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Symptoms from Patients as the Primary Information Source for Real-time Surveillance

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Abstract

The aim of this study was to identify whether patients could become the primary data source for symptom based real-time surveillance. The study investigated people's attitude towards providing symptom information electronically before a consultation, and how they preferred to carry out the reporting. Data was collected by distributing questionnaires to 83 respondents. The results show that 96 percent of the respondents had a positive attitude towards providing information about their symptoms to the GP's office as soon as possible after falling ill. Over half of the respondents preferred to use e-mail or a web-interface to perform this task. Eighty four percent were willing to have their symptom data stored in their EPR and 76 percent agreed that the GP might access and present the symptoms together with the prevalence of matching diseases in order to assist the diagnostic process during the next consultation. This study indicates that patients could become the primary data source for symptom based surveillance in countries with high e-readiness.

Keywords:

Doctor patient communication, Electronic symptom reporting, Disease surveillance, Syndromic surveillance, Social networks

Introduction

The importance and relevance of disease surveillance and management is emphasized through the recent swine-flu pandemic, and through the facts that infectious diseases account for around 25 percent of all deaths in the world [1]. However, studies show that traditional disease surveillance systems struggle with a considerable reporting lag that limits early detection and timely response to outbreaks [2, 3]. Consequently, there is a demand for new electronic surveillance systems capable of eliminating unnecessary delays, and reducing the risk of data corruption [3].

Methods exploiting clinical data that exist at a stage before a confirmed diagnosis, e.g. symptoms, are commonly referred to as syndromic surveillance [4], or symptom based surveillance. Typically, in syndromic surveillance the frequency of illnesses is monitored using a specified set of clinical features (e.g., fever and respiratory complaints, skin rashes, diarrhoea) in a given population of a given geographic region, regardless of specific diagnoses [5]. It is the real time nature of the syndromic systems that makes them valuable for outbreak monitoring and detection [4]. Syndromic surveillance is considered useful for general public health, quality improvement, epidemiology, patient safety and research [4]. However, perhaps most important is its usefulness in clinical medicine [4], where it can make clinicians aware of community trends and enable them to issue the right tests and improve their diagnostic assessment [6].

Ideally, information should be entered once and used often [6]. Secondary use of clinical data, for instance structured documentation from the electronic patient record (EPR), unstructured narrative text, or laboratory results, is expected to have an enormous potential [7]. Today the necessary technologies are available to extract and present surveillance data from EPRs, laboratories, and hospitals [8]. However, the validity of a syndromic surveillance system depends on the quality of the collected and presented data, both in terms of representativeness and completeness [9]. One of the most challenging steps in utilizing such systems and technologies is to define the optimal data sources [10]. Unfortunately, data sources such as ICPC codes, free-text fields in the EPR, and data generated in conjunction with laboratory orders and results might have serious limitations [11]. One explanation is that the data entered into the EPR by the general practitioner (GP) is intended for other purposes than disease and/or syndromic surveillance, and produced in a different context. In general, use of data for secondary purposes influences data quality [12]. Consequently, the information must be disentangled from the context in which it was produced [12], and transformed into the new context of disease or syndromic surveillance. This process is particularly challenging with regards to real time data.

The Patient as the Primary Information Source

Thus, at the present, the challenge is to collect real time data of proper quality that is produced also for the purpose of disease or syndromic surveillance. Since patients could be seen as the GP's primary source of information on the current prevalence of infectious diseases [13], it seems appropriate to exploit this primary source further by collecting symptom information directly from the patients. In countries with high e-readiness, such as Norway where at least 80 percent of the population (15 years and older) are Internet users [14], this information could be reported electronically. This represents a new approach to syndromic surveillance that might provide more data of better quality than what is available today, and at an earlier stage. One of the core questions is, however, if patients would be willing to provide this symptom data.

This paper presents an investigation of people's attitudes towards providing symptom information electronically before a medical consultation and how they prefer to carry out this type of reporting. Further, the study investigates to which degree people acquire information prior to the medical consultation.

Methods

Data collection was performed by distributing 83 questionnaires among the population of the city of Tromsø in Northern Norway during March 2009. A convenience sample was drawn by approaching people directly, and having them fill out the questionnaire immediately after agreeing to participate. Data was collected at diverse public locations, including a student hostel, the university library, a research centre, the airport, and various social venues (cafés). However, attitudes towards health and information technology could be envisioned to vary based on age, gender, and level of education. In this regard the sampling procedure aimed to approximate a representative distribution of these demographic variables in the sample. The respondents were at least 16 years old as this is the requirement to consent to participation in health related research projects in Norway. Foreigners received the questionnaires in English. The questionnaires were piloted on a small sample.

The questionnaire consisted of 13 items, which represented a combination of multiple choice and free text (comments), and prioritization of alternatives. In addition to demographics (age, gender, nationality, and level of education) participants were asked several questions aimed at assessing their attitudes towards providing their GP with symptom information using electronic media. This also included items concerning medical visits (last 12 months) and whether or not they acquired information about symptoms and problems prior to the medical consultation. The questionnaires contained no information identifying a person or questions regarding personal health status. Respondents spent 5-10 minutes completing the questionnaire. Three questionnaires were excluded from the analysis due to incomplete answers. Selections of free-text responses were subject to a content analysis identifying dominant themes related to the specific questions. SPSS 16.0 was used for the statistical analysis.

Results

Demographics

A total of 80 questionnaires were included in the survey. The sample characteristics are show in Table 1. The youngest participant was aged 16 years, the oldest 70 years, and the age mean was 36.7 years. A higher proportion of females (81 %) than males (58 %) reported having visited the GP in the last twelve months.

Table 1 - Numbers of participants in each category of the sample. Tromsø, Norway, March 2009

Nationality	Norwegian: 77		Foreign: 3		
Gender	Female: 36		Male: 44		
Age	[16-22]	[23-32]	[33-42]	[43-52]	[53-70]
n	20	15	16	13	16
Education	Primary and lower secondary school: 5 Undergraduate: 16		Upper secondary school: 30 Bachelor/Master: 29		

Acquiring information prior to the medical consultation

The majority of the respondents (68 percent) had visited their GP during the last 12 months, while 31 percent had not. Also, the majority (78 percent) of the respondents usually had a clear opinion about their diagnosis before they visited the GP, while 14 percent answered "seldom" and 5 percent "never". An independent samples t-test was used to show that there was a significant difference between those who had visited their GP in the last 12 months (mean = 1.16), and those who had not (mean = 1.44) with regard to "having a clear opinion about the diagnosis" prior to the medical consultation (scale, 1 = "often", 2 = "seldom", 3 = "never"), $t = -2.18$, $df = 74$, $p < .05$. Respondents were asked to select up to four sources for their "opinion about the diagnosis". Sixty nine percent answered that they made use of previous experience, 55 percent discussion with family, friends, and colleagues, 41 percent searched the Internet, and 19 percent medical books. Four respondents commented that they had some level of medical education. Information based on, partly or mainly, newspapers represented only nine percent, TV/radio eight percent, and information from pharmacies eight percent.

The respondents were asked if they used the Internet to check out or "Google" their symptoms prior to a consultation. Sixty one percent did, 41 percent frequently, 20 percent more infrequently, while 35 percent never did. Of those who used the Internet, 16 respondents commented by free-text that they conducted this kind of search because the information on the Internet is available and easy to access. Sixteen respondents commented that they conducted this search to clarify their symptoms, and to get a preliminary idea about the nature of their problems. Nine respondents commented that they used the Internet to diagnose themselves, where six of these nine emphasized that they did not intend to consult a GP if they were successful. Of those who never used the Internet, 10 respondents commented that they had not needed that due to not having been ill, or not having symptoms they did not recognize. The remaining eight respondents expressed a lack of interest in symptoms and uncertainty with regard to quality of information on the Internet.

Providing information prior to the medical consultation

Nearly all of the respondents, 96 percent, had a positive attitude towards providing information about their symptoms to the GP's office as soon as possible after falling ill (61 percent "yes", 35 "maybe"). Only one of the positive respondents commented on why, and that was because "this is the future - it has to be done like this", while two sceptical respondents found this approach too time consuming.

The positive respondents preferred to provide the GP with this symptom information as soon as possible after becoming ill, 39 percent by e-mail, 25 percent by web-interface, and 13 percent by the mobile phone Internet service (WAP). Thirteen percent preferred to provide this information by a computer or PDA at the GP's waiting room.

A linear multiple regression analysis was performed to investigate which variables could predict the respondents "attitude towards providing symptom information prior to a medical consultation using electronic media". Variables were selected based on a correlation analysis and theoretical assumptions (Table 2). Model 1 accounted for approximately eight percent of the variance of the dependent variable. The analysis showed that the attitude towards providing symptom information prior to a medical consultation was predicted by "medical visits in the last twelve months (yes/no)".

Table 2 - Summary of multiple regression analysis for Age, Gender, Level of Education, and Medical visits, and Pre-consultation use of the Internet predicting Respondents' attitudes towards providing symptom information electronically. Tromsø, Norway, March 2009.

Model	Variable	B	SE B	β
1	(Constant)	.98	.19	
	Medical visits	.33	.13	.28**
2	(Constant)	.92	.39	
	Medical visits	.27	.15	.23
	Age	-.00	.00	-.09
	Gender	.02	.13	.02
	Level of Education	-.02	.07	-.03
	Pre-consult Internet	.21	.14	.18

Note. *$*p < .05$; $**p < .01$; $R^2 = .08$ for Model 1 ($p < .05$).*

The respondents were asked for their opinion regarding possible re-use of the reported symptoms. Eighty four percent of the respondents were willing to have their reported symptom data stored in the EPR at the GP office. In addition, 76 percent accepted that the GP might access and present the symptoms alongside the prevalence of matching diseases in order to assist the diagnostic process during the next consultation.

Regarding the storage of reported symptoms in the electronic journal system, four respondents commented that this would provide better documentation related to their problems, and would be a good way to update their personal health record. Further, four respondents commented that the fact that the GPs would be able to repeatedly access the reported symptoms could play a positive role in having their case thoroughly investigated. This, in turn, would be beneficial for them as patients, and maybe also save time. One person had the opposite view, worrying that "the info would lead the GP to be 'sloppy' ". On the other hand four commented that privacy and security had to be guaranteed. Two respondents were unhappy with electronic storage in general and afraid that unauthorized people (e.g., insurance companies) could get access to the data.

As to presenting the symptoms alongside the prevalence of the diseases matching the symptoms, two respondents commented that this might help the GP to identify the patient's problem and contribute to a more effective and time-saving consultation, while two commented that this is a tool that must be used with extreme caution not to scare people.

When asked if they would be willing to report the symptoms directly into a surveillance system without going through the GP's office/system, 43 percent were positive, 49 percent were negative, while nine percent did not reply to this question. Five sceptical respondents worried about the quality and would like the GP to confirm their symptoms before using them for surveillance. Of the positive respondents, two answered that they would report the symptoms since it would help early detection of diseases, four commented on the importance of anonymity, and one expressed concern whether the quality would be sufficient.

The respondents were asked for suggestions and user requirements with regard to how they wanted to provide information to such a system, the output they would like to receive, and other functional requirements. Security was highly prioritized by six respondents. For a surveillance system without GP's involved, the respondents suggested that the patients should be kept anonymous. Further, six respondents commented that it is most important that such a system is extremely easy to use (e.g., easily accessed, no need to set a lot of parameters, easily comprehensible information and questions). If possible, visual guidance should accompany the questions. Three respondents wished to have a response from the system with regard to diagnosis and possible treatment.

Respondents were asked to select up to three sources that they would trust when presenting them surveillance information. Eighty nine percent answered that they would trust their GP, 70 percent the Norwegian Institute of Public Health, and 60 percent the local university. Only 10 percent would trust the Internet, six percent the TV, three percent Google Flu trend, and between one and three percent would trust the local or national newspapers.

Discussion

The results show that the respondents are predominantly positive with regard to providing symptom information electronically to their GP. Ninety-six percent of respondents indicated that they would be willing to do this immediately after feeling ill. Over half of the respondents indicated that they would prefer to use e-mail or a web-interface to perform this task, rather than WAP-interface or technology in the GP-office's waiting room. This implies that people are motivated to use the most readily available technologies, and the technologies with which they are accustomed. Also, it points to a preference towards home-based solutions. Further, the respondents accepted that their symptoms could be stored in the EPR system. This will enable the GP to access these data at future consultations and present these alongside the prevalence of local diseases matching these symptoms, in order to assist in the diagnosing process.

In general, it appears that "medical visits (last twelve months)" is a central variable in this context. First, the variable is included in the regression model (Table 2, Model 1) as a significant predictor of respondents' attitudes towards providing symptom information. However, this model only explains 8 percent of the variance in the dependent variables. Thus, several other variables, not included in this study, are also relevant in explaining people's attitudes towards providing symptom data electronically. Second, having visited the doctor during the last twelve months is associated with being more likely to form an opinion about one's own diagnosis. However, the meaning of this variable is somewhat ambivalent, as it might both reflect a respondent's attitude towards health (i.e., being preoccupied with health issues) and indirectly, health status (i.e., visits equals poorer health). Inclusion of other variables (health status and other health-related attitudes) would be necessary to understand this relationship better.

The majority of the respondents were sceptical regarding reporting symptoms directly to a surveillance system without going through the GP's office. However, this still might be a possible approach since the 43 percent expressing a positive attitude could be sufficient to provide a representative outbreak picture.

Research on computer-mediated communication (CMC) has indicated that mediated communication is often associated with higher levels of self-disclosure [15]. These findings have been replicated for medically relevant communication, in both pre-clinical and clinical settings [16-21] and in anonymous, peer-support settings [22]. In sum, people appear more willing to disclose socially sensitive health information using CMC. They report more and/or more serious symptoms, and they comment that it feels easier disclosing their health problems in an anonymous setting. It seems worth mentioning that this is apparently irrespective of whether the information will be seen by health professionals at a later stage [e.g., 17], thus rendering the patient non-anonymous for all practical purposes. Our findings related to this published evidence support the viability of a patient-centric symptom-reporting tool.

The presented study utilizes a non-probabilistic sampling technique, and this limits the generalizations that can be drawn from the data. However, we believe that the care taken to ensure approximate representation with regard to gender and age allows for generalization to a certain extent. The fact that more females than males in our sample reported having visited the GP during the last twelve months underlines this viewpoint by reflecting the general population's behaviour regarding the use of health services. The sample is probably unrepresentative in terms of older age groups (50+), and the group with low level of education (only five participants).

Based on this survey we know the respondents say that they would report symptoms. However, we also know that there is a considerable gap between people's intentions/attitudes and their behaviour. Consequently, there is a need for studies that investigate if people/patients actually are able to report symptoms electronically. As to the willingness to report symptoms, encouraging experiences have been gained from large-scale volunteer efforts. This includes free and open source software development, distributed computing, and the Wikipedia project [23]. Evidence directly relevant to syndromic surveillance has also been published. Epidemiological data has been gathered from patients using web based questionnaires [24], and websites like "whoissick.org or sicklike.me, which ask users to enter their symptoms, demonstrate that consumers are willing to actively participate in surveillance" [25], (p. 8). The Great Influenza Survey in Netherland and Belgium (www.degrotegriepmeting.nl), which is based on weekly voluntary online participation of the population, supports this impression. We believe that future disease surveillance systems will be a combination of patient-centred symptom reporting systems, and surveillance systems utilizing other both formal and informally sources.

Conclusion

This study supports the hypothesis that patients could become the primary data source for symptom based real-time surveillance. In a patient-centred symptom reporting system the data would be produced for the purpose of surveillance, which would simplify the production of surveillance information of proper quality, provided that the symptoms are reported with sufficient quality. However, in order to draw a final conclusion, larger studies are needed.

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References

[1] WHO. World Health Organization. Report on infectious diseases: Removing Obstacles to Healthy Development. 1999 [Last downloaded: 3. April 2008]; Available from: http://www.who.int/infectious-disease-report/index-rpt99.html.

[2] Jajosky RA, Groseclose SL. Evaluation of reporting timeliness of public health surveillance systems for infectious diseases. BMC Public Health 2004 Jul 26;4:29.

[3] Jansson A, Arneborn M, Skarlund K, Ekdahl K. Timeliness of case reporting in the Swedish statutory surveillance of communicable diseases 1998-2002. Scand J Infect Dis 2004;36(11-12):865-72.

[4] Mandl KD, Overhage JM, Wagner MM, Lober WB, Sebastiani P, Mostashari F, Pavlin JA, Gesteland PH, Treadwell T, Koski E, Hutwagner L, Buckeridge DL, Aller RD, Grannis S. Implementing syndromic surveillance: a practical guide informed by the early experience. J Am Med Inform Assoc 2004 Mar-Apr;11(2):141-50.

[5] Reingold A. If syndromic surveillance is the answer, what is the question? Biosecur Bioterror2003;1(2):77-81.

[6] Foldy SL. Linking better surveillance to better outcomes. MMWR Morb Mortal Wkly Rep 2004 Sep 24;53 Suppl:12-7.

[7] Einbinder JS, Bates DW. Leveraging Information Technology to Improve Quality and Safety. IMIA Yearbook of Medical Informatics 2007 Methods Inf Med 2007;46 (Suppl. 1):22-9

[8] Bellika JG, Sue H, Bird L, Goodchild A, Hasvold T, Hartvigsen G. Properties of a federated epidemiology query system. Int J Med Inform 2007 Sep;76(9):664-76.

[9] Buehler JW, Hopkins RS, Overhage JM, Sosin DM, Tong V. Framework for evaluating public health surveillance systems for early detection of outbreaks: recommendations from the CDC Working Group. MMWR Recomm Rep 2004 May 7;53(RR-5):1-11.

[10] Henning KJ. Overwiew of Syndromic Surveillance: What is syndromic surveillance? MMWR Morb Mortal Wkly Rep 2004 Sep 24;53 Suppl:5-11.

[11] Johansen MA, Scholl J, Hasvold P, Ellingsen G, Bellika JG. "Garbage in, garbage out": extracting disease surveillance data from epr systems in primary care. Proceedings of the 2008 ACM conference on Computer supported cooperative work; San Diego, CA, USA: ACM; 2008.

[12] Berg M, Goorman E. The contextual nature of medical information. Int J Med Inform 1999 Dec;56(1-3):51-60.

[13] Johansen MA, Johnsen JA, Hartvigsen G, Ellingsen G, Bellika JG. Bridging the gap between patients' expectations and general practitioners' knowledge through disease surveillance. Stud Health Technol Inform 2009;150:423-7.

[14] Andreassen HK, Bujnowska-Fedak MM, Chronaki CE, Dumitru RC, Pudule I, Santana S, Voss H, Wynn R. European citizens' use of E-health services: a study of seven countries. BMC Public Health 2007;7:53.

[15] Joinson AN. Self-disclosure in computer-mediated communication: The role of self-awareness and visual anonymity. European Journal of Social Psychology 2001;31:177-92.

[16] Robinson R, West R. A comparison of computer and questionnaire methods of history-taking in a genito-urinary clinic. Psychology and Health 1992;6:77-84.

[17] Ferriter M. Computer aided interviewing and the psychiatric social history. Social Work and Social Sciences Review 1993;4:255-63.

[18] Webb PM, Zimet GD, Fortenberry JD, Blythe MJ. Comparability of a computer-assisted versus written method for collecting health behavior information from adolescent patients. Journal of Adolescent Health 1999;24:383-8.

[19] Jarlais DD, Paone DC, Milliken J, Turner CF, Miller H, Gribble J, Shi Q, Hagan H, Friedman SR. Audio-computer interviewing to measure risk behavior for HIV among injecting drug users: A quasi-randomized trial. The Lancet 1999;353:1657-61.

[20] Hasley S. A comparison of computer-based and personal interviews for gynecologic history update. Obstetrics and Gynecology 1995;85(4):494-8.

[21] Michaud P-A, Narring F, Ferron C. Alternative methods in the investigation of adolescent's sexual life. Journal of Adolescent Health 1999;25:84-90.

[22] Kummervold PE, Gammon D, Bergvik S, Johnsen J-AK, Hasvold T, Rosenvinge JH. Social support in a wired world: Use of online discussion forums in Norway. Nordic Journal of Psychiatry 2002;56(1):59-65.

[23] Benkler Y, Nissenbaum H. Commons-based Peer Production and Virtue. The Journal of Political Philosophy 2006;14(4):394-419.

[24] Eysenbach G, Diepgen TL. Epidemiological data can be gathered with world wide web. Bmj 1998 Jan 3;316(7124):72.

[25] Eysenbach G. Infodemiology and infoveillance: framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. J Med Internet Res 2009;11(1):e11.

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