Public Awareness of Sepsis Is Low in Sweden

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Background. Sepsis is a serious and common condition with high mortality and morbidity. The public awareness, knowledge, and perception of sepsis in Sweden are unknown.

Methods. A survey was performed using an online interview distributed to adults, aged 18–74, between March 6 and 9, 2015.

Results. A total of 1001 people responded to the survey. Twenty-one percent of participants had heard of sepsis, whereas more than 86% had heard of each of the other conditions listed; for example, stroke (95%), chronic obstructive pulmonary disease (COPD) (95%), and leukemia (92%). Of those who had heard of sepsis, 93% responded that it is an infection or blood poisoning in an open question. The respondents who had heard of each disease estimated its mortality. For sepsis, the mortality was estimated at an average of 30%, which was at the same level as estimated mortalities for prostate and breast cancer but lower than for stroke, COPD, and leukemia.

Conclusions. The awareness and knowledge of sepsis is low. The mortality for sepsis is not as overestimated as for many other diseases. The lack of awareness of sepsis might be a target to improve the outcome for sepsis patients by reducing the prehospital delay and hence enable early interventions. An increased general awareness might also raise interest for funding for research in this area and for its priority in healthcare support.

Keywords. awareness; knowledge; sepsis; septic chock; severe sepsis.

Sepsis is an immense health problem, with an incidence of more than 300/100 000 people a year, and it is estimated that 30 million cases of sepsis occur globally every year [1, 2]. It has a high mortality, causing more deaths than, or in the same range as, stroke or any kind of cancer [1, 3–5]. Furthermore, sepsis causes great morbidity, it is amongst the most common reasons for intensive care, and it has profound negative long-term effects on survival, cognitive and functional ability, and healthcare use [6–9].

In spite of the impact on health caused by sepsis, only a minority of the population is aware of sepsis. According to surveys done in 2002 and 2003 from United States, United Kingdom, France, Italy, Spain, and Singapore, 4%–19% had heard the term sepsis [10, 11]. The number was higher in Germany (53%) and in a similar survey from South Korea in 2013 (77%). However, only 22% and 35% of the Germans and Koreans, respectively, who had heard the term sepsis selected 1 acceptable definition from a list of options [10, 12]. Not surprisingly, there are national variations, and the awareness in Sweden is as yet unknown.

During the 1980s and 1990s, media campaigns succeeded in making people seek medical care earlier for serious symptoms consistent with acute myocardial infarction (AMI). Phrases such as “Time is muscle” were launched [13]. Recently, similar campaigns aiming to reduce prehospital delay for stroke symptoms with the Face-Arm-Speech-Time (FAST) test have managed as well to get patients with major stroke to present early at hospitals [14].

It is well established that septic patients also require early recognition and acute management to reduce mortality. Therefore, The Surviving Sepsis Campaign has published recommendations on diagnostic measures and the need for antibiotic therapy to be initiated within 1 hour for patients diagnosed with severe sepsis and septic shock [15].

Nonetheless, prehospital delay should also be targeted to enable early interventions; however, to achieve
behavioral change, an understanding of the target population is crucial.

Therefore, the awareness of sepsis and the seriousness of the syndrome must be included in the political agenda, and a proportional part of healthcare and research resources must be allocated. The objective of this study was to assess awareness, knowledge, and perception of sepsis in Sweden.

METHODS

The survey was conducted using an online interview, administered to members of YouGov Sweden’s (www.yougov.com) panel of respondents, during March 6–9, 2015. YouGov Sweden’s panel of respondents consists of 60 000 registered, Swedish inhabitants, aged 15 or more, who have agreed to take part in surveys. YouGov Sweden recruit respondents through multiple sources. Members of the panel were selected randomly according to the sample definition, which was age 18 to 74, and the invitations did not reveal the subject of the survey. The selection is representative of the Swedish adult population regarding age, gender, and region. Selected members were invited by e-mail, which provided a link to the survey.

The responding sample was weighted to the composition of the population to provide a representative reporting sample regarding the factors considered when selecting respondents. The survey included questions on awareness of sepsis and other diseases and their mortality, knowledge of sepsis, and blood poisoning among those who had heard of these diseases and a question on money donations to a number of charity organizations (see Supplementary Data).

Statistics

Categorical variables are expressed as numbers (%) and are compared using the $\chi^2$ test. $P$ values < .05 are considered to be statistically significant. The survey is not based on probability sampling, and therefore no margin of error is calculated.

RESULTS

In total, 1001 people responded to the survey, basic demography is shown in Table 1. Eighty-six percent of participants responded that they use some kind of social media at least once a month.

Two of 10 Swedish adults have heard of sepsis (214 of 1001), but 9 of 10 have heard of the other diseases listed (Figure 1). Women were significantly more likely to have heard the term sepsis than men, 29% vs 14%, respectively ($P < .001$). There were no differences between the age groups in having heard of sepsis.

Ninety-two percent (197 of 214) of those who had heard of sepsis could correctly identify the statement that it is an infectious disease. In an open question, a majority of those who had heard of sepsis (84%) described it as blood poisoning.

Regarding the term blood poisoning, 90% claimed they have heard of it. This proportion is still lower than corresponding figures for AMI (96%) and stroke (95%). Ninety-two percent of those who claimed to have heard of blood poisoning responded that it is an infectious disease at the multiple choices question. When posed as an open question, the result differed in that 62% claimed that blood poisoning is due to bacteria or an infection, and, of those, 49% mentioned the localization of the infection in the blood. Nineteen percent claimed that blood poisoning is a disease of the blood caused by foreign substances, and 18% could not answer the question. Eleven percent mentioned that blood poisoning is due to a wound, a thorn, or a bite, whereas only 2 individuals mentioned other causative infections.

The estimated disease mortality, among those who claimed to have heard of a certain disease, was on average 49% for chronic obstructive pulmonary disease (COPD), 43% for leukemia, 40% for AMI, 30% for sepsis, and 22% for blood poisoning (Figure 2).

In Sweden 2015, almost every other person (48%) had been donating money to one of the charity organizations mentioned.

| Table 1. Basic Demography of the Respondents |
|---------------------------------------------|
| Characteristics                  | % (n = 1001) | % Weighted |
|---------------------------------------------|
| Gender                               |          |           |
| Female                               | 49.9     | 49.5      |
| Male                                 | 50.1     | 50.5      |
| Age                                  |          |           |
| 18–34 years                          | 30.5     | 31.0      |
| 35–54 years                          | 37.1     | 37.0      |
| 55–74 years                          | 32.5     | 32.0      |

Figure 1. A bar chart of the percentage of respondents who have heard of the listed conditions (n = 1001). Abbreviations: AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease.
Most of them were directed towards particular illnesses such as cancer and heart and lung diseases (Figure 3).

**DISCUSSION**

The awareness of sepsis in the Swedish population is low, 21%. It coincides roughly with what Phua et al [11] found for Singapore and Rubulotta et al [10] assessed for United States and Western Europe, except for Germany where sepsis education has been performed. This is remarkable because both the incidence and mortality is higher than for well recognized diseases such as breast and prostate cancer [1, 5].

The consciousness of blood poisoning is high, 92%. Perhaps this number can partly be credited to a famous Swedish author, Astrid Lindgren. A large part of the Swedish population has read her books. In one of them, which takes place in the beginning of the last century, the hero rides in a blizzard to save his friend, who has an infected wound and is at risk of dying from blood poisoning [16].

The term blood poisoning has disadvantages as well, which is illustrated by the answers to the open question: “What kind of illness is blood poisoning?” Sixty-two percent answered that it is an infection or that it is due to bacteria. The association of blood poisoning with dirty objects and wounds can be misleading in understanding when to seek care. The words are not interchangeable, and we advocate that the word sepsis should be spread in favor of blood poisoning. Sepsis might be perceived as a foreign term, but other Latin and Greek terms such as diabetes and psoriasis are commonly known.

We did not ask any further questions about knowledge of other diseases than sepsis and blood poisoning. However, a survey on stroke awareness was performed in Sweden 2011 where 87% of participants knew that it affects the brain and 86% of participants could report at least 1 risk factor [17]. Since then, a Swedish version of the FAST campaign has been launched to reduce prehospital delay for stroke.

A question where the respondents estimated the mortality for sepsis and other diseases was included to assess the perception of the seriousness of sepsis. Among those who had heard of sepsis, the mortality for sepsis was, on average, estimated to be 30%, which is fairly accurate because studies assess the in-hospital mortality rate to be 15%–30% [1]. For the other diseases included, the mortality was generally overestimated. For example, for COPD, the mortality was estimated to 49%, whereas the 1-year mortality rate for COPD in Sweden is 5.1% [18].

Given the high incidence of sepsis, the term is obviously not commonly used by healthcare workers when informing patients and relatives. Healthcare workers can probably contribute to the awareness by applying the term sepsis when informing patients, as well as in systematic registrations, for example for discharge diagnoses. However, in a recently accomplished study, <60% of

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**Figure 2.** Respondents’ estimation of mortality (mean) of the listed conditions. Only those who have heard of each condition estimated the mortality. Abbreviations: AMI, acute myocardial infarction; COPD, chronic obstructive pulmonary disease.

**Figure 3.** Percentage of respondents who have donated money to a list of charity organizations (n = 1001). The Ulla-Carin Lindquist Foundation’s aim is amyotrophic lateral sclerosis (ALS) research.
the patients who fulfilled the criteria for severe sepsis or septic shock were given a sepsis diagnosis code at discharge or in the death certificate [19]. Many studies of incidence and mortality are based on registrations of diagnosis, and they are probably underestimating sepsis’ burden of disease. Accurate data is important and might, together with a general awareness of sepsis, improve its weight in political considerations to prioritize health interventions and support research or promoting other actors for fundraising. The need to address this is obvious when looking at the disproportion in mortality and research funding.

Almost half of the adult population is donating money to a number of charity organizations, many aimed for particular illnesses. Many donations are directed to various cancer foundations. In Sweden, there is as yet no such organization aimed for supporting sepsis research.

An online survey, using a professional survey company’s panel of respondents, excludes people who do not have online access or do not speak Swedish; moreover, the response rate is relatively low. We assume that the awareness and knowledge of sepsis do not exceed our result to a great extent in groups excluded.

Nevertheless, our study has strengths as well; the panel of respondents provide us with a representative sample in regards to basic demography; the assessment of awareness of other diseases, some of the same frequency and urgency as sepsis, some less frequent, gives us a benchmark for awareness.

The lack of awareness might be a target for improving the management of sepsis. One cannot conclude that better awareness leads to better survival in sepsis, because many factors influence the delays in seeking healthcare, but it can be a feasible and promising attempt, until novel therapies and biomarkers can improve the outcome.

There are many reasons to believe that media campaigns may be successful in this regard. Similar to AMI and stroke, there is a substantial effect on survival with decreased time to therapy [20–22]. Prehospital delays have been shortened for AMI and stroke after media campaigns [13, 14]. Sweden has universal health insurance and generally good access to emergency healthcare, factors that are known to remove barriers when seeking emergency care [23].

CONCLUSIONS
In conclusion, we found the awareness and knowledge of sepsis in Sweden to be low. In addressing this shortage, we can provide a path towards improved outcome for sepsis patients by reducing the prehospital delay and by raising interest for funding for research in this area.

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Supplementary Data
Supplementary material is available online at Open Forum Infectious Diseases online (http://OpenForumInfectiousDiseases.oxfordjournals.org/).

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