

Research article

The challenge of involving elderly patients in primary care using an electronic communication tool with their professionals: a mixed methods study

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ABSTRACT

Background Elderly patients in primary care often have multiple health problems, with different healthcare professionals involved. For consistency in care, it is required that communication amongst professionals and patient-systems (patient and informal-carers) be well tuned. Electronic-communication can make it easier for patient-system to be active in care.

Objective To examine whether an e-communication tool (Congredi) designed for professionals, including a care plan and secure e-mail, is usable for patient-systems and what their experiences are.

Methods In a multi-method study, home-dwelling elderly patients with two or more professionals were invited to use Congredi; data were gathered from the system after 42 weeks. Also semi-structured interviews were undertaken with patient-systems with topics retrieved from literature. Analysis took place by two researchers independently; the themes were extracted together by consensus.

Results Data about actual use of the tool were gathered from 22 patients. Four profiles of Congredi-users were distinguished, varying in intensity of use. Data from interviews with members of patient-systems ($n = 7$) showed that they were motivated and able to use Congredi. Barriers in daily use were limited participation of professionals, unanswered e-mail and not being alerted about actions. Despite limitations, patient-systems retained their motivation.

Conclusion Congredi was usable for patient-systems. The barriers found seem not to be tool-related but primarily user-related. An important barrier for daily use was limited active participation of involved professionals in a complete feedback loop. Potential for future implementation was found, as patient-systems were intrinsically motivated for better feedback with the professionals, even though in this study it only partly met their expectations.

Keywords: eHealth, healthcare delivery, patient care management, patient participation, multidisciplinary communication, primary care, nursing

INTRODUCTION

Elderly patients in primary care often have multiple health problems, with different health care professionals involved.¹ For consistency in care, it is required that communication amongst all be well tuned.² Much can be gained if patient-systems communicate productively with involved professionals.^{3–7} This is underscored by the chronic care model, which states that an informed, active patient-system in interaction with a prepared, proactive practice team improves the quality of patients' outcomes.^{7–9}

Evidence shows that eHealth technology, including electronic communication, can make it easier for the patient-system (patient and informal-carers) to be active in care.^{10–16} With the advent of eHealth, it is relevant to understand in which way e-communication tools can support patient-systems to become active.^{14,17–19} From the literature, it has become clear that successful eHealth interventions need to contain a complete feedback loop (CFL).¹⁶ According to Gee *et al.*, the CFL should consist of five stages of communication in which both professionals and patient-systems have an active role: (1) transmission of data and information about patients' health status, (2) interpretation of data and information using previously established knowledge and/or wisdom and the use of evidence-based standards, (3) address the specific need of the individual patient, (4) timely feedback to the patient addressing their needs, and (5) regular repetition of the feedback loop.¹⁶

Besides promising outcomes, researchers have identified challenges that occur and need attention when implementing e-communication tools.^{20–26} First, barriers concerning the technical aspects of the tool have been identified: ease of use, perceived usefulness, efficiency of use, availability of support, comfort in use and site location.²⁰ Second, patient characteristics such as low income, education, cognitive impairment, low computer literacy low social support and high illness burden have been shown to influence the use of e-communication.^{20,21} Third, professional characteristics influence the use of the tools. For instance, healthcare providers beliefs (is the tool useful for professionals and patient);^{22–24} the fact that general practitioner adoption of e-mail remains low even though it is easily available²⁶ and professionals do not give equal priority to e-communication (nurses are more conscientious than physicians);²² low computer literacy, insufficient basic formal training in health IT applications, physicians' concerns about more work; workflow issues; problems related to new system implementation, including concerns about confidentiality of patient information; depersonalization; incompatibility with current health care practices; lack of standardization and problems with reimbursement.²⁰ Fourth, barriers to implementation can also be found at the institutional level. There are concerns about confidentiality and security²⁵ unclarity in the implementation process concerning decisions about roles, sufficient time and sufficient competence of professionals.^{22,24}

The challenge in this study is to find out whether it is feasible to connect a newly developed professional tool, which has been shown to work, to patients. Given that e-communication between professionals and patient-systems seems to be helpful, a prerequisite is that patient-systems are able and motivated to use the tools.¹⁸ The aim of this study was to describe the use and experiences of patients with an e-communication tool (Congredi) that was selected by partners in primary care.²⁷

METHODS

The following research question was addressed: is an e-communication tool for professionals (Congredi) usable for elderly patient-systems to participate in care?

Design

A mixed-methods design was chosen.^{17,28,29} To examine the actual use of Congredi by patient-systems quantitative data were retrieved from the Congredi data system during 42 weeks. Also, data were gathered from individual interviews with members of patient-systems to examine their experiences, motivation and satisfaction with Congredi. The interviews were semi-structured and were scheduled to take 30 minutes. All interviews were audio-recorded and transcribed verbatim. Respondents were offered the choice of being interviewed face-to-face or by telephone.

Intervention

Congredi is a communication tool developed for professionals by professionals.²⁷ It consists of patient records with a care plan and a communication channel (secure e-mailing). Professionals use it to communicate about the care of a mutual patient. For each patient, a record is initiated, with a care plan based on the Social, Functional, Mental, Physical and Communication domain model.¹⁸ In the plan, current care problems are assessed, involved professionals make observations and care actions are assigned. The secure e-mail channel can be used for sending and receiving e-mail to colleagues about the care plan. One professional is appointed as a coordinator of the patient record and is responsible for linking other professionals. All professionals can update the care plan. To achieve optimal communication in the CFL about a mutual patient, there are two conditions: first that all involved professionals link to the patient-record and second that they are active and react to communication of others.

The intervention consisted of giving patient-systems access to their Congredi record through a patient portal, enabling them to view their care plan and to communicate with the professionals. They could actively contribute by monitoring the care plan and communicating or giving feedback about their needs to their professionals. The intervention was limited to providing access to the communication tool for professionals; no specific adjustments for patients were made with respect to professional jargon or addition of specific paragraphs of special interest for the patient-system.

Inclusion in the sample

The study population consisted of the patient-systems (patient and informal-carers) of elderly patients with two or more professionals involved. A convenience sample was recruited. The professionals invited patient-systems with whom they already had good communication, using face-to-face contact, telephone or unsecure e-mail, and they expected they were capable of using Congredi. These patient-systems were invited to become a Congredi-user by the general practitioner or nurse. To enter Congredi, patients had to give informed consent to start a patient-record and to link relevant healthcare professionals to it. Part of the approached population, namely, those who became active users of Congredi, was invited for an interview by e-mail from their coordinating professional.

Variables and measures

Actual use was mapped quantitatively with variables from the system. First, the characteristics of the patients (age and gender) and the discipline of the coordinating professional were retrieved. Second, data about the actual use of Congredi by the patient-system were gathered: duration, the number of professionals involved per Congredi record, the frequency of use and the type of actions. Duration of active use was defined as the number of weeks within which patients were active in Congredi, starting from the first time they logged on and ending at the end of the measuring period or, if patients stopped prematurely, the date of the last action by the patient-system. The date of the last action was defined as the date followed by a period of at least 12 weeks in which no actions took place. Frequency of use included all actions that took place when the user logged on to Congredi. The types of action encompassed Congredi record views and e-mail communications (receiving, sending and reading). Last, the number of prematurely stopping patients was retrieved.

From the interviews, three types of variables about experiences with the use of Congredi were retrieved. First, the characteristics of the patient-system-member were gathered: role (patient or informal carer), gender, age, living situation, social activity, education level, computer competency, relation to patient, distance to patient and intensity of care. Second, the users' perception of usability of Congredi was assessed (technical problems, attractiveness and user-friendliness). Third, motivation, expectations, experiences and satisfaction with Congredi were discussed.

Table 1 Description patients in the Congredi records

Variables	Active pat n = 22 (%)
Age	
<70	3 (13,6)
71–80	3 (13,6)
81–90	13 (59,1)
>90	3 (13,6)
Gender	
Male	8 (38,1)
Female	13 (61,9)
Missing	1

Analysis

Quantitative data were described using frequencies in Statistical Package for the Social Sciences 20. The data concerning the actual use of Congredi were analysed at patient-system level; the system did not have the option to distinguish between the users of the patient-system, thus also not between patients and informal-carers. When more than one professional from the same profession was involved (e.g. several district nurses), one person represented the sub-group. Due to privacy considerations, we used only anonymous data from Congredi; therefore, it was not possible to link the interviewees to a Congredi record.

Data on motives and experiences, encouraging and impeding factors have been gathered through interviews. Semi-structured interviews were held, ensuring that all topics in the topic list (Appendix 1) were discussed. The topic list was compiled from themes found in the literature. With regard to usability, a fairly strict structure was made in advance by carefully monitoring technology, user-friendliness and attractiveness. The other components (motives, experiences and satisfaction) were also structured. Each theme was launched with an open question to give the respondents the space to tell their own story. The interviews were scheduled to take 30 minutes. All interviews were audio-recorded and transcribed verbatim. Respondents were offered the choice of being interviewed face-to-face or by telephone. One researcher (CJ) conducted all the interviews, and two researchers (CJ, WR) analysed the results independently. The themes were extracted together and discussed until consensus was reached.

RESULTS

Description patient-systems in Congredi

Forty-six patient-systems were offered the opportunity to log on to Congredi. Twenty-two patient-systems actually logged in (47.9%) and thus had an active patient record in Congredi. The majority of the patients in the Congredi records were female and between the age of 80 and 90 years old (Table 1). In 20 of the 22 patient records, the coordinator was a nurse. The other two coordinators were general practitioner and elderly care consultant.

All patient-systems (n = 22) that had logged on to Congredi were invited for an interview. Seven members of a patient-system accepted the invitation; all were informal-carers and a child of the patient: three sons and four daughters (Table 2). The majority was over 50 years of age, had followed post-secondary school education, did not live with the patient but their own family, had a (voluntary) job and felt they were highly competent computer users. Four lived near to their parent (cycling distance). All reported that, within the patient-system, they had the task of monitoring Congredi.

Actual use of Congredi by patient-systems

Results pertaining to the duration of use show that from the moment the 22 patient-systems had registered in Congredi, there were activities in their record from 1 to 38 weeks during

Table 2 Description of members of the patient-system who gave an interview

In-formal carer	Sex	Age	Relation to patient	Education level	Distance to patient	Intensity informal care (visit + telephone)	Computer competency	Living situation	Social activity
A	F	>65	Child	University	Far	Weekly	High	Partner	Retired
B	F	50–65	Child	University	Far	Weekly	High	Partner + children	Job
C	F	>65	Child	Secondary	Far	Weekly	High	Solo	Volunteer
D	M	50–65	Child	University	Near	Daily	High	Partner	Job
E	M	50–65	Child	Vocational	Near	Daily	High	Partner	Job
F	M	50–65	Child	Vocational	Near	Weekly	High	Partner	Job
G	F	<50	Child	University	Near	Weekly	High	Solo	Job

the 42-week observation period (Table 3). Fifteen were still active at the end of this period; seven stopped prematurely.

The number of professionals active in Congredi records was on average 3.82. This varied from one to nine professionals (1x1, 7x2, 4x3, 3x4, 2x5, 2x6, 2x7 and 1x9). It was unclear whether this constituted all involved professionals.

Concerning the frequency of use results showed that the total number of activities by patient-systems in their Congredi record varied from 1 to 179. Several activities were performed: 17 patient-systems viewed their records varying from 1 to 124 times, sent e-mail to professionals varying from 1 to 33 times, received e-mail from professionals varying from 1 to 22 times and read e-mail varying from 1 to 22 times.

Four patient-system profiles were distilled from these results.

- *Collaborators*: Five patient-systems (22, 7%) viewed the record more than five times and sent, received and read e-mail. All were still active at the end.
- *Consumers*: Five patient-systems (22, 7%) viewed the record between two and five times, read all received e-mail, but hardly sent e-mail.

- *Casuals*: Seven patient-systems (31, 6%) viewed the record once, read their e-mail irregularly and did not send any e-mail.
- *Non-Consumers*: Five patient-systems (22, 7%) registered in Congredi but performed no further activities. They all received e-mail from their professionals, but did not read them. Four stopped prematurely.

Usability of Congredi experienced by patient-systems

The interviews yielded information concerning the usability of Congredi. The informal-carers did not experience technical problems: they were able to log on to Congredi, instructions were clear and technical support was not needed. They had some comments on the user-friendliness of Congredi. All mentioned that they would have appreciated an alert when they received e-mails. Professional jargon was not mentioned as a barrier. Some also commented that the care plan could have been more 'attractive' for them; in the layout it was not clear to them, which care actions had been agreed.

Table 3 Activities of patient-systems in Congredi

Patients/activities	Non-consumers average (range)	Casuals average (range)	Consumers average (range)	Collaborators average (range)	Total patients average (range)
Active period (wks)	5 (1–14)	7 (1–27)	4,8 (2–8)	33,2 (27–38)	12,3 (1–38)
Prematurely stopped	80%	11%	40%	0,00%	31,80%
Professionals linked	6,2 (2–7)	2,1 (1–3)	4 (2–6)	5,6 (4–9)	3,8 (1–9)
Doss views	0,0	1 (0–1)	2,6 (2–3)	50,2 (11–124)	12,2 (0–124)
E-mails sent	0,0	0,0	0,2 (0–1)	15,2 (1–33)	3,5 (0–33)
E-mails read	0,0	0,7 (0–3)	0,4 (0–1)	10,6 (1–33)	2,7 (0–33)
Tot.act. (doss view, e-mails read and sent)	0,0	1,7 (1–4)	3,2 (2–5)	76 (13–179)	18,6 (0–179)
E-mails not read	3 (1–7)	0,6 (0–2)	0,0	0,0	0,9 (0–7)
E-mails received	3 (1–7)	1,3 (0–4)	0,4 (0–1)	10,6 (1–22)	3,6 (0–22)

Motivation and expectations, experiences and satisfaction of the patient-systems

Motivation

The informal-carers had an intrinsic motivation for using Congredi: they wanted a better overview of the care for their parent, a check on appointments made and to be informed about incidents and to collaborate more effectively with all professionals involved. In most cases, the collaboration with the coordinating professional was already perceived as good before Congredi. This experience had built their trust and helped in their decision to try Congredi when their professional invited them.

'In my opinion, it seemed to me a good thing that there is a kind of central point where you can always find out what's going on'.

Expectations

The informal-carers expected that Congredi would be 'a point where everything comes together', where an overview of the actual care plan and care actions could be obtained. It would be an easy way to communicate with relevant professionals about their opinions or issues. It would help them to take care of their parent because they could see updates on the care plan, feedback on the visits of professionals to their parents and to be informed about incidents. One informal caregiver expected that the amount of work would decrease because she could do more coordination from a distance when change in the care situation was needed.

'The agreement was actually that if there were reports about my mother, they would be entered in the system. So then I could see what conversations she had or whether something was going on with her. And I could also report something if I found something wrong or I could report if I was worried myself'.

Experiences and satisfaction

For some informal-carers, Congredi lived up to their expectations. They checked Congredi as a regular activity and were satisfied with the communication with the professional. Others found routinely checking Congredi was taxing because there often was no new information. For some, this was a reason to stop.

Informal-carers experienced a limitation because not all relevant professionals were linked to Congredi. Furthermore, some informal-carers reported that e-mails sent to professionals were not answered; this did not work as an incentive for the further use of the tool. The amount of work for the informal caregivers did not decrease.

Informal-carers perceived it as supportive when professionals reacted to their e-mail about observations and worries. Some informal-carers felt more involved when using Congredi; they checked for messages regularly and felt it as their responsibility to respond and share their observations. They felt that they were making a contribution to the

care process. Others went back to their old form of collaboration and involvement using telephone, face-to-face contact or unsecure e-mail, because Congredi did not add value for them. Informal-carers perceived only small effects on the care plan (observed malnutrition by informal carer led to dietary advice). They also experienced small improvements in collaboration with the professionals by the use of Congredi (using e-mail to give feedback felt as collaboration). In general, patient-systems were satisfied with the actual execution of care. The use of Congredi did not make a difference on that count.

'Yes and this general practitioner I ask a question and there is no answer ... yes, well I think just leave it'.

'That overview did not happen. E-mailing is the only way I get something into it ... and then I don't get a response. And the particular GP, whom I specifically mailed with the neurologist's information, never saw it! And this was all important information. So yes, that works very demotivatingly. I can tell you that'.

'If I think my mother is not doing well then I'll send an e-mail about it: it may be sensible to visit my mom to see what you think of her yourself. The nurse then reports: I have visited your mother and talked to her ... for example, her sister died recently and she finds this very hard, and then such a feedback. But what has been discussed between the GP and the nurse, you do not actually see that. Or actions that need to be taken. Too little'.

'Yes, I would recommend it. It's because everything goes digital. And in this city, they obviously use Congredi so I would recommend them to use that, because that's how it works. It can certainly improve and then it's handy'.

DISCUSSION AND CONCLUSION

Discussion

General findings

Ultimately, almost half of the patient-systems that logged in were hardly active. At a first glance, this seems low. But, we were dealing with the implementation of a technological innovation of which it is known that the adoption starts with a relatively small group. Rogers argues that the adoption of an innovation takes place in stages; it starts with a select group of innovators and early adopters and then proceeds to the early and late majority.³⁰ We, therefore, concluded that the extent of participation of those that logged in (a quarter of all patient-systems approached) is reasonable.

Amongst the group of users (50%), four user-profiles (collaborators, consumers, casuals and non-consumers), based on the intensity of use of the e-communication tool, were found. Half was regularly active in Congredi (collaborators and consumers), some were occasionally active (casuals), but also one quarter was not active.

The main users appeared to be the informal-carers. Those that gave an interview were all informal-carers. However, due to blinding, it is not known in which profile category the interviewed patient systems were active. However, it is plausible that they came from the collaborator and consumer group because, from the statements in the interviews, it can be deduced that the interviewees have at least looked at their Congredi records several times. So, it can be concluded that seven of the ten members of the collaborators and consumers were interviewed. It might be hypothesised that their characteristics provide a profile of collaborators and consumers: sons or daughters, over 50 years, highly educated, competent in computer-use and socially active which seems in line with other findings.³¹

The fact remains, however, that quite a number is not participating. Technical issues were not found to be a barrier because all users logged in without problems and did not require helpdesk support. From the interviews, we learned that instructions were sufficient. Because Congredi is a tool developed for professionals, it is quite conceivable that certain characteristics, such as professional jargon, would be experienced by patient systems as a barrier, but this was not the case; it was not mentioned as a barrier. However, there was a need for a certain degree of tailoring because this was a trigger for several informal-carers to stop using Congredi. Some tailoring of the screens was named, as was also an alert when there was any form of action such as mutation in the care plan or e-mail.

Issues on implementation of e-communication tools

The invitation for an interview was accepted in all cases by informal-carers. This was not unexpected, as they are known to play a crucial role in the care of these patients.^{31,32} It is, therefore, presumed that informal-carers were quite active within the study population. Continual support is important to them which may be why they were motivated to use Congredi.³² Human support from the provider has been shown to increase compliance, but it was not examined how often the patient-systems were proactively urged to use Congredi.³³ In further implementation, this aspect needs attention. It is also advisable to focus on the informal-carers.^{29,34}

We noted that professional jargon was not named as a barrier for use by the informal-carers. An explanation may be that the informal-carers who were interviewed were mainly highly educated and that they were sufficiently trained in these matters as semi-experts in the disease status of their parent.^{32,33} In this study, a tool that had been shown to be feasible for professionals was offered to patients without making many adjustments. Other studies show that modifying language is not necessary.^{10,35} The benefits of having information surmount language problems; however, tailoring of content is recommendable. In summary, it may, therefore, be possible to introduce e-communication technologies that have not yet been fully developed for patient-systems.

Limitations and future research

The number of active patient-systems was found to be a limitation in this study. Professional- and patient-related factors may play a role. Three components could be distinguished: (1) characteristics related to the professional (amongst others netiquette), (2) characteristics of the patient (state of health and active role of the patient-system) and (3) characteristics of the caregiver–patient relationship (trust and the degree of insistence on using Congredi).

In our research, as in others, it seemed that the professionals who were using an e-communication tool could do this better; the new professional–patient communication patterns in the CFL need attention.^{17,21–23,26} A CFL is important as a catalyst for effective eHealth technologies.^{11,16} Congredi was found to be suitable for the CFL because all five stages of the CFL could be run through.¹⁶ However, although the Congredi system appears to meet the conditions for the CFL, patient-systems perceived the CFL to be limited. An explanation could be found in the way of use by the professionals. The records showed that on average 3.82 professionals were connected. That seems a realistic number considering the patient population, though the interviews showed that not all professionals were linked and not all were active because patient-systems did not receive reactions to their e-mails. Both were experienced as a barrier.

Concerning the patient-related factors, research shows a relationship among poor health, multi-morbidity, many doctor visits and high e-communication.³⁶ Because our patient-population partly met these characteristics it could be assumed that this group was amenable to an e-communication tool, specifically when their situation worsens.³⁷ Another influencing factor on the use of eHealth systems is trust.^{33,37–39} The sample selection was based on trust between patient and professional, which may have led to an active role as nearly half of the sample logged on to Congredi.

We did not perform sophisticated qualitative analyses; we focused primarily on the topics that were known from the literature, and in the interviews no other topics were raised, even if explicitly asked.

CONCLUSION

Congredi, an e-communication tool developed for professionals, was usable for patient-systems, but an alert was wanted when professionals had performed action in the Congredi record. The barriers found seem not to be tool-related but primarily user-related. Limited active participation of involved professionals in the CFL was an important barrier. Potential for future implementation was found, because patient-systems were intrinsically motivated for better feedback with the professionals, even though in this study it only partly met their expectations.

APPENDIX 1: INTERVIEW SCHEDULE CONGREDI WITH TOPIC LIST

Context question

- Can you tell me about your illness and the reason why you are receiving care?
- What kind of care are you receiving?
- How is your living situation?
- How are your contacts with the caregivers?

Personal characteristics

- Are you patient or informal carer?
- Relationship to patient
- Year of birth
- Education
- Living situation in relation to (informal) care
- Computer skills
- Role of internet in daily life (how often, what)
- Informal carer: degree of involvement in care
- Informal carer: family situation
- Informal carer: job or other obligation.

Initial question: Did you use Congredi?

- Log on
- Your data
- Questionnaires and care plan
- Messages.

(Ask per functionality whether they have used it, and if so, how they experienced this, and if not, why not?)

Then, let the interviewee talk as much as possible and submit subjects.

In any case, the following topics must be considered (possibly by the researcher through open questions. Order random).

Use

- How were you connected? How was it offered to you? Did you receive explanation about the use?
- What did you use it for? (Together with family/carer, keep control over my care with carers, check if the appointments made are listed and performed, check data, e-mail with my carers.)
- Readability of the healthcare provider's texts.
- Support when using Congredi: granddaughter or case manager, or else.
- Ease of use Congredi: slow, difficult and attractive.

Motivation use of Congredi

- Why did you want to use Congredi?
- What was the reason you wanted to be connected?
- What were your expectations of Congredi?
- Have they come out?
- Has your care changed compared to when you were not connected to Congredi?

Use experiences

- How did you perceive the use of Congredi?
- Did you gain anything using Congredi? Example?
- Did it help?
 - See care plan
 - E-mail contact
 - See data.
- What does Congredi mean for your (chronic) disease?
- Has the use of Congredi changed how you experience your health? Do you feel fitter, for example, are you more optimistic or do you feel more depressed? Example?

Collaboration with caregivers

- Has using Congredi changed your contact with your healthcare providers?
 - What matters have changed? Example? (Experienced as a partner, direct contact with my healthcare providers, quick answer to my questions and answers were helpful, so healthcare providers will contact me if necessary, my data was in order.)
- Has it helped you to improve collaboration with the healthcare provider?

Involvement in your care process

- Do you feel that, using Congredi, you can control and guide your care and influence it?
 - What has changed? Example? (Frequency of care, amount of face-to-face contacts less, digital contacts more. What are your feelings about this? Did you feel that you should not telephone anymore?)

Execution of care

- Did using Congredi help you to carry out your care as intended? How? Example? (e.g. you can read it in the care plan, exact instructions)

Finishing

- Can you name positive experiences with Congredi?
- Can you name negative experiences with Congredi?
- Is there anything else you want to say about your experiences with Congredi/care?
- If you would advise someone, would you recommend Congredi?
- If I have additional questions, may I call you again?

End interview

1. Thank your respondent for the interview.
2. Indicate that you can still talk about everything if you want to. Leave e-mail address.

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