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Original Paper

Word Frequency and Content Analysis Approach to Identify Demand Patterns in a Virtual Community of Carriers of Hepatitis C

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Abstract

Background: Orkut, a Brazilian virtual social network, is responsible for popularization of the Internet among people of low income and educational level. It's observed that rapid growth of virtual communities can be reached by low cost Internet access in community local area network houses. Orkut poses an important social resource for Brazilian patients with chronic conditions like hepatitis C virus (HCV) carriers, who face several obstacles in adapting to everyday difficulties.

Objective: Identify Patterns of Recurring Demands (PRD) expressed in messages posted by members of virtual communities dedicated to HCV carriers.

Methods: Pre-selection: we identified terms commonly associated to HCV on generic Internet searches (primary Keywords - Kps); Kps were used to identify the most representative HCV communities in a virtual community site (Orkut); all messages published along 8 years on all topics of the community were collected and tabulated; the word frequency was used to construct a "word cloud" (graphic representation of the word frequency) on which was applied a content analysis technique.

Results: The most cited terms expressed: search for information about medications (prescribed and "forbidden"); emphasis on counting time, which were interpreted as surviving expectations; frequent mention of God, doctors, and "husbands" (female carriers were 68%). These elements provided material for further research – they will be useful in the construction of categories in discourse analysis.

Conclusions: The present work is a disclosure of preliminary findings considered original and promising. The word frequency/content analysis approach expressed needs of social support and material assistance that may provide subsidies for further qualitative approach and public health policies aimed to HCV carriers. The study of PRD by word frequency may be useful in identifying demands underestimated by other means.

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KEYWORDS

Internet; online communities; hepatitis C virus carrier; social support; qualitative research; content analysis; social behavior

Introduction

Psychological complications and physical symptoms arising from hepatitis C are well-known and described as consequence and conditioning factor for recurrence [1]. Therefore, this combination of problems, treatment side effects, perspective of recurrence, and need for radical lifestyle changes, brings challenges to hepatitis C virus (HCV) carriers. It would be impossible to tolerate such obstacles for a long time without the social support from spouses, relatives, friends, and other HCV carriers. It is believed that the support coming from specialized virtual communities (VCs) represents an important resource for HCV patients who encounter obstacles in adapting to everyday difficulties. The Internet offers several tools for organization of virtual networks of chronic patients, which are here presented as an object of study.

The purpose of the present research note is to identify patterns of recurring demands (PRD) posted by members of VCs organized by Brazilian HCV carriers. These preliminary results raised promising hypothesis that will be used by qualitative research experts. A broader "discourse analysis" will be organized based on VC postings and focus groups with HCV carriers in assistance environments.

Methods

Methodology can be summarized as an incremental Internet search in decreasing dimensions of coverage, as described in detail by Carvalho et al [2]. We employed open access algorithms (Google insights) to identify the most common terms associated to HCV in general searches—referred here as primary Keywords (Kps) as expressions of casual and indistinct interest. Orkut was chosen because of its long existence (established in January 2004) and its popularity in Brazil. In Orkut, thematic discussions are organized into “topics” in which messages are posted. The site also has special features for searching in which Kps were applied to disclose “specialized” (carriers) VCs. The VCs that mentioned any of the Kps at least once were selected. We assessed the "relevance weight" among Orkut HCV communities by choosing the ones in which Kps were more frequent. Associations of Kps applied among the most popular and active VCs can neutralize bias caused by arbitrary choices in the pre-selection process. This criteria is based on other algorithms like “page rank” [3], which estimates the relevance of a site using the number of highest expression links directed to it. From this set of VCs, the most representative were chosen by its time of existence, number of members, and mainly by the Kps frequency in discussions. This Dominant Community was considered for study. The relationship of the Dominant Community with its peers was studied through the Community Association Map (CAM, Figure 1), which defines the interrelationships between communities [4] to portray and confirm their dominance around a core of common interests. We developed scripts to collect and tabulate all messages published on all topics over eight years of the community’s existence. A “word cloud” (in which word’s size is proportional to it’s frequency) was generated in wordle to provide a graphic representation of the word frequency (Figure 2).

Figure 1. The Community Association Map (CAM) shows interrelationship between communities of users with the Dominant Community and confirm their dominance around a core of common interests.

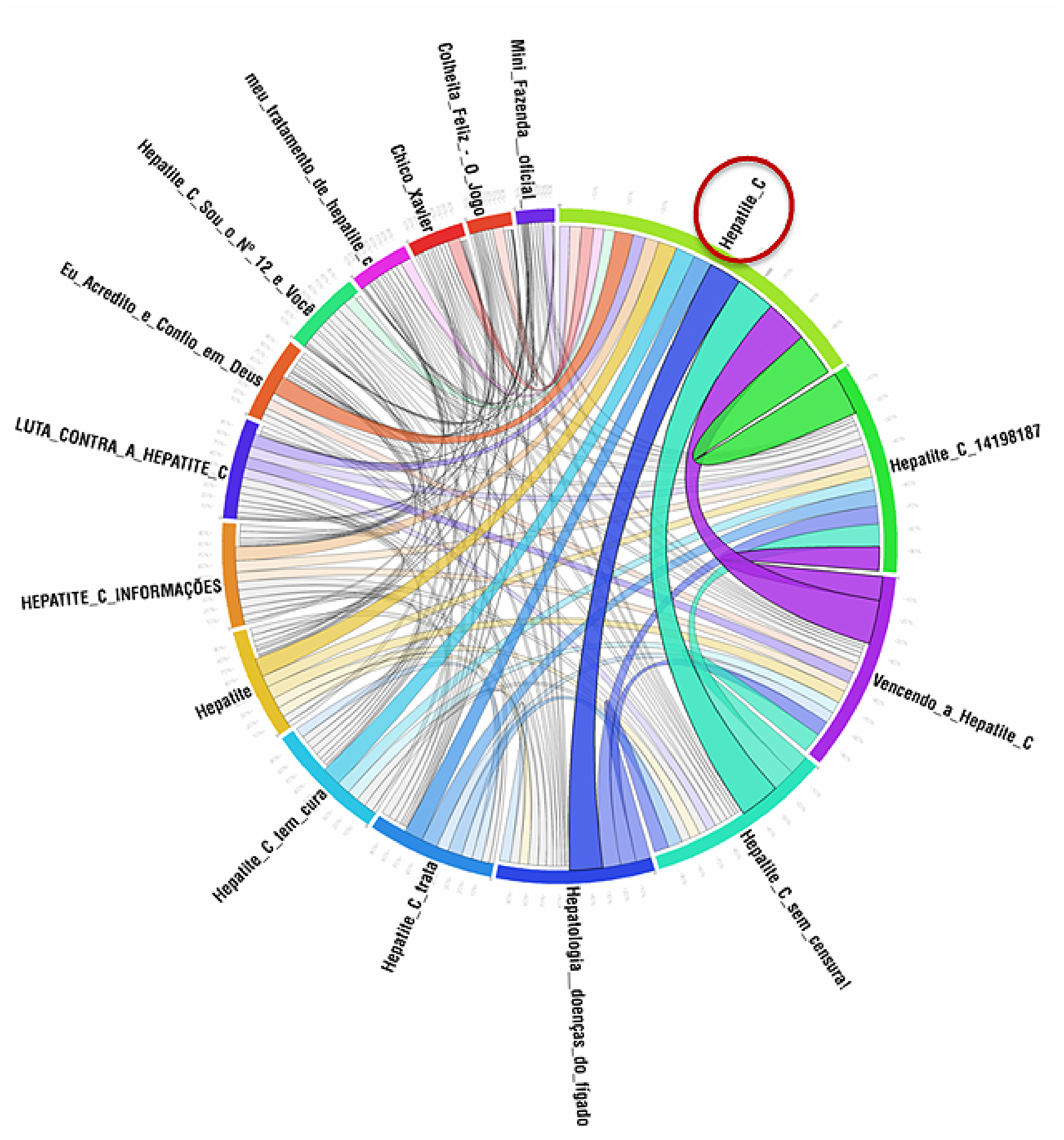


Figure 2. Word cloud of the Dominant Community forum.

Results

Hepatitis C

The main *Kps* associated with “*Hepatite C*” found on Google were (in Portuguese): *consulta hepatite c; cura hepatite c; exame hepatite c; hepatite c cronica; hcv; medicamento hepatite c; medico hepatite c; prevencao hepatite c; remedio hepatite c; sintomas hepatite c; transmissao hepatite c; tratamento hepatite c; vacina hepatite c; virus hepatite c*. The search using these *Kps* in Orkut resulted in 1476 communities. The highest occurrences of *Kps* were found in: *Hepatite C* = 588 topics, *HIV - BR* = 208; *hepatite C* = 183; *Hepatologia: doenças do fígado* (Hepatology: liver disease) = 107; *hepatite c informações* = 129. In these communities, 20,000 messages were posted by 9066 members (may be overestimated - users might belong to multiple communities).

“Hepatite C” (ID 216788 on Orkut) was considered the *Dominant Community* because it gathered the largest volume of public content. It was created by a HCV carrier a few months after the Orkut’s launch. It is not associated to any commercial or government institution, and in 2453 days, it gathered 1292 members—68% women and 32% men.

Content of Messages Posted on “Hepatite C”

The message volume in the Dominant Community remained low until the first quarter of 2009, thereafter the number of messages increased significantly, as shown in Figure 3, which matches with the popularization of the site in Brazil [5]. Of the total 47,005 terms found on all topics in 8 years of available content, the most recurring words in frequency analysis (discarding articles, prepositions, and numerals) are presented in Table 1, which also presents a subset of other prominent words (that refers to HCV therapy and potentially toxic drugs to carriers). From the most cited drugs, *interferon* and *ribavirin* shared six of the eight stronger relationships between drugs cited in the same message. These findings suggest a demand by the strong association between ribavirin and interferon—its continuing use is a frequent problem to patients of Brazilian healthcare system [6]. The three types of information that are most frequently found with this association are *preço* (price), *bula* (medication user instructions), and *efeitos colaterais* (side effects).

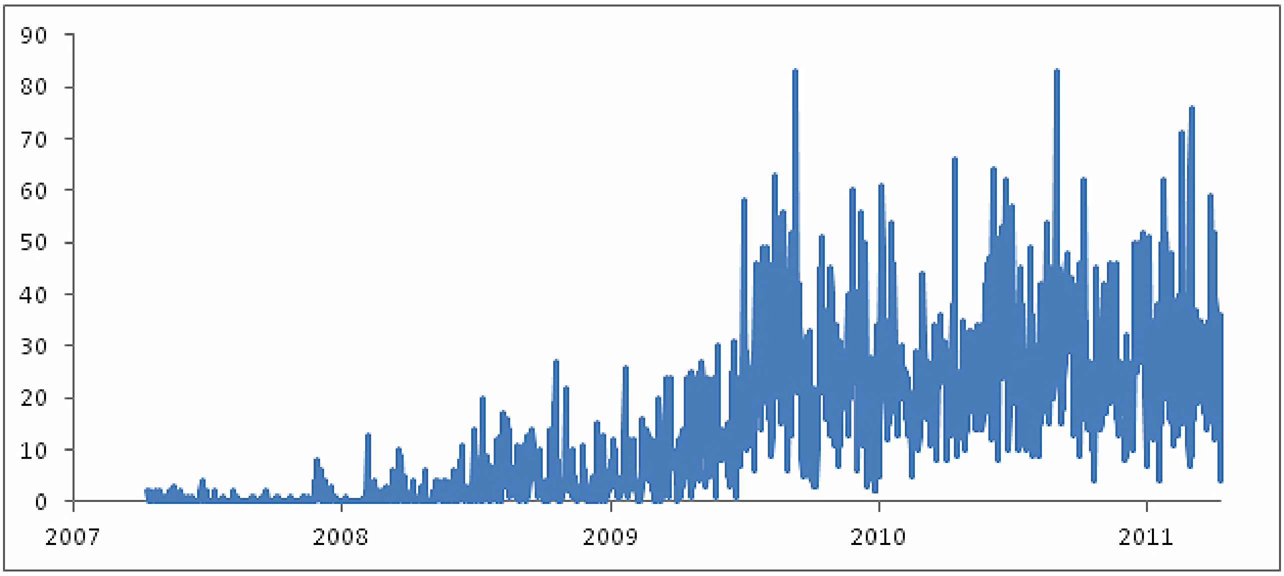
Table 1. Subset of prominent words from the *Dominant Community* forum (translated to English).

Words	Citations
Most recurring words in frequency analysis	
Treatment	9581
God	4077
Hepatitis	3329
Physician	2800
Virus	2674
Interferon	2281
Husband	971
Well	3411
Do	2822
Ribavirin	1288
Patients	1279
Recurrent words related to the passage of time	
Day	3156
Always	2852
Week	2285
Then	2170
Years	1771
Months	1454
During	1199
Therapies for the control of HCV [a]	
Interferon	1554
Ribavirin	1048
Erythropoietin	317
PEGASYS	201
Folic acid	157
PEGINTRON	130
Filgrastim	109
Silymarin (alternative treatment)	63
Potentially toxic drugs to CHCV [b]	
TYLENOL	121
Omeprazole	80

[a] HCV=hepatitis C virus

[b] CHCV=chronic hepatitis C virus

Figure 3. Historical evolution of messages per day posted at the Dominant Community forum.



Discussion

Principal Findings

The PRD on the Internet are presented here as a low cost method easily applicable for guiding qualitative researchers on data collection. Hypotheses, linking concepts, and “bounding ideas” are essential for the portrayal of social support and can be easily weakened by bias and personal assumptions - which can be preventable by the PRD analysis. The HCV carriers are vulnerable to several psychological conditions and depressive symptoms that are usually identified and reported among them [7,8]. The Identification of PRD in communities with chronic diseases may expand our comprehension about their needs for social networks, presenting demands perhaps underestimated by public health policy makers. It’s interesting to notice that the results presented here support other conclusions recently reached by other methods. Sousa [6] describes carriers expressing their suffering strongly attached to expectations of obtaining medicines and healing in the context of the passage of the weeks, months, and years of survival. The elements described herein provide a basis for further, more detailed, research, in which the PRD are consolidated into central ideas for the construction of analysis categories. The primary purpose of the paper was to furnish unbiased material to a qualitative approach, which could reach findings applicable beyond the immediate boundaries of the study. According to qualitative research literature [9,10], it’s especially effective in cultural research, which deals with values, opinions, and perspectives that can be generalized in a broader view.

Another interesting aspect concerning the method refers to the study of VC through algorithms, a field underused so far despite several remarkable alternatives. In addition to reduced costs compared to conventional field research, there is an opportunity to capture discourses posted in moments of desperate need for support. Here, Internet VCs seem to transcend their merely informative context [11], and acquire a unifying force aimed at overcoming great obstacles [12]. Besides posting messages on topics for mutual enlightenment and social support, maybe HCV carriers feel more comfortable talking about personal difficulties and living conditions when compared to conventional medical consultation enviroment. In general, stigmatized diseases or health conditions encourage individuals to use Internet as a main source of information and environment for sharing experiences [12-14]. Such preferences are not limited to the possibility of hiding identities in the face of uncomfortable topics, but also include the VC role of social support. Pattern analysis identified frequent use of words that suggest a need for spiritual support (God: 4077 citations) and social support (husband, 971). Words indicating the need for material support/care were extensively mentioned: *treatment* (9581), *doctor* (2800), and *interferon* (2281), and the association between *Interferon* and *Ribavirin* (also described by Sousa [6]). These results reinforce evidence that patients with chronic diseases have a distinct profile of engagement in virtual communities. We found agile dissemination of certain content and thematic consistency associated with interest in news about innovative therapies (new formulations of interferon; alternative therapies).

Conclusion

The present work is a disclosure of preliminary findings considered original and promising. The word frequency / content analysis approach expressed needs of social support and material assistance that may provide subsidies for further qualitative approach and public health policies aimed to HCV carriers.

Research on PRD requires small resources in its development in contrast with important outcomes in terms of depiction of demands from patients with chronic diseases underestimated by other perspectives. The word frequency and content analysis can furnish hypotheses, linking concepts, and “bounding ideas,” which are essential for the portrayal of collective ideas and social support demands. The present findings describe some evidence of need for social and material support that may subside public policies aimed at carriers of HCV.

Acknowledgments

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Conflicts of Interest

None declared.

References

1. Carta MG, Angst J, Moro MF, Mura G, Hardoy MC, Balestrieri C, et al. Association of chronic hepatitis C with recurrent brief depression. J Affect Disord 2012 Dec 10;141(2-3):361-366. [doi: 10.1016/j.jad.2012.03.020] [Medline: 22609196]
2. Carvalho D, Madeira W, Okamura M, Lucena C, Zanetta S. A practical approach to exploit public data available on the Internet to study healthcare issues. 2012 Presented at: the XXXII Congress of the Brazilian Computer Society, XII Workshop on Medical Informatics; 2012; Curitiba, PR, Brazil.
3. Brin S, Page L. The anatomy of a large-scale hypertextual web search engine. Comput. Netw and ISDN Systems 1998;33:107-117.
4. Carvalho DBF, Fuks H, Lucena CJP. Community Association Map: Processing Inter-Community Relationships. In: WEBIST 2012 - Proceedings of the 8th International Conference on Web Information Systems and Technologies. Porto, Portugal: SciTePress; 2012 18-21 Presented at: 8th International Conference on Web Information Systems and Technologies; 2012/2/18; Porto, Portugal p. 665-670.
5. Araújo LLP, Rios R. The popularization of the Social Network Sites and the Okutinization Phenomenon. 2012 Jun 14 Presented at: XIV Congresso de Ciências da Comunicação na Região Nordeste; 14/6/2012; Recife URL: http://www.intercom.org.br/papers/regionais/nordeste2012/resumos/R32-0590-1.pdf>
6. Sousa VV, Cruvinel KPS. Being a hepatitis C carrier: feelings and expectative. Texto contexto - enferm 2008;17(4):689-695.
7. Litwin H. Physical activity, social network type, and depressive symptoms in late life: An analysis of data from the National Social Life, Health and Aging Project. Aging Ment Health 2012;16(5):608-616 [FREE Full text] [doi: 10.1080/13607863.2011.644264] [Medline: 22296412]
8. Shiovitz-Ezra S, Litwin H. Social network type and health-related behaviors: Evidence from an American national survey. Soc Sci Med 2012 Sep;75(5):901-904. [doi: 10.1016/j.socscimed.2012.04.031] [Medline: 22682660]
9. Jankowski NW. Qualitative research community media. In: Jensen K, editor. A Handbook of Qualitative Methodologies for mass communication research. London, New York: Routledge; 1991:163-174.
10. Jupp V. The SAGE Dictionary of Social Research methods. London: SAGE; 2006:32-33.
11. Fernandez-Luque L, Karlsen R, Bonander J. Review of Extracting Information from the Social Web for Health Personalization. J Med Internet Res 2011;13(1):e15.
12. Greene JA, Choudhry NK, Kilabuk E, Shrank WH. Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. J Gen Intern Med 2011 Mar;26(3):287-292 [FREE Full text] [doi: 10.1007/s11606-010-1526-3] [Medline: 20945113]
13. Berger M, Wagner TH, Baker LC. Internet use and stigmatized illness. Soc Sci Med 2005;61(8):1821-1827.
14. Setoyama Y, Yamazaki Y, Namayama K. Benefits of peer support in online Japanese breast cancer communities: differences between lurkers and posters. J Med Internet Res 2011;13(4):e122 [FREE Full text] [doi: 10.2196/jmir.1696] [Medline: 22204869]

Abbreviations

CAM: Community Association Map
HCV: hepatitis C virus
Kps: primary keywords
PRD: patterns of recurring demands
VC: virtual community

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Original Paper

Scalable Decision Support at the Point of Care: A Substitutable Electronic Health Record App for Monitoring Medication Adherence

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Abstract

Background: Non-adherence to prescribed medications is a serious health problem in the United States, costing an estimated $100 billion per year. While poor adherence should be addressable with point of care health information technology, integrating new solutions with existing electronic health records (EHR) systems require customization within each organization, which is difficult because of the monolithic software design of most EHR products.

Objective: The objective of this study was to create a published algorithm for predicting medication adherence problems easily accessible at the point of care through a Web application that runs on the Substitutable Medical Apps, Reusuable Technologies (SMART) platform. The SMART platform is an emerging framework that enables EHR systems to behave as “iPhone like platforms” by exhibiting an application programming interface for easy addition and deletion of third party apps. The app is presented as a point of care solution to monitoring medication adherence as well as a sufficiently general, modular application that may serve as an example and template for other SMART apps.

Methods: The widely used, open source Django framework was used together with the SMART platform to create the interoperable components of this app. Django uses Python as its core programming language. This allows statistical and mathematical modules to be created from a large array of Python numerical libraries and assembled together with the core app to create flexible and sophisticated EHR functionality. Algorithms that predict individual adherence are derived from a retrospective study of dispensed medication claims from a large private insurance plan. Patients’ prescription fill information is accessed through the SMART framework and the embedded algorithms compute adherence information, including predicted adherence one year after the first prescription fill. Open source graphing software is used to display patient medication information and the results of statistical prediction of future adherence on a clinician-facing Web interface.

Results: The user interface allows the physician to quickly review all medications in a patient record for potential non-adherence problems. A gap-check and current medication possession ratio (MPR) threshold test are applied to all medications in the record to test for current non-adherence. Predictions of 1-year non-adherence are made for certain drug classes for which external data was available. Information is presented graphically to indicate present non-adherence, or predicted non-adherence at one year, based on early prescription fulfillment patterns. The MPR Monitor app is installed in the SMART reference container as the “MPR Monitor”, where it is publically available for use and testing. MPR is an acronym for Medication Possession Ratio, a commonly used measure of adherence to a prescribed medication regime. This app may be used as an example for creating additional functionality by replacing statistical and display algorithms with new code in a cycle of rapid prototyping and implementation or as a framework for a new SMART app.

Conclusions: The MPR Monitor app is a useful pilot project for monitoring medication adherence. It also provides an example that integrates several open source software components, including the Python-based Django Web framework and python-based graphics, to build a SMART app that allows complex decision support methods to be encapsulated to enhance EHR functionality.

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KEYWORDS

electronic health record; personal electronic health record; hospital information systems; medical informatics applications; accountable care organizations; medication adherence

Introduction

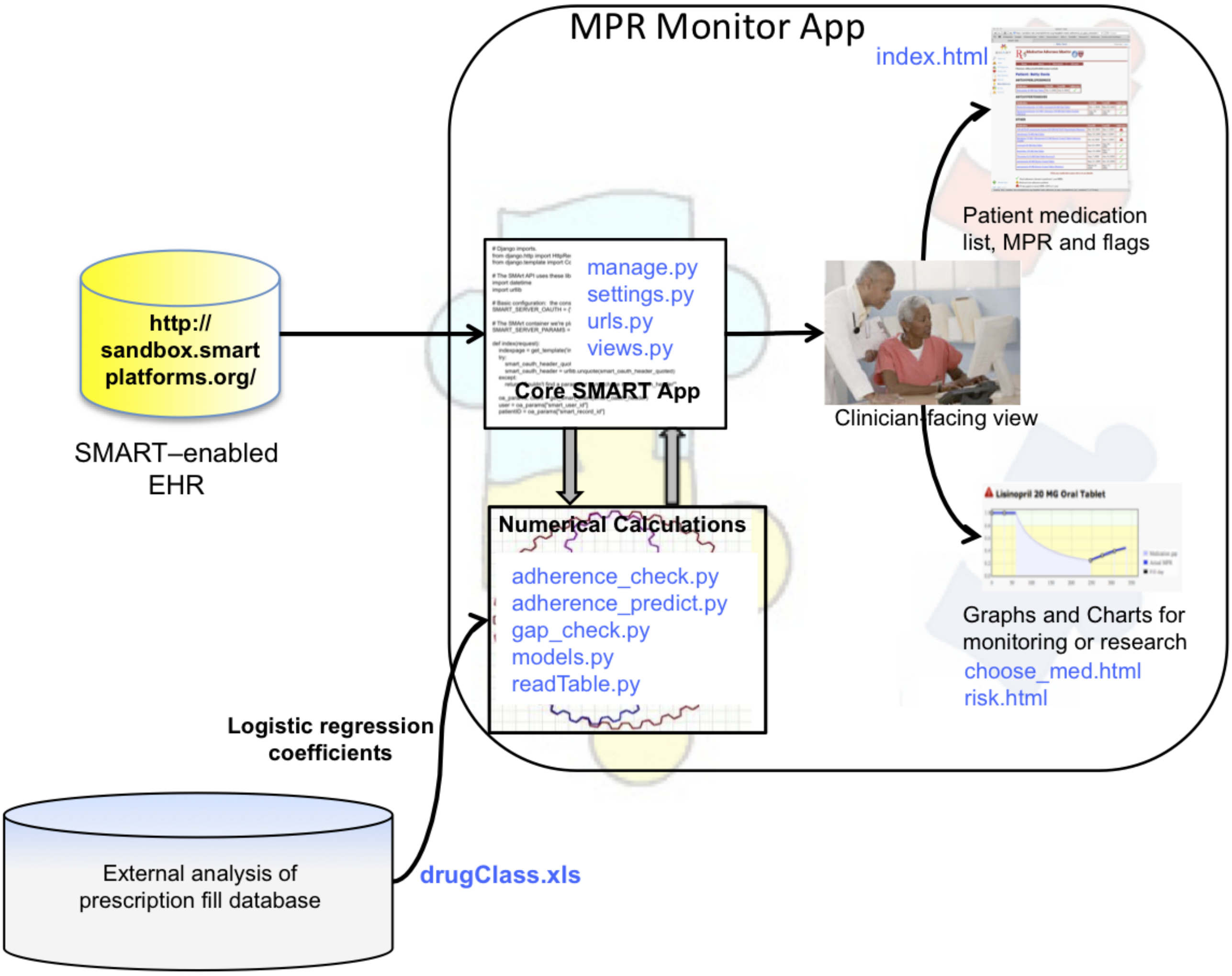
Non-adherence to prescribed medications is a serious health problem costing an estimated $100 billion per year in the United States [1]. Despite considerable research on poor medication adherence based on retrospective electronic health records (EHR) data analyses, there are few real-world implementations of systems that provide adherence related feedback to clinicians at the point of care [2]. While poor adherence should be addressable with point of care health information technology (IT), integrating new solutions with existing EHR systems require buy-in and customization within each organization. Such integration is made more difficult by the monolithic software design of the majority of EHR products [3].

The software application described in this paper was designed to operate within the Substitutable Medical Apps, Reusable Technology (SMART) framework. SMART [4] is funded by The Office of the National Coordinator for Health Information Technology through the Strategic Health IT Advanced Research Projects (SHARP) program. The goal of the SMART project is to specify an application programming interface to enable use of substitutable applications on EHRs—essentially reimagining EHRs as smartphone-like platforms that run apps [4-6].

The SMART Medication Possession Ratio (MPR) Monitor app implements a recently published medication adherence prediction algorithm [7], which can help identify poor adherers early. The app presents an interface to a physician with information about individual patients. It was designed to access patient prescription fulfillment information from a SMART-enabled EHR, which is currently represented by the SMART reference EHR [8]. Patient data obtained from the EHR is used as input to an adherence prescription algorithm to determine whether a patient is likely to be non-adherent after one year, based on data obtained within the first 60 to 120 days following the first prescription fill. The algorithm used to predict the likelihood of future adherence was derived independently of the MPR Monitor app by statistical modeling with data from a large national insurance prescription fulfillment dataset. In addition to one-year non-adherence predictions, other clinically useful data is computed and displayed. This includes a gap-check algorithm that determines if gaps greater than 30 days have occurred at any time during the prescription for each medication. The organization of the app is illustrated in Figure 1. The figure shows file names from the application code in blue letters in the figure to illustrate the modularity and also as a visual guide for those who would use this as an example for writing a SMART app. The files in the “Core SMART App” box are standard required files for any Django application. SMART-specific code is embedded in these. Codes for numerical simulation are pure python calculations and have no references to SMART or Django. The graphical displays are html and JavaScript, as needed by standard Django programs.

The goal of the MPR Monitor app is to present information to an authorized clinician in a graphical form that can be quickly reviewed to determine if additional action is required. The modular design of this app will allow alternate or additional computations with the prescription data that is obtained by the core app from the EHR, incorporation of new coefficients into the app when external data allows, or addition of new visual components to the physician view. In this way, the MPR Monitor can evolve in functionality with no changes to the EHR programming interface. Our implementation demonstrates an approach to building an application that delivers clinical decision support at the point of care using EHR data. The software design decisions discussed herein are intended to serve as an example and template for other applications that run on top of a SMART-enabled EHR.

Figure 1. The SMART platform allows data to be accessed from any SMART-enabled electronic health record. The modular design illustrated here shows components in the MPR Monitor app. Each of the components attached to the core app may be modified without affecting the others. Additional components, such as new displays, may be added independently of the others. Actual file names from the application code are shown in blue letters in the figure.



Methods

Software Application Development

Several design decisions were made. Some are common to all Web application design, others specific to the SMART Application Program Interface (API). SMART Apps using the SMART API can be embedded within any SMART-enabled system, which is often an EHR system used by physicians, but might also be a personal health record used by patients, or a data-analytics platform such as [9] used by researchers. Patient data used for adherence monitoring must be marshaled by the SMART container, often an EHR, and exposed by a SMART API.

The SMART framework allows considerable flexibility for choosing programming language, frameworks, and support packages. A SMART app can access the SMART API using either simple Javascript calls from a client library or using standard OAuth authentication and REST (REpresentational State Transfer), a style of software architecture for distributed systems such as the World Wide Web) calls to a SMART container. Both of these approaches can be used to get at the same underlying data. The latter approach is appropriate for applications that may need to perform significant computational processing, such as when using additional external data sources as the MPR Monitor app does.

A SMART REST app may be written in any language with existing OAuth libraries. One such widely used language is Python. Since Python is a general purpose programming language with well-developed libraries for many data analysis tasks, including statistics, analytics, and graphical display, it was a versatile choice for building the MPR Monitor app. A commonly used Python framework for Web application development is Django. Although the server-side processing performed by the MPR Monitor app is relatively simple, we wanted to develop the application within a general framework like Django so that it may serve as an example for more complex app development.

The Django Web framework [10] uses Python as its core programming language. Other python-based Web frameworks exist, but Django is one of the most widely used in commercial applications and is capable of handling complex Web interface demands. We chose Django for the MPR Monitor because it will enable great flexibility for adding future functionality. It also enables the MPR Monitor app to be used by others as a general-purpose template for creating a wide range of new SMART apps.

Because the Django is written in Python, mathematical and statistical modules written with powerful Python libraries, as illustrated by the "embedded MPR calculation" box in Figure 1, are easily integrated into the framework. Statistical algorithms can be written entirely in Python code, which can also easily wrap code written in other languages such as R and C++. In this way, analytics can be embedded directly into the app to create flexible and sophisticated EHR functionality.

We emphasize that this medication adherence app is intended to be a useful tool monitoring medication adherence that can evolve over time, while providing a general example for app developers, particularly clinical researchers who confront real-world health IT challenges and may wish to quickly assemble apps for testing new ideas. The components made for monitoring non-adherence risk discussed below can easily be modified and assembled into new apps.

Non-Adherence Checks

The MPR Monitor implements three different non-adherence checks. Two of these, the 30-day gap check and the actual MPR < 0.8 check, are indications of a current adherence problem. These two algorithms run on all prescription drugs in the medical record, regardless of drug class. Any medication found to be currently non-adherent is flagged using a bright red warning triangle. A third check uses a logistic regression model to predict non-adherence at one year, based on prescription fill information at 60, 90, or 120 days following the first fill. The goal of the prediction is to detect a potential non-adherence problem and alert the clinician before non-adherence becomes an actuality. The logistic regression is run on all medications that pass the 30-day gap detection test, but only for medications in the three drug classes for which regression models are currently available, which include antihyperlipidemics, antihypertensives, and oral hypoglycemics. A medication for which the patient is non-adherent is flagged with a yellow warning triangle.

Algorithm Implementation

The origins of the MPR Monitor began with an approach to medication adherence that was based on monitoring prescription-filling behavior [11,12]. Although this approach was an indirect measure of adherence to a prescribed medication regime, patients who do not fill a prescription are unlikely to be taking the medication as prescribed. Thus, fulfillment histories provide a practical approach to detecting non-adherence. In a retrospective study of dispensed medications from a large private insurance plan, Jonikas and Mandl, analyzed over 8.5 million prescriptions and described an approach that predicted adherence problems one year from the first fulfillment by analyzing the initial 2 to 4 months of fulfillment data [7]. The primary variable predicted was the medication possession ratio (MPR), a measure of the number of days a patient possessed a prescribed medication (based on prescription fulfillment history) divided by the number of days since the first prescription fill:

MPR = (Number of fills * daily doses per fill) / (total days since first fill)

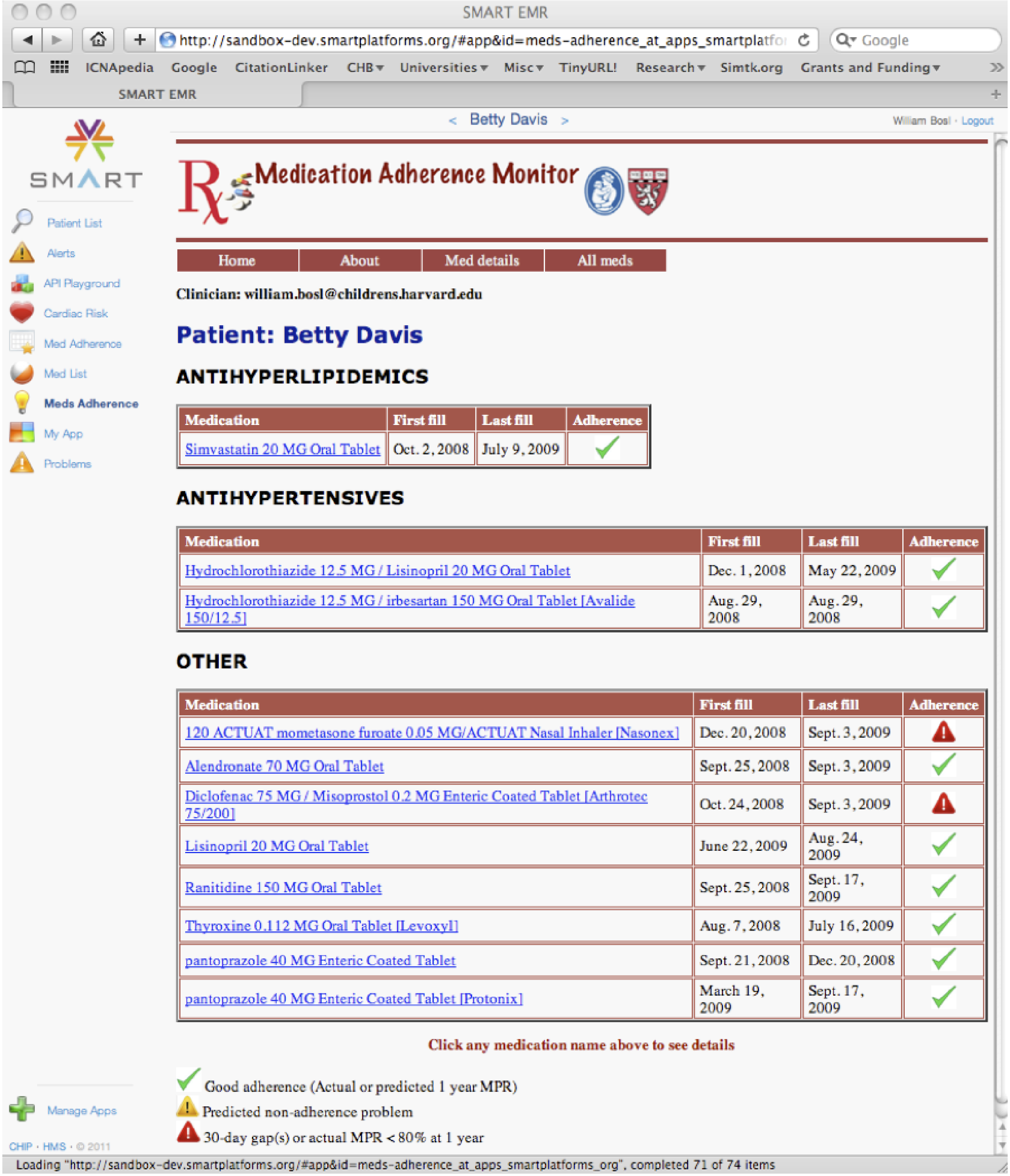
Two tests were implemented for early identification of patients at risk for non-adherence. The first was a straightforward 30-day gap check used on every medication in the patient's record. The gap check subtracts the number of daily medication doses from the elapsed time since the first fulfillment. If the gap is greater than 30 days, an alert is triggered. We consider this a more serious issue, since non-adherence is already detected and use a red warning symbol to visually alert the clinician. An example of the red warning triangle can be seen in Figures 2 and 3.

A second test for non-adherence uses a logistic regression model with two independent input variables, the patient's age and the MPR value at the time of the prediction, to predict a binary outcome, acceptable or poor adherence, one year after the first fulfillment. The logistic regression parameters were determined separately for three classes of drugs: antihyperlipidemics, antihypertensives, and oral hypoglycemics. These drug classes were selected because improved health outcomes for these chronic medications require consistent adherence over time [13-16]. Models to predict MPR value at one year from the first prescription fill were computed at 60, 90, and 120 days from the first fill for each of the three different drug classes. The model description and coefficients were published in the free-access paper [7], yielding publicly accessible, quantitative research results. The MPR app demonstrates a way to embed these results in a clinical decision support tool that may be interoperable with existing EHR systems. Since future *predicted* non-adherence might be considered less serious than actual non-adherence, a yellow warning triangle is used to visually signal this adherence problem, as illustrated in Figure 4.

The second drug in Figure 4, cyclobenzaprine hydrochloride, is typically used as a muscle relaxant to relieve acute skeletal muscle pain or injury. No predictive modeling was done for this class of medications, thus predicted non-adherence is not possible. Importantly, however, if the type of logistic regression coefficients derived for the three drug classes previously described [7] becomes available for this or any other drug classes, the coefficients can easily be added to an external text file that contains this information for the app, thus extending its capability. Because the SMART app was designed to be interoperable with any SMART-enabled EHR, such an extension will not affect or require any changes to the way the app operates with these databases.

The MPR can easily be computed at every time for which medication data for a patient is available and may be used in an additional test for non-adherence. A common indication of non-adherence is when the MPR is below 0.8. Thus for any prescription medication in the EHR, if the MPR is less than 0.8 at the latest time in the record, it is considered a non-adherence indication and is flagged with a red triangle. It is no longer a predicted, future non-adherence issue, but a present condition. A graphical display of the MPR values may be selected so that a clinician can visually see when low MPR values or gaps occur throughout the prescription history. This is illustrated in Figures 3 and 4.

Figure 2. The first page displayed to the clinician for a single patient lists all the currently prescribed medications, grouped by categories for which logistic predictions are currently possible in the internal model. These groupings may be useful to the clinician beyond their use in non-adherence prediction. Easily viewed symbols are used to flag actual or predicted adherence problems.



Clinician: william.bosl@childrens.harvard.edu

Patient: Betty Davis

ANTIHYPERLIPIDEMICS

Medication	First fill	Last fill	Adherence
Simvastatin 20 MG Oral Tablet	Oct. 2, 2008	July 9, 2009	✓

ANTIHYPERTENSIVES

Medication	First fill	Last fill	Adherence
Hydrochlorothiazide 12.5 MG / Lisinopril 20 MG Oral Tablet	Dec. 1, 2008	May 22, 2009	✓
Hydrochlorothiazide 12.5 MG / irbesartan 150 MG Oral Tablet [Avalide 150/12.5]	Aug. 29, 2008	Aug. 29, 2008	✓

OTHER

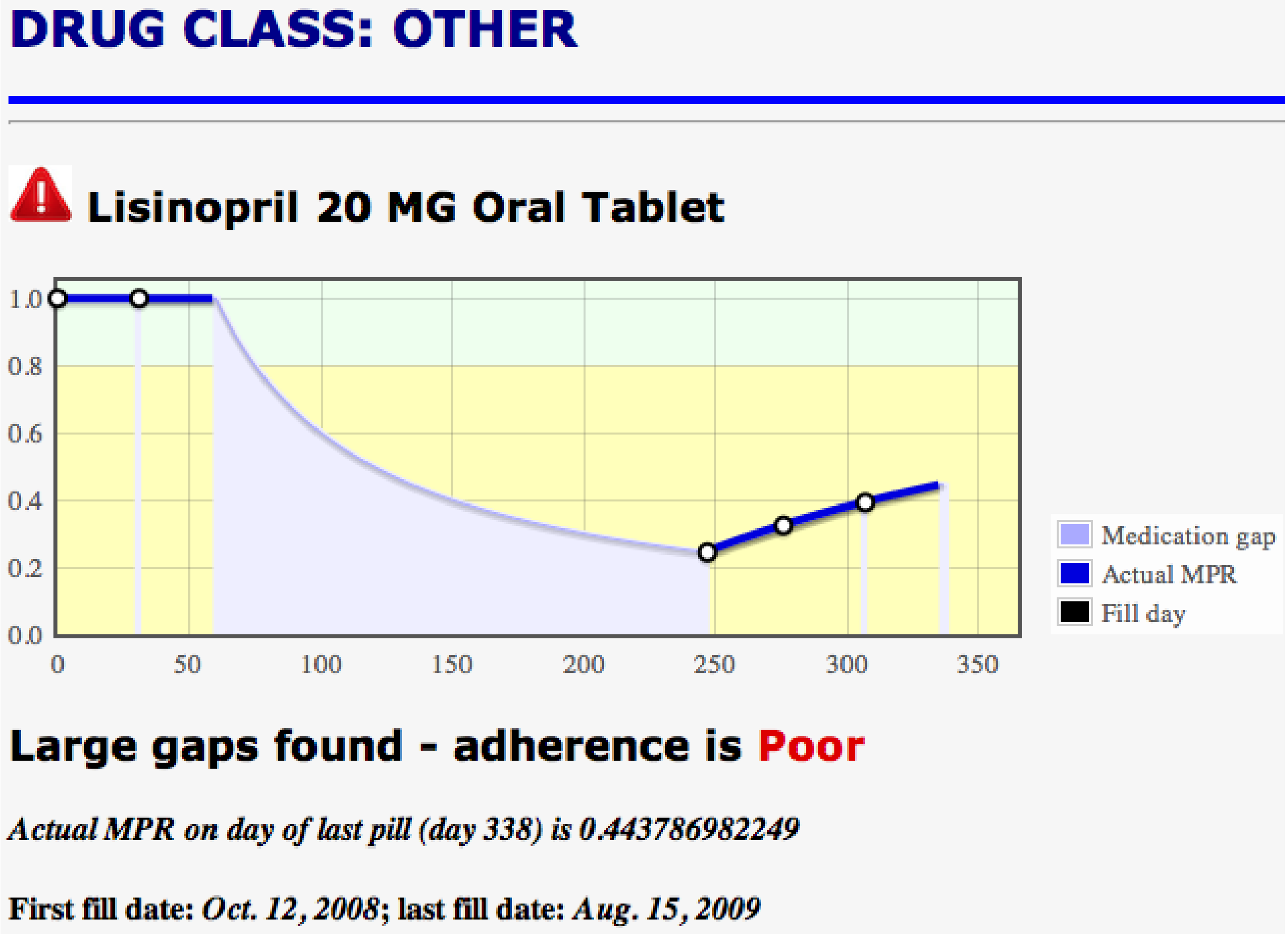
Medication	First fill	Last fill	Adherence
120 ACTUAT mometasone furoate 0.05 MG/ACTUAT Nasal Inhaler [Nasonex]	Dec. 20, 2008	Sept. 3, 2009	⚠
Alendronate 70 MG Oral Tablet	Sept. 25, 2008	Sept. 3, 2009	✓
Diclofenac 75 MG / Misoprostol 0.2 MG Enteric Coated Tablet [Arthrotec 75/200]	Oct. 24, 2008	Sept. 3, 2009	⚠
Lisinopril 20 MG Oral Tablet	June 22, 2009	Aug. 24, 2009	✓
Ranitidine 150 MG Oral Tablet	Sept. 25, 2008	Sept. 17, 2009	✓
Thyroxine 0.112 MG Oral Tablet [Levoxyl]	Aug. 7, 2008	July 16, 2009	✓
pantoprazole 40 MG Enteric Coated Tablet	Sept. 21, 2008	Dec. 20, 2008	✓
pantoprazole 40 MG Enteric Coated Tablet [Protonix]	March 19, 2009	Sept. 17, 2009	✓

Click any medication name above to see details

✓ Good adherence (Actual or predicted 1 year MPR)
⚠ Predicted non-adherence problem
⚠ 30-day gap(s) or actual MPR < 80% at 1 year

Loading "http://sandbox-dev.smartplatforms.org/#app&id=meds-adherence_at_apps_smartplatforms_org", completed 71 of 74 items

Figure 3. Detailed graphical information about a specific drug fulfillment history appears when the user clicks on any drug from the list shown in Figure 2.



DRUG CLASS: OTHER

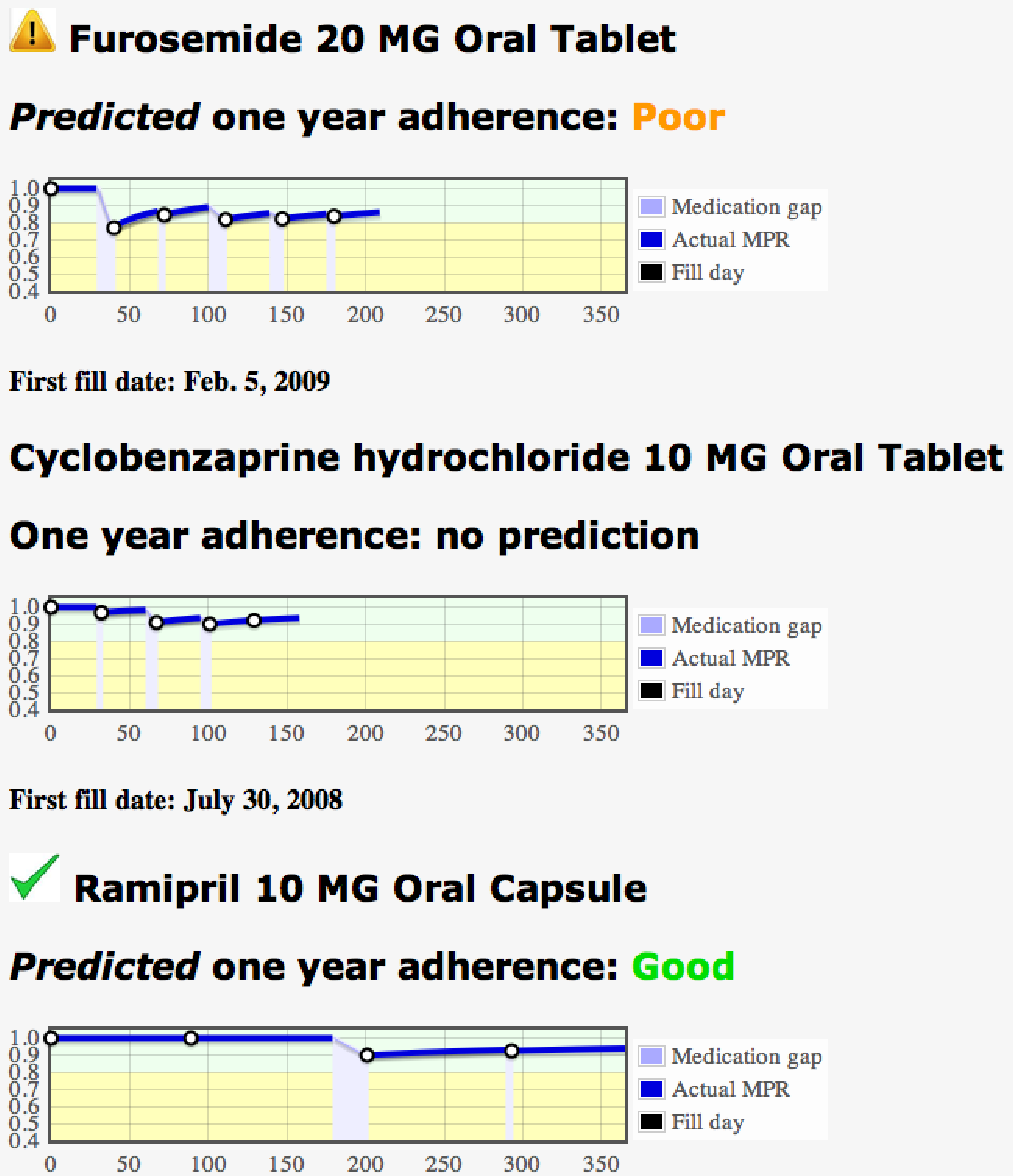
Lisinopril 20 MG Oral Tablet

Large gaps found - adherence is Poor

Actual MPR on day of last pill (day 338) is 0.443786982249

First fill date: ***Oct. 12, 2008*****; last fill date:** ***Aug. 15, 2009***

Figure 4. Detailed MPR information for each medication can be displayed in graphical form. Cyclobenzaprine is not in one of the classes for which a 1-year adherence prediction can be made. No current non-adherence issues are detected (gap check and low MPR check), so no warning flags are shown. A green check is not displayed because no future prediction can be made. The one-year MPR for Furosemide is predicted to be below 0.8 at one year in this case, based on patient information and MPR value at 120 days, even though the MPR value at 120 days and the latest date (200 days) is above the threshold. Prescription fill data for Ramipril is available for a full year, and the actual 1-year MPR is above threshold (0.8), so a green check is displayed.



⚠ **Furosemide 20 MG Oral Tablet**

Predicted **one year adherence: Poor**

First fill date: Feb. 5, 2009

Cyclobenzaprine hydrochloride 10 MG Oral Tablet

One year adherence: no prediction

First fill date: July 30, 2008

✓ **Ramipril 10 MG Oral Capsule**

Predicted **one year adherence: Good**

Results

The MPR Monitor App

Currently, the MPR Monitor app is designed for use by a physician or health care provider to quickly review all medications in a patient record for potential non-adherence. The initial app screen shown once a patient has been chosen is presented in Figure 2. All medications are listed, along with the date of first prescription fill, last fill, and a color-coded symbol that visually indicates adherence level: a green check for adherence, a red warning symbol for current non-adherence (current MPR < 0.8 or a 30-day gap), and a yellow warning symbol for predicted non-adherence if the regression model has determined that non-adherence is likely at 1 year, based on model predictions from the latest MPR available from 60, 90, or 120 days after the first fill.

If more information about the fulfillment history for a particular medication is desired, the user may click on any medication listed and a plot like that shown in Figure 3 will appear. This page shows visually if a patient possesses medication based on the last fill and current date and assumes that the patient is taking the medication. After all doses have run out, if there has been no succeeding fulfillment, a gap is indicated by a break in the MPR line. The actual value of the MPR is calculated and shown for every data point. In this way, the health care provider can visualize an entire year of fulfillment history for the medication. It may also be useful to see all medication fulfillment graphs of a patient at one time. This can be requested by clicking the “All Med” button at the top of any page. Plots such as those in Figure 3 appear for all medications. The plots and simple adherence indicators enable health care providers to quickly see medication adherence problems for any patient. Colors, symbols, and shading were used to make visual interpretation of the plot immediate, once the caregiver becomes familiar with the app. Additional detailed information is included in text or numerical form, such as exact MPR values, fulfillment dates, and dosage.

Gaps are easily visualized as gray dropout regions. The running MPR value is shown as a bright blue line. Prescription fill events are shown as circles on the graph. Mouse-over the graph lines will reveal a pop-up display with precise day and MPR values at any point on the graph. Non-adherence predictions are not made for medications that do not belong to one of the drug classes for which the regression model was designed. However, the current adherence in the case illustrated here is poor, based on a 196-day gap. The gap check is done for all prescription medications in the medical record. The required model inputs that are automatically accessed by the app are patient age at time of first fulfillment, the MPR on the prediction day, and the prediction day, either 60, 90, or 120 days since the first fill. This information is either read directly from the EHR (patient age) or derived from information contained in the record (prescription fulfillment history).

The analytics implemented in this app are relatively simple, but illustrate an important principle of reusable technologies: new apps directed at different clinical settings and diseases can be assembled quickly by adopting components from other apps. The core SMART app, the “embedded” calculations component, and the clinician-facing displays are all designed to be reusable components.

Users may run the application remotely using the SMART development sandbox, which can be accessed at [8]. Links to the source code repository may be found on GitHub [17]. The software is listed as the MPR Monitor and can be found either directly on GitHub or through the SMART website listed above.

Interface Functionality and Design

Designing a Web interface requires considerable attention to the needs of the client–in this case a busy clinician who will review the medication fulfillment information for each patient. In a clinical setting, we felt that the most important information needed was a complete listing of all the medications that a patient was prescribed, together with a clear and obvious adherence status symbol for each medication. A green check mark indicated adequate adherence, while a yellow or red triangle, a universal warning symbol, signaled an adherence problem requiring attention. We chose to differentiate actual adherence problems (signified by a 30-day gap in medication or an MPR value below 0.8) and predicted adherence problems (where the MPR is greater than 0.8 but is predicted by the app to fall below 0.8 at the 1-year mark). Although the internal criteria for determining adherence or non-adherence might change in future implementations of the app as more data is incorporated into the predictive model, the meaning and use of the bright colored symbols should remain the same.

If a physician desires more information about a specific medication, clicking on the drug name will bring up a graphical display and the MPR values of a patient for a specific prescription over time, generated by Flot. Flot is an open source graphing package that uses the JavaScript plotting library for jQuery, with a focus on simple usage, professional appearance, and interactive features. The Flot package is self-contained in the code distribution of MPR Monitor app. Calls to Flot functions are embedded within the html interfaces found in the standard Django “template” directory. Flot enabled a few interactive features to be built into the app, such as the ability to point the cursor to any point on a graph of the patient’s MPR curve over time and read the numerical value at that time. This interactive feature can be tested on the SMART sandbox. Shading and colors make it visually obvious where adherence was determined to be a concern, according to the adherence criteria built into the app.

In the design of the MPR Monitor app, drug class information was read from an external file, packaged locally with the application in a simple text file. A separate text file contains the regression model coefficients together with the applicable drug class and patient age. This enables the app to be updated with new information in the future if further regression models are tested and become available. The app can thus evolve without new programming or app installation by supplying a configuration file with updated model data.

The SMART MPR Monitor app is currently installed in the SMART reference container (a skeletal EHR with the SMART application programming interface) where it can be used and tested. General information about SMART apps is available on the SMART project home page [4], where which users can create an account and run installed apps on the SMART reference container. Once a new account is created, users can go to the sandbox [8], load the MPR Monitor, and run the app on sample patients provided in the sandbox.

Discussion

Principal Findings

We have developed a modular application that detects medication non-adherence, is easily maintained and upgraded as new research or data becomes available, and has sufficient generality to be used as an example for other SMART apps.

The design choices were made to enable open source statistical, graphical, and decision support Python packages to be assembled in a SMART-enabled app. Software can be downloaded and modified.

The need for informatics tools that monitor non-adherence to prescriptions is representative of a more general emerging need for more sophisticated data analysis tools that can access, integrate, and find diagnostic information in a wide variety of patient data types. Physicians have always needed to be skilled at gathering diverse sources of data from examinations and tests, synthesizing the data into a diagnosis, and determining a therapeutic strategy based on current medical knowledge and the patient's particular circumstances. However, advances in medical technology are producing enormous quantities of data that introduce new challenges to the physician for integrating all the information into clinical decision making. As EHRs are deployed widely to collect and manage medical data, and thus help to control costs, improve coordination of care, and eliminate errors, flexible integration of software applications with the EHR would extend their capabilities, and also create a broad market for apps.

In its current form, the MPR Monitor has a modular architecture that includes a clinician-facing interface, statistical routines that compute medication adherence information such as the MPR, and graphical display webpages that report information to the clinician. These can be easily modified or new modules appended to quickly assemble new apps that utilize information from any SMART-enabled EHR system with custom or reusable analytics.

Conclusions

Non-adherence to prescribed medications has many potential causes. Patients may not be able to afford the medications, while some may simply forget or confuse multiple drugs. Others may not understand the importance of continuing a regiment even if they feel better before the regiment ends. Regardless of the cause, the first step in solving the problem is to identify patients who are non-adherent, or those who are likely to be non-adherent before the problem arises.

The SMART API enables ready diffusion of software code and algorithms in the form of apps that can interact with any EHR that has been modified to support the SMART interoperability standard. The MPR Monitor presented illustrates how a SMART application can be implemented in practice. Because SMART apps are readily substituted, future similar apps with improved features, or better evidence-based methods can readily replace the existing versions. The community of users can then determine which apps will be adopted and which will fade away from disuse, just as the value of commercial apps is decided.

Acknowledgments

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Conflicts of Interest

None declared.

References

1. Bosworth HB, Granger BB, Mendys P, Brindis R, Burkholder R, Czajkowski SM, et al. Medication adherence: a call for action. Am Heart J 2011 Sep;162(3):412-424. [doi: 10.1016/j.ahj.2011.06.007] [Medline: 21884856]
2. Middleton B. The clinical decision support consortium. Stud Health Technol Inform 2009;150:26-30. [Medline: 19745260]
3. Mandl KD, Kohane IS. Escaping the EHR trap--the future of health IT. N Engl J Med 2012 Jun 14;366(24):2240-2242. [doi: 10.1056/NEJMp1203102] [Medline: 22693995]
4. Mandl KD. SMART. URL: http://smartplatforms.org/ [accessed 2012-12-06] [WebCite Cache ID 6ChruPzNo]
5. Mandl KD, Kohane IS. No small change for the health information economy. N Engl J Med 2009 Mar 26;360(13):1278-1281. [doi: 10.1056/NEJMp0900411] [Medline: 19321867]
6. Mandl KD, Mandel JC, Murphy SN, Bernstam EV, Ramoni RL, Kreda DA, et al. The SMART Platform: early experience enabling substitutable applications for electronic health records. J Am Med Inform Assoc 2012;19(4):597-603 [FREE Full text] [doi: 10.1136/amiajnl-2011-000622] [Medline: 22427539]
7. Jonikas MA, Mandl KD. Surveillance of medication use: early identification of poor adherence. J Am Med Inform Assoc 2012;19(4):649-654 [FREE Full text] [doi: 10.1136/amiajnl-2011-000416] [Medline: 22101969]
8. Mandl, DK. SMART. URL: http://sandbox.smartplatforms.org/login [accessed 2012-12-06] [WebCite Cache ID 6ChuDzGhc]
9. Murphy SN, Weber G, Mendis M, Gainer V, Chueh HC, Churchill S, et al. Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2). J Am Med Inform Assoc 2010;17(2):124-130 [FREE Full text] [doi: 10.1136/jamia.2009.000893] [Medline: 20190053]
10. Alchin M. Pro Django. In: Pro Django (Pro). New York City, NY, USA: Apress; Dec 17, 2009.
11. Balkrishnan R. The importance of medication adherence in improving chronic-disease related outcomes: what we know and what we need to further know. Med Care 2005 Jun;43(6):517-520. [Medline: 15908845]

12. Siegel D, Lopez J, Meier J. Antihypertensive medication adherence in the Department of Veterans Affairs. Am J Med 2007 Jan;120(1):26-32. [doi: 10.1016/j.amjmed.2006.06.028] [Medline: 17208076]
13. Choudhry NK, Fischer MA, Avorn J, Liberman JN, Schneeweiss S, Pakes J, et al. The implications of therapeutic complexity on adherence to cardiovascular medications. Arch Intern Med 2011 May 9;171(9):814-822. [Medline: 21555659]
14. Krousel-Wood M, Thomas S, Muntner P, Morisky D. Medication adherence: a key factor in achieving blood pressure control and good clinical outcomes in hypertensive patients. Curr Opin Cardiol 2004 Jul;19(4):357-362. [Medline: 15218396]
15. Ho PM, Spertus JA, Masoudi FA, Reid KJ, Peterson ED, Magid DJ, et al. Impact of medication therapy discontinuation on mortality after myocardial infarction. Arch Intern Med 2006 Sep 25;166(17):1842-1847. [doi: 10.1001/archinte.166.17.1842] [Medline: 17000940]
16. Ho PM, Rumsfeld JS, Masoudi FA, McClure DL, Plomondon ME, Steiner JF, et al. Effect of medication nonadherence on hospitalization and mortality among patients with diabetes mellitus. Arch Intern Med 2006 Sep 25;166(17):1836-1841. [doi: 10.1001/archinte.166.17.1836] [Medline: 17000939]
17. Mandl, DK. SMART sample apps. URL: https://github.com/chb/smart_sample_apps [accessed 2012-12-06] [WebCite Cache ID 6ChuQRU50]

Abbreviations

API: application program interface
EHR: electronic health record.
IT: information technology
MPR: Medication Possession Ratio
SHARP: Strategic Health IT Advanced Research Projects
SMART: Substitutable Medical Apps, Reusable Technology

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Review

The Computerized Medical Record as a Tool for Clinical Governance in Australian Primary Care

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Abstract

Background: Computerized medical records (CMR) are used in most Australian general practices. Although CMRs have the capacity to amalgamate and provide data to the clinician about their standard of care, there is little research on the way in which they may be used to support clinical governance: the process of ensuring quality and accountability that incorporates the obligation that patients are treated according to best evidence.

Objective: The objective of this study was to explore the capability, capacity, and acceptability of CMRs to support clinical governance.

Methods: We conducted a realist review of the role of seven CMR systems in implementing clinical governance, developing a four-level maturity model for the CMR. We took Australian primary care as the context, CMR to be the mechanism, and looked at outcomes for individual patients, localities, and for the population in terms of known evidence-based surrogates or true outcome measures.

Results: The lack of standardization of CMRs makes national and international benchmarking challenging. The use of the CMR was largely at level two of our maturity model, indicating a relatively simple system in which most of the process takes place outside of the CMR, and which has little capacity to support benchmarking, practice comparisons, and population-level activities. Although national standards for coding and projects for record access are proposed, they are not operationalized.

Conclusions: The current CMR systems can support clinical governance activities; however, unless the standardization and data quality issues are addressed, it will not be possible for current systems to work at higher levels.

(Interact J Med Res 2013;2(2):e26) doi:10.2196/ijmr.2700

KEYWORDS

clinical governance; electronic health records; general practice; realist evaluation; quality assurance; health care

Introduction

Clinical governance is an approach to ensuring quality and accountability that incorporates the obligation that patients are treated according to best evidence (Textbox 1).

Computerized medical records (CMR-see Textbox 2) provide a viable mechanism for implementing clinical governance [1]. Computers are involved in all aspects of the clinical interaction-from consulting room to system-level use of large systems that might control entitlement to treatment, screening, recall, and on-line booking of services [2,3]. In Australia, the UK and Netherlands, primary care is highly computerized, with almost all primary care physicians using a CMR; while in the US and Canada, primary care is less computerized, with the hospital sector leading the way [3]. Between 20% and 40% of the clinical consultation is spent interacting with the computer [4-6].

It is important to understand the context within which records are created [7]. Simply having a CMR does not guarantee the creation of a complete record usable for clinical governance purposes; the interaction with the computer in the consultation is complex and evolving [8]. Using a CMR is not a neutral act [9]; there are barriers to using the computer and coding systems [10] and interfacing with them constrains what is recorded [11,12]. However, the CMR does enable the running of decision support programs that can reduce errors, [13] and it can improve quality though audit/feedback cycles [14]. There are issues about the governance of these records and the repositories derived from these data; and formal governance structures are often lacking [15].

We carried out this investigation to see, firstly, how the nature of the design of different vendors' CMR systems enable and constrain clinical governance and, secondly, how individuals and groups might use computers differently as tools to measure quality and to achieve clinical governance objectives. We describe an assessment tool that would enable others to assess the extent to which any CMR could act as a mechanism within their health care context to support clinical governance.

Textbox 1. What is clinical governance?

Clinical governance is a term first used within the UK National Health Service (NHS) to describe a process for maintenance, improvement, monitoring, and accountability for clinical standards.

The NHS clinical governance process made chief executives responsible and accountable for clinical quality in their organization alongside business goals and budgetary control.

Clinical governance also challenged the "clinical freedom" of doctors. Up to its inception, a doctor only needed to justify their actions in terms of them judged to be reasonable by a group of peers. The onus changed to one where clinicians are expected to deliver best practice, usually as defined in evidence-based guidelines, and to participate in clinical audits of their standards of care.

Persistent deviation from guidelines, or being an outlier in audit might be the cause for review.

Textbox 2. Terminology used in the relation to computerized medical records.

Classification system

A range of terms exists to describe CMR systems. The classifications reflect differences in the following areas:

1. Purpose: Intended to be a life-long or partial record of a patient's health or medical treatment.
2. Disciplinary base: Based on the "medical model" or a broader "health" record.
3. Proprietorship: Owned and controlled by the patient or their proxy, or by the health care provider or health care system.

Definitions:

Electronic health record (EHR): A complete "cradle to grave" record of the health and health care provided to an individual.

Computer-based patient record: Historic term for an EHR-like concept. Sometimes used to indicate "all health related data".

Electronic medical record: Records of the part of a patients care held by a specific medical provider or department. Health care providers generally aim for these to be enterprise wide.

Electronic patient record: Similar to EHR, a lifelong record of health and health care provided.

Personal health records: A complete medical and health care record controlled by the patient or their proxy.

Our preferred term:

Computerized medical record (CMR): This is a generic term, similar to digital medical record, which implies that this is a record under the custodianship of a medical or health care provider, and is inclusive of partial and complete records.

Methods

Background

This study was a component of a larger systematic review and realist synthesis of clinical governance in primary care [16]. The CMR had the allure of being an unrealized tool to support clinical governance, measuring quality, conducting clinical audit, and ensuring safety (Textbox 3). We therefore undertook an analysis of CMR systems used in Australia, exploring the extent to which the CMR supported clinical governance, including to what extent this reflects contextual factors that may be unique to the Australian context. In keeping with the main study framework, we performed a structured analysis in conjunction with key themes emerging in the main study from a literature review and informant interviews. We analyzed seven CMR products used in Australia, and also their capacity to deliver clinical governance. We concluded by developing a maturity framework for CMRs in relation to clinical governance, and classified the maturity of the various CMRs.

Textbox 3. Scope and role of an information system to support clinical governance.

Computerized information systems can use routine data, and specially captured additional data (eg, patient questionnaires) to audit quality.

Clinical governance makes demands of managers, clinicians, and information systems:

- Managers: Responsible and accountable for clinical standards within their organization; including mechanism for measuring them.
- Doctors: Clinicians are now expected to deliver best practice as defined in evidence-based guidelines; and participate in clinical audit.
- Information systems: It should play a role beyond individual patient care, practice, and locality audits. The CMR should enable practices to benchmark quality, and governments to see there is return on investment by ensuring it supports evidence-based practice.

Patients' views of the service and their "experience" of healthcare are an important measure of quality, which is missing in current systems.

Realist Evaluation

We carried out a review from a realist perspective, mirroring the approach of the main study [17], modifying the approach previously used to explore the success and failures of the UK National program for IT [18]. A realist perspective is useful in assessing complex interventions as it aims to develop explanatory analyses of why and how these interventions may work in particular settings and contexts. The realists mantra is: "Context (C)" plus causal link with an appropriate "Mechanism (M)" results in an "Outcome (O)"; in other words, "C+M=O". Part of the realist perspective is that effects are reported according to the three Ws: "*What Works, for Whom, and in What circumstances.*"

In realist evaluations, there can sometimes be difficulty in distinguishing context and mechanism. In this analysis, the context (C) is the Australian primary health care context, and the mechanism (M) is the CMR system used at the point of care. Our outcome measure (O) was the ability to produce clinical governance outputs through the ability to monitor quality of care against given criteria and standards. This combination describes how in the Australian context (C), the CMR, might contribute as a mechanism (M) to deliver the outcome measure (O), clinical governance (C+M=O) (Figure 1).

Context

We mapped the primary care context using Lusignan's 4 component classification [8]:

1. Organization: We considered the ways in which primary health care was organized at the practice, locality, and at the national level in Australia.
2. Individual clinicians: We considered the level of knowledge, skill in operation, and attitude toward CMR among individual general practitioners.
3. Clinical task: We considered the clinical context during which the CMR would be used. This was usually a one-to-one clinical consultation, in which the presence of the desk-based CMR created a triadic clinical relationship [19].
4. Technology: We considered the features of the technology, which are unique to the particular context. Australia is in the process of enhancing broadband access, but this is unequally distributed around the country.

The contextual features discovered through this review were then analyzed in concert with the mechanisms of the CMR described below to develop a nuanced understanding of how the CMR operated in this particular environment to produce governance outcomes.

Mechanism

To identify the ways in which the CMR operated in relation to clinical governance, we used the Donabedian [20] classification of structure and process elements to describe the three types of mechanism by which CMRs may enable the delivery of improved clinical governance: structures, processes of care and review, and processes that impact on outcome. In this study, the software settings were considered to be process elements. For example, a key enabler of clinical governance-such as the presence of a unique patient identifier within the system, essential for data aggregation-would be listed as a key component of the mechanism provided by the CMR.

1. "Structures" included the physical structures and design features (including conventions for room layout, record architecture, and linkages).
2. "Processes of care and review" included software capabilities such as the issuing of prescriptions.
3. "Processes that may impact upon on patient outcomes" included elements such as the ability of the CMR system to detect and block all serious drug interactions.

Each of these categories was subcategorized to produce the detailed tool across the categories (Table 1). The CMR structure was divided using the Open EHR model of the four separate components of a CMR system: interface, clinical archetypes, coding system, and database.

Outcome

We explored factors related to clinical governance outcomes occurring at the level of the patient, the health care provider, and the setting (ie, impact at the population- or health system-level) [21].

Assessment Tool

We created a new assessment tool (Multimedia Appendix 1), a bi-axial tool, where the previously-described taxonomies of mechanism and context occupied each of the axes. The cells of the grid are populated with outcomes related to clinical governance for patients/clients, the provider, and the broader population level.

Assessing the Top Six Brands and One Example of a CMR System With a Low User Base

The top six CMR systems measured in terms of user base [22] were evaluated using this tool (Textbox 4). We also examined a CMR system with a small installation base (and therefore less organizational resources within the company) as a comparator. For each system, we used either software in demonstration mode or installed software in training mode. The testing was done with simulated patient data, and independently of the software providers, to explore how the system might retain clinical data and enable clinical governance activities. The tool was applied by one researcher and checked for accuracy by experienced users of each system. We elected not to disclose or publish comparison between brands, instead keeping our focus on whether the current generation of CMRs provide a viable mechanism for implementing clinical governance.

Maturity Framework

We developed a CMR maturity model, again using the Donabedian classification into structures (including IT architecture issues), process and outcomes, using existing consensus about CMR maturity [23-25]. At the structural level, we looked at the number of vendors and their market share, use of standards and interoperability, and the use of unique patient identifiers and clinical coding (eg, single national coding system). The processes were graded from passive reporting through to active decision support-again looking at individual patient, practice or locality and population levels. Outcomes data were expressed in terms of feedback about quality (Figure 2).

The process and potential of the CMR to influence clinical governance outcomes were graded into a four-level model (Table 2). This grading is multi-dimensional: (1) the agency of the CMR: namely, does the CMR play a passive or dependent role compared to an active or autonomous role in delivering clinical governance, (2) the level of complexity of the transaction and whether or not it is adaptive [26], (3) the degree of integration with other information systems, and (4) the physical integration and linkage processes underpinning it.

Table 1. Donabedian based assessment of CMR as a mechanism to support clinical governance.

Structures	Element explored
System Architecture (eg, Open EPR model)	Interface, clinical archetypes, database type, coding systems
Information & Decision Support	Drug databases, interactions, clinical calculators
System Linkages	Patient registrations, laboratory links, Email
Search Function	Across populations, practices, Export functions
Patient access/Control	Access to information through web portals, etc. Attribution
Processes–care and review	
Quality Markers	Data quality, information quality, system accreditation
Billing/Pay for Performance	Routine data use, parallel billing system
Supports population level data outputs	Small area, sentinel networks, epidemiology
Processes that impact on outcomes (demonstrated within the system)	Critical incidents / near misses / confidential reporting; surrogate markers of quality and outcomes/Clinical audit; true outcome measures

Textbox 4. Software packages reviewed.

Medical Director 2 (Health Communication Network, Sydney, NSW)

Best Practice (Best Practice Software, Bundaberg, Queensland)

Genie (Genie solutions, Brisbane, Queensland)

Medtech32 (Medtech Global, Melbourne, Victoria)

Plexus (iSoft, Sydney, NSW)

Profile (Intrahealth Systems, Sydney, NSW)

Promed (Promedicus Systems, Melbourne, Victoria)

Table 2. CMR and CG maturity model: moving through passive, interactive, and autonomous modes.

Level 1	Level 2	Level 3	Level 4
Simple		Complex	Adaptive systems
External adverse event reporting (no use of system)	Reporting involving information from CMR	Reporting using the CMR as vehicle	Interactive reporting where CMR sends and receives information, informing user of the risks
Simple prescribing	Prescribing with limited functions (interaction checking)	“Intelligent” prescribing where CMR uses local information such as guidelines to inform prescribing decisions	“Autonomous” prescribing where system integrates internal and external information to determine optimal management
Simple audit feedback loops	Audit data compared with external data to assess performance	Audit data pooled and used to develop local benchmarks as well as population health activities	Real-time data aggregation and assessment to allow ‘just in time’ monitoring of population, during pandemics, for example
Largely External to CMR	Integrated in CMR	CMR linked to other information sources	Integrated into health system
Distributed database			Interoperable data
Isolated Linkage Integration			

Figure 1. Overview model of the method to appraise whether in the context of Australian primary care the CMR provided a mechanism for driving clinical governance.

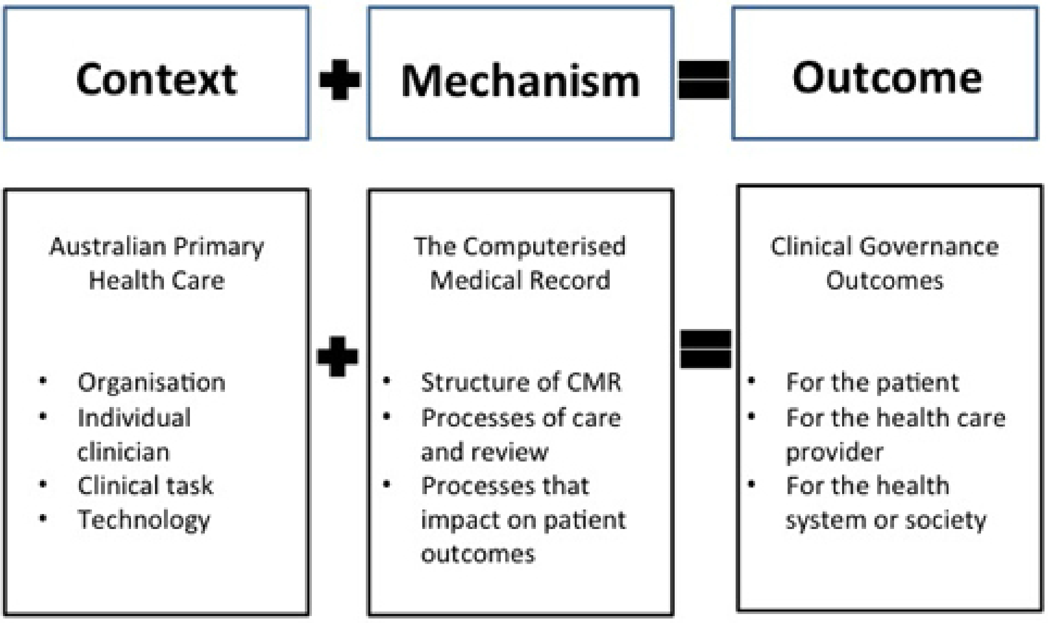
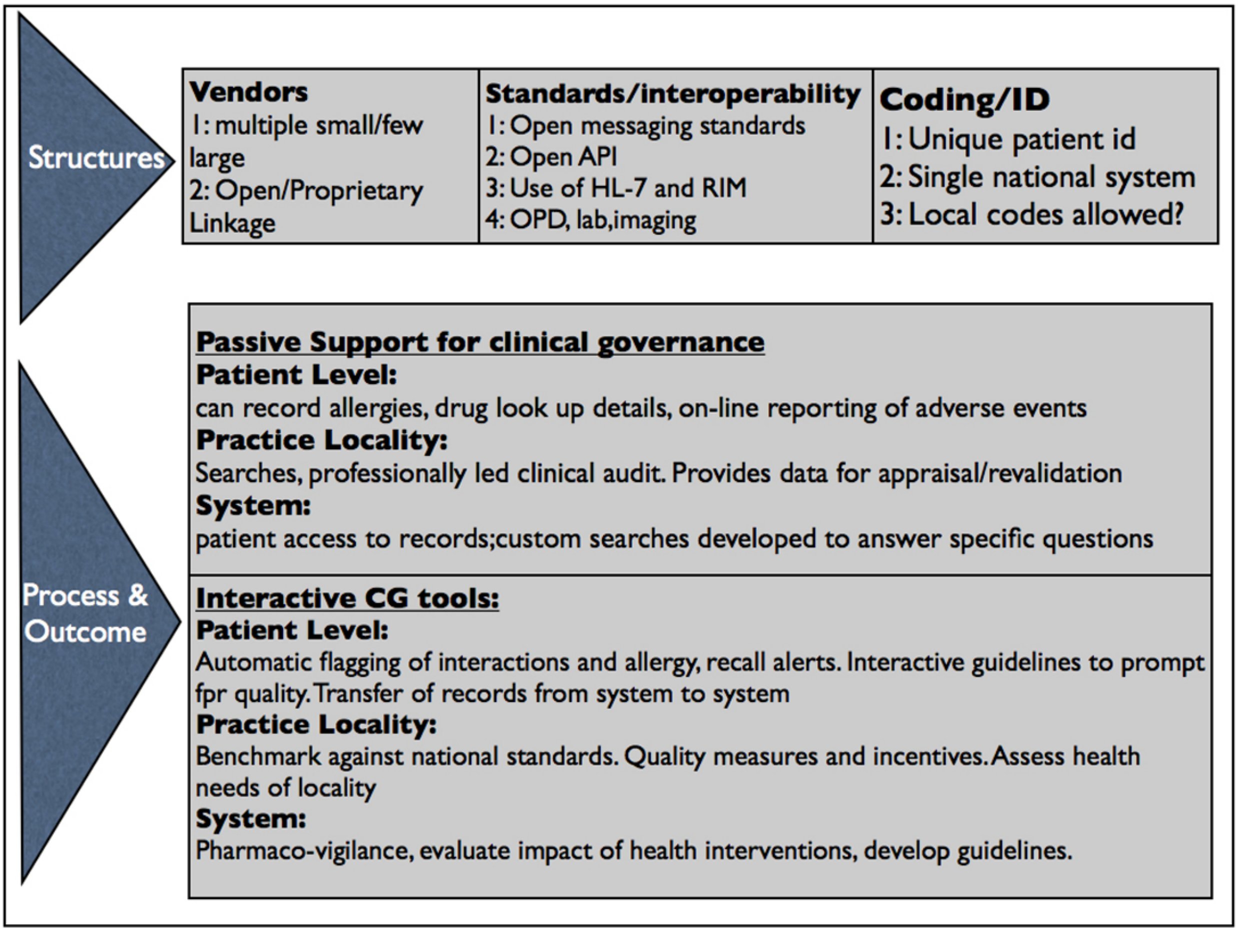


Figure 2. Schema of the maturity framework.



Vendors
1: multiple small/few large
2: Open/Proprietary Linkage

Standards/interoperability
1: Open messaging standards
2: Open API
3: Use of HL-7 and RIM
4: OPD, lab,imaging

Coding/ID
1: Unique patient id
2: Single national system
3: Local codes allowed?

Passive Support for clinical governance
Patient Level:
can record allergies, drug look up details, on-line reporting of adverse events
Practice Locality:
Searches, professionally led clinical audit. Provides data for appraisal/revalidation
System:
patient access to records;custom searches developed to answer specific questions

Interactive CG tools:
Patient Level:
Automatic flagging of interactions and allergy, recall alerts. Interactive guidelines to prompt fpr quality. Transfer of records from system to system
Practice Locality:
Benchmark against national standards. Quality measures and incentives. Assess health needs of locality
System:
Pharmaco-vigilance, evaluate impact of health interventions, develop guidelines.

Results

Context

Organizational

In Australia primary care is delivered via general practice through around 7000 discrete practices. Practices in Australia have a variety of ownership structures including corporate owners, partners, associates, and sessional general practitioners (GPs). Some CMRs enabled varying degrees of control according to status within the practice-owner, employee, etc. Patients are free to visit any GP of their choice, and GPs act as gatekeepers to secondary care. Mobility of patients between practices means that they lack the stable population denominator of registration based systems such as those found in the UK or Netherlands. Funding is largely fee-for-service underpinned by a national insurance scheme, but there are many accessory payments [27] and other programs [28]. The CMR systems also allowed for different role-based access for nurses and receptionists. Standards for clinical governance have been introduced by the Royal Australian College of General Practitioners [29].

The Individual Clinician

The GPs in Australia are trained in the Australian General Practice Training Program. The curriculum for training [29] includes a specific section on eHealth focussed on the practical use of computers, but not their application as a tool for clinical governance. A total of 98% of GPs have a computer on their desk, which they use them for clinical purposes [30]. Most GPs use their CMR for recall, maintenance of immunization registers, monitoring of population health, making clinical notes, and/or recording diagnoses using a clinical coding system [30]. There are some 22+ clinical packages in the market. Over 40% of GPs are involved in some sort of audit or quality assurance cycle associated with using their computer data, usually mediated by the local Division of General Practice [31]. These activities require good data and appropriate extraction techniques.

Technology

Although doctors use many sources of information in the consultation [32], it is the clinical packages that can have the largest impact on the clinical outcomes. In general practice, the government has encouraged good data recording through its Practice Incentive Program. Practices have received payments for recording allergies and the creation of summary data in their CMRs.

We identified four technological issues that compromise clinical governance activities:

- Different (and local) coding systems make national and international comparison of quality more challenging.
- The absence of standards meant CMR vendors can choose to develop and implement their own messaging ‘standard’

for use between variants of their program including use of varying flavors of Health level-7 (HL7), with much less scope for quality control and minimizing the risk of inbuilt errors.
- Patient access to the record was absent. Such facilities are not part of the Australian landscape yet.
- Backup facilities were not inbuilt functions of the software, but were integrated into general system backups according to accepted guidelines.

Clinical Task

The individual clinician had little influence on the software processes. In comparison with paper records, we felt the CMR disempowered the clinicians–in effect ceding many areas of control to the organization or the technology. Customization options were minimal. Some programs did not allow individual doctors to change their passwords without going through an administrator. Access controls for all staff were either set by the program or customisable by a designated administrator.

A significant amount of data required to perform key clinical tasks is now provided by third parties, who have to be trusted themselves to have proper governance systems. The responsibility, governance, and overall control of these information sources sit outside of the CMR. For example, drug information was derived from either government sources or from the industry. Until 2009, the most popular general practice software incorporated screen drug advertising. An audit of these advertisements found that 95% were non-compliant with the Medicines Australia Code of Conduct, though there was a little evidence that this impacted upon prescribing practice [33,34]. Most programs sourced travel medicine advice from a variety of industry sources. Immunization schedule data was the one area that used a common, validated source (the federal government).

There are significant gaps and variability between Australian CMR systems in their drug interaction checking [35], though these issues are international [36]. While there are standards about CMR functionality they largely fail to include how applications should perform in clinical environments [37] especially as the CMR becomes more ‘active’ in the patient space [38].

Some areas were easy to ascribe to an actor, but others were quite complex. Drug Interactions, for instance, required taking an externally provided database, integrating it into the program, and then allowing GPs to potentially customize the level of alert setting, and then integrate all of that into the consultation. Others such as practice audit required a reliable software process that was then dependent on a practice system to make best use of the information.

Table 3. Contextual elements that support and limit clinical governance using computerized medical records.

Context	Reviewed Elements
Organizational	Accessible by different cadres of practice staff[a]
	Accreditation standards includes clinical governance[a]
	Patients are not enrolled, and can be very mobile[b]
Individual clinician	Clinicians receive training in operating computers[a]
	Nearly half of Australian GPs are involved in quality audits[a]
Clinical task	Individual clinicians have little autonomy over the software system, and must respond to its settings[b]
Technology	Variety in coding systems[b]
	Lack of standardization[b]
	No patient access[b]
	No back-up systems for CMR itself[b]

[a] Contextual elements that support clinical governance using computerized medical records.

[b] Contextual elements that limit clinical governance using computerized medical records.

Mechanism: The CMR

Mechanism: Structures

All systems generated a unique identifier for each patient, and all recorded the Medicare number (a non-unique number used for the federal insurance scheme). All CMR systems utilized a graphical user interface and all had standard clinical archetypes such as history, examination, past history, and social history. All were able to provide a summary view although differences in those views were apparent [39]. All were able to code diagnosis and problem list data, although four different coding systems were used: International Classification of Primary Care, International Classification of Disease version 10 (ICD-10), Pyefinch, and Doctor Command Language. One system that used the ICD-10 classification incorporated the ICD-10 procedure code; thus, the system included more extensive classification on complications of cataract procedures than it did on hypertension. The system required so much clicking to turn off the classification system that doctors reported bypassing the classification system altogether.

None used the Systematised Nomenclature of Medicine–Clinical Terms, the official Australian standard and none required data to be entered in a coded fashion, and two of the coding systems are specific to that brand of software. All the CMR systems allowed attribution of data according to login or according to source. Some incoming data (such as specialist letters) required manual attribution, while for data such as pathology, the attribution was automatic.

Every CMR system was able to accept pathology and radiology as atomized data (either HL7 or Pathology Interchange Format). All programs allowed linking of requests with received reports. Four packages allowed both generation of electronic documents and receipt. All used proprietary systems to do this, with little ability to work cross platform.

The CMR systems (in keeping with the genesis of software systems as electronic prescribing packages) had comprehensive drug databases. Most used the database from MIMS Australia, otherwise using information from a variety of sources. Data regarding Australia's Pharmaceutical Benefits Scheme (PBS), which detailed government subsidies for most drugs, was sourced from the PBS itself. All had the ability to generate drug interactions, although users were able to set the level of drug interaction alerts and in several systems turn them off altogether. Use and availability of drug calculators (weight/dose calculators or warfarin calculators) was extremely variable. All packages had a variety of other external information sources available from within the system.

All CMR systems had immunization information; many had travel information, and one had an extensive library of text based health information resources within the program.

All programs have search functions built into the system. Most have some inbuilt searches (patients over 65 years, eligible patients without a cervical smear in the last five years) that relate to funding initiatives or chronic disease management. The ability to do other searches was quite variable and often required significant computer/database knowledge

Mechanism: Processes of Care and Review

Only four of the CMR systems were able to participate in regional data quality activities. These activities revolve around the Australian Primary Care Collaborative program, The Practice Health Atlas and the PEN Clinical Audit tool [31]. All these activities require the use of an external tool to interrogate the program's database and generate pooled data. One other package had its own tool to perform similar functions. All programs were able to generate pay-for-performance lists, according to the particular funding initiative.

Mechanism: Processes That May Impact on Outcome

No system had inbuilt data quality checks (prescribing insulin without a diagnosis of diabetes for example). One system had its own 'in-house' sentinel/research network ability; no other program had such a designated function.

Table 4. Mechanisms that support and limit clinical governance from computerized medical records.

Mechanism	Reviewed Elements
Structures	External resources (eg, MIMS) included[a]
	Alert to drug interactions[a]
	Accept pathology and radiology results as atomised data[a]
	Limited search facilities[b]
	Variable drug dose calculators[b]
	No standardized coding system[b]
Processes of care and review	Can generate pay for performance[a]
	Half allow data extraction to participate in audits[b]
Processes related to outcomes	No inbuilt data checks for quality[b]
	Only one allows in-house sentinel data search facility[b]

[a] Mechanisms that support clinical governance using computerized medical records.

[b] Mechanisms that limit clinical governance using computerized medical records.

Outcomes

Overview

When context (Table 3) and mechanism (Table 4) were explored together, we found that the contextual limitations associated with the technology landscape and clinician autonomy over the CMR compounded the limitations identified in the analysis of mechanisms, associated particularly with processes. The result is that these systems have limited demonstrable outcomes in relation to clinical governance.

Demonstrated Outcomes for the Patient or for the Health Care Provider

Most medical records are computerized and widely used for clinical governance activities, but these approaches are fragmented [16]. None of the packages dealt effectively with health outcomes, in the sense that they were able to adequately demonstrate improved care from within their own processes. Assessing health outcomes required an interpretive process by accessing and comparing external data. The tool asked for 'surrogate markers of quality' and 'outcome measures', neither of which was particularly well or sufficiently defined to be assessed. However, in the future, these features will become of prime importance.

Outcomes at Population Level

None of the CMRs was able to deal directly with these issues. However, the ability of the systems to provide data to inform activities at this level is increasingly crucial for health system management if we want to be able to explore what population interventions might have impact. Medicare locals, the regional support bodies for primary care services, are able to use the data for informing practice at a local level [40], but the ability for this data source to influence national activities is currently poor.

Maturity Framework

At the structural level, Australian CMRs are well developed but there is scope for further progress against our maturity framework. Lacking are open standards, as yet no implementation of a standard coding system, and probably too many vendors in a relatively small market.

Australian primary care is therefore largely at level 2, with some systems only supporting level 1 and with some systems offering level 3 models. There was no evidence of level 4 systems. Some CMR systems had features that from the international perspective must be a developmental blind alley. The local coding systems are one of these; it is unlikely to ever become part of an interoperable health system.

Discussion

Principal Findings

In the Australian context, at practice and locality level the CMR works well, and is being used to facilitate clinical governance activities. Nearly all practices have systems with search functionality that enable participation in clinical audit.

However, while practices and localities are widely engaged in clinical governance processes, these are usually being done in an uncritical way. In particular, there is little attention given to data quality, or the obligation to code clinical conditions in standardized extractable fashion.

The record structures are often proprietary and there is a dearth of open architectural models, with many mission critical functions happening within a black box.

Implications of the Findings

Benchmarking standards at a national or international level will be challenging if poor data quality and the disparate nature of record systems and system architecture remain unaddressed. Although not a registration based system, denominators such as those who attended in the last year can be used to make comparisons between practices and systems.

It is not possible to have lossless conversion of data held in one coding system to another, and the use of idiosyncratic coding systems increases the risk of data loss. While statistical techniques, in particular multiple imputation [41], can be used to compensate for missing data, this is never the same as having complete data. Black box data extraction processes and audit systems tend to foster uncertainty about the validity of findings.

Disease registers are much more challenging to set up when there is incomplete coded data, and patients with a condition not on a disease register are not going to benefit from computerized prompts or recall. Their standard of care may also be lower. This data quality and use issue will become a major problem as more information is shared.

Comparison With the Literature

The complexity of the clinician-patient-computer interaction, touched on in the introduction, is reflected elsewhere in the literature. Patient-centered care [38,42] and relationship-centered care [43] have taken hold and been shown to affect the outcomes. Computerization is changing the balance of power in the interaction [44].

There is no requirement for CMR systems to provide any specific functionality whatsoever, no set of criteria over information use, and no standards over usability or even formally recommended testing protocols [37]. The ‘Swiss cheese’ model of error [45] highlights how gaps in complex systems can result in errors, which in turn can raise patient safety issues. Drug interaction checking is an example of this, with interaction resources needing to be integrated into the prescribing package and then used by the clinician. While the UK National Program for IT has been much criticized, the one area that appears to have stood the test of time has been the rigid implementation of a drug dictionary and messaging standards [46].

Patient access to their records has become the norm elsewhere [47] and increased openness may help ensure good governance. Australia has aspirations to provide patient access through the National “Personally Controlled Electronic Health Record” program. Online access is no panacea; however, uptake of access to very different models of online summaries of care has been poor uptake in both England and France [48].

A comparison with the UK system of CMR driven pay-for-performance suggests that there may be quality gaps that computer mediated incentives might help close [49,50]. Additionally, the UK Primary Care Information Service (PRIMIS) has promoted data quality through a wide range of initiatives. The PRIMIS approach has been one of facilitation and feedback rather than financial incentives. These have been clinically focussed and included looking at disparities in data quality heart disease and improving patient safety [51,52]. However, more recently, the English NHS has gone through a game changing transformation with extraction of data on a National Scale through a system called the General Practice Extraction Service This gives the potential to extract data to measure quality and clinical governance on a national scale. The GPES system has its own Independent Advisory Group (SdeL is the Royal College of General Practitioners representative) to: “*Consider the risks and benefits in order to assess whether the extraction is in their view appropriate and in the public interest.*”

Limitations of the Method

The evaluation took place at a point in time in 2009, and each package has gone through several upgrades over that time. As such, this analysis is not meant as a detailed critique of the packages with recommendations. It is quite possible that many of the comments here may no longer apply to a specific package. Moreover, it is the first discussion of the increasing influences on clinical governance by CMRs, with a framework that can be applied serially or in different contexts. What is lacking in planning and development is a consistent approach to thinking about CMRs and clinical governance, and what systemic controls should be there.

We might have explored the extent to which the standardization of record formats might have aided comparison and measurement of quality. The Royal College of Physicians, UK, has been very active in trying to standardize records reporting handovers, including admission and discharge [53]; it is likely that such a process would facilitate the implementation of clinical governance process. Although we make reference to the Open EHR initiative in our method we have not fully described its potential impact on standardization, and therefore toward being able to contribute to governance by facilitating the measurement and compare clinical standards on different systems. The two elements of Open EHR we believe that contributes most are its clinical models program, which enables researchers and practitioners to build sharable archetypes of clinical concepts [54]; and the specification program that defines data, services, and application program interfaces and offers the allure of quality certification of systems [55].

There are also other models we might have used for example: Yousuf et al have proposed an adoption model that includes: user attitude and skills base together with good leadership, IT-friendly environment, and good communication [56]. Lau et al have identified factors that influence adoption, and that it includes people, organization, implementation, and the macro environment [57].

These models share some similarity in that they both identify socio-technical aspects of implementation. Had we used either of these models, our subheadings might have been different but our findings are unlikely to have changed. Our selection driven by the wish to emphasize the interaction between organization (which included governance), the individual clinician, the clinical task (which should be of quality) and the technology; and not predefined success factors or progressive levels that should be reached.

Call for Further Research

The observations in this study have not been tested in a controlled trial and are retrospective in nature. Although we have approached this study from a neutral position of identifying factors that helped and hindered there may be bias. One author (CMP) is very familiar with many of the brands of Australian CMR and may have been susceptible to *familiarity bias* [58], and pointed out issues he was previously aware of. However, SdeL does not share this bias, instead having his experience framed in other countries' CMR systems. Our assertion is that the CMR is as an instrument of and for clinical governance. At the very least, the CMR provides the tools to enable clinical audit and retrospective analysis of data. At its best the CMR can flag, recall, remind to monitor, and provide information support, and taking an ever more active role in the consultation. The current use of CMRs in Australia supports clinical governance at the individual patient, practice and possibly locality level; but provides no insights at the national level. Where the CMR does not facilitate clinical audit, individual practitioners are blocked from raising quality standards. We need to further test this hypothesis in prospective trials.

Conclusions

We have developed a framework for evaluating how CMR systems support clinical governance in a particular context; and whether the CMR has helped to achieve those goals. By applying the tool to several different brands of Australian CMRs, we have highlighted the issues that exist today, but importantly shown a graded way forward using a simple model and maturity framework that we hope can be readily followed by clinician users of these systems.

The limitations of the process relate to the heterogeneity of the data and their sources, the continuing change over time, but above preeminent is the lack of implementation of standards. While CMR implementation in Australia has enabled better clinical governance improving systems technical capability and rigorous standardization is needed to enable more comprehensive assessment of quality and outcomes for patients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Software assessment schema.

[PDF File (Adobe PDF File), 62KB - ijmr_v2i2e26_app1.pdf]

References

1. de Lusignan S. Clinical Governance. In: Bevir M, editor. Encyclopedia of Governance - 2 volume set. Thousand Oaks, California: Sage Publications, Inc; 2007:99-101.
2. Purves IN. Facing future challenges in general practice: a clinical method with computer support. Fam Pract 1996 Dec;13(6):536-543 [FREE Full text] [Medline: 9023531]
3. Jha AK, Doolan D, Grandt D, Scott T, Bates DW. The use of health information technology in seven nations. Int J Med Inform 2008 Dec;77(12):848-854. [doi: 10.1016/j.ijmedinf.2008.06.007] [Medline: 18657471]
4. Bui D, Pearce C, Deveny E, Liaw T. Computer use in general practice consultations. Aust Fam Physician 2005 May;34(5):400 [FREE Full text] [Medline: 15887950]
5. Pearce C, Kumarpeli P, de Lusignan S. Getting seamless care right from the beginning - integrating computers into the human interaction. Stud Health Technol Inform 2010;155:196-202. [Medline: 20543329]
6. Kumarapeli P, de Lusignan S. Using the computer in the clinical consultation; setting the stage, reviewing, recording, and taking actions: multi-channel video study. Using the computer in the clinical consultation; setting the stage, reviewing, recording, and taking actions: multi-channel video study J Am Med Inform Assoc Published Online First: 14 December 2012 2012-00 2012:e67-e75. [doi: 10.1136/amiajnl-2012-001081]
7. Campbell SM, Sweeney GM. The role of clinical governance as a strategy for quality improvement in primary care. Br J Gen Pract 2002 Oct;52 Suppl:S12-S17 [FREE Full text] [Medline: 12389764]
8. Pearce C, Trumble S. Computers can't listen--algorithmic logic meets patient centredness. Aust Fam Physician 2006 Jun;35(6):439-442 [FREE Full text] [Medline: 16751862]
9. de Lusignan S, Wells SE, Hague NJ, Thiru K. Managers see the problems associated with coding clinical data as a technical issue whilst clinicians also see cultural barriers. Methods Inf Med 2003;42(4):416-422. [doi: 10.1267/METH03040416] [Medline: 14534643]
10. de Lusignan S. The barriers to clinical coding in general practice: a literature review. Med Inform Internet Med 2005 Jun;30(2):89-97. [doi: 10.1080/14639230500298651] [Medline: 16338797]
11. Tai TW, Anandarajah S, Dhoul N, de Lusignan S. Variation in clinical coding lists in UK general practice: a barrier to consistent data entry? Inform Prim Care 2007;15(3):143-150. [Medline: 18005561]
12. Shachak A, Reis S. The impact of electronic medical records on patient-doctor communication during consultation: a narrative literature review. J Eval Clin Pract 2009 Aug;15(4):641-649. [doi: 10.1111/j.1365-2753.2008.01065.x] [Medline: 19522722]
13. Borycki E, Kushniruk A. Identifying and preventing technology-induced error using simulations: application of usability engineering techniques. Healthc Q 2005;8 Spec No:99-105 [FREE Full text] [Medline: 16334081]
14. de Lusignan S, van Weel C. The use of routinely collected computer data for research in primary care: opportunities and challenges. Fam Pract 2006 Apr;23(2):253-263 [FREE Full text] [doi: 10.1093/fampra/cmi106] [Medline: 16368704]
15. Reti SR, Feldman HJ, Safran C. Governance for personal health records. J Am Med Inform Assoc 2009 Feb;16(1):14-17 [FREE Full text] [doi: 10.1197/jamia.M2854] [Medline: 18952939]
16. Phillips CB, Pearce CM, Hall S, Travaglia J, de Lusignan S, Love T, et al. Can clinical governance deliver quality improvement in Australian general practice and primary care? A systematic review of the evidence. Med J Aust 2010 Nov 15;193(10):602-607. [Medline: 21077818]
17. Pawson R, Tilley N. Evidence Based Policy, a Realist Perspective. In: Realistic evaluation. London: Sage; 1997.
18. de Lusignan S. Improving Data QualityClinical Records: Lessons from the UK National Program about Structure, ProcessUtility. 2009 Presented at: In: de Lusignan S. editor. 1st International Conference on Information Technology Interfaces; 2009; Dubrovnik.
19. Scott D, Purves I. Triadic relationship between doctor, computer and patient. Interacting Comput 1996;8(4):347-363.
20. Donabedian A. Evaluating the quality of medical care. Milbank Mem Fund Q 1966 Jul;44(3):Suppl:166-Suppl:206. [Medline: 5338568]
21. Holzemer WL, Reilly CA. Variables, variability, and variations research: implications for medical informatics. J Am Med Inform Assoc 1995 Jun;2(3):183-190 [FREE Full text] [Medline: 7614119]
22. Sweidan M, Reeve JF, Brien JA, Jayasuriya P, Martin JH, Vernon GM. Quality of drug interaction alerts in prescribing and dispensing software. Med J Aust 2009 Mar 2;190(5):251-254. [Medline: 19296790]
23. de Lusignan S, Teasdale S, Little D, Zapp J, Zuckerman A, Bates DW, et al. Comprehensive computerised primary care records are an essential component of any national health information strategy: report from an international consensus conference. Inform Prim Care 2004;12(4):255-264. [Medline: 15808027]
24. de Lusignan S. The optimum granularity for coding diagnostic data in primary care: report of a workshop of the EFMI Primary Care Informatics Working Group at MIE 2005. Informatics in primary care 2006;14(2):255-264.
25. de Lusignan S, Teasdale S. Achieving benefit for patients in primary care informatics: the report of a international consensus workshop at Medinfo 2007. Inform Prim Care 2007;15(4):255-261. [Medline: 18237483]
26. Ellis B. Complexity in practice: understanding primary care as a complex adaptive system. Inform Prim Care 2010;18(2):135-140. [Medline: 21078236]

27. Pearce C, Phillips C, Hall S, Sibbald B, Porritt J, Yates R, et al. Following the funding trail: financing, nurses and teamwork in Australian general practice. BMC Health Serv Res 2011;11:38 [FREE Full text] [doi: 10.1186/1472-6963-11-38] [Medline: 21329506]
28. Department of Health and Ageing. Practice Incentives Program URL: http://www.medicareaustralia.gov.au/provider/incentives/pip/index.jsp [accessed 2013-04-25] [WebCite Cache ID 6G9c4yEIq]
29. Royal Australian College of General Practitioners. The RACGP Curriculum for General Practice. Melbourne: RACGP; 2011.
30. McInnes DK, Saltman DC, Kidd MR. General practitioners' use of computers for prescribing and electronic health records: results from a national survey. Med J Aust 2006 Jul 17;185(2):88-91. [Medline: 16842064]
31. Pearce C. Electronic medical records--where to from here? Aust Fam Physician 2009 Jul;38(7):537-540 [FREE Full text] [Medline: 19575073]
32. Davies K. The information-seeking behaviour of doctors: a review of the evidence. Health Information and Libraries Journal 2007:1.
33. Harvey KJ, Vitry AI, Roughead E, Aroni R, Ballenden N, Faggotter R. Pharmaceutical advertisements in prescribing software: an analysis. Med J Aust 2005 Jul 18;183(2):75-79. [Medline: 16022612]
34. Henderson J, Miller G, Pan Y, Britt H. The effect of advertising in clinical software on general practitioners' prescribing behaviour. Med J Aust 2008 Jan 7;188(1):15-20. [Medline: 18205556]
35. Sweidan M, Reeve JF, Brien JA, Jayasuriya P, Martin JH, Vernon GM. Quality of drug interaction alerts in prescribing and dispensing software. Med J Aust 2009 Mar 2;190(5):251-254. [Medline: 19296790]
36. Ammenwerth E, Schnell-Inderst P, Machan C, Siebert U. The effect of electronic prescribing on medication errors and adverse drug events: a systematic review. J Am Med Inform Assoc 2008;15(5):585-600 [FREE Full text] [doi: 10.1197/jamia.M2667] [Medline: 18579832]
37. Pearce C, Shachak A, Kushniruk A, de Lusignan S. Usability: a critical dimension for assessing the quality of clinical systems. Inform Prim Care 2009;17(4):195-198. [Medline: 20359396]
38. Ash JS, Berg M, Coiera E. Some unintended consequences of information technology in health care: the nature of patient care information system-related errors. J Am Med Inform Assoc 2004 Apr;11(2):104-112 [FREE Full text] [doi: 10.1197/jamia.M1471] [Medline: 14633936]
39. Pearce C, Arnold M, Phillips CB, Trumble S, Dwan K. The many faces of the computer: an analysis of clinical software in the primary care consultation. Int J Med Inform 2012 Jul;81(7):475-484. [doi: 10.1016/j.ijmedinf.2012.01.004] [Medline: 22325592]
40. Pearce C, Shearer M, Gardner K, Kelly J. A division's worth of data. Aust Fam Physician 2011 Mar;40(3):167-170 [FREE Full text] [Medline: 21597524]
41. Blankers M, Koeter MW, Schippers GM. Missing data approaches in eHealth research: simulation study and a tutorial for nonmathematically inclined researchers. J Med Internet Res 2010 Dec;12(5):e54 [FREE Full text] [doi: 10.2196/jmir.1448] [Medline: 21169167]
42. Stewart M, Brown J, Weston W, McWhinney L, McWilliam C, & Freeman T. Patient-centered Medicine: Transforming the Clinical Method: Transforming the Clinical Method (Patient-Centered Care Series). Oxford: Radcliffe Medical Press; 2003.
43. Potter SJ, McKinlay JB. From a relationship to encounter: an examination of longitudinal and lateral dimensions in the doctor-patient relationship. Soc Sci Med 2005 Jul;61(2):465-479. [doi: 10.1016/j.socscimed.2004.11.067] [Medline: 15893060]
44. Pearce C, Arnold M, Phillips C, Trumble S, Dwan K. The patient and the computer in the primary care consultation. J Am Med Inform Assoc 2011 Apr;18(2):138-142 [FREE Full text] [doi: 10.1136/jamia.2010.006486] [Medline: 21262923]
45. Reason J. Human error: models and management. BMJ 2000 Mar 18;320(7237):768-770 [FREE Full text] [Medline: 10720363]
46. Hannan A. Providing patients online access to their primary care computerised medical records: a case study of sharing and caring. Inform Prim Care 2010;18(1):41-49. [Medline: 20429977]
47. Swindells M, de Lusignan S. Lessons from the English National Programme for IT about structure, process and utility. Stud Health Technol Inform 2012;174:17-22. [Medline: 22491103]
48. de Lusignan S, Seroussi B. A comparison of English and French approaches to providing patients access to Summary Care Records: scope, consent, cost. Stud Health Technol Inform 2013;186:61-65. [Medline: 23542968]
49. Elliot-Smith A, Morgan MA. How do we compare? Applying UK pay for performance indicators to an Australian general practice. Aust Fam Physician 2010 Feb;39(1-2):43-48 [FREE Full text] [Medline: 20369134]
50. Stevens PE, Farmer CK, de Lusignan S. Effect of pay for performance on hypertension in the United kingdom. Am J Kidney Dis 2011 Oct;58(4):508-511. [doi: 10.1053/j.ajkd.2011.06.010] [Medline: 21816527]
51. Horsfield P, Teasdale S. Generating information from electronic patient records in general practice: a description of clinical care and gender inequalities in coronary heart disease using data from over two million patient records. Inform Prim Care 2003;11(3):137-144. [Medline: 14680536]

52. Avery AJ, Savelyich BS, Teasdale S. Improving the safety features of general practice computer systems. Inform Prim Care 2003;11(4):203-206. [Medline: 14980059]
53. Carpenter I, Ram MB, Croft GP, Williams JG. Medical records and record-keeping standards. Clin Med 2007 Aug;7(4):328-331. [Medline: 17882846]
54. Duftschmid G, Chaloupka J, Rinner C. Towards plug-and-play integration of archetypes into legacy electronic health record systems: the ArchiMed experience. BMC Med Inform Decis Mak 2013;13:11 [FREE Full text] [doi: 10.1186/1472-6947-13-11] [Medline: 23339403]
55. Hoerbst A, Ammenwerth E. Quality and Certification of Electronic Health Records: An overview of current approaches from the US and Europe. Appl Clin Inform 2010;1(2):149-164. [doi: 10.4338/ACI-2010-02-R-0009] [Medline: 23616834]
56. Yusof MM, Kuljis J, Papazafeiropoulou A, Stergioulas LK. An evaluation framework for Health Information Systems: human, organization and technology-fit factors (HOT-fit). Int J Med Inform 2008 Jun;77(6):386-398. [doi: 10.1016/j.ijmedinf.2007.08.011] [Medline: 17964851]
57. Lau F, Price M, Keshavjee K. From benefits evaluation to clinical adoption: making sense of health information system success in Canada. Healthc Q 2011;14(1):39-45. [Medline: 21301238]
58. Shabot MM. Ten commandments for implementing clinical information systems. Proc (Bayl Univ Med Cent) 2004 Jul;17(3):265-269 [FREE Full text] [Medline: 16200110]

Abbreviations

CMR: computerized medical records
EHR: electronic health record
GP: general practitioners
HL-7: Health level-7
ICD-10: International Classification of Disease version 10
NHS: National Health Service
PBS: Pharmaceutical Benefits Scheme

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Original Paper

Integrating Telehealth Care-Generated Data With the Family Practice Electronic Medical Record: Qualitative Exploration of the Views of Primary Care Staff

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Abstract

Background: Telehealth care is increasingly being employed in the management of long-term illness. Current systems are largely managed via "stand-alone" websites, which require additional log-ons for clinicians to view their patients' symptom records and physiological measurements leading to frustrating delays and sometimes failure to engage with the record. However, there are challenges to the full integration of patient-acquired data into family physicians' electronic medical records (EMR) in terms of reliability, how such data can best be summarized and presented to avoid overload to the clinicians, and how clarity of responsibility is managed when multiple agencies are involved.

Objective: We aimed to explore the views of primary care clinicians on the acceptability, clinical utility, and, in particular, the benefits and risks of integrating patient-generated telehealth care data into the family practice EMR and to explore how these data should be summarized and presented in order to facilitate use in routine care.

Methods: In our qualitative study, we carried out semi-structured interviews with clinicians with experience of and naïve to telehealth care following demonstration of pilot software, which illustrated various methods by which data could be incorporated into the EMR.

Results: We interviewed 20 clinicians and found 2 overarching themes of "workload" and "safety". Although clinicians were largely positive about integrating telehealth care data into the EMR, they were concerned about the potential increased workload and safety issues, particularly in respect to error due to data overload. They suggested these issues could be mitigated by good system design that summarized and presented data such that they facilitated seamless integration with clinicians' current routine processes for managing data flows, and ensured clear lines of communication and responsibility between multiple professionals involved in patients' care.

Conclusions: Family physicians and their teams are likely to be receptive to and see the benefits of integrating telehealth-generated data into the EMR. Our study identified some of the key challenges that must be overcome to facilitate integration of telehealth care data. This work particularly underlines the importance of actively engaging with clinicians to ensure that systems are designed that align well with existing practice data-flow management systems and facilitate safe multiprofessional patient care.

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KEYWORDS

telehealth care; family practice; data management

Introduction

Background

The changing global demography poses the twin challenges of an aging population, who suffer from a high and increasing prevalence of long-term conditions, and the falling numbers of people who can provide care for them. This realization has catalyzed international interest in self-monitoring and self-management of long-term conditions as one possible solution to this problem. Telehealth care, which uses information technologies (IT), to support such self-monitoring has the potential to be particularly useful in this context [1]. It has been used in a wide variety of conditions, principally the management of congestive heart failure (CHF) [2], diabetes mellitus [3], hypertension [4], chronic obstructive pulmonary disorder (COPD) [5], and asthma [6]. In most models of care, patients record symptoms (eg, breathlessness and cough) and physiologic data (eg, weight, blood pressure—BP, peak expiratory flow, and blood glucose). These data are then relayed via the Internet to a central server from where these are made available in a variety of summarized forms to both the patients and clinicians by providing alerts when preset symptom scores or physiologic parameters are breached. Clinicians may view data as needed, for example, daily for less stable conditions such as COPD and CHF or less frequently where there is less likelihood of rapid deterioration such as hypertension or diabetes.

Telehealth Care Data and Electronic Medical Records

The adoption of new IT systems of care is sometimes met with resistance from health practitioners, this often, at least in part, stemming from fears of increased workload [7,8]. Usability of such systems is paramount in determining if they will be successfully integrated within normal working patterns [9,10]. Throughout the course of our program of randomized controlled trials (RCTs) in telehealth care [11], a recurring issue has been the inability to integrate telehealth care-generated data into the electronic medical records (EMR) of family physicians [12-14]. Data are, therefore, usually stored on a separate website, which necessitates additional security log-ons and, in some cases, double entry of data resulting in lengthening of the consultation [15] and possibly introducing new data security risks. Finding a solution to these issues will become increasingly important as telehealth care systems become more widely deployed. The challenges of interoperability and data integration particularly affect care coordination, which is increasingly viewed as an essential component of patient-centered comprehensive care (reflected in the United States, for example in the concept of the patient-centered medical home) [16,17].

The National Institutes of Health in the United States held a conference in 2009 on the future of telehealth and identified the integration of telehealth data into EMR as a high impact topic that could potentially determine the success and future of telehealth [18]. Systems are now being developed to support integration of telehealth care-generated data into the EMR. However, it is not clear what preference physicians and general practice staff may have in terms of the types of data they would like uploaded into their systems, how these data should be summarized, what data reliability considerations should be considered (eg, the accidental inclusion of erroneous readings, such as improbably low weights, normally ignored by clinicians), and what medicolegal concerns clinicians may have.

We aimed to investigate the views of family physicians and their teams on the acceptability and clinical utility of integrating telehealth care data into EMR. In particular, we sought to understand what they viewed as the risks and benefits of importing such data and how they should be presented and summarized in order to maximize acceptability and thereby facilitate use.

Methods

Design

We undertook a qualitative study—through general practices in Edinburgh, Scotland, United Kingdom—which consisted of semi-structured interviews with primary care practice staff following demonstration of pilot software, which illustrated a variety of methods by which data could be incorporated into the EMR.

Sampling and Recruitment of Practices and Participants

From practices that had been involved in our RCTs of telehealth care monitoring in hypertension and diabetes, a family physician and a practice nurse who were personally involved in telehealth care management were selected. However, we also considered it important to determine the views of family physicians and nurses who may be less familiar with telehealth care technology as those practices who had agreed to take part in telehealth care studies may preferentially have interested “early adopters” [19,20] and any large scale roll-out of telehealth care will need to involve those who tend to embrace such technologies less readily.

We therefore aimed to purposefully sample physicians and practice nurses representing a range of ages from telehealth care experienced and naïve practices, from areas of differing socioeconomic levels, and family practice size. Initial contacts were made through a personal approach to potentially suitable clinicians who had taken part in our telehealth RCTs. We also approached practices who had previously been invited to take part in the RCTs, but had decided not to and also other nonparticipating practices in the Lothian research network. In addition, we interviewed two specialist community respiratory physical therapists who had participated in previous telehealth care research and could provide complementary insights into how the integration of telehealth data into the primary care EMR could impact on the wider multidisciplinary care team.

Data Generation

The interviewees were shown pilot software developed by the Department of Health's National Health Service Connecting for Health (CfH) Informatics Directorate Assistive Technology Programme team in association with Newham Primary Care Trust London, which was designed to link patient accrued data from the Philips Motiva [21] telehealth system with the EMIS [22] Web GP EMR system (which is one of the most commonly used systems in the United Kingdom). This was shown as a PowerPoint presentation and animation on a laptop computer. This pilot software enables interoperability between health care systems, allowing telehealth care-generated data (eg, BP readings) to be viewed using the family practice EMR system and then permanently filed into the patient EMR. A full description and screenshots from the system are included in Multimedia Appendix 1. Clinicians who had not been involved with telehealth care were, in addition to the presentation, given details of how a telehealth care system works and given an indication of the quantity and quality of data that are expected to be generated by such systems.

In depth, face-to-face interviews with family physicians and practice staff were carried out at the practices following the software demonstration. Interviews were digitally audio-recorded and transcribed. An initial topic guide (see Multimedia Appendix 2), based on established research on diffusion of innovation in health service organizations [23], was used to aid discussion, and this guide was reviewed and iteratively refined during the process of data collection and analysis.

Data Analysis

Thematic analysis [24] was used to identify the factors that might influence the integration of telehealth care-generated data into the family practice EMR. Analysis was supported by NVivo. Transcripts were repeatedly read and coded to include both anticipated and unanticipated themes. Analysis was ongoing to allow emerging themes to be fed back into the data collection. Constant comparison was employed to ensure that the thematic analysis represented all perspectives and negative cases were actively sought [25].

A coding framework was drawn up by the research team as new themes emerged. The coding framework was informed by the aims of the research and research questions and previous research in examining the processes whereby telehealth innovations are developed, implemented, and sustained [7,23]. As analysis was ongoing, the content of the latter interviews could be examined against the coding framework (Textbox 1). We limited interviews to 20 as it was clear that no new insights were being generated beyond the 15th interview and saturation had been achieved. The ongoing discussion of the findings among the project team for analysis enhanced the trustworthiness of the findings.

During the emergence of the data, it became apparent that several of the themes provided an outline of the "optimal" telehealth care system design desired by family physicians and their teams. These data were, therefore, further discussed by the project team and combined to create a model data pathway for a telehealth integration system (Figure 1).

Textbox 1. Thematic organization.

Perceptions of workload:

System design

Previous experience of telehealth systems

Efficiencies through improved access

Ease of use

Training and support

Data management

Amount of data

Flexibility of data parameters

Data flows

Data coding

Payment

Safety:

Impact on professional-patient relationship

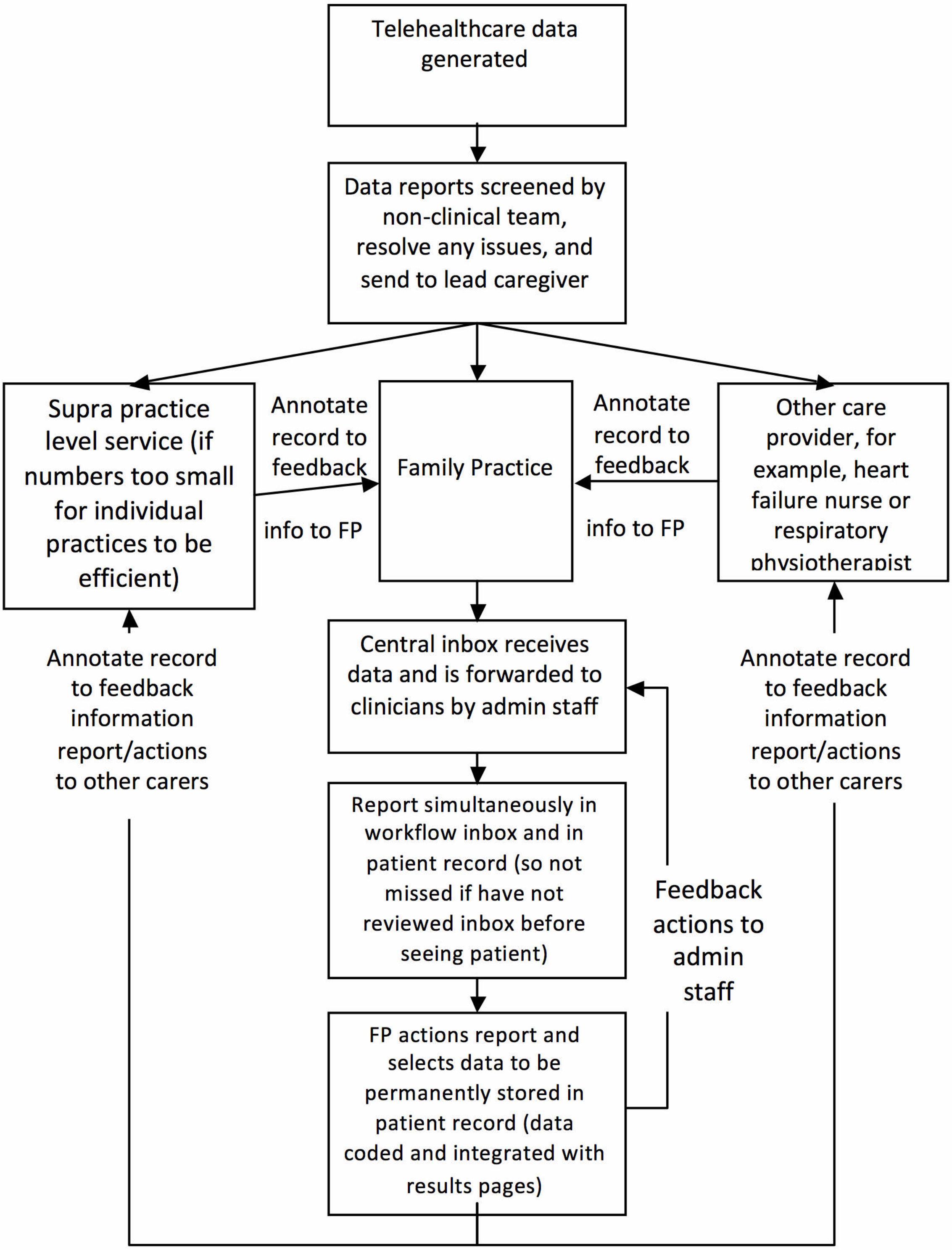
Data quality

Risks of data overload and error

Confidentiality

Liability

Figure 1. Model data pathway for telehealth integration system.



Results

Participants' Characteristics and Software Demonstration

The completed dataset comprised 20 participants. We recruited 10/20 (50%) professionals with experience of telehealth care and 10/20 (50%) without any prior experience, 10/20 (50%) were family physicians, 8/20 (40%) practice nurses, and 2/20 (10%) specialist respiratory physical therapists. The participant's characteristics, including who had experience of telehealth care, are outlined in Multimedia Appendix 3. The software was demonstrated either in the participants' own home or in workplace according to their preference and the interview took just under an hour.

Main Themes

Overarching Themes

The main themes identified are discussed below and summarized in Textbox 1. In addition to these key themes, there was discussion of the utility of telehealth more generally; however, this is not discussed here as similar findings have been published elsewhere [12,13,26].

There were two overarching themes, which encompassed the barriers and facilitators to integrating patient accrued data. These were:

- *Perceptions of workload* which incorporated the importance of good system design and training, the likely quantity of data that would have to be processed, and if physicians should be given additional payment for overseeing the integrated data.
- *Safety* which encompassed concerns about the possible impact on physician-patient consultation, confidentiality issues, data quality, error due to data overload, interprofessional communication and responsibilities, and, related to these issues, concerns about liability.

Perceptions of Workload

System Design

Previous Experience of Telehealth System Design

Participants with preexisting knowledge of telehealth were generally most positively disposed toward IT and were more enthusiastic about integrating telehealth care data into the EMR. This positive attitude arose because their previous involvement in telehealth was colored by the frustrating and time-consuming experience of having to access an additional website for results. However, other participants described their own lack of IT experience or expertise may deter them from adopting and, in turn, adapting to new systems. For some clinicians, suggestion that they should engage with additional IT posed a seemingly insurmountable barrier.

> *Some people would absolutely freak out, even some of our colleagues. I don't know if that's the sort of... anybody's said that, because some people are just absolutely at breaking point with regard to using technology and some people it's just the last kind of thing that they can take, do you know what I mean?* [Family physician—FP3 Telehealth care naïve—TN]

Efficiencies Through Improved Access

The pervasive benefit from adopting an integrated system was seen to be improved access to data. When access involved an additional log-on many doctors and nurses (except those directly involved in a trial) did not access these data; however, they felt that with data integrated into the EMR they would definitely utilize it for patient management.

> *It's just the fact that you had to then print off all the details from your telehealth and then transfer all those details into the patient's notes. … So, if it was transferring into the patients' clinical notes automatically I think it would be great.* [Practice nurse—PN9 Telehealth care experienced—TE]

Despite concerns over increasing workload, there was recognition of the potential for an integrated telehealth system to reduce consultations and home visits while enhancing patient care.

> *Certainly going to give you a better picture of really where a patient is sitting at, if you're getting all these current results coming in… What I'm trying to say, you might prevent a whole load of unnecessary visits, medications, if you're actually getting a clearer picture of where they are.* [PN19 TN]

Ease of Use

Among all participants, it was a priority that any future system is simple to use and terms such as "user friendly" and "intuitive" arose frequently in their discourse. "Reducing the number of clicks... that you need in order to deal with something..." [FP10 TE] was deemed essential.

> *Yeah, keeping it, probably, keeping it simple, keeping it easily accessible, so, you know, a click away is always what they say for a lot of these things, and clear and concise with not, you know, just keeping the information basic without having to read through screeds and screeds [a lot] of stuff that's potentially not necessary for what your job entails.* [PN15 TE]

Training and Support

Although the demonstrated system appeared relatively easy to use, training was thought important and this would, as suggested, have to be tailored to individuals' IT knowledge. Any additional new software for managing the integrated data, including setting preferences for displaying data and warnings, needed to closely resemble the existing EMR as much as possible. It was suggested that if the screen presentation, commands, short-cuts, etc for displaying the data were similar to the EMR, this would reduce the training required. Training could also be assisted by a few members of staff particularly trained as "on-site experts", who could provide a first line of support to the practice, and by follow-up training sessions scheduled once physicians and nurses have trailed the system.

> *No, I think you'd try and design it so there was virtually no training required. You'd try and design so that the dataflow was no different to dataflow in*

> *the practice... depending on other sources, cause you can make it different...* [FP7 TE]

Data Management

Developing a System

Overall, it was felt that barriers to adoption would be greatly reduced by developing a system that was as compatible as possible with existing working practices:

> *You need to pick a system that does what you want it do, whereas what we were given here [previous telehealth system] was a system and we had to try fit with it. Whereas, actually, the idea of telehealth is it needs to fit with what you're doing.* [PT4 TE]

Amount of Data

The participants felt it was important that a system should allow choice of exactly what, and how much, data get imported into the EMR as otherwise "you don't see the wood from the trees" [FP7 TE]. It was considered essential that the EMR was not "cluttered" with telehealth information to the detriment of other clinical information. The amount of data desired also varied according to the disease being monitored and who was the main case manager. They suggested that a filtering facility may be beneficial on the working screen, allowing display of imported data among routine health care consultations, or remove it to view consultations alone. Data summaries were preferred as opposed to raw figures. Therefore, for some, graphical presentation summarizing patient data with easy access to a fuller report from within the EMR were viewed as extremely useful. However, views on the utility of graphical presentation were mixed and related to personal preference. The ability to choose format was therefore desirable. Participants who preferred graphical data described this as a useful aid in consultation with patients.

> *What primary care wants is the report... but you probably don't need all the 40 values... and, I suppose, telehealth is no different… you know, what you want is the range... for that person, and somebody can give you the variability.* [FP7 TE]

Flexibility of Data Parameters and Alerts

All clinicians valued the flexibility to set data parameters specific to each patient, which trigger an alert if readings fall outside these limits, with the caveat that parameters were easily set and visible alongside any results they received. There were concerns, however, about who set parameters and lines of responsibility; how often these would need to be updated (eg, when people's clinical condition or treatment changed); the workload involved; and how all care teams would be alerted when and why they had been altered.

> *Being able to use the parameters and decide who it's going to, I like that, that you can set it for that. Because every patient is so different and you do worry that there's just a blanket approach, which there just can't be with patients because they're so individual—yeah.* [FP3 TN]

In this context, alerts prompting people to revise data parameters were discussed, with mixed views on their utility. Some clinicians felt that these were unnecessary as they should review settings as part of their usual management. Other clinicians were concerned that such reminders would quickly become an annoyance with the risk that they became immune to them or missed them if they popped up and faded. There was agreement that there should be the option to turn them off.

> *I think, it could be useful, I think, if you're going to design that you probably want to design an option to turn the pop-ups on or off… I, personally, don't like those [referring to fading reminders] because if you've turned it on, and you're talking to the patient, because, and not looking at the screen, you might not see it.* [FP17 TN]

Data Flows

Data flows arose as an important aspect of the system design. Data flow depended on the disease and number of patients being monitored. For most conditions, physicians felt that data should initially be screened by a nonclinical worker (eg, a telehealth care service), to screen out any technical problems (eg, people not taking measurements, faulty equipment, etc) as the workload was too great and not an efficient use of their time.

> *If you have... a thousand patients on telehealth, it's not an effective use of clinician time, so, we're back to the nonclinician following an algorithm of whether to phone, or not… one of the lessons we learnt with telehealth in Lothian was that doing it at a practice level is not very efficient....* [GP7 TE]

Doctors stressed that those messages requiring "action" should be sent to the lead care provider and those for "information only" sent to the entire care team and clearly labeled as such. A priority was that data, particularly "action" messages, did not go astray.

> *Yes, there has to be some way of making sure that somebody sees important—yes, I think there has to be some grading of how urgent things are… if you could set parameters above which something would flash up or—but, yes, the reception staff who are directing things would sort that out.* [FP13 TN]
>
> *So, you need, you, probably, want all data information to go into a central point in the practice... and then somebody to workflow it in the practice... otherwise if I go off on holiday for 3 weeks then it's going to sit in my inbox for 3 weeks... and nothing's going to happen.* [FP7 TE]

There was concern that telehealth integration could potentially disrupt existing plans of care. Consequently, interdisciplinary communication and the development of service agreements, as to who dealt with what information and how this was communicated to the entire team, were seen as essential to the implementation and safe delivery of the service.

> *But it seems that there could become this situation where we're getting results, the specialist nurses are already going in and there could be this scenario of who's dealing with what?* [FP3 TN]

Several physicians and nurses suggested that ensuring data (which did not require emergency action) that reached the appropriate case manager could be assisted by normalization within the current data flows to assimilate everyday dealings with existing data sources such as laboratory results or hospital letters. Existing practice flows included a central practice inbox, visibility of abnormal results in clinician's workflow and individual records simultaneously, and the ability to feedback to other practice staff and care teams for any actions taken based on these results without adding excessively to the clinical workload. A model pathway based on these discussions is shown in Figure 1.

Data Coding

Another important design feature was enabling imported data to not only appear on the consultation page, but also simultaneously populate the clinical records result pages, including graphs. Presentation of data needed to be clearly delineated from other information, and imported data should not occupy much space on the consultation screen. For example, it was suggested that incoming telehealth messages should be visually distinct from other messages in the inbox and state exactly what data are enclosed. This would be achieved by ensuring data entries were appropriately coded and it was suggested that codes should allow differentiation of telehealth readings from readings taken in the practice or elsewhere (linked color coding or annotation).

> *I think it'll be quite important to somehow integrate it so that if you wanted to see all the blood pressures they would all be there regardless of where they were taken, so that it's not a completely separate system but that you would actually have everything at a glance. At the same time though, be it with a different color or a note or something, to say that they were from a different system or home readings.* [FP12 TN]

Color was also thought to help information processing. Highlighting normal parameters on the graph as shaded or colored was suggested; these should ideally be values set for specific patients and not generic.

> *Color just because, like I said previously, there's so much to read, there's so much to do… Certainly, the graph's good because it's instant and you can—it instantly tells you we need to look at that.* [PN11 TN]

Reimbursement

Clinicians identified financial incentive as a strong driver toward implementing an integrated system. Some thought that additional financial incentives were required to persuade family physicians to adopt the system, and for taking on additional workload. However, it was also recognized that in the United Kingdom, data recording to demonstrate the achievement of targets in the management of long-term conditions is already financially incentivized under the Quality and Outcomes Framework (QOF) [27]. The integrated system had the potential to facilitate this.

> *I mean that sounds a bit, blunt but yes, it [family practice] is a business and they [family physicians] are always looking for ways to make extra cash…* [PN19 TN]

> *If you market it from a QOF point, I think every GP practice would take it on. ….. Just always market it as that, it's going to help you get your QOF points.* [PN18 TE]

Safety

Professional-Patient Relationship

Positively, it was considered that integrated delivery of care may encourage self-management and mutual respect between clinicians and patients. The integrated system was unlikely to influence clinicians' manner, as most have adapted to computers within their patient consultation. However, concern over moving toward a data-focused approach was raised including potentially missing clinical cues and interpreting data in a vacuum.

> *I suppose, general practice, I suppose, always focuses on people, patients, persons, real people, and of course recordings are part of a picture, but I think you have to be careful you don't get caught up with what the machine is saying you feel, rather than actually how you do feel, and I think there is a wee danger, if you become too focused simply on measurements, actually that becomes your goal.* [FP1 TN]

Data Quality

Participants identified risks associated with patient self-monitoring, their competence in taking readings, the resultant quality of data, and the implications of integrating the data permanently into clinical records. Ways of handling these concerns included ensuring patients' received good training that their equipment and techniques are reviewed.

> *All of a sudden you've got a reading which makes no clinical sense. If you could somehow remove that or put it there but not actually making it count with a reason for it… you can't delete them, you just have to put a comment on it….* [FP12 TN]

Risks of Data Overload and Error

Increased workload was predicted in checking incoming results and also "actioning" anything abnormal, and work overload risked negative consequences on care.

> *I don't know... if you're inundated with too much information, and it's all normal information then the ones that need acting on might, it's easier to miss them.* [FP17 TN]

Confidentiality

There was acknowledgement among participants that confidentiality of data could be a risk associated with integration of telehealth data into the EMR; however, greater concern was expressed over the confidentiality of current paper-based results and the Web-based telehealth system.

Protective factors were the existence of health care professionals' codes of conduct and obtaining informed consent from patients.

> *The other thing is the website that we use at the moment, I'm not sure how safe it is, from an*

> *information governance point of view, and I think that's been a bit of the issues about populating it with more patient data.* [Physical therapist (PT)4 TE]

Liability

Medicolegal liability of integrating telehealth data was considered a risk by some participants. However, in contrast to our expectations, most participants felt that the integrated system was not different from any other results and would not place them at increased medicolegal risk; in fact it may even be protective.

> *I think that would be a massive concern, and I think particular of one of my partners would be absolutely catatonic looking at this, don't send me things unless you want me to take responsibility. And I think it's that thing of the collusion of anonymity if loads of people are getting results who exactly is dealing with it?* [FP3 TN]

> *But it's like anything, any result that comes through, you know, from that point of view, you've, the minute it lands in your docman [laboratory result management system], or on your desk then that's you, you've got to sort it out, haven't you, so.* [PN15 TE]

Textbox 2 presents a summary of clinician recommendations arising from these in-depth interviews and Figure 1 shows a model of how data might be integrated with minimal disruption to current data management pathways.

Textbox 2. Summary of clinician recommendations.

1. Any system must be simple and compatible with existing EMR system
2. Clear lines of responsibility must be agreed in terms of who must make the first response to abnormal results. This is likely to differ by the condition monitored
3. Lead carers would receive and deal with "action" data reports and the other care team members would only require much less regular "information-only" summaries
4. Data flows should be normalized to as closely resemble existing incoming data flows as possible (for proposed pathway, see Figure 1) and include a mechanism to feedback information to other care team members
5. Minimizing the amount of imported data is essential and screen filters may be useful
6. Graphical presentation and the use of color are helpful to summarize data and indicate data parameters; however, easy access to an attachment of the full dataset from a summarized chart is extremely useful
7. Flexibility of data alert parameters is beneficial only if they are easy to set
8. Coding of incoming telehealth data to identify which data are patient accrued (possibly color coded) is desirable.
9. Training should involve the instruction of several "on-site" experts who can assist other practice members and IT support, both in practice and from the software company, need to be easy to access
10. Gradual introduction of any new system, initially with small numbers of patients/conditions

Discussion

Principal Findings

Our study showed that participants were generally very positive about prototype software designed to improve integration of telehealth data with the EMR and were eager to explain what aspects of the system would increase its acceptability and facilitate its use. System design, in particular, was explored in detail, which enabled the design of a proposed data pathway modeled on clinicians' preferences (Figure 1) and a list of recommendations to aid implementation of such software (Textbox 2). The key factors were ease of use; receiving as little incoming data as clinically necessary, the normalization of data flows, and ensuring clear lines of communication and responsibility for different clinicians involved in the care of the patient. Liability concerns while expressed were not a major issue, nor were concerns regarding the reliability of the patient accrued data.

Strengths and Limitations

A strength of our study was that the project team came from a mixed background of clinical, research, and IT experience that provided rounded understanding and input into the creation of the coding framework. In addition, the research fellow had broad experience as a clinician, researcher, and public health specialist; thus perhaps enabling more frank discussion as the researcher appreciated the context in which the interviewees were working and the way in which this technology may interact with their working practices.

While we were successful in recruiting a range of clinicians from both telehealth naïve and experienced practices in a range of practice size and deprivation, it may be that those expressing an interest in this type of study were more interested in technology than the general population. As in previous studies the use of demonstration software helped stimulate discussion; however, the ability to interact with the software in a "live" situation would have been preferable. The EMIS EMR software was unfamiliar to some using alternative EMR software and this may have reduced their ability to see the full potential of the integrative software. Finally, the research was carried out in only one country which raises potential issues in respect of transferability.

Comparison With Prior Work

Our results are in keeping with the literature—including the normalization process model (NPM), which has been established as a useful framework in considering introducing telehealth care for chronic conditions [28]. Normalization has been defined as “an ongoing cycle of activity aimed at making a new practice ‘fit in’ with the work of individuals and their context of practice” [29]. Our overarching theme “perceptions of workload” reflected the NPM dimension of “interactional workability” in terms of how the work would take place and whether the telehealth innovation would increase or decrease the ease and efficiency of their work. This theme also incorporated elements of “contextual integration” in terms of how the health care organizations may provide resources to reimburse the additional time and effort required by the telehealth innovation. Our other overarching theme of “safety” relates to the concepts of “relational integration” and “skill set workability” in terms of how the telehealth care system may alter the health care team relationships, division of labor, boundaries of practice, accountability, and confidence in the safety of the system [30].

Our findings also reflected the broader literature on conditions that influence clinicians’ decision to adopt or reject innovations in health care settings in that we identified the influence of “system antecedents” on the adoption of an integrated system [19,23,31]. Participants’ prior experience with telehealth care particularly acted as a driver toward an integrated system as they understood difficulties with the existing system, could visualize the potential of integration, and this overcame resistance to change [32]. Ease of use of the system was another important driver to adoption which is a common feature of several existing models of information technology acceptance [33] and is defined as “the degree to which a person believes that using a particular system would be free of effort” [34]. Additional drivers to adoption were identified as enhanced patient care, confidentiality, and financial benefit.

Likely barriers to adoption were participants’ unfamiliarity with IT, negative experience with implementation of preceding IT systems, and particularly the compatibility of the integrated system with their normal work practices and ethos. Compatibility of telehealth with health care delivery has previously been acknowledged as having an important role in determining telehealth adoption [35]. Furthermore, the need to ensure clear evidence-based care plans that inform decision making [16], and the importance of recognizing any additional workload which may arise as a result of non-face-to-face clinical encounters have been identified as challenges in multiple settings, including the emerging concept of the patient-centered medical home [17].

Other perceived challenges included workload, ensuring data quality and confidentiality, liability risks, and sustainability. Surprisingly, liability was not as strong a concern as has been suggested by previous studies [27,36,37] as many saw the additional data as no different from other sources of data with which they were used to dealing and taking responsibility for. The principal risk perceived by these clinicians was increased workload. If, however, the system was designed to accommodate their needs and usual practices, they could also see substantial benefits in terms of accessing and streamlining telehealth data, potentially reducing consultations and home visits and enhancing patient care.

Our recent systematic review of eHealth literature [1] identified that considerable changes to consultation dynamics and workflow processes can occur with the introduction of telehealth care. For an integrated system, the potential changes included more immediate patient demands and altered care pathways. Consequently, participants emphasized the importance of interdisciplinary communication and service agreements to delineate roles and responsibilities in the delivery of care.

Conclusions

There is a growing evidence base informing deliberations on the use of telehealth to manage long-term conditions. A key success consideration is how the technology integrates into routine practice and for this to happen it must be seen as both easy to use and effective. The lack of integration of telehealth data with the EMR has been a source of frustration for the physicians and nurses attempting to use these systems in trial contexts [12,14]. Our study has demonstrated the potential acceptability and clinical utility of a telehealth integrated system among primary care clinicians, with specific caveats strongly expressed by the participants to ensure compatibility with existing care practices and normalization of data flows. Our work has provided clear pointers to the system design preferred by clinicians and should therefore contribute to future systems development as telehealth care moves from an experimental phase to a technology that is embedded into routine models of care delivery.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Description and screenshots from EMIS.

[PDF File (Adobe PDF File), 356KB - ijmr_v2i2e29_app1.pdf]

Multimedia Appendix 2

Topic guide.

[PDF File (Adobe PDF File), 7KB - ijmr_v2i2e29_app2.pdf]

Multimedia Appendix 3

Characteristics of participants.

[PDF File (Adobe PDF File), 4KB - ijmr_v2i2e29_app3.pdf]

References

1. McLean S, Protti D, Sheikh A. Telehealthcare for long term conditions. BMJ 2011 Feb 03;342:d120-d120 [FREE Full text] [doi: 10.1136/bmj.d120]
2. Polisena J, Tran K, Cimon K, Hutton B, McGill S, Palmer K, et al. Home telemonitoring for congestive heart failure: a systematic review and meta-analysis. J Telemed Telecare 2010;16(2):68-76. [doi: 10.1258/jtt.2009.090406] [Medline: 20008054]
3. Polisena J, Tran K, Cimon K, Hutton B, McGill S, Palmer K. Home telehealth for diabetes management: a systematic review and meta-analysis. Diabetes Obes Metab 2009 Oct;11(10):913-930. [doi: 10.1111/j.1463-1326.2009.01057.x] [Medline: 19531058]
4. McKinstry B, Hanley J, Wild S, Pagliari C, Paterson M, Lewis S, et al. Telemonitoring based service redesign for the management of uncontrolled hypertension: multicentre randomised controlled trial. BMJ 2013;346:f3030 [FREE Full text] [Medline: 23709583]
5. McLean S, Nurmatov U, Liu JL, Pagliari C, Car J, Sheikh A. Telehealthcare for chronic obstructive pulmonary disease: Cochrane Review and meta-analysis. Br J Gen Pract 2012 Nov;62(604):e739-e749 [FREE Full text] [doi: 10.3399/bjgp12X658269] [Medline: 23211177]
6. McLean S, Chandler D, Nurmatov U, Liu J, Pagliari C, Car J, et al. Telehealthcare for asthma. Cochrane Database Syst Rev 2010(10):CD007717. [doi: 10.1002/14651858.CD007717.pub2] [Medline: 20927763]
7. May C, Harrison R, Finch T, MacFarlane A, Mair F, Wallace P, Telemedicine Adoption Study Group. Understanding the normalization of telemedicine services through qualitative evaluation. J Am Med Inform Assoc 2003;10(6):596-604 [FREE Full text] [doi: 10.1197/jamia.M1145] [Medline: 12925553]
8. Cresswell KM, Bates DW, Sheikh A. Ten key considerations for the successful implementation and adoption of large-scale health information technology. J Am Med Inform Assoc 2013 Jun;20(e1):e9-e13. [doi: 10.1136/amiajnl-2013-001684] [Medline: 23599226]
9. Broens TH, Huis in't Veld RM, Vollenbroek-Hutten MM, Hermens HJ, van Halteren AT, Nieuwenhuis LJ. Determinants of successful telemedicine implementations: a literature study. J Telemed Telecare 2007;13(6):303-309. [doi: 10.1258/135763307781644951] [Medline: 17785027]
10. Cresswell K, Morrison Z, Crowe S, Robertson A, Sheikh A. Anything but engaged: user involvement in the context of a national electronic health record implementation. Inform Prim Care 2011;19(4):191-206. [Medline: 22828574]
11. The Telescot Programme. URL: http://www.telescot.org/ [accessed 2013-07-09] [WebCite Cache ID 6Hz12CjRN]
12. Hanley J, Ure J, Pagliari C, Sheikh A, McKinstry B. Experiences of patients and professionals participating in the HITS home blood pressure telemonitoring trial: a qualitative study. BMJ Open 2013;3(5) (forthcoming) [FREE Full text] [doi: 10.1136/bmjopen-2013-002671] [Medline: 23793649]
13. Fairbrother P, Ure J, Hanley J, McCloughan L, Denvir M, Sheikh A, The Telescot programme team. Telemonitoring for chronic heart failure: the views of patients and healthcare professionals---a qualitative study. J Clin Nurs 2013 Mar 4 (forthcoming). [doi: 10.1111/jocn.12137] [Medline: 23451899]
14. Ure J, Pinnock H, Hanley J, Kidd G, McCall Smith E, Tarling A, et al. Piloting tele-monitoring in COPD: a mixed methods exploration of issues in design and implementation. Prim Care Respir J 2012 Mar;21(1):57-64 [FREE Full text] [doi: 10.4104/pcrj.2011.00065] [Medline: 21785816]
15. Alexandru CA, McKinstry B. Usability evaluation of clinician web back-ends to telemonitoring systems: two case-studies in Scotland. Stud Inform Control 2012;21(2):181-190.
16. Berenson RA, Hammons T, Gans DN, Zuckerman S, Merrell K, Underwood WS, et al. A house is not a home: keeping patients at the center of practice redesign. Health Aff (Millwood) 2008;27(5):1219-1230 [FREE Full text] [doi: 10.1377/hlthaff.27.5.1219] [Medline: 18780904]

17. Kellerman R, Kirk L. Principles of the patient-centered medical home. Am Fam Physician 2007 Sep 15;76(6):774-775 [FREE Full text] [Medline: 17910291]
18. Ackerman MJ, Filart R, Burgess LP, Lee I, Poropatich RK. Developing next-generation telehealth tools and technologies: patients, systems, and data perspectives. Telemed J E Health 2010;16(1):93-95 [FREE Full text] [doi: 10.1089/tmj.2009.0153] [Medline: 20043711]
19. Rogers EM. Diffusion of Innovations. 5th edition. New York: Free Press; 2003:283.
20. Sheikh A, Cornford T, Barber N, Avery A, Takian A, Lichtner V, et al. Implementation and adoption of nationwide electronic health records in secondary care in England: final qualitative results from prospective national evaluation in "early adopter" hospitals. BMJ 2011;343:d6054 [FREE Full text] [Medline: 22006942]
21. Philips Motiva. URL: http://www.healthcare.philips.com/main/products/telehealth/products/motiva.wpd [accessed 2013-07-09] [WebCite Cache ID 6Hz19ZwCs]
22. EMIS. URL: http://www.emis-online.com/ [accessed 2013-11-18] [WebCite Cache ID 6LDhBPQ1B]
23. Greenhalgh T, Robert G, Macfarlane F, Bate P, Kyriakidou O. Diffusion of innovations in service organizations: systematic review and recommendations. Milbank Q 2004;82(4):581-629 [FREE Full text] [doi: 10.1111/j.0887-378X.2004.00325.x] [Medline: 15595944]
24. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000 Jan 8;320(7227):114-116 [FREE Full text] [Medline: 10625273]
25. Eisenhardt K. Building theories from case study research. Acad Manage Rev 1989 Oct 01;14(4):532-550. [doi: 10.5465/AMR.1989.4308385]
26. Fairbrother P, Pinnock H, Hanley J, McCloughan L, Sheikh A, Pagliari C, et al. Exploring telemonitoring and self-management by patients with chronic obstructive pulmonary disease: a qualitative study embedded in a randomized controlled trial. Patient Educ Couns 2013 May 4 (forthcoming). [doi: 10.1016/j.pec.2013.04.003] [Medline: 23647981]
27. The National Institute for Health and Care Excellence. About the Quality and Outcomes Framework (QOF). URL: http://www.nice.org.uk/aboutnice/qof/ [accessed 2013-07-09] [WebCite Cache ID 6Hz1EIcrI]
28. Mair FS, Hiscock J, Beaton SC. Understanding factors that inhibit or promote the utilization of telecare in chronic lung disease. Chronic Illness 2008;4:110. [doi: 10.1177/1742395308092482]
29. Finch TL, Mair FS, O'Donnell C, Murray E, May CR. From theory to 'measurement' in complex interventions: methodological lessons from the development of an e-health normalisation instrument. BMC Med Res Methodol 2012;12(69):3. [doi: 10.1186/1471-2288-12-69]
30. May C, Finch T, Mair F, Ballini L, Dowrick C, Eccles M, et al. Understanding the implementation of complex interventions in health care: the normalization process model. BMC Health Serv Res 2007;7:148 [FREE Full text] [doi: 10.1186/1472-6963-7-148] [Medline: 17880693]
31. Cresswell K, Sheikh A. Organizational issues in the implementation and adoption of health information technology innovations: an interpretative review. Int J Med Inform 2013 May;82(5):e73-e86. [doi: 10.1016/j.ijmedinf.2012.10.007] [Medline: 23146626]
32. Clark M, Goodwin N. Sustaining innovation in telehealth and telecare. WSDAN briefing paper. WSD Action Network. The Kings Fund URL: http://www.kingsfund.org.uk/sites/files/kf/Sustaining-innovation-telehealth-telecare-wsdan-mike-clark-nick-goodwin-october-2010.pdf [accessed 2013-07-09] [WebCite Cache ID 6Hz1rMYv8]
33. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Quarter 2003:425-478. [doi: 10.2307/30036540]
34. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Quarter 1989:319-340.
35. Vuononvirta T, Timonen M, Keinänen-Kiukaanniemi S, Timonen O, Ylitalo K, Kanste O, et al. The compatibility of telehealth with health-care delivery. J Telemed Telecare 2011;17(4):190-194. [doi: 10.1258/jtt.2010.100502] [Medline: 21339305]
36. Anderson JG. Social, ethical and legal barriers to e-health. Int J Med Inform 2007;76(5-6):480-483. [doi: 10.1016/j.ijmedinf.2006.09.016] [Medline: 17064955]
37. Catwell L, Sheikh A. Evaluating eHealth interventions: the need for continuous systemic evaluation. PLoS Med 2009 Aug;6(8):e1000126 [FREE Full text] [doi: 10.1371/journal.pmed.1000126] [Medline: 19688038]

Abbreviations

BP: blood pressure
CHF: congestive heart failure
COPD: chronic obstructive pulmonary disorder
EMR: electronic medical records
FP: family physician
IT: information technologies

NPM: normalization process model
PN: practice nurse
PT: physical therapist
QOF: quality and outcomes framework
RCTs: randomized controlled trials
TE: telehealth care experienced
TN: telehealth care naïve

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Original Paper

Aftershocks Associated With Impaired Health Caused by the Great East Japan Disaster Among Youth Across Japan: A National Cross-Sectional Survey

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Abstract

Background: The Great East Japan earthquake, subsequent tsunamis and the Fukushima nuclear incident had a tremendous impact on Japanese society. Although small-scale surveys have been conducted in highly affected areas, few have elucidated the disaster's effect on health from national perspective, which is necessary to prepare national policy and response.

Objective: The aim of the present study was to describe prefecture-level health status and investigate associations with number of aftershocks, seismic intensity, a closer geographical location to the Fukushima Nuclear Power Plant, or higher reported radiation dose in each prefecture even after adjusting for individual socioeconomic factors, by utilizing individual-level data acquired from a national cross-sectional Internet survey as well as officially reported prefecture-level data.

Methods: A Japanese government research institute obtained 12,000 participants by quota sampling and 7335 participants were eligible for the analysis in an age range between 17 and 27 years old. We calculated the percentage of people with decreased subjective health in each prefecture after the earthquake. Variability introduced by a small sample size for some prefectures was smoothed using empirical Bayes estimation with a random-intercept logistic model, with and without demographic factors. Multilevel logistic regression was used to calculate adjusted odds ratios (ORs) for change of subjective health associated with prefecture-level and individual-level factors.

Results: Adjusted empirical Bayes estimates were higher for respondents commuting in the northeast region (Iwate 14%, Miyagi 19%, and Fukushima 28%), which faces the Pacific Ocean, while the values for Akita (10%) and Yamagata (8%) prefectures, which do not face the Pacific Ocean, were lower than those of Tokyo (12%). The values from the central to the western region were clearly lower. The number of aftershocks was coherently associated with decreased health (OR 1.05 per 100 times, 95% CI 1.04-1.06; *P*<.001) even after adjusting for covariates (OR 1.02 per 100 times, 95% CI 1.00-1.05; 1.32 per 1000 times, 95% CI 1.03-1.71; *P*=.049). In contrast, seismic intensity of the initial earthquake (OR 0.87, 95% CI 0.65-1.17; *P*=.36), radiation dose (OR 1.16, 95% CI 0.82-1.64; *P*=.41), and distance from the Fukushima Nuclear Power Plant (OR 1.00, 95% CI 0.99-1.00; *P*=.66) were not. Change in job condition (OR 2.05, 95% CI 1.72-2.45; *P*<.001), female (OR 1.43, 95% CI 1.19-1.69; *P*<.001), higher age (OR 1.06 per year, 95% CI 1.02-1.11; *P*=.005), and duration of evacuation longer than 4 weeks (OR 1.44, 95% CI 1.06-1.97; *P*=.02) seemed to decrease perceived health status.

Conclusions: We found nationwide differences that show decreased health status because of the Great East Japan disaster according to prefecture. The number of aftershocks, change in work conditions, being female, a higher age, and duration of the evacuation were risk factors for the population after the major earthquake, tsunamis, and nuclear incident.

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KEYWORDS

earthquakes; health communication; Internet; nuclear power plants; risk management

Introduction

The Great East Japan earthquake (Tohoku earthquake) on March 11, 2011 and the subsequent tsunami had a tremendous impact on Japanese society [1]. Furthermore, the Fukushima nuclear accident, ranked 7, which is the most severe on the International Nuclear Event Scale, forced large numbers of people and industries to evacuate the area [2,3]. The explosion at the Fukushima Nuclear Power Plant (NPP) released substantial amounts of radioactive materials into the sea [4] and into the atmosphere, resulting in higher levels of radiation reaching as far as the Tokyo metropolitan area, which is 200-300 km away from the Fukushima NPP [5]. A record number of 3945 aftershocks during March after the initial earthquake and nearly 10,000 aftershocks over the following 2 years have been a stark feature of the disaster [6,7]. The persistent aftershocks and lack of credible information provided by authorities of the national government caused distress among people across Japan [8-10]. Despite such concern about health nationwide, there were no rapid assessments of nationwide health status and implementation of strategic announcements, partly because of the logistical challenges involved, but mainly because of the absence of preparedness and coordination between the central and local governments, medical communities, nongovernmental organizations, and volunteer groups [1]. Assessing public health status promptly across a nation is of major relevance to health policy decision makers as well as researchers looking at disasters.

Unlike impromptu and unsystematic surveys on health, many younger persons tried to empower others in disaster-struck areas promptly through the use of Internet technologies. Physicians and hospital officials in affected areas reported their medical resource status utilizing email lists or social media such as Twitter, which made a definite difference in the disaster response compared with the Great Hanshin earthquake of 1995 [11]. Information on bed availability and so on was collected and became available to the public within the first 48 hours of the earthquake using Google Map technology [11]. Furthermore, use of geographical information system facilitated deployment of medical teams because it provided data on radiation risks in Fukushima promptly [12]. Many younger persons, who were in their early 40s or younger who were not health care professionals, also took the initiative to gather and diffuse relevant information, garner support, and raise money for quake relief [1,13]. Substantially, many people throughout the nation used the Internet to seek accurate information and to also access the mass media. This was in some ways similar to the public health emergency response in the United States after the 9/11 attacks [1,11-14]. The Internet has now been adopted widely enough in Japanese society, especially in the younger generation cohort, to be a valuable assessment tool in a public health emergency.

Public health assessments as well as constructive advice via the Internet have unique advantages in terms of a more rapid and broader reach [1,11,13,15,16]. Specifically, surveys via the Internet are able to reach more citizens distant from the devastated area, as well as those in highly affected areas, or those with mild health complaints who have not visited a medical facility [15,16]. Most previous studies regarding the effects of the disaster on health have actually been limited to mostly severely affected areas in northeastern Japan, except for a few studies focusing on distance from the epicenter [8,17] and the effect of aftershocks on psychological stress [8]. Most previous studies limited attention to presumed high-risk populations within a highly affected area. For example, previous studies included those with cardiovascular diseases [18,19] and diabetes mellitus [20] or other diseases [21-23], the elderly [24-26], evacuees [24-26], children [27,28], workers [29-31], nonprofessional volunteers [32], caregivers [33], and pregnant women [34] in a disaster area. The limited attention seems to have been common among disaster studies. One study of the previous Niigata-Chuetsu earthquake in 2004 showed that being female had a higher odds ratio of psychological distress [35]. Furthermore, studies showed the importance of preventing mothers from having symptoms of psychological distress caused by anxiety about the health of their children and separation from family members [36-38]. We believed that the inherent restricted nature of surveys after a disaster in Japan is attributed to the scarce knowledge of potential effects on nationwide health status after a massive disaster. This would complicate a coordinated national response to a disaster.

Although the elderly or children may be the most vulnerable, a previous study indicated disruption of work after natural disaster as being independently associated with decreases in general mental and physical health among university students [39]. Another recent report revealed a significant regional difference in the perception of risk among Japanese university students in a severely hit region, an indirectly affected Tokyo region, and mostly unaffected western regions [40]. Students in the Tokyo region were anticipated to be at increased risk of a future earthquake compared with those in a victimized region as well as western Japan, although the perceived risk of further nuclear risks was approximately the same for these regions [40]. In the case of the Chernobyl disaster, people living relatively far from the disaster site tended to be more concerned about the political and economic situation [41]. To our knowledge, there are few studies on health nationwide that examine geographical factors as well as social factors after large-scale disasters such as that in Japan. Because the Tohoku disaster may have affected nationwide health in every age range due to its nuclear radiation release, persistent aftershocks, widespread concern, and expected differences in these factors among regions [1-10,17,40,41], we wanted to evaluate its impact nationwide, especially among those in their late teens or 20s who typically are seen as less vulnerable. These data are crucial for national planning, programs and recovery.

We hypothesized that there are positive associations between the decreased subjective health of the young population nationwide and a larger number of aftershocks, a closer geographical location to the Fukushima NPP, or a higher reported radiation dose in the atmosphere in each region even after adjusting for individual socioeconomic factors. Therefore, the aim of the present study is to describe prefecture-level health status and investigate the associations mentioned above after adjusting for individual socioeconomic factors, utilizing individual-level data acquired from a national cross-sectional survey as well as officially reported prefecture-level data.

Methods

Data Acquisition

The data for this secondary analysis, an Internet survey on the effects of the Great East Japan Disaster on career and wage among a young generation (2012), were provided by the Social Science Japan Data Archive, Centre for Social Research and Data Archives, Institute of Social Science, The University of Tokyo. The Internet survey was conducted in January 2012 to investigate the short-term effect of the Great East Japan earthquake on the wages of college or high-school graduates focusing on the role of the quality of education, by the Economic and Social Research Institute, Cabinet Office, Government of Japan [42]. The survey was conducted according to ethical guidelines for social science research and study participation was voluntary. We did not apply for a research approval from an ethics committee because this secondary analysis used data edited by the Social Science Japan Data Archive that offers archived data to academic researchers and students without any ethical or financial requests. The data had been carefully edited so it was impossible to identify individuals from any analyses.

Participants

The survey recruited 12,000 young voluntary participants of a major Internet service in Japan based on quota sampling method [42]. The Economic and Social Research Institute reported that they followed this method rather than random sampling methods due to advantages in rapid assessment, and because random sampling does not always secure valid study participants [42]. The survey subjects graduated from college or high school between March 2009 and March 2011 across Japan, with a resultant age range of 17-27 years old. In this age range, there were 1.2 to 1.5 million peers in each year and 5% more females than males [43]. Consequently, we obtained 7335 participants after we removed participants with data missing for the prefectures in which they commuted. The graduation rates were 23.0% in 2009, 22.1% in 2010, 18.8% in 2011, and 19.1% in 2012. The remaining 17.1% of respondents had graduated from high school and would graduate from college or other schools in 2013 or later. The duration of employment after graduation varied from 0 (25%) to more than 51 months (2.6%), with a triple peak at 10 (10.2%), 22 (7.2%), and 34 months (5.5%) because the survey was conducted in January, taking into account the typical start of the fiscal year for businesses in April. Approximately 93% of respondents did not report clearly defined adverse effects caused by the disaster. A small percentage of these participants experienced the loss of second-degree relatives (0.3%) and 0.3% experienced injuries caused by the disaster. Other adverse events included collapse of their house or official evacuation because of the crisis at the Fukushima NPP.

Perceived Health Status

The survey asked questions directly related to the disaster. The data included a change of self-perceived health status after the disaster. The question asked was, “Did your health status change because of the Great East Japan Disaster?” There were seven categories for answers: highly improved, improved, relatively improved, unchanged, relatively decreased, decreased, and highly decreased. We categorized these seven categories into two, not-decreased and decreased, because we intended to focus on the binary difference between health and poor health. Furthermore, few respondents answered “highly improved” and “improved,” so the two categories seemed to provide a valid comparison. This binary health status change was set as the outcome variable.

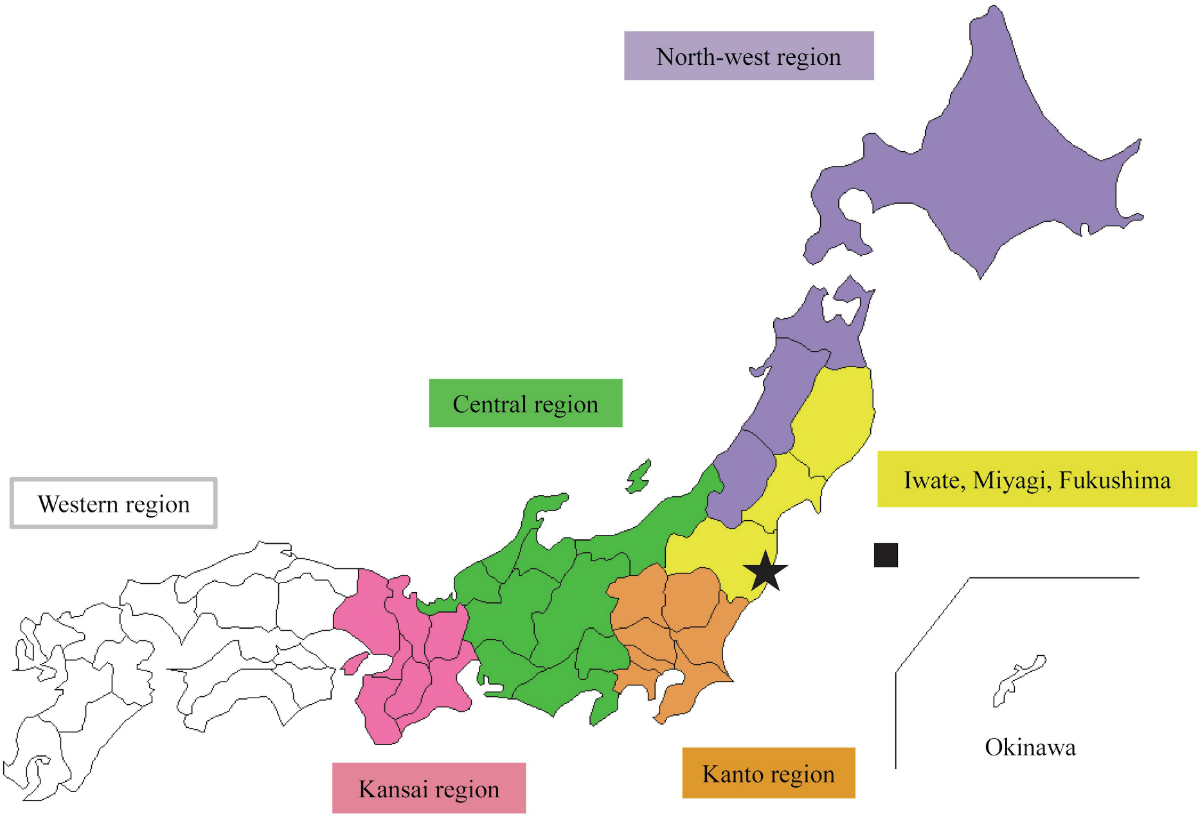
Prefecture-Level Predictors for Health Status

We categorized geographic location based on prefectures where respondents commuted according to the values assigned by the Japan Meteorological Agency Seismic Intensity scale (JMA-SI), 0-7, and the radiation dose published by the Ministry of Education, Culture, Sports, Science and Technology (MEXT) of Japan [6,44]. When levels of JMA-SI were recorded in a prefecture, we assigned the largest value as the indicator. The value of the radiation dose was considered a continuous variable, which was determined on March 20, 2011 when it was first made available by MEXT and on January 1, 2012 when the survey was conducted [44]. We calculated the distance in a straight line between each capital city of a prefecture and the Fukushima NPP and included the number of aftershocks from March 11, 2011 to January 31, 2012 recorded in the JMA database [7].

Six Area Indicators in Japan

We introduced six area indicators: Northwest region; Iwate, Miyagi, and Fukushima; Kanto region; Central region; Kansai region; and Western region as shown in Figure 1. The Northwest region was an indirectly affected region because it was within the Tohoku area; however, it did not suffer at all from the tsunami and was relatively distant from the Fukushima NPP. Iwate, Miyagi, and Fukushima were directly affected regions because these three areas were most affected by the tsunami, the Fukushima incident, and persistent aftershocks. The Kanto region was an indirectly affected region because it did not bear much of the impact from the tsunami, but suffered from persistent aftershocks as well as anticipation about radiation. The Central and Kansai regions were indirectly affected regions that are relatively distant from Fukushima, but nearer compared to western Japan. The Western region was set as the control group because they were distant from Fukushima and had fewer aftershocks.

Figure 1. Map of Japan divided into six area indicators. The black square indicates the epicentre of the earthquake. The black star indicates the location of the Fukushima NPP.



Individual-Level Demographic Factors

Marital status was based on current status, so that widows or divorcées were classified as not married. These participants were categorized in the following manner: never married, 94.1%; married, 5.8%; widows, 0.1%; and divorced, 0.2%. Respondents were asked to answer "No" to the questions about change in employment if the corresponding conditions were caused by intentional career changes or other personal reasons. If a person had lived apart from other family members before the disaster, respondents were asked to answer "No" to questions about separation from their families. A change of working conditions included a reduction of sales (5.1%), reduction and upgrade of graduate recruitment (2.9%), merger and acquisition (0.8%), attrition (1.8%), damage of plants or capital (7.2%), temporary suspension of business (8.1%), and reduction of compensation (2.1%). Participants answered only when the condition was true. Individual economic status was assessed according to income. A difference in income between in 2010 and after the disaster in 2011 was categorized as "minus 2 levels" or "plus 1 level," where a unit of "level" represented approximately one million yen. In contrast, an expected decrease of income in the 2012 fiscal year was answered yes or no.

Statistical Analysis

We calculated the percentage of people with decreased self-perceived health status in each prefecture. Because sampling error from the Internet survey seemed to render the percentages highly variable due to the small sample size in individual prefectures, we smoothed the actual percentages with empirical Bayes predictions from the multilevel (mixed effects) logistic regression by introducing random intercepts for 47 prefectures and an overall constant (the mean across all clusters/population mean) [45]. The empirical Bayes predictions can effectively "shrink" the actual percentages to a population mean, according to each prefecture's size [46]. To adjust for differences in individual demographic factors between prefectures, we also fitted the model with gender, age, education, marital and employment status, changed job condition, income, death of family member[s], being a parent, family separation, and evacuation. Consequently, the prediction for each prefecture is presented by a regression standardization method [47]. In theory, regression standardization estimates the expectation of an outcome had all individuals been assigned a variable of interest at the specified level (an index level). Because the variable of interest in the analysis was a prefecture membership (incorporated as random intercepts) and index levels were the 47 indicators of prefectures in Japan, we presented the adjusted empirical Bayes predictions for 47 prefectures as the sum of the random intercepts and the mean of 7335 predictions from fixed parts of the model (ie, individual demographic factors) averaged over the whole population, followed by expit transformation: $\exp(\eta + \gamma_i)/[1 + \exp(\eta + \gamma_i)]$ for mean linear prediction η of fixed effects and a random effect γ_i in prefecture i (i=1,…, 47). Because expit of mean of individual predictions differs from mean of expit of individual predictions, our adjusted empirical Bayes predictions approximated the standardized percentages in first order.

To identify a regional association between the change of self-perceived health status and environmental factors (prefecture-level variables), the odds ratios (ORs) and their 95% CIs were calculated from fixed-effects logistic models. Predictor variables included (a) radiation dose, distance from the Fukushima NPP, JMA-SI, and number of aftershocks from March 11, 2011 to January 31, 2011 with or without (b) the area indicators in Japan. We calculated crude and adjusted ORs from univariable and from multivariable-adjusted logistic models, respectively. Model 1 included prefecture-level variables (a), Model 2 included the area indicator (b), and Model 3 simultaneously introduced all prefecture-level variables (a) and (b). We fitted different models for sensitivity analysis rather than for model building with a rejection of unnecessary covariates, although Akaike's Information Criterion (AIC, which measures prediction error by estimating the mean of Kullback-Leibler divergence over asymptotic sampling distributions) was presented not so as to search for an accurate prediction, but just as a reference for readers.

To simultaneously estimate the association of prefecture-level variables and demographic variables (individual-level variables), including loss of family, changes in work conditions, individual economic status, experience of evacuation and separation from family, to self-perceived health status, we fitted multilevel logistic regression models that included random-intercepts for 47 prefectures and the above prefecture- and individual-level variables. The sensitivity of individual-level effects to adjustment for prefecture-level variables was analysed by fitting different models conducted in the same manner as above: Model 1 included individual-level variables only; Model 2 adjusted Model 1 with the prefecture-level variables (a); and Model 3 simultaneously adjusted for prefecture-level variables (a) and area indicators (b).

The variables included in the models were selected from a questionnaire regarding the existing literature, which investigated the effects of the disaster on subsequent distress. Because of unclear previous knowledge on interactions, we did not conduct stratified analyses and did not include interaction terms in the multivariable models. Conformity with a linear gradient in the model was checked graphically before fitting regression models. All statistical and graphical analyses were conducted using R version 3.0.1 for Windows. The lme4 and glmmML packages were primarily used.

Results

Overview

Respondents' demographic characteristics are shown in Table 1. Those with decreased perceived health status tended to include more females, slightly more often changed their job condition, left their family member(s) for a longer duration, and had evacuated longer than those without decreased perceived health status.

Prefecture-Level Changes in Health Status

The decrease in self-perceived health status differed significantly among respondents in the prefectures as shown in Table 2.

Compared with Tokyo, respondents commuting in Miyagi and Fukushima prefectures, which are located adjacent to Fukushima, showed a statistically significant decrease in health status. Respondents commuting in Iwate and Tochigi prefectures also reported an increased reduction in health status, although the differences were not statistically significant. The values were higher for respondents commuting in the Tohoku area (Iwate, Miyagi, and Fukushima), which faces the Pacific Ocean, while the values for Akita and Yamagata prefectures, which do not face the Pacific Ocean, were lower than those of Tokyo. In contrast, there were many prefectures where respondents' health status was less likely to be reduced, particularly in Hokkaido and the central and western regions of Japan. In addition to those in Tokyo, those commuting in Okinawa, Kochi, and Toyama prefectures also reported a high frequency of decreased health status. In general, young people commuting in Tokyo reported a relatively higher reduction of their perceived health status compared with those commuting in many western regions of Japan.

Table 1. Demographic characteristics by the change of subjective health.

Variables	Perceived health status Decreased (n=649) n (%) or mean (SD)	 Not decreased (n=6686) n (%) or mean (SD)
Gender, n (%)		
Male	262 (40.37)	3097 (46.32)
Female	387 (59.63)	3589 (53.68)
Age, n (%)		
17 years old	4 (0.62)	49 (0.73)
18 years old	5 (0.77)	107 (1.60)
19 years old	14 (2.16)	196 (2.93)
20 years old	24 (3.70)	372 (5.56)
21 years old	38 (5.86)	459 (6.87)
22 years old	77 (11.86)	794 (11.88)
23 years old	107 (16.49)	984 (14.72)
24 years old	127 (19.57)	1363 (20.39)
25 years old	132 (20.34)	1269 (18.97)
26 years old	67 (10.32)	623 (9.32)
27 years old	54 (8.32)	470 (7.03)
Mean age (SD)	23.74 (2.04)	23.48 (2.17)
Education, n (%)		
College students	462 (71.19)	4701 (70.31)
Not college students	187 (28.81)	1985 (29.69)
Marital status, n (%)		
Married	42 (6.47)	390 (5.83)
Not married	607 (93.53)	6296 (94.17)
Employment status, n (%)		
Regular employee	248 (38.21)	2375 (35.52)
Not regular employee	401 (61.87)	4311 (64.48)
Changed job condition, n (%)		
Yes	245 (37.50)	1371 (20.51)
No	404 (62.25)	5315 (79.49)
Difference of income 2011–2010[a], mean (SD)	0.27 (1.50)	0.20 (1.38)
Expected income in 2012, n (%)		
Will be decreased	45 (6.93)	361 (5.40)
Will be increased/stable	604 (93.07)	6325 (94.60)
Number of deaths of family members, n (%)		
> 1	3 (0.46)	16 (0.24)
0	646 (99.54)	6670 (99.76)
Having a child/children, n (%)		
Yes	24 (3.70)	263 (3.93)
No	625 (96.30)	6423 (96.07)
Duration left for the family member(s), n (%)		
> 4 weeks	66 (10.17)	396 (5.92)

Variables	Perceived health status	
	Decreased (n=649)	Not decreased (n=6686)
	n (%) or mean (SD)	n (%) or mean (SD)
≤ 4 weeks	583 (89.83)	6290 (94.08)
Duration of evacuation, n (%)		
> 4 weeks	91 (14.02)	528 (7.90)
≤ 4 weeks	558 (85.98)	6158 (92.10)

[a] Change of categorical level, where a unit of "level" represented approximately one million yen. Example: difference is −2 when the level was 5 in 2010 and 3 in 2011.

Table 2. Commuting location and the decreased self-perceived health.

	JMA-SI (level) [a]	Radi (μSv/h)	Quake (times)	Decreased (n)	Not decreased (n)	Decreased (%)	*P* value
Miyagi	7	0.111[b]	2841	28	93	23.1	.002[d]
Fukushima	6	2.5[c]	4211	26	44	37	<.001[e]
Tochigi	6	0.154	1552	11	43	20	.09
Iwate	6	0.027	2304	9	40	18	.19
Ibaraki	6	0.176	3422	16	78	17	.20
Aomori	5	0.02	818	8	36	18	.25
Tokyo	5	0.048	691	232	1643	12.37	Reference
Chiba	5	0.033	1526	22	176	10.9	.73
Akita	5	0.034	644	3	26	10	1.00
Saitama	5	0.057	946	21	187	10.1	.37
Nagano	5	0.069	868	8	73	10	.60
Kanagawa	5	0.049	435	40	387	9.4	.09
Yamagata	5	0.04	862	3	33	8	.61
Gunma	5	0.08	939	6	75	7	.22
Niigata	5	0.047	817	6	82	7	.13
Yamanashi	5	0.044	262	2	30	7	.42
Gifu	4	0.062	212	9	106	7.8	.18
Hokkaido	4	0.027	395	17	229	6.9	.01[f]
Shizuoka	4	0.037	371	11	172	6.0	.008[d]
Aichi	4	0.041	79	19	533	3.4	<.001[e]
Toyama	3	0.047	77	8	50	14	.69
Shiga	3	0.034	57	7	56	11	1.00
Nara	3	0.048	42	5	61	8	.34
Fukui	3	0.045	54	3	47	6	.27
Hyogo	3	0.037	47	18	290	5.8	<.001[e]
Kyoto	3	0.039	43	12	208	5.5	.002[d]
Mie	3	0.046	38	5	87	5	.048[f]
Osaka	3	0.043	43	31	693	4.3	<.001[e]
Ishikawa	3	0.046	88	2	52	4	.056
Shimane	2	0.036	38	3	31	9	.79
Wakayama	2	0.032	92	4	45	8	.51
Okayama	2	0.049	31	5	109	4.4	.007[d]
Totori	2	0.063	21	0	28	0	.04[f]
Tokushima	2	0.039	29	0	41	0	.007[d]
Kochi	1	0.026	33	4	26	13	.78
Kagawa	1	0.053	21	3	40	7	.36
Nagasaki	1	0.029	21	3	40	7	.36
Fukuoka	1	0.037	25	14	224	5.8	.002[d]
Oita	1	0.05	39	2	39	5	.22

	JMA-SI (level) [a]	Radi (μSv/h)	Quake (times)	Decreased (n)	Not decreased (n)	Decreased (%)	*P* value
Hiroshima	1	0.05	52	7	147	4.5	.002[d]
Kumamoto	1	0.027	75	2	49	4	.08
Kagoshima	1	0.035	130	1	41	2	.053
Ehime	1	0.047	28	1	60	2	.007[d]
Saga	1	0.04	12	0	19	0	.16
Okinawa	0	0.021	56	5	29	15	.60
Miyazaki	0	0.027	44	3	24	11	1.00
Yamaguchi	0	0.094	21	4	61	6	.17

[a] JMA-SI, Japan Meteorological Agency seismic intensity; Radi, radiation dose on March 20, 2011 (μSv/h); Quakes, total number of aftershocks from March 11, 2011 to January 31, 2012.

[b] Obtained initially at 19:00 on March 29, 2011.

[c] Obtained initially at 13:00 on April 6, 2011.

[d] Mean < .01.

[e] Mean <.001.

[f] Mean < .05.

Empirical Bayes Predictions of the Percentages of Decreased Health Status

Empirical Bayes estimates from random-effects logistic models of each prefecture's proportion of respondents with decreased self-perceived health status, as well as the actual percentages from Table 2 are plotted in Figure 2 according to JMA-SI level.

The percentages of respondents commuting in Tochigi and Ibaraki prefectures as well as Iwate, Miyagi, and Fukushima are the highest. Surprisingly, the percentages for respondents commuting in Tokyo and Chiba are higher compared with the rest of Japan. In contrast, the percentage of reports of decreased health status from central to the western region (Aichi, Osaka, and prefectures located at more western than them) is clearly lower (Figure 3).

Figure 2. Percentage of respondents reporting decreased self-perceived health status and empirical Bayes estimates in each prefecture. JMA-SI, Japan Meteorological Agency Seismic Intensity. For the same JMA-SI levels, we determined the rank order of prefectures based on the values of adjusted empirical Bayes estimates. In adjusted empirical Bayes estimates, percentages were also adjusted according to demographic factors (gender, age, education, marital and employment status, changed job condition, income, death of family member[s], being a parent, family separation, and evacuation).

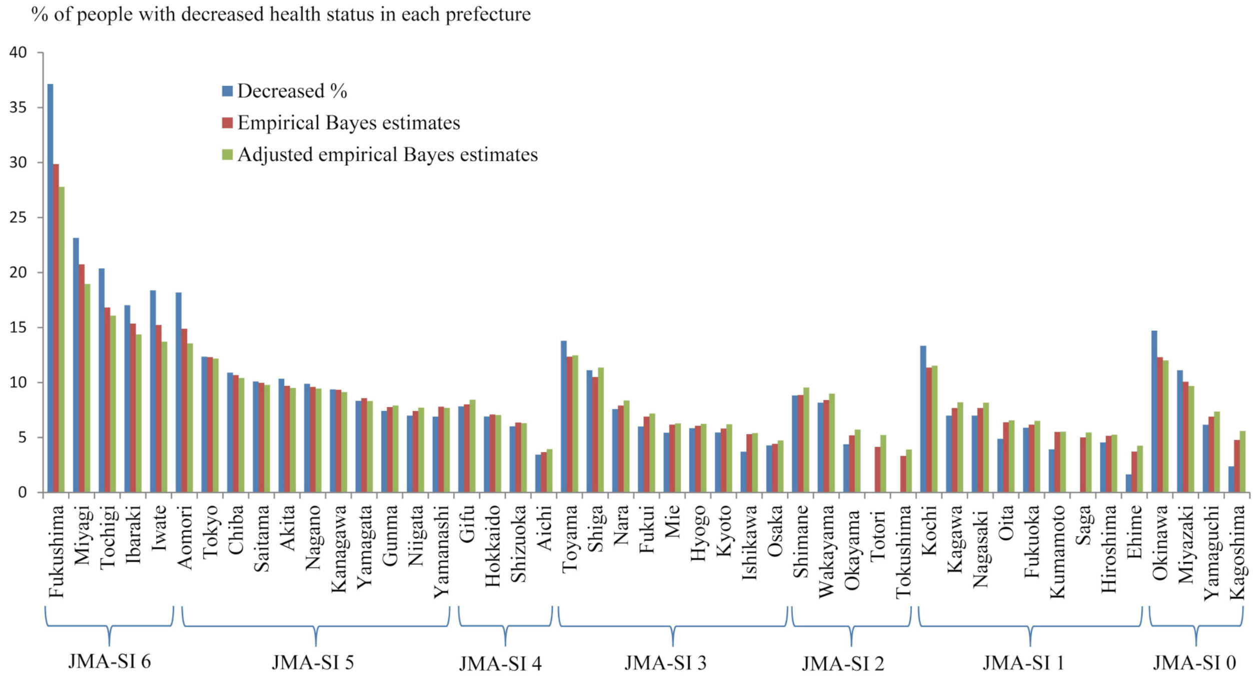
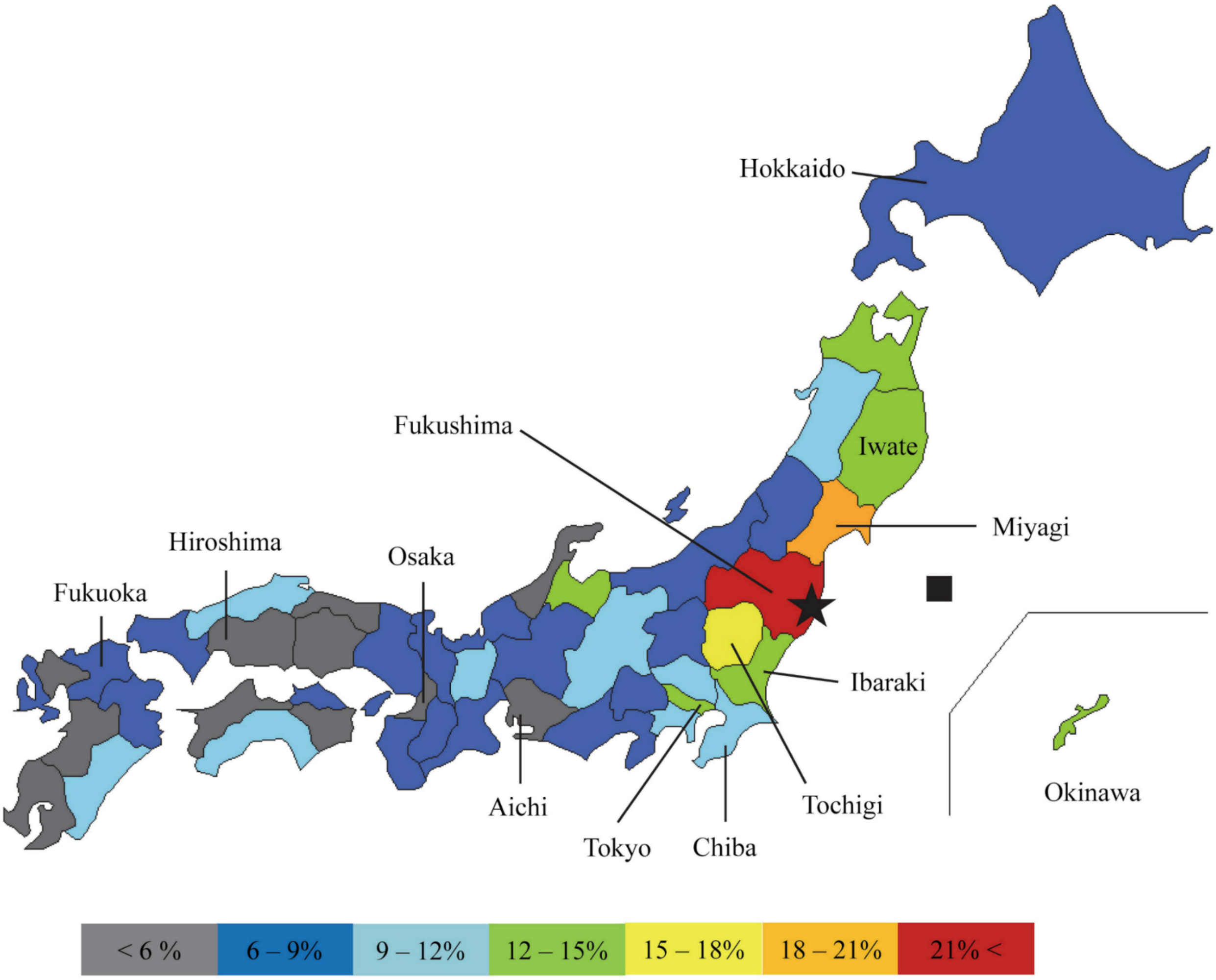


Figure 3. Map of Japan depicting adjusted empirical Bayes estimates for percentage of people with decreased self-perceived health status. Red (>21%), orange (18%–21%), yellow (15%–18%), chartreuse green (12%–15%), aquamarine (9%–12%), blue (6%–9%), and gray (<6%). The black square indicates the epicenter of the earthquake. The black star indicates the location of the Fukushima NPP.



Prefecture-Level Factors Associated With Decline in Health Status

The regional association between the change of self-perceived health status and prefecture-level variables estimated from fixed-effects logistic models are depicted in Table 3. From Model 1, the total number of quakes (OR 1.03, 95% CI 1.01-1.05; *P*<.001) and the seismic intensity of the primary quake (OR 1.18, 95% CI 1.08-1.29; *P*<.001) were associated with the prevalence of the decreased self-perceived health, but after adjustment for regional areas (Model 3), the association of seismic intensity vanished (OR 0.90, 95% CI 0.68-1.20; *P*=.48). On the other hand, the area of Iwate, Miyagi and Fukushima (OR 6.29, 95% CI 4.25-9.32; *P*<.001 in Model 2) was strongly associated with decreased self-perceived health even after adjustment for the prefecture-level factors in Model 3 (OR 4.63, 95% CI 1.10-19.57; *P*=.04).

The results from random-intercept multilevel logistic models for the probability of decreased self-perceived health status including individual-level demographic variables and/or prefecture-level variables are presented in Table 4. Each model provided essentially the same results. Change in job condition (OR 2.05, 95% CI 1.72-2.45; *P*<.001), female (OR 1.43 [=1/0.70, inverse of OR for male 0.70, 95% CI 0.59-0.84]; *P*<.001), higher age (OR 1.06 per year, 95% CI 1.02-1.11; *P*=.005), and duration of evacuation longer than 4 weeks (OR 1.44, 95% CI 1.06-1.97; *P*=.02) seemed to decrease perceived health status in Model 3. As in Table 3, the total number of quakes (OR 1.02 per 100 times, 95% CI 1.00-1.05; *P*=.049) was strongly associated with decreased self-perceived health after adjustment for individual-level demographic factors. The OR became 1.32 (95% CI 1.03-1.71) per 1000 times. The area of Iwate, Miyagi, and Fukushima (OR 4.45, 95% CI 0.99-20.01; *P*=.052) and Kanto region (OR 2.94, 95% CI 0.94-9.18; *P*=.06) also showed a strong association. As a reviewer pointed out, although Model 3 probably suffers from the unstability of estimates due to multiple collinearity (eg, evacuated seemed obviously a function of distance to epicenter), our models provided coherent results for these variables.

The radiation levels reported relatively soon, or considerably after the Fukushima NPP crisis and the distance from the nuclear power plant are not significantly associated with decreased health status after adjusting for covariates and potential covariates. The death of family members is not significantly associated with decreased health status because of the small number of events.

Table 3. Prefecture-level factors associated with decreased health status: regional-level logistic regression analysis.

Independent variables	Crude OR[a] (95% CI)	Model 1 Adjusted OR (95% CI)	Model 1 *P* value	Model 2 Adjusted OR (95% CI)	Model 2 *P* value	Model 3 Adjusted OR (95% CI)	Model 3 *P* value
From Fukushima NPP[b] (km)	0.99 (0.99-1.00)	1.00 (0.99-1.00)	.29	–	–	1.00 (1.00-1.00)	.65
Radiation[c] (μSv/hr)	2.09 (1.72-2.55)	1.16 (0.87-1.53)	.31	–	–	1.11 (0.81-1.51)	.51
Total quakes[d] (x10^{-2})	1.05 (1.04-1.06)	1.03 (1.01-1.05)	<.001	–	–	1.03 (1.00-1.05)	.02
JMA-SI[e]	1.38 (1.29-1.47)	1.18 (1.08-1.29)	<.001	–	–	0.90 (0.68-1.20)	.46
Northwest region	0.98 (0.68-1.44)	–	–	1.69 (1.07-2.67)	.02	2.11 (0.80-5.58)	.13
Iwate, Miyagi, and Fukushima	3.95 (2.93-5.34)	–	–	6.29 (4.25-9.32)	<.001	4.63 (1.10-19.57)	.04
Kanto region	1.82 (1.55-2.14)	–	–	2.37 (1.77-3.16)	<.001	2.93 (0.99-8.66)	.05
Central region	0.57 (0.44-0.74)	–	–	1.05 (0.73-1.52)	.77	1.34 (0.56-3.23)	.51
Kansai region	0.53 (0.41-0.67)	–	–	1.01 (0.72-1.43)	.97	1.23 (0.65-2.32)	.53
		AIC[f] value = 4252		AIC value = 4244		AIC value = 4241	

[a] OR, odds ratio

[b] NPP, nuclear power plant

[c] Radiation, radiation dose on March 20, 2011 (μSv/h)

[d] Total quakes, total number of aftershocks from March 11, 2011 to January 31, 2012

[e] JMA-SI, Japan Meteorological Agency seismic intensity

[f] AIC, Akaike's Information Criterion

Table 4. Individual- and prefecture-level factors associated with decreased health status: multilevel logistic regression analysis with random-intercept for 47 prefectures.

		Model 1		Model 2		Model 3	
Independent variables	Crude OR[a] (95% CI)	Adjusted OR (95% CI)	*P* value	Adjusted OR (95% CI)	*P* value	Adjusted OR (95% CI)	*P* value
Regular employee (ref: not)	0.89 (0.75-1.05)	0.85 (0.71-1.01)	.07	0.85 (0.71-1.01)	.06	0.85 (0.71-1.02)	.07
Change in job condition (ref: not)	2.35 (1.98-2.79)	2.12 (1.77-2.52)	<.001	2.05 (1.72-2.45)	<.001	2.05 (1.72-2.45)	<.001
Difference in income 2010–2011 (million yen incr.)	1.03 (0.98-1.09)	1.03 (0.97-1.09)	.35	1.03 (0.97-1.09)	.34	1.02 (0.97-1.09)	.35
Income will decrease (ref: not)	1.31 (0.95-1.80)	1.31 (0.94-1.83)	.11	1.31 (0.94-1.82)	.11	1.31 (0.95-1.84)	.10
Sex (male=1, female=0)	0.78 (0.67-0.92)	0.71 (0.60-0.84)	<.001	0.71 (0.60-0.84)	<.001	0.70 (0.59-0.84)	<.001
Age (year)	1.06 (1.02-1.10)	1.06 (1.02-1.11)	.006	1.06 (1.02-1.11)	.005	1.06 (1.02-1.11)	.005
Marital status (Married = 1)	1.12 (0.80-1.55)	0.94 (0.66-1.33)	.72	0.92 (0.65-1.30)	.64	0.92 (0.65-1.30)	.63
College student (ref: not)	1.04 (0.87-1.25)	1.00 (0.82-1.22)	.99	0.99 (0.82-1.22)	.996	1.00 (0.83-1.27)	.95
Family separation (> 4 weeks; ref: not)	1.80 (1.37-2.37)	1.22 (0.85-1.74)	.28	1.21 (0.85-1.74)	.28	1.21 (0.85-1.73)	.30
Evacuation (> 4 weeks; ref: not)	1.90 (1.50-2.41)	1.48 (1.08-2.03)	.01	1.45 (1.06-1.98)	.02	1.44 (1.06-1.97)	.02
Death of family members (ref: not)	1.94 (0.56-6.66)	2.33 (0.66-8.26)	.19	2.28 (0.65-8.03)	.20	2.34 (0.66-8.26)	.19
Having a child/children (ref: not)	0.94 (0.61-1.44)	0.93 (0.60-1.44)	.75	0.94 (0.61-1.45)	.77	0.93 (0.59-1.44)	.74
From Fukushima NPP[b] (km)	0.99 (0.99-1.00)	–	–	0.99 (0.99-1.00)	.57	1.00 (0.99-1.00)	.66
Radiation[c] (μSv/hr)	2.09 (1.72-2.55)	–	–	1.17 (0.80-1.69)	.42	1.16 (0.82-1.64)	.41
Total quakes[d] ($x10^{-2}$)	1.05 (1.04-1.06)	–	–	1.04 (1.01-1.06)	.002	1.02 (1.00-1.05)	.049
JMA-SI[e]	1.38 (1.29-1.47)	–	–	1.07 (0.96-1.20)	.24	0.87 (0.65-1.17)	.36
Northwest region	0.98 (0.68-1.44)	–	–	–	–	2.21 (0.78-6.26)	.14
Iwate, Miyagi, and Fukushima	3.95 (2.93-5.34)	–	–	–	–	4.45 (0.99-20.01)	.05
Kanto region	1.82 (1.55-2.14)	–	–	–	–	2.94 (0.94-9.18)	.06
Central region	0.57 (0.44-0.74)	–	–	–	–	1.49 (0.59-3.78)	.40
Kansai region	0.53 (0.41-0.67)	–	–	–	–	1.32 (0.66-2.62)	.43
		AIC[f]: 4185		AIC: 4155		AIC: 4158	

[a] OR, odds ratio

[b] NPP, nuclear power plant

[c] Radiation, radiation dose on March 20, 2011 (μSv/h)

[d] Total quakes, total number of aftershocks from March 11, 2011 to January 31, 2012

[e] JMA-SI, Japan Meteorological Agency seismic intensity

[f] AIC, Akaike's Information Criterion

Discussion

Three Novel Findings

We first illustrate a prefecture-level difference that shows decreased health status because of the Great East Japan Disaster. Our study found three novel findings. First, the present study shows a coherent association between decreased health status and number of aftershocks. Second, the prefecture-level radiation dose reported after the Fukushima Nuclear Crisis and the distance from the NPP of each prefecture are not significantly associated with decreased health status after adjusting for covariates and potential covariates. Third, we showed coherently that changes in job condition, being female, higher ages in the late teens and 20s, and duration of evacuation longer than 4 weeks were associated with a nationwide decreased health status even after adjusting for regional-level and prefecture-level variables.

Related Factors for the Three Novel Findings

People living relatively far from the disaster site tended to be more concerned about the political and economic situation [41]. The same study indicated that concerns about future health may have stimulated greater awareness of physical sensations, according to results indicating that subjective health was partially mediated by perceptions of hazard and risk [41]. Students in the Kanto region felt that they were at higher risk of a future earthquake compared with those in Western Japan [40]. Historically, the significant number of aftershocks in eastern Japan, including the Kanto region, would make subjective health decrease via a perception of hazard and risk for future earthquakes. This assumption might be valid from a nationwide perspective because radiation dose reported at the prefecture-level and at a distance from the Fukushima NPP were not significantly associated with decreased subjective health. Prefecture-level differences in subjective health could not be simply explained by radiation dose reported or distance from the Fukushima NPP. Rather, the health of youth nationwide is affected by aftershocks and sociodemographic factors.

Consistent with a previous study [39], change in work conditions after the disaster was independently associated with decreases in the subjective health of a young cohort nationwide. Changes in work conditions, whether this was derived from natural disasters, might cause depressive symptoms, a larger burden from work, or economic decline. Being female was robustly indicated as a significantly associated factor consistent with a previous study [35], although we could not determine the reason from the present data. Surprisingly, a higher age within the age range of 17-27 years showed a significant association. We believe that our common sense tends to perceive a higher age as a risk factor for many health problems, but generally we think of this for those aged over 65 or higher. This common thinking about age range, such as those “aged 65 or older” or “children” may result in ignorance on the impact of these events at various ages. Our data regarding an association of decreased subjective health with evacuation from the disaster area must be interpreted with care. To the best of our knowledge, there has been no evidence that evacuation from a disaster area, or from Kanto region to Western region, is a risk factor for those in their late teens or 20s. Previous studies indicated evacuation as a risk factor for high mortality or hospitalization among the elderly because relocation affects living and care quality [25,48], and also the loss of their social network, which results in psychological distress [49].

Strengths of the Study

We believe that the present study has several significant strengths. First, we considered self-perceived health, which could include both physical and psychological aspects of health. This allowed us to evaluate general health as a whole rather than focusing on specific diseases. For instance, we could include relatively moderate illnesses that would escape inclusion in studies based on hospital records. A previous study reported that people who were professionally exposed to a disaster reported more physical and mental health complaints even in the absence of abnormal clinical laboratory values [50]. Therefore, it is definitely of value to include subjective health rather than to focus only on objective clinical diagnosis even while assuming that the percentages of self-reported illness are higher than those of clinically verified illnesses as indicated by a previous study [51]. Second, we included all prefectures in Japan rather than focusing only on the devastated area. This study thus illuminates otherwise likely-to-be-missed effects on the health of a population across the nation.

Limitations

Our study has several limitations. First, respondents may not represent the entire population of Japanese of the same age range because the data were not collected randomly. Therefore, the data may be biased toward participants possessing higher Internet literacy or health status and who are more likely to answer the questionnaire voluntarily. Despite the relatively limited target population analyzed here, we are confident that the results can be generalized to this entire age group across Japan, because of the common ability to access the Internet among those in this age range. Second, our data was derived from a cross-sectional survey, which does not allow determination of the direction of the relationships between demographic variables and self-perceived health status. Third, there is no information on specific reasons why participants answered that they were experiencing diminished health. However, the questionnaire was sufficiently well-controlled because all questions always included the criterion, “because of the disaster,” and not just “after the disaster.” Therefore, we could assume that we minimized the probability that the reported decrease in subjective health was derived from other causes. Last, one question asked study participants, “In what prefecture do you commute?” Therefore, we could not predetermine the location of residence. Because some employees or students might commute between prefectures, the distribution shown in the map of Japan may change if we specified the location of residence. Despite these limitations, the data presented here on post-earthquake subjective health status of this age group across the nation are worth reporting.

Implications for Future Disaster Preparedness and Health Policy

Future major earthquakes may affect health among the broader population, including youth, across the nation via persistent aftershocks and other socioeconomic disruption. Assessing public health status promptly across a nation is of major relevance to health policy decision makers as well as researchers looking at disasters. Assessments via the Internet may be a better measure in public health emergencies and subsequent phases compared to traditional paper-and-pencil-based surveys, especially for subgroups accustomed to Web technologies [52]. Differences in response characteristics and optimizing designs of Web surveys have been examined in some countries [15,16,52,53]. The effects of long-term low-dose radiation exposure on health and useful measurement technologies will be further elucidated in the future [54]. Traditional surveys may suffer from recall bias and low response rates, and impede arriving at reliable results. Rapid and cost-efficient assembly of health information requires the utilization of e-health technologies as well as epidemiological insights to provide better information to all decision makers. Researchers should be cautious in continuing with unconscious old-fashioned strategies for health assessments after a disaster and should better utilize epidemiology and information technologies to further knowledge in this field.

Conclusions

We first investigated the extent to which subjective health of participants in each prefecture across Japan decreased as a result of the Great East Japan Disaster. We found that the number of aftershocks was coherently associated with decreased subjective health. In contrast, radiation dose and distance from the Fukushima NPP were not associated. A Web-based survey can provide valuable information on public health issues after a disaster, especially if information technologies are developed that integrate with epidemiology research.

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Conflicts of Interest

None declared.

References

1. Shibuya K, Hashimoto H, Ikegami N, Nishi A, Tanimoto T, Miyata H, et al. Future of Japan's system of good health at low cost with equity: beyond universal coverage. Lancet 2011 Oct 1;378(9798):1265-1273. [doi: 10.1016/S0140-6736(11)61098-2] [Medline: 21885100]
2. Ohnishi T. The disaster at Japan's Fukushima-Daiichi nuclear power plant after the March 11, 2011 earthquake and tsunami, and the resulting spread of radioisotope contamination. Radiat Res 2012 Jan;177(1):1-14. [Medline: 22059981]
3. Tanigawa K, Hosoi Y, Hirohashi N, Iwasaki Y, Kamiya K. Loss of life after evacuation: lessons learned from the Fukushima accident. Lancet 2012 Mar 10;379(9819):889-891. [doi: 10.1016/S0140-6736(12)60384-5] [Medline: 22405787]
4. Buesseler KO, Jayne SR, Fisher NS, Rypina II, Baumann H, Baumann Z, et al. Fukushima-derived radionuclides in the ocean and biota off Japan. Proc Natl Acad Sci U S A 2012 Apr 17;109(16):5984-5988 [FREE Full text] [doi: 10.1073/pnas.1120794109] [Medline: 22474387]
5. Nagaoka K, Sato S, Araki S, Ohta Y, Ikeuchi Y. Changes of radionuclides in the environment in Chiba, Japan, after the Fukushima nuclear power plant accident. Health Phys 2012 Apr;102(4):437-442. [doi: 10.1097/HP.0b013e31823bc2d3] [Medline: 22378205]
6. The official reported table of number of aftershocks over Japan Meteorological Agency seismic intensity level 1 after the main quake on March 11 in 2011. URL: http://www.seisvol.kishou.go.jp/eq/2011_03_11_tohoku/yukan1.pdf [accessed 2013-05-17] [WebCite Cache ID 6Gfz3xkTe]
7. Database of Japan Meteorological Agency seismic intensity levels. URL: http://www.seisvol.kishou.go.jp/eq/shindo_db/shindo_index.html [accessed 2013-05-17] [WebCite Cache ID 6Gfz5LeaQ]
8. Honma M, Endo N, Osada Y, Kim Y, Kuriyama K. Disturbances in equilibrium function after major earthquake. Sci Rep 2012;2:749 [FREE Full text] [doi: 10.1038/srep00749] [Medline: 23087814]
9. Matsuoka Y, Nishi D, Nakaya N, Sone T, Noguchi H, Hamazaki K, et al. Concern over radiation exposure and psychological distress among rescue workers following the Great East Japan Earthquake. BMC Public Health 2012;12:249 [FREE Full text] [doi: 10.1186/1471-2458-12-249] [Medline: 22455604]

10. Rubin GJ, Amlôt R, Wessely S, Greenberg N. Anxiety, distress and anger among British nationals in Japan following the Fukushima nuclear accident. Br J Psychiatry 2012 Nov;201(5):400-407 [FREE Full text] [doi: 10.1192/bjp.bp.112.111575] [Medline: 22995630]
11. Nagamatsu S, Maekawa T, Ujike Y, Hashimoto S, Fuke N, Japanese Society of Intensive Care Medicine. The earthquake and tsunami-observations by Japanese physicians since the 11 March catastrophe. Crit Care 2011;15(3):167 [FREE Full text] [doi: 10.1186/cc10261] [Medline: 21722338]
12. Nagata T, Kimura Y, Ishii M. Use of a geographic information system (GIS) in the medical response to the Fukushima nuclear disaster in Japan. Prehosp Disaster Med 2012 Apr;27(2):213-215. [doi: 10.1017/S1049023X1200060X] [Medline: 22587878]
13. Sato N, Yamazaki M. How generation next is rebuilding Japan. Boston: Harvard Business Publishing; 2011. URL: http://blogs.hbr.org/cs/2011/05/how_generation_next_is_rebuild.html [accessed 2013-05-04] [WebCite Cache ID 6LdvrhxDx]
14. Kittler AF, Hobbs J, Volk LA, Kreps GL, Bates DW. The Internet as a vehicle to communicate health information during a public health emergency: a survey analysis involving the anthrax scare of 2001. J Med Internet Res 2004 Mar 3;6(1):e8 [FREE Full text] [doi: 10.2196/jmir.6.1.e8] [Medline: 15111274]
15. van den Berg MH, Overbeek A, van der Pal HJ, Versluys AB, Bresters D, van Leeuwen FE, et al. Using Web-based and paper-based questionnaires for collecting data on fertility issues among female childhood cancer survivors: differences in response characteristics. J Med Internet Res 2011;13(3):e76 [FREE Full text] [doi: 10.2196/jmir.1707] [Medline: 21955527]
16. Ekman A, Dickman PW, Klint A, Weiderpass E, Litton JE. Feasibility of using Web-based questionnaires in large population-based epidemiological studies. Eur J Epidemiol 2006;21(2):103-111. [doi: 10.1007/s10654-005-6030-4] [Medline: 16518678]
17. Sugiura H, Akahane M, Ohkusa Y, Okabe N, Sano T, Jojima N, et al. Prevalence of insomnia among residents of Tokyo and osaka after the great East Japan earthquake: a prospective study. Interact J Med Res 2013;2(1):e2 [FREE Full text] [doi: 10.2196/ijmr.2485] [Medline: 23612152]
18. Aoki T, Fukumoto Y, Yasuda S, Sakata Y, Ito K, Takahashi J, et al. The Great East Japan Earthquake Disaster and cardiovascular diseases. Eur Heart J 2012 Nov;33(22):2796-2803 [FREE Full text] [doi: 10.1093/eurheartj/ehs288] [Medline: 22930461]
19. Omama S, Yoshida Y, Ogasawara K, Ogawa A, Ishibashi Y, Nakamura M, et al. Influence of the great East Japan earthquake and tsunami 2011 on occurrence of cerebrovascular diseases in Iwate, Japan. Stroke 2013 Jun;44(6):1518-1524. [doi: 10.1161/STROKEAHA.111.000442] [Medline: 23640824]
20. Ogawa S, Ishiki M, Nako K, Okamura M, Senda M, Sakamoto T, et al. Effects of the Great East Japan Earthquake and huge tsunami on glycaemic control and blood pressure in patients with diabetes mellitus. BMJ Open 2012;2(2):e000830 [FREE Full text] [doi: 10.1136/bmjopen-2012-000830] [Medline: 22505311]
21. Shiga H, Miyazawa T, Kinouchi Y, Takahashi S, Tominaga G, Takahashi H, et al. Life-event stress induced by the Great East Japan Earthquake was associated with relapse in ulcerative colitis but not Crohn's disease: a retrospective cohort study. BMJ Open 2013;3(2) [FREE Full text] [doi: 10.1136/bmjopen-2012-002294] [Medline: 23396562]
22. Kanno T, Iijima K, Abe Y, Koike T, Shimada N, Hoshi T, et al. Hemorrhagic ulcers after Great East Japan Earthquake and Tsunami: features of post-disaster hemorrhagic ulcers. Digestion 2013;87(1):40-46. [doi: 10.1159/000343937] [Medline: 23343968]
23. Yamanda S, Hanagama M, Kobayashi S, Satou H, Tokuda S, Niu K, et al. The impact of the 2011 Great East Japan Earthquake on hospitalisation for respiratory disease in a rapidly aging society: a retrospective descriptive and cross-sectional study at the disaster base hospital in Ishinomaki. BMJ Open 2013;3(1) [FREE Full text] [doi: 10.1136/bmjopen-2012-000865] [Medline: 23293238]
24. Yasumura S, Goto A, Yamazaki S, Reich MR. Excess mortality among relocated institutionalized elderly after the Fukushima nuclear disaster. Public Health 2013 Feb;127(2):186-188. [doi: 10.1016/j.puhe.2012.10.019] [Medline: 23158829]
25. Nomura S, Gilmour S, Tsubokura M, Yoneoka D, Sugimoto A, Oikawa T, et al. Mortality risk amongst nursing home residents evacuated after the Fukushima nuclear accident: a retrospective cohort study. PLoS One 2013;8(3):e60192 [FREE Full text] [doi: 10.1371/journal.pone.0060192] [Medline: 23555921]
26. Tsubokura M, Takita M, Matsumura T, Hara K, Tanimoto T, Kobayashi K, et al. Changes in metabolic profiles after the Great East Japan Earthquake: a retrospective observational study. BMC Public Health 2013;13:267 [FREE Full text] [doi: 10.1186/1471-2458-13-267] [Medline: 23521922]
27. Minoura T, Yanagida N, Watanabe Y, Yamaoka A, Miura K. [The effects of great East Japan earthquake on patients with food allergy in Miyagi Prefecture]. Arerugi 2012 May;61(5):642-651. [Medline: 22705786]
28. Usami M, Iwadare Y, Kodaira M, Watanabe K, Aoki M, Katsumi C, et al. Relationships between traumatic symptoms and environmental damage conditions among children 8 months after the 2011 Japan earthquake and tsunami. PLoS One 2012;7(11):e50721 [FREE Full text] [doi: 10.1371/journal.pone.0050721] [Medline: 23209817]
29. Ohkouchi S, Ebina M, Kamei K, Moriyama H, Tamai T, Shibuya R, et al. Fatal acute interstitial pneumonia in a worker making chips from wooden debris generated by the Great East Japan earthquake and tsunami. Respir Investig 2012 Dec;50(4):129-134. [doi: 10.1016/j.resinv.2012.09.001] [Medline: 23199976]

30. Shigemura J, Tanigawa T, Saito I, Nomura S. Psychological distress in workers at the Fukushima nuclear power plants. JAMA 2012 Aug 15;308(7):667-669. [doi: 10.1001/jama.2012.9699] [Medline: 22893158]
31. Nishi D, Koido Y, Nakaya N, Sone T, Noguchi H, Hamazaki K, et al. Peritraumatic distress, watching television, and posttraumatic stress symptoms among rescue workers after the Great East Japan earthquake. PLoS One 2012;7(4):e35248 [FREE Full text] [doi: 10.1371/journal.pone.0035248] [Medline: 22558130]
32. Haraoka T, Hayasaka S, Murata C, Ojima T. Prevention of injuries and diseases in non-professional disaster volunteer activities in the Great East Japan Earthquake areas: a preliminary study. Public Health 2013 Jan;127(1):72-75. [doi: 10.1016/j.puhe.2012.09.005] [Medline: 23158956]
33. Sawa M, Osaki Y, Koishikawa H. Delayed recovery of caregivers from social dysfunction and psychological distress after the Great East Japan Earthquake. J Affect Disord 2013 Jun;148(2-3):413-417. [doi: 10.1016/j.jad.2012.11.011] [Medline: 23261132]
34. Sugihara G, Suda S. Need for close watch on children's health after Fukushima disaster. Lancet 2011 Aug 6;378(9790):485-486. [doi: 10.1016/S0140-6736(11)61250-6] [Medline: 21821184]
35. Kuwabara H, Shioiri T, Toyabe S, Kawamura T, Koizumi M, Ito-Sawamura M, et al. Factors impacting on psychological distress and recovery after the 2004 Niigata-Chuetsu earthquake, Japan: community-based study. Psychiatry Clin Neurosci 2008 Oct;62(5):503-507. [doi: 10.1111/j.1440-1819.2008.01842.x] [Medline: 18950368]
36. Anwar J, Mpofu E, Matthews LR, Shadoul AF, Brock KE. Reproductive health and access to healthcare facilities: risk factors for depression and anxiety in women with an earthquake experience. BMC Public Health 2011;11:523 [FREE Full text] [doi: 10.1186/1471-2458-11-523] [Medline: 21718519]
37. Heiervang KS, Mednick S, Sundet K, Rund BR. The psychological well-being of Norwegian adolescents exposed in utero to radiation from the Chernobyl accident. Child Adolesc Psychiatry Ment Health 2011;5:12 [FREE Full text] [doi: 10.1186/1753-2000-5-12] [Medline: 21496337]
38. Hibino Y, Takaki J, Kambayashi Y, Hitomi Y, Sakai A, Sekizuka N, et al. Relationship between the Noto-Peninsula earthquake and maternal postnatal depression and child-rearing. Environ Health Prev Med 2009 Sep;14(5):255-260 [FREE Full text] [doi: 10.1007/s12199-009-0090-0] [Medline: 19568831]
39. Peek-Asa C, Ramirez M, Young T, Cao Y. Flood-related work disruption and poor health outcomes among university students. Prehosp Disaster Med 2012 Dec;27(6):503-508. [doi: 10.1017/S1049023X1200129X] [Medline: 23031409]
40. Goodwin R, Takahashi M, Sun S, Gaines SO. Modelling psychological responses to the Great East Japan earthquake and nuclear incident. PLoS One 2012;7(5):e37690 [FREE Full text] [doi: 10.1371/journal.pone.0037690] [Medline: 22666380]
41. Havenaar JM, de Wilde EJ, van den Bout J, Drottz-Sjöberg BM, van den Brink W. Perception of risk and subjective health among victims of the Chernobyl disaster. Soc Sci Med 2003;56(3):569-572. [Medline: 12570974]
42. The Short-Term Effect of the Great East Japan Earthquake on the Wage of College Graduates : the Role of the Quality of Education. 287. ESRI Discussion Paper Series No URL: http://www.esri.go.jp/en/archive/e_dis/abstract/e_dis287-e.html [accessed 2013-05-17] [WebCite Cache ID 6GfwdHu1X]
43. Population projection data. The Statistics Bureau and the Director-General for Policy Planning of Japan. URL: http://www.stat.go.jp/data/jinsui/2011np/#a05k23-a [accessed 2013-05-17] [WebCite Cache ID 6GfwZbTB4]
44. Ministry of Education, Culture, Sports, Science and Technology, Japan. Reading of environmental radioactivity level by prefecture URL: http://radioactivity.nsr.go.jp/en/list/192/list-1.html [accessed 2013-05-17] [WebCite Cache ID 6GfwVy1BS]
45. Gelman A, Hill J. Data Analysis Using Regression and Multilevel/Hierarchical Models. New York: Cambridge University Press; 2007.
46. Greenland S, Robins JM. Empirical-Bayes adjustments for multiple comparisons are sometimes useful. Epidemiology 1991;2(4):244-251. [Medline: 1912039]
47. Greenland S. Introduction to regression modelling. In: Rothman KJ, Greenland S, Lash TL, et al , editors. Modern Epidemiology, Third Edition. Philadelphia: Lippincott, Williams and Wilkins; 2008:418-455.
48. Bernard AM, Hayward RA, Rosevear J, Chun H, McMahon LF. Comparing the hospitalizations of transfer and non-transfer patients in an academic medical center. Acad Med 1996;71(3):262-266. [Medline: 8607926]
49. Oyama M, Nakamura K, Suda Y, Someya T. Social network disruption as a major factor associated with psychological distress 3 years after the 2004 Niigata-Chuetsu earthquake in Japan. Environ Health Prev Med 2012;17(2):118-123 [FREE Full text] [doi: 10.1007/s12199-011-0225-y] [Medline: 21710149]
50. Huizink AC, Slottje P, Witteveen AB, Bijlsma JA, Twisk JW, Smidt N, et al. Long term health complaints following the Amsterdam Air Disaster in police officers and fire-fighters. Occup Environ Med 2006;63(10):657-662 [FREE Full text] [doi: 10.1136/oem.2005.024687] [Medline: 16644894]
51. Havenaar J, Rumyantzeva G, Kasyanenko A, Kaasjager K, Westermann A, van den Brink W, et al. Health effects of the Chernobyl disaster: illness or illness behavior? A comparative general health survey in two former Soviet regions. Environ Health Perspect 1997;105 Suppl 6:1533-1537 [FREE Full text] [Medline: 9467078]
52. Kongsved SM, Basnov M, Holm-Christensen K, Hjollund NH. Response rate and completeness of questionnaires: a randomized study of Internet versus paper-and-pencil versions. J Med Internet Res 2007;9(3):e25 [FREE Full text] [doi: 10.2196/jmir.9.3.e25] [Medline: 17942387]

53. Ekman A, Klint A, Dickman PW, Adami HO, Litton JE. Optimizing the design of Web-based questionnaires--experience from a population-based study among 50,000 women. Eur J Epidemiol 2007;22(5):293-300. [doi: 10.1007/s10654-006-9091-0] [Medline: 17206467]
54. Yasumura S, Hosoya M, Yamashita S, Kamiya K, Abe M, Akashi M, Fukushima Health Management Survey Group. Study protocol for the Fukushima Health Management Survey. J Epidemiol 2012;22(5):375-383 [FREE Full text] [Medline: 22955043]

Abbreviations

AIC: Akaike's Information Criterion
JMA-SI: Japan Meteorological Agency seismic intensity
MEXT: Ministry of Education, Culture, Sports, Science and Technology
NPP: Nuclear Power Plant
OR: odds ratio

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Original Paper

Website Visitors Asking Questions Online to Lung Cancer Specialists: What Do They Want To Know?

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Abstract

Background: In 2003 the Dutch Lung Cancer Information Centre (Longkanker Informatie Centrum) launched a website containing information on lung cancer accessible to anyone.

Objective: Our study aim was to inventorize the information needs of the visitors of this website by analyzing the questions they asked the lung cancer specialists in the websites interactive section “Ask the Physician”.

Methods: The first 2000 questions posted up until May 2006 have been classified by visitors’ wish, type of required information, identity, gender, and phase during treatment course.

Results: Our results show that 1893 (1158/1893, 61%) of the questions were asked by a loved one/caregiver and (239/1893 13%) by patients. 1 out of 3 questions was asked by a daughter/grand-daughter. Most questions concerned specific information on lung cancer and lung cancer course (817/1893, 43%). The most inquired specific information topics were therapy side effects, diagnostics, general information on lung cancer, and regular therapy. Furthermore, questioners wanted to verify their own doctor’s information (122/1893, 6%), a diagnosis (267/1893, 14%), and a prognosis (204/1893, 11%).

Conclusions: Lung cancer patients and their caregivers asked the most questions in the interactive website section. The most frequently requested information was more detailed information. These include specific information on lung cancer (regular therapy, diagnostics, and disease symptoms), verification of what the doctor has said, diagnosis, and prognosis. Most of the requested information could have been obtained from treating specialists, indicating that current information supply to lung cancer patients and their caregivers may not be matching their needs sufficiently. The further implementation of an online dialogue with lung cancer specialists might be a solution.

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KEYWORDS

Internet; lung neoplasms; medical informatics; information services; patient education; information needs; caregivers

Introduction

The Internet has changed the position of patients within the healthcare system. Currently, the Internet is widely used as a resource for health related information [1-4]. Ybarra et al [5] have reported a percentage of 73% Internet use among Americans, of whom 56% reported using the Internet as a resource for health information. A few health care providers already utilize the potential of the Internet [6-9] such as, the "emaildoctor" [10]. However, these physicians are still forerunners and not disease specific specialists, possibly making information superficial and not up-to-date, resulting in resistance against these practices among medical specialists.

As a result of an initiative of doctors, patients, nurses, and other professionals involved with lung cancer, the Dutch Lung Cancer Information Centre (DLIC) was founded. There were not a lot of information available on lung cancer in the Netherlands and lung cancer patient groups were poorly organised [11].

This centre is meant for lung cancer patients, their relatives or loved ones, and people seeking information about lung cancer. The centre of the activities of DLIC is the website [12]. Since its launch in 2003, the DLIC website has been visited very often and has reached a steady number of 20,000 visitors per month. The number of monthly visitors are striking, considering that lung cancer incidence and prevalence respectively are around 10,500 and 14,000 per year in the Netherlands [13,14]. Results from our previous study have shown that caregivers of lung cancer patients are the largest group of visitors of the website [11]. Deducted from the total number of visitors and visitor type [11], around 1600 patients and 11,800 caregivers visit the DLIC website each month [13].

The most popular page of the DLIC website is the interactive section "Ask the Physician", which was launched in March 2004 [15]. Through this web page, visitors can ask lung cancer specialists specific questions about lung cancer. Since the launch of this interactive web page 7 years ago, approximately 6400 questions have been posted. Furthermore, around 500 people per day visit the section "Ask the Physician" to read these questions and their answers.

The large number of questions in the section "Ask the physician" indicates that website questioners, presumably lung cancer patients and their caregivers, are in need of information on lung cancer. Studying these questions might give more insight into the identity of these specific visitors and in their information needs. It is important to define these needs as it might help defining guidelines for a better way of addressing lung cancer information by treating specialists. There are many studies published about looking for health related information on the Internet, but we did not find any studies addressing online interaction between questioners and lung cancer specialists. The aim of this study was to classify the asked questions posed on the DLIC website into categories so as to give an overview of the types of persons who visit the website and their information needs.

Methods

Overview

The main objective of the DLIC for answering questions in the interactive section "Ask the Physician" is to give support to questioners, clarify, and indicate where possibilities can be found with their own specialist. If lifestyle advices or smoking were mentioned by questioners, smoking was systematically discouraged, while exercise and a healthy diet were encouraged. Diagnoses were never stipulated, initial opinions were not challenged, and no other treatment suggestions were made.

Every time new visitors used the interactive section to ask a question, they had to fill in a form and give their name and email address. Each form and each question with the matching answer have been carefully read retrospectively by our team members (RMS and CL). After reading, categories were deducted from the form/question/answer according to their content and set in a database. If it was impossible to determine any of the categories of the visitors, items were classified as unknown.

The questions have been categorized into the next items determined by our research group (see Table 1).

Analysis

The first 2000 questions asked until May 2006 on the webpage "Ask the Physician" [12] have been imported to a Microsoft Access database and then categorized and analysed according above mentioned items.

Ethical Approval

According to Dutch law, this study does not need approval by an ethical review board.

Table 1. Categories.

Categories	Possible outcomes
Questioner identity	
	Student
	Patient
	Caregiver: child/grandchild, partner, other family members, no family
	Person who fears lung cancer
	Other
	Unknown
Gender	
	Male
	Female
Phase of illness/phase in lung cancer procedure	
	Before diagnosis-symptoms only
	Before diagnosis-after X-ray
	After diagnosis
	Time of choosing therapy
	After surgery
	During therapy
	After therapy
	After healing or recovery
	Terminal stage
	After death
	Other
	Unknown
Type of information requested	
	Specific information on lung cancer or lung cancer therapy Diagnosis
	Prognosis
	Treatment advice
	Explanation of doctor’s words
	Terminology questions
	Help with a choice
	Lifestyle advice
	Help with essay/paper
	Other
	Unknown
Specific information: specific information topics	
	Lung cancer information in general
	Therapy side effects
	Symptoms of disease
	Regular therapy
	Alternative therapy
	Experimental therapy
	Diagnostics

Categories	Possible outcomes
	Lung cancer prevention
	Disease progression
	Other

Results

General

Since its launch in March 2004, the webpage “Ask the Physician” has been widely visited. Data on the numbers of visitors, page views, questioners, questions, lung cancer incidence, and prevalence in the Netherlands are not shown in current manuscript but are available on request.

During our defined study period (March 2004-May 2006), 2000 questions have been asked by 1200 people. One person asked 107 questions on her own, and the information seeking behavior of this person was not likely to be representative for the majority of questioners using the interactive webpage. This person was excluded.

Eighty percent (1199/1893, 80%) of the people who asked questions on the interactive webpage asked one question. The rest (694/1893, 20%) asked one or more additional questions. Around 1% of the people asked more than 10 questions. In total 1893 questions have been analysed.

Who Asks Questions?

Tables 2 and 3 give the demographics of the persons asking questions on the webpage. The majority of questions were asked by caregivers of lung cancer patients (1158/1893, 61%). Thirteen percent (243/1893, 13%) of all the questions were asked by patients. Of the total study group around one third (849/1893, 33%) of questions were asked by daughters and granddaughters. The category “*unknown*” has been applied when demographics of the questioners could not be found.

Regarding the percentages of questions asked by caregivers and lung cancer patients, caregivers asked 4.8 times more questions than patients in a period of 27 months. This means that 212 questions were asked by caregivers per 100 patients per year.

Moment of Asking Questions

All questions asked by patients and caregivers (n=1394) were asked at different phases during lung cancer procedure. Most questions arose during therapy (376/1394, 27%), after therapy (223/1394, 16%) and after diagnosis (209/1394, 15%). Questions were also asked at the terminal stage of illness (125/1394, 9%), before diagnosis after the first X-ray (112/1394, 8%), and after surgery (98/1394, 7%).

What Did the Visitors Ask?

Table 4 provides an overview of the wanted information by questioners. Patients (n=243) requested specific information (122/243, 50%), wanted to verify doctor’s information (25/243, 10%) and a diagnosis (20/243, 8%) or a prognosis (19/243, 8%) in the most cases. Other questioners (n=1650) wanted specific information (695/1650, 42%), a diagnosis (247/1650, 15%), a prognosis (185/1650, 11%) and to verify doctor’s information (6%).

The category “verify doctor’s information” means that a questioner checked whether the information given by the specialist was true: “the doctor has told me that I can choose between chemotherapy and radiotherapy as therapy, is this true?” The category “clarify doctor’s explanation” means that the questioner wanted an explanation of what the specialist had said: “My father has lung cancer and will be treated with chemotherapy. The doctor has said that with treatment my father has 30% chance. What does he mean?” The category “unknown” has been applied when the purpose of the questions was unclear or unknown.

Specific Information Topics on Lung Cancer and Lung Cancer Therapy

In the case of questions regarding specific information, the number of topics asked exceeds the number of requests for information on lung cancer and lung cancer therapy (Tables 4 and 5) because questions generally contained several topics people wanted to know about.

When patients wanted specific information, the most frequently discussed topics were (see Table 5) therapy side-effects (29/145, 20%), diagnostics (28/145, 19%), regular therapy (26/145, 18%), experimental therapy (15/145, 10%) and disease symptoms (14/145, 10%).

When other questioners requested specific information, the most frequently asked questions were about therapy (196/931, 21%), general information on lung cancer (140/931, 15%), diagnostics (113/931, 12%), disease symptoms (109/931, 12%), therapy side effects (100/931, 11%) and disease course (102/931, 11%).

Table 2. Questioner’s identity type.

Questioner identity (n questions=1893)	n	%
Caregiver	1158	61.17
Patient	243	12.84
Person who fears lung cancer	239	12.63
Student	55	2.91
Other	30	1.58
Unknown	168	8.87

Table 3. Questioner’s identity type by gender.

Category		n	%
Gender (n questions=1893)			
	male	415	21.92
	female	1225	64.71
	unknown	253	13.37
Gender of patients (n=243)			
	male	66	27.2
	female	144	59.3
	unknown	33	13.6
Gender of caregivers: male, female, unknown (n=1158)			
	male	190	16.41
	female	835	72.11
	unknown	133	11.49
Children/grandchildren (n=849)			
	male	123	14.49
	female	622	73.26
	unknown	104	12.25
Partner (n=180)			
	male	48	26.67
	female	126	70.00
	unknown	6	3.33
Other family members (n=83)			
	male	11	13.25
	female	55	66.27
	unknown	17	20.48
No family (n=46)			
	male	8	17.39
	female	32	69.57
	unknown	6	13.04

Table 4. What was asked in the first instance: topics, patients, and other questioners.

Topics	Patients (n=243) n (%)	Other questioners (n=1650) n (%)	Total group (n=1893) n (%)
Specific information	122 (50.2)	695 (42.12)	817 (43.16)
Verify doctor’s information	25 (10.3)	97 (5.88)	122 (6.44)
Diagnosis	20 (8.2)	247 (14.97)	267 (14.10)
Prognosis	19 (7.8)	185 (11.21)	204 (10.78)
Treatment advice	14 (5.8)	85 (5.15)	99 (5.23)
Other	11 (4.5)	69 (4.18)	80 (4.23)
Terminology	10 (4.1)	66 (4.00)	76 (4.01)
Clarify doctor’s explanation	7 (2.9)	71 (4.30)	78 (4.12)
Advice, references	6 (2.5)	36 (2.18)	42 (2.22)
Help with a choice	4 (1.6)	19 (1.15)	23 (1.22)
Lifestyle advice	3 (1.2)	30 (1.82)	33 (1.74)
Unknown	2 (0.8)	3 (0.18)	5 (0.26)
Help with essay/paper	0 (0.0%)	47 (32.85)	47 (2.48)

Table 5. Topics of required specific information on lung cancer and lung cancer therapy, patients, and other questioners.

Topics of specific information	Patients (n=145) n (%)	Other questioners (n=931) n (%)
Therapy side-effects	29 (20.0)	100 (10.7)
Diagnostics	28 (19.3)	113 (12.1)
Regular therapy	26 (17.9)	196 (21.1)
Experimental therapy	15 (10.3)	50 (5.4)
Disease symptoms	14 (9.7)	109 (11.7)
What can it be?	11 (7.6)	52 (5.6)
Disease course	9 (6.2)	102 (11.0)
General information on lung cancer	7 (4.8)	140 (15.0)
Other	5 (3.4)	51 (5.5)
Alternative therapy	1 (0.7)	6 (0.6)
Lung cancer prevention	0 (0.0)	12 (1.3)

Discussion

Principal Findings

In this study, we looked at information that was requested from online lung cancer specialists by visitors of the DLIC website. Most questions were asked by lung cancer patients and their caregivers (especially daughter and granddaughter). There are many studies published about looking for health related information on the Internet, but studies about asking specific questions to online (lung) specialists are rare. This distinguishes our present study. Our study results show that most frequently requested information was more detailed information about lung cancer (such as regular therapy, diagnostics, and disease symptoms), verification of doctor’s words, diagnosis and prognosis. This kind of information could have been obtained from treating physicians, implying that the supplied information to lung cancer patients and their caregivers may be insufficient with regard to their needs. Beside this, the impressive number of questions asked on the website indicates that patients and caregivers are willing to participate in online dialogues with specialists.

Before comparing our results with data from other studies, it should be mentioned that we have chosen to analyse all questions regardless if they were from one person or a different one. Since the number of persons who asked more than 1 question is substantial (20%), this may have influenced our results. An argument for our approach is that each question was different and was asked during different phases of lung cancer procedure. Each question should thus be considered as one item regardless of who asked it.

Similarities and differences between our results and other study results can be seen. We found that (1158/1893, 61%) of the questions were asked by caregivers. The result confirms our observations in our previous study [11] and other studies that a large percentage of caregivers use the Internet. Norum et al [16] reported that 60% of patients' partners used Internet and Ybarra et al [17] found that support seekers were significantly more likely to be patients' caregivers.

In our study, (243/1893, 13%) of the questions were asked by patients. Studies of Fleisher et al [18] and Mold et al [19] stated that 15 to 20% of patients in their study were *indirect* Internet users. Miles et al [20] gave a percentage of 24%. Our results are different and add to existing study data because present study gives the percentage of patients who are *direct* Internet users. Furthermore, our study group only included lung cancer patients. According to Eysenbach's study, only 16% of all information seeking cancer patients was a lung cancer patient [21], which is more comparable to our findings. This relatively low percentage of lung cancer patients looking for information and asking questions online could be explained by differences in gender, age, and socio-economic status. The majority of questioners were young women and the biggest group of questioners was a daughter or granddaughter. Women look for health related information on the Internet more often than men and a younger age is associated with a greater Internet use [3,16,21-30]. It is known that lung cancer patients usually are elderly males of low social levels. This is associated with a limited tendency to use the Internet [31]. Although data on age and gender of all patients who asked questions on the website were not completely available, we assume that the Dutch lung cancer patients do not differ from lung cancer patients elsewhere and thus go on the Internet less often than their female caregivers. Additionally, lung cancer patients' strategies to look for medical information differ from other cancer patients. They are more likely to be passive in seeking information than other cancer patients [32]. Thus, they will ask their caregivers to look for information for them and look less actively themselves. In this manner, a lot of lung cancer patients were getting information from the DLIC website indirectly.

Considering the number of visitors per year attending the website and the number of questions asked by caregivers and lung cancer patients, the question rises whether present results are representative for the total website visiting population of caregivers and lung cancer patients. According to our data, about 212 questions are being asked by caregivers per 100 patients per year for the 14,000 annual cases in the Netherlands. The number of visitors of the DLIC website per year appears relatively larger than the number of questions asked. A plausible explanation for this fact may be that many visitors already found the answers to their questions in the websites general information or in the questions in the section "Ask the physician". Another explanation may be that visitors solely visited the website to look for information and that some of them may not dare to ask questions. If we compare present results with the poll "visitor identity" we had performed in our previous study [11], the percentages of lung cancer patients and caregivers correspond well with each other. Thus, questions asked by visitors on the website are quite representative for the total visitor population.

Our study found that most information seeking behavior occurred during therapy, after therapy, and after diagnosis. Other studies show similar results, indicating that most patients seek explanatory information just after their diagnosis and before starting treatment; or just after diagnosis (49%) or during treatment (31%) [33,34].

Information seekers had specific questions. Most of them wanted specialized information about a specific topic concerning lung cancer, a diagnosis, a prognosis, or to verify doctor's information. The most frequently asked topics of specific information about lung cancer in present study were regular therapy, diagnostics, general information about lung cancer, therapy side effects and disease symptoms. A number of studies investigated the most wanted information topics by Internet users, and found that information related to treatment (80%) [35], information about a condition, symptoms, advice about symptoms and treatment [36], information on cancer screening/diagnosis, support services, psychosocial issues, and general cancer site information [37], were the most wanted topics. Rutten et al [38], found that the most frequent information needs of cancer patients were information on treatment (38.1%), specific on cancer (12.8%), rehabilitation (12.2%), and prognosis (10.8%).

It is noteworthy that patients of our study were more interested in trials and side effects than the other questioners, who were mostly caregivers.

Further Research

Given the questions on the webpage "ask the Physician" and the fact that most answers could have been obtained from the treating physician/specialist, it could be concluded that for many of these lung cancer patients and caregivers visiting the website, information given during specialist consultations was unclear, insufficient, not well understood or not well remembered. This has also been mentioned in several studies [39-41]. However, since we do not know whether caregivers asking questions on the website were actually present during consultations with treating physicians, we cannot conclude that the given information was indeed unclear and insufficient to patients or to them. Neither can we conclude that the information was not given, not well understood, or not well remembered because we were not present during consultations as well. Submission of a question does not necessarily indicate that information has not been provided. We do not know what information has been given. Beside this, investigators in a recent study have found age and prognosis to be predictive for poor information recall in cancer patients [42]. Patients and caregivers may have had difficulties to remember medical information. Additionally, the information needs of lung cancer patients differ from their caregivers', as illustrated by our study. Nevertheless, as noticeable in our results, (151/1893, 8%) of the questions concerned an explanation of doctor's words or terminology, indicating that a (small) part of the information given by treating specialists is actually not clear. Also the large number of questions on the website still is a signal that the medical information supply of lung cancer patients and their caregivers does not completely match their information needs. This phenomenon is an interesting indication that lung cancer patients and their caregivers are open and willing to participate in online dialogues with treating specialists. In our previous study [11], we already showed with a visitor satisfaction poll that the majority of visitors were very positive about the usefulness of the website and its interactive page. Thus, we suggest an adaptation, and hopefully subsequently possible amelioration of the medical information supply to lung cancer patients and their caregivers. Suggestions for improvement could be to survey repeatedly about the information needs of lung cancer patients and their caregivers, giving printed or written information to patients and caregivers [43-45], encouraging email contact and online dialogue with specialists for questions [8,9], directing to reliable Internet sources of information for complementary information [11], and repeat the information given during consultations.

Further research is needed to explore the reasons why lung cancer patients and their caregivers turn to online lung specialists for information. The importance and role of caregivers during treatment should also be investigated since they appear to be involved in the information supply of lung cancer patients in present study.

Conclusions

Lung cancer patients and their caregivers asked most questions in the interactive section of the DLIC website. The most frequently requested information was more detailed and specific information about lung cancer (regular therapy, diagnostics and disease symptoms), verification of what the doctor has said, diagnosis, and prognosis. Most of the requested information could have been obtained from treating specialists, indicating that the information supply of lung cancer patients and their caregivers may not be matching their needs sufficiently. Since lung cancer patients and caregivers seem to be appreciating and willing to use online interactive dialogue with lung cancer specialists, further implementation of such dialogue might be a solution.

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Conflicts of Interest

None declared.

References

1. Baker L, Wagner TH, Singer S, Bundorf MK. Use of the Internet and e-mail for health care information: results from a national survey. JAMA 2003 May 14;289(18):2400-2406. [doi: 10.1001/jama.289.18.2400] [Medline: 12746364]
2. Bansil P, Keenan NL, Zlot AI, Gilliland JC. Health-related information on the Web: results from the HealthStyles Survey, 2002-2003. Prev Chronic Dis 2006 Apr;3(2):A36 [FREE Full text] [Medline: 16539777]
3. Fox SRL. The November 26. Washington, DC: Pew Internet and American Life Project; 2000. The Online health care revolution: how the Web helps Americans take better care of themselves URL: http://www.pewInternet.org/Reports/2000/The-Online-Health-Care-Revolution.aspx [accessed 2010-12-21] [WebCite Cache ID 5v8icIbqm]
4. US Department of Commerce. February. 2002. A nation online: How Americans are expanding their use of the Internet URL: http://www.ntia.doc.gov/opadhome/digitalnation/index_2002.html [accessed 2010-12-21] [WebCite Cache ID 5v8iKYdfx]
5. Ybarra ML, Suman M. Help seeking behavior and the Internet: a national survey. Int J Med Inform 2006 Jan;75(1):29-41. [doi: 10.1016/j.ijmedinf.2005.07.029] [Medline: 16129659]
6. Ferguson T. Online patient-helpers and physicians working together: a new partnership for high quality health care. BMJ 2000 Nov 4;321(7269):1129-1132 [FREE Full text] [Medline: 11061737]
7. Fox S, Fallows D. Internet Health Resources. Health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access URL: http://www.pewInternet.org/Reports/2003/Internet-Health-Resources.aspx [accessed 2010-12-21] [WebCite Cache ID 5v8iu2JuK]
8. Kane B, Sands DZ. Guidelines for the clinical use of electronic mail with patients. The AMIA Internet Working Group, Task Force on Guidelines for the Use of Clinic-Patient Electronic Mail. J Am Med Inform Assoc 1998 Jan;5(1):104-111 [FREE Full text] [Medline: 9452989]
9. Eysenbach G, Diepgen TL. Evaluation of cyberdocs. Lancet 1998 Nov 7;352(9139):1526. [doi: 10.1016/S0140-6736(05)60334-0] [Medline: 9820312]
10. Mol R. 2010. Homepage emaildokter URL: http://www.emaildokter.nl/ [accessed 2010-12-21] [WebCite Cache ID 5v8jU0bWf]
11. Linssen C, Schook RM, The AM, Lammers E, Festen J, Postmus PE. A web site on lung cancer: who are the users and what are they looking for? J Thorac Oncol 2007 Sep;2(9):813-818. [doi: 10.1097/JTO.0b013e31811f472a] [Medline: 17805058]
12. Website van het Longkanker Informatiecentrum. December 21. 2010. Homepage URL: http://www.longkanker.info/ [accessed 2010-12-21] [WebCite Cache ID 5v8jae1HR]

13. Rijksinstituut voor Volksgezondheid en milieu, Nationaal Kompas Volksgezondheid. Omvang van het probleem. Longkanker URL: http://www.nationaalkompas.nl/gezondheid-en-ziekte/ziekten-en-aandoeningen/kanker/longkanker/omvang/ [accessed 2010-12-21] [WebCite Cache ID 5v8iybohn]
14. IKNL Integraal Kankercentrum Nederland, Nederlandse kankerregistratie. Kerncijfers over kanker-Prevalentie en incidentie tumoren onderste luchtewegen. 2013. Kankerregistratie URL: http://cijfersoverkanker.nl/ [accessed 2013-07-10] [WebCite Cache ID 6I0Z2wLEY]
15. Longkanker Informatiecentrum. December. 2010. Webpagina: Vraag het een arts URL: http://www.longkanker.info/faq/overzicht.asp [accessed 2010-12-21] [WebCite Cache ID 5v8jfYpLC]
16. Norum J. Evaluation of Norwegian cancer hospitals web sites and explorative survey among cancer patients on their use of the Internet. J Med Internet Res 2001 Oct;3(4):E30 [FREE Full text] [doi: 10.2196/jmir.3.4.e30] [Medline: 11772545]
17. Ybarra M, Suman M. Reasons, assessments and actions taken: sex and age differences in uses of Internet health information. Health Educ Res 2008 Jun;23(3):512-521 [FREE Full text] [doi: 10.1093/her/cyl062] [Medline: 16880222]
18. Fleisher L, Bass S, Ruzek SB, McKeown-Conn N. Relationships among Internet health information use, patient behavior and self efficacy in newly diagnosed cancer patients who contact the National Cancer Institute's NCI Atlantic Region Cancer Information Service (CIS). Proc AMIA Symp 2002:260-264 [FREE Full text] [Medline: 12463827]
19. Mold JW, Cacy JR, Barton ED. Patient-physician E-mail communication. J Okla State Med Assoc 1998 Sep;91(6):331-334. [Medline: 9763766]
20. Miles J, Petrie C, Steel M. Slimming on the Internet. J R Soc Med 2000 May;93(5):254-257 [FREE Full text] [Medline: 10884770]
21. Eysenbach G. The impact of the Internet on cancer outcomes. CA Cancer J Clin 2003 Nov;53(6):356-371. [Medline: 15224975]
22. Baker L, Wagner TH, Singer S, Bundorf MK. Use of the Internet and e-mail for health care information: results from a national survey. JAMA 2003 May 14;289(18):2400-2406. [doi: 10.1001/jama.289.18.2400] [Medline: 12746364]
23. Basch EM, Thaler HT, Shi W, Yakren S, Schrag D. Use of information resources by patients with cancer and their companions. Cancer 2004 Jun 1;100(11):2476-2483 [FREE Full text] [doi: 10.1002/cncr.20261] [Medline: 15160355]
24. Metz JM, Devine P, DeNittis A, Jones H, Hampshire M, Goldwein J, et al. A multi-institutional study of Internet utilization by radiation oncology patients. Int J Radiat Oncol Biol Phys 2003 Jul 15;56(4):1201-1205. [Medline: 12829160]
25. Mills ME, Davidson R. Cancer patients' sources of information: use and quality issues. Psychooncology 2002;11(5):371-378. [doi: 10.1002/pon.584] [Medline: 12228870]
26. Norum J, Grev A, Moen MA, Balteskard L, Holthe K. Information and communication technology (ICT) in oncology. Patients' and relatives' experiences and suggestions. Support Care Cancer 2003 May;11(5):286-293. [doi: 10.1007/s00520-002-0437-1] [Medline: 12690539]
27. Pautler SE, Tan JK, Dugas GR, Pus N, Ferri M, Hardie WR, et al. Use of the Internet for self-education by patients with prostate cancer. Urology 2001 Feb;57(2):230-233. [Medline: 11182326]
28. Pereira JL, Koski S, Hanson J, Bruera ED, Mackey JR. Internet usage among women with breast cancer: an exploratory study. Clin Breast Cancer 2000 Jul;1(2):148-53; discussion 154. [doi: 10.3816/CBC.2000.n.013] [Medline: 11899653]
29. Satterlund MJ, McCaul KD, Sandgren AK. Information gathering over time by breast cancer patients. J Med Internet Res 2003 Jul;5(3):e15 [FREE Full text] [doi: 10.2196/jmir.5.3.e15] [Medline: 14517106]
30. Smith RP, Devine P, Jones H, DeNittis A, Whittington R, Metz JM. Internet use by patients with prostate cancer undergoing radiotherapy. Urology 2003 Aug;62(2):273-277. [Medline: 12893334]
31. Rutten LJ, Squiers L, Hesse B. Cancer-related information seeking: hints from the 2003 Health Information National Trends Survey (HINTS). J Health Commun 2006;11 Suppl 1:147-156. [doi: 10.1080/10810730600637574] [Medline: 16641080]
32. Eheman CR, Berkowitz Z, Lee J, Mohile S, Purnell J, Rodriguez EM, et al. Information-seeking styles among cancer patients before and after treatment by demographics and use of information sources. J Health Commun 2009 Jul;14(5):487-502 [FREE Full text] [doi: 10.1080/10810730903032945] [Medline: 19657928]
33. Manfredi C, Czaja R, Price J, Buis M, Janiszewski R. Cancer patients' search for information. J Natl Cancer Inst Monogr 1993(14):93-104. [Medline: 8123363]
34. Manfredi C, Czaja R, Buis M, Derk D. Patient use of treatment-related information received from the Cancer Information Service. Cancer 1993 Feb 15;71(4):1326-1337. [Medline: 8435809]
35. Monnier J, Laken M, Carter CL. Patient and caregiver interest in Internet-based cancer services. Cancer Pract 2002 Nov;10(6):305-310. [Medline: 12406053]
36. Shuyler KS, Knight KM. What are patients seeking when they turn to the Internet? Qualitative content analysis of questions asked by visitors to an orthopaedics Web site. J Med Internet Res 2003 Oct 10;5(4):e24 [FREE Full text] [doi: 10.2196/jmir.5.4.e24] [Medline: 14713652]
37. Squiers L, Finney Rutten LJ, Treiman K, Bright MA, Hesse B. Cancer patients' information needs across the cancer care continuum: evidence from the cancer information service. J Health Commun 2005;10 Suppl 1:15-34. [doi: 10.1080/10810730500263620] [Medline: 16377598]

38. Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). Patient Educ Couns 2005 Jun;57(3):250-261. [doi: 10.1016/j.pec.2004.06.006] [Medline: 15893206]
39. Jones R, Pearson J, McGregor S, Gilmour WH, Atkinson JM, Barrett A, et al. Cross sectional survey of patients' satisfaction with information about cancer. BMJ 1999 Nov 6;319(7219):1247-1248 [FREE Full text] [Medline: 10550091]
40. Turner S, Maher EJ, Young T, Young J, Vaughan Hudson G. What are the information priorities for cancer patients involved in treatment decisions? An experienced surrogate study in Hodgkin's disease. Br J Cancer 1996 Jan;73(2):222-227 [FREE Full text] [Medline: 8546910]
41. Chen X, Siu LL. Impact of the media and the Internet on oncology: survey of cancer patients and oncologists in Canada. J Clin Oncol 2001 Dec 1;19(23):4291-4297. [Medline: 11731511]
42. Jansen J, Butow PN, van Weert JC, van Dulmen S, Devine RJ, Heeren TJ, et al. Does age really matter? Recall of information presented to newly referred patients with cancer. J Clin Oncol 2008 Nov 20;26(33):5450-5457. [doi: 10.1200/JCO.2007.15.2322] [Medline: 18936478]
43. Iconomou G, Vagenakis AG, Kalofonos HP. The informational needs, satisfaction with communication, and psychological status of primary caregivers of cancer patients receiving chemotherapy. Support Care Cancer 2001 Nov;9(8):591-596. [Medline: 11762969]
44. Iconomou G, Viha A, Koutras A, Koukourikou I, Mega V, Makatsoris T, et al. Impact of providing booklets about chemotherapy to newly presenting patients with cancer: a randomized controlled trial. Ann Oncol 2006 Mar;17(3):515-520 [FREE Full text] [doi: 10.1093/annonc/mdj098] [Medline: 16344276]
45. Rassin M, Levy O, Schwartz T, Silner D. Caregivers' role in breaking bad news: patients, doctors, and nurses' points of view. Cancer Nurs 2006 Jul;29(4):302-308. [Medline: 16871098]

Abbreviations

DLIC: Dutch Lung Cancer Information Centre

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Original Paper

An Evaluation Framework for Defining the Contributions of Telestration in Surgical Telementoring

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Abstract

Background: An increasing quantity of research in the domain of telemedicine show a growing popularity and acceptance of care over distance systems among both clinicians and patients. We focus on telementoring solutions, developed for providing remote guidance to less experienced surgeons. Telestration is often regarded as an extra functionality of some telementoring systems. However, we advocate that telestration must be viewed as a core feature of telementoring due to its advantages.

Objective: To analyze and define concepts, parameters, and measurement procedures to evaluate the impact of using telestration while telementoring.

Methods: A systematic review of research dealing with telestration during remote guidance sessions was performed by querying three major online research databases (MEDLINE, Association of Computing Machinery, and Institute of Electrical and Electronics Engineers) using a predefined set of keywords (“laparoscopy”, “annotate”, “telestrate”, “telestration”, “annotation”, “minimally invasive”, and “MIS”).

Results: The keyword-based search identified 117 papers. Following the guidelines for performing a systematic review, only 8 publications were considered relevant for the final study. Moreover, a gap in research defining the impacts of telestration during telementoring was identified. To fill this niche, a framework for analyzing, reporting, and measuring the impacts of telestration was proposed.

Conclusions: The presented framework lays the basics for the structured analysis and reporting of telestration applied to telementoring systems. It is the first step toward building an evidence knowledge base documenting the advantages of live video content annotation and supporting the presented connections between the concepts.

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KEYWORDS

telementoring; telestration; annotation; impact; benefits; theoretical models; evaluation framework

Introduction

The shift from open to laparoscopic surgery presents a fertile ground for an expansion of telemedicine (a set of medical practices without direct physician-patient interaction that are often realized via interactive audio-video communication [1]). Advances in information and communication technologies have resulted in the development of relatively low cost and high reliability devices as a medium for telemedical solutions. The demand for telementoring systems in laparoscopic surgery, comprising the real-time interactive teaching of techniques by an expert surgeon to a student at a distant site [1], in laparoscopic surgery was partially motivated by the decreasing ratio of general practice surgeons to population, a problem that is predicted to increase in the future [2]. Studies have shown the benefits of using telementoring, especially in the field of laparoscopic surgery [3,4]. Time and cost reductions as well as a more efficient surgical education are only a few of the many, mostly evident advantages of this developing technology [3].

Telementoring has been discussed extensively in the literature, with multiple solutions demonstrated for laparoscopic surgery [5,6]. Its place in surgery has been described by Doarn [7] as “a natural fit”. Furthermore, videoconferencing has gained increasing popularity in all fields of medicine, especially in follow-up and out-patient treatment [8-10].

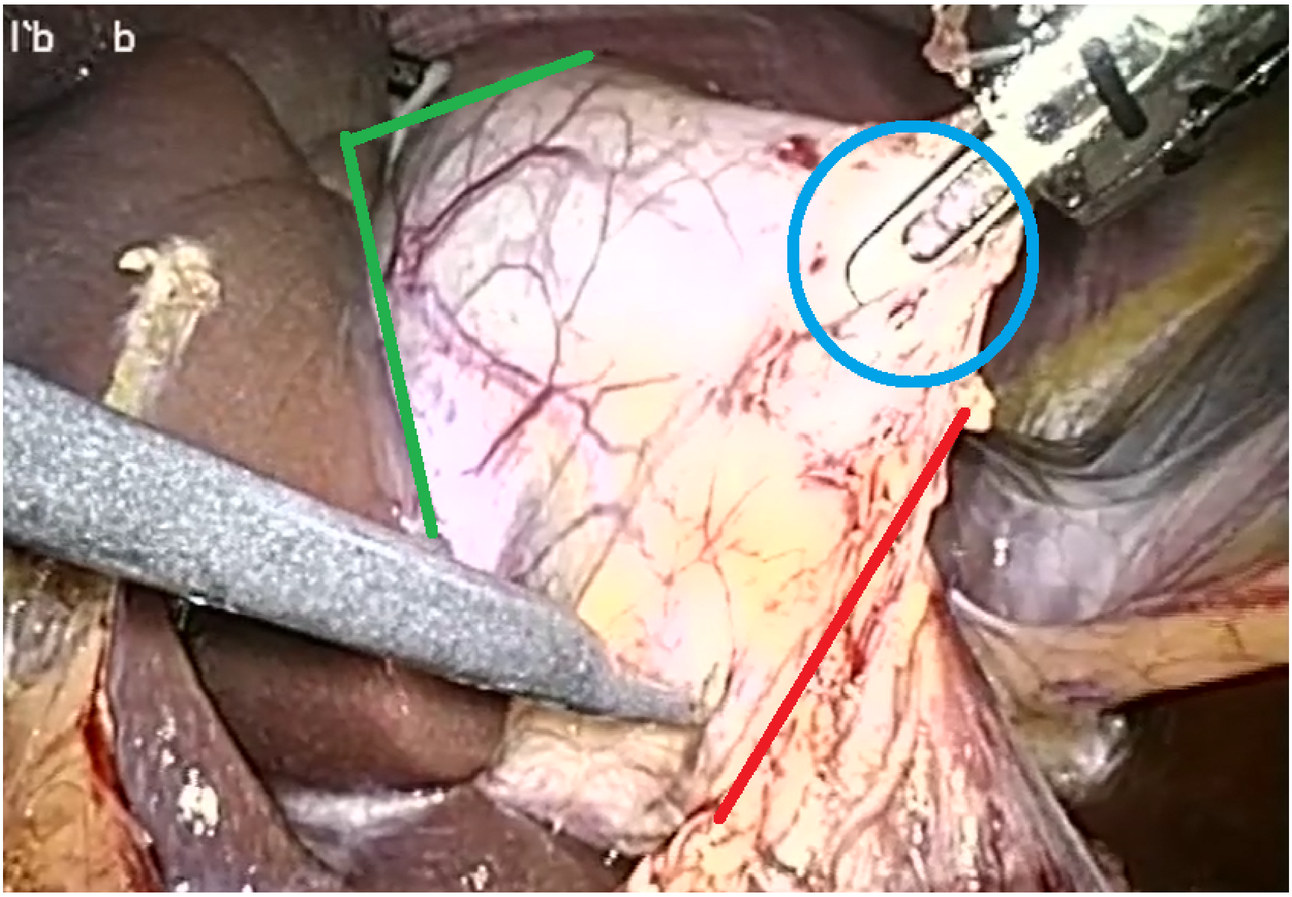
In spite of the recent advances in mobile devices, the current body of literature tends to limit the telementoring approach to stationary platforms. However, the Mobile Medical Mentor project team advocates using mobile devices for telementoring due to additional benefits compared to the stationary ones [11]. The fact that mentors rarely stay at one location and are highly mobile should be sufficient impetus for further exploration of mobile platforms for telementoring. Having a telementoring device within reach should increase the availability of experts. Therefore, the main challenge is to ensure that the required telementoring infrastructure is available on a mobile medium [11].

Telestration is defined as a technique for enabling the drawing of freehand markups (annotations) over image or video (Figure 1). Although it is mostly used in commenting on sports and weather forecasts, it often attracts the attention of medical personnel [12,13]. In the domain of telemedicine, telestration is normally considered to be an additional accessory function of telementoring systems. As the overall impacts and benefits of telestration are not clear, this paper aimed to analyze the available studies reporting the use of telestration to form a systematic assessment of the reported outcomes of using telestration in minimally invasive surgery (MIS).

The paper is structured as follows: after a short introduction to the developing domain of telemedicine, the motivation for using telementoring systems is presented. The telestration feature is analyzed in greater detail.

The Methods Section defines the procedures that were followed to summarize the current body of knowledge in using telestration and guidelines to develop the evaluation framework. The Results Section represents the achievements of a systematic review procedure and highlights the identified gap in the available research. The following section discusses the identified niche in research, introducing an evaluation framework for analyzing, measuring, and reporting the impacts of using telestration during telementoring sessions. Evaluation biases and confounders were analyzed in the Discussion Section.

Figure 1. Surgical telestration.



Methods

Overview

This section is divided into two sub-sections, the first of which describes the search process for relevant research. This search was performed to summarize the available body of knowledge in evaluating the impacts of telestration applied to telementoring systems. The second part studies the development of an evaluation framework in more detail by introducing the methodology for developing theoretical models.

Systematic Literature Review

To form a solid basis for this research, a systematic literature review of telementoring applications that include a telestration feature in MIS was performed. The review was carried out following the guidelines defined by Kitchenham [14]. The aim of reviewing the available body of literature in the field was motivated by the need for a summarized and structured evidence knowledge base. Moreover, we intended to identify the gaps in current research and develop guidelines for further investigation of the domain [14,15].

The search for related studies was limited by publication date (1992-2012) due to technological progress. Search results (published before 1992) were considered too old to be relevant. Three major online research databases (MEDLINE, Association of Computing Machinery [ACM], and Institute of Electrical and Electronics Engineers [IEEE]) were selected as data sources for the review. The search was performed on the 13th of November, 2012. The selected databases were queried using the same set of keywords, containing combinations of the following terms: “laparoscopy”, “annotate”, “telestrate”, “telestration”, “annotation”, “minimally invasive”, and “MIS”. Keywords were selected based on earlier research in the domain [3,11,12], in accordance with the corporate decision of the co-authors. The results of the search were analyzed by one reviewer to determine the eligibility of the studies. We admit the possible weakness of including only one reviewer in the study selection process; however, due to the narrow focus and straightforward evaluation of the papers, this bias should be minimal.

Developing the Evaluation Framework

The methodology presented by Sjøberg et al [16] was employed to develop the theoretical fundamentals for evaluating the impacts of the technology. The initial focus was to define the basic elements of the theory-constructs. We aimed to use concrete and easily measurable concepts instead of abstractions. This approach makes the framework less universal; however, our purpose was to develop a specialized evaluation methodology for a narrow field telestration system. Relationships between the concepts were defined to highlight the existing dependencies. The framework was supplemented by explanations and a description of the scope. Constructs, relationships, and explanations are the main components for developing theoretical models [16].

Results

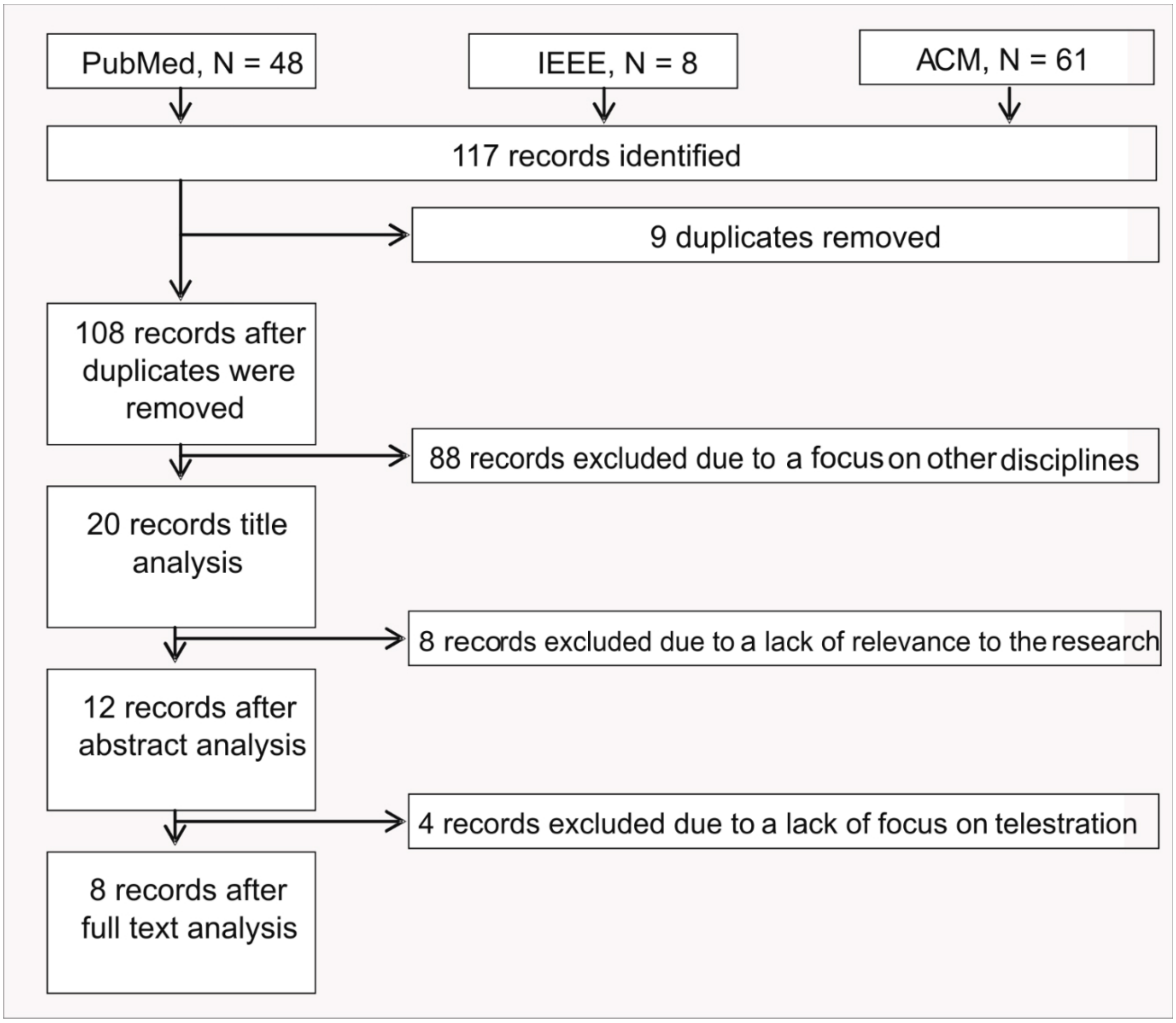
Systematic Literature Review

The keyword-based search resulted in 117 papers in total, as shown in Figure 2. We aimed to identify and analyze papers reporting the use of telestration feature. The main focus was on the analyses of the impacts of telestration to the overall procedure toward research-based proof of the benefits for telementoring. Nine instances were discarded as duplicates. Title analysis resulted in 88 exclusions due to a focus on other disciplines. An additional 8 records were discarded after analyzing the abstracts of the papers due to a lack of relevance to the current research topic. Only 12 (10%) studies were considered eligible for the final stage-full text analysis, which revealed that only 8 papers were relevant for the current study: [13,17-23] (4 papers were excluded due to lack of focus on telestration).

The review was performed to assess the impacts and benefits of telestration as applied to telementoring systems and then analyze these data in a systematic manner. The study revealed a gap of knowledge in assessing the outcomes of telestration. All of the selected studies reported the use of telestration; however, no analysis or assessment of its impacts was identified. The only outcome was a significant improvement of the mentoring session due to the ability to annotate graphic content, reported in 3 papers [18,20,21]. No support for the claims was provided, making them sound subjective. The remainder of the papers declared the feature to be an integral part of the telementoring system; although, no additional details were made available.

The purpose of the review was to assess the potential benefits of telestration in telementoring based on reported experiences. However, we were unable to achieve our goal due to the lack of existing research. The shortage of publications motivated the need to propose an evaluation framework for analyzing the outcomes of telestration in the scope of telementoring.

Figure 2. Systematic review flow diagram.



Definition of Concepts and Theoretical Models

An extra layer of interaction and complexity is added by providing the ability to annotate the graphic content used in a telementoring session. On the one hand, telestration simplifies pointing actions, eliminating the need for discussion to define the exact location in the visual representation; while on the other hand, it introduces extra complexity into the workflow model of the procedure. This complexity includes controlling of the telementoring system and annotations as well as extra hardware in the operating room. In this Section, we aim to define the potential benefits of telestration and discuss the impact of telestration on the outcome of the overall procedure.

To define the influence of telestration while telementoring, the outcomes were divided into Educational and Clinical Impact groups, highlighting the direct influence of the education process on potentially improved patient outcome (see Figure 3). To lay the basis for determining the impact of this feature, we focus on the case of laparoscopic surgery as an initial point for a video conferencing-based telementoring and surgical education. The laparoscopic procedure was selected because of its high visual component and the fact that the procedure is already transmitted to a monitor, which allows the easy adoption of the mentoring approach. As the local surgeon, hereafter referred to as mentee, is observing the progress of the procedure on the monitor, sharing this representation with a remote mentor is highly feasible. However, representation sharing and verbal interaction between endpoints (a common telementoring approach) is not sufficient in some cases. From an educational perspective (Figure 4) telestration is a feature that adds interactivity to the learning process, which should result in increasing quality of education through more comprehensive instructional material. An increased quality of education (defined quantitatively as increasing scores in the rating scale) should be enough impetus to suggest the possibility of a shorter duration of surgical training. This change could potentially lead to a rising number of highly experienced medical personnel and lower education costs. However, a lack of research leaves the assumptions poorly supported until the validation of the framework on real-life cases.

From a clinical perspective, the overall goal is the improved patient outcome, defined quantitatively as the ratio and severity level of complications, as shown in Figure 5. We assume that the use of the telestration feature in mentoring should result in increased accuracy of the surgical decisions, relation A in Figure 5, and overall mentoring process as the exact location of interest can be defined visually instead of more ambiguous verbal description. Secondly, the duration required to indicate the exact location in the operative field should decrease, resulting in a decreased duration of the overall procedure, relation C in Figure 5. We assume that following more accurate directions of the mentor should also decrease the duration of the procedure, relation D in Figure 5, help avoid clinical errors and shorten the recovery period, contributing to the overall goal–improved patient outcome, relation E in Figure 5. Moreover, shorter recovery and hospitalization is directly related to lower costs of treatment. The concept of “surgical education” represents the connection of educational and clinical outcomes, depicted in Figure 3, while relation B in Figure 5 summarizes the impacts of telestration with respect to improving surgical education as discussed above. F is one of the fundamental relations in the model dealing with the direct impact of improved education on the final well-being of the patient.

Another important aspect that should not be omitted is time consumption. From the perspective of the mentor, time savings contribute to a reduction of the workload as well as increased availability of the expert. The mentee should also experience decreased time consumption, resulting in shorter duration of the overall procedure. These issues pose the following question: given that the resources available in the hospital are constant, is it possible to treat more patients during the same period of time by decreasing the duration of the procedure? Moreover, the costs of the treatment should also diminish.

To summarize the Section, we assume that telestration is a feature that improves telementoring techniques. However, due to lack of studies on the possible impacts on the overall mentoring process, our claims remain poorly supported. Only the most obvious relations were discussed due to the simplicity of the models. Other dependencies may exist.

Figure 3. Impacts of telestration.

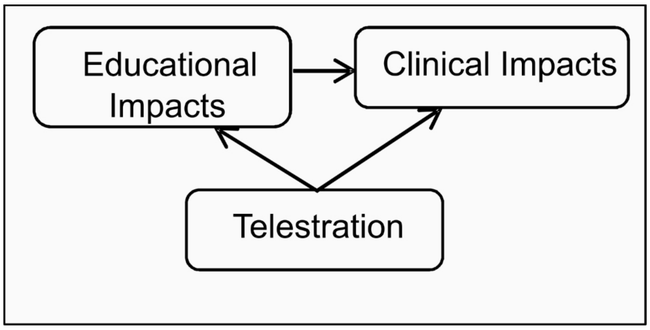


Figure 4. Educational outcomes of telestration.

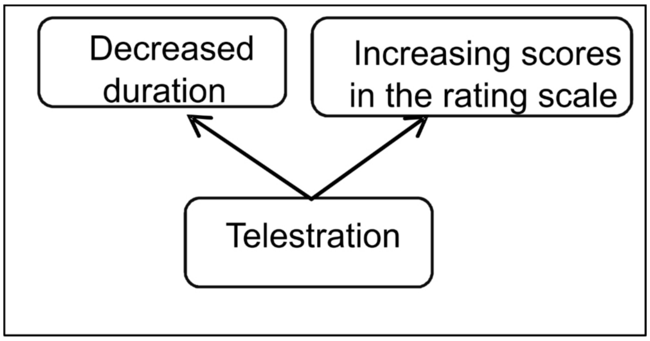
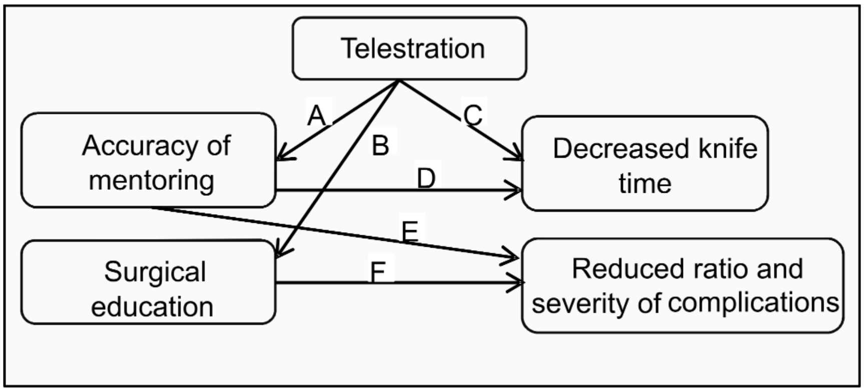


Figure 5. Clinical outcomes of telestration.



Impact Measurement

To prove the hypotheses formulated in Section Definition of Concepts and Theoretical Models, a measurement system needs to be established. The purpose of such system is to assess if the introduction of a particular feature resulted in expected outcomes. This system calls for a comparison of measurements before and after the procedure workflow was supplemented by the new technology.

Evaluating the educational outcomes, shown in Figure 4, is straightforward, as the "decreased duration" and "increasing scores in the rating scale" concepts are easy to measure. The same strategy applies to relations C and D ("decreased knife time") as well as E and F ("reduced ratio and severity of complications"), which refer to the clinical outcomes of telestration in Figure 5. The established Clavien-Dindo classification of surgical complications is proposed as a metric for assessing the grade of postoperative complications [24]. Relation B in Figure 5 represents the link between telestration and improved educational outcomes, depicted in Figure 3. The main challenge is to prove the dependency between using telestration and improved accuracy of mentoring (relation A, Figure 5). Although this dependency may appear self-evident, due to the increased accuracy of pointing actions, a reliable measure is complicated. Therefore, we propose a combined measure for determining the existence and benefits of this relationship. This measure assesses the following: (1) the number of guidance misinterpretations (possibly leading to errors), (2) the number of requests to clarify the advice, (3) the total time spent on guidance during the procedure, and (4) the number of mentoring interruptions to the flow of the procedure. The combined score is used to determine the accuracy of the mentoring accompanied by telestration. The measures are summarized in Table 1.

To evaluate our hypotheses, a comparison of measures before and after introducing the technology to the operating room must be performed. ALFA Toolkit [25] is one of the tools for analyzing the captured videos, including assessing the durations and other parameters. Results from similar research prove the feasibility of using the tool for the analysis of multi-channel videos in order to measure the impacts of the technology on the workflow of the procedure [26-28]. Three video sources (the output from the laparoscopic camera, the telementoring video and an overview of the operating room, which captures the actions of the surgical team as well as the laparoscopic and telementoring monitors) accompanied by an audio record will be used to evaluate the changes in the procedure workflow. The analysis requires a manual video coding to determine the start and end points of a particular event. This step may become ambiguous; therefore, it should be performed by multiple independent coders. Average value should be used in a case of coders' disagreement, kappa coefficient should be reported. The following parameters should be encoded and measured using combined videos of the procedure:

- Start and end point of the procedure (knife time)
- Number of guidance misinterpretations
- Number of requests to clarify the guidance
- Start and end point of every telementoring interaction between mentor and mentee
- Initiator of each interaction

Duration and timing-based measures are automatically collected by ALFA Toolkit during the coding process, while the numerical data (number of misinterpretations and clarification requests, initiator of the interaction) is recorded by the coders in an MS Excel sheet, which is combined with the values exported from ALFA toolkit for further analysis. Average values together with dispersion coefficients are used to represent the final results.

Table 1. Measurement system.

Parameter	Relationship in Figure 5	What is measured?	Measure unit
Knife time	C	Duration: starting point–first incision, end point–end of the procedure.	Minutes, seconds
Ratio and severity level of complications	E, F	Number of complications / overall number of performed procedures and severity of the complications, if any.	Ratio coefficient and a grade in the Clavien-Dindo classification scheme for surgical complications [24]
Score in rating scale (surgical education)	B	Scores in the predefined scale to measure the progress of education.	Rating score
Duration (surgical education)	B	Duration required to reach the same level in the rating scale.	Hours
Accuracy of mentoring	A	1) Number of guidance misinterpretations (possibly leading to errors), 2) Number of requests to clarify the guidance, 3) Total time spent on guidance during the procedure, and 4) Number of interruptions of the flow of the procedure for mentoring.	Combined score

Discussion

Principal Findings

Research biases were analyzed in detail by Hartman et al [29] to increase the awareness of methods of mitigating their undesirable impacts. Although a number of biases were studied, in this phase of the project, the most attention is given to measurement-related biases.

An accurate measure of the parameters defined in Table 1 is a challenge. However, to achieve accurate results in each experiment, the requirements for the analyzed procedure and stakeholders should be formalized to keep them as standard as possible. Unfortunately, the observed procedures are never the same, even if a strictly predefined workflow is followed. Moreover, the human factor shapes the workflow according to the preferences and previous experiences of the surgeon in charge. Complete control of the mentioned factors may be impossible; however, to increase the accuracy, only very similar procedures are to be studied and represented in the final results. The similarity of the cases is based on preoperative data (medical imaging, observations, etc.). Moreover, it is assumed that the remote mentoring approach is also highly influenced by the social connection between mentor and mentee, their previous experiences in telementoring, and their current attitudes. An accurate determination of the levels of experience of mentor and mentee is also a subjective parameter influencing the final results of the study. Randomization of the observed procedures and surgical team may be a way to achieve more consistent results in this case.

From the point of view of the measurement process itself, ambiguity is also inevitable. To avoid biases in duration and score estimation based on video representation, only the consensus decision of the project team should be considered correct.

The presented framework addresses the theoretical side of the project. It was developed as a methodology section for the on-going research. Logical relations between the concepts are represented in order to understand the influence of the technology on procedural workflow and define it in a measurable manner. The research still suffers from the lack of evidence and validation on real life test cases.

To conclude the section, we admit the potential weaknesses of the proposed research caused by the mentioned biases. The list of the biases influencing the final outcome of the experiment is not exhaustive; however, we aimed to mention only the most obvious cases.

Conclusions

The paper aimed to summarize the experience of using telestration during telementoring sessions to highlight the impacts of this feature on the mentoring process and workflow of the procedure. However, an absence of research reflecting the use of telestration was identified. Therefore, a framework for analyzing the impact of live video content annotation was proposed. To keep the models simple and adaptable, easy-to-measure concepts were employed and only the most obvious dependencies were discussed. To support our claims and the presented models, an impact measurement procedure was defined.

The presented framework and impact measurement procedures form a methodology for the further analysis and reporting of research on telestration and telementoring systems. Having a more formalized method should increase the quality and quantity of publications in this field, providing an evidence-based knowledge base supporting the development of the telementoring domain and the introduction of new technologies and features with the aim of improving patient outcomes.

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Conflicts of Interest

None declared.

References

1. Guidelines for the surgical practice of telemedicine. Society of American Gastrointestinal Endoscopic Surgeons. Surg Endosc 2000 Oct;14(10):975-979. [Medline: 11080420]
2. Williams TE, Ellison EC. Population analysis predicts a future critical shortage of general surgeons. Surgery 2008 Oct;144(4):548-54; discussion 554. [doi: 10.1016/j.surg.2008.05.019] [Medline: 18847638]
3. Augestad KM, Chomutare T, Bellika JG, Budrionis A, Lindsetmo RO, Delaney CP. Clinical and Educational Benefits of Surgical Telementoring. In: Patel HRH, Joseph JV, editors. HRH Patel and Joseph JV. Simulation Training in Laparoscopy and Robotic Surgery. London: Springer London; 2012:75-89.
4. Augestad KM, Lindsetmo RO. Overcoming distance: video-conferencing as a clinical and educational tool among surgeons. World J Surg 2009 Jul;33(7):1356-1365 [FREE Full text] [doi: 10.1007/s00268-009-0036-0] [Medline: 19384459]

5. Rothenberg SS, Yoder S, Kay S, Ponsky T. Initial experience with surgical telementoring in pediatric laparoscopic surgery using remote presence technology. J Laparoendosc Adv Surg Tech A 2009 Apr;19 Suppl 1:S219-S222. [doi: 10.1089/lap.2008.0133] [Medline: 18976120]
6. Damore LJ, Johnson JA, Dixon RS, Iverson MA, Ellison E, Melvin W. Transmission of live laparoscopic surgery over the Internet2. The American Journal of Surgery 1999 Nov;178(5):415-417. [doi: 10.1016/S0002-9610(99)00203-2]
7. Doarn CR. Telemedicine in tomorrow's operating room: a natural fit. Semin Laparosc Surg 2003 Sep;10(3):121-126. [Medline: 14551654]
8. Merrell RC, Doarn CR. Is it time for a telemedicine breakthrough? Telemed J E Health 2008 Aug;14(6):505-506. [doi: 10.1089/tmj.2008.8499] [Medline: 18729745]
9. Lim EC, Seet RC. In-house medical education: redefining tele-education. Teach Learn Med 2008;20(2):193-195. [doi: 10.1080/10401330801991931] [Medline: 18444209]
10. Steventon A, Bardsley M, Billings J, Dixon J, Doll H, Hirani S, Whole System Demonstrator Evaluation Team. Effect of telehealth on use of secondary care and mortality: findings from the Whole System Demonstrator cluster randomised trial. BMJ 2012 Jun;344:e3874 [FREE Full text] [Medline: 22723612]
11. Budrionis A, Augestad KM, Bellika JG. Telestration in Mobile Telementoring. In: Proceedings of The Fifth International Conference on eHealth, Telemedicine, and Social Medicine (eTELEMED 2013). 2013 Feb 24 Presented at: The Fifth International Conference on eHealth, Telemedicine, and Social Medicine (eTELEMED 2013); 2013; Nice, France p. 307-309 URL: http://www.thinkmind.org/index.php?view=article&articleid=etelemed_2013_16_40_40278
12. Budrionis A, Augestad KM, Patel HRH, Bellika JG. Towards Requirements for Telementoring Software. In: Proceedings of Scandinavian Conference on Health Informatics (SHI2012). 2012 Presented at: Scandinavian Conference on Health Informatics (SHI2012); 2012 October 2-3; Linköping, Sweden p. 27-33 URL: http://www.ep.liu.se/ecp/070/005/ecp1270005.pdf
13. Zhou Q, Liu D. Interactive visual content sharing and telestration: A novel network multimedia service. In: Proceedings of 14th International Conference on Intelligence in Next Generation Networks (ICIN). 2010 Presented at: 14th International Conference on Intelligence in Next Generation Networks (ICIN); 2010 October 11-14; Berlin, Germany URL: http://ieeexplore.ieee.org/xpl/login.jsp?tp=&arnumber=5640915&url=http%3A%2F%2Fieeexplore.ieee.org%2Fiel5%2F5623872%2F5640879%2F05640915.pdf%3Farnumber%3D5640915 [doi: 10.1109/ICIN.2010.5640915]
14. Kitchenham B. Keele University Technical Report TR/SE-0401 ISSN:1353-7776, National ICT Australia Ltd NICTA Technical Report 0400011T.1. Keele, UK: Keele University; 2004. Procedures for Performing Systematic Reviews URL: http://tests-zingarelli.googlecode.com/svn-history/r336/trunk/2-Disciplinas/MetodPesquisa/kitchenham_2004.pdf [accessed 2013-07-16] [WebCite Cache ID 6I9y74kUs]
15. Kitchenham B, Brereton OP, Budgen D, Turner M, Bailey J, Linkman S. Systematic literature reviews in software engineering – A systematic literature review. Information and Software Technology 2009;51:7-15. [doi: 10.1016/j.infsof.2008.09.009]
16. Sjøberg DIK, Dybå T, Anda BCD, Hannay JE. Building Theories in Software Engineering. In: Shull F, Singer J, Sjøberg DIK, editors. Guide to Advanced Empirical Software Engineering. London, UK: Springer-Verlag London; 2008:312-336.
17. Tan GY, Goel RK, Kaouk JH, Tewari AK. Technological advances in robotic-assisted laparoscopic surgery. Urol Clin North Am 2009 May;36(2):237-49, ix. [doi: 10.1016/j.ucl.2009.02.010] [Medline: 19406324]
18. Agarwal R, Levinson AW, Allaf M, Makarov D, Nason A, Su LM. The RoboConsultant: telementoring and remote presence in the operating room during minimally invasive urologic surgeries using a novel mobile robotic interface. Urology 2007 Nov;70(5):970-974. [doi: 10.1016/j.urology.2007.09.053] [Medline: 18068456]
19. Rafiq A, Moore JA, Zhao X, Doarn CR, Merrell RC. Digital Video Capture and Synchronous Consultation in Open Surgery. Annals of Surgery 2004;239(4):567-573. [doi: 10.1097/01.sla.0000118749.24645.45]
20. Schulam PG, Docimo SG, Saleh W, Breitenbach C, Moore RG, Kavoussi L. Telesurgical mentoring. Initial clinical experience. Surg Endosc 1997 Oct;11(10):1001-1005. [Medline: 9381336]
21. Ali MR, Loggins JP, Fuller WD, Miller BE, Hasser CJ, Yellowlees P, et al. 3-D telestration: a teaching tool for robotic surgery. J Laparoendosc Adv Surg Tech A 2008 Feb;18(1):107-112. [doi: 10.1089/lap.2007.0051] [Medline: 18266586]
22. Visentini-Scarzanella M, Merrifield R, Stoyanov D, Yang GZ. Tracking of irregular graphical structures for tissue deformation recovery in minimally invasive surgery. Med Image Comput Comput Assist Interv 2010;13(Pt 3):261-268. [Medline: 20879408]
23. Bauer JJ, Lee BR, Stoianovici D, Bishoff JT, Janetschek G, Bunyaratavej P, et al. Remote telesurgical mentoring: feasibility and efficacy. In: Proceedings of the 33rd Annual Hawaii International Conference on System Sciences. 2000 Presented at: 33rd Annual Hawaii International Conference on System Sciences; 2000 January 4-7; Hawaii, US URL: http://ieeexplore.ieee.org/xpl/articleDetails.jsp?arnumber=926802 [doi: 10.1109/HICSS.2000.926802]
24. Dindo D, Demartines N, Clavien PA. Classification of surgical complications: a new proposal with evaluation in a cohort of 6336 patients and results of a survey. Ann Surg 2004 Aug;240(2):205-213. [Medline: 15273542]
25. de Lusignan S, Kumarapeli P, Chan T, Pflug B, van Vlymen J, Jones B, et al. The ALFA (Activity Log Files Aggregation) toolkit: a method for precise observation of the consultation. J Med Internet Res 2008;10(4):e27 [FREE Full text] [doi: 10.2196/jmir.1080] [Medline: 18812313]

26. Pflug B, Kumarapeli P, van Vlymen J, Ammenwerth E, de Lusignan S. Measuring the impact of the computer on the consultation: an open source application to combine multiple observational outputs. Inform Health Soc Care 2010 Jan;35(1):10-24. [doi: 10.3109/17538150903358693] [Medline: 20302436]
27. Gibbings-Isaac D, Iqbal M, Tahir MA, Kumarapeli P, de Lusignan S. The pattern of silent time in the clinical consultation: an observational multichannel video study. Fam Pract 2012 Oct;29(5):616-621. [doi: 10.1093/fampra/cms001] [Medline: 22291439]
28. De Lusignan S, Kumarapeli P, Debar S, Kushniruk AW, Pearce C. Using an open source observational tool to measure the influence of the doctor's consulting style and the computer system on the outcomes of the clinical consultation. Stud Health Technol Inform 2009;150:1017-1021. [Medline: 19745467]
29. Hartman JM, Forsen JW, Wallace MS, Neely JG. Tutorials in clinical research: part IV: recognizing and controlling bias. Laryngoscope 2002 Jan;112(1):23-31. [doi: 10.1097/00005537-200201000-00005] [Medline: 11802034]

Abbreviations

ACM: Association of Computing Machinery
IEEE: Institute of Electrical and Electronics Engineers
MIS: minimally invasive surgery

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Original Paper

Remote Monitoring for Implantable Defibrillators: A Nationwide Survey in Italy

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Abstract

Background: Remote monitoring (RM) permits home interrogation of implantable cardioverter defibrillator (ICD) and provides an alternative option to frequent in-person visits.

Objective: The Italia-RM survey aimed to investigate the current practice of ICD follow-up in Italy and to evaluate the adoption and routine use of RM.

Methods: An ad hoc questionnaire on RM adoption and resource use during in-clinic and remote follow-up sessions was completed in 206 Italian implanting centers.

Results: The frequency of routine in-clinic ICD visits was 2 per year in 158/206 (76.7%) centers, 3 per year in 37/206 (18.0%) centers, and 4 per year in 10/206 (4.9%) centers. Follow-up examinations were performed by a cardiologist in 203/206 (98.5%) centers, and by more than one health care worker in 184/206 (89.3%) centers. There were 137/206 (66.5%) responding centers that had already adopted an RM system, the proportion of ICD patients remotely monitored being 15% for single- and dual-chamber ICD and 20% for cardiac resynchronization therapy ICD. Remote ICD interrogations were scheduled every 3 months, and were performed by a cardiologist in 124/137 (90.5%) centers. After the adoption of RM, the mean time between in-clinic visits increased from 5 (SD 1) to 8 (SD 3) months (*P*<.001).

Conclusions: In current clinical practice, in-clinic ICD follow-up visits consume a large amount of health care resources. The results of this survey show that RM has only partially been adopted in Italy and, although many centers have begun to implement RM in their clinical practice, the majority of their patients continue to be routinely followed-up by means of in-clinic visits.

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KEYWORDS

implantable defibrillator; remote monitoring; follow-up

Introduction

Remote Monitoring

Remote monitoring (RM) has been developed in order to handle the increasing number of patients with implantable cardiac devices, and who therefore require follow-up visits. Indeed, follow-up visits of implantable cardiac devices are the most frequent activities performed at arrhythmia services [1], and place a great burden on health care providers [2].

RM systems include a patient monitor that, using radiofrequency telemetry, allows data transmission without patient intervention. The patient's information is sent to a secure network server via the telephone connection. The clinical staff can review device information on a secure Internet-accessible website. These systems provide full device interrogation, monitoring for arrhythmias, and surveillance of device performance from the patient's home. Moreover, RM systems can alert the physician via phone or email, in the case of programmable parameters, about clinical or device issues. RM has many potential benefits, both for the patient and for the follow-up center. Indeed, it was shown to detect events more quickly and more frequently [3,4], specifically facilitating the early detection of technical issues and clinical anomalies [5], and thus to decrease the time to a clinical decision [6], reduce urgent in-clinic visits [7,8], and mortality [9].

RM systems are currently available for almost all makes of implantable cardioverter defibrillator (ICD) and have been operational in Europe for about 10 years.

Aim

To date, only few and contradictory data were presented on the actual adoption of RM in routine clinical practice in Italy and Europe [10,11]. The aim of this survey was to investigate the current practice of ICD follow-up in Italy and to evaluate the adoption and routine use of RM.

Methods

The Questionnaire

There were 206 Italian centers implanting ICDs that replied to an *ad hoc* questionnaire sent in July 2012.

A complete list of participating centers is reported in Multimedia Appendix 1. The participating centers constituted a representative sample (206/432, 47.7%) of the 432 Italian ICD implanting centers listed in the 2011 edition of the Italian ICD Registry of Italian Society of Arrhythmology and Pacing (AIAC) [12], which includes almost all implanting centers in Italy. According to published data from the AIAC Registry, the survey centers performed 5534 (61.50%) of the 8998 *de novo* ICD implantation procedures carried out in 2011 in Italy. Figure 1 shows the replies to this survey came from centers with a wide range of annual ICD implantation volumes.

The centers were asked to describe their practice of ICD follow-up. Specifically, they reported on the actions performed during routine device follow-up, the time required for follow-up examinations, the involvement of health care personnel, the interval between scheduled follow-up visits, and their use of RM. The complete list of survey questions is listed below.

Routine ICD follow-up:

- Number of ICD patients in follow-up (single-, dual-chamber, CRT-D)
- Number of routine in-clinic visits per year
- Mean duration of in-clinic visits (single-, dual-chamber, CRT-D)
- Number and type of health care personnel involved in in-clinic visits
- Proportion of visits with ICD reprogramming
- Clinical evaluation performed at the time of routine ICD follow-up
- Presence of a structured heart failure management program in the center

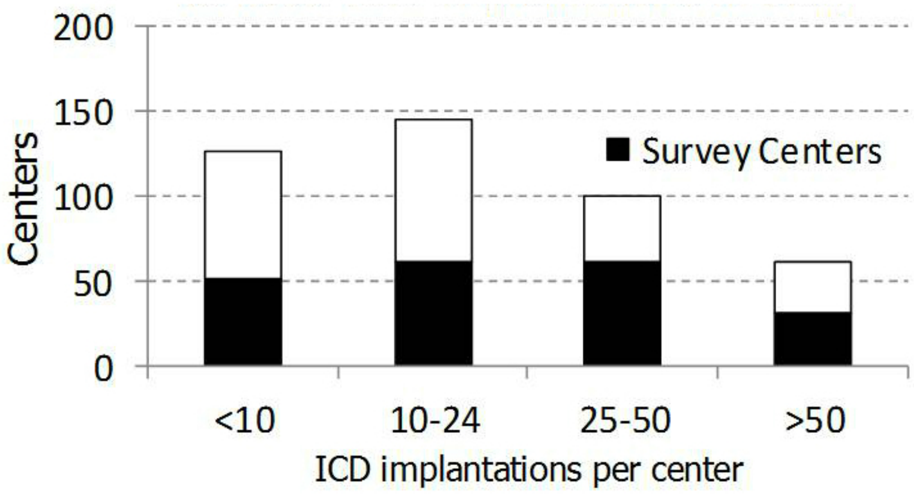
Adoption and routine use of RM:

- Number of ICD in remote follow-up (single-, dual-chamber, CRT-D)
- Number of routine in-clinic visits per year in RM patients
- Frequency of scheduled remote interrogations
- Number and type of health care personnel involved in remote visits

The Data

Continuous data are expressed as means (standard deviations) or medians and interquartile ranges. Categorical data are expressed as percentages. Differences between mean data were compared by means of a t test for Gaussian variables, and by the Mann-Whitney nonparametric test for nonGaussian variables. Differences in proportions were compared by means of chi-square analysis or Fisher's exact test, as appropriate. A P value <.05 was considered significant for all tests. All statistical analyses were performed by means of STATISTICA software, version 7.1 (StatSoft, Inc, Tulsa, OK, USA).

Figure 1. Volume of de novo implantations in the 432 Italian ICD implanting centers and the 206 Italia-RM survey centers in 2011 (published data from the national AIAC Registry).



Results

Routine ICD Follow-Up

The frequency of routine in-clinic visits was 2 per year in 158/206 (76.7%) centers, 3 per year in 37/206 (18.0%) centers and 4 per year in 10/206 (4.9%) centers. Figure 2 shows the frequency of scheduled visits in relation to ICD implantation volumes; only a trend toward less frequent visits was seen in high-volume centers (*P*=.07).

Follow-up examinations were performed by a cardiologist in 203/206 (98.5%) centers and by more than one health care worker in 184/206 (89.3%). In 133/206 (64.6%) survey centers, the patient's clinical status was not assessed during routine in-clinic follow-up, these visits being devoted exclusively to checking the ICD. In 75/206 (36.4%) centers, ICD patients were included in structured heart failure management programs. The reported duration of in-clinic follow-up visits was 15 (SD 7) minutes for single-chamber ICD, 16 (SD 8) minutes for dual-chamber ICD, and 20 (SD 9) minutes for cardiac resynchronization therapy ICD (CRT-D). Device reprogramming was required in (10%) (25th-75th percentile: 7-20) of visits.

Adoption and Routine Use of RM

There were 137/206 (66.5%) responding centers that had already adopted an RM system for remote ICD interrogation. Figure 3 shows the proportions of centers using RM, stratified by ICD implantation volume.

In centers currently using RM systems, the proportion of ICD patients remotely monitored was 15% (25th-75th percentile: 5-30) for single-chamber ICD, 15% (25th-75th percentile: 5-35) for dual-chamber ICD, and 20% (25th-75th percentile: 10-42) for CRT-D. Remote ICD interrogations were scheduled every 3 months (25th-75th percentile: 1-3), and were performed by a cardiologist in 124/137 (90.5%) centers (*P*<.001 versus in-clinic visits). After the adoption of RM, the mean time between visits increased from 5 (SD 1) to 8 (SD 3) months (*P*<.001). Specifically, the frequency of in-clinic visits was decreased in 41/105 (39.0%) of centers routinely performing 2 visits per year in nonRM patients, in 15/24 (62.5%) of centers performing 3 visits per year, and 5/7 (71.4%) of centers performing 4 visits per year (*P*=.04).

Figure 2. Frequency of scheduled in-clinic follow-up visits in relation to ICD implantation volume.

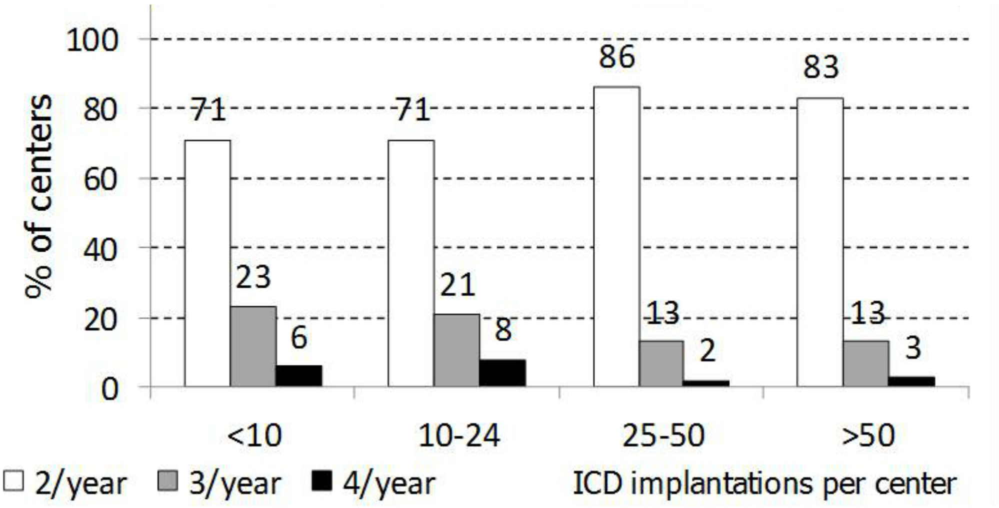
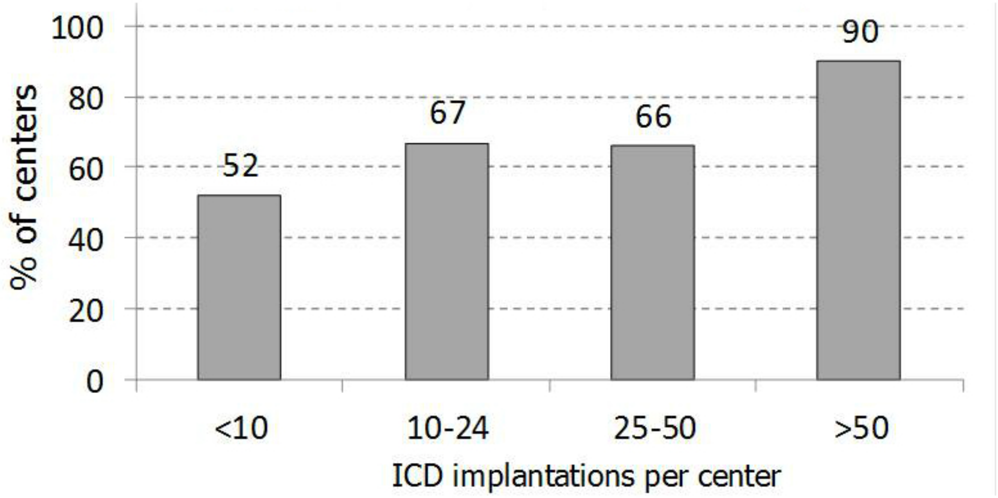


Figure 3. Current RM utilization, stratified by ICD implantation volume.



Discussion

Results of the Survey

The results of the Italia-RM survey confirm that, in current clinical practice, in-clinic ICD follow-up visits consume a large amount of health care resources. Internet-based RM is becoming a new standard for the follow-up of patients with active implantable cardiac devices [13]. Nonetheless, the results of this survey show that it is not extensively used in Italy. Although the majority of Italian centers have begun to implement RM in their clinical practice, most of their patients continue to be followed-up by means of routine in-clinic visits.

A joint European Heart Rhythm Association (EHRA)-Eucomed survey [2] conducted in centers in seven European countries indicated that, in “real-world” clinical practice, resource utilization related to the follow-up of implantable cardiac devices places a considerable burden on arrhythmia services. The survey revealed that most follow-up examinations involved two staff members (usually a cardiologist and a nurse), and that visits lasted about 20 minutes. The authors hypothesized that most arrhythmia services may be reaching, or have already reached, their maximum workload capacity; this is in agreement with the findings of a previous survey conducted by the Heart Rhythm Society, which showed that follow-up examinations were the most frequent activities performed by electrophysiologists [1].

Clinical Evaluations

In agreement with these findings, we ascertained that 184/206 (89.3%) of follow-up visits involved two staff members, and that a cardiologist attended 203/206 (98.5%) of examinations. By contrast, in the majority of survey centers, clinical evaluation by physicians was not performed at the time of routine device follow-up, although recommendations suggest that the clinical status of the patient should be reviewed during follow-up, as it may influence subsequent management [14]. Clinical evaluations may not be performed owing to the lack of time and resources, or may be carried out separately from the device check by physicians in charge of the clinical management of the patient. However, only a minority of responding centers reported including ICD patients in structured heart failure management programs.

Interestingly, it was recently demonstrated that patients who did not undergo clinical examination during device follow-up visits had a better attitude towards RM and were more appreciative of its timesaving advantage [15]. Thus, it was suggested that the stimulus to experience new device-check modalities could lie substantially in perceiving the current modalities as unsatisfactory. Anyhow, published reports on preliminary experiences of RM have consistently shown a high level of patient acceptance and satisfaction with RM [16,17]. Therefore, the limited adoption in current clinical practice should not be ascribed to a lack of acceptance by patients.

RM Usage in European Clinical Practice

In 2010, an EHRA survey measured the use of RM in 61 European centers in 15 countries [10]. The authors reported that 52/61 (85%) of the centers already had experience of RM systems, and that management of the data collected in the majority of these centers was delegated to a dedicated allied professional. In 2011, a second survey, performed in 40 EHRA centers, showed less encouraging results [11]; RM was reportedly used routinely in CRT-D and ICD patients by only half of the centers.

The Italia-RM nation-wide survey analyzed the practice of ICD follow-up and the current use of RM systems in a large number of implanting centers in Italy. The participating centers represent about half of the Italian implanting centers and performed 5534/8998 (61.50%) of all ICD implantation procedures in 2011. Moreover, the participating centers displayed wide variability in the volume of procedures and were well distributed throughout the country.

Our analysis showed that RM systems have so far been adopted by 137/206 (66.5%) of centers for remote ICD interrogation. In each center, the median proportion of patients remotely monitored ranged from 15% of single-chamber ICD to 20% of CRT-D. The more frequent use of RM in CRT-D may be explained by the need to monitor sicker patients with greater continuity. Nonetheless, a recent analysis of the actions taken during in-clinic follow-up examinations suggested that the lower incidence of visits eliciting clinical or device-related action in the single- or dual-chamber ICD population should encourage the use of RM in these patients [18].

Device Reprogramming

In our survey, device reprogramming was reported to be necessary in 10% of visits. Similarly, Mascioli et al [18] reported that device reprogramming was performed in 12% of scheduled visits. Boriani et al [2] reported a higher proportion of device reprogramming (about 30%) and a significant impact of reprogramming on the duration of the visit. However, it has been demonstrated that, following an initial optimization period, the frequency of device reprogramming declines and RM systems may become a more attractive alternative to in-clinic visits [19].

In general, RM may be timesaving for scheduled, nonactionable transmissions, while transmissions with clinically important findings and poor patient compliance have considerable workflow implications [20]. Therefore, in order to implement RM in standard clinical practice, new organizational models need to be developed in which nurses are responsible for training patients, entering and reviewing data, submitting critical cases to physicians, contacting patients, and ensuring patient compliance [21,22]. Recently, Ricci et al [23] reported that an outpatient clinic workflow model based on primary nursing could be extremely effective and could reduce resource consumption. Specifically, they showed that nurses could perform 76% of remote interrogation sessions. However, our results revealed that, in the vast majority of centers, remote ICD interrogations continued to be performed by a cardiologist.

RM Visit Scheduling

In accordance with recommendations [14], routine in-clinic ICD examinations were performed every 3-6 months in our centers. However, it seems that high-volume centers tend to schedule visits less frequently, although this trend was nonsignificant. Similarly, the use of RM systems seems to be greater in high-volume centers. However, the main reason for adopting RM appears to be the prospect of improving the quality of care rather than reducing the workload in the centers. Indeed, remote transmissions were scheduled every 3 months; thus, the interval between ICD interrogations was reduced. Moreover, although the adoption of RM generally enabled the time between in-clinic visits to be increased, the majority of centers that scheduled less frequent visits prior to the adoption of RM were seen to have maintained the same number of in-clinic visits per year.

Remote Interrogation of ICD Patients

The first reports on RM systems for the remote interrogation of ICD patients in Europe date back to around 10 years ago. Nonetheless, the results of the present survey show that it has only been partially adopted in Italy and that the majority of ICD patients continue to be followed-up by means of routine in-clinic visits.

Ostensibly, RM is more attractive for high-volume centers, where arrhythmia services may be overcrowded. Moreover, within each center, RM may be preferentially allocated to patients undergoing *de novo* ICD implantation, patients who are more compliant, or those to whom standard in-clinic visits cause greater inconvenience.

Appropriate reimbursement by health care systems and insurance companies, which is currently lacking in Italy and other European countries, is critical to stimulating the widespread adoption of RM [24]. Similarly, the adoption of new organizational models in the centers is warranted, in order to effectively and efficiently implement RM in standard clinical practice, converting this innovative approach to a cost-saving solution for patients, hospitals, and the public payer [23,25].

Conclusions

In conclusion, in-clinic ICD follow-up visits currently consume a large amount of health care resources. Internet-based RM has been developed as a cost-effective solution for the management of patients with implantable cardiac devices. However, we showed that RM has only partially been adopted in Italy and, although many centers have begun to implement RM in their clinical practice, the majority of their patients continue to be routinely followed up by means of in-clinic visits.

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Conflicts of Interest

Francesco Accardi and Sergio Valsecchi are employees of Boston Scientific, Inc. Boston Scientific manufactures and sells implantable cardiac devices and RM systems.

Multimedia Appendix 1

A complete list of participating centers.

[PDF File (Adobe PDF File), 38KB - ijmr_v2i2e27_app1.pdf]

References

1. Deering TF, Clair WK, Delaughter MC, Fisher WG, Garlitski AC, Wilkoff BL, et al. A Heart Rhythm Society Electrophysiology Workforce study: current survey analysis of physician workforce trends. Heart Rhythm 2010 Sep;7(9):1346-1355. [doi: 10.1016/j.hrthm.2010.07.026] [Medline: 20659587]
2. Boriani G, Auricchio A, Klersy C, Kirchhof P, Brugada J, Morgan J, European Heart Rhythm Association, Eucomed. Healthcare personnel resource burden related to in-clinic follow-up of cardiovascular implantable electronic devices: a European Heart Rhythm Association and Eucomed joint survey. Europace 2011 Aug;13(8):1166-1173 [FREE Full text] [doi: 10.1093/europace/eur026] [Medline: 21345922]
3. Crossley GH, Chen J, Choucair W, Cohen TJ, Gohn DC, Johnson WB, PREFER Study Investigators. Clinical benefits of remote versus transtelephonic monitoring of implanted pacemakers. J Am Coll Cardiol 2009 Nov 24;54(22):2012-2019. [doi: 10.1016/j.jacc.2009.10.001] [Medline: 19926006]
4. Varma N, Epstein AE, Irimpen A, Schweikert R, Love C, TRUST Investigators. Efficacy and safety of automatic remote monitoring for implantable cardioverter-defibrillator follow-up: the Lumos-T Safely Reduces Routine Office Device Follow-up (TRUST) trial. Circulation 2010 Jul 27;122(4):325-332 [FREE Full text] [doi: 10.1161/CIRCULATIONAHA.110.937409] [Medline: 20625110]
5. Halimi F, Clémenty J, Attuel P, Dessenne X, Amara W, OEDIPE trial Investigators. Optimized post-operative surveillance of permanent pacemakers by home monitoring: the OEDIPE trial. Europace 2008 Dec;10(12):1392-1399 [FREE Full text] [doi: 10.1093/europace/eun250] [Medline: 18775878]
6. Crossley GH, Boyle A, Vitense H, Chang Y, Mead RH, CONNECT Investigators. The CONNECT (Clinical Evaluation of Remote Notification to Reduce Time to Clinical Decision) trial: the value of wireless remote monitoring with automatic clinician alerts. J Am Coll Cardiol 2011 Mar 8;57(10):1181-1189. [doi: 10.1016/j.jacc.2010.12.012] [Medline: 21255955]
7. Mabo P, Victor F, Bazin P, Ahres S, Babuty D, Da Costa A, COMPAS Trial Investigators. A randomized trial of long-term remote monitoring of pacemaker recipients (the COMPAS trial). Eur Heart J 2012 May;33(9):1105-1111 [FREE Full text] [doi: 10.1093/eurheartj/ehr419] [Medline: 22127418]
8. Landolina M, Perego GB, Lunati M, Curnis A, Guenzati G, Vicentini A, et al. Remote monitoring reduces healthcare use and improves quality of care in heart failure patients with implantable defibrillators: the evolution of management strategies of heart failure patients with implantable defibrillators (EVOLVO) study. Circulation 2012 Jun 19;125(24):2985-2992 [FREE Full text] [doi: 10.1161/CIRCULATIONAHA.111.088971] [Medline: 22626743]
9. Saxon LA, Hayes DL, Gilliam FR, Heidenreich PA, Day J, Seth M, et al. Long-term outcome after ICD and CRT implantation and influence of remote device follow-up: the ALTITUDE survival study. Circulation 2010 Dec 7;122(23):2359-2367 [FREE Full text] [doi: 10.1161/CIRCULATIONAHA.110.960633] [Medline: 21098452]
10. Halimi F, Cantù F, European Heart Rhythm Association (EHRA) Scientific Initiatives Committee (SIC). Remote monitoring for active cardiovascular implantable electronic devices: a European survey. Europace 2010 Dec;12(12):1778-1780 [FREE Full text] [doi: 10.1093/europace/euq399] [Medline: 21097482]
11. Marinskis G, van Erven L, Bongiorni MG, Lip GY, Pison L, Blomström-Lundqvist C, Scientific Initiative Committee, European Heart Rhythm Association. Practices of cardiac implantable electronic device follow-up: results of the European Heart Rhythm Association survey. Europace 2012 Mar;14(3):423-425 [FREE Full text] [doi: 10.1093/europace/eus020] [Medline: 22355191]
12. Proclemer A, Zecchin M, Lunati M, Bongiorni MG, Padeletti L. Registro Italiano Pacemaker e Defibrillatori. GIAC 2012;15:145-172. [doi: 10.1718/1159.12762]

13. Dubner S, Auricchio A, Steinberg JS, Vardas P, Stone P, Brugada J, et al. ISHNE/EHRA expert consensus on remote monitoring of cardiovascular implantable electronic devices (CIEDs). Europace 2012 Feb;14(2):278-293 [FREE Full text] [doi: 10.1093/europace/eur303] [Medline: 22232544]
14. Wilkoff BL, Auricchio A, Brugada J, Cowie M, Ellenbogen KA, Gillis AM, Heart Rhythm Society (HRS), European Heart Rhythm Association (EHRA), American College of Cardiology (ACC), American Heart Association (AHA), European Society of Cardiology (ESC), Heart Failure Association of ESC (HFA), Heart Failure Society of America (HFSA). HRS/EHRA Expert Consensus on the Monitoring of Cardiovascular Implantable Electronic Devices (CIEDs): description of techniques, indications, personnel, frequency and ethical considerations: developed in partnership with the Heart Rhythm Society (HRS) and the European Heart Rhythm Association (EHRA); and in collaboration with the American College of Cardiology (ACC), the American Heart Association (AHA), the European Society of Cardiology (ESC), the Heart Failure Association of ESC (HFA), and the Heart Failure Society of America (HFSA). Endorsed by the Heart Rhythm Society, the European Heart Rhythm Association (a registered branch of the ESC), the American College of Cardiology, the American Heart Association. Europace 2008 Jun;10(6):707-725 [FREE Full text] [doi: 10.1093/europace/eun122] [Medline: 18480075]
15. Gramegna L, Tomasi C, Gasparini G, Scaboro G, Zanon F, Boaretto G, et al. In-hospital follow-up of implantable cardioverter defibrillator and pacemaker carriers: patients' inconvenience and points of view. A four-hospital Italian survey. Europace 2012 Mar;14(3):345-350 [FREE Full text] [doi: 10.1093/europace/eur334] [Medline: 22080472]
16. Ricci RP, Morichelli L, Quarta L, Sassi A, Porfili A, Laudadio MT, et al. Long-term patient acceptance of and satisfaction with implanted device remote monitoring. Europace 2010 May;12(5):674-679 [FREE Full text] [doi: 10.1093/europace/euq046] [Medline: 20200019]
17. Marzegalli M, Lunati M, Landolina M, Perego GB, Ricci RP, Guenzati G, et al. Remote monitoring of CRT-ICD: the multicenter Italian CareLink evaluation--ease of use, acceptance, and organizational implications. Pacing Clin Electrophysiol 2008 Oct;31(10):1259-1264. [doi: 10.1111/j.1540-8159.2008.01175.x] [Medline: 18811805]
18. Mascioli G, Curnis A, Landolina M, Klersy C, Gelmini GP, Ruffa F, ATHENS Investigators. Actions elicited during scheduled and unscheduled in-hospital follow-up of cardiac devices: results of the ATHENS multicentre registry. Europace 2011 Dec;13(12):1766-1773 [FREE Full text] [doi: 10.1093/europace/eur233] [Medline: 21764815]
19. Lunati M, Gasparini M, Santini M, Landolina M, Perego GB, Pappone C, InSync ICD Italian Registry Investigators. Follow-up of CRT-ICD: implications for the use of remote follow-up systems. Data from the InSync ICD Italian Registry. Pacing Clin Electrophysiol 2008 Jan;31(1):38-46. [doi: 10.1111/j.1540-8159.2007.00923.x] [Medline: 18181908]
20. Cronin EM, Ching EA, Varma N, Martin DO, Wilkoff BL, Lindsay BD. Remote monitoring of cardiovascular devices: a time and activity analysis. Heart Rhythm 2012 Dec;9(12):1947-1951. [doi: 10.1016/j.hrthm.2012.08.002] [Medline: 22864266]
21. Varma N, Ricci RP. Telemedicine and cardiac implants: what is the benefit? Eur Heart J 2013 Jul;34(25):1885-1895. [doi: 10.1093/eurheartj/ehs388] [Medline: 23211231]
22. Ricci RP, Calcagnini G, Castro A, Giada F, Igidbashan D, Landolina M, et al. [Consensus document on remote monitoring of cardiac implantable electronic devices: technology, indications, organizational models, acceptability, responsibility, and economic issues]. G Ital Cardiol (Rome) 2011 Jun;12(6):450-467. [doi: 10.1714/835.9311] [Medline: 21691382]
23. Ricci RP, Morichelli L, D'Onofrio A, Calò L, Vaccari D, Zanotto G, et al. Effectiveness of remote monitoring of CIEDs in detection and treatment of clinical and device-related cardiovascular events in daily practice: the HomeGuide Registry. Europace 2013 Jul;15(7):970-977. [doi: 10.1093/europace/eus440] [Medline: 23362021]
24. Schloh M, Fernando R, Baldeweg R, Bulté L, Pavlovic Y. PWC. 2013. White Paper: "Moving towards good practice in the reimbursement of CIED telemonitoring" URL: http://www.eucomed.org/uploads/Modules/Publications/whitepaper_reimbursementciedtelemonitoring.pdf [accessed 2013-04-11]
25. Zanaboni P, Landolina M, Marzegalli M, Lunati M, Perego GB, Guenzati G, et al. Cost-utility analysis of the EVOLVO study on remote monitoring for heart failure patients with implantable defibrillators: randomized controlled trial. J Med Internet Res 2013;15(5):e106 [FREE Full text] [doi: 10.2196/jmir.2587] [Medline: 23722666]

Abbreviations

AIAC: Italian Society of Arrhythmology and Pacing
CRT-D: cardiac resynchronization therapy ICD
EHRA: European Heart Rhythm Association
ICD: implantable cardioverter defibrillator
RM: remote monitoring

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Original Paper

Effectiveness of YouTube as a Source of Medical Information on Heart Transplantation

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Abstract

Background: In this digital era, there is a growing tendency to use the popular Internet site YouTube as a new electronic-learning (e-learning) means for continuing medical education. Heart transplantation (HTx) remains the most viable option for patients with end-stage heart failure or severe coronary artery disease. There are plenty of freely accessible YouTube videos providing medical information about HTx.

Objective: The aim of the present study is to determine the effectiveness of YouTube as an e-learning source on HTx.

Methods: In order to carry out this study, YouTube was searched for videos uploaded containing surgical-related information using the four keywords: (1) “heart transplantation”, (2) “cardiac transplantation”, (3) “heart transplantation operation”, and (4) “cardiac transplantation operation”. Only videos in English (with comments or subtitles in English language) were included. Two experienced cardiac surgeons watched each video (N=1800) and classified them as useful, misleading, or recipients videos based on the HTx-relevant information. The kappa statistic was used to measure interobserver variability. Data was analyzed according to six types of YouTube characteristics including “total viewership”, “duration”, “source”, “days since upload”, “scores” given by the viewers, and specialized information contents of the videos.

Results: A total of 342/1800 (19.00%) videos had relevant information about HTx. Of these 342 videos, 215 (62.8%) videos had useful information about specialized knowledge, 7/342 (2.0%) were found to be misleading, and 120/342 (35.1%) only concerned recipients’ individual issues. Useful videos had 56.09% of total viewership share (2,175,845/3,878,890), whereas misleading had 35.47% (1,375,673/3,878,890). Independent user channel videos accounted for a smaller proportion (19% in total numbers) but might have a wider impact on Web viewers, with the highest mean views/day (mean 39, SD 107) among four kinds of channels to distribute HTx-related information.

Conclusions: YouTube videos on HTx benefit medical professionals by providing a substantial amount of information. However, it is a time-consuming course to find high-quality videos. More authoritative videos by trusted sources should be posted for dissemination of reliable information. With an improvement of ranking system and content providers in future, YouTube, as a freely accessible outlet, will help to meet the huge informational needs of medical staffs and promote medical education on HTx.

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KEYWORDS

heart transplantation; Internet; medical informatics; online videos; YouTube; e-learning

Introduction

Heart transplantation (HTx) is still the gold standard in the treatment of end-stage heart failure for appropriate candidates [1]. Since the first successful human-to-human HTx was performed in 1967, the survival quality and life span of HTx recipients have improved tremendously [2]. Between 1982 and 2009, there were 97,911 cases of HTx in the world, according to the Registry report of the International Society for Heart and Lung Transplantation (ISHLT) [3]. Along with the evolving development in patient selection, surgical techniques, perioperative care, and clinical follow-up, the outcomes of HTx have improved over the past four decades [1]. The overall survival rates after HTx show inspiring results from the data of ISHLT: five-year overall survival rates were 62.49-68.94%, ten-year 47.53-52.08%, and fifteen-year 29.63-37.05% [4]. Furthermore, the quality of life of HTx recipients is excellent. For instance, if including housewife recipients, approximately 90% of the adult recipients returned to their job following HTx in Japan [5]. Nevertheless, the volumes of HTx recently slowly declined, largely due to a critical organ donor shortage, and there were approximately 2200 cases yearly in the United States [6,7]. Therefore, the shortage of live surgical cases has led to reduced opportunities to witness this major operation, especially for medical students and trainee doctors.

At present, the Internet has become the largest and most up-to-date source for medical information worldwide [8]. In North America alone, 74% of adults use the Internet daily, and 80% of all users search for health-related information [9-11]. Acquiring and sharing medical information via the Internet offers extraordinary electronic-learning (e-learning) possibilities and has gradually changed the learning habits of medical professionals. When questions about health care arise, physicians increasingly turn to the Internet, which has changed the way medical students learn, communicate, and share specialized information, rather than to journals and textbooks [12,13]. Major search engines, such as Google, are often the first place physicians go for information [13-15]. Since 2005, YouTube has become the third most visited site on the Internet, after Facebook and Google [9,16]. Presently, there are over 4 billion hours of video being watched per month on YouTube, with 72 hours of video uploaded per minute, triple the statistical outcome in 2010 [17,18]. Therefore, the YouTube website is currently the leading audiovisual information center of medically relevant videos [13]. Numerous individuals, organizations, hospitals, and academic institutions from around the world have uploaded plenty of freely accessible medical videos onto the YouTube website. Moreover, the new generation of medical professionals is inclined to use social networks, online communities, and multiple media to learn specialized knowledge, because these means possess a nature of immediacy and parallelism when presenting information [19]. Currently, 94% of medical students actively participate in social media applications, compared to 79% of residents and 42% of physicians [19,20].

Some scholars have evaluated YouTube as a source of medical information on H1N1 influenza, papillomavirus vaccination, prostate cancer, and kidney stone [21-24]. However, until now, little is known about the characteristics of existing YouTube videos focusing on HTx. To our knowledge, there is no investigation to have examined the quality of videos related to HTx on YouTube. In this study, our aim is to assess the overall situation of specialized medical information in HTx-related YouTube videos.

Methods

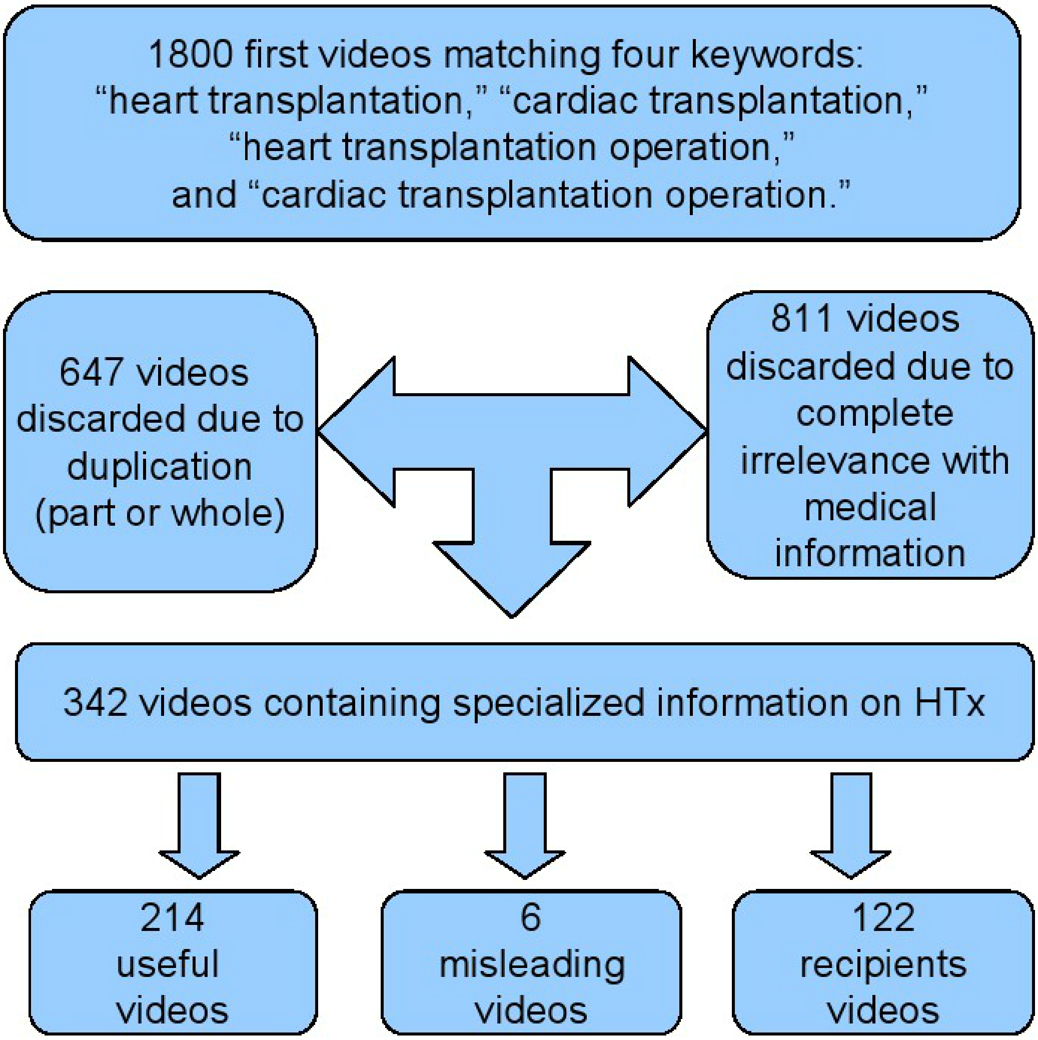
Determination of HTx-Related Videos

This trial was conducted as a cross-sectional analysis. The website YouTube (YouTube, LLC, San Bruno, CA) was searched according to "relevance" priority for the following keywords: "heart transplantation", "cardiac transplantation", "heart transplantation operation", and "cardiac transplantation operation." All the videos containing relevant information about HTx before February 01, 2013 were included in this study. The total number of videos that appeared in the searching was 6930. However, 95% of people conducting an online search will watch no further than the first 60 videos of output, and most researchers for similar studies on YouTube videos usually chose the first 200 to 300 videos as their data sources [24-26]. Thus, we viewed and analyzed the first 1800/6930 (25.97%) videos (600 in 3750 "heart transplantation", 600 in 1200 "cardiac transplantation", 300 in 770 "heart transplantation operation", and 300 in 1210 "cardiac transplantation operation"), on the assumption that no medical practitioner would go beyond the first 300 to 600 videos even for a serious e-learning goal. English language (comments or subtitles) in the video was a prerequisite for inclusion. Among all the videos, those meeting this inclusive criterion were further viewed. Data evaluation was independently conducted by two experienced cardiac surgeons (H-M Chen and X-B Liao) blind to each other. After discarding all the videos that were either duplicated, which have partially or completely identical content with shorter durations (part or whole, 647/1800, 35.94%), or completely irrelevant with medical knowledge (811/1800, 45.05% such as the names of some songs or electronic games), all the videos containing specialized medical information on HTx (342/1800, 19.00%, such as surgical lectures or live broadcasts) were classified from the aspect of information and knowledge as useful, misleading, and recipients videos (Figure 1). This classifying methodology of our study was conducted in accordance with the observations of Sood et al [24,27,28].

First, the video was grouped under the "useful" category if it contained scientifically correct information about any aspect of HTx such as donor procurement, surgical techniques, perioperative management, rejection control, clinical follow-up, new technologies, or the issues about medical humanities (eg, history of HTx, appealing for organ donation, etc). Second, the video was categorized as “misleading” if it contained scientifically incorrect or unproven information for now (eg, self-healing from serious heart failure by the help of the God rather than medical service; asserting that mechanical circulatory support is currently a practical alternative to HTx, but without convincing proof existing in the literature; oversight during the delivery and preservation of cardiac graft; and dissemination for abandoning HTx in end-stage heart failure patients). Finally, if the video described recipients’ personal experience rather than medical information of HTx per se (eg, for raising donation, expressing gratitude, advertising hospitals, etc), it was called a “recipients video.”

In case the investigators’ designation was not identical, the video was reevaluated with both surgeons and a united assessment was conducted. The kappa statistic was used to measure interinvestigator variability.

Figure 1. A graphic display of the classifying process of HTx-related videos.



Basic Communicative Analyses of HTx-Related Videos

Videos were categorized according to the “source” into four groups: namely, hospital/university channel (H/UC), independent user channel (IUC), medical dotcom channel (MDC), and news agency channel (NAC) [21,24]. These four categories were determined after watching all the videos and were chosen on the basis of the primary themes that emerged. Data were analyzed according to six kinds of YouTube characteristics that include (1) “total viewership”, (2) “duration”, (3) “source”, (4) “days since upload”, (5) “scores” given by the viewers, and (6) specialized information contents of the videos. To begin with the evaluation process, first, the “scores” of videos were used to describe the general evaluation of each video, which were determined by subtracting the total number of “dislikes” from the total number of “likes” designated by antecedent viewers at the statistical point in time. In our opinion, the higher positive value of “scores” may mean higher recognition of antecedent viewers and more attractive to new viewers.

Data were analyzed with SPSS version 19.0 (SPSS Inc) and presented as mean (SD). When more than two groups of means were compared (eg, mean “duration”, mean number of “days since upload”, and mean “scores” for four source groups), data were analyzed for statistical significance using a one-way analysis of variance (ANOVA) followed by a Tukey comparison of all groups. Before running the analysis, data were checked to determine if they met the assumptions of ANOVA (homogeneity of variances and data were sampled from the Gaussian distribution). *P* value less than .05 was considered statistically significant.

Results

Top 10 YouTube Videos After Searching With the Term “Heart Transplantation”

After the first-step search with four key terms, the vast majority of the output consisted of nonmedical or minute-medical videos without meaningful and specialized information (such as live but shaking or silent videos of less than 10 seconds). For example, a YouTube search for the term “heart transplantation” returned 3750 videos, and the top 10 outcomes sorted by relevance are provided in Table 1. Observably, the first four videos and the last three videos are useful for medical professionals. However, three intermediate videos (ranked 5th, 6th, and 7th) are all the advertisements of an electronic game named “Surgeon Simulator 2013.” In short, 3 days after uploading, the number of their “total viewership” accounted for 291,760/1,069,235 (27.28%) of the number of whole “total viewership” of these 10 videos. Furthermore, the “scores” of these 3 videos, which are completely uncorrelated with HTx, unexpectedly showed high value (1003, 394, and 2469, respectively).

Classification of HTx-Related Videos

Of all the YouTube videos that were viewed, 342/1800 (19.00%) videos were classified into three groups containing medical information on HTx (total duration, 2373.8 minutes). Details for the inclusion of these videos are shown in Figure 1. The kappa coefficient of agreement on classification of videos between two surgeons was .89, which is usually in the “almost perfect” agreement range (.81-.99) [39]. The classification of these HTx-relevant videos based on their usefulness with details of other characteristics is given in Table 2. The mean duration of 342 videos was 6.94 minutes (SD 11.59, range 0.5-93), the mean scores of them showed 18.77 (SD 99.69, range 42 to 1148), and the mean viewers/day (since the date videos being uploaded)” were 15.95 (SD 67.14, range 0.02-785.30).

The majority of the useful videos were mainly posted by strong reputation such as H/UC (88/214, 41.1%) and NAC (64/214, 29.9%) (Table 2). For example, the “batsonhospital” channel provided the third ranked video in Table 1, which documented a success story about the fourth pediatric HTx in the Batson Children’s Hospital at the University of Mississippi Medical Center (see Multimedia Appendix 1). On the contrary, IUC delivered a majority of the misleading videos (5/6, 83%) and recipients videos (45/126, 35.7%). Detailed analysis of useful videos is shown in Table 3. Videos uploaded by H/UC occupied the vast proportion both in numbers (88/214, 41.1%) and total duration in minutes (657.05/1723.7, 38.12%) among all videos. No statistically significant difference was noted in the mean “duration” (*P*=.55), mean “days since upload” (*P*=.25), and mean “scores” (*P*=.28) among useful videos based on “source” by ANOVA. However, useful IUC (40/214, 18.7%) videos had significantly higher mean “viewers/day” than H/UC videos (*P*=.006) and NAC videos (*P*=.046).

Communicative Analyses of Useful and Misleading Videos

Useful videos were also analyzed based on the medical information they delivered. All useful videos contained HTx-related information on at least one or more of the following aspects: (1) live demonstration of HTx, (2) brief introduction of surgeries, (3) release of new technologies, (4) scholar viewpoints by experts, or (5) medical humanities. For example, videos were categorized as “medical humanities” if the main message of the videos portrayed the history of HTx or brainstormed on the issue of organ donation after brain death. Content analysis of useful videos with respect to the above five aspects is presented in Table 4. The annual number of useful HTx-related videos shows an uptrend since 2007, especially with a growth spurt in 2012 (Figure 2).

Compared with useful videos, the misleading videos demonstrated the following characteristic: fewer numbers, shorter total and mean “duration”, but higher mean “scores” and mean “viewers/day” (Table 2). These results suggest that the misleading videos might have a more influence on audience compared to useful videos. However, because the data of misleading videos presented a non-Gaussian distribution with a small number of samples (just 6 videos), we did not further analyze these data.

Table 1. A summary of the top ten videos ranked by their “relevance”[a] resulting from a YouTube search for “heart transplantation” (HTx) on February 01, 2013.

Rank	Video title	Number of viewers	Days since upload	Scores	Description[b]	Reference
1	Heart transplantation	141,443	384	393	Showing orthotopic “bicaval” technique	[29]
2	Heart transplant surgery	188,083	898	307	Showing a brief scene of HTx	[30]
3	Revived Heart Transplant Program at Batson Children’s Hospital builds on a 20-year legacy	3052	265	5	The revived HTx program built on a 20-year history at the University of Mississippi Medical Center	[31]
4	Heart transplant procedure from Montefiore-Einstein, NYC	430,349	1904	1003	HTx with a panel discussion presented by the cardiothoracic surgeons of the Montefiore-Einstein Heart Center on an OR-Live webcast	[32]
5	Surgical Nightmare! Heart Transplant Masterclass - Surgeon Simulator 2013	18,060	3	394	Advertisement (ad) for an electronic game “Surgeon Simulator 2013”	[33]
6	Surgeon Simulator 2013 - Successful heart transplant [Rating: A++]	253,614	3	2469	Ad for an electronic game “Surgeon Simulator 2013”	[34]
7	Heart transplant surgery with live audience	20,086	2	355	Ad for an electronic game “Surgeon Simulator 2013”	[35]
8	Heart transplant part 1	13,676	368	33	Classical and valuable video describing HTx	[36]
9	Implanted heart pumps keep patients in need of transplants alive	240	3	2	KPBS Health Reporter talked about left ventricular-assist device and heart donation	[37]
10	Heart transplant steps simplified by Dr Sandeep Attawar	341	56	2	HTx live broadcast	[38]

[a] The term “relevance” refers to the default ranking system for YouTube queries and is determined based on Google algorithm.

[b] Description states the kind of content present in the videos.

Table 2. Detailed characteristics of different categories of YouTube videos with relevant information on HTx.

Characteristics	Useful videos	Misleading videos	Recipients videos	Total HTx-related videos
Number of videos, n (%)	214 (62.6)	6 (1.7)	122 (35.7)	342 (100)
Total duration in minutes (%)	1723.7 (72.61)	26.0 (1.10)	624.1 (26.29)	2373.8 (100)
Mean duration in minutes (SD)	8.05 (13.36)	4.33 (5.33)	5.12 (7.58)	6.94 (11.59)
Mean number of days on YouTube (SD)	582.59 (498.23)	594.17 (519.39)	433.16 (404.05)	529.49 (471.27)
Mean scores (SD), range	16.83 (85.73) 42 to 979	46.50 (110.53) 2 to 272	20.82 (120.47) 0 to 1148	18.77 (99.69) 42 to 1148
Total viewership, n (%)	2,175,845 (56.09)	1,375,673 (35.47)	327,372 (8.44)	3,878,890 (100)
Mean views/day (SD), range	14.31 (53.74) 0.02-523.26	202.07 (324.64) 0.16-785.30	9.69 (38.77) 0.02-359.41	15.95 (67.14) 0.02-785.30
Source				
H/UC[a]	88	0	30	118
IUC[b]	40	5	45	90
MDC[c]	22	0	11	33
NAC[d]	64	1	36	101

[a] Hospital/university channel.

[b] Independent user channel.

[c] Medical dotcom channel.

[d] News agency channel.

Table 3. Detailed characteristics of "useful videos" on YouTube uploaded by different sources.

Characteristics	Hospital/university channel	Independent user channel	Medical dotcom channel	News agency channel
Useful videos, N=214 (%)	88 (41.1)	40 (18.7)	22 (10.3)	64 (29.9)
Total duration in minutes, 1723.7 (%)	657.05 (38.12)	320.40 (18.59)	263.00 (15.26)	483.25 (28.03)
Mean duration in minutes (SD)	7.47 (14.04)	8.01 (8.21)	11.95 (21.55)	7.55 (11.35)
Mean number of days on YouTube (SD)	558.67 (456.60)	641.07 (657.85)	412.14 (377.99)	637.53 (456.25)
Mean scores (SD), range	6.70 (34.80) 1 to 327	35.98 (103.36) 1 to 514	6.09 (13.62) 1 to 58	22.47 (126.70) 42 to 979
Total viewership (n) (%)	310,252 (14.26)	1,036,597 (47.64)	88,925 (4.09)	740,071 (34.01)
Mean views/day (SD), range	6.02 (23.82)[a] 0.07-220.87	39.36 (107.42)[a,b] 0.02-523.26	10.08 (20.89) 0.08-74.50	11.49 (34.40)[b] 0.02-224.75

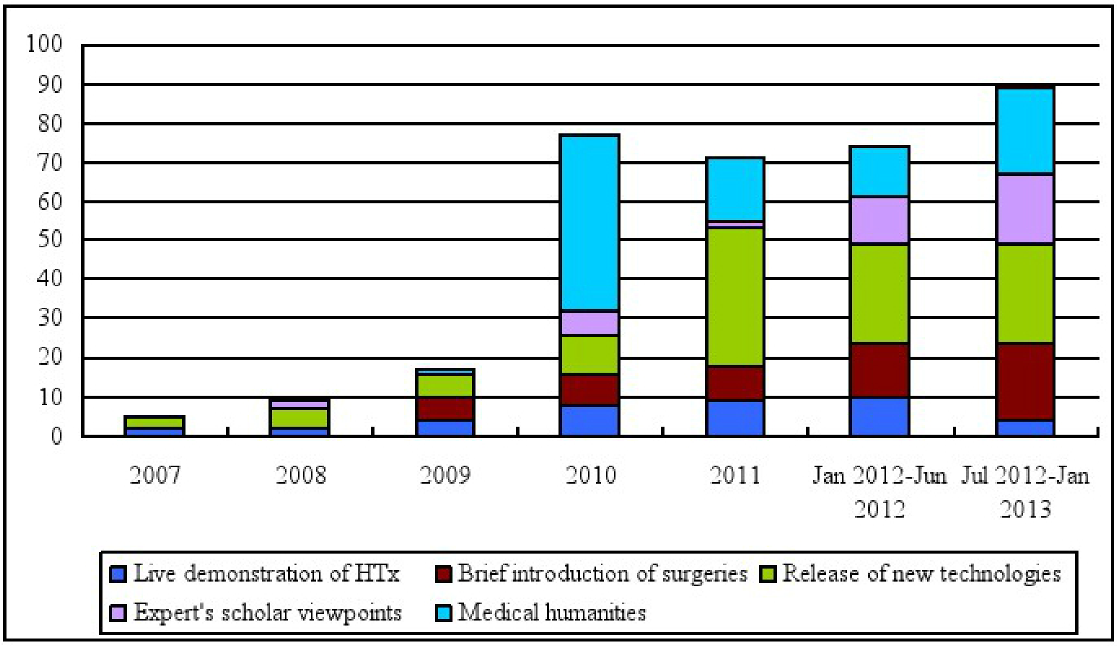
[a] *P*=.006

[b] *P*=.046

Table 4. Detailed content analysis of "useful videos" from five aspects.

Aspects	Hospital/university channel, n (%)	Independent user channel, n (%)	Medical dotcom channel, n (%)	News agency channel, n (%)	Total, n (%)
Live demonstration of HTx	6 (22.2)	11 (40.7)	5 (18.5)	5 (18.5)	27 (9.4)
Brief introduction of HTx	31 (38.7)	17 (21.2)	18 (22.5)	14 (17.5)	80 (27.9)
Release of new technologies	34 (49.3)	11 (15.9)	6 (8.7)	18 (26.1)	69 (23.9)
Experts' scholar viewpoints	19 (52.7)	7 (19.5)	5 (13.9)	5 (13.9)	36 (12.5)
Medical humanities	18 (23.7)	17 (22.4)	6 (7.9)	35 (46.1)	76 (26.4)
Coverage on the above five aspects	108 (37.5)	63 (21.9)	40 (13.9)	77 (26.7)	288

Figure 2. The annual numbers of useful HTx-related videos.



Discussion

Principal Results

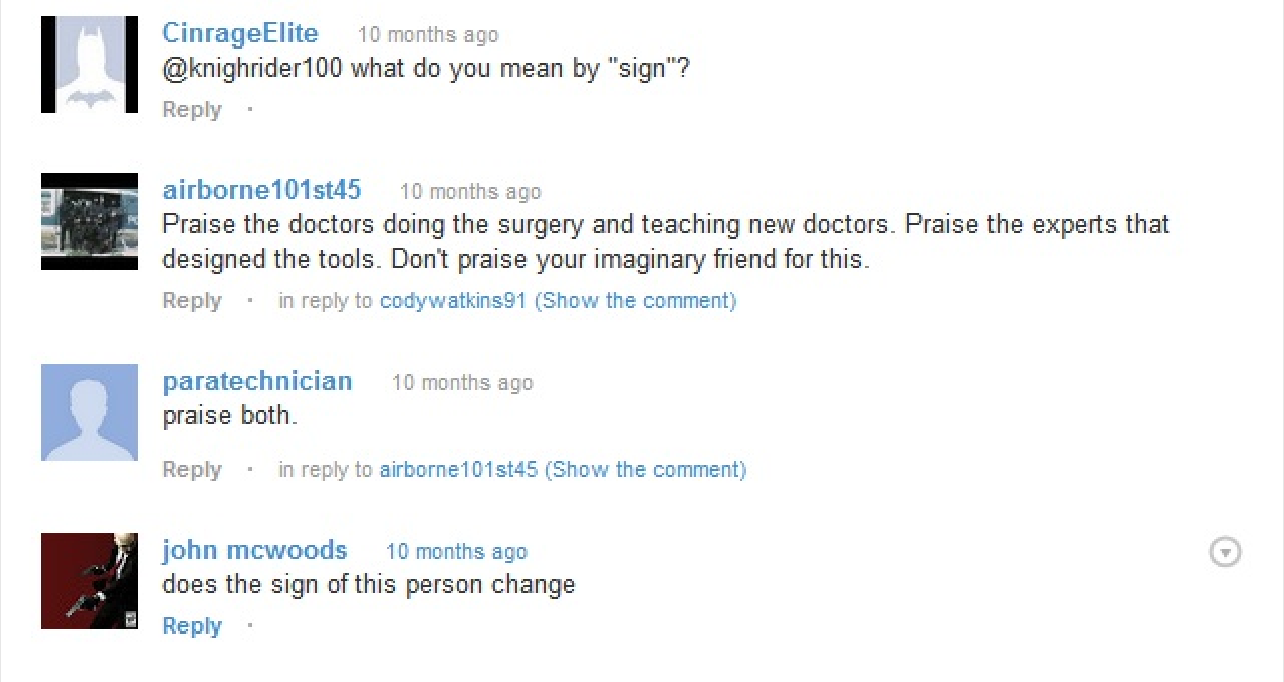
With the rise in popularity of the website YouTube, there is now another route by which medical professionals can learn the specialized knowledge. YouTube enables physicians and institutions with strong reputation to upload multimedia clips of medical knowledge on their channels. For instance, in Table 1, the fourth top video relevant to HTx (see Multimedia Appendix 2) had a high total viewership, which encompassed a live HTx operation with a panel discussion at the Montefiore-Einstein Heart Center, on September 19, 2007. This webcast-featured video portioned the scene of HTx as well as detailed descriptions of surgical techniques. The “scores” (1003 on February 1, 2013) of this video were very high, and it has won a lot of commendableness from physicians and patients, such as “Praise the doctors doing the surgery and teaching new doctors. Praise the experts that designed the tools...” (see Figure 3, comment from a YouTube user named “airborne101st45”).

YouTube videos provide us an effective way to actively engage with our worldwide colleagues, by subscribing and responding to high-quality clips from the respected individual surgeons. Although there is no information available on how many of the viewers of these videos were medical personnel, it is obvious that those high-quality videos can be used by medical staff and can improve the learning outcomes of physicians. For instance, in the live implantation video of a left ventricular assist device (LVAD, Heartmate II) as a bridge to HTx (see Multimedia Appendix 3), Dr Arie Blitz brought clarity and “even made laymen to understand the patients by seeing these procedures” (appraisement from a YouTube user named “Pat Stewart”, see Figure 4). After reviewing utterly specialized questions, such as why not performing a transapical aortic valve combined with LVAD implantation, Dr Arie Blitz always gave counterparts prompt and active responses (Figure 5).

However, our study demonstrated that the majority of HTx-related videos were easily available yet often without expertise information. Considering all the videos that were uploaded before February 1, 2013, YouTube had nearly 7000 videos by searching the keywords about HTx, yet only 342 of the 1800 (19.00%) videos were actually related. Furthermore, in about 40 hours of coverage of these videos, only 72.61% of them contained useful specialized information about this challenging surgery. At present, many reliable academic institutions, such as ISHLT, have not exerted their positive and dominant impacts to increase the signal-to-noise ratio of HTx-related YouTube videos, through uploading their high-quality videos for viewing by people. For example, the American Association for Thoracic Surgery (AATS) has been registered as an organizational user (AATSVideos) on November 7, 2012. However, there were only 21 videos as open resources, which contain nothing about HTx. Interestingly, the striking “Watch AATS Video” sign always stays at the top of AATS website, and there are five links to the Cardiothoracic Surgery Network (CTSNet), which deposited 159 authoritative videos of cardiac surgeries until April 12, 2013. Therefore, even with a newest video titled “Left Ventricular Aneurysm Resection and LVAD Implantation Through Median Sternotomy” (Multimedia Appendix 4) on CTSNet, there was no HTx-related video in AATSVideos Channel. On April 12, 2013, the number of subscribers of “AATSVideos” Channel was still five, and two of the five guys were the authors (X-B Liao and H-M Chen) of this paper. Therefore, with the accumulation of a lot of unrelated videos, there is an exigent need to upload reliable, high-quality HTx-related videos, by professional medical educators, institutions, and organizations.

In addition to the lack of goal-oriented contents from authoritative organizations and trustworthy individuals, there is a real risk of dissemination of misleading information by YouTube. In our study, we found that the maximum-weight misleading video (see Multimedia Appendix 5) accounted for 88.27% (1,214,312/1,375,673) of total viewership, and it arouse a significant support with a “scores” number of 272 (345 “likes”; 73 “dislikes”). The video was uploaded on November 11, 2008 and featured one 13-year-old British girl who claimed to refuse HTx. Her option was obviously irrational and unscientific, thus inevitably, it would negatively affect some viewers. Paradoxically, “She changed her decision when her situation worsened, she underwent the surgery at the Great Ormond City Hospital” (see Figure 6, comment from a YouTube user named “Sorgutentarer”). Nevertheless, this video is still online. Today, content generation is no longer limited to the health care professionals; Web 2.0 services and platforms have empowered patients to create and interact videos with various forms of patient-generated content [40]. Therefore, it is understandable that the emergence of quality-without-assurance videos prompts skepticism and worries along with the obvious information overload.

Figure 3. A screenshot of the commendable from Web viewers (on April 12, 2013).



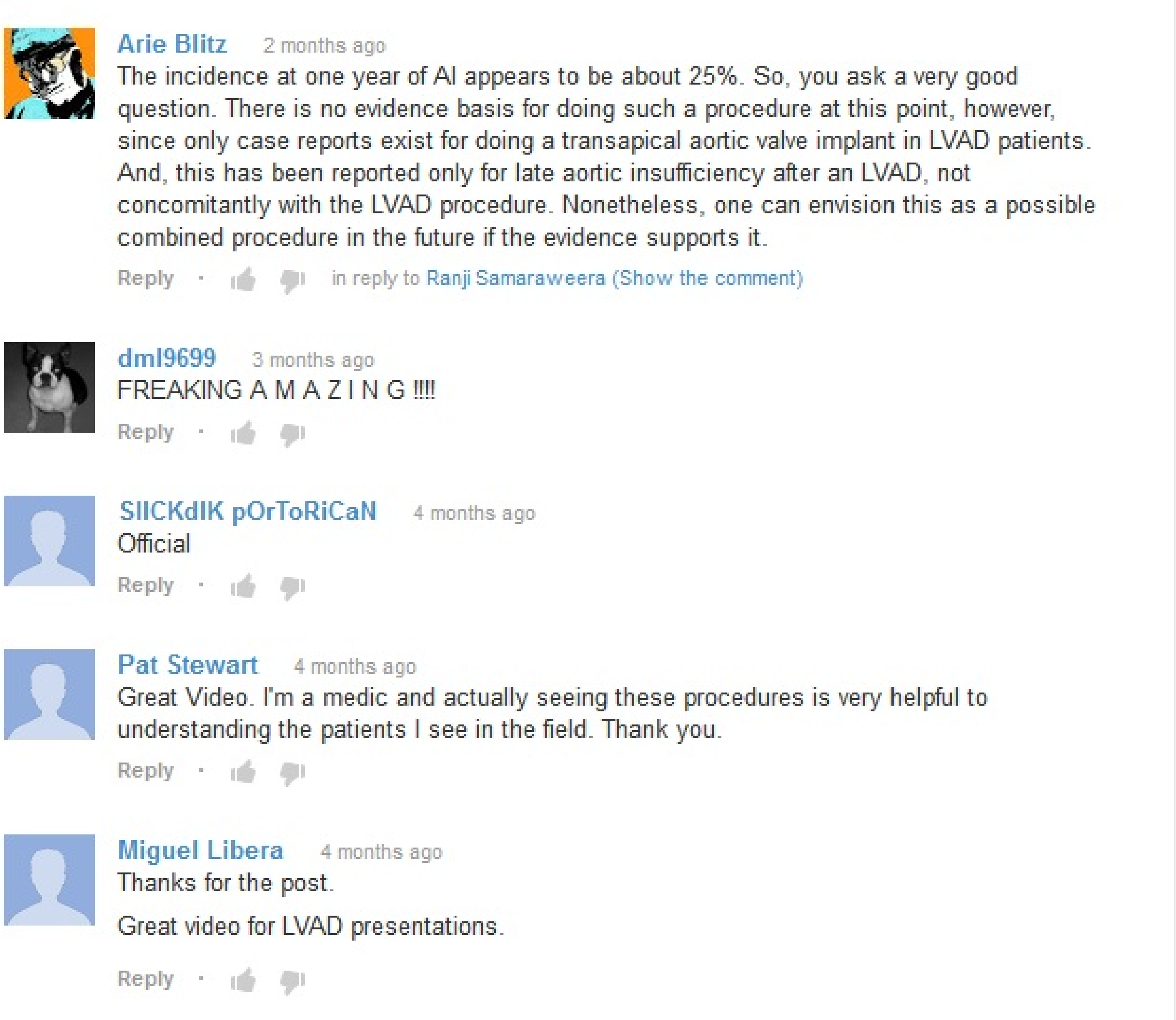
CinrageElite 10 months ago
@knighrider100 what do you mean by "sign"?
Reply ·

airborne101st45 10 months ago
Praise the doctors doing the surgery and teaching new doctors. Praise the experts that designed the tools. Don't praise your imaginary friend for this.
Reply · in reply to codywatkins91 (Show the comment)

paratechnician 10 months ago
praise both.
Reply · in reply to airborne101st45 (Show the comment)

john mcwoods 10 months ago
does the sign of this person change
Reply ·

Figure 4. A screenshot of the comments from Web viewers (on April 12, 2013).



Arie Blitz 2 months ago

The incidence at one year of AI appears to be about 25%. So, you ask a very good question. There is no evidence basis for doing such a procedure at this point, however, since only case reports exist for doing a transapical aortic valve implant in LVAD patients. And, this has been reported only for late aortic insufficiency after an LVAD, not concomitantly with the LVAD procedure. Nonetheless, one can envision this as a possible combined procedure in the future if the evidence supports it.

Reply · in reply to Ranji Samaraweera (Show the comment)

dml9699 3 months ago

FREAKING A M A Z I N G !!!!

Reply ·

SlICKdlK pOrToRiCaN 4 months ago

Official

Reply ·

Pat Stewart 4 months ago

Great Video. I'm a medic and actually seeing these procedures is very helpful to understanding the patients I see in the field. Thank you.

Reply ·

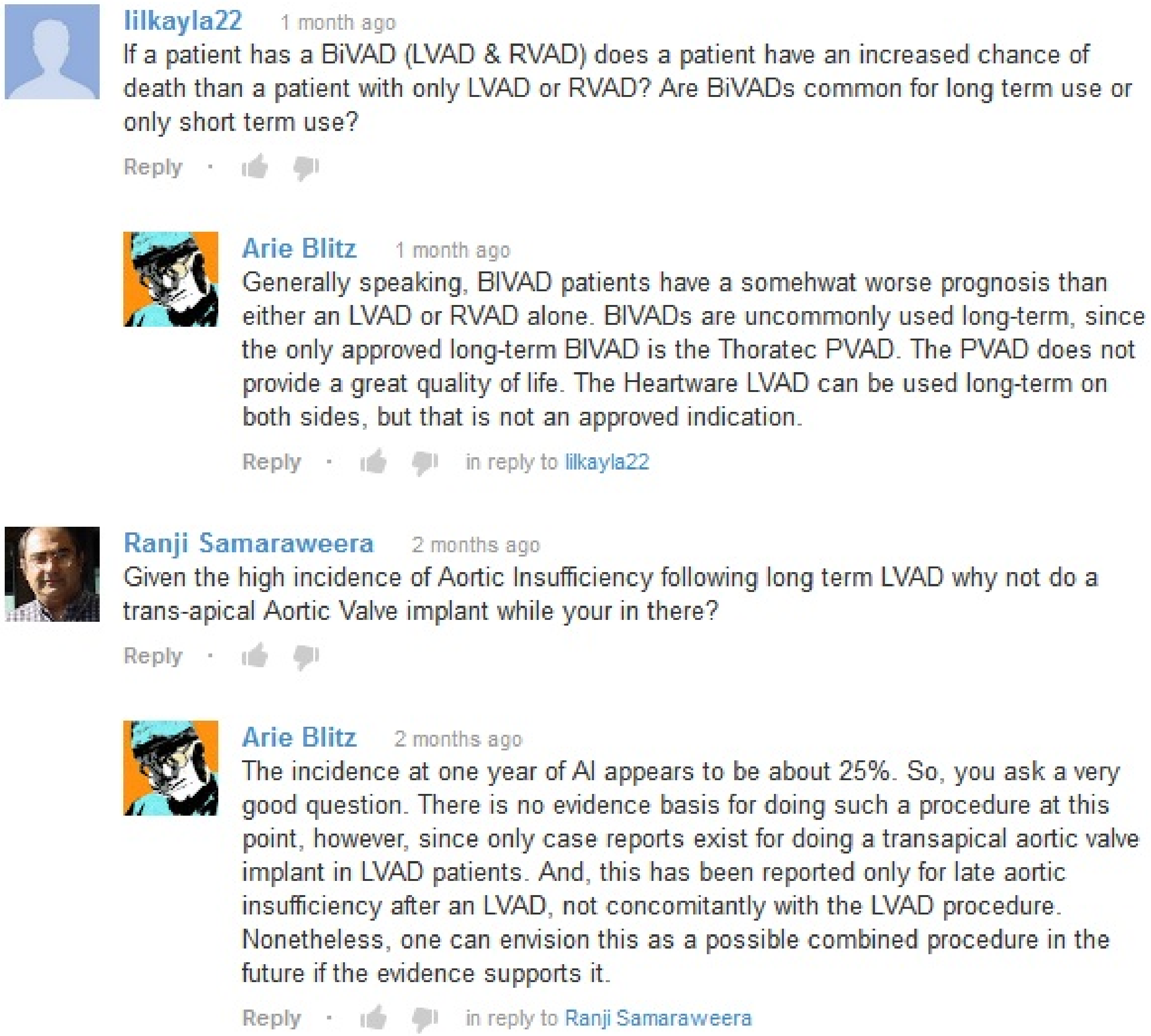
Miguel Libera 4 months ago

Thanks for the post.

Great video for LVAD presentations.

Reply ·

Figure 5. A screenshot of the utterly specialized BiVAD-related discussions (on April 12, 2013).



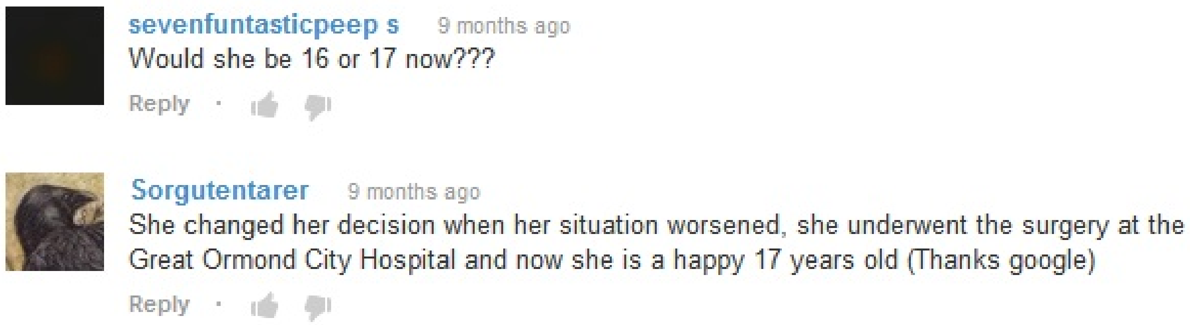
lilkayla22 1 month ago
If a patient has a BiVAD (LVAD & RVAD) does a patient have an increased chance of death than a patient with only LVAD or RVAD? Are BiVADs common for long term use or only short term use?

Arie Blitz 1 month ago
Generally speaking, BIVAD patients have a somehwat worse prognosis than either an LVAD or RVAD alone. BIVADs are uncommonly used long-term, since the only approved long-term BIVAD is the Thoratec PVAD. The PVAD does not provide a great quality of life. The Heartware LVAD can be used long-term on both sides, but that is not an approved indication.
in reply to lilkayla22

Ranji Samaraweera 2 months ago
Given the high incidence of Aortic Insufficiency following long term LVAD why not do a trans-apical Aortic Valve implant while your in there?

Arie Blitz 2 months ago
The incidence at one year of AI appears to be about 25%. So, you ask a very good question. There is no evidence basis for doing such a procedure at this point, however, since only case reports exist for doing a transapical aortic valve implant in LVAD patients. And, this has been reported only for late aortic insufficiency after an LVAD, not concomitantly with the LVAD procedure. Nonetheless, one can envision this as a possible combined procedure in the future if the evidence supports it.
in reply to Ranji Samaraweera

Figure 6. A screenshot of the comments from web viewers about the misleading video (on April 12, 2013).



sevenfuntasticpeep s 9 months ago
Would she be 16 or 17 now???

Sorgutentarer 9 months ago
She changed her decision when her situation worsened, she underwent the surgery at the Great Ormond City Hospital and now she is a happy 17 years old (Thanks google)

Optimizing Directions

Given the problems above, two measures can be implemented by YouTube to improve its functionality with a more efficient way of providing high-quality medical videos. First, a professional community targeting at medical education can be built to inspire specialized videos uploading and consumption, just as iTunes U. Since introduced in 2007, Apple's iTunes U courses (more than 2500) on a variety of topics have topped a billion downloads, and these courses are contributed by over 2400 educational institutions including universities, colleges, K-12 schools, and districts [40]. As the most advantageous online video provider, YouTube can take use of its incomparably competitive edge to encourage physicians, hospitals, and institutions to upload more instructional videos. Besides, this professional community will bring about specialized ranking outputs by separating e-learning-oriented viewers from common ones just for recreational needs. Based on the specialized community, searching experiences of the users can be optimized and remembered by mining social network characteristics [41], such as an expert assessment model that can strength weight of user rating in ranking factors [42]. Video providers can be scored based on their specialty approbation, and their score can be taken into account and reflected in the ranking system. Moreover, graphical model can be used in social community and medical experts can be distinguished from amateurs [43,44]. Thus more accurate recommendation of relevant videos can be given. Fernandez-Luque et al used a link-based analysis based on a metric called "HealthTrust" to acquire diabetes content from YouTube [45]. Their result indicated that social network analysis could be used to identify trustworthy multimedia in health communities.

Second, more precise and personalized lists of video after searching on YouTube should be provided. When a medical practitioner wants to access HTx-related videos, the most common way is to input keywords (eg, "heart transplantation"), wait for automatic operation embedded in the YouTube search tool, and then look over the videos according to the search result list in sequence. The purposes of viewers for viewing the videos are different, in which some physicians want to look for similar experience as reference for their clinical decision-making or operative skills, and other trainees wish to look up correct and useful information just as learning materials. Though out of different purposes, they don't expect to be distracted by irrelevant, even misleading information. To meet professional requirements with the least disturbance, YouTube ranking system should be refined and improved.

In the current YouTube ranking system, there are two comprehensive aspects of ranking factors: (1) "content", which is out of the video self-characteristics, such as correlation between search keywords, video title, and description, and (2) "engagement", which is contributed by viewer interaction in YouTube social community. There are 12 different detailed factors that are used to determine rank of each video (Table 5) [46]. With the help of these factors, YouTube not only explores the correlation between search keywords and candidate videos but also takes popularity of videos into account. However, the ranking system is mainly based on the relationship of viewership or hits, although YouTube has updated its algorithm with video-discovery features, such as "time watched" [47].

In the present study, it was found that the "scores" of three advertisement videos of "Surgeon Simulator 2013", an electronic game, were unexpectedly high. However, they were completely uncorrelated with HTx (Table 1). On the other hand, the results of this study showed that IUC videos had significantly higher mean "viewers/day" than H/UC and NAC videos. This phenomenon reflected that viewers are more interested in personal experiences about HTx rather than in professional conferences or didactic lectures, irrespective of authenticity or authority of multimedia materials. Thereupon, this ranking system is still focusing on the popularity of videos, not exactly the accuracy and correlation between videos' contents and searching keywords.

It is required to take deeper use of social network relationship among viewers. Users' historical viewing records can be regarded as personal profile, so system can supply personalized search results according to each user's preference, by using techniques in recommendation system [41], such as collaborating filter and opinion mining [48]. For instance, for a user whose historical viewing records include plenty of cardiac surgery videos, if he/she searches HTx, there is a great possibility that the desired videos are specialized materials for e-learning, other than personal experience sharing just as a recipient. Furthermore, it may benefit the ranking effect to mine literal information generated by viewers via using natural language processing (NLP) techniques, because it can strengthen the correlation between videos and search keywords [49]. So far, superficial literal features on video have been focused on YouTube ranking system; however, there is no evidence that showed that the comments generated by viewers have been noticed enough as they deserved. Most comments contain viewers' affection response to these videos; therefore, comments can be used to adjust video rating as a feedback. To date, researches on how to efficiently retrieve medical-related videos from YouTube are still few in number. Commonly, collocations in the context are much more informative than frequent phrases [50,51]. Thus, it is probably a suitable means to extract content-related video by NLP-discovered phrases rather than keywords [52,53].

Table 5. YouTube ranking factors.[a]

Content	Engagement
Title	Views
Description	Inbound links
Tags	Social shares
Transcriptions	Embeds
Channel authority	Comments
Delivery	Likes and favorites

[a] Reprinted with permission from Chelaru et al [46].

Study Limitations

First, our study was confined to the content analysis of HTx-related videos retrieved on February 01, 2013. This cross-sectional observation is like a snapshot of information distribution, but the actual source from YouTube is swiftly expanding as one never-ending documentary. Second, our classification method was subjective. However, the kappa coefficient demonstrated fairly high agreement between two cardiac surgeons. We did not extrapolate the percentage of “useful” and “misleading” videos in our dataset to all the HTx-related YouTube videos. Furthermore, our analysis of the comments and the social interactions of viewers and uploaders was based on pure observation without a solid methodological approach. The “scores” are based on “likes” or “dislikes”, and it may not be an excellent indication of viewer preferences or video quality on medical contents. Third, non-English language video clips were excluded, which included some valuable videos, such as many French language HTx-related videos. Fourth, we did not revalidate the results in other networking platforms, such as Baidu or Facebook. Finally, this study was limited to a direct search on YouTube, so we might have missed some valuable surgical videos that could be viewed at other available health information websites.

Conclusions

This study demonstrates a panoramic view of HTx-related videos on YouTube until February 1, 2013. The results of this study showed that YouTube benefits medical professionals by providing a substantial amount of specialized information. However, casting YouTube to find HTx-related videos is currently inefficient. As more young medical trainees are eagerly participating in social media and e-learning activities, it is reasonable to promote and optimize the dissemination of free and valuable medical videos via YouTube. It is clear from the results of this study that the quality of surgical specialized information in YouTube videos is very heterogeneous and the process of e-learning is not without pitfalls. The reasons include that (1) the content of most videos often lacks institutional or peer quality control, thus the specialized information shared may be not accurate; (2) finding informative and trustworthy targets is hampered by the vast amount of seemingly relevant videos via current ranking system. To solve these problems, we are expecting changes in two aspects. First, more authoritative videos by trusted sources should be posted. Second, ranking system based on present YouTube algorithm may be evolved by adding some elements like peer review, social network analysis, or NLP techniques. With the endeavors of professional individuals, academic institutions, and e-learning communities, YouTube, the leading video streaming websites, will help to meet huge informational needs of medical staffs and promote medical education on HTx.

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Authors' Contributions

The authors XBL, HMC, XLZ, and VADJP were involved in the study design; XBL, HMC, ZBX, ZSY, KY, and MO participated in the data collection; XBL, HMC, ZKH, LQY, XLZ, and VADJP participated in the discussion and interpretation of the results; and XBL, HMC, ZKH, and VADJP led the manuscript drafting. All authors have read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

The Revived Heart Transplant Program at Batson Children's Hospital builds on a 20-year legacy.

[MP4 File (MP4 Video), 109MB - ijmr_v2i2e28_app1.MP4]

Multimedia Appendix 2

The heart transplant procedure from Montefiore-Einstein, NYC.

[MP4 File (MP4 Video), 135MB - ijmr_v2i2e28_app2.MP4]

Multimedia Appendix 3

Example of a high-quality surgical educational video “Heartmate II LVAD Implantation. Arie Blitz, MD” uploaded by “Arie Blitz” channel. It was originally from the YouTube website, reproduced under Creative Commons Attribution License.

[FLV File, 93MB - ijmr_v2i2e28_app3.FLV]

Multimedia Appendix 4

A newest video titled “Left Ventricular Aneurysm Resection and LVAD Implantation Through Median Sternotomy” available on the website of CTSNet; however, it cannot be accessed from “AATSVideos” Channel. It was reproduced under Creative Commons Attribution License.

[MP3 File, 5MB - ijmr_v2i2e28_app4.mp3]

Multimedia Appendix 5

The maximum-weight misleading video “13-year-old British girl” uploaded by “uniquerocks” Channel. It was from originally from the YouTube website, reproduced under Creative Commons Attribution License.

[MP4 File (MP4 Video), 3MB - ijmr_v2i2e28_app5.MP4]

References

1. Bruschi G, Colombo T, Oliva F, Botta L, Morici N, Cannata A, et al. Heart transplantation: 25 years' single-centre experience. J Cardiovasc Med (Hagerstown) 2013;14(9):637-647. [Medline: 23340045]
2. Hassoulas J. Transplantation of the heart: an overview of 40 years' clinical and research experience at Groote Schuur Hospital and the University of Cape Town: Part I. Surgical experience and clinical studies. S Afr Med J 2012 Jun;102(6 Pt 2):350-352. [Medline: 22668902]
3. Kirk R, Edwards LB, Kucheryavaya AY, Benden C, Christie JD, Dobbels F, et al. The registry of the international society for heart and lung transplantation: fourteenth pediatric heart transplantation report--2011. J Heart Lung Transplant 2011 Oct;30(10):1095-1103. [doi: 10.1016/j.healun.2011.08.005] [Medline: 21962017]
4. Kaczmarek I, Meiser B, Beiras-Fernandez A, Guethoff S, Überfuhr P, Angele M, et al. Gender does matter: gender-specific outcome analysis of 67,855 heart transplants. Thorac Cardiovasc Surg 2013 Jan;61(1):29-36. [doi: 10.1055/s-0032-1331467] [Medline: 23258761]
5. Kitamura S. Heart transplantation in Japan: a critical appraisal for the results and future prospects. Gen Thorac Cardiovasc Surg 2012 Oct;60(10):639-644. [doi: 10.1007/s11748-012-0110-7] [Medline: 22898800]
6. Bennett LE, Keck BM, Hertz MI, Trulock EP, Taylor DO. Worldwide thoracic organ transplantation: a report from the UNOS/ISHLT International Registry for thoracic organ transplantation. Clin Transpl 2001:25-40. [Medline: 12211789]
7. Stehlik J, Edwards LB, Kucheryavaya AY, Aurora P, Christie JD, Kirk R, et al. The Registry of the International Society for Heart and Lung Transplantation: twenty-seventh official adult heart transplant report--2010. J Heart Lung Transplant 2010 Oct;29(10):1089-1103. [doi: 10.1016/j.healun.2010.08.007] [Medline: 20870164]
8. Rössler B, Lahner D, Schebesta K, Chiari A, Plöchl W. Medical information on the Internet: quality assessment of lumbar puncture and neuroaxial block techniques on YouTube. Clin Neurol Neurosurg 2012;114(6):655-658.
9. Williams D, Sullivan SJ, Schneiders AG, Ahmed OH, Lee H, Balasundaram AP, et al. Big hits on the small screen: an evaluation of concussion-related videos on YouTube. Br J Sports Med 2013 Feb 27. [doi: 10.1136/bjsports-2012-091853] [Medline: 23446643]
10. Briones R, Nan X, Madden K, Waks L. When vaccines go viral: an analysis of HPV vaccine coverage on YouTube. Health Commun 2012;27(5):478-485. [doi: 10.1080/10410236.2011.610258] [Medline: 22029723]
11. Yoo JH, Kim J. Obesity in the new media: a content analysis of obesity videos on YouTube. Health Commun 2012;27(1):86-97. [doi: 10.1080/10410236.2011.569003] [Medline: 21809934]
12. Davies K, Harrison J. The information-seeking behaviour of doctors: a review of the evidence. Health Info Libr J 2007 Jun;24(2):78-94. [doi: 10.1111/j.1471-1842.2007.00713.x] [Medline: 17584211]
13. Raikos A, Waidyasekara P. How useful is YouTube in learning heart anatomy? Anat Sci Educ 2013 Apr 5. [doi: 10.1002/ase.1361] [Medline: 23564745]
14. Simmons RN, Ellis JI, Dellavalle RP. Dermatology Internet resources. Dermatol Clin 2009 Apr;27(2):193-199, vii. [doi: 10.1016/j.det.2008.11.009] [Medline: 19254663]
15. Tourinho FS, de Medeiros KS, Salvador PT, Castro GL, Santos VE. Analysis of the YouTube videos on basic life support and cardiopulmonary resuscitation. Rev Col Bras Cir 2012;39(4):335-339 [FREE Full text] [Medline: 22936234]
16. Alexa the Web information company: global top sites. URL: http://www.alexa.com/topsites [accessed 2013-04-11] [WebCite Cache ID 6FmquRVgR]
17. Carroll MV, Shensa A, Primack BA. A comparison of cigarette- and hookah-related videos on YouTube. Tob Control 2013 Sep;22(5):319-323. [doi: 10.1136/tobaccocontrol-2011-050253] [Medline: 22363069]
18. YouTube. YouTube Statistics URL: http://www.youtube.com/yt/press/statistics.html [accessed 2013-04-11] [WebCite Cache ID 6FmrQA9PE]

19. Chu LF, Erlendson MJ, Sun JS, Clemenson AM, Martin P, Eng RL. Information technology and its role in anaesthesia training and continuing medical education. Best Pract Res Clin Anaesthesiol 2012 Mar;26(1):33-53. [doi: 10.1016/j.bpa.2012.02.002] [Medline: 22559955]
20. Bosslet GT, Torke AM, Hickman SE, Terry CL, Helft PR. The patient-doctor relationship and online social networks: results of a national survey. J Gen Intern Med 2011 Oct;26(10):1168-1174 [FREE Full text] [doi: 10.1007/s11606-011-1761-2] [Medline: 21706268]
21. Pandey A, Patni N, Singh M, Sood A, Singh G. YouTube as a source of information on the H1N1 influenza pandemic. Am J Prev Med 2010 Mar;38(3):e1-e3. [doi: 10.1016/j.amepre.2009.11.007] [Medline: 20171526]
22. Ache KA, Wallace LS. Human papillomavirus vaccination coverage on YouTube. Am J Prev Med 2008 Oct;35(4):389-392. [doi: 10.1016/j.amepre.2008.06.029] [Medline: 18675530]
23. Steinberg PL, Wason S, Stern JM, Deters L, Kowal B, Seigne J. YouTube as source of prostate cancer information. Urology 2010 Mar;75(3):619-622. [doi: 10.1016/j.urology.2008.07.059] [Medline: 19815255]
24. Sood A, Sarangi S, Pandey A, Murugiah K. YouTube as a source of information on kidney stone disease. Urology 2011 Mar;77(3):558-562. [doi: 10.1016/j.urology.2010.07.536] [Medline: 21131027]
25. Backinger CL, Pilsner AM, Augustson EM, Frydl A, Phillips T, Rowden J. YouTube as a source of quitting smoking information. Tob Control 2011 Mar;20(2):119-122. [doi: 10.1136/tc.2009.035550] [Medline: 20966132]
26. Madan AK, Frantzides CT, Pesce CE. The quality of information about laparoscopic bariatric surgery on the Internet. Surg Endosc 2003 May;17(5):685-687. [doi: 10.1007/s00464-002-8610-7] [Medline: 12618943]
27. Azer SA, Aleshaiwi SM, Algrain HA, Alkhelaif RA. Nervous system examination on YouTube. BMC Med Educ 2012;12:126 [FREE Full text] [doi: 10.1186/1472-6920-12-126] [Medline: 23259768]
28. Strychowsky JE, Nayan S, Farrokhyar F, MacLean J. YouTube: a good source of information on pediatric tonsillectomy? Int J Pediatr Otorhinolaryngol 2013 Jun;77(6):972-975. [doi: 10.1016/j.ijporl.2013.03.023] [Medline: 23598152]
29. YouTube. Heart transplantation URL: http://www.youtube.com/watch?v=_SDXsjM23_E [accessed 2013-04-11] [WebCite Cache ID 6FnDVh2aY]
30. YouTube. Heart transplant surgery URL: http://www.youtube.com/watch?v=bdIZkasIDas [accessed 2013-04-11] [WebCite Cache ID 6FnDfoqg5]
31. YouTube. Revived Heart Transplant Program at Batson Children's Hospital builds on a 20-year legacy URL: http://www.youtube.com/watch?v=r1xLPTqy9w4 [WebCite Cache ID 6FmOQ8YK]
32. YouTube. Heart transplant procedure from Montefiore-Einstein, NYC URL: https://www.youtube.com/watch?v=cOBWMITf3co [accessed 2013-04-09] [WebCite Cache ID 6FmR4K6fp]
33. YouTube. Surgical Nightmare! Heart Transplant Masterclass - Surgeon Simulator 2013 URL: http://www.youtube.com/watch?v=d8NxS7X1sd4 [accessed 2013-04-10] [WebCite Cache ID 6FnDxSNHR]
34. YouTube. Surgeon Simulator 2013 - Successful heart transplant [Rating: A++] URL: http://www.youtube.com/watch?v=kjEAjvuLv00 [accessed 2013-04-11] [WebCite Cache ID 6FnE4iAMO]
35. YouTube. Heart transplant surgery with live audience URL: http://www.youtube.com/watch?v=Py2YJlKEAnk [accessed 2013-04-11] [WebCite Cache ID 6FnEDluLW]
36. YouTube. Heart transplant part 1 URL: http://www.youtube.com/watch?v=ouTf7jEVDAc [accessed 2013-04-11] [WebCite Cache ID 6FnGL7hof]
37. YouTube. Implanted heart pumps keep patients in need of transplants alive URL: http://www.youtube.com/watch?v=9AD_KXFsK6Q [accessed 2013-04-10] [WebCite Cache ID 6FnGRhtY2]
38. YouTube. Heart transplant steps simplified by Dr Sandeep Attawar URL: http://www.youtube.com/watch?v=tjsC22qdZE8 [accessed 2013-04-11] [WebCite Cache ID 6FnGgGUtz]
39. Viera AJ, Garrett JM. Understanding interobserver agreement: the kappa statistic. Fam Med 2005 May;37(5):360-363 [FREE Full text] [Medline: 15883903]
40. Tsukayama H. Apple says iTunes U tops a billion downloads. 2013. URL: http://articles.washingtonpost.com/2013-02-28/business/37342273_1_itunes-apple-ceo-downloads [accessed 2013-04-09] [WebCite Cache ID 6FkAaK3NV]
41. Gou L, Chen HH, Kim JH, Zhang XL, Giles CL. SNDocRank: a social network-based video search ranking framework. In: Proceedings of the 10th International Conference on Multimedia Information Retrieval. New York, NY, USA; 2010 Presented at: ACM; Mar 29-31, 2010; Philadelphia, Pennsylvania, USA p. 367-376. [doi: 10.1145/1743384.1743443]
42. Susarla A, Oh J, Tan Y. Social networks and the diffusion of user-generated content: evidence from YouTube. Info Sys Res 2011 Apr 08;23(1):23-41. [doi: 10.1287/isre.1100.0339]
43. Ahmad MA, Zhao X. COLBERT: a scoring based graphical model for expert identification. In: Advances in Social Computing: Lecture Notes in Computer Science. Bethesda, MD: Springer Berlin Heidelberg; 2010:180-188.
44. Hopcroft J, Lou TC, Tang J. Who will follow you back?: reciprocal relationship prediction. In: Proceedings of the 20th ACM International Conference on Information and Knowledge Management. 2011 Presented at: ACM; 2011; New York, NY, USA p. 1137-1146. [doi: 10.1145/2063576.2063740]
45. Fernandez-Luque L, Karlsen R, Melton GB. HealthTrust: a social network approach for retrieving online health videos. J Med Internet Res 2012;14(1):e22 [FREE Full text] [doi: 10.2196/jmir.1985] [Medline: 22356723]

46. Chelaru SV, Orellana-Rodriguez C, Altingovde IS. Can social features help learning to rank youtube videos? In: Proceedings of the 13th International Conference on Web Information Systems Engineering.: Springer; 2012 Presented at: ACM; Nov 28-30, 2012; Paphos, Cyprus p. 552-566. [doi: 10.1007/978-3-642-35063-4_40]
47. Jarboe G. YouTube Algorithm Change: 'Time Watched' Key to Higher Video Search Rankings. URL: http://searchenginewatch.com/article/2218696/YouTube-Algorithm-Change-Time-Watched-Key-to-Higher-Video-Search-Rankings [accessed 2013-04-09] [WebCite Cache ID 6FkIEXYNi]
48. Maragoudakis M, Loukis E, Charalabidis Y. A review of opinion mining methods for analyzing citizens' contributions in public policy debate. In: Electronic Participation: Lecture Notes in Computer Science. Berlin, Germany: Springer; 2011:298-313.
49. Leung KW, Li CH, Ip TK. Commentary-based video categorization and concept discovery. In: Proceedings of the 2nd ACM Workshop on Social Web Search and Mining. 2009 Presented at: ACM; Nov 2, 2009; New York, NY, USA p. 49-56. [doi: 10.1145/1651437.1651446]
50. Bekhuis T, Kreinacke M, Spallek H, Song M, O'Donnell JA. Using natural language processing to enable in-depth analysis of clinical messages posted to an Internet mailing list: a feasibility study. J Med Internet Res 2011;13(4):e98 [FREE Full text] [doi: 10.2196/jmir.1799] [Medline: 22112583]
51. Bird S, Klein E, Loper E. Natural Language Processing With Python. Sebastopol, CA: O'Reilly Media; 2009.
52. Syed-Abdul S, Fernandez-Luque L, Jian WS, Li YC, Crain S, Hsu MH, et al. Misleading health-related information promoted through video-based social media: anorexia on YouTube. J Med Internet Res 2013;15(2):e30 [FREE Full text] [doi: 10.2196/jmir.2237] [Medline: 23406655]
53. Wu ST, Kaggal VC, Dligach D, Masanz JJ, Chen P, Becker L, et al. A common type system for clinical natural language processing. J Biomed Semantics 2013;4(1):1 [FREE Full text] [doi: 10.1186/2041-1480-4-1] [Medline: 23286462]

Abbreviations

AATS: American Association of Thoracic Surgery
ANOVA: one-way analysis of variance
CTSNet: Cardiothoracic Surgery Network
HTx: heart transplantation
H/UC: hospital/university channel
ISHLT: International Society for Heart and Lung Transplantation
IUC: independent user channel
LVAD: left ventricular assist device
MDC: medical dotcom channel
NAC: news agency channel
NLP: natural language processing

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