

Refereed papers

Seniors' views on the use of electronic health records

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ABSTRACT

In the Mauricie and Centre-du-Québec region of the province of Quebec, Canada, an integrated services network has been implemented for frail seniors. It combines three of the best practices in the field of integrated services, namely: single-entry point, case management and personalised care plan. A shared interdisciplinary electronic health record (EHR) system was set up in 1998. A consensus on the relevance of using EHRs is growing in Quebec, in Canada and around the world. However, technology has outpaced interest in the notions of confidentiality, informed consent and the impact perceived by the clientele. This study specifically examines how frail seniors perceive these issues related to an EHR. The conceptual framework is inspired by the DeLone and McLean model whose

main attributes are: system quality, information quality, utilisation modes and the impact on organisations and individuals. This last attribute is the focus of this study, which is a descriptive with quantitative and qualitative component. Thirty seniors were surveyed. Positive information they provided falls under three headings: (i) being better informed; (ii) trust and consideration for professionals; and (iii) appreciation of innovation. The opinions of the seniors are generally favourable regarding the use of computers and the EHR in their presence. Improvements in EHR systems for seniors can be encouraged.

Keywords: electronic health record, integrated care, seniors

Background

In February 1997, an integrated services network for frail seniors was set up in the Bois-Francs area within the Mauricie and Centre-du-Québec region in the province of Quebec, Canada.^{1,2} It was designed to correct several deficiencies related to co-ordination of health care and services for frail seniors.^{3–10} It combines what are considered as three of the best practices in the field of integrated care, namely: single-entry point, case management and individualised service plans.¹¹ Within this network, co-ordination is a central component. It relies on a team of case managers who are responsible for triage, information, orientation, follow-up and evaluation. Their duties involve:

- developing individualised service plans with frail seniors and their family support networks
- negotiating and co-ordinating the planned services with providers
- ensuring that these services are in fact delivered at the proper time
- ensuring that services are adjusted to any changes in the health profile or in the family support network
- ensuring that services are evaluated.

Within this model of integrated care, interactions among professionals and between care facilities are more frequent than in usual care and this is mainly due to a greater need for consensus and follow-up in the individualised services plans. To support interactions between professionals and facilities, a shared interdisciplinary electronic health record (EHR) was set up in 1998.¹² It contains:

- identification and consent management
- security and confidentiality measures
- health profile
- medications profile
- functional status measure
- individualised services plan and its revision system
- follow-up memos
- requests for services
- data extractor.

At the end of 2004, the EHR was used by 250 professionals to support services provided to more than 5000 frail seniors.

With the rapid development in the field of EHRs, a certain number of questions must be raised. Among them, one of the most significant is how to make sure that the point of view of frail seniors is taken into consideration regarding issues such as sharing computerised health data, confidentiality and informed consent. These issues are rarely raised in the literature but are specifically addressed in the present study, which is embedded in a larger research programme aimed at evaluating several facets of an interdisciplinary

information system for frail seniors that includes EHRs.¹³

Literature review

Electronic health record to support professional practice

Many articles are available on EHRs in international literature. In these studies, EHRs are for the most part used within the same healthcare unit or within the same facility such as a hospital. The rare studies in which an EHR is used in an interdisciplinary context deal with a single type of clientele.^{14–16} Only a few studies address computerisation of data within integrated healthcare systems, such as for seniors, cardiac patients or other chronic illnesses.^{17–19}

Seniors' views on sharing information, confidentiality and consent

Few studies deal with what frail seniors or their families know about EHRs, or with their concerns about computerisation. Among those that do, there is no consensus regarding patients' degree of knowledge. Some studies indicate that patients do have a good understanding of EHRs, while others show that they do not.^{20–22} Ridsdale and Hudd conclude that an EHR must be sufficiently user-friendly in order for patients to feel it can be easily used, to see the data and be reassured that it remains confidential.²¹ They note that very old patients would accept the EHR even when on-screen data is complex. These authors suggest that the most important factor of all is patients' trust in their physician. A recent study comes to the same conclusions after examining how patients suffering from chronic heart failure access their EHR, and how they feel this affects their relationship with the professionals caring for them. Overall, the patients are satisfied with the information they find in their EHR and this has a positive impact on their acceptance of the planned therapy.¹⁷

In studies where professionals used laptop computers for home visits, patients stated that they were better informed of their care plan and had better interaction with healthcare providers.^{23,24} In other studies, seniors felt that the professionals were more involved with the computer than with them as patients.²⁵ For medical practice, many studies have shown that introducing an EHR does not decrease patient satisfaction.^{12,20,21,26–28}

There are, however, very few studies that deal specifically with confidentiality and consent. In these

studies, results conclude that seniors have little concern for confidentiality, and even when they are concerned, they allow data to be made available on the condition that their physician gives consent.^{21,22,29-31} The literature is so rare on this point that Barber says that '... the need is for a clear policy about the use of patient data ... providing openness, transparency and security for patients and healthcare professionals ...'.³² Layman also suggests that 'A multi-pronged solution that incorporates adherence to regulations and standards, promotion of codes of conduct and ethics, and creation of a culture of info-ethics is recommended'.³³

Summary

There is wide consensus on the relevance of using an EHR when caring for frail seniors. The EHR used in the Mauricie and Centre-du-Québec region certainly differs from others due to its interdisciplinary character and especially its deployment across several levels and types of facilities. There are numerous factors encouraging or constraining the use of an EHR but, in general, good knowledge of the system by the professionals and patients' trust in the professionals increase EHR acceptability and use. Frail senior patients can be interested in and easily accept this type of innovation. However, technology has outpaced interest in the notions of confidentiality, informed consent and the impact perceived by the clientele. This study specifically deals with how these issues are perceived by frail seniors.

Conceptual framework

The conceptual framework selected for this study is inspired by the DeLone and McLean model.³⁴ It has often been used in studies evaluating the introduction and impact of computerisation.³⁵⁻³⁷ The central concepts of the model can be summarised as follows: system quality, information quality, utilisation modes, and the impact on organisations and on individuals. The central concept of impact on individuals is composed of two main attributes, which are the effect of the system on the professionals and the effect of the system on the clientele. This study addresses the latter.

Methods

Population and sampling

This is a descriptive study using a mixed design including qualitative and quantitative approaches. In 2001, a

sample of elderly people was selected from a population of 2500, according to three main criteria. The primary criterion was the fact of having an active EHR. The second criterion was related to having had a case management episode during the previous six months. The third criterion was having a fully completed measure of functional status using the *système de mesure de l'autonomie fonctionnelle* (SMAF), a negatively-scored standardised instrument, widely validated in comparable environments.^{38,39} The sample of seniors was then stratified in relation to level of functional status measured by the SMAF (SMAF ≤ -30 or SMAF > -30), and in relation to living arrangements (own home or private facility). These stratifications produced a subset of 206 eligible individuals who were all personally contacted to determine if they considered that they had experience of their EHR. A total of 56 seniors stated that they had previous experience with the EHR and, among them, 30 agreed to be interviewed. The 26 seniors who refused stated they were too weak or too ill to participate in an hour-long interview. They were also those with the lowest SMAF scores (SMAF ≤ -30).

Instruments and procedures

The interviews were conducted at the seniors' homes and lasted an average of 50 minutes. The three main topics addressed were: (1) free and informed consent regarding data transmission via the EHR; (2) general reactions to computer use and the EHR; and (3) perceived advantages, disadvantages and impact of computer use and the EHR. The interviews were conducted in two parts. First, a questionnaire comprising 20 closed questions was administered. The questionnaire was previously tested. Answers were either on a 4-point (ranging from Strongly Agree to Strongly Disagree) or on a Yes/No scale. An additional choice of 'I do not know' was possible when the 4-point scale was used. The following are three examples of statements or questions included in the questionnaire regarding consent and confidentiality: 'When my permission was requested, I felt free to accept or refuse'; 'I am confident that only authorised persons will have access to my records'; and finally: 'When professionals used a computer during the home or office visit, were you interested to look at the screen?' Answers were analysed using the statistical software SAS-V8.

After completion of the questionnaire, six open-ended questions were asked. These had been pre-tested. An example of a question is: 'Are you concerned by the fact that data on your health could be shared over the network?' Answers were analysed by two independent researchers using the software NVivo-V1.3.

Results

Participants' profile

As shown in Table 1, the mean age of the participants was 78. Women formed the majority. Approximately one-quarter was married. Most seniors lived in their own homes and were retired. As could be expected, since participants were frail seniors, the large majority of them considered their health to be poor or only acceptable.

Participants' views

Results from the closed questions

As presented in Table 2, the results show that a majority of seniors were in agreement with the statement that they felt free to consent to the use of the EHR. The majority considered themselves fairly well informed. Nonetheless, 40% stated either they did not

remember being informed that they could withdraw consent at any time, or that they did not know.

The majority of seniors stated that they were not invited to look at the screen or at their EHR contents but for those who said they were, they said they had not much interest in looking at or consulting the EHR.

Results from the open-ended questions

Information available and follow-up

The participating seniors felt that the information was quickly available and complete. They felt that the professionals possessed a great deal of data on their health and lifestyle. They stated: '*They know my whole life story!*'; '*It's all there.*' These expressions briefly summarise comments made concerning the information contained in the EHR. Seniors felt that the EHR gave professionals better information about their health and life situations in general. They consistently noted that the EHR appeared to make work easier for the healthcare workers. They said that information

Table 1: Participants' profiles

Characteristics	Men <i>n</i> =10	Women <i>n</i> =20	Total <i>n</i> =30
Age (mean)	78.0	78.2	78.1
Civil status	(%)	(%)	(%)
Single	10.0	13.3	23.3
Married	16.7	10.0	26.7
Divorced/Separated	3.3	10.0	23.3
Widowed	3.3	23.3	26.7
Education	(%)	(%)	(%)
Primary	26.7	43.3	70.0
Secondary	3.3	10.0	13.3
College/University	3.3	13.3	16.7
Living arrangements	(%)	(%)	(%)
Personal home	16.7	60.0	76.7
Family home	3.3	0.0	3.3
Private seniors' home	13.3	6.7	20.0
Work	(%)	(%)	(%)
At work	0.0	3.3	3.3
At home	0.0	33.3	33.3
Retired	33.3	30.3	63.3
Perceived quality of health	(%)	(%)	(%)
Excellent	0.0	3.3	3.3
Good	13.3	13.3	26.7
Poor	10.0	46.7	56.7
Bad	10.0	3.3	13.3

Table 2: Participants' views – quantitative section

Statements	Completely or partially disagree (%)	Completely or partially agree (%)	Don't know (%)
Consent			
1 When my permission was requested, I felt free to consent or refuse	0.0	100.0	0.0
2 I was well informed	5.6	88.8	5.6
3 Explanations were clear	11.1	84.3	5.6
4 I was informed I could withdraw my consent at any time	27.8	61.8	11.1
5 I had sufficient time to decide	10.0	84.4	5.6
Information			
6 I knew what it was all about	11.1	83.3	5.6
7 I was informed I could access my file	38.9	38.9	22.2
8 I feel confident that only authorised persons will have access to my records	0.0	88.9	11.1
Practice			
9 I felt the professional had to stop talking to me when working in my file	53.4	43.3	3.3
10 I felt this file was a nuisance	93.3	6.7	0.0
11 I felt the professional was not listening to me when working with the file	96.7	0.0	3.3
12 I felt less satisfied because of the file	93.3	3.3	3.3
13 I don't like it when the professional uses the file when I'm there	100.0	0.0	0.0
General Questions			
	Yes (%)	No (%)	
14 Occasionally, do professionals use a computer during the home or office visit?	100.0	0.0	
15 When professionals used a computer during the home or office visit, were you interested to look at the screen?	41.4	58.6	
16 Were you invited to look at the screen?	17.3	82.7	
17 Did you look at the screen?	31.0	69.0	
18 Were you interested to know or see more?	33.3	66.7	
19 Were you offered to see more of the file?	6.9	93.1	
20 Did you read the information in your file?	15.4	84.6	

was exchanged more quickly between professionals and between healthcare facilities. They appreciated that the data were available, especially for those professionals directly involved in the health care or services they received. They expressed this as follows: *'Healthcare workers are better informed and more knowledgeable about what I might need.'*

Some of them felt that computerisation is unavoidable and that it would not have a negative impact on the quality of data. *'I felt important. I prefer the computer. We need to keep up with progress. I am pleased my record is computerised.'* Among those interviewed, some did mention that there might be fewer errors with an EHR. However, one or two respondents did

mention the possibility that errors could slip in during data collection: *'In my opinion, there are only advantages as long as the data is not lost.'*

Finally, some individuals pointed out that their follow-up care seemed more systematic. They seemed to have an impression of professionalism and effectiveness from the use of modern tools. They said: *'They know what they are doing ... They have all the information ... Everything is there.'* These statements illustrate and summarise the comments made about the information contained in the EHR.

Timeliness and accessibility

Other comments were made regarding the fact that the information is quickly available and that this saves time. An overall impression of effectiveness is the result for many: *'The healthcare workers know what they are doing.'* The participating seniors believed that the EHR reduced the risk of error and ensured better co-ordination during follow-up. Some explained that using this technology gave the impression of being clear, correct and effective. However, they did often emphasise that this technology is mainly a tool for the professionals. They had difficulty in saying what advantages it might have for them. They stated that they were not the best to judge the issue, noting: *'I do not know the advantages, but I am sure there are many.'* Some of the elderly mentioned the fact that they were not obliged to repeat themselves thanks to the EHR. Others, however, did not find that there was less repetition. Seniors perceived that it might be more rapid and effective, and generally emphasised that they did not see any change or any reason not to use the computerised system. However, they had a general impression of effectiveness, accuracy and better communication and co-operation among healthcare workers. For the seniors, this aspect was seen both as reassuring and encouraging since they felt that healthcare workers were using the best tools available to provide care.

Confidentiality and security

Seniors felt that their data were safe in an EHR: *'I have a computer myself and I know how it works. You need a password to do anything. So I am not concerned if someone attempts to break in.'* *'I am sure the records are well protected at the facility [sic].'* Several mentioned: *'I can trust the professionals.'*

Among those interviewed, some specified that they felt safe with all the measures taken to ensure the security of personal information. Some did express concern over possible errors and some with confidentiality: *'Well, I believe that some individuals with bad intentions could look at my record but that is not really disturbing since there is nothing in it that is revealing.'*

'I am fairly confident, there are nosy people everywhere.'

Convergence between the sources of information

It can be concluded that the results from the closed questions converge with the open ones. Both demonstrate that seniors were relatively favourable towards the EHR. They saw no major disadvantage to its use. They felt that the data contained in an EHR was useful and accessible more quickly to the professionals who were caring for them or providing services. The question of consent was less clear. The responses obtained to questions dealing with access to the records and the right to withdraw consent revealed in fact that this information, while apparently presented and stated in the documents given to the individuals, escaped many. Some seniors felt that when they accepted services they accepted as a matter of course that their information would be made available. Most of them felt that their consent to health care and the fact that information circulates electronically could be revoked at any time, but for a large proportion, consent procedure was still unclear. They nevertheless had confidence in the professionals who were involved in their health care and services.

Discussion

The central concept explored in this study was the impact on the individual caused by an innovation such as the EHR. More specifically, the intent was to determine how the seniors who had already used it viewed this new type of information system. Positive comments made by the seniors fall into three categories: (1) being better informed; (2) trust in professionals; and (3) appreciation of innovation.

Being better informed

The majority of seniors stated that the EHR improved the quality of the information. They felt that all the information was available and, as a result, the health care and services they received would be increasingly appropriate. Some individuals said that they did not remember that they had access to the contents of their record or that they could withdraw consent if they so wanted. Even when this information appears in writing in the documents given to the individuals, it would be advisable to review the format and the content of information exchanged between healthcare workers and the individual patients when consent is

initially obtained or when it is renewed. Very few expressed concern to the effect that the information would not remain confidential. Available literature also finds that individuals using an EHR have little concern for confidentiality and accept that their data are made available on the condition that their physician gives consent and that adequate security is ensured.^{21,22,29-31} This illustrates the importance of providing more information to seniors and their families regarding their rights and the measures taken to ensure the confidentiality of the information.

Trust for professionals

It is very apparent that seniors place their confidence in the professionals providing their health care and services. The EHR seems to have made this confidence explicit in a context where seniors might have a limited view of the technology. This dimension is less explicit in the literature.^{17,18,40} The results of this study are therefore innovative in this regard. Nonetheless there is a need to develop a true partnership with seniors so that the model, which supports clinical practice, also includes empowerment and the development of self-care management.

Appreciation of innovation

This impact was rather unexpected since current literature does not mention it. On the contrary, several studies have observed that the older the individual (including healthcare workers), the more resistant they were to innovation.⁴¹⁻⁴³ This finding strengthens interest in other studies involving frail seniors and their families regarding the perception of and the integration of technological innovation.

Limitations

This study does have certain limitations. It was conducted as part of a research programme that examined several aspects of professional practice within a network of integrated services. Participating seniors therefore knew that various types of innovation would be introduced into their care delivery system, and the EHR was one facet. It is possible that individuals who agreed to participate were more open than others to accepting innovation of various kinds. In this sense, they could have provided us with a more optimistic view than anticipated. The specific social and geographic foundations of this study might mean that its potential for generalisation is relatively limited. Nevertheless, many of the results observed do agree with available literature and reinforce evidence that

the EHR is deemed acceptable, although it must be used in a transparent manner and in a way that empowers individuals to remain vigilant and well informed.

Conclusion

The goal of this study was to understand how seniors perceive the EHR in terms of consent and confidentiality and what they see as the advantages that its use offers. It is important to remember that the EHR in this study was implemented to meet new requirements for data exchange generated by the initial network of integrated services for frail seniors. Nowhere else in Quebec is there an EHR simultaneously linking so many professionals, services, levels of care and types of facilities. The professionals were faced with the dual challenge of mastering the implementation of an integrated services network with the new methods it involved, while at the same time learning computer skills as well as EHR content and techniques.

For seniors, this innovation was perceived as quite positive. Overall, their comments were favourable concerning use of the EHR as well as concerning the use of a computer in their presence. Seniors in the Mauricie and Centre-du-Québec region feel that their health information circulates faster between professionals and health facilities. Continuous improvement of EHR for seniors should therefore be encouraged.

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CONFLICTS OF INTEREST

None.

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