not as a substitute or replacement for physical meetings. Human contact and human interactions are inherent to nursing (56), and relationships between patients and health care professionals are important in palliative care (57). However, that does not negate the positive experiences of eHealth applications found in this review. A thought before the study, was that perhaps patients in palliative care would be too seriously ill to manage or want to use eHealth applications, and that older patients would find it difficult to use. However, the results show that the majority of patients in palliative care, regardless of age and illness, could and wanted to use eHealth in addition to traditional care. There will be possibilities and challenges with eHealth applications, for example with regards to patient integrity (19), and there is reason to ponder implementation of eHealth in palliative care, but with a holistic view of individual's needs, eHealth can contribute to increased values in several levels within health care systems in palliative care.

Limitations

There are a number of limitations to consider in this study. A plethora of different terms are used within the area of eHealth, and it is possible that some terms were missed in our search strategies. Patients in various palliative care settings have been included in this review, however, without classifying interventions, diagnoses or care context. Language restrictions may have resulted in information bias for studies published in languages other than English. An integrative review comprises a qualitative approach, and synthesis of various types of research findings may be challenging. For credibility and trustworthiness, we have strived for transparency in reporting methods and found that the themes were consistent throughout the included studies.

Conclusions

E-Health applications promoted equal, individualized care, and may be a tool to promote accessibility and patient participation in palliative care settings. Furthermore, care transparency increased with eHealth communication when patients and families received more information, and experiences were that patient safety and feelings of security also were enhanced. At organizational and societal levels, eHealth may contribute to sustainable development and more efficient use of resources in healthcare settings and palliative care.

Declarations

Ethics approval and consent to participate

Not relevant for an integrative review, however, ethical considerations in the studies were included in the review process.

Consent for publication

Not applicable.

Availability of data and materials

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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No funding was received for this study.

Authors' contributions

CW, BW and AK designed the study; CW and BW performed database searches, collected data and performed initial analyses of data; CW, BW and AK discussed results, finalized analyses and potential implications of the results; CW, BW and AK drafted the manuscript with tables and appendices; all authors read and approved the final manuscript.

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Abbreviations

CASP = critical appraisal skills program

HCP = health care professional

ICT = information and communication technology

TAM = technology acceptance model

UN = United Nations

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Table

Table 1. Quality evaluation structured by CASP guidelines.

Study authors	Q1. aims	Q2. method	Q3. design	Q4. recruitment	Q5. data collection	Q6. relationship	Q7. ethics	Q8. data analysis	Q9. findings	Q10. value
Benze et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	5
Bonsignore et al.	Y	Y	Y	Y	Y	Y	N	Y	Y	5
Cooley et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	5
Hennemann-Krause et al.	Y	Y	Y	Y	Y	N	Y	Y	Y	5
Hoek et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	5
Pinto et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	5
Tieman et al.	Y	Y	Y	Y	Y	Y	Y	Y	Y	5
Timmerman et al.	Y	Y	Y	N	Y	N	Y	Y	Y	5
van Gorp et al.	Y	Y	Y	Y	Y	N	Y	Y	Y	5
Vitacca et al.	Y	Y	N	Y	Y	Y	Y	Y	Y	5

Figures

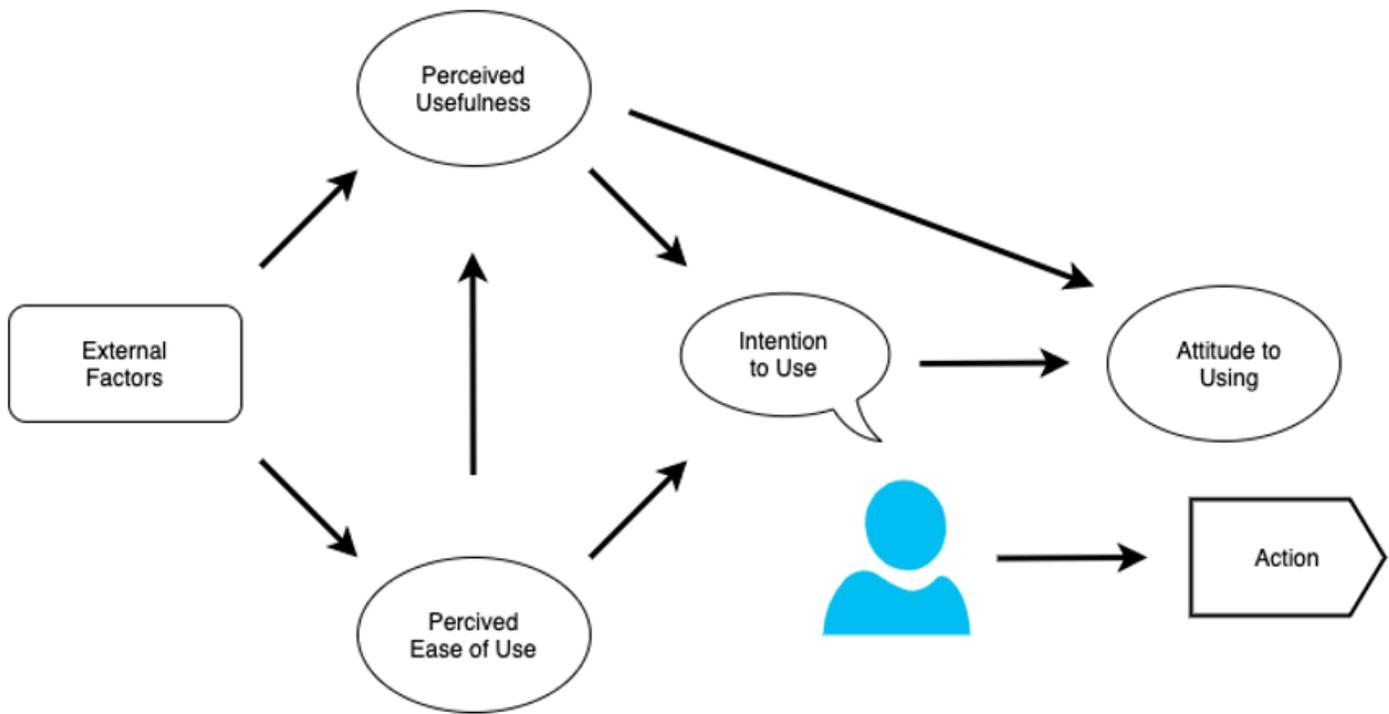


Figure 1

Visual overview of the Technology Acceptance Model (TAM).

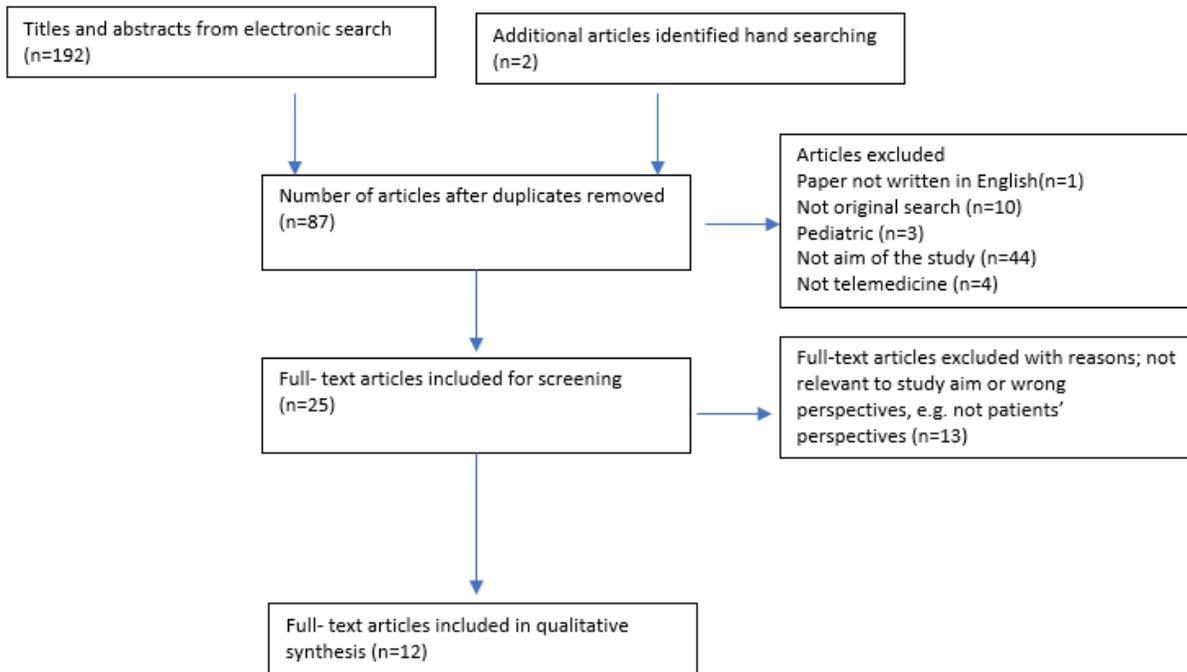


Figure 2

Search and inclusion process as outlined by Moher et al. (31)

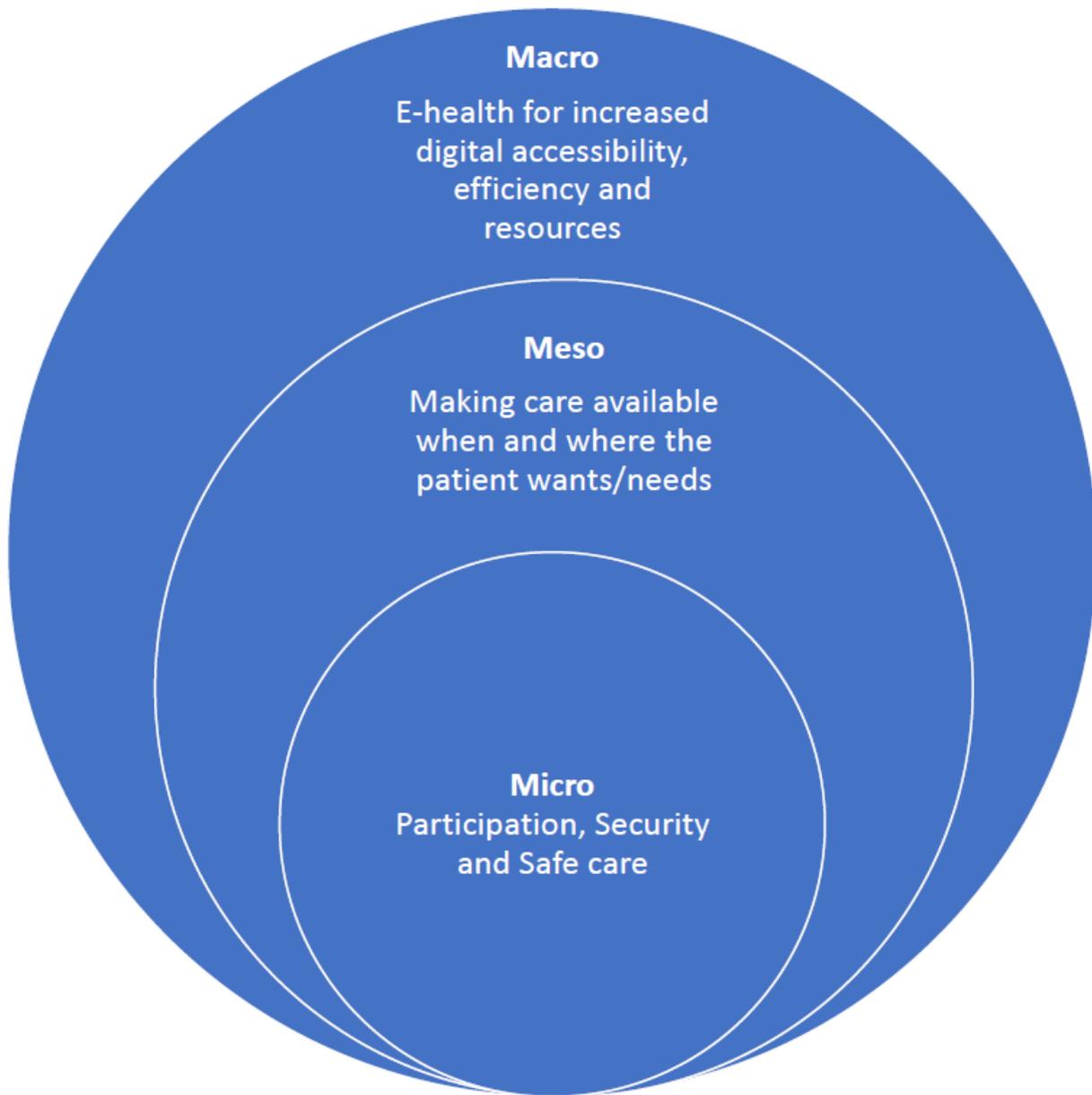


Figure 3

The findings of this review may be regarded in a health systems perspective

Supplementary Files

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- [Appendix120200225.pdf](#)
- [PRISMA2009checklist.pdf](#)