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Published online: 02 Oct 2020.

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Digital health support – a good thing, but not for me. Experiences of family caregivers and healthcare staff

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ABSTRACT

There is an increased belief in the benefits of information and communication technologies (ICT) in healthcare, but the perceived benefits of ICT in family caregiver support need to be explored. This qualitative interview study aimed to describe how family caregivers and healthcare staff in COPD care experience ICT. The results showed that both family caregivers and staff had limited interest in ICT and stated that it might be better for a new generation but not for themselves. Both groups preferred face-to-face meetings instead of contact via ICT. Meeting the needs of an ageing population will require that health services adopt new technologies. Still, the importance of eye contact must not be underestimated, particularly when encountering fragile patients and their spouses.

Introduction

The use of information and communication technologies (ICT) continues to increase in society, but not in all groups (Swedish Internet Foundation, 2018). About 5% of Swedish people never use the internet, and, among all, 11% use the internet less than once a day. Of the people who never use the internet, most are aged above 65 years, are to a larger extent women, have less income, and more often live in rural areas, live alone, and are unemployed or on sick leave. This is similar to a study in 17 European countries, where it was reported that an average of 49% of persons above 50 years had used the internet in the last seven days, with differences between the countries (König et al., 2018) such that younger elderly, males, persons with higher education, and persons with prior experience of technology were more likely to use the internet.

Patient information and education

Patients affected by chronic diseases need knowledge about their disease and what strategies they might use in order to relieve as many symptoms as possible related to the consequences of the disease. The recent GOLD executive summary recommends providing education to patients with chronic obstructive pulmonary disease (COPD) (Vogelmeier et al., 2017), for example, about smoking cessation, exercise, or breathing strategies (Stoilkova et al., 2013; Vogelmeier et al., 2017). In contrast to patients affected by cancer, who have been found to gain benefits from

computer- or internet-based interventions (Ryhänen et al., 2010; Salonen et al., 2014), the tools relating to education for patients affected by COPD are mostly printed materials (90.5%) and only a minority include internet-based education (9.5%) (Stoilkova et al., 2013). Moreover, there is not enough evidence to recommend ICT for the management of COPD (McCabe et al., 2017).

Skills in using ICT – eHealth literacy

A study in Iran of hospitalised patients' use of ICT found that the most important sources of information were patient education, searching health information, and physician contact, and that the factors that affected the use of ICT were the patient's IT skills, access to communication technology tools, and perceived usefulness of the tool (Zare & Jebraeily, 2018). ICT as a way of supporting vulnerable patients' self-care was explored in a review of the benefit of using electronic, mobile and telehealth tools for vulnerable patients with chronic disease (Parker et al., 2018). It was found that most studies sought to persuade vulnerable patients to believe that they could self-manage their conditions, but there were none or limited interaction with the patients. The level of interest could be related to eHealth literacy, which is defined as "the ability to seek out, find, evaluate and appraise, integrate, and apply what is gained in electronic environments toward solving a health problem" (Norman & Skinner, 2006, p. 1). A recent web-based survey in United States of patients affected by COPD found that the patients reported moderate levels of eHealth literacy (Stellefson et al., 2018). Higher eHealth literacy was associated with very severe COPD, lower lung-specific health-related quality of life, and greater COPD knowledge. Family caregivers in Iran have been found to have a poor level of eHealth literacy and those with higher eHealth literacy were found to have higher skills in obtaining health and medical information from the internet (Soleimaninejad et al., 2019)

ICT for supporting relatives and family caregivers

Although most studies in ICT support are related to those directed at patients, there is some evidence of ICT approaches directed at relatives of patients who are affected by various different diseases and conditions, that is, relatives of patients who are affected by cancer (Leow & Chan, 2016; Morris et al., 2018; Tang et al., 2014) and relatives of older people (Barbabella et al., 2016). Internet-based support for family caregivers could be beneficial in that it could result in a sense of inclusion and belonging (Newman et al., 2019), but no evaluated IT approaches for supporting relatives of patients affected by COPD were found.

ICT and healthcare staff

ICT and eHealth interventions could benefit healthcare staff, however, there are a number of barriers to performing their successful implementation. Workload is often reported as the biggest concern among healthcare staff, as an eHealth intervention may disrupt current processes. It is also common that healthcare staff report that undefined roles and change of work practice are potential issues when implementing eHealth interventions (Granja et al., 2018). Healthcare staff often report that they prefer face-to-face communication compared to eHealth interventions, and they also view eHealth as impersonal. Personal preconceptions among healthcare staff about eHealth interventions should also be considered as a potential barrier in the implementation process (Granja et al., 2018).

In summary, internet use is more limited in elderly patients and among those with lower education. Furthermore, there is not enough evidence to recommend ICT in COPD management. The difficulty in engaging patients in ICT could be due to poor eHealth literacy in both patients with COPD and their family caregivers. This, together with healthcare staff's hesitation to use it, could be reasons for the limited literature about ICT support to COPD family caregivers. Thereby, there are a number of issues that need further investigation in how family caregivers of patients affected by COPD and healthcare staff in COPD care view ICT and eHealth interventions.

Aim

The aim was to investigate how ICT and eHealth interventions in COPD care are experienced by family caregivers and healthcare staff.

Methods

This study is a part of a large interview study concerning well-being in family caregivers of COPD patients and their experiences and need for support and contact with healthcare staff. The main study focused on the elements of well-being, burden, and communication experienced by the family caregivers through qualitative interviews with semi-structured, open-ended questions (Strang et al., 2018). To gain deeper insight about how communication and ICT were related, questions about IT, computer habits, and support via apps were posed at the end of each interview. The opinions about digital support were gathered from two perspectives: the family caregivers, and healthcare staff working with COPD patients.

Participants

Individuals with personal experience of living with a person affected by COPD (GOLD stage III–IV) were recruited during October 2016–October 2018 in a multicultural catchment area in the south-west of Sweden. Staff at three hospitals contacted eligible participants and handed them written information about the study in either Swedish or, if not fluent in Swedish, their native language (i.e. Finnish, Bosnian, Arabic, Spanish, or Turkish). A purposive maximum variation sampling strategy was adopted, aiming to obtain a wide range of participants with regard to gender, age, country of birth, and language (Patton, 1990). In total, 36 family caregivers (14 women and 22 men) agreed to participate. Most of them cohabited with the patients, and were in their mid-sixties to mid-eighties, with the exception of two adult daughters and two sons, one cousin, and one daughter-in-law, who were in their mid-thirties to mid-forties. Furthermore, 17 healthcare staff from three of the hospitals were interviewed about their opinions and experiences of digital support. All worked in pulmonary clinical settings with COPD patients and had worked in healthcare for between 10 and 40 years (see Table 1).

Measurement

Both focus group interviews and individual interviews with semi-structured questions were conducted in order to elicit a multiplicity of interactions and to obtain a range of experiences. The interviews were conducted face-to-face at the hospitals, except for two interviews, which were conducted by telephone. The interviews started with an open question about the participant's interest and experience of IT (i.e. smartphones, computer, websites, and applications concerning healthcare support, hereafter referred to as IT). Thereafter, additional questions were posed such as: "Could you, please tell me more about it, would you like to have contact about healthcare matters through IT?" The duration of the interview sessions varied between 20 and 70 minutes. At the end of each interview, two final questions focused on internet-related topics. The interviews were audio-recorded and transcribed verbatim.

Data analysis

The interviews were analysed with qualitative manifest and latent content analysis, focusing on similarities and differences between parts of the texts and on the manifest and latent content (Krippendorff, 2004). The analysis process was performed in several steps, in accordance with the steps described by Graneheim and Lundman (2004). The interviews with relatives and the interviews

Table 1. Characteristics of informal caregivers and healthcare staff.

Informal caregivers (n=36)	
Age (yr)	
35–45	6
45–65	7
65–85	23
Gender	
Men	22
Women	14
Relation to the patient	
Spouse/partner	30
Adult child	4
Daughter-in-law	1
Cousin	1
Employment	
Retired	23
Working	11
Unemployed	2
Healthcare staff (n=17)	
Gender	
Men	2
Women	15
Occupation	
Nurse	10
Physician	3
Allied health personnel:	4
Counsellor	
Occupational therapist	
Physiotherapist	
Care coordinator	
Work experience (yr)	10–40

with staff were analysed separately and constituted two domains. First, all the interview texts were read several times to obtain a global sense of the entire set of material. Next, the data were divided into meaning units and then condensed, whilst still preserving the core message, and then marked with codes. The software application, Microsoft Excel, extended with sorting functions in Visual Basic, was used in the coding process. Citations were highlighted to support the analysis. After a preliminary comparison and sorting of the codes, six themes and one superordinate main theme were identified (Table 2). Discussions were held between all authors throughout the analysis, involving a back-and-forth movement between the whole text and its parts.

According to Graneheim et al. (2017), trustworthiness in qualitative studies implies offering the most probable interpretations and can be described using three concepts: *credibility*, that is, how to find participants who have experiences of the phenomenon and how data and the analysis address the intended aim; *dependability*, which deals with instability, the researchers' pre-understandings, design-induced changes and also the challenge of deciding which codes and quotes are to be included in a category. Finally, there is *transferability*, which refers to how the results together with an accurate and rich description of the context of the study, could be transferred to other groups or settings. Trustworthiness was ensured by an ongoing process of reflection on these concepts.

Table 2. How ICT in COPD care is experienced by family caregivers and healthcare staff.

	Main theme: A good thing, but not for me.	
	Family caregivers' perspective	Healthcare staff members' perspective
Themes	Lack of interest	Slightly positive – in future
	Complement – but not a replacement	Probably good – but not for me
	Face-to-face creates trust	Face-to-face creates real meeting

Ethics approval and informed consent

Each participant was provided with both written and oral information prior to the interviews. At the start of each interview, the same information was repeated before participants signed an informed consent form. Ethical approval for this study was obtained from the Regional Ethics Committee in Gothenburg, Sweden (Dnr: 645-16).

Results

The result of this study showed that both family caregivers and the healthcare staff had very limited interest in digital support and stated that it might be better for a new generation, but not for themselves and not now. They both preferred a face-to-face meeting instead of contact via web pages and applications.

Family caregivers' perspective

Lack of interest

More than half of the caregiver participants did not possess a computer or a smartphone, and they were not familiar with apps or websites. The reason for this was that they felt too old and had no interest in learning. Accordingly, they did not see the need for digital support because they did not have a device and lacked knowledge and interest in computers.

> I: Do you see any benefits of using apps?
> P: No, no, not me. I have been a cleaner, and always managed without computers. I know that is the case today, but it's not for me (Woman, 73)

The support they asked for was to some extent provided by healthcare professionals, by home care, or COPD Schools, that is, through contact persons within the healthcare profession. They stated that ICT and eHealth interventions could not offer them personal contact and they did not see how digital care could guide them to the appropriate service for assistance. The reasons they provided for not using IT were that they perceived apps as impersonal, they did not want to write on phones, or press "keys and buttons"; they wanted to meet real people. The participants were reluctant to use computers; one expressed it as being like: *talking to a dead thing [computer]. I'm not against development, but I think humans should be first. (Woman, 70)*

One participant pointed out that web pages were not interactive and therefore they preferred phone calls instead when needed. Another expressed a hope to learn more about computers, but because her husband could not be left alone, this was impossible. Furthermore, some participants considered that it was difficult to rely on the information online, as there was so much dishonesty and false information.

> Because we can find anything in the computer and you can lie and write anything. But I think we are honest when we are face to face. I think that's the only right thing. (Man, 69)

Another disadvantage with digital care identified by the caregiver participants was that the doctor could miss opportunities to use their clinical eye if they did not meet the patient physically. For example:

> But still, the doctor misses too. How can patients meet a doctor in the app? Should patients film themselves? The doctor cannot squeeze and smell via the computer. I do not know how it works. (Man, 88)

Complement – but not a replacement

Some believed that they already possessed the information and knowledge that they needed. If they were interested in obtaining more, they could always use Google. For others, it was enough to be provided with support and information from friends or family. Some caregiver participants had a

generally positive view of IT, even though it was not applicable for themselves in their contact with healthcare services. A few participants were familiar with computers and used Google, social media, and computers at work. They felt that apps could be good for society at large, such as banking, industry, and music. Even in healthcare, they could see the benefits of, for example, text messages, transportation service apps, seeking healthcare assistance through the healthcare information web service, and being able to read about COPD on the pages online. Some of them, who did not know how to use the internet, could get help from their children. One of the family caregivers thought the apps were helpful and hoped that her mother would have access to "education for older people about the internet". For another, the wife of a patient had benefited from ICT and eHealth interventions for visually impaired people. Some thought digital support could be seen as a complement to usual care, but not a replacement. A general thought was that it would be easier for children and young people to adopt the new methods, but still, there were also concerns that much could be missed.

> Obviously, if there are people who cannot meet someone in person and approve IT appliances, then it's certainly okay. It may be good for the youngsters. Nevertheless, not for me! (Woman, 65)

Personal contact is superior

Most respondents felt that personal contact was far superior than contact through IT. An important concern was to know who to turn to if they had questions and to know they were welcome as relatives.

> I am aware of that you cannot get rid of her illness but it's important that I know who to turn to when she's getting bad. I usually call the nurse and it feels good and safe. (Man, 63)

In these contexts, the participants spoke of the importance of face-to-face and direct contact, as it felt trustworthy and instilled confidence. Having face-to-face meetings with healthcare professionals provided warmth and support. In addition, many stated that it was more pleasant and rewarding to meet a nurse or doctor face-to-face, instead of being referred to IT.

> But it is much easier to meet people. A computer can never replace it. No, no, no. Absolutely not. It's not possible. I've said that before too. It's like we do not dare to communicate with each other eye to eye today. Not about important matters. (Woman, 75)

The caregiver participants described how information can also be difficult to absorb when being referred to IT. Obtaining verbal information from the healthcare staff was more valuable. Some also had contact with family caregiver associations. Thereby, they were not only provided with adequate information, but they could also gain access to each other and exchange experiences about being family caregivers.

> I: If the medical care ordered information via the internet – would you use it?
> IP: No, but I attended twice a family meeting arranged by the nurse. I think it gave me a lot more. Then it will be a personal meeting. It's my cup of tea, to talk face to face. (Man, 70)

Healthcare staff members' perspective

May be positive – in future

Among the staff, there was a generally positive attitude towards digital care. As an example, they mentioned well-designed instructional films about COPD or COPD pages on Facebook, where patients and relatives could converse with each other. They emphasised that digitisation is a natural part of future care, but mainly for young people who are accustomed to using IT. A few stressed the benefits of digital solutions due to the limited financial resources and lack of staff. However, there was an expression that, while digitalisation was beneficial in general, it was not

totally suitable just now. Some had started developing COPD information and making it available online but the actual use of it was extremely limited.

> P: This COPD web page is amazingly good, and they have also added a home care education for those people who work there. So that's really good.
> I: Is it something you might use here?
> I: P No, I have not used it so much here. It's a bit behind the times here, you see. (Nurse, 50)

Might be good – but not here

Despite a positive attitude towards digital support in general, there were still many doubts about digitisation among the staff. One common reason was simply a lack of interest in digitisation. One healthcare staff participant expressed that they felt a sense of losing control when using IT. Many of the staff knew that there was COPD training on the web, but they themselves did not refer relatives or patients to these pages. Doubts about advocating digitisation were also due to the fact that patients affected by COPD and their relatives were an older, more vulnerable, and fragile group. Their patients did not have computer skills, could not speak the language, some were illiterate, and it was difficult to give tips and advice via apps or the web. The healthcare staff participants were weary of everything becoming more and more about technology and concerned that personal contact, including body language, and the opportunity to mirror it, were being put aside.

> But then we cannot ignore the fact that many in our patient group have difficulties to manage IT. It has, of course, to be appropriate for the person who will use it. These patients are a little bit older and they do not cope with computers. We have a large foreign population here with the language barriers and other difficulties. (Physician, 60)

There was also a fear that it will be too easy for a patient or a relative in the future to post a question to the net-doctor, even about the simplest troubles, instead of relying on their own capacity or consulting with family members as they had previously done.

The personal meeting is superior

The importance of the face-to-face meeting was emphasised by many nurses. As all people are unique, it is important to be able to see the patient in front of them in order to give personal advice. In a face-to-face meeting, the staff perceived that they have the opportunity to see the patient's body language and to mirror it, and to adapt the conversation to suit the individual patient or relative. At these meetings, the staff are also able to respond to personal questions and to observe their emotional wellbeing first-hand and thus adapt the conversation to that particular person. A physical meeting creates more opportunity to instil security and peace. The meeting itself is important. It has an inherent energy, which creates a connection, where patients and relatives can ask their own questions, and where they can be recognised.

> When a nurse has face-to face contact with families, the nurse can see the sadness in their eyes, and you get so much in the meeting that you can never get in an app. A physical encounter can never be replaced by an app, but it can be a good complement. (Nurse, 65)

> Yeah, the relatives can ask their questions online, but when you meet them in a room, physically, it calms in a special way – if it is something that is worrying or so on. (Nurse, 40)

The lack of interest in the digital applications by the staff became obvious when they spoke about providing support to the relatives. The staff could feel it was rude to refer relatives or patients to an impersonal website when they wanted to meet a staff member.

> I: Do the relatives use online-instructions?
> P: Well, that's probably neither here nor there. But if I should start with myself: I want a personal meeting. I can get angry at various establishments that refer me to different web pages. I want a living person to talk to and the real meeting is when I have the patient in front of me. (Nurse, 55)

The staff agreed that in order to succeed in getting patients and relatives to make use of the web support, it was important to introduce it through personal contact in connection with a physical meeting. These resources were about providing general information about such issues as the illness, or exercise programmes, but the interactive opportunity was missing from these websites.

I: Do you use ICT and eHealth interventions for relatives?
P: No, I do not have experience of IT, except I may refer relatives and patients to the COPD web, if they want to know more about the disease. They have not asked for such a thing, but I often use the "*Online Healthcare Guide*", but very few patients use it. (Paramedic, 45)

Discussion

The results from this study show that personal interaction is vital to the family caregivers and healthcare staff in COPD care. The results also show that both family caregivers and healthcare staff acknowledged that ICT could have benefits, but with some reservations. The reservations were related to the notion that ICT could be regarded as a complementary element of support for the relatives, but not a substitute. Healthcare staff realised that ICT would be accessed more in the future and might be more useful in other contexts. A previous study from the Netherlands has reported patient concerns about ICT being used as a means of support (Mathijssen et al., 2018). For example, ICT might replace face-to-face interactions with healthcare providers and thereby make the care less personal. Similar findings have been reported in other studies from UK and Canada (Currie et al., 2015; Steele Gray et al., 2014).

Our study showed that both family caregivers and healthcare staff emphasised and preferred face-to-face meetings rather than using the internet. The caregiver participants wanted to be seen in person instead of being referred to a smart phone app or a website. This finding is in line with recent research that underlines the importance of being seen and the value of human eye contact, whilst not being seen can cause negative consequences for the individual. Wirth et al. (2010), in a study of undergraduate students in the United States, demonstrated the importance of eye gaze, that is, being seen and recognised. Participants who received an averted eye gaze instead of a direct eye gaze experienced being excluded and ignored (Wirth et al., 2010). Hietanen et al. (2008) studied adults in Finland and found that eye contact and gaze aversion between two persons even influences neural mechanism effects, but only when participants were facing a real person, not when they were looking at a picture of a face. This shows that the face-to-face interaction plays a vital role for patients and may relieve stress among their relatives. The studies above align well with our results. The family caregivers wanted to talk to a real person, they wanted to be listened to and be met in an empathic way, and to not be referred to a computer. This is also relevant to the issue of staff having difficulties finding time to "care for" family caregivers and not acknowledging them. It is important for the staff to acknowledge family caregivers when they encounter them, at the very least by catching their gaze with a warm "hello, how do you do".

Furthermore, we have to take into account that there is a large group of fragile elderly people, who are not used to new ICT, who may risk exclusion from healthcare services as more and more support is transferred to ICT and eHealth interventions (Swedish Internet Foundation, 2018). The severity of symptoms and their duration also need to be factored in. For example, patients with COPD, suffering from both death anxiety and fear of living due to the increasing heavy symptom burden (Strang et al., 2014), cannot be supported solely by ICT. In contrast to malignant diseases, which have a short deterioration phase, the deterioration associated with COPD will continue and will affect patients' and relatives' lives for an extended period of time (Cruz et al., 2017). Relatives of patients, who are dying from cancer, although they are living in the presence of death, can often sense a new dimension in life due to the limited life expectancy (Melin-Johansson et al., 2012). This is not the case for relatives of people affected by COPD, because both patients and families have to live a restricted life for a very long time and need continuous support throughout

the illness trajectory from staff, indicating that ICT might not be a suitable solution for relatives of patients affected by COPD.

However, ICT and eHealth interventions in healthcare represent a phenomenon that has come to stay. For example, personally controlled electronic health records have been found to be helpful in keeping patients informed and updated, and promote self-management (Hanna et al., 2017); symptom monitoring systems can help improve symptom relief (Oldenmenger et al., 2016). Therefore, it is important that the staff should be familiar with them. They must, however, be given sufficient time to reflect on, and to decide when to use ICT and eHealth interventions and when to avoid them. There is growing evidence that people who benefit from ICT and eHealth interventions get more social support, feel less lonely, and obtain more help to manage various health conditions (Morris et al., 2014; Tates et al., 2017). These results are seen, for example, in diabetes care (Greenwood et al., 2017), breast cancer care (Phillips et al., 2017), but especially for people with an interest in technology within these groups (McCabe et al., 2017).

Workload is one of the most important barriers for staff in implementing eHealth solutions (Granja et al., 2018). Adequate education is needed, including in the associated social and communication skills, and ethical considerations of digitalisation in patient care (Konttila et al., 2019). ICT and eHealth interventions can be useful for some groups, for example, young, well-educated patients, but it is vital to proceed with caution when implementing ICT and eHealth interventions with elderly and otherwise vulnerable groups of patients. One example from our study was that, on those occasions when relatives had used ICT and eHealth interventions, the staff had been sitting next to them and had introduced the web pages, that is, provided a face-to-face introduction. Thereafter, the family caregiver could use the web pages at home. Crampton et al. (2016) have provided more examples of how to improve health ICT in patient-clinician communication, for example, by supporting the patient-clinician interaction rather than interfering with it, and by increasing information sharing between patients and clinicians.

There are a number of factors affecting success or failure when designing and implementing eHealth solutions. From the healthcare staff's perspective, several factors are vital; for example, determining whether the eHealth solution should be fitted into a pre-established workflow (Granja et al., 2018). If an eHealth solution is fitted into an existing workflow, it is possible that the healthcare staff only view it as a hurdle in their interaction with the patient. Instead different possibilities of using eHealth solutions could be considered, with the focus on re-designing the interaction between the patients and the healthcare staff.

As summarised in the review by Granja et al. (2018), the healthcare staff also see eHealth solutions as something that can undermine personal contact with the patient and other healthcare staff. Some patients and patient groups may need more or less face-to-face meetings with the healthcare staff, therefore, designing eHealth solutions to tailor them for the most suitable patient groups may be a way of increasing acceptance of such technological advancements among healthcare staff in the future. To get healthcare staff involved in creating and implementing eHealth solutions, it is vital that they see that eHealth solutions have a positive impact in clinical care. It is also important to work with user-centred design to increase acceptance of eHealth solutions among both healthcare staff and patients (Granja et al., 2018).

Meeting the needs of an ageing population will inevitably require that health services adopt new technologies and adapt how support is provided. Future generations may be more accepting of digital interactions, and internet or mobile applications might be a good solution. Still, we must not undervalue the importance of eye contact and face-to-face meetings, particularly when encountering fragile, older patients and their next-of-kin. Based on the findings from the present study, it could be suggested that ICT should be a complement to face-to-face human interaction, not a substitute for it.

Acknowledgements

Disclosure statement

No potential conflict of interest was reported by the author(s).

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References

Barbabella, F., Poli, A., Andreasson, F., Salzmann, B., Papa, R., Hanson, E., Efthymiou, A., Döhner, H., Lancioni, C., Civerchia, P., & Lamura, G. (2016). A web-based psychosocial intervention for family caregivers of older people: Results from a mixed-methods study in three European countries. *JMIR Research Protocols*, *5*(4), e196. https://doi.org/10.2196/resprot.5847

Crampton, N. H., Reis, S., & Shachak, A. (2016). Computers in the clinical encounter: A scoping review and thematic analysis. *Journal of the American Medical Informatics Association*, *23*(3), 654–665. https://doi.org/10.1093/jamia/ocv178

Cruz, J., Marques, A., & Figueiredo, D. (2017). Impacts of COPD on family carers and supportive interventions: A narrative review. *Health & Social Care in the Community*, *25*(1), 11–25. https://doi.org/10.1111/hsc.12292

Currie, M., Philip, L. J., & Roberts, A. (2015). Attitudes towards the use and acceptance of eHealth technologies: A case study of older adults living with chronic pain and implications for rural healthcare. *BMC Health Services Research*, *15*(1), 162. https://doi.org/10.1186/s12913-015-0825-0

Graneheim, U. H., Lindgren, B. M., & Lundman, B. (2017). Methodological challenges in qualitative content analysis: A discussion paper. *Nurse Education Today*, *56*, 29–34. https://doi.org/10.1016/j.nedt.2017.06.002

Graneheim, U. H., & Lundman, B. (2004). Qualitative content analysis in nursing research: Concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today*, *24*(2), 105–112. https://doi.org/10.1016/j.nedt.2003.10.001S0260691703001515

Granja, C., Janssen, W., & Johansen, M. A. (2018). Factors determining the success and failure of eHealth interventions: Systematic review of the literature. *Journal of Medical Internet Research*, *20*(5), e10235. https://doi.org/10.2196/10235

Greenwood, D. A., Gee, P. M., Fatkin, K. J., & Peeples, M. (2017). A systematic review of reviews evaluating technology-enabled diabetes self-management education and support. *Journal of Diabetes Science and Technology*, *11*(5), 1015–1027. https://doi.org/10.1177/1932296817713506

Hanna, L., Gill, S. D., Newstead, L., Hawkins, M., & Osborne, R. H. (2017). Patient perspectives on a personally controlled electronic health record used in regional Australia. *Health Information Management Journal*, *46*(1), 42–48. https://doi.org/10.1177/1833358316661063

Hietanen, J. K., Leppänen, J. M., Peltola, M. J., Linna-Aho, K., & Ruuhiala, H. J. (2008). Seeing direct and averted gaze activates the approach-avoidance motivational brain systems. *Neuropsychologia*, *46*(9), 2423–2430. https://doi.org/10.1016/j.neuropsychologia.2008.02.029

König, R., Seifert, A., & Doh, M. (2018). Internet use among older Europeans: An analysis based on SHARE data. *Universal Access in the Information Society*, *17*(3), 621–633. https://doi.org/10.1007/s10209-018-0609-5

Konttila, J., Siira, H., Kyngäs, H., Lahtinen, M., Elo, S., Kääriäinen, M., Kaakinen, P., Oikarinen, A., Yamakawa, M., Fukui, S., Utsumi, M., Higami, Y., Higuchi, A., & Mikkonen, K. (2019). Healthcare professionals' competence in digitalisation: A systematic review. *Journal of Clinical Nursing*, *28*, 745–761. https://doi.org/10.1111/jocn.14710

Krippendorff, K. (2004). *Content analysis. An introduction to its methodology*. Sage.

Leow, M. Q., & Chan, S. W. (2016). Evaluation of a video, telephone follow-ups, and an online forum as components of a psychoeducational intervention for caregivers of persons with advanced cancer. *Palliative and Supportive Care*, *14*(5), 474–478. https://doi.org/10.1017/S1478951516000225

Mathijssen, E. G., Vriezekolk, J. E., Eijsbouts, A. M., van den Hoogen, F. H., & van den Bemt, B. J. (2018). Support needs for medication use and the suitability of eHealth technologies to address these needs: A focus group study of older patients with rheumatoid arthritis. *Patient Preference and Adherence*, *12*, 349–358. https://doi.org/10.2147/PPA.S152759

McCabe, C., McCann, M., & Brady, A. M. (2017). Computer and mobile technology interventions for self-management in chronic obstructive pulmonary disease. *Cochrane Database of Systematic Reviews*, *5*, CD011425. https://doi.org/10.1002/14651858.CD011425.pub2

Melin-Johansson, C., Henoch, I., Strang, S., & Browall, M. (2012). Living in the presence of death: An integrative literature review of relatives' important existential concerns when caring for a severely ill family member. *The Open Nursing Journal*, *6*, 1–12. https://doi.org/10.2174/1874434601206010001

Morris, J. N., Ohan, J., & Martini, A. (2018). An investigation of support services available by internet searching to families impacted by a parent's cancer. *Psycho-oncology*, *27*(1), 114–124. https://doi.org/10.1002/pon.4478

Morris, M. E., Adair, B., Ozanne, E., Kurowski, W., Miller, K. J., Pearce, A. J., Santamaria, N., Long, M., Ventura, C., & Said, C. M. (2014). Smart technologies to enhance social connectedness in older people who live at home. *Australasian Journal on Ageing*, *33*(3), 142–152. https://doi.org/10.1111/ajag.12154

Newman, K., Wang, A. H., Wang, A. Z. Y., & Hanna, D. (2019). The role of internet-based digital tools in reducing social isolation and addressing support needs among informal caregivers: A scoping review. *BMC Public Health*, *19*(1), 1495. https://doi.org/10.1186/s12889-019-7837-3

Norman, C. D., & Skinner, H. A. (2006). eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research*, *8*(4), e27. https://doi.org/10.2196/jmir.8.4.e27

Oldenmenger, W. H., Witkamp, F. E., Bromberg, J. E., Jongen, J. L., Lieverse, P. J., Huygen, F. J., Baan, M. A. G., van Zuylen, L., & van der Rijt, C. C. (2016). To be in pain (or not): A computer enables outpatients to inform their physician. *Annals of Oncology*, *27*(9), 1776–1781. https://doi.org/10.1093/annonc/mdw250

Parker, S., Prince, A., Thomas, L., Song, H., Milosevic, D., & Harris, M. F. (2018). Electronic, mobile and telehealth tools for vulnerable patients with chronic disease: A systematic review and realist synthesis. *BMJ Open*, *8*(8), e019192. https://doi.org/10.1136/bmjopen-2017-019192

Patton, M. Q. (1990). *Qualitative evaluation and research methods*. Sage.

Phillips, S. M., Conroy, D. E., Keadle, S. K., Pellegrini, C. A., Lloyd, G. R., Penedo, F. J., & Spring, B. (2017). Breast cancer survivors' preferences for technology-supported exercise interventions. *Supportive Care in Cancer*, *25*(10), 3243–3252. https://doi.org/10.1007/s00520-017-3735-3

Ryhänen, A. M., Siekkinen, M., Rankinen, S., Korvenranta, H., & Leino-Kilpi, H. (2010). The effects of internet or interactive computer-based patient education in the field of breast cancer: A systematic literature review. *Patient Education and Counseling*, *79*(1), 5–13. https://doi.org/10.1016/j.pec.2009.08.005

Salonen, A., Ryhänen, A. M., & Leino-Kilpi, H. (2014). Educational benefits of internet and computer-based programmes for prostate cancer patients: A systematic review. *Patient Education and Counseling*, *94*(1), 10–19. https://doi.org/10.1016/j.pec.2013.08.022

Soleimaninejad, A., Valizadeh-Haghi, S., & Rahmatizadeh, S. (2019). Assessing the eHealth literacy skills of family caregivers of medically ill elderly. *Online Journal of Public Health Informatics*, *11*(2), e12. https://doi.org/10.5210/ojphi.v11i2.10149

Steele Gray, C., Miller, D., Kuluski, K., & Cott, C. (2014). Tying eHealth tools to patient needs: Exploring the use of eHealth for community-dwelling patients with complex chronic disease and disability. *JMIR Research Protocols*, *3*(4), e67. https://doi.org/10.2196/resprot.3500

Stellefson, M. L., Shuster, J. J., Chaney, B. H., Paige, S. R., Alber, J. M., Chaney, J. D., & Sriram, P. S. (2018). Web-based health information seeking and eHealth literacy among patients living with chronic obstructive pulmonary disease (COPD). *Health Communication*, *33*(12), 1410–1424. https://doi.org/10.1080/10410236.2017.1353868

Stoilkova, A., Janssen, D. J., & Wouters, E. F. (2013). Educational programmes in COPD management interventions: A systematic review. *Respiratory Medicine*, *107*(11), 1637–1650. https://doi.org/10.1016/j.rmed.2013.08.006

Strang, S., Ekberg-Jansson, A., & Henoch, I. (2014). Experience of anxiety among patients with severe COPD: A qualitative, in-depth interview study. *Palliative and Supportive Care*, *12*(6), 465–472. https://doi.org/10.1017/S1478951513000369

Strang, S., Osmanovic, M., Hallberg, C., & Strang, P. (2018). Family caregivers' heavy and overloaded burden in advanced chronic obstructive pulmonary disease. *Journal of Palliative Medicine*, *21*(12), 1768–1772. https://doi.org/10.1089/jpm.2018.0010

Swedish Internet Foundation. (2018). *Svenskarna och internet 2018. En årlig studie av svenska folkets internetvanor. English title: Swedes and Internet 2018. An annual study of the Swedish people's internet habits.* https://www.iis.se/docs/Svenskarna_och_internet_2018.pdf

Tang, W. P., Chan, C. W., So, W. K., & Leung, D. Y. (2014). Web-based interventions for caregivers of cancer patients: A review of literatures. *Asia-Pacific Journal of Oncology Nursing*, *1*(1), 9–15. https://doi.org/10.4103/2347-5625.135811

Tates, K., Antheunis, M. L., Kanters, S., Nieboer, T. E., & Gerritse, M. B. (2017). The effect of screen-to-screen versus face-to-face consultation on doctor-patient communication: An experimental study with simulated patients. *Journal of Medical Internet Research*, *19*(12), e421. https://doi.org/10.2196/jmir.8033

Vogelmeier, C. F., Criner, G. J., Martinez, F. J., Anzueto, A., Barnes, P. J., Bourbeau, J., Celli, B. R., Chen, R., Decramer, M., Fabbri, L. M., Frith, P., Halpin, D. M. G., López Varela, M. V., Nishimura, M., Roche, N., Rodriguez-Roisin, R., Sin, D. D., Singh, D., Stockley, R., Vestbo, J., Wedzicha, J. A., & Agusti, A. (2017). Global strategy for the diagnosis, management and prevention of chronic obstructive lung disease 2017 report: GOLD executive summary. *Respirology*, *22*(3), 575–601. https://doi.org/10.1111/resp.13012

Wirth, J. H., Sacco, D. F., Hugenberg, K., & Williams, K. D. (2010). Eye gaze as relational evaluation: Averted eye gaze leads to feelings of ostracism and relational devaluation. *Personality and Social Psychology Bulletin*, *36*(7), 869–882. https://doi.org/10.1177/0146167210370032

Zare, Z., & Jebraeily, M. (2018). Patients' perceptions of applying information and communication technology tools in self-care and factors affecting it. *Acta Informatica Medica*, *26*(2), 102–105. https://doi.org/10.5455/aim.2018.26.102-105