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Exploring childhood immunization among undocumented migrants in Sweden - following qualitative study and the World Health Organizations Guide to Tailoring Immunization Programmes (TIP)

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ABSTRACT

Objectives: National vaccination coverage in Sweden is high. Recurrent outbreaks of measles and rubella however highlight some immunity gaps in the population. Current knowledge about immunization status of undocumented migrant children is scant. The World Health Organization/Europe has developed the Guide to Tailoring Immunization Programmes (TIP) to assist countries in diagnosing barriers and motivators to vaccination in communities with low vaccination coverage. Based on the TIP guide, the objective of this study was to explore determinants to vaccination among undocumented immigrants, using qualitative approach.

Study design: The study consisted of three steps: (i) an initial workshop for problem statement; (ii) qualitative research for increased understanding of the vaccination practices of children in the undocumented community; and (iii) a second workshop to incorporate the qualitative interview findings together with data from key stakeholders into a conceptual framework.

Methods: This was a qualitative study featuring interviews of seven undocumented parents recruited at non-governmental clinics, three nurses at Child Health Centers, and information from key stakeholders retrieved at workshops as part of the TIP process.

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Results: The content analysis revealed two main themes: parental fear of being questioned and parental acceptance of child immunization. Undocumented parents had a positive view and attitude toward childhood immunization but expressed strong fear of being asked for identification papers at healthcare facilities. Owing to lack of knowledge on entitlements of the undocumented among health personnel, parents were incorrectly rejected when seeking care for their children. Frequent mobility among undocumented may limit access to complete the immunization schedule. Undocumented parents mistrust healthcare providers and avoid health facilities, further delaying childrens' access to health care, including immunization services.

Conclusions: The findings of this study confirm the complexity of barriers that undocumented parents face regarding childhood immunization. The TIP guide offers a valuable process for a deeper understanding of the determinants of immunization challenges among undocumented migrants.

Introduction

Immunizations are one of the most efficient public health measures for preventing disease, saving more than 2.5 million lives worldwide each year.[1] In 2017, 21,315 cases of measles were reported in the World Health Organization (WHO) European region.[2] An estimate of 700,000–1000,000 infants born yearly in Europe do not receive all childhood immunization and pockets of low immunization coverage have been documented.[3] Across Europe, migrants of all categories and status face significant barriers in access to health care. Legal restrictions have been documented as the most significant barrier.[4] The majority of the European Union (EU) countries lack regulations on migrant immunizations.[5] Research and data are scarce regarding the immunization coverage among migrants and in particular the undocumented migrants' experience on access to immunization services. A search for original articles published between 1985 and 2018 in PubMed, Scopus, and Web of Science, using keywords including 'undocumented', 'migrants', and 'vaccination', was conducted. Studies retrieved were mainly of quantitative nature and covering topics such as recommendations, policies, and immunization strategies targeting immigrants. No qualitative studies that included the perspective of undocumented migrant's attitudes toward childhood vaccination was found.

Sweden sustains a high and stable vaccination coverage for the second dose of measles, mumps, and rubella (MMR) vaccination among children aged 2 years, above the recommended (95%) by WHO.[6] The Public Health Agency of Sweden (PHAS) is responsible for national coordination of the surveillance and prevention of communicable diseases including monitoring the national immunization program (NIP). The NIP is offered free of charge, and the county councils and municipalities are responsible for the implementation through the Child Health Centers (CHCs) and School Health Services. Reported outbreaks of measles caused by imported cases indicate local pockets of susceptible individuals. Between 2012 and 2015, there were 30, 51, 26, and 22, respectively, cases of measles reported in Sweden.[6]

The number of refugees living in Sweden has increased in the years 2014–2015, granting residence permits to more than 209,000 asylum seekers during the last 5 years (2014–2017).[7] Undocumented migrants refer to third-country nationals without a valid permit authorizing them to reside in an EU Member State.[8] It is a heterogeneous group of individuals of different backgrounds, legal status and origin, and in Sweden mainly composed of rejected asylum seekers. In 2010, the undocumented community was estimated at 10,000–35,000 people, including 2000–3000 children.[9] Currently, the community is growing owing to the high number of rejected asylum applications. In 2000, a Parliament regulation was passed granting asylum-seeking and most groups of undocumented children the same rights to medical, health, and dental care as resident children. A law about health care for individuals without permission to stay in the country was passed in July 2013,[10] which expanded this right to all undocumented children and introduced the right to health and dental 'care that could not be deferred' for undocumented adults. Undocumented migrants are extremely vulnerable, often living under precarious conditions with limited access to health care.[11] Owing to fear of being disclosed and deported, information about living conditions is scarce. A general view among non-governmental organizations (NGOs) and individuals working with undocumented migrants is that the majority live in the three largest cities and particularly in suburb areas inhabited with many migrants characterized by a low socio-economic standard. Undocumented migrants may thus be more exposed to vaccine preventable diseases (VPDs).

In Sweden, all asylum seekers are offered health screening free of charge, including an evaluation of their immunization status. Between 2011 and 2016, an average of 60% of adults accepted the offer of health screenings. By law, child health services and school health services are obliged to offer complementary immunization to children up to 18 years of age.

Evidence before this study

Vaccination is one of the most important public health interventions for preventing diseases. While it represents one of the most cost-effective healthcare investments available and contributes significantly beyond health, reducing poverty, and offering economic and social benefits to the whole of society, some population groups are missed by such a lifesaving intervention. Reaching and vaccinating these vulnerable populations is of critical importance in delivering universal health coverage and assuring equitable access and utilization of immunization services.

The South-North migration flow to Europe during the last few years has raised questions about possible suboptimal vaccination coverage among the migrant population and their susceptibility to vaccine-preventable diseases endemic to some European countries.

Current knowledge regarding the immunization status of undocumented migrant children is scarce. A search for original articles published until 2018 in PubMed, Scopus, and Web of Science, using keywords including 'undocumented', 'migrants', and 'vaccination', was conducted. Studies retrieved were mostly of quantitative nature based on surveys of Public Health Authorities and mainly covering topics such as recommendations, policies, and immunization strategies targeting immigrants. We found no qualitative studies that included the perspective of undocumented migrant's attitudes toward childhood vaccination.

Added value of the study

The aim with our study was to explore undocumented migrants (parents) views, attitudes, and experiences on childhood immunization, using a qualitative approach and *the Guide to Tailoring Immunization Programmes (TIP)*, developed by the WHO Regional Office for Europe. The TIP guide presents a process to diagnose barriers and motivators for vaccination in communities with low vaccination coverage. TIP promotes the use of multiple information sources, performing qualitative research studies, review of the literature as well as incorporating additional information from experts and stakeholders through engaging workshops.

The study highlights that despite perceived risk of diseases and an intention to vaccinate, undocumented migrant parents face barriers, related to their social and legal status, that restrict their access to health services and result in them not vaccinating their children.

Implications of the available evidence

The systematic approach of the TIP guide and way of analyzing and presenting qualitative findings facilitated the understanding of the barriers and motivating factors to childhood immunization.

TIP helped create an integral and contextual situational analysis that went not only beyond a conventional background characteristics and individual profiling but also considered the legal, structural, administrative, and financial obstacles beyond the influence of the healthcare community.

Our findings suggest that there are numerous structural barriers that undocumented migrants faced at different levels with regard to childhood immunization. Findings also confirms the complexity of barriers which potentially will affect the future health of undocumented children. Improving access for undocumented immigrants requires additional and specific efforts to restore trust in the health system and better communicate migrant parent rights to health care.

Based on our experience, the TIP guide is a valuable tool for deeper understanding of factors influencing vaccination decision-making among vulnerable and hard-to-reach communities such as undocumented migrants.

Most children eventually enroll in primary school, where the vaccine coverage has been high (>95%) among students in grade 6.[6]

The European Region remains committed to achieving the goals of the European Vaccine Action Plan (2015–2020).[1] The WHO European Regional Office (WHO Europe) has developed the 'Guide to TIP', offering a step-by step process through which to identify underserved populations with lower immunization and to better understand their barriers and motivators to vaccination.[12–14] The TIP process consists of two phases: a formative phase to get a thorough understanding of the situation and to clarify a problem statement; and a second phase that entails designing of interventions, implementation and evaluation. TIP is underpinned by behavioral science methods and social marketing models and takes into consideration the context of social determinants explored from several perspectives.

This study is part of a larger project using the TIP approach, piloted by the PHAS in Sweden in 2013, in reaching unvaccinated and undervaccinated children in three communities; the anthroposophic,[15] Somali,[16] and undocumented migrants. This study explored barriers and motivators to childhood vaccination among undocumented immigrants.

Methods

TIP guide steps

It was designed according to the formative research phase of TIP, consisting of three steps: (i) an initial workshop to define the situation and problem statement; (ii) qualitative study for increased understanding of the vaccination practices of children in the undocumented community; and (iii) a second workshop to incorporate the qualitative interview findings together with data from key stakeholders and into a conceptual framework.

i. Workshop one to define the problem statement

A 2-day stakeholder workshop, hosted by PHAS and WHO, was held to apply the TIP diagnostic framework in Stockholm. Specific objectives were to share and gather information on the current immunization situation and system, conduct a Strengths, Weaknesses, Opportunities, Threats (SWOT) analysis, create a common understanding of the steps of the TIP approach, and review current knowledge regarding the MMR vaccination status and social and health-seeking behavior determinants of the undocumented community in Sweden. The highly participatory workshops were facilitated by WHO and involved a broad range of partners and key stakeholders including representatives of the PHAS, ECDC Health Communications Unit, Karolinska Institute, Regional Preventive Child Health Services, Stockholm County Council, and the WHO Europe. Notes were taken during the workshops to summarize the findings. A consensus on a problem statement and the methodology of the following parts of the project were reached at the end of the workshop.

ii. Qualitative study design

Setting and participants

Individual in-depth interviews with seven parents and three child health nurses were conducted. The undocumented parents with preschool children (<7 years) were recruited through purposive sampling in close collaboration with clinics serving undocumented immigrants in Stockholm and Gothenburg, Sweden. The parents came from six different countries, Africa, South America, Asia, and the Middle East, and the majority were former asylum seekers being undocumented for less than 3 years. They were recruited either through announcement in pamphlets, by direct invitation by the healthcare providers or by the author (K.G.R.) assisted by a volunteer at the NGO clinics. Information about the study and the invitation to participate were provided in English, Spanish, Mongolian, Dari, and Russian and posted in the waiting room at the Red Cross clinic in Stockholm. In Gothenburg, the information was given orally by the healthcare providers.

Three CHC nurses working in areas with a high proportion of immigrants were also included in the study. They were recruited with the assistance of senior Public Health Pediatricians in Stockholm and Gothenburg.

Data collection

A semistructured interview guide was developed, based on the problem statement and conclusions from the first TIP workshop, including exploring experiences of child immunizations, attitudes, barriers, and motivators to vaccination and access to health care. Interviews were held in locations and time points chosen by the participants. Each interviewee gave their informed consent, either written or orally. It was emphasized that participation was voluntary and that the information would be confidential and anonymous. Data were collected from May–August 2013 by first author (K.G.R.), and saturation was reached with seven parents where no additional information was forthcoming. All three nurses available in Child Health Centers serving undocumented families were interviewed. Interpreters were used for all interviews with parents, except for Spanish and English. Interviews with nurses were conducted in Swedish.

Data analysis

The process of data analysis was performed in a sequential way: firstly, content analysis of the qualitative interviews, followed by a second workshop where the qualitative findings and data obtained from key informants and stakeholders were all mapped onto a conceptual framework. All interviews were audio-recorded, transcribed verbatim, then reviewed, and analyzed using content analysis.[17] Once transcribed, texts were read through several times by the author to obtain a sense of the material. The data were analyzed using Swedish and English: the initial coding was done in Swedish, except for the single interview conducted in English. The texts were coded and related to different topics. All codes were translated to English by K.G.R. to analyze with A.K. Afterwards, codes were grouped into themes. The developed themes were refined.

iii. Workshop two for mapping process

A second stakeholder workshop was subsequently held with the research team to discuss the research findings and identify possible evidence-based solutions and interventions. This included a description of parental profiles, mapping of parental motivators and barriers to vaccination, communication needs, and preferred channels, as well as an understanding of their key influencers, facilitators, and relationships with healthcare providers.

Additional information of the contextual aspects was obtained from the key informants present during workshop 2—an interdisciplinary group with broad knowledge represented by vaccine experts, senior pediatricians, health communicators, stakeholders at the county councils, researchers as well as volunteers and care providers working at nongovernmental clinics serving undocumented immigrants.

Table 1 – Summary of themes and categories.

Theme				
Parental fear of being questioned			Parental acceptance of childhood immunizations	
Fear of being detected	Difficulties in immunization follow-up	Distrust overriding the knowledge of rights	Vaccine acceptance	Knowledge of importance of vaccines

The additional information along with the results of the qualitative interviews of the parents were combined by the research team into a conceptual framework in terms of facilitators and barriers for childhood immunizations, using the illustrative profile of bubble maps included in the TIP guide.[14]

Ethical considerations

The study received ethical approval for the interviews from the Regional Ethics Committee in Stockholm, Sweden, Dnr 2013/678–31/3.

Results

Results are presented in two sections; first, findings from the qualitative interviews with themes and categories (A) (see Table 1), followed by the conceptual mapping according to TIP (B) (see Figure 1).

A. Qualitative study findings

Parental fear of being questioned

Fear of being detected

Fear of being asked of their legal status or being identified were always present, affecting the everyday life of the undocumented families and children. Parents expressed a strong sense of fear of disclosure when seeking health care for either their children or themselves. Some had previously sought healthcare services for adults while others had never dared to seek as an undocumented migrant.

> I'm so scared and so ashamed that I don't have a residence permit. It's difficult to seek health care. I'm always so scared because I have no address, I'm afraid of what will happen and I feel constant fear of being discovered. (Parent).

The nurses commented that many families are afraid of visiting healthcare facilities because of lack of trust in the health staff based on their previous experiences, despite knowing that CHCs would welcome them. One nurse commented that it may take several visits before a family dare to reveal their legal status. The parents often stated that they were waiting for their papers or gave different reasons for not having documents.

The nurses pointed out that they cannot ask too many questions at once, and they have to assess the situation carefully to not scare the families away once they visit the CHC. Parents mentioned different ways of keeping their children healthy to try to avoid attending healthcare clinics such as using homemade herbal remedies, teaching their children proper hygiene, keeping them from playing with water and getting wet, or simply praying for them.

> I try to keep an eye on them so they don't get sick. I teach them good hygiene; it should be clean so they don't get germs. (Parent).

Difficulties in immunization follow-up

The families move frequently because of their illegal status, which complicates the follow-up of children's health and immunization status at the CHCs. The nurses observed that many undocumented children had incomplete vaccination histories and individualized schedules. The greatest challenge for the nurses was to get the parents to come to the centers for follow-up visits. Some parents, however, did choose to travel far to visit the same CHC where they felt safe. Mostly, parents who keep in contact with the CHC often complete the immunization schedule.

Parents generally had no detailed knowledge of the immunization program, but they tried to follow the schedule and trusted the health professionals' guidance. Parents mentioned that their children had been vaccinated, either in their country of origin or in transit. Some parents had more detailed information on which immunizations their children had received. Others just knew that the children were vaccinated and had received what they needed according to schedule.

> I know they have received vaccines against measles, rubella and hepatitis in country X. (Parent).

Distrust overriding the knowledge of rights

In the spring of 2013, the degree of entitlement to health care varied depending on whether or not the undocumented parents had previously applied for asylum. Parents expressed awareness of their children's entitlement to health care. However, when they sought health care for their child at primary healthcare facility, they had (incorrectly) been turned away because of lack of personal identification papers (ID). They expressed not trusting the nurses to provide them access to care, either because of rumors or their previous experiences.

> The children have the right to go to the hospital for treatments even if they don't have the permit or a phone number. But if I go to the hospital, they tell me to bring an ID. (Parent).

Parental acceptance of childhood vaccines

Vaccine acceptance

All parents expressed gratitude for their access to childhood immunizations. They gladly accepted old and newly introduced vaccines in the NIP. Most parents were familiar with mandatory NIPs in their home country and used to be called for childhood vaccination. Consequently, the question whether to choose to vaccinate or not was never raised at CHCs.

Parents were mainly concerned that their children would develop high fever after immunization and needing medical attention. Some parents were also worried about the pain associated with the injection.

My girl was born here. There is no vaccine that I have declined. I've always been very careful to vaccinate. (Parent).

Knowledge of importance of vaccines

Parents were aware of the importance and benefits of immunizations, although they mainly wanted to vaccinate their children to keep them healthy, avoid diseases, and thereby avoid seeking health care. Nurses reinforced that awareness and knowledge of the importance of immunizations was high among undocumented migrants. Some were also aware of the risks associated with childhood diseases. According to the nurses, many families come from countries where they knew of people who had died from a VPD. Many undocumented families, however, have large difficulties in their everyday lives, therefore the visits to the CHC are not something they prioritize, as the child gets older.

In the past when there were no vaccines, many got measles and died. With vaccines they get a milder disease. (Parent).

B. Conceptual mapping

The conceptual mapping was based on both the qualitative findings and additional information from the key stakeholders and experts, which together was used to visualize parental enablers and barriers to immunizations (Fig. 1). The vulnerable situation of undocumented parents was highlighted as a barrier for vaccinations at different levels. Overall, parents' attitudes to vaccinations or the intention to vaccinate are facilitating factors whereas the uncertain social situation results in low prioritization of vaccination. Consequently, the parents seem to be facing a structural problem rather than barriers at the individual level regarding acceptance of vaccinations.

Discussion

Knowledge about immunization status of undocumented migrant children is limited, and qualitative studies on the topic is even more scarce. To our knowledge, our study is the first qualitative study aiming to explore undocumented parents' views, attitudes, and experiences on childhood immunizations.

Attitudes to immunization

Lack of knowledge and negative attitudes toward immunization for parents have previously been identified as a major determinant for child underimmunization generally.[18] The findings in our study revealed that undocumented parents had a positive attitude to immunization and believed that immunization was beneficial for their child's health. The parental attitudes were therefore not considered a barrier for

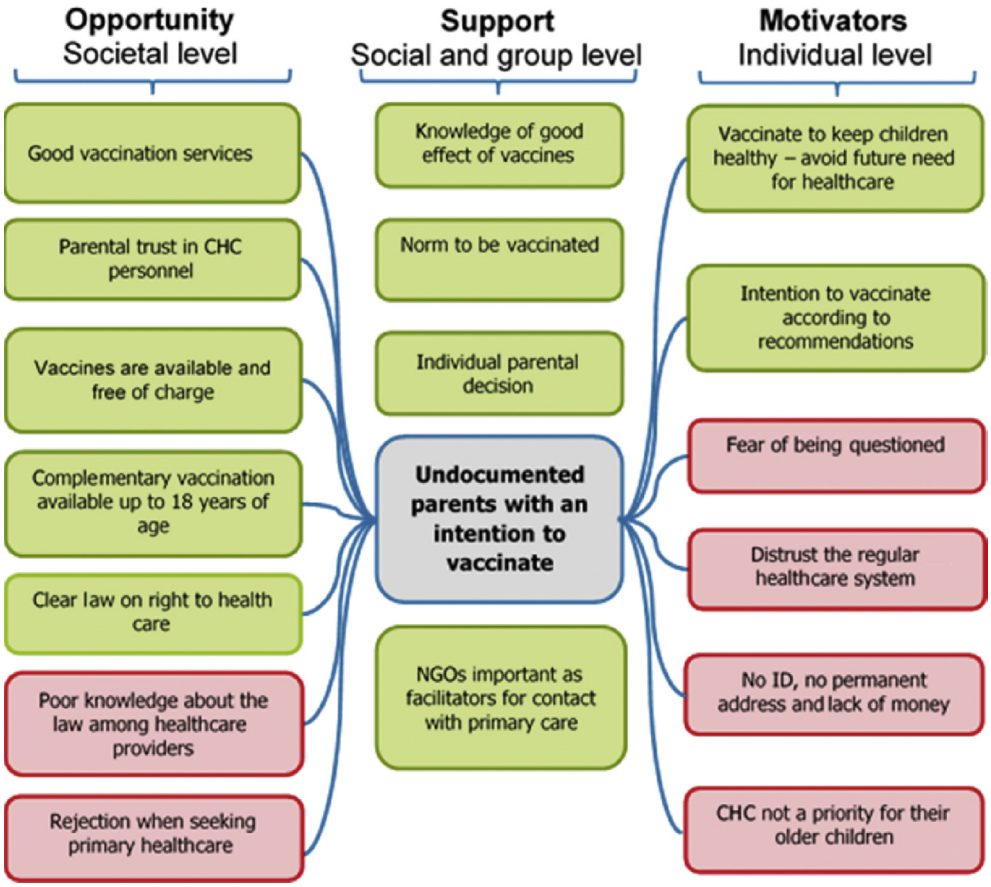

Fig. 1 – Conceptual map indicating barriers (red) and motivators (green) for undocumented migrant parents with an intention to vaccinate their children. CHC, Child Health Centers. (For interpretation of the references to colour in this figure legend, the reader is referred to the Web version of this article).

child immunization. Further, healthcare providers have often been identified as an important factor in decision-making for immunizations.[19] The interviewed parents exhibited a high degree of trust in the nurses at the CHC but to a less degree in healthcare providers at primary health facilities. Thus, the positive relationship between healthcare providers and parents may impact continuity of care as well as maintenance of confidence in vaccines.

Previous studies have assessed factors associated with vaccination confidence and hesitancy[19,20] as well as parental decision-making for childhood vaccinations.[21,22] Vaccine hesitancy or refusal of immunizations among the undocumented parents in our current study was not an issue. None of the parents had considered the option of not vaccinating their children. They all had an intention to vaccinate their child or children.

Access and barriers to health care

Our findings showed that undocumented parents faced a structural barrier related to legal issues rather than a barrier on the individual level with regard to childhood immunizations. The systematic approach of the TIP method and its structured way of presenting qualitative findings facilitated the understanding of the barriers and enabling factors from various perspectives. Moreover, the TIP method helped to create a more complete and contextual situational analysis that went beyond mere individual characteristics and profiling and to also consider legal issues as well as structural, administrative, and financial obstacles outside the influence of the healthcare providers. Barriers in accessing health care for undocumented migrants have been known previously.[23,24] Our results highlight important barriers regarding access to preventative health care, including immunization services; the interviewed parents described experiences of being rejected, questioned, or being asked for identification, despite entitlement to care for their children. Similar findings regarding access to health care have been presented previously in other studies in Stockholm and elsewhere.[21,24,25] Children are often subjected to the same immigration control measures as their parents, independently of the children's' entitlements.[26] Thus, parents' undocumented status hinders efforts to obtain proper health care for their children.

Knowledge of the healthcare system, structures, and awareness is crucial, and lack of understanding of the healthcare system or unfamiliarity with rights have also previously been identified as barriers to access to health care.[27–29] Parents seemed to be aware of their child's entitlement, but they did not trust the system. Entitlement issues have been mentioned as a major barrier for access to health services for migrants in EU. Improving access for undocumented immigrants requires additional and specific efforts to restore trust in the health system as well as improved knowledge among health personnel on legal aspects and human rights of undocumented migrants, for instance.

The TIP approach

The TIP offers a process and contextual approach to gain knowledge and understanding of the situation of vulnerable and hard-to-reach communities such as undocumented migrants. The combination of qualitative research and stakeholder workshops with interdisciplinary expertise and key informants was valuable to achieve the best possible picture of the situation. The mapping facilitated the identification of key determinants influencing decision-making and use of vaccination services based on environmental and institutional opportunity factors, social and supportive ability factors, and personal motivation factors.[14] Based on our experience, the TIP is a valuable tool for structuring the research and problem statement. The TIP is however a rather new approach and has so far been implemented in only four countries in the European Region.[13] A review of the implementation in these countries was recently conducted, concluding that, in the future, the TIP framework should go beyond identification of susceptible groups and diagnosis of challenges and have a stronger focus on the design of strategies and appropriate and effective interventions to ensure long-term changes. In addition, the European Vaccine Action Plan 2015–2020 identifies tailored, innovative strategies as a crucial approach in reaching hard-to-serve groups with suboptimal vaccination coverage.[1] Public health authorities are searching for effective strategies to promote demand for vaccination and address vaccine hesitancy. There is, however, no strong evidence for any specific intervention, but generally, multicomponent and dialogue-based interventions were shown to be most effective in addressing hesitancy.[30] Strategies and interventions should be properly and specifically tailored to both these issues in context. Rigorous process and impact evaluation of the intervention should be performed as well as sharing of lessons learnt.[30]

Methodological considerations

The methodology has been considered to achieve trustworthiness through the research process.[17] Throughout the analysis process, data were discussed within the interdisciplinary research team which included different cultural and professional backgrounds to strengthen the dependability. Credibility refers to confidence in how well data and analysis address the intended focus of the research. Research on undocumented migrants is a very sensitive issue, and therefore the research team regularly raised ethical issues and implications of the study objectives, data collection, and reporting. The apprehensive and clandestine nature of undocumented migrants made the research complex and challenging. Therefore, meetings and discussions with medical staff and volunteers at the NGO clinics as pre-interview fieldwork were valuable to increase the understanding and knowledge about the undocumented community.

Only parents visiting the NGO clinics were interviewed which may have left out even more vulnerable migrant groups. Statements and answers, in particular from the parents, may have been influenced by perceived social desirability, or not being totally open to interpreters may have led to information being lost. Parents accepting to be interviewed may have been more positive toward vaccination than those not accepting; however, the interviews with the nurses reinforced the views of the interviewed parents.

Conclusions

The study confirms the complexity of barriers that the undocumented parents face regarding childhood immunization. Access for childhood immunization for undocumented immigrants requires improvements of the health system to increase the parents trust in health professionals.

The TIP approach offers a process for deeper understanding of the determinants of immunization challenges among undocumented migrants.

Author statements

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Ethical approval

The study received ethical approval for the interviews from the Regional Ethics Committee in Stockholm, Sweden, Dnr 2013/678–31/3.

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Conflict of interest

The authors declare no conflict of interest.

Authors' contributions

K.G.R., A.K., A.L., and H.A. designed the study. K.G.R. collected qualitative data. All authors, K.G.R., E.B., A.L., R.B., H.A., and AK, actively participated in TIP workshops for data collection and interpretation for conceptual mapping. K.G.R. and A.K. performed qualitative data analysis. K.G.R., A.K., A.L., and E.B. participated in data interpretation of qualitative data. K.G.R. and E.B. drafted the report. A.K., A.L., H.A., and R.B. participated in the final revision of the report.

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