

Attitude @ E-Health

A qualitative study on the attitude of formal caregivers towards E-Health to support self-management for persons with severe mental illness

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Abstract

Background: In the Netherlands about 216,000 people have severe mental illness. To gain rehabilitation or recovery, self-management is important. Self-management can be supported via E-Health, but the implementation of E-Health programs often fails. This is partly caused by the attitude of formal caregivers, but there is not much is known about their attitude towards E-Health programs to support self -management of persons with severe mental illness.

Aim & research question: The aim is to get insight in the attitude of professionals to facilitate the implementation of E-Health: Therefore, the research question is: "What is the attitude of formal caregivers towards E-Health programs to support self-management of persons with severe mental illness?"

Method: A qualitative study, with semi-structured interviews was carried out. The analyzing procedure was based on the Grounded Theory approach. The population consisted of psychiatrists and nurses who work with people with severe mental illness in a Flexible Assertive Community Treatment team in an organization for mental health in The Netherlands.

Results: In the attitude, different themes were distinguished. The central theme consisted of concern: all formal caregivers expected problems if they use E-Health. When formal caregivers were thinking about possibilities, enthusiasm prevails. When they think about the risks skepticism prevails

Conclusions Scepticism and concern of formal caregivers can be a barrier in implementing E-Health. There might be an underlying fear that E-Health affects the basic principles of their craftsmanship, just like talking and assessing in personal face-to-face contact.

Recommendations: While implementing E-Health, attention is needed to prepare formal caregivers for their new role that is needed if E-Health is implemented . Research on the development of strategies to support formal caregivers in their new role is recommended.

Keywords: E-Health, Self-management, Severe mental illness, Attitude, Formal caregivers

Samenvatting

Achtergrond: In Nederland hebben 216.000 mensen een ernstige psychiatrische stoornis. Bij rehabilitatie en herstel, is zelfmanagement van belang. Zelfmanagement kan worden ondersteund via E-Health, maar de implementatie van E-Health programma's is zelden succesvol. Dit wordt deels veroorzaakt door de attitude van zorgverleners. Er is echter weinig bekend over de attitude van zorgverleners ten opzichte van E-Health programma's om zelfmanagement van mensen met ernstige psychische aandoeningen te ondersteunen.

Doel en onderzoeksvraag: Het doel van het onderzoek is om de implementatie van E-Health faciliteren met behulp van de volgende onderzoeksvraag: "Wat is de houding van zorgverleners ten opzicht van E-Health programma's om het zelfmanagement van mensen met een ernstige psychiatrische stoornis te ondersteunen?"

Methode: Een kwalitatief onderzoek werd uitgevoerd. Psychiaters en verpleegkundigen die werken met mensen met een ernstige psychiatrische stoornis in een Flexibele Assertive Community Treatment team bij een organisatie voor geestelijke gezondheidszorg in Nederland werden geïnterviewd. De analyse was gebaseerd op de gefundeerde theoriebenadering.

Resultaten: Er werden verschillende thema's onderscheiden in de houding van zorgverleners. Het centrale thema bestond uit bezorgdheid. Wanneer zorgverleners aan mogelijkheden dachten, bedachten ze hoe hun bezorgdheid kon verminderden en werden zij enthousiast. Als ze gefocust waren op risico's, zagen ze geen oplossingen zagen en overheerste scepticisme.

Conclusies Scepticisme en bezorgdheid van hulpverleners kunnen een belemmering vormen bij de implementatie van E-Health. Er lijkt sprake van een onderliggende angst dat E-Health de fundamentele beginselen van het vakmanschap, zoals het voeren van gesprekken en het beoordelen van mensen in persoonlijk face-to-face contact, bedreigt.

Aanbevelingen: Bij de implementatie van E-Health is aandacht is nodig om hulpverleners voor te bereiden op hun nieuwe rol die vereist is bij het gebruik van E-Health is. Onderzoek naar de ontwikkeling van strategieën om hulpverleners te ondersteunen in hun nieuwe rol wordt aanbevolen.

Sleutelwoorden: E-Health, Zelfmanagement, Ernstige psychiatrische stoornise, Attitude, Hulpverleners

Introduction

In The Netherlands, 42.7% of the people have had a mental disorder ever in life and 18% in the last 12 months (1). About 1.3 % (216.000 people) suffer from a severe mental illness (SMI), as defined by Delespaul and colleagues (2). The treatment and care for persons with SMI is mostly provided by a multidisciplinary team with a shared caseload. This form of treatment and care is known as “*function assertive community treatment*” (3) (FACT)). FACT is the reference model of outpatient care for those with SMI (2,3). Psychiatrists are supervising the treatment and the task of nurses is to support rehabilitation or the process of recovery and to reinforce self-management strategies (4). In this study, self-management is defined as: “*an individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition efficacious self-management encompasses ability to monitor one’s condition and to affect the cognitive, behavioral and emotional responses necessary to maintain a satisfactory quality of life, thus, a dynamic and continuous process of self-regulation is established*” (5).

In order to reinforce self-management of persons with SMI, E-Health can be useful (6). The Dutch Council for Public (7) defined E-Health as: “*the use of new information and communication technologies, particularly internet technology, to health and health care*”. E-Health programs were at least as effective as usual care or non-technological approaches (8). The benefits on medication management were even larger, while no studies reported negative effects (9). Persons with SMI were positive and satisfied about E-Health interventions (10-13) and showed a high compliance with E-Health interventions, up to 100% (11,12). However, implementing E-Health programs is much more time-consuming and complex than initially foreseen (14). Several factors have been identified that influence the implementation of E-Health (15), and the attitude of formal caregivers is identified as one of those factors (15,16,17). Attitude can be defined as “*the direction of thought (beliefs), feelings and actions with different degrees of intensity*” (18).

The attitude of formal caregivers reveal concern for the assumption that use of internet could strengthen paranoia and that computerized support might replace face to face contact (16). According to formal caregivers, potential barriers for the use of E-Health are the lack of access to computers and skills for using them of persons with SMI, as well as diminished reading skills (16). On the other hand, formal caregivers see benefits in giving their patients more control while they can monitor them from a distance and formal caregivers appreciate the modern way of communication with patients (16). Wright-Berryman and colleagues (6) reported that five out of six formal caregivers preferred a web-based self-management program instead of a paper version, and Monthuy-Blanc and colleagues (17) showed that the general Technology Acceptance Model (19) also applies for mental health providers. This

model shows that perceived usefulness will have a positive impact on attitudes towards technology, and perceived ease of use will positively influence perceived usefulness.

Problem statement, aim and research question

The implementation of E-Health programs often fail. This is partly caused by the attitude of formal caregivers. Currently, there is a lack of knowledge about the starting points for implementation relating to the attitude of formal caregivers towards E-Health programs to support self-management of persons with SMI. Therefore, this study aims to get insight in the attitude of formal caregivers towards self-management supporting programs via E-Health for those with SMI, in order to facilitate the implementation. To address this goal, the following research question was formulated:

“What is the attitude of formal caregivers towards E-Health programs to support self-management of persons with severe mental illness?”

Method

A qualitative study, based on the grounded theory approach (20) was carried out to get insight in the attitude, because qualitative studies focuses on the view of people, their perceptions, interpretations and meanings (20-23). Face-to-face, semi-structured interviews were held and during the interviews, the researcher (IdH) tended to build rapport to stimulate participants to talk freely (21).

Participants

FACT-teams of two mental health organizations, situated in urbanized areas of The Netherlands were selected by convenience sampling. Psychiatrists and nurse practitioners who work in a FACT-team were included, because they indicate treatments and interventions to reinforce self-management of persons with SMI. There were no exclusion criteria.

Invitation e-mails with an information letter were sent by the researcher to all six nurse practitioners and all seven psychiatrists who worked in the eight selected FACT-Teams. If they were willing to participate, an appointment was made by e-mail. If they did not respond within a week, a second e-mail was send. If they did not respond to the second e-mail within a week, the researcher called them.

Data collection

The data was collected between January and May 2014. Interviews with an average duration of one hour were held by the researcher in a quiet room at the workplace of the participants. The main concepts, like E-Health, SMI and self-management were orally defined by the researcher before each interview. An interview guide (appendix 1) was used to make sure that every important topic was addressed. Usefulness, ease of use, accessibility, and if E-Health will fit with the current way of working (15,16,18,24), were the main topics in literature and those became topics in the interview guide. The first question of every interview was: "What is your opinion about E-Health for people with SMI to support their self-management?" Beside the selected topics, participants were encouraged to raise any issue that seems relevant to them. After two interviews, the interview skills of the researcher were discussed by the supervisor (BvG) and it was discussed if there was a need to add topics to receive an answer to the research question, no topics were added. The interviews were audio recorded and verbatim transcribed. Saturation was achieved after the ninth interview, in which no new additional information emerged (20).

Analysis

The following steps were taken by the researcher to analyze the data : 1) open coding, text fragments were given a code, for example: "isolation"; 2) assembling codes into a category:

“isolation” assembles with other codes into the category “human contact”; 3) merging categories into a theme (25): the category human contact was classified under the theme “concern”. The data-analysis was conducted iteratively with data-collection, and newly collected data were constantly compared with earlier obtained data (24) to discover similarities or differences between the interviews. By arranging and rearranging and discussing the codes, categories and themes with a supervisor, code tree was developed. An independent researcher (SR) coded two interviews (20) and the differences were discussed. This led to an adjusted coding tree, which was tested by coding a third interview by the independent researcher (24). The computer program Excel was used for coding, categorizing and theming the data.

Trustworthiness

Quality enhancement strategies were used to increase the trustworthiness (20). Space triangulation took place by selecting FACT-teams of two organizations, this increased the transferability. The dependability was enlarged by using an interview guide and verbatim description of the interviews enhanced the credibility and authenticity. Member checks took place by sending the transcriptions to the participants for feedback and writing field notes after each interview, those enlarged the credibility. Decision points in analyzing were kept in a logbook to enlarge the dependability and confirmability. The supervisor reviewed the process during the whole study and important decisions were discussed with a mentor (IP) and peers of the University Medical Center Utrecht. Those strategies enhanced the confirmability and credibility.

Ethical consideration

A study protocol was sent to the scientific committees of the two mental health organizations and they gave permission. The study was conducted according to the principles of the Declaration of Helsinki, Version Seoul, October 2008, and in accordance with the Medical Research Involving Human Subjects Acts (26). All participants signed an informed consent. The data has been anonymized and stored in a database of the Radboud university medical center. Only the researcher and the supervisor got the code to the identity of the participants.

Results

Five nurse practitioners and four psychiatrists of seven FACT-teams were interviewed. Table 1 shows their characteristics. Two psychiatrists refused to participate because of a full schedule, one psychiatrist did not respond to e-mails or calls and one nurse practitioner had to cancel the appointment because of personal circumstances.

[table 1 about here]

In the attitude of the participants, three different themes occurred, those were concern, enthusiasm and skepticism. The themes were merged from categories as showed in table 2, this table also included quotes of each category. All themes were seen in all participants and the themes were more or less equally distributed between seven participants. One participant was mostly skeptic and another participant showed more enthusiasm than the others did.

[table 2 about here]

Concern

“Vulnerability, requirements to the computer system, human contact, ignorance and requirements to implementation”, were categories of the theme concern.

Vulnerability of people with SMI regarding the use E-Health, because of the nature of their diseases, was mentioned by all participants. The presumed vulnerability was based on problems caused by cognitive impairments related to concentration or executive functions. Because of those impairments, participants believed that working with computers would be hard for many persons with SMI. Participants also assumed that E-Health could strengthen paranoia and some feared overstimulation and a limitless use of E-Health. A lack of illness awareness was mentioned as interfering negatively with the use of E-Health, just like a loss of energy, interest and initiative. Some participants thought that co-morbid addictions can cause a lack of interest also.

Participants expressed concerns if special requirements to the computer system or web designs, mostly connected to the vulnerabilities of people with SMI, will not be addressed. Those requirements included an easy web-design with pale colors, the possibility to interact and avoiding large amounts of text. Participants saw value in tailored programs and they claimed that those programs should be easy to use and the efforts should be clear. Support of an information technology (IT) specialists was also required by participants and they saw the security of the system to protect privacy and quality of the E-Health application as crucial.

All participants feared that E-Health might replace human contact. They saw face-to-face contact as an essential aspect of their work, according to them face-to-face contact is most effective for a proper assessment and interaction. Face-to-face contact was also seen as necessary to motivate and stimulate persons with SMI to therapy compliance. Some participants were concerned that the level of isolation could increase if people have less life contact with formal caregivers or peers. None of the participants was a proponent of solely E-Health treatment, if E-Health would be implemented, they require blended care.

The knowledge and skills of them self or their colleagues were doubted by many participants. They feared a proliferation of E-Health applications without knowing which ones are reliable. Some participants named that colleagues have difficulties working with ordinary computer programs, and they feared that providing more advanced E-Health will cause problems for them. Some also thought that a number of their colleagues are too paternalistic to work with E-Health, because they would not have confidence in the abilities of people with SMI to live their life without the support they receive now. Some participants feared a devaluation of their own profession or the profession of colleagues, if a digital program will do their work.

Participants claimed that the benefits of E-Health must be clear for both providers and users and that they need leaders in their organization who promote the use of E-Health. According to many participants, it is best to start with providers and users who already have the skills to use a computer or smartphone. They assumed that those are relatively young people.

Enthusiasm

The categories: “better accessibility, more efficiency, useful applications, possibilities, and pleased to join”, were collected in the theme enthusiasm.

Participants expected a better access to healthcare, when they use E-Health, because they could serve more people in less time. They also expected a better accessibility, for people with SMI would be able to use E-Health whenever they want and were ever they want. All participants foresaw more efficiency in their work by declining the administration time and the travelling time on home visits and they predicted that it would be easier to make appointments, to arrange repeated prescriptions and that their work would become easier in general.

Possibilities were seen in applications to increase the therapy compliance, insight and illness awareness, and to give education and information by video tutorials or pictograms were seen as promising, just like applications for crisis plans, mobile devices for assessments and videoconferencing. Serious gaming, with or without physical training was seen as high potential for adoption by the target group by one respondent. In addition, they opined it would be valuable if people with SMI can log in into their own electronic health record. The

possibility of the involvement of relatives through E-Health was named and they pointed out that people with SMI can have contact with peers through a forum. According to most participants, E-Health could support formal caregivers in the case of standardized work, like routine outcome measuring and physical examination. Existing applications to deal with hallucinations or mood swings were judged as beneficial by participants.

Many participants were pleased to join the developments in the digital world, and they said they were enthusiastic about the idea to work in a modern way and they were curious about the way it would work out in practice. Several participants did suggestions to increase internet access for people with SMI, like the use of computers in the public space of their own working site, the use of computers of family or relatives, or the provision of special devices by the health insurer.

Skepticism

The theme skepticism assembled the following categories: “way of working, lack of investment, no fit with E-health and cynicism”.

Nearly all participants thought that their current way of working does not fit with E-Health programs. They predicted that it will take time before it is common to use E-Health in their daily work and judged their devices and systems as unsuitable for E-Health. Based on their experiences, participants did not believe that their organization will invest enough to buy appropriate devices or organize enough IT support. A few participants thought that the organization has no good policy and invest too little finances, so the development and implementation of E-health will stagnate. Others thought that the culture of the organization is not stimulating, because there are E-health applications available, but besides e-mail and SMS, it is not common to use them.

Some parts of treatment were judged by participants as not suitable for E-Health, just like monitoring of extrapyramidal side effects of medication, assessment on how someone is doing, and crisis interventions. All participants asserted that only a few people with SMI have devices for E-Health, they believed that most people with SMI do not have money to buy the devices or that people with SMI do not give priority to buy this devices. The estimates of the 'internet penetration rate' varied from 5% till 50%.

Cynicism revealed as a few participants predicted that people with SMI are not able or not willing to use E-Health at all and some participants saw self-management and E-Health applications to support this, as a paradox. One participant argued that the more accessible supplies are offered, the more the demands will raises and people will become more dependent at the end.

Discussion

In the attitude of formal caregivers different themes were distinguished, those themes were concern, enthusiasm and skepticism. Participants showed lots of concerns as the mentioned vulnerabilities of persons with SMI and also when they made special requirements connected to the vulnerabilities. Skepticism prevailed when they talked about potential risks, assumed impossibilities or site effects. Indeed, participants doubted the ease of use of E-Health for those with SMI. On the other hand, participants were enthusiastic about the usefulness of E-Health applications, they saw lots of opportunities and they expected that their work would be more efficiently if they can provide E-Health. The Technology Acceptance Model (17) reads that perceived usefulness and perceived ease of use have a positive impact on attitudes towards technology. In this model, usefulness refers to the efficiency, relevance and effectiveness of the computer system, and the ease of use refers to control, readability, navigation, consistency, and feedback of an interface. Van der Krieke and colleagues (27) stated that the design of web-based support systems should be based on mental models of people with SMI. Therefore, they recommended transparency of procedures, a limited amount of text, and the use of video material. Visual displayed words help to compensate deficits in attention, concentration, memory and auditory processing. Rotondi and colleagues (12,28,29) concluded that E-Health programs should contain lower level modules with familiar phrasing, text at low reading level, as simple and sparse as possible. Based on these findings the conclusion can be drawn that formal caregivers already see the usefulness of E-Health, and if one want to influence the attitude positively, attention must be paid to the right level of difficulty and the special requirements for web designs to increase the ease of use for persons with SMI.

Rotondi et al. (12) claimed that E-Health support is a de-stigmatizing way of supporting persons with SMI and Van der Krieke (30) wrote in her dissertation that the restraint of formal caregivers towards E-Health applications for persons with SMI might contribute to a renewed exclusion. The philosopher Anders (31) stated that people are unconsciously ashamed when they face the relative perfection of technique; he argued that humans see themselves as inferior beings compared to technique. He calls this the 'Promethean Shame'. It is possible that the concept of the "Promethean Shame" is still relevant as an explanation for the concern and skepticism in the attitude of professionals; professionals might be afraid that E-Health programs will fill their unicity as human, and exceed their professional skills. Many participants mentioned concerns about the assumed decreasing of human contact if E-Health is implemented and they do not believe that a computer program can monitor side effects of medication, or interfere in case of a crisis, as proper as themselves,. At the same time, some participants feared a devaluation of their profession. Kirmaier (32) claimed that

psychiatry have no choice but to involve into the digital world to deliver contemporary care, because people with psychiatric diseases already search in on the internet for treatment. According to Coeckelbergh (33) the craftsmanship in “high tech” healthcare is threatened. He stated that craftsmanship is changing and special attention and stimulation is needed to develop a new form of craftsmanship. It is possible that the underlying reason for the concern and skepticism is anxiety for a changing craftsmanship. By means of this anxiety, formal caregivers might hinder the involvement in the digital world and unintentionally contribute to a renewed exclusion of those with SMI. If formal caregivers have insight in this dynamism, they can make a rational choice about their viewpoint, instead of being driven by unconscious feelings with probably an unwanted outcome.

This study has limitations. A convenience sample selected two organizations in an urbanized area. It is possible that the urge for using E-Health is less in urbanized areas compared to rural areas, because the distances and the travelling times are relative short, so the need to use E-Health can be less in urbanized areas and this can affect the attitude. The researcher herself works as a nurse practitioner with persons with SMI, this might have ensured prejudice. The researcher also works in the same organizations (on other sites) as the participants and this might have influenced the participants in any way. The strength of the study is that a supervisor with no working experiences in mental health and no relationship with the organizations reviewed the whole study. Another strength is the involvement of an independent coder, to discuss the analyses of the researcher.

Conclusion

Formal caregivers have concerns about E-health to support self-management for those with SMI and they have doubts about the ease of use. Formal caregivers get enthusiastic if they think about usefulness of E-Health, but they get sceptic if they think about the difficulties and risks. The underlying reason for concern and skepticism, might be anxiety to let go the well-known craftsmanship, because it is obviously that the craftsmanship of formal caregivers will change if E-health is implemented. This anxiety can hinder the implementation of E-Health.

Recommendations

The implementation of E-Health affects the basic principles of craftsmanship of formal caregivers, thence implementation of E-health for people with SMI will be complex. Well-designed E-Health programs, should be implemented in phases. Formal caregivers need time, clues, supervision and support to shape themselves for their new role and develop a new kind of craftsmanship. Research on the development of strategies to prepare formal caregivers for their new role is necessary.

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Table 1, characteristics of participants

Profession	Gender	Average age (range)	Average years of experience with SMI (range)	Experience with E-Health
4 psychiatrists	2 male	44 (35-51)	6 (3-10)	2 e-mail 2 none
5 nurse practitioners	4 male	40 (31-49)	15 (5-23)	2 e-mail and SMS 2 e-mail 1 SMS

Table 2, Themes, Categories and Quotes

Theme	Category	Quote
Concerns	Vulnerability	<i>Well, I think that when someone suffers from negative symptoms, this person has no desire to turn on the computer.</i>
	Requirements of the system	<i>I wonder how you can apply this for people with SMI, because they are often the more severe patients, where you just .., my experience is that you very individual fill in what someone needs. While addictions, for that matter, are easier to deal with, comparing to people with for example, SMI or a psychotic or bipolar disorder.</i>
	Human contact is	<i>The downside is that if you're lonely, you encounter no other people anymore and so you become more lonely.</i>
	Ignorance of formal caregivers	<i>If I'm looking at my own smartphone, uh, I think it's a lot of hassle.. If I have to read things, or if I have to write things, then eh .. for example, well I think eh.. Maybe for the younger generation, because they do so much more with their smartphone, but I think..</i>
	Implementation Issues	<i>But I don't think that you can say to people with very serious symptoms, people who are not able to develop the skills, you make demands and they can't meet them, by saying: go and buy a smartphone and download an app.</i>
Enthusiasm	Better Accessibility	<i>It's all about communications and the communication tools we use are fairly outdated, it's like twenty years ago actually, so the access is not that big. I mean: this morning I had a conversation about somatic care: must we start a group. Than we can serve eight people out of the two hundred and eighty we should serve, so the accessibility of the current way of working is small, despite our good intentions.</i>
	More efficiency	<i>Then you know what you're talking about. You can feel it, you're still in it. And otherwise you have to remembered, what was that again? So I do believe that I is very effective.</i>
	Useful applications	<i>Yeah, I'm thinking, suppose someone says: now I feel tense, and then phone tells you: well, according to your crisis plan, you have to do this, or you have to do that, stand-alone programs or eh</i>

		<i>prosthesis, you could offer people where they cannot handle it by themselves.</i>
	Possibilities	<i>I was thinking about IMR, the course: it might also be fine as a booster: if people have done the course and they like to do some reading again.. Of course they have a folder, but some people prefer E-Health, because they don't have that folder anymore, lost it.</i>
	Pleased to join	<i>And there may be colleagues who have to make a bit of a change in the way they are, thinking, but yes I would apply if there is a good application, the sooner the better for me.</i>
Scepticism	Way of working	<i>What role do the provider have in this, is his role taken over by the computer or is there still a role for him? People don't like new things.</i>
	No fit with E-Health	<i>It is horrible, it's a patchwork of software and of course it do not communicate with each other. It's a miracle that it can function anyway.</i>
	Lack of investment	<i>An in-depth investment: yeah, everything is so unsure, you just have wait and see if you get it back, so you don't know. You don't see that all that money back immediately, so why should you do it?</i>
	Cynicism	<i>Yes, there is something paradoxical in it. We are talking about self-management, which means that the patient eventually get a greater control over his own life. And what do we do now, with this kind of methods? Control them more closely.</i>

Appendix 1

Interview guide

- ✓ What is your opinion about E-Health for people with SMI to support their self-management?
- ✓ If there was a program to support self-management for people with SMI, would you use it? Can you tell why you will or will not use it?
- ✓ What are the demands for a E-Health program for people with SMI? – for the ease of use – to be usable – in the view of the symptoms of their illness?
- ✓ According to you, what are the values of such a program for people with SMI? And for you as a professional?
- ✓ Are there downsides of E-Health, can you describe them?
- ✓ What is your opinion about E-Health in the current, daily way of working?
- ✓ Which adjustments must be done by you? And by people with SMI? Can they do these adjustments?
- ✓ What are the points for attention when implementing in the view of the specific characteristics of people with SMI?
- ✓ What are the points for attention when implementing in the view of your current way of working?
- ✓ Are there other things you like to add?