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Abstract

Purpose: To illuminate the experience of nurses providing healthcare to undocumented migrants in a voluntary network.

Methods and sample: In a qualitative study, semi-structured interviews were conducted with RNs regarding their experience of providing healthcare to undocumented migrants within a voluntary network. The interview transcripts were analysed using the inductive method of content analysis.

Findings: Three main categories emerged – structural inadequacy, ethical dilemmas and challenges, and personal impact and insights. The informants were driven by a strong ethical approach and a great sense of responsibility as human beings and as nurses.

Conclusion: Engaging with the voluntary network allowed the informants to cope with their frustration and feelings of inadequacy which emerged when confronted with institutionalized injustice in the conventional healthcare system.

Keywords: dilemmas, ethics, migrants, undocumented migrants, meaning, voluntary work

Introduction

Healthcare systems worldwide – often vital for refugees – face an increasing challenge to adapt to global migration (1). Reports have shown that healthcare professionals often experience increased stress when caring for undocumented migrants. Also, knowledge of the formal regulations for patients without documents and personal identity numbers is often inadequate (2–3). In most regions of the world, nurses are the main caregivers (4), and as a consequence, great responsibility is put upon them.

Refugees seeking asylum in Sweden enter a process that can end in one of two ways: either the asylum seeker is granted asylum (i.e., recognized as a refugee by law) or the person is rejected (5). The term *undocumented migrant* refers to a refugee who unlawfully resides in Sweden and hides from the authorities to avoid deportation. This is most commonly the result of the rejection of their application for asylum (6). The number of undocumented migrants residing in Sweden today is estimated at between 10,000 and 35,000 (5).

Undocumented migrants as a patient group are vulnerable – they suffer a greater risk of poor physical, mental and social health than legal citizens (7). This vulnerability can be directly traced to factors such as their insecure legal status and poor social conditions (1). In

addition, the lack of a personal identity number threatens patient safety, impairs the quality of care, and increases the risk of malpractice because of insufficient documentation due to the lack of a personal identity number (2).

Furthermore, the constant fear of deportation has been proven to cause prolonged stress which also results in serious health consequences (8). Research shows that the fear of deportation inhibits undocumented migrants from seeking healthcare (9). A Swedish study in 2005 found that 67% of the respondents (undocumented migrants) perceived the risk of being arrested to be very or extremely high when seeking healthcare (10).

In most countries, healthcare offered to undocumented migrants is limited to emergency care (1). Therefore, to be attended, the undocumented migrant patient has to wait for a less serious condition to become serious enough to be treated in emergency care. Chronic diseases like cancer, diabetes, high blood pressure, heart conditions and more are not necessarily counted as acute. However, if left untreated, they will turn into life-threatening conditions (6).

In an American study by Asgari and Segar (11), two main categories were identified as barriers to seeking healthcare for refugees. The first is *internal barriers*. Examples of internal barriers are a fatalistic view of one's life, feelings of guilt and shame surrounding one's condition or status, the fear of being deported, and not knowing one's rights. The second category is *structural barriers*. Examples of structural barriers include the price of treatment, the lack of continuity, the lack of an interpreter, and cultural misunderstandings. The results of their study is confirmed in the British study by Bhatia and Wallace (12) and an Australian study by Omeri et al. (13).

Assuming that all humans are equal due to their human nature, one must conclude that the right to health is a universal right (4). The Universal Declaration of Human Rights includes the right to health for all (1), and the concept of 'the right to health' can be found in various international treaties and at least 100 national constitutions (4). A common counter-argument is that the mere presence of undocumented migrants in the host country is a crime, and thus, the state has no obligation to offer equal healthcare. This is an empty argument because a criminal human being shares the same right to healthcare as any non-criminal human being. The general acceptance or passivity regarding the substandard healthcare offered to undocumented migrants is based on the assumption that undocumented migrants are not equally human (14).

Advocating social justice has been a cornerstone of nursing practice since the birth of the profession (15). Nursing is a holistic social practice, with the prevention of illness

regarded as fundamental as curing illness. In line with this, the International Council of Nurses concludes that the need for healthcare is universal and that healthcare must be provided equally (16).

To hide from the authorities to avoid deportation is illegal in Sweden, but this is not legally penalized (17). Further, it is not illegal to aid an undocumented migrant with healthcare, food and shelter. However, to voluntarily disclose information of an undocumented migrant's whereabouts to the authorities is a violation of the ethical codes of all health professions which can lead to prosecution (17–18). Healthcare professionals are confronted daily with choices by which the lawfully desirable choice does not correspond with the ethically desirable one (19).

In July 2013, just over a year before this study, a new law regarding undocumented migrants' right to healthcare in Sweden was put into effect. According to the fifth paragraph, undocumented migrants should be offered healthcare on the same conditions as refugees in the asylum-seeking process. Paragraph seven specifies the healthcare undocumented migrants are entitled to: 'treatment that cannot be deferred' (see next paragraph), maternal healthcare, abortion healthcare and contraceptive advice (20).

A majority of Swedish healthcare organizations have collectively rejected the practical utility of the concept of 'treatment that cannot be deferred' because it poses a great risk to patient security and is not consistent with medical ethics. Which treatment can be deferred and which cannot is an ethical dilemma that falls on the individual healthcare professional in a specific situation. To be forced to make a decision between the law and ethics has shown to cause great stress for healthcare professionals. In line with this, the Swedish Board of Health and Welfare has concluded that to prioritize treatment on criteria other than medical need is unethical (2).

The laws regulating access to healthcare for refugees rests upon and maintains the idea that the refugees are responsible for their precarious situation. Therefore, the healthcare offered to this patient group is often considered charity or generosity from the state. However, according to the Universal Declaration of Human Rights, the state holds a medical responsibility to all persons residing within its borders (1).

According to Barnes (15), the responsibilities of nurses can be divided into private responsibility (towards individual patients and patient groups) and public responsibility (to serve the common good by influencing politics, etc.). The International Council of Nurses (ICN) states that nurses are expected to advocate politics that prioritize the healthcare needs of vulnerable groups (16). Nurses have the unique opportunity to influence

the political agenda. They can turn political attention towards vulnerable groups because the knowledge and insight they hold gives them the opportunity to help bureaucrats raise public awareness and form opinion. Also, the value of anecdotes as a political tool that puts a face on the debate should not be underestimated (21). Dogan et al. (22) conclude that nurses and the state share the responsibility to initiate and participate in action that meets the healthcare needs of the entire society, especially those of vulnerable groups.

Voluntary networks providing healthcare to undocumented migrants have existed in Sweden since 1995 (17). These voluntary networks consist of volunteer nurses, physicians, dentists, interpreters and physiotherapists who have no political or religious affiliations. Globally, humanitarian NGOs like these voluntary networks increasingly act as alternative caregivers as a reaction to the state's failure to take responsibility (8). In 1998 one such voluntary network was established in Gothenburg. Though some of the voluntary networks in Sweden have been shut down after a new law increased the right to healthcare for undocumented migrants, the network in Gothenburg is still active and is open once a week – every Wednesday night since 2008 – and in collaboration with the Red Cross. The healthcare they provide consists mainly of support and information, and only minor medical issues are treated. However, what distinguishes these patients are the many Post Traumatic Stress Disorder (PTSD) cases and serious medical conditions left untreated for previously stated reasons.

The purpose of this study is to illuminate the experiences of nurses providing healthcare to undocumented migrants in a voluntary network. Most studies on healthcare for undocumented migrants focus on the refugees' experiences (11–13). However, this study aims to contribute knowledge and insight regarding healthcare for undocumented migrants by examining the opinions and experiences of active volunteer nurses.

Method

Conducting interviews was considered the most appropriate form of survey for investigating the opinions and experiences of nurses giving healthcare to undocumented migrants in a voluntary network.

Sample

The participants were nurses with experience of working in the voluntary network in Gothenburg. An overview of the participants' general characteristics is shown in Table 1.

Table 1. Participants' characteristics

Via email, a description of the study and an offer to participate was sent to all nurses active in the voluntary network. This was sent a few weeks prior to the interviews, and a gatekeeper was used. One week prior to the interviews, another email was sent out to remind possibly interested participants of the study. This method generated four participants.

To increase the number of participants, the gatekeeper then provided names and contact information to a few nurses who the gatekeeper thought would be interested in participating, but who had not yet agreed to participate. These nurses were then contacted by phone. This method generated another three participants and resulted in seven participants in total.

Data Collection

Interviews were scheduled in the participants' home town of Gothenburg after an approval to conduct the study was obtained from the head of the unit at the voluntary network. The first author (in association with a nurse) participated in the interview phase, both attending each interview but with the shifting roles of active interviewer and passive listener. The data was recorded and transcribed continuously during the interviews.

The participants chose the location of the interviews. One interview was conducted in the participant's home, one was in a group study room at a hospital, and the rest were conducted in facilities provided by the Red Cross Foundation. The length of the interviews varied from 16 to 45 minutes. This was due to the participants' varying inclination to speak freely.

The participants were provided with an informative letter describing the purpose of the study before each interview. Thereafter, any questions from the participants were answered verbally, and letters of consent were signed. The interviews were semi-structured with ten open, pre-prepared questions to ensure essential topics were covered (23). The semi-structured interview method was chosen because it allows the participants to interpret the open questions freely (23). The questions concerned the informants' background, personal reason for working at the clinic, their general perception of conventional healthcare for undocumented migrants, and possible differences between their work at the clinic and in the

conventional healthcare system. In addition, they were asked to remember specific events, whether good or bad, and whether they felt safe working at the clinic. They were also asked if they felt content with the healthcare they provided. Follow-up questions were added to the prepared questions when deemed necessary, and clarifications were also provided when needed. The interviews were promptly recorded and transcribed after each session.

Data analysis

The transcripts were analysed by the first author, according to inductive content analysis by Elo and Kyngäs (24) and Graneheim and Lundman (25). First, each transcript was read through separately. Thereafter, notes made up of words, theories or short phrases summarizing what was said were made in the margins of the transcripts. The notes were then compiled onto a blank sheet. Over time, a list of categories began to appear in this overview of overlapping (or similar) notes. These categories were refined and reduced in number in collaboration with the last author, bearing the process of the data collection (the researchers' accounts of the interviews) in mind. As a result, the refined categories became the seven subcategories presented under 'Findings'. The subcategories were then merged into three main categories, and each main category was assigned a colour. The transcripts were read again, but this time with the main categories in mind. Data that fell under a main category was marked with the assigned colour. The colour-coded material was then sorted under each main category, enhancing reliability and ensuring that the categories were correctly interpreted (see Table 2 for an example).

Table 2. Example of analysis

Ethical considerations

Prior to the interviews, the participants received verbal and written information regarding the purpose, methods and consequences of the study. The confidentiality of all data, the optional nature of participating (i.e. the ability to discontinue participation at any time), and that all data would be anonymized after the transcription process were emphasized.

Bias and subjective influence were prevented by asking as open and neutral questions as possible (23). Confidentiality was pursued by handling quotations with the

utmost caution in order to avoid statements being tracked to a specific person. The recorded data was kept on a USB device which was safely stored.

Findings

The following table is a presentation of the three main categories and seven subcategories which emerged from the analysis. The statements building the categories are exemplified with quotations.

Table 3. Result with main categories and subcategories

Structural inadequacy

The opinions of the informants varied in regard to the organization's formal structure. Informants who had been with the organization longer spoke of the weekly reception nights as well-organized events, while informants who had been with the organization for less than a year perceived these nights as chaotic and stressful.

...because there are a lot of people, the tempo is high, and it's... it's kind of organized chaos. And I feel that there is organized chaos in healthcare generally.
(Informant A)

Limits in the organization

The most significant difference between the informants' regular healthcare jobs and the work at the clinic turned out to be issues regarding patient safety and ensuring quality.

There are so many things missing. And the documentation is all on paper, so things can be missed, drug lists aren't complete /.../ So if you're to see it from a patient safety perspective, it's like two different worlds. Who guarantees the quality? Who sees to that? It is hard to do in a voluntary organization to the same extent. (Informant G)

The limited financial and material resources of the clinic was brought up as a reason for feelings of inadequacy, discontentment and stress. Further, due to lack of space and limited

time, intimate conversations between patients and nurses often took place in the noisy and crowded waiting room. As a result, continuity and feedback with a patient was perceived to be nearly impossible.

More than healthcare

Caring for undocumented migrants proved to be challenging for the informants because the health problems the patients suffered from are often a direct result of their precarious situation: “It’s somewhere between a cough and a residence permit” (Informant A).

Although the informants were pleased that there was something they could do to help, the frustration that there was so little they could do was equally present.

Ethical dilemmas and challenges

It was apparent that all of the informants were motivated by the strong belief that undocumented migrants live under unjust demands, and the state is failing to ensure their human rights.

The challenge of being dedicated

Undocumented migrants are a group – a patient group that do not receive the healthcare they should, and I think they should have it. And when society doesn’t take responsibility for it, volunteers have to. (Informant D)

The informants felt compelled and eager to do whatever they could. They considered it their duty as human beings to engage, and their competence as nurses allowed them to actually do something to help. The voluntary network functioned as a venue for this.

Caring in practice

Caring for undocumented migrants at the clinic is different from caring for patients in the conventional healthcare system. When caring for this patient group, the informants felt that they need to be more supportive. They also felt a duty to create greater feelings of safety and

calmness and made a greater effort to meet with the patients to ensure they felt seen and heard as they had their symptoms checked.

The situation of being an undocumented migrant doesn't change with healthcare. It can only be somewhat mitigated. (Informant C)

Further, the possibility and importance of showing a welcoming attitude was emphasized.

Personal impact and insights

Caring for this patient group was perceived to be more demanding and required more from the nurses than in regular healthcare situations. Some of the informants felt that the work at the clinic was somewhat terrifying because their personal responsibility and the pressure of doing a good job felt greater.

Challenges of working as a nurse in a voluntary network

I've been wanting to work here for a long time, but it hadn't felt like a good idea until now, after I got some nursing experience, because it's really independent and a big responsibility. It's important that nothing goes wrong. (Informant F)

Almost all of the informants expressed feelings of personal inadequacy. It was hard for these healthcare professionals when they often could not offer necessary healthcare to the patients.

Understanding the situation of the undocumented migrant

Maybe it's not always about them needing healthcare. It's more about the meeting... Of course it's about informing [them], but also about [them] being seen and having someone to talk to. (Informant B)

The informants spoke of their experiences at the clinic as eye-opening and fulfilling. Meeting these patients gave them insight into the undocumented migrants' lives and their conditions. This was heavy to bear, but at the same time, it was something they talked about with genuine positivity.

Emotional responses

The insights and increasing knowledge of the conditions undocumented migrants live under was something that affected the informants in many ways.

I had a tuberculosis patient. He had been previously admitted to hospital and was undergoing treatment, but was homeless now. He had spent the last two nights sleeping outside, and I was scared because I felt that this was going to go so terribly badly. (Informant E)

Several conflicting feelings emerged during the interviews: the respondents' sense of connection and fellowship were matched with great concern for the patients' real possibility of getting better.

Discussion

The results of this study show that the informants had developed a strong ethical approach and a great sense of responsibility towards their patients – a responsibility they took on as fellow human beings and nurses. Rassim (26) confirms that taking responsibility is an aspect of the profession that nurses highly value, and this signifies strong ethical feelings regarding their profession. As human beings, the motivation for the informants was empathy and political frustration. Also, as nurses, they have the perception that engaging in the voluntary network is a natural part of the profession – “because I am a nurse, I can and should do this.” This falls in line with the result of Rassim's study (26), where, through interviews with nurses, he explored their feelings about their profession. The nurses interviewed expressed a great sense of responsibility regarding the patients – stronger than the feeling of responsibility towards the profession or the institution where they worked.

The informants felt that the responsibility for the undocumented migrants' healthcare was theirs, which Berlinger and Raghavan (9) confirm is what happens when society lacks supportive functions. Tiedje and Plevak (8) conducted a study in America where they interviewed healthcare professionals who volunteered at a clinic for undocumented migrants. Their results correlated well with the results of this study: the sense of responsibility was expressed as “It is my duty as a fellow human being to give back” and “I work here out

of compassion, but also for humanitarian reasons”. It appears as though the sense of responsibility, although a heavy burden, is experienced as something positive by the voluntary nurses. The nurses in this study highly value the ICN code of ethics for nurses when they actively work to counteract suffering.

More than one reason accounts for why the informants perceived that their volunteer work affected them more than the work in their regular jobs. Caring situations that did not go according to plan or turn out perfectly were hard for them to shrug off. Also, the caring situations that did turn out according to plan were problematic because the informants knew that the situation the undocumented migrants would return to would not be safe. Caring for undocumented migrants was proving to be harder than caring for patients who have a home and social stability (18). Social justice has been an integral part of nursing since the days of Florence Nightingale (15), and it was obvious that the informants experienced strong feelings of inadequacy at the realization that the problems facing these patients cannot be solved with healthcare. The Social board of Sweden (2) and Doctors of the World (3) both found that caring for undocumented migrants leads to increased stress on healthcare professionals, which this study strengthens.

The ethical dilemma the informants face when working at the clinic is, in itself, an emotional burden. Tschudin and Davis (4) defined an *ethical dilemma* as the experience of a demand that cannot be met in full nor avoided. This also proved to be accurate in the results of this study. The demand was expressed as a will to do more than ‘just healthcare’, while all of the informants concluded that they had no real possibility to do more. However, despite knowing they could not do everything, they could not refrain from doing something.

Moral anxiety is defined (4) as the suffering of a person who is aware of a moral issue, takes responsibility for the issue, and makes a moral judgement of which action to take, but is then forced (by real or perceived limitations) to participate in morally wrongful behaviour. A common way of dealing with the pain produced by moral anxiety is to limit who is included in one’s moral community; for example, to limit the feelings of responsibility to only the people closest to you or the patients in front of you. The informants in this study deal with their moral anxiety in a completely different way: they choose to include every person in their moral community. The only reasonable conclusion for this is that, even though it is more demanding, they feel it is worth it.

The sense of purpose from working at the clinic was primarily due to three reasons: the fellowship of meeting others who are equally engaged in social justice, that the work at the clinic was a counterbalance to their regular jobs, and the satisfaction that although

they can not do everything, at least there is something they can do. Tiedje and Plevak (8) stated that the fellowship that volunteers experience is grounded in the unification of their shared moral ambition to fill the void created by politics.

Although the informants felt inadequate, they still expressed gratitude and satisfaction in this way of engaging. For the ethically oriented and responsible nurse, it is a practical impossibility to wait for society's slow wheels of bureaucracy to find satisfactory solutions for vulnerable groups (9). Tschudin and Davis (4) further state that a sense of meaning arises, despite the feelings of inadequacy, because the satisfying feeling of 'I can do something' is stronger.

Methodology considerations

In order to increase credibility, heterogeneity among the informants is crucial. It allows for different perspectives in the field to be enlightened (25). This study included seven informants – five women and two men – with ages ranging from between 28 and 34. The homogeneity of this group was estimated to be a representation of the nurses who volunteered in the voluntary network and therefore considered satisfactory. However, given that the gatekeeper partially selected the participants, there is a risk of selection bias.

The analysis was conducted by the two authors. This increases the credibility of the results because the perceptions of both were taken into consideration and were thoroughly processed (26). To give the reader an opportunity to follow the categorization, quotes are presented in the results along with the themes and categories.

According to Graneheim and Lundman (25), there is always a risk of the alteration of decisions and considerations during the analysing process. The data of this study is clearly influenced by the low structured interviews: different follow-up questions result in different data. Strong opinions regarding the conventional healthcare offered to undocumented migrants emerged during the interviews, and great frustration was apparent among all of the participants. However, these political opinions were excluded from the results of this study because they are deemed not relevant to the purpose of the study.

The transferability of a qualitative study can be suggested, but in the end, this is something for the individuals to decide for themselves (25). Several findings in the data were reoccurring, which suggests that they may be transferred to comparable situations.

Conclusion

The purpose of this study is to illuminate the experiences of nurses providing healthcare to undocumented migrants in a voluntary network. The informants who participated in the study were all motivated by an ethically strong approach and a great sense of responsibility. In the conventional healthcare system, they suffered from not being able to carry out their professional duties as they wished. Further, they witnessed vulnerable undocumented migrants being denied the healthcare they needed and were entitled to. This suffering motivated them to act by engaging in voluntary work which allows them to channel their frustration and gives them a sense of fellowship and a strong sense of purpose. The feeling that there was not much they could do stood in contrast to this, but did not hold them back.

The results of this study prove that there is a way to deal with the frustration and feelings of inadequacy which emerge when a person is confronted with institutionalized injustice within conventional healthcare. Also, feelings of hopelessness can be lessened through acting in accordance to one's beliefs while, at the same time, hoping that society will move in the same direction.

The institutions that train nurses have the possibility and responsibility to prepare future nurses to better deal with and navigate through the increasingly globalized world of today. Education that emphasizes the need for reflection will increase the awareness of individual nurses regarding personal values and cultural perspectives which emphasize the need for social justice, responsibility and global ethics. This is absolutely necessary to avoid moral suffering and to prevent illness within all patient groups.

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