Health care professionals’ attitudes to health care for undocumented migrants: A study in light of Act (2013:407)

Degree Project in Medicine

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Abstract

Health care professionals’ attitudes to health care for undocumented migrants: A study in light of Act (2013:407)

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Introduction: In July 2013 a new law, Act (2013:407), was introduced in Sweden. This law qualified undocumented migrants to receive health care to the same extent as asylum seekers.

Aim: The aim of this study was to investigate how Act (2013:407) is understood and applied by health care professionals in Region Västra Götaland.

Methods: The study involved a secondary analysis of data from a questionnaire, answered by health care professionals in Region Västra Götaland between November 2015 and January 2016. The data used in this study was related to a fictitious case about an undocumented migrant, and the answers were analyzed by using descriptive statistics and thematic analysis.

Results: 90% of the respondents considered that the undocumented woman in the fictitious case had a right to health care, and were willing to offer it themselves. The
thematic analysis resulted in four main themes and nine sub-themes. The main themes identified were: *No difference in health care, Reduced health care for undocumented patients, Factors related to undocumented patients that may affect their health care, and Other factors that may affect undocumented patients’ health care.*

**Conclusion:** The analysis of the free-text answers illustrated a variation in attitudes to the dealing with the undocumented woman and in the application of Act (2013:407). Undocumented migrants’ lack of knowledge about the health care system and their rights as well as a fear of being reported to authorities were thought to constitute barriers to health care in accordance with prevalent legislation.

**Key words:** Undocumented migrants, Act (2013:407), Human rights
Introduction

In July 2013 a new law, Act (2013:407) concerning Health Care for Certain Aliens Residing in Sweden Without the Necessary Permission, was introduced in Sweden [1]. This law qualified undocumented migrants to receive health care to the same extent as asylum seekers. This study investigates how Act (2013:407) is understood and applied by health care professionals in Region Västra Götaland in order to address barriers to health care for undocumented migrants.

A migrating world

A large number of people in the world are migrating. In 2015, 65 million people around the world were forcibly displaced [2]. This is the highest number since World War II. Of these, 41 million were internally displaced persons, 21 million were refugees and 3 million were asylum seekers. Approximately half of all refugees worldwide came from only three countries: Syria, Afghanistan and Somalia. The countries hosting the largest number of refugees were Turkey, Pakistan and Lebanon. Children below 18 years constituted half of the refugee population. Worldwide, there were 2 million new asylum applications in 2015. Almost 160 000 of these were in Sweden which therefore was the world’s third largest recipient of asylum applications that year. The number of asylum seekers in Sweden in 2015 was twice as high as the year before, and never before have there been that many applications for asylum in Sweden [3, 4]. The prognosis for 2016 and 2017 is a decrease in the number of asylum applications to between 28,000 and 50,700 per year [5]. The number of asylum applications in Sweden 2013-2016 is illustrated in figure 1.
Different terms are used to describe people residing in a country without required permissions. Terms like “irregular migrants”, “unauthorized migrants”, “illegal migrants” and “illegal aliens” all refer to this group of people [6, 7]. In this paper the term “undocumented migrants” is used; this includes people who have entered the country illegally and never applied for asylum as well as asylum seekers who have been rejected and are hiding from authorities to avoid deportation. The number of undocumented migrants in the European Union is estimated to be between 1,9 million and 3,8 million [8]. That is 1% of the entire population in the union. The number of undocumented migrants in Sweden in 2011 was estimated to be between 10,000 and 35,000 [9].

Undocumented migrants in Sweden

It is difficult to get well-detailed information about the health status of undocumented migrants in Sweden. Studies of public health are usually based on registers with personal...
identification numbers, and since undocumented migrants lack these numbers they are not included. Another reason for the limited knowledge about their situation is that undocumented migrants are staying away from authorities, and that might include health care services, in fear of being reported to the police or immigration authorities [10].

Despite the difficulties in obtaining information about the health status of undocumented migrants some studies have been carried out. One has shown that the reasons for medical contact among undocumented migrants correspond well with the pattern seen in general practice [11]. An exception was the portion of contacts related to pregnancy that was more than twice as high in a clinic for undocumented migrants compared to general practices in Denmark. A higher prevalence of psychiatric illnesses among undocumented migrants has also been observed. In a Swedish study, the prevalence of depression was ten times higher among undocumented patients compared to Swedish patients. In the same study, the undocumented patients also showed high levels of suicidal thoughts [12]. A comparative study of causes of death has shown that external causes, including suicide, are more common among undocumented migrants compared to Swedish citizens [6].

Undocumented migrants in Sweden are afraid of visiting health care centers; according to a study by the Swedish branch of Doctors Without Borders in 2005, many undocumented migrants do not even attempt to seek care because of high costs and fear of being reported to the police by the health care staff [12]. Two out of three respondents felt that their risk of being arrested by authorities at a hospital was high, and 82% had experienced barriers to accessing health care, direct such as being refused care, or indirect such as
being too afraid to visit hospitals. Some of them reported that they personally knew someone who had been reported to the police in connection with a hospital visit. Such incidents may, according to the authors of the article, have been the result of health care professionals incorrectly believing that they have to report these patients to the police. These results are from a study conducted before the law of health care for undocumented migrants was introduced in Sweden. However, the results are still relevant and of interest because of the risk of implementation gap, a term used to describe the gap between theory and practice. In this case it could mean that health care professionals deny undocumented migrants health care or report them to authorities without legal ground. Even if this only occurs occasionally it might make up a barrier to access health care for the migrants [10].

**Human rights perspective**

The right to health as a human right is expressed in several international covenants, of which Sweden has ratified most. When it comes to health care for undocumented migrants, the most important of these is the *International Covenant on Economic, Social and Cultural Rights* by the United Nations. In its 12th article, this covenant establishes the “right to the highest attainable standard of physical and mental health” as a human right [13]. This right is further specified in *General Comment 14* where it is stated that member states are under the obligation to not deny nor limit equal access to preventive, curative and palliative health services to any person, including undocumented migrants [14]. Another UN document, *General Comment 19*, also clarifies that undocumented migrants are covered by human rights when stating that “all persons irrespective of their
nationality, residency or immigration status, are entitled to primary and emergency care” [15].

A review article by Suess et al from 2014 analyzed the right to health care for undocumented migrants in Europe. They found a high degree of variability regarding health care entitlements for undocumented migrants in the European countries and a frequent legal restriction of access to health care. In most of the European countries, they observed a gap between human rights and the level of health care entitlements for undocumented migrants [16]. The Swedish situation was analyzed by Biswas et al in 2012, before Act (2013:407) was instituted. They found restrictions on access to health care for undocumented migrants in Sweden, at odds with the international human rights treaties that Sweden has ratified, and the right to health was therefore considered violated by Sweden [17]. In 2006, The United Nation Special Rapporteur on the right to health visited Sweden in order to investigate if the health care of Sweden was in accordance with human rights and the “right to the highest attainable standard of physical and mental health”. The Rapporteur concluded that Sweden was not acting in accordance with its human rights obligations since asylum seekers and undocumented migrants were not offered health care on the same basis as Swedish residents [18].

The introduction of Act (2013:407)

The most fundamental law of the health care legislation of Sweden is (1982:763) Health and Medical Services Act. In this act it is declared that the county councils of Sweden are obligated to offer complete health care to those registered in the county [19]. Prioritizations in the health care system shall be made in accordance with an ethical
platform. This consists of the principle of human dignity, the principle of health care by need, and the principle of cost and effectiveness [20]. In July 2013 Act (2013:407) concerning Health Care for Certain Aliens Residing in Sweden Without the Necessary Permission was introduced, extending the obligations of the county councils to also apply to undocumented migrants. This law offers undocumented migrants over 18 years

- health care and dental care that cannot be deferred
- maternal health care
- health care related to abortion
- contraceptive counselling
- health care in accordance with Communicable Diseases Act
- a health examination

Children under 18 years are offered health care, medical care and dental care to the same extent as registered children. In conclusion, the level of health care offered to undocumented migrants is, since the introduction of Act (2013:407), the same as that for asylum seekers in Sweden [1].

In 2015, The Swedish Agency for Public Management (Statskontoret) published a report evaluating the implementation of the new law [21]. They concluded that most of the undocumented migrants visiting medical centers are offered health care in accordance with Act (2013:407). However, in some cases the county councils did not fulfill the obligations of the law when denying some undocumented patients health care. These cases were usually related to inadequate knowledge about the new law among health care professionals, and the Swedish Agency for Public Management concluded that more could be done by the county councils in educating health care professionals about the new law. The report also showed that during the three 6 months’ periods that were
assessed, the costs for health care for undocumented migrants increased every period. This was thought to be related to increasing knowledge about the new law among undocumented migrants and among health care professionals. However, the costs for health care to undocumented migrants were still low, only a third of the expected cost.

Doctors of the World, a non-governmental organization (NGO) in Stockholm that supports undocumented migrants, analyzed the implementation of the new law 18 months after it was introduced [22]. They found that 77% of the undocumented migrants they had guided to health care services received health care, although sometimes after assistance from the NGO. 19% were denied health care for incorrect reasons, and 2% were denied health care because it could be deferred. Two other NGOs conducted similar studies, showing that about 10% of the patients were denied health care [23, 24]. The findings of these NGOs coincide with those of The Swedish Agency for Public Management: the main reason for barriers to health care for undocumented migrants is connected to inadequate knowledge about the new law among the health care professionals, especially administrative professionals.

Health care that cannot be deferred

In the preparatory works of Act (2013:407), several consulted organizations emphasized that it was not clear what was meant by “health care that cannot be deferred” and how it could be implemented in the Swedish health care system. Therefore, The National Board of Health and Welfare (Socialstyrelsen) was asked by the Swedish government to clarify what the expression means. In their report, they gave examples of aspects to consider when making this decision: the severity of the present condition, the risk of progress to a
severe condition, the risk that a denying of health care will result in a need of more extensive health care and the possibilities to avoid resource-demanding acute health care [25]. They concluded that the expression “health care that cannot be deferred” is not compatible with the ethics of the medical profession, is not applicable in health care practice and could jeopardize patient safety. They emphasized that most diagnoses have a fluctuating process and the needs of health care can vary between different patients with the same diagnosis and for one patient at different times. Therefore, they found it neither ethically nor medically possible or appropriate to specify some diagnoses or medical conditions that can be deferred. Instead, the responsible doctor in the particular case is the one to decide whether health care can be deferred or not.

Health care professionals’ perspective

Health care professionals’ attitudes toward providing health care to undocumented migrants have been assessed in a Canadian study by Ruiz-Casares et al [26]. The attitudes of clinicians, administrators and support staff in hospitals and primary care centers were investigated. They found that foreign-born respondents and those working in primary care were more likely to endorse broad or full access to health care services for undocumented patients. Many support staff, often the first point of access, hold restrictive attitudes toward entitlement for undocumented migrants. Ruiz-Casares et al also identify a dilemma that health care professionals frequently face when meeting undocumented patients; the professionals may breach legal or financial regulations if they provide health care, or breach human rights and their own professional code if refusing to give health care.
The knowledge about Act (2013:407) among health care professionals of Region Västra Götaland have been investigated by Hansen et al [27]. A majority of the respondents reported that they did not know the act well, and less than a third reported that they had been informed about the law by their employer. They also found that the participants of the study were not concordant with the National Board of Health and Welfare concerning the expression “health care that cannot be deferred”.

**Aim**

Because of the risk of an implementation gap, it is not possible to get the whole picture of the health care for undocumented migrants only by examining legal and political documents. It is also necessary to investigate the knowledge and application of prevalent legislation among health care professionals. Therefore, the aim of this study is to investigate how Act (2013:407) is understood and applied by health care professionals in Region Västra Götaland. The research questions are as follows:

- How is Act (2013:407) applied by health care professionals?
- What differences in health care, if any, do health care professionals perceive there to be for undocumented migrants compared to other individuals?
- What barriers, if any, are there for undocumented patients to receive health care in accordance with the legislation?
Methods

Study design

The present study is a cross-sectional study of health care professionals’ application of Act (2013:407). The study involved a secondary analysis of data from a questionnaire, answered by health care professionals in Region Västra Götaland between November 2015 and January 2016 [27]. Of the data used in the present study, a small part was constituted by closed-ended questions, related to a fictitious case. The main part of data was constituted of free-text answers from open-ended questions, related to a fictitious case. An advantage of open-ended questions is that they allow the respondents to include more information, including feelings, attitudes and understanding of the subject. However, the analysis of free-text answers is usually more complicated since data cannot be aggregated and quantitatively analyzed as for closed-ended questions. Instead the analysis has to be made by using a qualitative method [28].

The questionnaire

This study is based on data collected as part of a previously conducted study, and data were collected using a web-based questionnaire [27]. The questionnaire was constructed by Hansen et al after a review of the literature on health care for undocumented migrants, in order to formulate questions of interest and relevance for the particular study at hand. It was written in Swedish, made up of 37 questions and took about 10 minutes to complete. The questions were related to different aspects of Act (2013:407), such as awareness, knowledge and perception of the law and its implementation. Most questions
were closed-ended, but there were also some open-ended ones. In addition, there were some demographic questions asking for gender, age, profession, working area and years of experience.

The questions used in the present study were related to a fictitious case and the answers have not been analyzed before. The description of the case and the questions analyzed in this study can be found in Appendix A. In this fictitious case a 39-year-old woman from Afghanistan was seeking care due to headache, anxiety, sleeping problems and stomach pain. She had no ID card, no residence permit, no assurance and no possibility to pay. The first question connected to this case, number 22, was whether the respondent thought the patient had a right to health care, and it was possible to answer with “yes” or “no”. The next question, number 23, was whether the respondent would offer healthcare to her, answered with “yes” or “no”. The following question, number 24, investigated what the health worker would do if the patient could not afford to pay the fee, answered by choosing from multiple choices (I offer the care she needs and let the administrative staff handle the payments; I offer free health care; I do not offer health care; I contact the responsible of my ward asking for advice; I do not know; other routines). The last two questions of this fictitious case were of open-ended character. The first of these, number 25, asked for differences in treatment for this patient compared to a Swedish citizen with the same symptoms, from the perspective of the health care professional. The second of these, number 26, asked for problems this patient could experience, compared to a Swedish citizen with the same symptoms, from the perspective of the patient.
Participants and data collection

The participants of this study were health care professionals in adult clinics in Region Västra Götaland, the second largest county in Sweden with about 1.6 million inhabitants [29]. The health care professionals targeted were doctors, nurses, managers and front desk staff, the former two categories constituting 90% of the total. An overview of the recruitment process is presented in Figure 2. In total 17,855 persons received the questionnaire and were asked to participate. They received the questionnaire via email between November 2015 and January 2016. The email addresses were received from the contact person for the Region Västra Götaland staff registry (Katalog i Väst) at each of the eight hospitals in the greater Gothenburg region as well as the public primary health care in the region. The response rate was 8.8% (1,568). The demographics of those who answered the questionnaire was compared with all of the persons who received it. The group of those answering was constituted by less women (73%) compared to the original sample (76%). It was also constituted of more doctors (33% compared to 28%) and less nurses (57% compared to 60%). To be able to perform the qualitative analysis a selection was made from the original 1,568 answers. Data were excluded if the respondents were working in pediatric care, since there is a great difference in the legal rights for children under 18 years compared to adults. Moreover, data were excluded if the respondents had not answered the open ended-questions that were to be analyzed, did not know whether they had dealt with undocumented migrants, had not answered the questions about their work place or how well they knew Act (2013:407). After this exclusion process, 774 answers remained. These were randomly divided into 4 groups, of which one (including 194 answers) was analyzed in this study. This selection was made because of the limited
time frame for the analysis. The 4 randomized groups were compared with regard to some of the closed-ended questions in the questionnaire: knowledge about Act (2013:407), experience of undocumented migrants, gender, age, working areas and profession. This comparison was not showing any major differences between the groups (data not shown). The demographics of the subgroup analyzed in this study are presented in table 1.

**Exclusion criteria**
- Working in pediatrics (n=20)
- Had not answered the open-ended questions (n=690)
- Had not answered whether they had dealt with undocumented migrants (n=79)
- Had not answered the questions about their work place (n=3)
- Had not answered how well they knew Act (2013:407) (n=2)

**Figure 2. Overview of the recruitment process.**
Table 1. *Demographic characteristics of the subgroup that was analyzed.*

<table>
<thead>
<tr>
<th>Demographics</th>
<th>% (n)</th>
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<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Woman</td>
<td>67    (130)</td>
</tr>
<tr>
<td>Man</td>
<td>32    (63)</td>
</tr>
<tr>
<td>Not answered</td>
<td>1     (1)</td>
</tr>
<tr>
<td><strong>Profession</strong></td>
<td></td>
</tr>
<tr>
<td>Doctor</td>
<td>40    (78)</td>
</tr>
<tr>
<td>Nurse</td>
<td>54    (105)</td>
</tr>
<tr>
<td>Other</td>
<td>6     (11)</td>
</tr>
<tr>
<td><strong>Working area</strong></td>
<td></td>
</tr>
<tr>
<td>Emergency care</td>
<td>44    (86)</td>
</tr>
<tr>
<td>Primary care</td>
<td>16    (32)</td>
</tr>
<tr>
<td>Psychiatics</td>
<td>16    (31)</td>
</tr>
<tr>
<td>Other</td>
<td>23    (45)</td>
</tr>
<tr>
<td><strong>Had dealt with undocumented migrants</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>74    (143)</td>
</tr>
<tr>
<td>No</td>
<td>26    (51)</td>
</tr>
<tr>
<td>Do not know</td>
<td>0     (0)</td>
</tr>
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<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>Median</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>45,3</td>
<td>45</td>
<td>23</td>
<td>68</td>
</tr>
<tr>
<td>Working experience (years)</td>
<td>20,5</td>
<td>20</td>
<td>0,25</td>
<td>45</td>
</tr>
</tbody>
</table>

Data analysis

Descriptive statistics was used to analyze the quantitative data of question 22-24.

Thematic analysis was chosen as the method for analyzing the qualitative data of question 25 and 26. Thematic analysis is a qualitative method for identifying and analyzing themes within data [30]. The method is usually used to analyze data constituted of text of some kind, for example interviews. Some advantages of the method are that it is flexible and can summarize key features of a large amount of data. Moreover, it is a relatively easy method to learn and practice, also for researchers with limited experience. The advantages of this method makes it well suited for the kind of data used in this study.
It has been used in studies with the same kind of data as in this study, for example in the analysis of the free-text responses from the open-ended questions of the *Wales Cancer Patient Experience Survey* [31].

Data were analyzed with thematic analysis in six phases, as described by Braun and Clarke [30], using computer software NVivo 11.0 for qualitative analyses. The phases of the process are illustrated in Figure 3. The purpose of the *first phase* was to become familiar with the content of the data. This was made by repeated reading of the data, with simultaneous note-taking. In the *second phase* the coding process started. A code identifies a component of the data that is of interest and constitutes “the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon” [32]. A single extract could be uncoded, coded once or coded many times, depending on whether it fit into none, one or several potential themes. In the *third phase* the codes were analyzed and combined in order to find overarching themes across the codes. When finding and creating themes, Patton’s criteria for internal homogeneity and external heterogeneity were considered, meaning that data within a theme should cohere together meaningfully, while there should be clear and identifiable distinctions between themes [33]. The *fourth phase* included reviewing and refining of the themes. Every theme was checked by reading the coded data extracts constituting it, to evaluate whether they formed a coherent pattern. Moreover, during this phase all of the original data were reread in order to see if the themes really represented the original data and to find relevant but previously uncoded data. In the *fifth phase* the themes were finally named and defined, in order to identify the essence of each theme. For every
theme an explaining and summarizing text was written, describing what the theme enclosed and what was of interest about it. The sixth and final phase of the analysis was the writing of the report (see “Results”). In this phase some extracts were selected and interpreted, in order to provide evidence and demonstrate the content of a theme.

Figure 3. Phases of thematic analysis.

Before the analysis began some decisions were made in order to detail in what way the analysis was to be conducted. A rich description of the data set was chosen, instead of one particular aspect. This was made since the questions themselves guided the respondents close to the issue. Moreover, an inductive approach to the data was chosen, since there was no specific theory or coding frame to put the codes into. The codes stood for themselves and the aim was to get themes strongly linked to the data itself; thus, the analysis was ‘data-driven’. A semantic approach for analysis was chosen, meaning that themes were identified from the actual words in the data. The contrary is a latent approach, looking for meanings beyond what is actually said, identifying underlying
ideas and assumptions. In the work of identifying themes, as described above, the researcher plays an active role in selecting what parts of data that are relevant. Therefore, there is a risk of bias from the researcher’s impact in this kind of analysis. This risk is inevitable, and is handled by a continuous assessment of the researcher’s possible impact on the analysis [34].

Ethical considerations

The study was conducted in accordance with Angered Hospital’s guidelines for research ethics, and the study protocol was reviewed and approved by the hospital’s research ethics committee [35, 36]. Before the respondents answered the questionnaire, they were informed about the study and had to give written consent to participate. The information given made clear that participation was anonymous and voluntary and could be ended at any time.

Results

Results of the quantitative analysis

The quantitative questions of the fictitious case, question 22-24, are briefly presented in this passage and in figure 4-6. The result of question 22, asking if the patient had a right to health care, is presented in figure 4. 174 of the respondents (90%) answered “Yes” and 20 (10%) answered “No”.
Figure 4. The answers of question 22: Do you think the undocumented woman has a right to health care?

The result of question 23, asking if the respondent would offer health care to the woman, is presented in figure 5. 172 of the respondents (89%) answered “Yes” and 22 (11%) answered “No”.

Figure 5. Answers of question 23: Would you offer health care to the undocumented woman?

The result of question 24, asking what the respondent would do if the patient lacked money, is presented in figure 6. On this question it was possible to choose more than one
option, and therefore the total number of answers exceeds the number of respondents. 107 of the respondents answered that they would offer the health care the undocumented woman needs and let the administrative staff handle the payments. 34 respondents answered that they would offer health care for free. Three respondents would not offer health care at all. 88 of them would contact the responsible of his/her ward and ask for advice. 10 respondents did not know what they would do and another 20 of them answered “other routines”.

![Question 24](image)

**Figure 6.** The answers of question 24: What would you do if the patient could not afford to pay the fee?

**Results of the qualitative analysis**

The analysis resulted in four main themes and nine sub-themes, presented in figure 7 and described below. The main themes identified were (a) *No difference in health care*, (b) *Reduced health care for undocumented patients*, (c) *Factors related to undocumented patients that may affect their health care*, and (d) *Other factors that may affect*...
undocumented patients’ health care. Main themes (a) and (b) are related to the first research question: “How is Act (2013:407) applied by health care professionals?” All main themes are related to the second research question: “What differences in health care, if any, do health care professionals perceive there to be for undocumented migrants compared to other individuals?” Main themes (c) and (d) are related to the third research question: “What barriers, if any, are there for undocumented patients to receive health care in accordance with the legislation?”

The thematic analysis was based on data from question 25 and 26 of the questionnaire. On question 25 the respondents wrote an average of 17 words, and from this question 194 codes were generated. On question 26 they wrote an average of 14 words, and 270 codes were generated. Each main theme was prevalent in between 9% (n=37) and 31% (n=119) of the total number of answers.
Figure 7. Main themes (blue) and sub-themes (green).
No difference in health care

For many of the respondents, the legal status as undocumented migrant was not affecting the treatment and follow-up health care for the undocumented woman in the fictitious case. Many simply stated that there was “no difference” in what health care that she should be offered compared to a similar patient with Swedish citizenship. Some of those who elaborated emphasized that they offered health care based on need, independent of the legal status of the patient.

No difference.

I want to treat everyone who is in need of health care, and will not make a difference if the person is undocumented or have a Swedish citizenship. It would not feel humane to deny health care to one who needs it.

Some respondents explained that their opinion only referred to their own working area and maybe not to the entire health care system. These respondents were usually working in some kind of emergency health care.

I would treat her as other patients. At the delivery ward where I work everyone gets the same health care since it is emergency care. In planned health care I do not know how they prioritize.

Reduced health care for undocumented patients

No follow-up

A reduction in health care in terms of not offering follow-up care for the undocumented woman was found in many answers. Some of the respondents refrained from offering follow-up health care because of legal aspects. On the one hand, there were health care professionals who were unsure of whether or not they were allowed to follow up the patient. There was uncertainty among them about the rights of the undocumented woman, as well as the extent of resources they were legally allowed to offer her. On the other
hand, some of the respondents were more certain that the patient was not having a legal right to get follow-up health care, and consequently they would not offer it.

If the examination doesn’t point at a potentially dangerous condition, such as suicidality or acute neurological condition, I am unsure whether the patient has a right to meet a welfare officer/psychologist, initiation of a pharmaceutical treatment has to be followed up… Now I get unsure of how much resources I am allowed to put on the patient.

[That] this patient would not have the right to follow-up in non-institutional care.

Health care including follow-up for the undocumented patient was concentrated on acute and serious causes while less serious conditions were not followed up in the same extent as for a Swedish citizen. For a Swedish citizen, less serious conditions would often be followed up while the undocumented woman would be offered a simpler, short-term treatment. For example, a Swedish citizen suffering from insomnia would be offered follow-up conversational therapy, while the undocumented woman would be offered pharmaceutical therapy.

If it only was tension headache and unspecific abdominal symptoms I would not take further measures, not call for another visit, which I usually would do.

The undocumented will not get follow-up in the same way and not for example long-term therapy if that is what one found necessary, but only short-term, symptomatic treatment.

In several cases when respondents answered that they would not offer a follow-up for the undocumented woman, it was emphasized she would be informed to seek care herself in case of deterioration.

Unfortunately, I think that I more seldom plan for follow-up visits. However, I clearly inform to return if it not gets better.

Some administrative barriers were described related to offering follow-up health care. Some respondents wanted to offer a follow-up but thought they would not be able to
carry it out for practical reasons. A main reason was difficulties to get in contact with undocumented patients, since they are often lacking address and frequently move to new accommodations.

If the patient does not have any permanent address she cannot be called for follow up.

Follow-up can usually not be offered since the patient does not know where she will be.

Several answers in this group only briefly stated that “it is difficult to perform a follow-up”. In the analysis this was understood as if the respondent would prefer to offer a follow-up, but it was not possible for practical and/or administrative reasons.

More difficult to plan for a follow-up of the patient.

To sum up, this theme showed that the undocumented woman would not be offered follow-up health care in the same extent as other patients. The respondents referred to legal aspects and to difficulties to get in contact with undocumented patients. This phenomenon was particularly seen for patients with less serious medical conditions.

**Limited investigation and treatment**

A pattern within the data was that the medical investigation of the undocumented woman was limited to exclude serious, acutely treatment-requiring conditions. When these causes had been excluded, the investigation was stopped and her condition was considered to be in the category of health care that can be deferred. Therefore, she was no longer having the right to health care and was denied further investigation and health care.

Exclude serious (life threatening or in other ways potentially seriously harming) disease and afterward stop a potential investigation.
If I, after a careful anamnesis, status and laboratory investigation, do not find any grounds for a condition that requires a speedy handling I would maybe not push the diagnostics and treatment further if the patient is lacking Swedish citizenship.

To concentrate the initial part of a medical investigation on excluding serious and acutely treatment-requiring conditions is a general approach, for all patients, in some parts of the health care system such as emergency care units. However, in this study there appeared to be a difference between undocumented and other patients in this regard, where the former were investigated to a lesser extent. Moreover, the questionnaire was specifically asking for differences between the patient groups. If a respondent answered something along the lines of “I will make a limited investigation, as I would do for any patient”, this answer was not included in this theme but instead categorized as “No difference in health care”.

It was also found that psychiatric causes of the symptoms were down-prioritized when it came to the decision of offering health care or not. Psychiatric conditions that were explicitly named were for example insomnia, anxiety, stress and tension headache. In some cases, no health care at all was offered for these conditions. In other cases, treatment of a simpler kind was offered such as pharmaceutical therapy instead of conversational therapy, which another patient would be offered.

If it is related to stress, no treatment.

Anxiety and insomnia I would probably not do more than relieve with drugs, not refer the patient to conversational therapy (which I might had done usually).

To sum up, this theme showed that health care in terms of medical investigation and treatment was more limited for the undocumented woman compared to other patients.
Two frequent patterns were that the investigation only should exclude serious causes and that psychiatric causes of symptoms were down-prioritized when it came to treatment.

Denying health care

One theme that was found was a denying of health care. A minority of the data of this theme was constituted by answers where the respondent denied health care for the undocumented woman. In these cases, she was not considered to be in an acute condition but in a condition where health care could be deferred. By referring to prevalent legislation, she was refused to get health care.

This is not an acute condition and therefore no health care is offered.

This woman is not acute sick and have not health care that CAN NOT be deferred – therefore she has not right to get health care in contrast to a Swedish citizen.

A majority of the answers were in response to the question asking for problems that the undocumented woman might face in the health care system. Among these answers, some simply stated “the risk of being denied health care”. Others explained that the reason for which she might be refused was that her condition, by health care professionals, was considered as health care that could be deferred. Other possible reasons of being denied health care were that the patient could not afford to pay or was not accepted in the reception desk since health care professionals might lack knowledge about how to handle the administration of these patients.

That the person receiving must estimate if this is a person that has the right to health care, can health care be deferred? Risks to be refused without health care.

Payment, that the undocumented one is refused health care just because he or she is lacking means of payment.
To sum up, this theme showed that the undocumented woman might run the risk of being denied health care, because it could be considered as health care that can be deferred or because of economic and administrative reasons.

Factors related to undocumented patients that may affect their health care

Lack of knowledge

One aspect of this theme is that the undocumented woman, according to the respondents, might lack knowledge about her legal rights. This could result in a limitation in health care, not caused by health care professionals or health care legislation but by the patient’s unawareness. One of the respondents mentioned that if the patient does not know her rights, she has to depend on the goodwill of the staff.

The individual might not be correctly informed about her right to health care.

It is difficult for her to hold her own, so she has to depend on the goodwill of the staff.

Another aspect of this theme is that the undocumented woman also is lacking knowledge about the Swedish health care system. The respondents described how undocumented patients often do not know to which part of the health care system they should go when they need help, for example if they should go to the primary care center or the emergency ward of the hospital.

To understand the society and the health care system in Sweden. For example self-care and choosing correct care level.

This theme was closely linked to the theme of communication difficulties. Several of the answers that were categorized as this theme also contained thoughts about linguistic and communicative shortcomings as contributory causes to the gap of knowledge.
Possible language problems, and therefore bad understanding why she cannot get treatment for her problems at an emergency care unit but are guided to primary health care.

To sum up, this theme showed that the undocumented woman might lack knowledge about her legal rights and the Swedish health care system. A contributory cause a lack of knowledge could be communication difficulties.

**Fear of being reported**

The fear of being reported by health care professionals was found as a potential barrier to health care for the undocumented woman. Some respondents were describing uncertainty among undocumented migrants about the possibilities and duties of the health care professionals to contact authorities such as the Swedish Migration Board and the police. This theme only captured the *fear* of being reported. The data did not indicate that health care professionals believed undocumented migrants were actually being reported to authorities. The risk of undocumented migrants being *denied* health care was mentioned by a large number of the respondents (see previous theme), but the risk of being *reported* was hardly mentioned by anyone.

- Fear of being “reported” to the police.
- A fear that the health care system is communicating with police/Swedish migration board.

**Other factors that may affect undocumented patients’ health care**

**Complicated administration**

The administration related to undocumented patients was described as complicated and time-consuming. The complicated administration was suggested to affect the health care professionals and the patients in different ways. For the health care professionals, it could
consume time and energy from an already pressed working situation. For the patients, it could lead to the risk of delayed health care and affected treatment. However, some respondents emphasized that the actual health care in the end was not affected appreciably by this.

Administrative tasks (writing prescription) becomes more difficult, more complicated.

Not as smooth and easy for the patient, gets the health care it should but a lot of questions, administration, and take a longer time.

The lack of personal identification numbers among undocumented migrants was presented as one of the reasons that was making administration more complicated. The administration of medical records was explained as difficult, and with no identification number it was not possible to place the patient in the booking system like other patients.

They might find it difficult to relate to personal identification numbers etcetera. This make record keeping difficult.

Health care professionals’ lack of knowledge and understanding

This theme was composed of data from question 26, asking for problems the undocumented woman might face in the health care system. The respondents described how health care professionals sometimes lack knowledge and understanding about the background and prevalent situation of undocumented migrants. They are often coming from a background of traumatic events, difficult for the health care professionals to imagine and understand.

They have much experience from their native country that we cannot easily understand.

They often come from traumatic situation and are in need of a specialized care. All health care units are not prepared to treat them correctly.
Some of the answers described that health care professionals might be prejudiced against the undocumented woman, minimizing or explaining away her symptoms as only related to social conditions. Symptoms that could be signs of a serious disease would then run the risk of being explained away as related to stress.

That one assumes it is of psychiatric nature “has gone through so much”.

I think the patient’s symptoms run the risk of being understood as related to stress without investigating other reasons, since the health care system assume she is in a difficult situation.

Poor access to pharmaceutical preparations

The undocumented woman might have poorer access to pharmaceutical preparations compared to other patients. Many respondents only said “difficult to get drugs” without specifying in what way. Of those who further elaborated, a majority highlighted the economic reasons: undocumented migrants are often short of money and cannot pay for their drugs at the pharmacy.

The patient can probably not afford to take out any drugs.

Some respondents mentioned that doctors should write prescriptions on papers instead of electronic ones. However, the writing of prescriptions was not described specifically as a problem concerning the access to health care for undocumented patients.

He/she might not have any money so even if we use paper prescriptions for this kind of patient, he/she might not be able to take out the drugs?

Some of the health care professionals explained that they prescribed different pharmaceutical preparations for undocumented patients compared to other patients. The reason for this was to offer cheaper drugs that the undocumented patients could afford.

I would take the economic situation of the patient into consideration when choosing for example drugs.
Communication difficulties

Communication problems were frequently described as a potential barrier for the undocumented woman when seeking health care. Essentially, the communicative difficulties highlighted were linguistic ones. A large number of the answers were brief, only saying “confusion of languages” or “communicative difficulties”. Communication difficulties were described in both ways: from the patient to the health care professional and vice versa. From the patient to health care professionals, difficulties for the woman in making herself understood and in expressing herself, in particular when describing symptoms, were mentioned.

Language, difficult to not be able to communicate pain and anxiety, demands good interpreters.

A Swede can explain his/her symptoms in a better way, and will probably be investigated.

From the health care professional to the patient, some respondents said that they sometimes were unsure whether their information had been understood by the patient.

Does she understand the information we give?

The patient might not understand because of confusion of languages and cultural differences. I don’t think they get the time that is needed to overcome these problems.

One way to overcome the linguistic communicative difficulties is to use interpreters. This was mentioned in some of the answers. However, some problems related to interpreters were also mentioned. First, it could be difficult to find interpreters, in particular in acute situations. Second, according to the respondents, interpreters do not completely overcome the linguistic barrier, and there is often uncertainty about what the interpreter has translated and if the other part has understood correctly.
It is difficult with language and interpreters, and if information has reached the patient.

The language. Difficult to find interpreters.

Discussion

Main findings

This study aimed to investigate how Act (2013:407) is understood and applied by health care professionals in Region Västra Götaland. The aim was also to identify potential differences in health care between undocumented migrants and other individuals, as well as potential barriers to health care for undocumented migrants. This was made by a quantitative and a qualitative analysis of data from a web-based questionnaire, answered by health care professionals in Region Västra Götaland. 90% of the respondents considered that the undocumented woman had a right to health care and would offer it themselves. Four main themes were identified in the qualitative analysis: (a) No difference in health care, (b) Reduced health care for undocumented patients, (c) Factors related to undocumented patients that may affect their health care, and (d) Other factors that may affect undocumented patients’ health care.

Discussion of the quantitative results

90 % of the respondents answered that they considered the undocumented woman had a right to health care and would offer it themselves. This is comparable with previous research that have shown that 80-90% of the undocumented patients were offered health
care [22-24]. This group of respondents are probably made up of a width of underlying ideas. Some might think the woman should be offered the same health care as any other patient, while some might think she only should be offered strictly limited health care.

Some answers might be based on Act (2013:407), while some might not. These underlying ideas of the respondents are of interest and were investigated in the analysis of the free-text answers. 10 % of the respondents answered that they would not offer her health care. A majority of the respondents of this group were probably categorized to the theme “Denying health care” in the qualitative analysis.

Discussion of the quantitative results

Variation in the application of Act (2013:407)

The main themes (a) *No difference in health care* and (b) *Reduced health care for undocumented patients* provide answers to the first research question, “How is Act (2013:407) applied by health care professionals?”, by illustrating a variation in its application. Concerning the treatment of the undocumented woman in the presented case, some were suggesting to treat her as any other patient, some were suggesting to offer reduced health care, and some were describing a risk of being denied health care. This variation in treatment could lead to uncertainty among undocumented migrants and a randomness for them when seeking health care. Whether or not they will be offered health care, and to what extent, seems to depend on the individual health care professional treating them, since major inter-individual differences exist concerning how they deal with undocumented migrants. The answers of the theme *Reduced health care for undocumented patients* were frequently referring to Act (2013:407), while this rarely
was seen in theme *No difference in health care*. This might be a result of that the respondents of the former theme find a legal ground of their actions, while the respondents of the latter theme are not acting from their understanding of Act (2013:407) but on another basis. For example, some of them were referring to the principle of health care by need found in the ethical platform and in *Health and Medical Services Act*. An arising hypothesis is that Act (2013:407) is used by some as an argument to limit the health care for undocumented migrants. If this hypothesis is correct, that is in contrast with the aim of the law to widen the health care for these patients [9]. The variation concerning the treatment of the undocumented woman could be a result of a lack of knowledge about the legislation among the respondents, but it could also be a result of a legislation that is not clear in itself and therefore is offering this variation.

**Reduced health care for undocumented patients**

Psychiatric causes of the symptoms were found to sometimes be down-prioritized when it came to treatment. This is especially noteworthy since previous studies have shown a multiple higher prevalence of psychiatric illnesses among undocumented migrants compared to others [6, 12, 37]. The prevalence of depression was ten times higher, and the prevalence of suicidal thoughts and completed suicides was higher as well. The morbidity and mortality of psychiatric illnesses could be considerably high [38]. In light of these circumstances, it is remarkable that the investigation and treatment of psychiatric conditions seem to be down-prioritized.
An important aspect of the sub-theme *Denying health care* is that some of the respondents denied health care because it was not considered to be an “acute” condition. This indicates a confusion by some respondents between the ideas of *acute* health care and health care that *cannot be deferred*. According to the government and The Swedish Agency for Public Management, health care that cannot be deferred should be understood as a widening of acute health care [21]. The respondents who are equating these concepts are therefore not acting in accordance with prevalent legislation and directives.

**Undocumented patients lack of knowledge and fear of being reported**

Some of the problems that the undocumented woman might face were not related to the legislation or health care professionals, but to undocumented migrants’ lack of knowledge about the health care system and their rights as well as a fear of being reported to authorities. They therefore run the risk of not receiving health care that they have a legal right to. When examining the themes of factors related to undocumented migrants, it is of importance to remember that no undocumented migrants have answered the questionnaire themselves; these themes are the health care professionals’ thoughts about undocumented migrants. To investigate these factors from the perspective of the undocumented migrants themselves is a subject for future research.

According to the respondents, the undocumented woman might lack knowledge about her legal rights. Previous studies have shown that pressures from NGOs sometimes were necessary before undocumented migrants were offered health care in accordance with Act (2013:407) [21]. Those who do not get into contact with an NGO like these could
end up in a situation where they cannot hold their own and therefore run the risk of being denied health care that they actually have legal right to. Health care professionals’ lack of knowledge about Act (2013:407) [27], in combination with a possible lack of knowledge among the undocumented patients themselves described in this present study, could result in a denying of health care that is breaching prevalent legislation. In light of this, a need for dissemination of information to undocumented migrants to increase their knowledge about their rights appears. This is a challenge for Region Västra Götaland as well as for other county councils. It does not matter what rights the legislation is offering the undocumented migrants, as long as the targeted group are not benefitted.

A fear of being reported to authorities was described as a potential barrier for the undocumented woman when seeking or wanting to seek care. This is in accordance with previous research that have identified this as a barrier for undocumented migrants to accessing health care [12]. Previous research has also found cases where undocumented patients were reported to authorities in connection to a hospital visit [12]. In this present study the problem of actually being reported was not found as a theme – only the fear of being reported. A possible reason for this is the method chosen which was probably not suitable to capture this. This is a subject for future research, since the question whether or not undocumented migrants run the risk of actually being reported is important. If their fear is legitimate it is serious since health care professionals, according to prevalent legislation, are not allowed to report them to authorities [39, 40]. If their fear is not legitimate, a challenge appears in letting the them feel safe when seeking care.
Other factors that may affect undocumented patients’ health care

A finding in the results was that health care professionals might lack knowledge about the traumatic background and present situation of many undocumented migrants. This could be an area where the health care professionals of Region Västra Götaland need further education. Sweden is in a process of an increasing number of people from traumatic backgrounds; undocumented migrants as well as new Swedish citizens [5]. To be able to offer these people health care of good quality, which is integral to support the possibility for integration, knowledge and understanding about their background and present situation is essential.

Methodological considerations

When generalizing and drawing conclusions about the application of Act (2013:407), as is done in this report, it is of importance to remember that this study has not investigated all aspects of this issue. What has been investigated is how the respondents would deal with the undocumented woman of the fictitious case, and their thoughts about potential differences and problems for her, compared to other patients. Some of the answers could clearly be considered as illustrating the application of the law, for example those who based their opinions by referring to Act (2013:407). Other respondents were basing their opinions on other grounds, and these answers could probably not be considered as describing the application of Act (2013:407). Some of the respondents might not be familiar with the legislation. It is of importance to not draw too far-reaching conclusions, or to generalize too much, about the application of Act (2013:407) in Region Västra Götaland. The results are rather examples of different interpretations of the law by health
care professionals and could thus be a basis for educational interventions and information.

One limitation that has to be considered is the low response rate of 8.8%. A low response rate is a common problem in studies based on web-based questionnaires [41]. There is always a risk of a non-response bias in a study like this, and the impact of it is increasing with a low response rate. This might lead to a study population that is not representative for all health care professionals. Requested participants who were more interested in health care for undocumented migrants and find it important to increase the quality of their health care, might have chosen to participate to a greater extent. A non-response bias like this could lead to a result that is showing more knowledge about undocumented migrants and more positive attitudes towards offering them health care, compared to the whole population of health care professionals. When comparing the sociodemographic data between the requested participants and those who answered the questionnaire, a slightly lower response rate among women was found compared to men. Moreover, the response rate of doctors was higher compared to nurses. This is contrary to previous studies that have shown a lower response rate among doctors compared to other health care professionals [42]. A possible reason for this difference could be that doctors more than nurses consider that the question of health care to undocumented migrants concerns them. Doctors are, more often than nurses, the ones to decide whether health care should be offered or not in these situations. The lower response rate among women probably reflect the numerical dominance of women among nurses. One way to improve response rate in future web-based studies is to use incentives [28]. Financial incentives, even small ones, have been shown to be more effective than nonmonetary incentives. To be able to
offer financial incentives a budget for this is necessary, which was not the case for this present study. Another way to improve the response rate in future studies is to work more with the design of the questionnaire, to make it more easy to read and to understand [28, 43].

A weakness of the method for analysis is that the answers of all respondents were analyzed together, without any possibilities to find differences between age categories, professions, gender and working areas. Differences between these groups would be of interest to investigate, but this was not made because of limited time frame and limited possibilities with the method chosen.

This study was based on data collected as part of a previously conducted study, and this affected the characteristics of the data. The original number of 1600 respondents were more than was possible to handle within the time frames of our study and therefore a selection of 194 participants was made. Many of the answers were short and did not reveal any underlying ideas. To be able to investigate the opinions of the health care professionals in a deeper way, another kind of qualitative data should be used, such as interviews which would offer data of more depth and width. This could be an area for future research.

Even though this study has some limitations and weaknesses, it succeeded in exploring and describing health care professionals’ attitudes and underlying ideas of health care for undocumented migrants, a poorly investigated area. As a qualitative study, there was a
large number of participants, from different working areas and of different professions. This resulted in a wide and rich describing of the health care professionals’ attitudes, presenting interesting findings that could be areas for further research and be a basis for designing education and information towards the health care professionals. This study overcame parts of the problem of an implementation gap between legislation and everyday-practice, by asking the health care professionals about a concrete case. However, there could still be a gap between theory and practice among the respondents. Were they actually answering what they would do, or maybe what they hope they would do or think one should do? This could be investigated by a comparison between real cases and the fictitious case of this study, and is a suggestion for future research.

Conclusions

A clear majority of the respondents considered that the undocumented woman of the fictitious case had a right to health care, and were willing to offer it themselves. The analysis of the free-text answers illustrated a variation in attitudes to the dealing with the undocumented woman and in the application of Act (2013:407). Differences in health care between the undocumented woman and other individuals were identified: concerning medical investigation, follow-up and access to pharmaceutical preparations. A noteworthy difference was a down-prioritizing in the treatment of psychiatric causes of symptoms. Several barriers to receive health care in accordance with Act (2013:407) were identified. Many of these were not caused by legal documents, but by other factors such as undocumented migrants’ lack of knowledge about the health care system and their rights, as well as a fear of being reported.
Populärvetenskaplig sammanfattning

Sjukvårdspersonals attityder till sjukvård för papperslösa: En studie i ljuset av Lag (2013:407)


Resultatet visade att en majoritet av respondenterna ansåg att den papperslösa kvinnan hade rätt till vård, och själva skulle ha erbjudit henne det. Analysen resulterade även i att fyra huvudteman i fritext-svaren identifierades: *Ingen skillnad i vård, Begränsad vård för papperslösa, Faktorer hos papperslösa som kan påverka deras vård, och Andra faktorer som påverkar papperslösas vård.*


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References


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Fiktivt fall

Läs igenom följande text och besvara därefter på efterföljande frågor:

En 39-årig papperslös kvinna från Afghanistan söker vård på din mottagning på grund av huvudvärk, ångest, sömnproblem och magont. Kvinnan har inga identitetshandlingar och inget
uppbehållstillstånd, hon har heller inga försäkringar eller möjligheter att betala.

22. Anser du att patienten har rätt till vård?

☐ Ja
☐ Nej

23. Skulle du ge patienten vård?

☐ Ja
☐ Nej

24. Om patienten inte har möjlighet att betala patientavgiften, hur går du till väga?

(Fler än ett svarsalternativ är möjligt.)

☐ Erbjuder den vård hen behöver och överlåter åt den administrativa personalen att i efterhand göra upp om ersättning
☐ Erbjuder fri vård
☐ Erbjuder ingen vård
☐ Kontaktar ansvarig/a på min arbetsplats och ber om råd
☐ Vet ej
☐ På min arbetsplats har vi rutiner vid dessa omständigheter vilket innebär att:

25. Från ditt perspektiv, vilka är de eventuella skillnaderna gällande behandling (inklusive uppföljande behandling) för denna patient jämfört med en patient med svenskt medborgarskap och liknande symptom?
26. Från patientens perspektiv, vad tror du är de specifika problem som denna patient skulle kunna stöta på, och som skiljer sig från dem en patient med svenskt medborgarskap och liknande symtom skulle kunna stöta på?
Frågor gällande din bakgrund

27. Har du någon gång i ditt arbete handlagt en papperslös individ?
   □ Ja
   □ Nej
   □ Vet ej

31. Kön?
   □ Kvinna
   □ Man
   □ Jag definierar mig som

32. Ålder?

33. Inom vilket område arbetar du?
   □ Akutsjukvård
   □ Primärvård
   □ Psykiatri
   □ Annat:

35. Vilket är ditt yrke?
   □ Läkare
   □ Sjuksköterska
   □ Receptionist
   □ Enhetschef
   □ Verksamhetschef
   □ Annat:

36. Hur länge har du arbetat inom vården?