EXPERIENCES OF GÖMDA IN SWEDEN:

EXCLUSION FROM HEALTH CARE FOR IMMIGRANTS LIVING WITHOUT LEGAL STATUS

Results from a survey by Médecins Sans Frontières

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Médecins Sans Frontières (MSF) is a medical humanitarian organisation, working in more than 70 countries across the world. Guided by the principles of medical ethics, MSF's focus is to support people in danger who for whatever reason do not have access to health care, regardless of race, religion, politics, or sex. MSF's work involves provision of direct medical care and raising awareness of the plight of the people we help.

Acknowledgements

MSF wishes to thank all individuals who participated in and helped with the drafting of this report. We thank Börje Andersson who helped with the data collection and Helena Harcourt who helped with translations. We thank Allen Keller from the Bellevue New York University (NYU) Program for Survivors of Torture and Annette Gerritsen from the VU University Medical Centre, Amsterdam, who generously shared their experience of similar studies and allowed MSF to use modifications of their questionnaires (1,2) and translated versions of Hopkins Symtom Checklist-25 (HSCL-25). We thank Hans Peter Söndergaard from the Centre for Torture Survivors, Stockholm, Ingvar Karlsson from the Rosengrenska Association and Solvig Ekblad, Karolinska Institutet and National Institute for Psychosocial Medicine for their analysis and comments on the results of the HSCL-25 questionnaire. We especially thank Sally Hargreaves, from the International Health Unit, Imperial College, London, UK for doing the preliminary analysis of the health and social questionnaire survey data and contributing to the write up and editing of the final report.

EXECUTIVE SUMMARY

Immigrants living without legal status in Sweden face major barriers to accessing health care. This group comprises individuals who have had their claims for asylum in Sweden rejected and immigrants who have never claimed asylum. None have the required documents to reside in Sweden and therefore live without legal status. A general term used to describe this group in Sweden is gömda, meaning "hidden". Médecins Sans Frontières (MSF's) experiences to date, and those of others who provide support to gömda in Sweden, indicate that these individuals are often vulnerable and marginalised with little support and face barriers to accessing appropriate health care.

Swedish legislation only allows for provision of "immediate health care" for gömda, which translates to provision to urgent care at an Emergency department in a hospital. Gömda are completely excluded from accessing primary health care or maternity care in most cases. There is no cost-reimbursement scheme for hospitals that care for gömda. Gömda have to bear the full cost of any treatment and medicine they receive, which in Sweden is often expensive and largely unaffordable to gömda without an income. Because of gömda's own fear of being reported to the police when visiting healt care facilities, and being subsequently sent back to their home country, they are often reluctant to approach health care facilities despite having health needs.

"I WOULDN'T EVEN DARE GO NEAR A HOSPITAL... THE FIRST THING THEY ASK YOU AT A HOSPITAL IS FOR YOUR IDENTIFICATION NUMBER."

In the absence of a formal national system to meet the health needs of this group through public health services, a number of non-governmental organisations (NGOs) provide medical support to gömda in Sweden on a voluntary basis. MSF has been assisting gömda in the Stockholm area since January 2004. During a 22-month period (January 2004-October 2005), 1 157 medical consultations were provided by a volunteer network of over 50 doctors, midwives, physiotherapists, nurses and psychologists to gömda who needed medical care and treatment.

In light of the current lack of data on the health and social needs of this group in Sweden, the MSF team ran a questionnaire survey of 102 patients between July and September 2005 who had used the MSF's service, in order to assess the key barriers to health care that gömda face, and more fully understand their social situation. In addition, we carried out a mental health questionnaire survey on 23 patients.

Although the sample size is relatively small, dominant themes have emerged from the data. Through the findings of the questionnaire surveys, and MSF's experiences to date providing medical services to gömda patients, we present in this report a picture of the health and social situation of this group in Sweden.

"I wouldn't even dare go near a hospital. If they catch me they will arrest me. The first thing they ask you at a hospital is for your identification number – if you don't have one they ask you lots and lots of questions.

Woman, age 28 years, from Africa

Key findings

- 82% of respondents reported facing barriers to health care in Sweden. These included *physical barriers* to accessing health care, as a result of high costs for medical consultations and medication or being refused care due to lack of valid documents, and *indirect barriers* stemming from fear of approaching services and being dissuaded from seeking care depite having health needs.
- The majority of respondents reported deterioration both in their physical health (65%) and mental health (64%) since living in Sweden without legal status.
- The respondents were diagnosed with a broad range of diseases including severe and chronic diseases such as asthma, tuberculosis and diabetes, all of which required them to access health care and medication.
- 63% of the respondents were women with specific health needs. 12 were pregnant and required antenatal check-ups.
- 67% of respondents reported that they felt their risk of being arrested by authorities at a hospital was either "quite high" or "extremely high", with 68% of respondents reporting that they felt extremely fearful of returning back to their country of origin. 53% reported that they would be killed or seriously injured if returned to their country of origin. This acted as a deterrent to gömda to approaching public health services despite health needs.
- Prevalence of clinically significant depression and anxiety was very high among the 23 respondents to the mental health questionnaire survey. These findings highlight the poor mental health status of gömda.
- 77% of respondents reported that they were dependent on other people since they were unable to support themselves exclusively on their income in Sweden. Many expressed concern that they would be unable to afford medical consultations and medication at public health services.

"I have been several years in Sweden. We came from Serbia during the war, through a refugee camp in Eastern Europe - with my wife and 2 children. However, we eventually failed our asylum claim in Sweden and are now hidden refugees. We asked a friend if we could stay with him for a few days. We ended up staying but were living in the cellar underneath the house with no windows and cement walls covered in mould. When Swedish people came to visit they were in shock when they saw it and how we lived. We spent almost 2 years living there."

Man, age 36 years, from Former Yugoslavia

The failure on the part of the Swedish government to recognise gömda as a patient group has led to the near total exclusion of these individuals from accessing non-emergency and routine health care in Sweden at this time. This research describes 102 patients with a variety of medical needs for which they could not access medical care and medication, including serious chronic diseases and pregnancy. This is a testimony in itself to gömda's exclusion from health care.

The absence of a legal framework and implementation guidelines to ensure that the health needs of this group in Sweden are met, and lack of government cost-reimbursement schemes at health care institutions, leads to difficult and improvised admission procedures at services. Public health services perceive gömda to be synonymous with loss of income. This inturn leads to stigmatisation and discrimination, and reluctance and fear by gömda to approach health care services. The health-seeking behaviour of gömda is greatly influenced by the disproportionate high costs for basic consultations and medication at health services. MSF's survey findings indicate that gömda tend to not seek care at all or delay seeking necessary health care.

MSF's recommendations

- *The Swedish government must provide a legal framework to allow access to health care for gömda at public health services in accordance with international human rights standards.*

- *The cost of health care and medication must be subsidised for gömda patients.*

- *The government must set up a cost-reimbursement scheme for health care services treating gömda patients.*

PART 1: CONTEXT

a) Immigration: Europe and Sweden

According to the International Organisation for Migration (IOM) one in every 35 people around the world is an international migrant (3). International migrants comprise a wide variety of groups – including asylum seekers, refugees, and migrant workers. In 2004, Sweden received 23 161 individual claims for asylum (4), which is high both in real numbers and per capita in comparison with other European Union (EU) countries. The same year, 4 318 asylum applicants were given a permanent residency permit in Sweden (4). However, only 372 (1.2%) of asylum applicants were given refugee status on first instance in 2004 (5).

In recent years there has been a dramatic increase of migrants residing without a legal status in the EU. Although there is little data available on the size and the needs of this group, it is estimated that between 120 000 and 500 000 people per year enter the EU by irregular means and the numbers are rising (6). The IOM estimated that in 1998 almost 3 million migrants without legal status live in Western Europe (6).

Migrants without legal status in Sweden comprise individuals who have had their claims for asylum in Sweden rejected (referred to internationally as failed asylum seekers) and immigrants who have never claimed asylum. None have the required documents to reside in Sweden and therefore live without legal status. A general term used to describe this group in Sweden is gömda, meaning “hidden”. This term will be used throughout this report. The exact number thought to be residing in Sweden is unknown; however, the Swedish Police Department has in their system approximately 15 000 individuals who are known to have failed their claim for asylum and are possibly residing without legal status in Sweden (7). Of the 405 gömda who presented to the MSF service between January 2004 and October 2005, by far the majority (75%) were failed asylum seekers.

The fight against illegal immigration is now a priority for EU Member States and policies directed towards this group have become more restrictive in nature (6). There has been considerable discussion between several EU countries which might lead to further restrictions regarding the access to and use of public services by illegal immigrants, particularly with respect to health services.

b) Access to health care

On arrival, there is evidence to suggest that both asylum seekers and migrants without legal status may well be relatively healthy; however, health is known to deteriorate over time. This may be as a result of the asylum process itself, or the poor socioeconomic situation they may find themselves in within their new host country (8,9). Illegal immigration in particular has been associated with poor health (3) and failed asylum seekers are considered to be a group with significant health needs (10).

Sweden and other EU Member States recognise the right of everyone to the “enjoyment of the highest attainable standard of physical and mental health” (11). Countries such as Belgium, France, Italy and Spain have set

up a legal framework that gives people without a legal status access to free or subsidised public health services. However, in practice, the legal entitlement does not always translate to provision of services.

In Sweden, there is no legal provision for free or subsidised health care for gömda. This applies equally to gömda as it does to tourists and temporary visitors to Sweden. According to the Swedish Health and Medical Services Act (12), local County Councils are obliged to offer "immediate health care" to everyone present in Sweden. MSF has not found any official definition or implementation guidelines as to what level of care "immediate health care" implies, leaving it up to each hospital manager to set the standards at each health care facility. Neither is there a government-financed cost-reimbursement scheme for the health care facilities providing medical care to gömda. Public health services therefore perceive gömda to be synonymous with loss of income, and are reluctant to treat this patient group. According to the organisation PICUM (Platform for International Cooperation on Undocumented Migrants) Sweden is among the most restrictive countries in the EU with respect to access to health care for individuals without legal status (13).

MSF's experiences indicate that when gömda do present themselves to public hospitals with an urgent or immediate health need (such as a heart attack or to deliver a baby), they are obliged to pay the full cost of their care and medication but will not be refused the treatment they require. However, many hospitals are reluctant to admit gömda with less urgent health problems, even though the presenting health need might have serious medical consequences if left untreated. Primary health care centres rarely accept gömda patients. Maternity centres will admit gömda but normally after advance payment in full, which in our experiences show is often unaffordable for most gömda.

For gömda, health care and medication will be charged at full cost, which is disproportionately higher than for Swedish nationals ***(Panel 1).***

Consultation/ medication type	Costs for Swedish nationals	Costs for gömda and tourists
Consultation with a doctor at an emergency department	260 sek* (27 euros)	2 000 sek (209 euros)
Consultation with a doctor at a primary health care clinic	140 sek* (15 euros)	1 400 sek (146 euros)
Consultation with a midwife at a Maternity centre	0 sek	500 sek (52 euros)
Delivery	0 sek	21 000 sek (2 197 euros)
Insulin treatment for diabetes (type 1)	1 800 sek (188 euros) per year**	13 200 sek (1 381 euros) per year

Panel 1: *Examples of charges for consultations and medication in Sweden.*

** Maximum cost for care over 12 months is 900 sek (94 Euros) regardless of what type of care is received.*

*** Maximum cost for all drugs for a 12 month period.*

Note: prices can vary between different health care institutions.

Gömda children who have previously been asylum seekers are entitled to full access to health care and dental care, with the same degree of entitlement as a Swedish national. However, gömda children who have not previously applied for asylum are not covered by the law and are only entitled to ”immediate care” at full cost (14). In MSF's experience, however, hospitals generally provide free care to all children whatever their status.

In addition, health services are accessible to asylum seekers who are still in the asylum process (14), including primary health care, maternity care, and continuous treatment for severe chronic diseases.

The anonymity of gömda who present to health care services is protected under Swedish law (15), and health care staff are not permitted to report gömda patients to the authorities. However, health care staff are obliged to respond to the police with basic yes/no answers when asked whether a particular individual is present at the hospital at that time (16).

c) Who assists gömda with health needs?

In light of the barriers to health care faced by gömda in Sweden, several non-governmental organisations (NGOs) and individual health care staff at public services provide health services specifically for gömda on a voluntary basis, services that run parallel to the public health care system. This parallel system relies on the goodwill, support, and hard work of a small number of professionals. The geographical coverage and the services offered, however, are limited. Funding for diagnostic tests such as radiographs, blood tests or ultrasound, for example, as well as emergency care and specialist care, has proved a particular obstacle for both NGOs and health care staff.

The four main medical networks supporting gömda in Sweden are:

- Médecins du Monde (MDM) in Stockholm (since 1995)
- Rosengrenska Foundation in Göteborg (since 1998)
- Delta Foundation in Malmö (since 2000)
- Médecins Sans Frontières in Stockholm (since 2004)

MSF's involvement began in January 2004, after an initial assessment that confirmed the health needs of gömda were not being met. The project was set up in Stockholm, a city with probably the highest concentration of gömda. MSF's project is now supported by a volunteer network of more than 50 specialist doctors, midwifes, and other health professionals who work within public and private health services. To access services, gömda contact the MSF project via a nurse-led telephone advice line. Where appropriate, the MSF nurse will arrange a consultation with the appropriate medical professional within the volunteer network. The consultation occurs at the regular working place of the volunteer staff, usually outside of normal working routines.

PART 2: RESEARCH

a) Methodology

The research was carried out over a 2 month period (July to September 2005) and involved carrying out two surveys: a questionnaire survey on health and social needs; and a mental health questionnaire, the Hopkins Symptom Checklist-25 (HSCL-25).

Respondents were either new patients or patients who had previously presented to the MSF network for medical assistance and who voluntarily agreed to participate. Respondents were selected from a complete list of all patients to the service, and all who were contactable were asked to participate. All patients gave their consent to take part in the survey with the agreement that their responses would remain anonymous and confidential. The MSF team administered the survey with the assistance of an interpreter where necessary.

102 gömda completed the first questionnaire on health and social needs. This questionnaire covered three main areas:

- basic demographic details;
- family and social situation in Sweden and in their home country;
- health experiences in Sweden - including health status, medical needs and barriers to health care.

The HSCL-25 questionnaire, which is a commonly used tool for indicating anxiety and depression (17), was used to determine the clinical levels of anxiety and depression of the respondents. Only new patients and for whom appropriate translations of the form were available (Arabic, English, Persian, Spanish and Swedish) were chosen to take part (23 respondents). Questionnaires were translated, back-translated and culturally adapted. The questionnaire was completed by respondents themselves and involved respondents answering questions with respect to their mental health status during the past week.

In addition, six gömda recounted their personal stories through in-depth interviews with an MSF researcher, excerpts of which are included in this report.

b) Respondent demographics

102 respondents completed the health and social questionnaire survey of whom 80 (78.4%) had previously claimed asylum but had been rejected. The remaining 22 (21.6%) respondents reported that they were living in the country without the necessary legal documentation.

Age and civil status

The average age was 35.3 years. No children under the age of 18 years completed the study. The majority of respondents were women. 48 (47.1%) respondents were married and among those, 30 (29.4%) of 102, were living with their spouse in Sweden ***(Table 1).***

Family composition

45 (44.1%) respondents had children under the age of 18 years. 50 (49.0%) reported having no children (situation unclear for remaining 7 respondents). Of the people with children, 36 (35.3%) had children living with them in Sweden ***(Table 1).***

Sex/civil status/ family composition	Number of respondents
Women	64 (62.7 %)
Men	38 (37.3 %)
Married	48 (47.1 %)
Living with spouse in Sweden	30 (29.4 %)
Has children under the age of 18 years	45 (44.1 %)
Children living with them in Sweden	36 (35.3 %)

***Table 1:** Sex, civil status and family composition*

Countries of origin

Respondents were from 34 different countries in the following regions ***(Table 2).***

Country/region of origin	N (%) of respondents
The Middle East (including Iran, Iraq, Turkey)	38 (37.3 %)
South and Central America	20 (19.6 %)
Former Soviet Union	18 (17.6 %)
Africa	13 (12.7 %)
South, East and Central Asia	7 (6.9 %)
Former Yugoslavia	6 (5.9 %)

***Table 2:** Country/regions of origin of respondents*

Time in Sweden

Respondents reported that at the time of the questionnaire survey, they had spent on average 3.6 years in Sweden. They reported having lived as gömda, without legal status, for an average 1.2 years.

c) Self-reported health status

66 (64.7%) of 102 respondents reported that their physical health status had deteriorated during the time that they had lived without legal status. 40 (39.2%) reported that their physical health deteriorated a lot, 28 (27.5%) reported it had stayed the same. 7 (6.9%) reported an improvement in their physical health (1 did not respond).

With respect to mental health, 65 (63.7%) of 102 reported a deterioration in their mental health. 48 (47.1%) felt that it had deteriorated a lot since they lived without legal status. 29 (28.4%) reported that their mental health had stayed the same, 6 (5.9%) noted an improvement (2 did not respond).

d) Medical needs

Of the 102 respondents, 14 (13.7%) were helped by MSF to access public health centres or hospitals. The remaining 88 (86.3%) were consulted within the volunteer MSF network. Respondents reported a variety of health problems to the MSF team and were subsequently referred to different specialists ***(Figure 1).***

37 consulted a general practitioner: 11 were diagnosed with abdominal disorders. 9 people had respiratory tract problems, including asthma. One respondent suffered from the effects of a suicide attempt in country of origin, and one had tuberculosis. Other problems included heart problems and diabetes.

18 women required treatment from a gynaecologist. 12 women needed maternity care. Of the 2 women who already delivered at the time of writing, 1 specifically mentioned having to pay off a bill of 21 000 SEK (2 260 Euros). 5 people were tested at a clinic for the treatment of sexually transmitted diseases (STD).

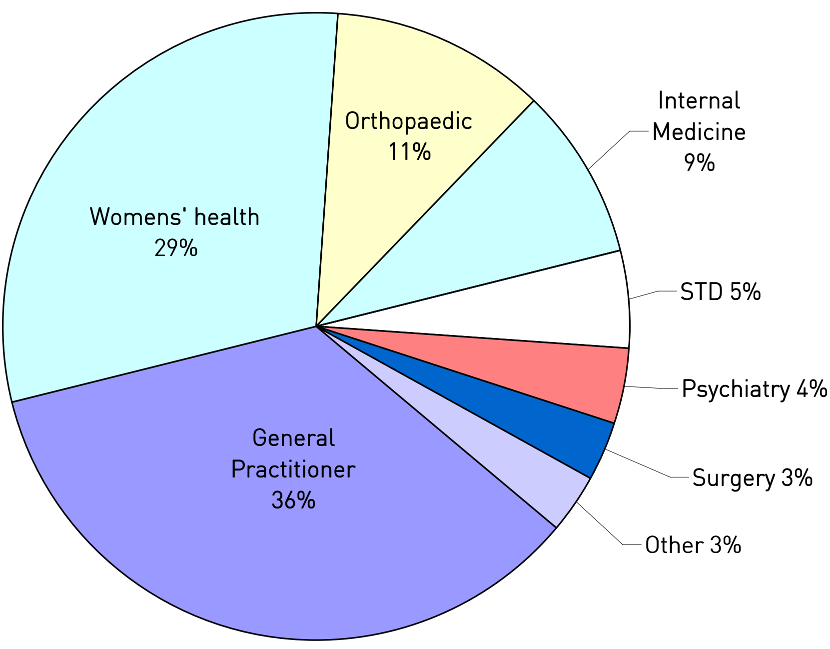


Figure 1: Referral services required by respondents

The 9 respondents requiring referral to specialists in internal medicine presented with a variety of serious problems, including un controlled diabetes, Graves disease (a thyroid disorder), partial paralysis, check up of a former ventricle cancer and suspected Chrone's disease (a disease causing inflammation of the small intestine). 3 patients who had severe cardiovascular disorders needed referral to a cardiac specialist. Most of the patients in this group are dependent on regular medical treatment and required follow-up care.

3 respondents required elective surgery that was facilitated by MSF. Of the 11 respondent requiring referral to orthopaedic specialists, 3 reported heavy physical work as the cause of their problems.

4 respondents were seen directly by a psychiatrist. Referrals directly to a psychiatrist are low because there is a lack of volunteer psychiatrists within the MSF network for whom to refer such patients.

e) Mental health status

23 respondents completed the Hopkins Symptom Checklist-25 (HSCL-25) questionnaire. Respondents answered to questions pertaining to levels of anxiety and depression and suicidal thoughts on a scale from 1 (not at all) to 4 (extremely) and values were calculated as an average per person. The threshold of 2.75 was used as a cut-off score to indicate diagnosis.

An analysis of the internal consistency or reliability of the completed questionnaires was made using the Cronbach's Alpha test, which indicates that the sampling was reliable with a good margin[a]. The findings from this study were compared with those of similar studies ***(Table 3)***. However, in light of the small sample size, comparisons with other studies should be made with caution.

Study	Anxiety	Depression	Moderately high level of suicidal thoughts	Extremely high level of suicidal thoughts
MSF's questionnaire survey of gömda in Sweden	47.8 %	56.6 %	23.8 %	14.3 %
Refugees from Iraq residing in Sweden (18)	32.1 %	29.8 %	7.1 %	7.1 %
Survey among Swedish participants (19)	5.3 %	5.5 %	1.2 %	0.7 %

Table 3: *Comparison of MSF's findings with other relevant studies*

[a)] *Values for Chronbach's alpha test were 0.856 (anxiety) and 0.853 (depression). A value above 0.8 is generally considered reliable.*

Findings from the HSCL-25 questionnaire indicate that the prevalence of depression was ten times higher than among Swedish participants and twice as high as that reported in a study of recently settled Iraqi refugees in Sweden. In addition, gömda showed high levels of suicidal thoughts compared with data from the other two studies.

"I see my wife suffering a lot from stress and trauma – she has chest pain and other stomach pains, back pain and really many things, I think she has taken all our stress over the time since we became refugees. I too lost weight and I was feeling so bad. I was so tired, I couldn't do anything and my voice used to shiver. It's a strange feeling – I felt like I had lost all of my power. I passed through all of that, but my wife didn't and tried to kill herself. But I hope things are getting better now."

Man, age 36 years, from Former Yugoslavia

18 of 23 respondents reported having sleeping disorders. 5 respondents specifically reported nightmares and/or sleeping less than 4 hours per night, which is indicative of post traumatic stress reactions. Such reactions may be related to their experiences both in their country of origin and their experiences in Sweden. Data from the health and social questionnaire survey indicate that many gömda reported traumatic experiences in their home countries. 69 (67.6%) respondents reported that they felt extremely fearful of being sent back to their country of origin, with 54 (52.9%) reporting that they were at risk of being killed or seriously injured if they were sent back.

f) Barriers to health care

55 (53.9%) of the respondents reported that they had not attempted to visit a doctor since becoming an illegal resident in Sweden. However, of this group 47 (46.1%) reported that they needed health care and medication but that they were deterred from approaching services because of a variety of barriers to care ***(Table 4)***. 46 (45.1%) of the respondents had attempted to approach health services, of whom 37 reported barriers to accessing appropriate health care (one did not respond) ***(Table 5).***

The majority 84 (82.2%) of the respondents experienced either physical barriers to accessing health care, such as being refused care, or indirect barriers to accessing care including being too afraid to approach a hospital.

Indirect barriers to care	Response n (%)
Fear of approaching services	25 (24.5 %)
Felt they were not entitled to seek care	13 (12.7 %)
Costs for consultations and medication	9 (8.8 %)
Total	**47 (46.0 %)**

***Table 4:** Indirect barriers to health care*

Physical barriers to care	Response n (%)
Charge for consultations and medication	14 (13.7 %)
Refused care by front-line staff at health care services	9 (8.8 %)
Other barriers to accessing care	14 (13.7 %)
Total	**37 (36.2 %)**

Table 5: *Physical barriers to health care*

Health seeking behaviour of those who were deterred from seeking health care

47 (46.1%) respondents reported being deterred from seeking health care ***(Table 4):***

- 25 (24.5%) of respondents reported that fear of approaching services an being reported to the authorities acted as a deterrent to seeking health care.
- 13 (12.7%) reported that they felt they were not entitled to seek health care and therefore did not approach services despite health needs.
- 9 (8.8%) respondents reported that the high costs of medical consultations and medication, which they could not afford, acted as a deterrent to approaching services despite having health needs.

"One day during winter, my daughter had problems breathing. It was late at night and I really didn't know what to do. I called a member of the Church and he said that regardless of how much it would cost, we had to get to a doctor. However, I didn't feel comfortable going to the hospital. I was so afraid that people would ask for my identification and would expel us straight away. I tried some syrup for my daughter and she felt a bit better. Although the member of the church told me to go, I never went to see a doctor because I was too afraid."

Woman, age 28 years, from Africa

The majority of the respondents 68 (66.7%) perceived a high risk of being reported to the authorities and being expelled from Sweden if they approached hospital services and were identified by front-line staff as gömda patients. 5 (4.9%) respondents reported that they knew personally of a close friend or a family member who had been arrested by the police either at the hospital or soon after the visit.

"I have a friend who went to hospital – he needed psychiatric care – he had no identification and when he could not identify himself to the staff the hospital called the police. He was arrested and put into detention in Stockholm - we had to get in touch with his lawyer for him as no-one could find him. He was in prison for 1 week and then deported. I'd say all illegal migrants are afraid of using health services because of stories like this."

Man, age 40 years, from the Middle East

"Many of the medical staff are willing to treat these patients if they come with medical needs. The problem comes from the system itself which makes it very difficult for patients to get further through and access medical staff. These people are treated like criminals; in Sweden, we all have prejudices against this group."

Nurse, hospital in Stockholm

Experiences of gömda who sought health care

37 (36.3%) of respondents encountered one or more of the following physical barriers to accessing health care ***(Table 5):***

- High costs of consultation and medication: 14 (13.7%).
- Refused care when unable to provide required documentation: 9 (8.8%).
- Other barriers: 14 (13.7%), which included difficulties or delay in accessing a doctor or specialist, and difficulties in accessing dental treatment. Two people reported having used someone else's national identification card in order to get attended.

"I needed urgently to go to hospital but it is hard in Sweden without papers – I get upset talking about it. I know it is their job at the reception desk to check you, but I feel so let down as I needed help at the time but they just refused."

Woman, age 30 years, from the Middle East

g) Socioeconomic situation

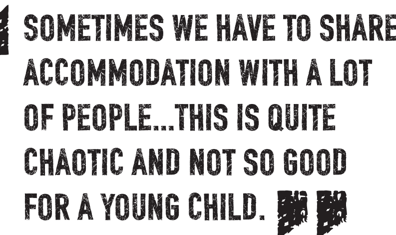
Respondents reported living in poor and precarious socioeconomic conditions. Gömda lack any form of social provision in Sweden and are not legally entitled to work.

"These people often live in a very bad situation in Stockholm. Many have nothing to go back to, however and some are very afraid of going back for various reasons. They are living here in cramped conditions, very excluded from mainstream society, and they experience a lot of stress and uncertainty about their future. They live in basements of apartments waiting for a job and trying to live a normal life but in destitute conditions".

Daniel Calero, Advisor on refugees and integration,
Diocese of Stockholm, Church of Sweden

Housing and employment

63 (61.8%) reported that neither they nor their partner could pay for housing in Sweden and were therefore reliant on friends, relatives, NGOs or members of religious associations for accommodation. Accommodation is usually overcrowded, short-term, and many respondents reported frequently moving around from house to house. Respondents reported working in irregular and part-time jobs. A large number of respondents reported having no income from work at all.



"I work 4 hours a day 5 days a week at 30** sek **(3.2** euros **) per hour. Gömda take any work to support their families. It is not easy to find work here – especially if you don't know how to speak Swedish ".

Woman, age 30 *years, from the Middle East*

Social provision and debt

78 (76.5%) reported that they were unable to support themselves exclusively on the income they received during the past month. 36 (35.3%) reported currently living in debt in Sweden. Debts ranged anything from 2 000 sek (209 Euros) to 75 000 sek (7 845 Euros). Respondents reported being in debt for a variety of reasons, including as a result of paying smugglers for travel documents and the journey to Sweden, and the payment of large hospital bills.

"My 4-year old daughter and I are completely alone here. I have no family here to help me. The Church supports me with clothes, housing and food – I don't know what I would be without them. Sometimes we have to share accommodation with a lot of people (2 or 3 people in a small bedroom). Every morning, the Church tells me where I can stay – sometimes 3 times a week or sometimes every day we move to the new house or flat with all our belongings. This is quite chaotic and not so good for a young child. She doesn't sleep well some times, she doesn't like all the people and sometimes becomes quite withdrawn."

Woman, age 28 years, from Africa

h) Summary of findings

This report is an attempt to highlight the key issues relating to the current health and social situation of gömda in Sweden. The key findings from the research are:

- 82% of respondents reported facing barriers to health care in Sweden. These included *physical barriers* to accessing health care, as a result of high costs for medical consultations and medication or being refused care due to lack of valid documents, and *indirect barriers* stemming from fear of approaching services and being dissuaded from seeking care depite having health needs.

- The majority of respondents reported deterioration both in their physical health (65%) and mental health (64%) since living in Sweden without legal status.
- The respondents were diagnosed with a broad range of diseases including severe and chronic diseases such as asthma, tuberculosis and diabetes, all of which required them to access health care and medication.
- 63% of the respondents were women with specific health needs. 12 were pregnant and required antenatal check-ups.
- 67% of respondents reported that they felt their risk of being arrested by authorities at a hospital was either "quite high" or "extremely high", with 68% of respondents reporting that they felt extremely fearful of returning back to their country of origin. 53% reported that they would be killed or seriously injured if returned to their country of origin. This acted as a deterrent to gömda to approaching public health services despite health needs.
- Prevalence of clinically significant depression and anxiety was very high among the 23 respondents to the mental health questionnaire survey. These findings highlight the poor mental health status of gömda.
- 77% of respondents reported that they were dependent on other people since they were unable to support themselves exclusively on their income in Sweden. Many expressed concern that they would be unable to afford medical consultations and medication at public health services.

Bisra and her family went into hiding after having their asylum application rejected in Sweden.

DISCUSSION AND RECOMMENDATIONS

Key barriers to health care for gömda in Sweden

The failure on the part of the Swedish government to recognise gömda as a patient group has led to the near total exclusion of this group from accessing non-emergency and routine health care in Sweden at this time. This research describes 102 patients with a variety of medical needs for which they could not access medical care and medication, including chronic diseases (diabetes and asthma), communicable diseases (sexually transmitted diseases and tuberculosis) and pregnancy. This is a testimony in itself to gömda's exclusion from health care.

The absence of legal framework and implementation guidelines to meet the health needs of this group in Sweden and lack of government cost-reimbursement schemes at health care institutions leads to difficult and improvised admission procedures. Some respondents were refused care when failing to present the necessary documents. Many other experienced difficulties or delay getting seen by a doctor.

MSF's experience to date shows that access to care at primary health care clinics in particular by gömda is extremely difficult. The alternative, seeking care directly at an emergency department is extremely costly. The health-seeking behaviour of gömda is greatly influenced by the disproportionately high costs for basic consultations and medication at health services. At a minimum it costs 2 000 SEK (209 Euros) for a basic medical consultation, which is much higher than the cost paid by a Swedish national. In light of their often precarious socioeconomic situation, the high costs acts as a major deterrent to gömda to approaching public health services.

The absence of any legal system to ensure access to services for gömda not only creates physical barriers but also leads to stigmatisation and discrimination of this patient group. Our research highlights that gömda in many cases do not even attempt to seek care, even when they have a medical reason to do so. The most common reasons for this are the high costs and their fear of being reported to the police by health-care staff and subsequently deported. Five respondents reported that they knew someone personally who had been taken by the police either at the hospital or soon after the visit. Such incidences may be the result of front-line staff contacting the Swedish immigration department with billing questions or the result of staff incorrectly believing that they have a duty to report gömda patients. MSF acknowledges that a high level of fear is prevalent among gömda, but that fear of approaching health care services is exacerbated by the discrimination they face at services due to their lack of recognition within the system.

Health implications

The majority of the respondents required referral to a general practitioner in the first instance. The fact that gömda are excluded from accessing primary health care services is therefore of concern. The lack of access to primary health care could have implications for their health status, particularly for individuals suffering from chronic diseases such as asthma and diabetes who need access to

continuous treatment. The problem is compounded by the fact that gömda tend to not seek care at all or defer seeking care until the last moment. In addition, detecting illnesses and medical problems at an early stage may lessen the risk of patients presenting in a worse state of ill health at emergency services, and requiring more costly in-patient care.

12 pregnant women in this study did not have access to antenatal check-ups prior to delivery. Lack of pre-delivery care means that the women are being excluded from routine national screening programmes, which could result in detrimental consequences for the mother and the child, for example mother to child transmission of infectious diseases and complications during delivery. MSF's experiences to date show that gömda are only able to attend Maternity Centres if they pay prior to the appointment taking place so many are reluctant to present to the service until the day of delivery.

The unwillingness of adults to approach health care services means that parents will also be reluctant to bring their children. Gömda children only have legal rights to access health care if they have been in the asylum process. No gömda children took part in this study; however, MSF's work to date has highlighted that many children are conditioned to the legal status of their parents; as a result, several of MSF's clients have avoided accessing medical care, and have therefore missed out on routine immunisations and other national childhood health initiatives.

The mental health questionnaire survey indicated high levels of depressive disorders and anxiety among this patient group. MSF's work has highlighted that gömda are fearful of being returned to their home country, fearful of approaching health services, and that a life hiding from the authorities in precarious conditions is extremely stressful. This undoubtedly impacts on their health status.

Key recommendations

- The Swedish government must provide a legal framework to allow access to health care for gömda at public health services in accordance with international human rights standards.
- The cost of health care and medication must be subsidised for gömda patients.
- The government must set up a cost-reimbursement scheme for health care services treating gömda patients.

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