Bridging the Gap between Patients’ Expectations and General Practitioners’ Knowledge through Disease Surveillance

Monika A. JOHANSEN,1 Jan-Are K. JOHNSEN, Gunnar HARTVIGSEN,2,3 Gunnar ELLINGSEN,4 Johan G. BELLIKA,2,3

Norwegian Centre for Telemedicine, University Hospital of North Norway, Tromsø, Norway
Department of Computer Science, University of Tromsø, Norway
Department of Telemedicine and e-Health, University of Tromsø, Norway

Abstract. In this paper we have investigated “to what degree patients trust their regular doctor to be fully informed about the prevalence of infectious diseases in their neighbourhood”, and what general practitioners (GPs) actually know. A representative sample of one thousand Norwegians (potential patients) was interviewed by telephone, and 13 GPs were interviewed individually or in focus groups. Nearly half of the patients trusted their GP to be more or less “fully informed” about the prevalence of infectious diseases in their neighbourhoods, while the GPs in reality were not well informed. We conclude that new surveillance solutions are needed. One promising approach is electronic retrieval of symptom data directly from patients.

Keywords. disease surveillance, human factors, decision support, system design, doctor patient communication

1. Introduction

The importance of disease surveillance and management has been emphasised in several WHO reports. Since infectious diseases cause around 25% of all deaths in the world [1], WHO works on strategies to detect outbreaks and stop their spread as early as possible [2]. Syndromic or symptom-based surveillance is of particular interest with a view to detecting outbreaks earlier than traditional disease surveillance [3]. Today, in most countries, information about the spread of infectious diseases is available from national institutes of health. The information is generally based on reports from laboratories, hospitals or general practitioners (GPs). A problem, however, is that such information might be several weeks old before it is broadcasted to the health care sector. Another challenge is to know how much knowledge GPs actually have about the prevalence of infectious diseases in their local community, and how and from whom they get this information. Further, we do not know what patients expect their local GP to know. Since the information patients provide to their GP will be influenced by what they expect their GP to know, and other aspects of the doctor-patient relationship, it is

1 Corresponding Author: Monika A. Johansen, Norwegian Centre for Telemedicine, University Hospital of North Norway, p.b.35, N-9038 Tromsø, Norway; E-mail: monika.johansen@telemed.no.
interesting to investigate patients’ expectations regarding local GPs, and compare them with the GPs’ actual knowledge about infectious diseases in the patient population.

This paper presents a quantitative study to investigate “to what degree patients trust their regular doctor to be fully informed about the prevalence of infectious diseases in their neighbourhood”, and a qualitative study to investigate “what general practitioners actually know”.

2. Methods

The survey investigating patients’ expectations regarding local GPs’ knowledge was conducted by including an additional question, aimed at the Norwegian respondents, as part of the e-health consumer trends survey supported by the European Union and WHO. The other questions and results from the EU-study have been reported elsewhere [4]. Professional polling agencies interviewed a representative randomised sample of 1001 Norwegians, at least 15 years old, by telephone in April-May 2007. The respondents were asked “To what degree do you trust your regular doctor to be fully informed about the prevalence of infectious diseases in your neighbourhood”. Responses were registered on a scale from 1 (“very high”) to 5 (“very low”). These scores were later recoded (reversed). SPSS 15.0 was used for the statistical analysis.

For the qualitative research, investigating what GPs actually know, an interpretative study approach was used [5, 6]. Data were collected through semi-structured individual interviews, semi-structured focus group interviews, and informal discussions. In total, 13 GPs were interviewed. First, individual interviews lasting from 1.5 to 2 hours were conducted with five GPs from different practices. To follow up these results [7], interviews lasting 1 and 1.5 hours were conducted with two strategically selected focus groups in order to promote a broader and more thorough discussion [8]. One of the GPs interviewed was responsible for the prevention of infectious diseases in his/her municipality. All interviews were recorded except for one of the individual interviews. The interviews were transcribed by a third person. Informed consent was obtained.

3. Results

3.1. What Patients Trust That Their GPs Know

Of the 1001 people interviewed, 888 replied to this specific question. Nearly half the respondents trusted their regular doctor to be more or less “fully informed” about the prevalence of infectious diseases in their neighbourhood, while around one quarter had less confidence in their GP (see Table 1). Women (18.2%) had higher confidence than men (10.8%) as indicated by the “very high” category, and overall women (mean 3.32) exhibited higher confidence than men (mean 3.12), \( t = -2.39, df = 886, p < .05 \). Also, respondents from villages and rural areas (mean 3.36) had higher confidence than those from urban areas (mean 3.10), \( t = -3.16, df = 886, p < .01 \). A multiple regression analysis was performed to investigate which variables predicted patients’ “confidence in the GP’s knowledge” (Table 2). Variables were selected based on a correlation analysis and theoretical assumptions. The analysis showed that patient’s trust in their GP was predicted by Location (“Where do you live”), medical visits in the last twelve
Table 1. To what degree the 888 respondents trusted their regular doctor to be fully informed about the prevalence of infectious diseases in their neighbourhood in total, crossed with gender, and crossed with place of residence

<table>
<thead>
<tr>
<th>Would you say...?</th>
<th>Total</th>
<th>Gender %</th>
<th>Where do you live? %</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Very high</td>
<td>14.4</td>
<td>10.8</td>
<td>18.2</td>
</tr>
<tr>
<td>Somewhat high</td>
<td>31.8</td>
<td>34.6</td>
<td>28.8</td>
</tr>
<tr>
<td>Neither high nor low</td>
<td>27.0</td>
<td>25.6</td>
<td>28.6</td>
</tr>
<tr>
<td>Somewhat low</td>
<td>14.9</td>
<td>14.3</td>
<td>15.4</td>
</tr>
<tr>
<td>Very low</td>
<td>11.9</td>
<td>14.8</td>
<td>9.0</td>
</tr>
<tr>
<td>Total</td>
<td>100</td>
<td>100</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 2. Summary of multiple regression analysis for age, gender, medical visits, and location predicting patients’ confidence in their GP’s knowledge about infectious diseases

<table>
<thead>
<tr>
<th>Model</th>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>(Constant)</td>
<td>3.12</td>
<td>.57</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>.20</td>
<td>.08</td>
<td>.08*</td>
</tr>
<tr>
<td>2</td>
<td>(Constant)</td>
<td>2.66</td>
<td>.13</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>.18</td>
<td>.08</td>
<td>.07*</td>
</tr>
<tr>
<td></td>
<td>Medical visits</td>
<td>.23</td>
<td>.10</td>
<td>.02*</td>
</tr>
<tr>
<td></td>
<td>Location</td>
<td>.13</td>
<td>.04</td>
<td>.11**</td>
</tr>
</tbody>
</table>

Note. *p < .05; **p < .01. R² = .02 for model 2 (p < .001).

months (yes/no), and gender. Age did not emerge as a predictor. The final model has a high level of unexplained variance (see Table 2), and although not uncommon for cross-sectional data, this suggests that the construct cannot be fully explained by demographical variables.

3.2. What the GPs Actually Know

The respondents reported that they were unable to keep themselves fully informed about the prevalence of infectious diseases in their neighbourhood, even though they used both public and more informal sources to gather information.

The public surveillance system operates through the Norwegian Institute of Public Health (NIPH). A description of the current epidemiological situation, including outbreaks, is published every second week in the MSIS reports on the NIPH home page. Previous work indicates that the collection and compilation of this data and the production of the reports lead to information that is several weeks old when it becomes available [7]. Also, the public system does not provide information about the local patient population [7]. The focus group interviews supported these findings. One focus group summed up the situation as follows: “The MSIS reports present ancient data. When we receive the reports people are dead and buried, or they have recovered.”

The Municipal Disease Prevention Doctor (MDPD) informs GPs about serious cases in his/her municipality. As reported earlier, some of the GPs worried that the MDPD did not have access to up-to-date information, since the current system depends on “some” GP discovering the situation first and then reporting it to the MDPD, or to the NIPH [7]. Another problem was that the GPs felt they had to be fairly sure that the diagnosis was correct, and preferred to receive confirmation from the laboratory, before they reported anything to either the MDPD or the NIPH. They were aware that this probably resulted in massive underreporting.
The primary source of information is actually a more informal one: the patients. In addition to reporting their own symptoms, patients often provide information about family members, colleagues, children in kindergarten or at school, or other patients at nursing homes with similar symptoms. The demand and reason for emergency appointments reported by the medical secretaries might also be the first information about a possible outbreak. This information is usually shared between colleagues at lunch or at joint meetings.

4. Discussion

The results from the survey indicate that patients have rather high confidence in their GP’s knowledge regarding infectious diseases. Nearly half of the patients trust their regular doctor to be “informed”, while around one quarter has less confidence in their GP. Respondents from villages and rural areas have higher confidence than respondents from urban areas. The explanation for this might be that GPs from villages and rural areas represent one of few authority figures in whom people generally have high confidence. Also, women have higher confidence in their GPs than men, perhaps reflecting the finding that women in general are more likely to exhibit health promoting behaviours and beliefs than men [9]. Patients that had visited their doctor in the last twelve months also have higher confidence in their GP’s knowledge than patients that had not.

As demonstrated by the interviews, the GPs are actually not very well informed. To diagnose and treat their patients, GPs want up-to-date information relevant to the local population [7], but this is not available through the current system. The SNOW project [10, 11] attempts to design a system to improve this situation by extracting and presenting local surveillance data from GPs’ EPR, laboratories and hospitals in real time. However, when patients visit their local GP, they are supposed to report all their symptoms to the GP, and the GP should enter all these symptoms in a standardised “symptom and diagnosis field” in the EPR. Studies have shown that GPs in general only enter one symptom in this file, not all [11, 12]. This is one reason why extracting symptom data from the GP’s EPR is unlikely to provide the desired overview [11].

In spite of what GPs enter in the EPR, patients are the GPs’ primary source about the prevalence of infectious diseases in their neighbourhoods. However, the sufficient motivation to report to their doctor might be lacking for patients at both ends of the “confidence in their GP’s knowledge scale”. On one hand, patients with very high confidence might not report relevant information since they believe that the GP already has this information. On the other hand, patients with very low confidence might be generally distrustful of their GP, and therefore not share information with her/him. Thus, in order to exploit this primary source of information more reliably, a system is needed that is independent of the patient’s level of trust towards their regular doctor. This can be realised by patients reporting symptoms directly to a neutral and public “patient-informer-based” surveillance system. The symptoms can be reported when they occur, not only during the consultation with the GP that might take place several weeks later. Such a system would represent a new approach for syndromic surveillance that might provide much more data of much better quality than what is available today, and at a much earlier stage. Symptoms could be reported by a special template that copies the data both into a temporary field in the patient’s EPR, and into the public surveillance system. If the symptoms are copied into the EPR, patients would have a
general interest in reporting correct data. The public system might also analyze symptoms and provide diagnostic aid for patients and links to further reading, to prepare the patient and make it possible to participate in the treatment decision during the next visit to the GP [13]. The individual symptoms could be presented to the GP when the patient arrives for a consultation together with the prevalence of diagnosed diseases that match these symptoms, and an overview of what is brewing based on symptoms reported by other local patients, to guide the GP in the diagnosing process.

Other data sources that might provide valuable input to such public surveillance system include Google Flu Trends (www.google.org/flutrends), and/or use of online social networks like for instance Facebook and MySpace. A study from the Netherlands showed that this approach is feasible in influenza surveillance; the information gathered is reliable, and the pattern of influenza cases is comparable to traditional approaches (http://nihi.net.nz/2008/12/09/influenza-tracking-project/).

5. Conclusion

To support diagnosis and treatment of their patients, GPs want up-to-date information relevant to the local patient population, but this is in general not available. Since patients might both trust their local GP to have this information, or might be distrustful in general, new surveillance solutions are needed. We suggest a new public system for symptom reporting that will minimize the importance of expectations and trust issues in the doctor-patient relationship, while providing the GP’s with up-dated information.

References