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The perspective of asylum-seeking caregivers on the quality of care provided by a Swiss paediatric hospital –a qualitative study

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Abstract

Objectives:

This study investigated the perspective of asylum-seeking caregivers on the quality of health care delivered to their children in a qualitative in-depth interview study.

The health of asylum-seeking children is of key interest for health care providers, yet knowledge of the perspective of asylum-seeking caregivers when seeking health care is limited.

Setting:

The study focused on one paediatric tertiary care hospital in Basel, Switzerland.

Participants:

Interviews were carried out with thirteen asylum-seeking caregivers who had presented with their children at the paediatric tertiary care hospital. Nine female and four male caregivers from Tibet, Eritrea, Afghanistan, Syria, Iraq, Albania, and Macedonia were included. A diverse sample was chosen regarding cultural and social background, years of residence in Switzerland, and reasons for seeking care.

A previously developed and pilot tested interview guide was used for semi structured in-depth interviews that took between 36 and 92 minutes. Data analysis and reporting was done according to consolidated criteria for reporting qualitative research (COREQ). The interviews were carried out until saturation was reached.

Results:

The interviewees described a mismatch of personal competences and external challenges. Communication barriers and unfamiliarity with new health concepts were reported as challenges. These were aggravated by isolation and concerns about their child's health. The following factors were reported to strongly contribute to satisfaction of health care delivery: a respectful and trustful caregiver-provider relationship, the presence of interpreters and immediate availability of treatment.

Conclusions:

A mismatch of personal competences and external challenges importantly influences the caregiver-provider relationship. To overcome this mismatch establishment of confidence was identified as a key factor. This can be achieved by availability of interpreter services, sufficient consultation time, and transcultural trainings for health care workers. Coordination between the family, the asylum and the medical system is additionally required to facilitate this process.

Strengths and limitations of this study

Strengths of this study:

- The inclusion of a cross-language concept and theoretical background.

- A thoroughly validated interview guide.

- A rigorous analysis, supported by an interdisciplinary research team.

Potential limitations of this study:

- As in-depth qualitative study, this study naturally comprises a relatively small sample as compared to larger quantitative studies. However, the study was performed until saturation was reached and interview partners were chosen to include a diverse study population regarding cultural and social background, years of residence in Switzerland, and reasons for seeking care.

- Nevertheless, we acknowledge that minor aspects might not have been sufficiently covered, or that other participants from very different contexts may still differ in their views.

Background

The recent increase of the global refugee population to 22,5 million people is the highest level ever recorded and poses challenges to health care systems and public health of host countries [1]. In 2017, European countries recorded 209,756 asylum claims by children [2]. Despite decreasing overall numbers of refugees arriving in Europe, national asylum services still registered over 115,000 asylum applications by children from January to September 2018 [3]. In Switzerland over 45, 000 asylum applications were registered in 2016 and 2017 [4]. The age of asylums seekers has dramatically decreased in the last decade with 82% of asylum seekers in Europe being aged below 35 years and approximately one third being children and adolescents below 18 years of age in 2017 [5].

Many refugees have had limited access to health care for years and therefore arrive in host countries with neglected health conditions [6-8]. The health of asylum-seeking children and adolescents is of key interest, as these represent an increasing refugee population in recent years and are a particularly vulnerable group [9-11].

Access to quality health care for asylum-seekers remains challenging and it is central to identify underlying reasons [12 13]. This needs to be done from the perspective of health care providers and asylum-seeking caregivers alike as the perception of challenges and expectations on quality of care provided may vary substantially [14 15].

Current understanding and evidence on challenges for the health care provision to asylum-seekers and refugees is growing. A recent systematic review focussed on qualitative studies investigating challenges and facilitators in providing health care to asylum-seekers and refugees. It identified three main fields influencing health care: the asylum process, the health care system and the health care encounter [16]. An important limitation of the review is that all included studies reported on the providers' perspective [16]. A recent review by our group on challenges in health care delivery to asylum-seekers and refugees in high-income countries included several studies assessing the asylum-seeking patients' perspective [17-28] and identified financial, legal, geographical and cultural challenges as additional external factors influencing access to health care (Brandenberger J, Tylleskär T, Sontag K et al.: The 3 C Model – a systematic literature review of challenges in health care delivery to migrants and refugees in high income settings).

Only few studies explored the perspectives of asylum-seeking caregivers. Two Australian studies investigated their perspective on the quality of antenatal and early child health care [24 28]. One study from the US focused on health beliefs of migrant parents, working on farms [23] and one European study investigated migrant caregivers perception on how to maintain their children healthy [29]. Therefore, studies assessing the perspective of asylum-seeking caregivers on quality of care provided to their children beyond the neonatal period and from Europe are lacking. To reduce this important knowledge gap, the aim of our study was to explore the perspective of asylum-seeking caregivers on the quality of care provided in a Swiss paediatric hospital.

Methods

Study design and setting

The study was designed as qualitative in-depth interview study at the University Children's Hospital Basel. The hospital is located in the city of Basel, which hosts the largest reception center for asylum-seekers in the area of Northwest Switzerland, where asylum-seekers are accommodated immediately after arrival for a maximum of three months [30]. The city of Basel also has various accommodations for accepted refugees and those in a prolonged asylum-seeking

evaluation process. The hospital receives referrals of children from the asylum reception centre and the various regional accommodations and asylum centres.

Study population

Caregivers of asylum-seeking children who presented to our hospital on working days were eligible for inclusion. We aimed to include a heterogeneous group of caretakers and performed purposive sampling using the following criteria to cover different perspectives: a) recent and distant (> 2 years) arrival in Switzerland; b) first and regular attendance to the hospital; c) presentation at the emergency department and at outpatient clinics; d) origin from different regions.

Potential participants were approached by the interviewer supported by a phone interpreter. Following oral consent, a separate appointment was scheduled with a face-to-face interpreter. Study participants' preference regarding language, dialect and gender of the interpreter was followed.

Sample size

Sample size determination was based on recommendations by the National Centre for Research Methods in the United Kingdom [31]. We aimed to achieve descriptive saturation, expected to perform 12 interviews and finally conducted 13. Saturation of the study results was discussed and determined by the interdisciplinary study team.

Data collection

An semi-structured interview guide (**Table 1 and Supplementary data 1**) was designed consisting of open questions mandatory to be covered, followed by facultative sub-questions to specify given answers and allowing reporting of emerging, not-previously specified topics [32].

Table 1: Interview guideline – practical design (translated version)

Introduction	it is more a conversation, not a strict interview; everything important and correct; present interviewer and role; confidentiality; maximum one hour; Audio recording ok?	Small-Talk Conversation, no interview; everything important and correct Answers also summarized by other parents confidentiality Maximum one hour Is audio recording ok?
Think about the moment before you came to the UKBB – what made you come?	Referrers? Presentation: basic Information? Communication? waiting times? Uncertainties?	How was it before you came? Has anyone signed up for you or did you do it yourself? first time at hospital? Referring? Did you know exactly what you need to do? (Information) Why did you come up to date, what illness did your child have? What was helpful when signing up or where did you need more support? Language? (Communication) Were there moments when you were not sure what to do?
Tell us what happened when you arrived at UKBB	arrived at reception and then? accompanying persons? felt understood in your concerns? what happened next? Doctor and nurse? did you think that what they did with your child is right? How did you feel?	You went to the reception / registration and then? Was someone there? Did you know how to proceed? Waiting times? Were you informed? Did you have an interpreter? Was this the first time? Did you need that before? What was helpful when signing up or where did you need more support? Did you understand you and your concerns? What happened then? Tell about the doctor and the care. Did you understand her? Was there an interpreter? Did you trust that what you did with your child is right? Did you feel safe at home? (Confidence)
How was the further care?	was the care as intended? what is different in your country of origin? would you go back to this hospital?	Was the care as you thought it would be? Were there situations where you thought it should be different or faster? Did you trust the doctors / other medical persons at the hospital? how did you feel? (sad, insecure, angry). What was especially great? What did you tell your friends? Concrete persons? What would have been different in your country of origin? What would you like to introduce here from your home country? What would you like to introduce in your home country from here? What role does religion play in the hospital for you? Would you go to the hospital again? Recommend it to your compatriots? If you would go there again, what would you like to be different? What should remain the same? Describe: what characterizes the perfect doctor for you? What the perfect nurse?
What was your general impression?	drugs received? did you receive further instructions / therapies from the doctor? do you think that what the doctor has suggested helps? If not, why? are more doctor visits planned? does your child have a pediatrician? know where to go for health issues?	Medication received? Recipe? How to take? How bought? Did you receive further instructions / therapies from the doctor? Do you think that what the doctor has suggested helps? If not, why? Did you do it differently? Did you have a contact person in case of uncertainty and questions after the hospital consultation? Are more doctor visits planned? Does your child have a pediatrician in Basel? If not, why not? If so, how did you find him? Do you know where to go for health issues (continuity of care)?
Wrap up	additions? was it easy to express your opinion? give phone number from interviewer for inquiries	From my point of view, we have addressed all topics. Many thanks for the valuable hints. Are there any additions from your point of view? How do you feel after the conversation? Do you have anymore questions? Was it easy to express your opinion? How could we best ask the opinion of their compatriots? How do you do that in your country? What else can we help you with? Give phone number from interviewer for inquiries
Context	where were you born? How did you come to Switzerand?	Where were you born? Where have you lived? How arrived in Switzerland? Already experiences with hospitals?
Back up	experiences at home with hospitals? what's better, what do you miss here? what tips for other parents, before they come to the hospital?	What experiences did you make with hospitals in your home country? / On the way to Switzerland? what is different here? what is better, what do you miss here? What tips for other parents, before they come to the hospital?

First row: mandatory to be covered in open questions; second and third row: sub-questions

The interview guide was reviewed by an external organizational psychologist with extensive experience in qualitative research. After external revision two pilot interviews were performed to test intelligibility, acceptability and extensiveness. A further revision was done based upon feed-back from the caregivers involved in the pilot interviews. To address the challenges in cross-language qualitative research [33-35] and minimize the language barrier, a cross-language concept was developed, describing steps of translation and quality control. The cross-language concept was developed using the guidelines on interpreter use of the Qualitative Forum of Social Science [36].

Baseline data was collected using a case report form (**Supplementary data 2**). The in-depth interviews were done according to participants' preference at their home, asylum residence or at the hospital. Interview duration was scheduled for 60 minutes and done once only. All interviews were audiotaped and transcribed as pure verbatim protocols [37] of the English/ German parts with anonymization of all patients. The transcriptions were reviewed in detail by the interpreter present during the interview according to the cross-language concept. Para-verbal reactions, interactions between family members, other observations and cultural aspects were documented in field notes and discussed by the interviewer and interpreter during debriefing.

The role of the interviewer

The interviewer (JB) is an experienced female clinician-scientist (MD) and conducted all pilot and study interviews. During the study period she was employed by the University Children's Hospital Basel in the migrant health service research group. She is experienced in qualitative research, received trainings in interview-techniques and qualitative research methods and has a special interest in global health. Not knowing JB beforehand, the interviewer's background, the

purpose and goals of the study were explained to the participants during the oral consent and repeated during the introduction phase of the interview.

Data analysis and reporting

Data analysis was done according to the qualitative content analysis of Mayring [37]. Reporting was guided by the consolidated criteria for reporting qualitative research (COREQ; **Supplementary data 4**) [38]. A codebook (**Supplementary data 3**) was prepared and refined in several steps, involving team discussion with JB, KS and CD. Four interviews were coded in parallel by each researcher to ensure the comprehensiveness of the codebook. Code categories were extracted, relations identified and abstracted in networks and graphs to generate a coding tree. The analysis was done using atlas.ti (ATLAS.ti 8 Scientific Software Development GmbH, Berlin). The entire study process was accompanied by the interdisciplinary Migration Research Group at the University of Basel.

Patient and Public involvement

During pilot interviews caregivers' feedback was obtained to improve the interview guide and the way the interviews were done. After the pilot phase all participants were asked if the method was suitable and how they felt about expressing their opinion in this way at the end of the interview. An interim expert panel discussion consisting of staff from the asylum-seeking reception center and the University Children's Hospital Basel was organized, to evaluate results. In addition, one interview participant reviewed the entire paper.

Ethics

As a quality assessment project of the University Children's Hospital Basel, there was no ethical approval required for this study. This was confirmed by the Ethics Committee of Northwest/Central Switzerland on October 4th 2017. We strictly adhered to international research

standards rigorously including information about entirely voluntary participation of the interviewees and the possibility to withdraw consent without any negative consequences, separation of research and clinical staff and data confidentiality.

Results

A total of 13 interviews were done and included in the analysis (**Figure 1**). The baseline characteristics of participating caregivers and the interview context are summarized in **Table 2**.

The results are presented in two sections, focusing on challenges and good practice reports.

Mismatch of competences and organizational challenges

Caregivers described mismatches between their personal sociocultural and language competences and the situation of health care. In addition, they faced organizational challenges, e.g. orientation in new surroundings after quick relocations. They described that this created tension leading to feelings of disorientation, dependency and anxiety. This was felt strongest early after arrival and for those who had not previously lived in a cultural context like Switzerland. It became also more pronounced, if there was an urgent threat such as the illness of their child.

> I was frightened. I didn't know the language, I didn't know anybody. I took care of my children and I didn't know where I was. […] I was extremely worried about [my sick child]. And I didn't know: what happens? Whom should I ask? Where should I go? I had no money with me. In fact, I didn't know where I was. (4; 2:21)

Caregivers who were unable to speak or understand a local language described communication as a challenge. The inability to sufficiently explain the medical history and complaints of their child was reported to be frustrating. Being highly dependent on interpreters, one caregiver recalled feelings of fear when the interpreter was late for the appointment.

> At my second visit I was a bit frightened as the interpreter was not there. I thought: oh my God: how can I understand now [what they say]? How can I talk to them? I was a bit

> nervous in this moment, this was a bit difficult. (13; 14:31)

Mismatch of health concepts

Caregivers explained that their own health concepts were shaped by their culture and previous experiences. They arrived with certain expectations about Swiss health care based on stories they had heard. One important topic was the use of medication. Two caregivers stated that they had wished to be prescribed more medication.

> In Afghanistan […] doctors have limited resources. We don't have many options. But if you go to the doctor […] you get medication and you get antibiotics if you have an inflammation or something like that. Here, that's not the case. You continue to be sick, after four or five consultations it gets better, yes, but maybe it would have been better anyway. (3; 29:46)

> In Syria, when my son or my daughter was sick, I just went to the pharmacy. It's like a supermarket. And then I buy […] antibiotics too, that's completely normal. (10; 7:24)

Some health concepts such as preventive services were reported to be unfamiliar. For one caregiver the detailed examination of the child during tuberculosis screening meant that her child was seriously sick. She was unable to imagine why this was required, if there was no obvious health problem. She explained that the idea of going to the hospital with an apparently healthy child was completely new to her.

> I knew my children were not having tuberculosis. However, I was frightened. Because they work so thoroughly [at the hospital] and they have done examinations, and that is why I was really frightened. (7; 4:40)

For some, also the way in which doctors communicate about health was unfamiliar. One caregiver mentioned that bad news was disclosed to her by five doctors which was a shocking and unpleasant experience. In addition, the information was given faster and much more directly compared to the way she was used to. She had wished that only one person had given here the information in small steps. Other caregivers, too, wished doctors would explain more about the disease, causes and resulting treatment.

Limited personal resources

For caregivers being part of a family was considered a resource and being separated from beloved ones was a psychological challenge. In many instances mothers explained to have arrived in Switzerland with their children but without their husbands. These were reported to have been forced to stay as soldiers or prisoners or had been killed before the family left. In case of limited financial resources, priority was given to the mother and children leaving the country. The lack of communication with them or other family members was contributing to the feeling of loneliness. It aggravated once a child got serious health problems and had to be admitted to the hospital.

> I had no clue about a health insurance, no clue about the law, the law here and the rules. I just endured these days there [on the ward]. […] I felt very lonely. My husband was not here at that time. That was very difficult. (3; 29:16)

Being a single caregiver had practical implications. For example, attendance to medical appointments was problematic as child care for healthy siblings is usually not available for asylum-seeking families. Another example was that the caregiver refused admission as she was unable to stay with her sick child.

> [The doctor] said you have to stay 7 to 10 days here with your son. That's what he told me just like this. And then I answered: I can't, I have [six] children and their father is not here. (4; 2:11)

Caregivers described how family members residing in neighboring countries could have been of psychological and practical support. However, as their asylum process was pending, they were not allowed to cross borders. One caregiver reported crossing the border to see family members for support in a desperate situation, and being caught by police.

One caregiver reported being alone made it difficult to give her child the prescribed medication. When she reported this to the doctor she was treated disrespectfully and asked to leave.

> That's what made me angry: we told the truth to him. We can't just lie [...]. Maybe the medication doesn't taste good, doesn't smell good. I thought: [...] if I tell it to him we could maybe change it. But he was angry and just left. He said: go home! So I went home. (5; 13:32)

External challenges

Caregivers also expressed difficulty to access health care, particularly if the asylum process was prolonged. In stations with pending asylum decision some participants reported that a health insurance card was not issued, which caused delays, additional administrative work and made caregivers feel inferior.

One caregiver described that the official person in charge brought the sick child to the hospital in a private car, took care of the administrative tasks and stayed with the family during the consultation. Another caregiver reported that the official person in charge was reluctant to address the family's health needs.

> Three years here. My chief [official in charge] said that I'm only parked here. But I'm not a car! We are parked here, 7 years by now! With F status [provisionally admitted refugees]. Tell me, why does it have to be like that? Parked! (9; 6:98)

Caregivers also described insufficient coordination between the asylum reception centers and the hospital. Two recently arrived mothers of admitted children did not have cash money. Unfamiliar with the system that they must buy their own food and unable to communicate that they had no money, the mothers fasted during several days or were eating form their children's meals.

Some caregivers explained that after the consultation was finished they did not know how to get back to their center. One caregiver had recently moved and did not recall her new address. Others reported to have been driven home by the interpreter or a taxi. One caregiver living in a rural area was worried not to be able to get home after the consultation and therefore left the emergency department in the middle of the consultation.

Understanding and responding to medical needs

12 out of 13 caregivers expressed a deep thankfulness for the health care their child received at the hospital. They also appreciated if help was offered in various situations by interpreters,

officials in charge of the asylum process, taxi drivers, engaged citizens, receptionists, social workers, nurses or doctors.

> It is impossible to describe, I can't describe it. Doctors or social workers, everybody supported and helped me. (4; 2:86)

Caregivers appreciated the fact that an interpreter was organized, and this led to trust as they felt understood in their most urgent need.

> I swear, if I can talk there, I have the feeling that I'm safe! (5;13:58)

All but one caregiver explained that they were impressed by the medical help their child received. They mentioned that in the past, they never experienced such a high level of medical care, neither at their home nor in transit countries.

> I don't think you see this facility in any other country. It was around half past 10 at night. We thought he swallowed something. […] We got really scared. […] The doctor said: he will call the lady who is doing the x-ray, from home. Wonderful! This is service to the King! She came from her home to do x-ray to our son. This is fascinating! (1;12:31)

When asked why they were satisfied with the quality of care, they emphasized the immediateness of medical care. They were used to wait hours, even days. Understanding and rapidly addressing the child's health needs lead to trust and the feeling of being understood and safe.

> I like the support. The quick treatment, everything included. Not like at home, really. [..] I'm so thankful, that the child is in good hands. (11; 8:54)

Access to good quality health care was for some caregivers one important reason why they continued to seek asylum in Switzerland.

> Sometimes I get nervous, I say: I'm dead, I have to leave. […] But then I think: I have to be thankful. I have a room and my child gets an immediate check-up if he is sick. (9; 6:91)

Showing respect

Almost all caregivers highly appreciated that they were treated in a respectful way. Respect was even more important, if they had made negative experiences with health care providers in the past.

> In Iran, they don't treat […] people from Afghanistan with respect. […] It is not like here. For example, at the reception: maybe they don't even give you a registration code, they don't listen to you. We are very satisfied and thankful, that we came to this country because we were always treated with respect (6; 3:18)

Simple and routine practice was acknowledged as good practice such as the doctor coming to the room of the patient and not vice-versa. Caregivers recalled that the doctor helped to undress the patient or approached the child in an appropriate and friendly way. One caregiver appreciated that the nurse was playing with the child during the consultation. This allowed her to concentrate on the doctor's explications. A caregiver from Iraq appreciated that the staff asked the eight-year-old daughter directly and therefore respected the child's opinion. A further caregiver appreciated that the staff adapted to the individual reactions of the children.

> What I liked: my children had two different behaviors. One cried and refused to cooperate. The nurse helped us. […] We helped each other. By the end both children received what they needed. (2;11:10)

Building trust through relationship

A trustful relationship to health care providers was central to all caregivers when evaluating the quality of health care. Two caregivers with children with chronic diseases visited the hospital frequently and described a family-like relationship with the staff.

> If I go [to the Children's hospital] I don't see it like a hospital. The nurses, the doctors and everything, they are like my family. (4; 2:90)

As verbal communication was frequently limited, non-verbal communication was important for building a trustful relationship. Two caregivers explicitly highlighted how they appreciated when the medical staff was smiling.

> If somebody smiles at me, a beautiful smile, that makes me really happy. Then I get a very beautiful feeling. And the doctor was nothing but happy and friendly and smiled all the time at me. (9;14:52)

A trustful caregiver-provider relationship allowed caregivers to accept unfamiliar health concepts. For example, one caregiver was unhappy about not being prescribed medication for her child, but she explained how this changed after a medical consultation at the emergency department.

> I thought she would get a lot of medication, as she had fever. But no: they only gave this suppository to her. […] They said: don't be frightened, your daughter will be fine. She just needs time to recover. And that was the right way. I went back, and that was right. So that is an ideal doctor to me: Who knows exactly what happens, without giving too many drugs. (10; 7:40)

Another caregiver had the concept that she should never leave her infant alone in the hospital. Her daughter was admitted with a chronic disease and the medical staff recommended to take rest at home and leave the infant alone in the hospital.

> It was a shock. We […] don't have this in our culture that mum leaves the baby. But later, I said it's very helpful to go out, really because the nurses were […] very, very good. Then I understood that: If I'm good, she will be good. […] […] We have to know that. That the doctor works for us, not against us. (12; 9:27)

Discussion

To our knowledge, this is the first study investigating the perspective of asylum-seeking caregivers on the quality of health care provided to their children in Europe.

The detailed analysis of the interviews displayed a range of challenges for asylum-seeking caregivers and their sick children. However, despite including a diverse group some universal challenges were noted. This included the development of a trustful relationship, communication including interpreter services and coordination between the health care and the asylum system. These findings conform results from a recent systematic review which identified communication, continuity of care and confidence as the three main factors influencing health care provision to migrants (Brandenberger J, Tylleskär T, Sontag K et al.: The 3 C Model – a systematic literature review of challenges in health care delivery to migrants and refugees in high income settings). However, our study also highlights important additional aspects for this group of patients specifically regarding confidence and continuity of care.

First, confidence was the key factor contributing to satisfaction of the study participants. Confidence was achieved through a trustful caregiver-provider relationship. This finding is also supported by other studies, e.g investigating mental health care delivery to migrants [17 26]. In some instances is has been described as the treatment itself [39]. The fact that very small actions such as a smile by the treating doctor, being helpful to undress and interacting in a playful way with the sick child, built trust is remarkable. This highlights that simple and easy steps may have important benefits for the health of asylum-seeking children and such knowledge needs to be included in transcultural training of health care workers.

Second, caregivers explained that challenges regarding the continuity of care were occurring at the intersection of the medical and the asylum system. Challenges included the asylum-process itself, transport and access to money. Our study identified that for a positive perception of health care delivery, these areas need to be well coordinated. This result is also echoed in a recent publication describing health care delivery models for migrants, which suggested including specialized case managers as one option to improve cooperation between services [40]. Connecting services may be facilitated by other interventions such as involvement of social workers and predefined referral pathways, and specialized migrant health teams.

Third, communication is important in all health care encounters and has been identified as a key barrier or facilitator in this study. Numerous earlier studies have investigated the negative influence of language barriers on patient experience, health literacy and patient-provider relationship [41] . Although the requirement of interpreters is not debated, most health care systems in Europe have not established payment policies for interpreter services. This results in frequent use of ad hoc non-professional interpreters, which is associated with considerable risk of interpretation errors leading to clinical consequences [42]. It is therefore important that costs of interpreter services are covered by health care insurances, which is currently advocated by a position paper published by the Swiss Hospital for Equity network (https://www.hospitals4equity.ch/).

Generally, the caregivers expressed very positive feelings for the medical care their children had received. Nearly all caregivers were very satisfied, giving detailed examples of individual support, fast and adequate medical care and a respectful and trustful approach by health care providers. There is a possibility that through selection bias only satisfied caregivers had agreed to participate. However, only one of the caregivers meeting the inclusion criteria refused to take part in the study. The approached caregivers were keen to be interviewed and appreciated the opportunity to express their opinion. In contrast, the hospital's earlier efforts to assess patient's satisfaction of asylum-seeking families using translated satisfaction questionnaires had an extremely low response rate. This may suggest that patient satisfaction inquiries using interviews instead of questionnaires are more acceptable to asylum-seeking caregivers.

A potential limitation originates form the number of performed interviews. However, interviews were rich in content and included a diverse study population regarding cultural and social background, years of residence in Switzerland and reasons for seeking care. The information gathered started to repeat after 11 interviews, signalizing saturation regarding the major themes. Nevertheless, we acknowledge that minor aspects might not have been sufficiently covered, or that other participants from very different contexts may still differ in their views. Strengths of this study are the inclusion of a cross-language concept and a solid theoretic background, a thoroughly validated interview guide and the rigorous analysis, supported by an interdisciplinary research team. Therefore, we believe that our findings are relevant to health services in many host countries caring for asylum-seeking families from various backgrounds.

Conclusion

A mismatch of personal competences and external challenges importantly influences the caregiver-provider relationship. To overcome this mismatch establishment of confidence was identified as a key factor. This can be achieved by availability of interpreter services, sufficient consultation time, and transcultural trainings for health care workers. Coordination between the family, the asylum and the medical system is additionally required to facilitate this process.

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Author’s contribution

JB and NR study conception; JB data acquisition; JB, KS, CD and NR data analysis,; JB wrote the first draft, JB, KS, CD, FJ, BP and NR revised the manuscript. All authors had access to the data and gave intellectual input. JB and NR affirm that this manuscript is an honest, accurate and transparent report of the results and that no important aspects have been omitted.

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Competing interests:

None declared.

Disclaimer:

The content is solely the responsibility of the authors and does not represent the official views of the funding bodies, which had no role in the design and conduct of the study; the collection, management, analysis and interpretation of the data; or the preparation, review or approval of the manuscript.

Ethics approval:

As quality control project, this research project doesn't fall under the remit of the cantonal or federal law HRA (Human Research Act). The EKNZ (Ethikkommission Nordwest- und Zentralschweiz) has reviewed the submitted documents and confirms that the research project fulfills the general ethical and scientific standards for research with humans (see Art.51 Abs 2 HRA).

Patient consent:

Oral informed consent obtained.

Data sharing statement:

No additional data available.

Figure 1 Legend:

Flow-chart, depicting the different phases of the patient recruitment and the cross-language concept including transcription, translation and understanding of language

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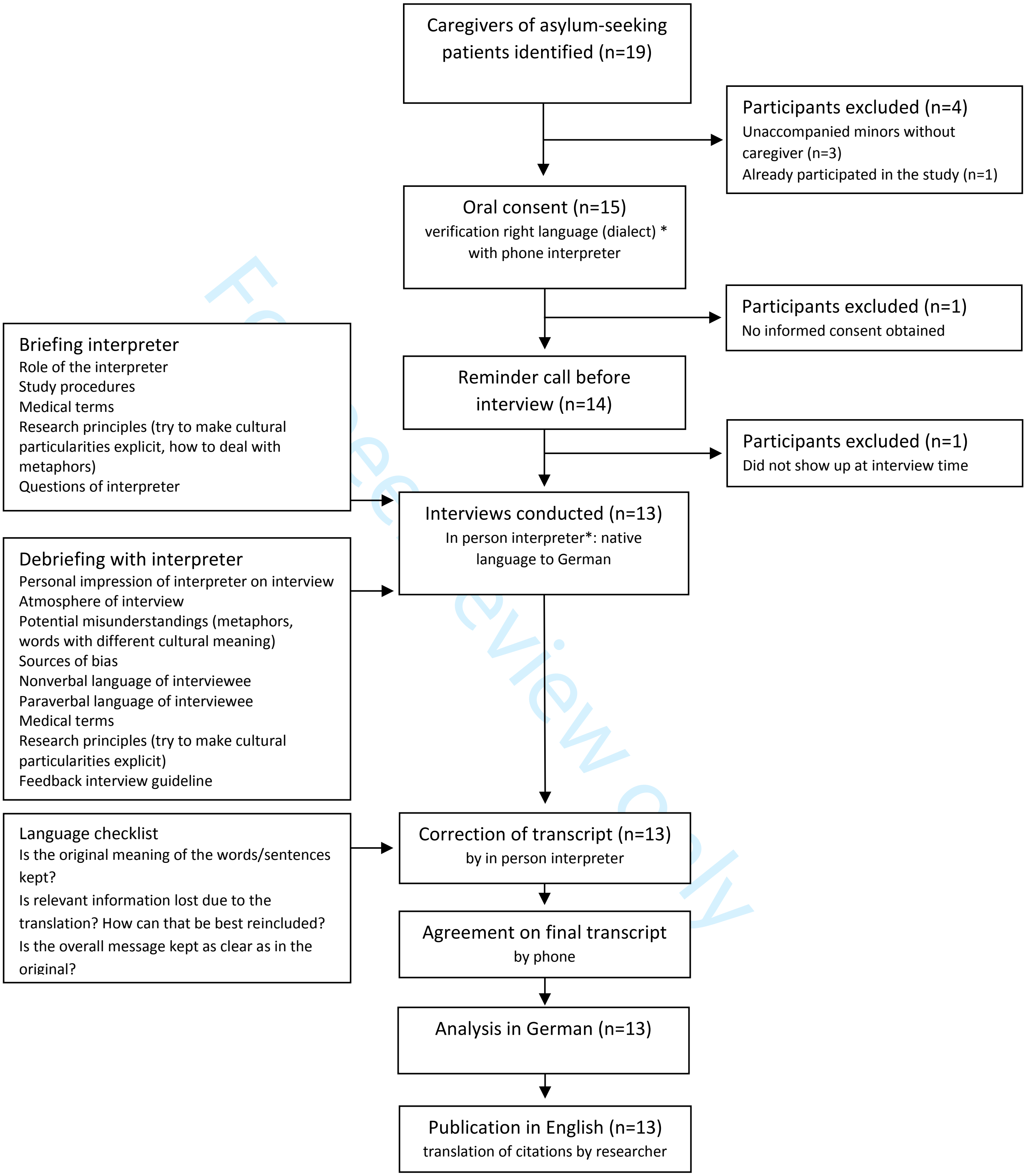
Figure 1: Flow chart of participant recruitment and integration of cross language concept



*= If communication in German/English not adequate

Supplementary Material

Supplementary Data 1: Interview guideline – theoretic design

1. *Context (ice breaker oder am Ende erfragt)*

- Könnten Sie uns erzählen, wo sie geboren sind, gelebt haben und wie Sie in die Schweiz gekommen sind?
    - **Waren Sie auf Ihrem Weg hierher mit Ihrem Kind in anderen Krankenhäusern / Einrichtungen?**
        - **Wenn ja im Ausland (welches Land)?**
        - **In der Schweiz?**
- Was hat Sie veranlasst ins UKBB zu kommen?
        - **Hat man Sie in das Kinderspital geschickt? Warum?**
    - **Haben Sie das Spital gut gefunden?**
- Welches Verkehrsmittel haben Sie benutzt?
    - **War es teuer herzukommen?**
- Sind sie in einem Migrationsprogramm das Sie unterstützt? Haben Sie einen persönlichen Betreuer?

2. *Communication*

- **Können Sie erzählen, wie die Konsultation am UKBB verlaufen ist?**
    - Sie kamen mit Ihrem Kind an die Anmeldung und dann?
        - Wie verlief die Kommunikation an der Anmeldung?
    - Welche Erkrankung hatte Ihr Kind?
        - War die Erklärung verständlich?
    - Wieviel medizinisches Personal haben Sie gesehen? War(en) ein Arzt(e) dabei? Wenn ja wieviele?
    - Was hat der Arzt gesagt, sollen Sie tun?
    - Welche Sprache(n) wurden mit Ihnen gesprochen?
- **Hat der Arzt einen Dolmetscher verwendet? Hat ein Bekannter für Sie übersetzt?**
        - Wenn ja per Telefon oder persönlich? Wie empfanden Sie das?
        - Wie konnten Sie mit dem Personal sprechen?
            - War es einfach? War es schwer? Warum?
- **Wie war die Kommunikation mit allen Angestellten des UKBB für Sie?**
    - Was fanden Sie gut?
    - Was fanden Sie schwierig?
    - Was könnte man besser machen? Was soll so bleiben?

3. *Continuity of care*

- **Nach der Vorstellung im UKBB, was haben Sie gemacht?**
    - Mussten Sie Medikamente zu Hause geben?
        - Wenn ja: haben Sie ein Rezept erhalten?
        - Wie haben Sie das Medikament besorgt?
    - Waren Sie bei einem anderen Arzt?
    - Hat Ihr Kind einen Kinderarzt? Wie haben Sie den gefunden?
    - Sind weitere Arztbesuche geplant?
- *Wenn sich der caregiver für ein anderes Procedere als das verordnete entschieden hat*:
- Können Sie erklären, weshalb Sie sich anders entschieden haben?
    - Denken Sie, dass das was der Arzt vorgeschlagen hat nicht hilft?
    - War es schwierig, das zu machen was Ihnen vorgeschlagen wurde?
- **Hat ihr Kind einen Kinderarzt in Basel?**
    - Wenn nein, weshalb nicht?
    - Wenn ja: wie haben Sie den gefunden?

4. *Confidence*

- **Beschreiben Sie: was wäre der perfekte Arzt für Sie? Was der perfekte Krankenpfleger?**
    - Wie würde man Sie behandeln? Was würde man tun?
- **Wie haben Sie sich während der Behandlung gefühlt?**
    - Waren Sie traurig, verärgert? Verunsichert?
        - Falls ja warum?
        - Was hätte man in Ihrem Herkunftsland anders gemacht?
        - Hatte nur eine Frau/nur ein Mann ihr Kind untersucht?
        - Was für eine Rolle spielt Ihre Religion im Krankenhaus für Sie?
- **Was denken Sie von den Personen, die sich um ihr Kind gekümmert haben?**
    - Gab es jemanden der es besonders gut gemacht hat? Was hat er gemacht?
    - Gab es jemanden der es nicht gut gemacht hat? Was hat er gemacht?
    - War die Betreuung so, wie Sie es sich gedacht haben?
        - War es besser/schlechter als Sie gedacht haben?
        - Was hätte besser sein sollen? Was war gut?
- **Würden Sie nochmal ins UKBB gehen?**
    - Wenn Sie nochmal dorthin gehen würden, was hätten Sie gern anders?
    - Was hätten Sie gern wieder genau so?

Supplementary Data 2: Case report form

bei der Rekrutierung ausfüllen:

Am UKBB vorstellig geworden am (dd/mm/yyyy):____

Department (NF/ MS/ Poliklinik) :____

ID-Nummer Interview care-giver (initi.Departm.&Nummer): ______-_________________________________

Alter des betreuten Kindes(Jahre & Monate/12): __________________Jahre ______________/12 Monate

Bekannte Erkrankungen des betreuten Kindes:____

mündliches Einverständnis Studienteilnahme erteilt (nein0 /ja1) ___________________________________

Sprachen des Care givers & Niveau(fliessend4 /gut3 /ausreichend2 /einzelne Worte1):________________

____

Dialekt____Interpreter

nein0/ja1___________________________Präferenz egal0/männlich1/weiblich2_____________

Berufliche Tätigkeit caregiver im Heimatland____

Berufliche Tätigkeit in der Schweiz____

Bildungsniveau des Caregivers (Höchste Ausbildung angeben: Analphabet1, Grundschulabschluss2, Abschluss

weiterführende Schule3, universitärer Abschluss4,)____________________________________

Geschlecht des care-givers (m1 /w2)____

Alter des care-givers (Jahre):____

Geburtsort des care-givers (Stadt & Land):____

In der Schweiz seit(Monate &Jahre):____

Beim Interview ausfüllen:

Aktueller Tag (dd/mm/yyyy)_________________ Uhrzeit (hh:mm)_________________________________

Ort Interview (EVZ1; Studienzentrum UKBB2;eigene Wohnung3)__________________________________

Zudem anwesende Personen beim Interview (Funktion): _______________________________________

Supplementary data 3: Code book including code definitions and frequency of appearance

	Kommentar	**Häufigkeit**
Abhängigkeit	= Beschreibung, in welcher der Caregiver von anderen Personen/Dingen abhängt	54
Adaptation Gesundheitskonzept	Veränderungen des eigenen Konzepts von Gesundheit/Gesundheitsversorgung aufgrund von Erfahrungen in schweizer Gesundheitseinrichtungen	19
Akute Krankheit Patient	= Erkrankung, die plötzlich aufgetreten ist / plötzliche Verschlechterung einer bereits vorhandenen Erkrankung, die mehr Hilfe benötigt als im sonstigen Zustand	9
Andere Kantone	= Aussagen über Kantone, in welchen der Caregiver sich aufgehalten hat ausserhalb von Basel-Stadt	32
Angestellte Wohnheim	= Aussagen, die Angestellte im Wohnheim betreffen	33
Angst Caregiver	= Emotionaler Zustand der Furcht des Caregivers im Hier und Jetzt	22
Ärger UKBB	= Beschreibung eines Gefühls der Unzufriedenheit und leichter Wut über das Kinderspital	4
Asylstatus	= rechtlicher Status, der die Möglichkeit im Land zu bleiben bestimmt	15
Ausdrücken der eigenen Meinung	= die Möglichkeit, uneingeschränkt seine persönliche Meinung kund zu tun	9
Beruf Caregiver	= Tätigkeit mit Lohnerwerb des Caregivers	12
Beziehung Caregiver - Patient	= das Verhältniss zwischen dem Patienten und seinem Caregiver	22
Bildung Caregiver	= Studium/Ausbildung des Caregivers	3
Chronische Krankheit Patient	= lang andauernde Krankheit, die nicht vollständig geheilt werden kann	21
In vivo	D: ja ich schwöre, wenn ich da ein bisschen sprechen kann	1
Dankbarkeit gegenüber UKBB	= Ausdrücken des Bedürfnisses, sich beim Kinderspital zu bedanken.	46
Dolmetscher: Amateur	= nichtprofessioneller Dolmetscher (ohne strukturiertes Training und entsprechendes Zertifikat)	14
Dolmetscher: prof.	= strukturiert ausgebildeter, zertifizierter Dolmetscher	31

Präsenz		
Dolmetscher: Telefon	= zertifizierter Dolmetscher, der über das Telefon übersetzt	16
Engagement Einheimischer	= intensiver Einsatz / Anstrengung von Menschen, die schon lange im Host-country des Asylsuchenden wohnen	20
Enttäuschung UKBB	= Beschreibung eines Gefühls der Traurigkeit aufgrund von nichterfüllten Erwartungen gegenüber dem Kinderspital	5
Erwartungen Caregiver	Leistungen, die der Caregiver vom UKBB/der Gesundheitsversorgung der Schweiz erwartet	22
Fachliche Kompetenz Administration UKBB	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Administration UKBB	13
Fachliche Kompetenz Ärzte	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Ärzte des UKBB	61
Fachliche Kompetenz Pflege	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Pflegenden des UKBB	28
Familie: getrennt	Beschreibung der Familie / familiären Struktur des Caregivers	19
Familie: zusammen	Beschreibung der Familie / familiären Struktur des Caregivers	8
Familiengefühl	= Beschreibung für Menschen die keine Verwandten sind familiäre Gefühle zu haben	5
Finanzen	= Finanzielle Situation Caregiver	44
Fluchtdauer	= Zeit vom Heimatland bis in das Hostcountry	12
Fluchtursache	= Gründe, die der Caregiver nennt, die dazu geführt haben, dass er und der Patient das Heimatland verlassen haben	13
In vivo	für mich sind König Kinderspital	1
Geschlechterrolle	= Beschreibungen des Caregivers, die die Unterschiedlichen Rollen von Geschlechtern aus seiner Sicht beschreiben	7
Geschwisterkinder	= Beschreibungen, die die Rolle der Geschwister betreffen	7
Gesundheitsinformation: gewusst	= Aussagen, die wichtige Hinweise für die Gesundheit des Patienten beinhalten welche dem Caregiver erklärt wurden	40
Gesundheitsinformation: nicht gewusst	= Aussagen, die wichtige Hinweise für die Gesundheit des Patienten beinhalten welche dem Caregiver NICHT erklärt wurden	17
Haltung Caregiver --> med. Personal	= Haltung, die der Caregiver gegenüber dem medizinischen Personal bzgl der sozialen/beruflichen Stellung hat	32

Haltung med.Personal --> caregiver	= Haltung, die das med. Personal gegenüber dem Caregiver bzgl der sozialen/beruflichen Stellung hat	32
In vivo	I think being a patient, our only duty is to bring our body to the hospital	1
In vivo	ich bin froh wenn im Kinderspital	1
In vivo	Ich denke dass Doktor nicht denke das ist fremde Kind	1
Informationsfluss	= Weitergabe von für die medizinische Betreuung relevanten Informationen	24
Infrastruktur UKBB	= Aussagen zur Ausstattung des UKBB	12
Integration	= Beschreibungen, die den Vorgang beschreiben, ein lokales Beziehungsnetzwerk aufzubauen	11
Kinderbetreuung	= Beschreibungen über die Organisation/ Möglichkeit der Aufsicht des Patienten / von Geschwistern	8
Kompetenz Sozialarbeiter	= Beschreibungen zu Fähigkeiten der Sozialarbeiter	8
Konzept Primärprävention	= Beschreibungen, die das Konzept der medizinischen Vorsorge beschreiben, welche darauf hinzielt Erkrankungen zu vermeiden	5
Kooperation Kanton – UKBB	= Zusammenarbeit der Kantone mit dem Kinderspital	10
Kooperation med. Personal - Caregiver	= Zusammenarbeit zwischen dem medizinischen Personal UKBB und dem Caregiver	11
Kooperation med. Personal - Patient	= Zusammenarbeit med. Personal und Patient	17
Kooperation SEM - UKBB	= Zusammenarbeit Angestellter des Bundes (vor allem EVZ/MIZ) und Verfahrenszentrums und des Kinderspitals	21
Koordination UKBB	= Beschreibung der Absprache von verschiedenen Organisationseinheiten innerhalb des UKBB	12
Krankenkasse	= Beschreibungen, die die Krankenkasse betreffen	26
Kulturelle Unterschiede	= Beschreibungen, die Unterschiede zwischen der Kultur in der Schweiz und anderen Ländern aufzeigen	56
Lächeln		2
Medikamente	= Beschreibungen, die Informationen zum Umgang mit Medikamenten beinhalten	53
Motivation medizinisches Personal	= Beschreibung der Motive des medizinischen Personals zur Handlungsbereitschaft	12

Niedergelassener Kinderarzt	= Beschreibungen, die die ambulanten Kinderärzte betreffen (nicht UKBB)	24
nonverbale Sprache	= Beschreibungen die die Kommunikation betreffen, die nicht mit Sprache zu tun hat, sondern mit allem was man sieht	13
Notfall	= Beschreibungen zur Notfallstation UKBB	17
paraverbale Sprache	= Beschreibungen, welche die Kommunikation über den sprachlichen Austausch, aber nicht deren Inhalt betreffen	4
Persönliche Kompetenz Administration UKBB	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Administration betreffen	7
Persönliche Kompetenz Ärzte	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Ärzte betreffen	50
Persönliche Kompetenz Pflege	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Pflegenden betreffen	25
Poliklinik	= Kommentare, die die Poliklinik betreffen	2
Religion	= Kommentare, die religiöse Auffassungen beschreiben	10
Rezeption	= Aussagen, die die Hauptrezeption (Eingangshalle UKBB) betreffen NICHT Administration	5
Schock Caregiver		12
Selbstständigkeit	= Beschreibungen, in welchen besonders hervorgehoben wird, dass etwas unabhängig von anderen durchgeführt wurde	7
Sicherheit	= Aussagen, die sich auf das Gefühl beziehen, sich in einer geschützten Umgebung zu befinden	28
Sorge Caregiver	= das Gefühl der Furcht vor negativen Ereignissen in der ZUKUNFT	30
Station	= Aussagen, die explizit die Stationen des UKBB betreffen	4
Transitländer	= Aussagen zu Ländern, in welchen der Caregiver sich zur "Durchreise" aufgehalten hat, die aber kein endgültiger Zielort waren.	22
Transport Flucht	= Verkehrs/ Mittel, mit welchen der Caregiver von der Heimat bis in die Schweiz gekommen ist	16
Triage	= Aussagen zur Station auf dem Notfall, in welcher Patienten der Schwere der Erkrankung nach klassifiziert werden	4
Überweisung	= Aussagen, die eine offizielle Zuweisung des Patienten an das Kinderspital betreffen	14

In vivo	Und Chef kommen, sagen nur holen vor Chef	1
UNHCR / NGO	= Aussagen über UNHCR / nicht Regierungsorganisationen	7
verbale Sprache	= aussagen, die die Kommunikation von verbalen Inhalten betreffen (NICHT von der Art und Weise der Sprache / der nichtverbalen Sprache)	56
Verständnis Gesundheit	= Beschreibungen der Perspektive des Caregivers auf das Gesundheit	32
Verständnis Gesundheitssystem	= Perspektive des Caregivers auf das Thema Gesundheitssystem	28
Vertraulichkeit	= Umgang mit der Diskretion bezüglich persönlicher Informationen	0
Vorerfahrung Gesundheitseinrichtung: anderer Kanton	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	13
Vorerfahrung Gesundheitseinrichtung: Heimat	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	30
Vorerfahrung Gesundheitseinrichtung: Transitland	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	21
Wartezeit	= Dauer vom Eintreffen im UKBB bis zur medizinischen Konsultation	24
In vivo	we have to know that. That this doctor works with us	1
Weg UKBB	= Beschreibungen der Anfahrt des Caregivers von seinem Aufenthaltsort zum UKBB	25
Weitere Behandlungen	= Beschreibungen von weiteren geplanten Behandlungen	16
In vivo	wenn ich da hingehe sehe ich das [...]wie Familie	1
In vivo	Wenn jemand sich selbstbewusst ist, dann hat er Vertrauen	1
Wohnsituation	= Ort sowie Beschreibung des Ortes, an welchem der Caregiver lebt	26
In vivo	You don’t have to ask, they are taking care	1
Zuständigkeit	= Beschreibungen die das Zuordnen von Aufgaben zu bestimmten Einrichtungen / Personen beschreiben	6

Supplementary Data 4: Consolidated criteria for reporting qualitative research 32-item checklist

No. Item	Guide questions/description	Reported on Page #
Domain 1: Research team and reexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7
3. Occupation	What was their occupation at the time of the study?	7
4. Gender	Was the researcher male or female?	7
5. Experience and training	What experience or training did the researcher have?	7
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7-8
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	6
12. Sample size	How many participants were in the study?	6
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Figure 1
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	6 and Table 2 (12)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Table 2 (12)
16. Description of sample	What are the important characteristics of the	Table 2 (12)

	sample? e.g. demographic data, date	
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6 and , Table 1 (7)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	8
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	8
20. Field notes	Were field notes made during and/or after the inter view or focus group?	8
21. Duration	What was the duration of the inter views or focus group?	8
22. Data saturation	Was data saturation discussed?	6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	8 and 9
Domain 3: analysis and %		
Data analysis		
24. Number of data coders	How many data coders coded the data?	9
25. Description of the coding tree	Did authors provide a description of the coding tree?	9 and Supp. Data 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	9
27. Software	What software, if applicable, was used to manage the data?	9
28. Participant checking	Did participants provide feedback on the findings?	9
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	13-21
30. Data and findings consistent	Was there consistency between the data presented and the findings?	13-21
31. Clarity of major themes	Were major themes clearly presented in the findings?	13-21
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	13-21

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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The perspective of asylum-seeking caregivers on the quality of care provided by a Swiss paediatric hospital –a qualitative study

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The perspective of asylum-seeking caregivers on the quality of care provided by a Swiss paediatric hospital –a qualitative study

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Word count: 4579

Abstract

Objectives:

This study investigated the perspective of asylum-seeking caregivers on the quality of health care delivered to their children in a qualitative in-depth interview study.

The health of asylum-seeking children is of key interest for health care providers, yet knowledge of the perspective of asylum-seeking caregivers when accessing health care is limited.

Setting:

The study took place in a paediatric tertiary care hospital in Basel, Switzerland.

Participants:

Interviews were done with thirteen asylum-seeking caregivers who had presented with their children at the paediatric tertiary care hospital. Nine female and four male caregivers from Tibet, Eritrea, Afghanistan, Syria, Iraq, Albania, and Macedonia were included. A diverse sample was chosen regarding cultural and social background, years of residence in Switzerland, and reasons for seeking care.

A previously developed and pilot tested interview guide was used for semi structured in-depth interviews between 36 and 92 minutes in duration. Data analysis and reporting was done according to consolidated criteria for reporting qualitative research (COREQ). The number of interviews was determined by saturation of data.

Results:

The interviewees described a mismatch of personal competencies and external challenges. Communication barriers and unfamiliarity with new health concepts were reported as challenges. These were aggravated by isolation and concerns about their child’s health. The following factors were reported to strongly contribute to satisfaction of health care delivery: a respectful and trusting caregiver-provider relationship, the presence of interpreters and immediate availability of treatment.

Conclusions:

A mismatch of personal competencies and external challenges importantly influences the caregiver-provider relationship. To overcome this mismatch establishment of confidence was identified as a key factor. This can be achieved by availability of interpreter services, sufficient consultation time, and transcultural trainings for health care workers. Coordination between the family, the government’s asylum system and the medical system is required to facilitate this process.

Strengths and limitations of this study

Strengths of this study:

- The inclusion of a cross-language concept and theoretical background.

- A thoroughly validated interview guide.

- A rigorous analysis, supported by an interdisciplinary research team.

Potential limitations of this study:

- As in-depth qualitative study, this study naturally comprises a relatively small sample as compared to larger quantitative studies. However, the study was performed until saturation in response was reached. Interview partners were chosen to include a diverse study population regarding cultural and social background, years of residence in Switzerland, and reasons for seeking care.

- Nevertheless, we acknowledge that minor aspects might not have been sufficiently covered, or that other participants from different contexts may have differing views.

Background

The recent increase of the global refugee population to 22.5 million people is the highest level ever recorded and poses challenges to health care systems and public health of host countries [1]. In 2017, European countries recorded 209,756 asylum claims by children [2]. Despite decreasing overall numbers of refugees arriving in Europe, national asylum services still registered over 115,000 asylum applications by children from January to September 2018 [3]. In Switzerland over 45, 000 asylum applications were registered in 2016 and 2017 [4]. The age of asylum-seekers has dramatically decreased in the last decade with 82% of asylum-seekers in Europe being aged below 35 years and approximately one third being children and adolescents below 18 years of age in 2017 [5].

Many refugees have had limited access to health care for years and therefore arrive in host countries with neglected health conditions [6-8]. The health of asylum-seeking children and adolescents is of key interest, as these represent an increasing refugee population in recent years and are a particularly vulnerable group [9-11].

Access to quality health care for asylum-seekers and refugees remains challenging and it is critical to identify underlying reasons [12 13]. This needs to be done from the perspective of health care providers as well as patients and their caregivers alike as the perception of challenges and expectations on quality of care provided may vary substantially [14 15].

Current understanding and evidence regarding challenges for the health care provision to asylum-seekers and refugees is growing. A recent systematic review focussed on qualitative studies investigating challenges and facilitators in providing health care to asylum-seekers and refugees. It identified three main fields influencing health care: the asylum process, the health care system and the health care encounter [16]. An important limitation of the review is that all included studies reported on the providers' perspective [16]. A recent review by our group on challenges in health care delivery to asylum-seekers and refugees in high-income countries included several studies assessing the asylum-seeking patients' perspective [17-28] and identified financial, legal, geographical and cultural challenges as additional external factors influencing access to health care [29] .

Very few studies have explored the perspectives of migrant caregivers and, to date, there have been no studies performed exclusively including asylum-seeking and refugee caregivers. Two Australian studies investigated their perspective on the quality of antenatal and early child health care [24 28]. One study from the US focused on health beliefs of migrant parents, working on farms [23] and one European study investigated migrant caregivers perception on how to maintain their children's health[30]. Therefore, studies assessing the perspective of asylum-seeking and refugee caregivers on quality of care provided to their children beyond the neonatal period and in the European context are lacking. To reduce this important knowledge gap, the aim of our study was to explore the perspective of asylum-seeking caregivers on the quality of care provided in a Swiss paediatric hospital.

Methods

Study design and setting

The study was designed as qualitative in-depth interview study at the University Children's Hospital Basel. The hospital is located in the city of Basel, which hosts the largest reception center for asylum-seekers in the area of Northwest Switzerland, where asylum-seekers are accommodated immediately after arrival for a maximum of three months [31]. The city of Basel also has various accommodations for accepted refugees and those in a prolonged asylum-seeking

evaluation process. The hospital receives referrals for children from the asylum reception centre and the various regional accommodations and asylum centres.

Study population

Caregivers of asylum-seeking children who presented to our hospital on working days were eligible for inclusion. We aimed to include a heterogeneous group of caretakers and performed purposive sampling using the following criteria to cover different perspectives: a) recent and distant (> 2 years) arrival in Switzerland; b) first and regular attendance to the hospital; c) presentation at the emergency department and at outpatient clinics; d) origin from different regions.

Potential participants were approached by the interviewer supported by a phone interpreter. Following oral consent, a separate appointment was scheduled with a face-to-face interpreter. Study participants' preference regarding language, dialect and gender of the interpreter was followed.

Sample size

Sample size determination was based on recommendations by the National Centre for Research Methods in the United Kingdom [32]. We aimed to achieve data saturation, expecting to include12 interviews until new data would mainly repeat information that was collected in previous interviews [33].. Saturation of the study results was discussed and determined by the interdisciplinary study team.

Data collection

A semi-structured interview guide (**Table 1 and Supplementary data 1**) was designed consisting of open questions mandatorily to be covered, followed by prompts to clarify given answers and allow for exploration of emerging, not-previously specified topics [34].

Table 1: Interview guideline – practical design (translated version)

Introduction	it is more a conversation, not a strict interview; everything important and correct; present interviewer and role; confidentiality; maximum one hour; Audio recording ok?	Small-Talk Conversation, no interview; everything important and correct Answers also summarized by other parents confidentiality Maximum one hour Is audio recording ok?
Think about the moment before you came to the UKBB – what made you come?	Referrers? Presentation: basic Information? Communication? waiting times? Uncertainties?	How was it before you came? Has anyone signed up for you or did you do it yourself? first time at hospital? Referring? Did you know exactly what you need to do? (Information) Why did you come up to date, what illness did your child have? What was helpful when signing up or where did you need more support? Language? (Communication) Were there moments when you were not sure what to do?
Tell us what happened when you arrived at UKBB	arrived at reception and then? accompanying persons? felt understood in your concerns? what happened next? Doctor and nurse? did you think that what they did with your child is right? How did you feel?	You went to the reception / registration and then? Was someone there? Did you know how to proceed? Waiting times? Were you informed? Did you have an interpreter? Was this the first time? Did you need that before? What was helpful when signing up or where did you need more support? Did you understand you and your concerns? What happened then? Tell about the doctor and the care. Did you understand her? Was there an interpreter? Did you trust that what you did with your child is right? Did you feel safe at home? (Confidence)
How was the further care?	was the care as intended? what is different in your country of origin? would you go back to this hospital?	Was the care as you thought it would be? Were there situations where you thought it should be different or faster? Did you trust the doctors / other medical persons at the hospital? how did you feel? (sad, insecure, angry). What was especially great? What did you tell your friends? Concrete persons? What would have been different in your country of origin? What would you like to introduce here from your home country? What would you like to introduce in your home country from here? What role does religion play in the hospital for you? Would you go to the hospital again? Recommend it to your compatriots? If you would go there again, what would you like to be different? What should remain the same? Describe: what characterizes the perfect doctor for you? What the perfect nurse?
What was your general impression?	drugs received? did you receive further instructions / therapies from the doctor? do you think that what the doctor has suggested helps? If not, why? are more doctor visits planned? does your child have a pediatrician? know where to go for health issues?	Medication received? Recipe? How to take? How bought? Did you receive further instructions / therapies from the doctor? Do you think that what the doctor has suggested helps? If not, why? Did you do it differently? Did you have a contact person in case of uncertainty and questions after the hospital consultation? Are more doctor visits planned? Does your child have a pediatrician in Basel? If not, why not? If so, how did you find him? Do you know where to go for health issues (continuity of care)?
Wrap up	additions? was it easy to express your opinion? give phone number from interviewer for inquiries	From my point of view, we have addressed all topics. Many thanks for the valuable hints. Are there any additions from your point of view? How do you feel after the conversation? Do you have anymore questions? Was it easy to express your opinion? How could we best ask the opinion of their compatriots? How do you do that in your country? What else can we help you with? Give phone number from interviewer for inquiries
Context	where were you born? How did you come to Switzerand?	Where were you born? Where have you lived? How arrived in Switzerland? Already experiences with hospitals?
Back up	experiences at home with hospitals? what's better, what do you miss here? what tips for other parents, before they come to the hospital?	What experiences did you make with hospitals in your home country? / On the way to Switzerland? what is different here? what is better, what do you miss here? What tips for other parents, before they come to the hospital?

First row: mandatory to be covered in open questions; second and third row: prompts as sub-questions

The interview guide was reviewed by an external organizational psychologist with extensive experience in qualitative research. After external revision two pilot interviews were performed to test intelligibility, acceptability and extensiveness. A further revision was done based upon feedback from the caregivers involved in the pilot interviews. To address the challenges in cross-language qualitative research [35-37] and minimize the language barrier, a cross-language concept was developed, describing steps of translation and quality control (Figure 1). The cross-language concept was developed using the guidelines on interpreter use of the Qualitative Forum of Social Science [38].

Baseline data was collected using a case report form (**Supplementary data 2**). The in-depth interviews were done according to participants' preference at their home, asylum residence or at the hospital. Interview duration was scheduled for 60 minutes and done once only. All interviews were audiotaped and transcribed as pure verbatim protocols [39] in either English or German with anonymization of all patients. The transcriptions were reviewed in detail by the interpreter present during the interview according to the cross-language concept. Para-verbal reactions, interactions between family members, other observations and cultural aspects were documented in field notes and discussed by the interviewer and interpreter during debriefing.

The role of the interviewer

The interviewer (JB) is an experienced female clinician-scientist (MD) and conducted all pilot and study interviews. During the study period she was employed by the University Children's Hospital Basel in the migrant health service research group. She is experienced in qualitative research, received trainings in interview-techniques and qualitative research methods and has a special interest in global health. Not knowing JB beforehand, the interviewer's background, the

purpose and goals of the study were explained to the participants during the oral consent and repeated during the introduction phase of the interview.

Data analysis and reporting

Data analysis was done according to the qualitative content analysis of Mayring [39].A codebook (**Supplementary data 3**) was prepared and refined in several steps, involving team discussion with JB, KS and CD. Four interviews were coded in parallel by each researcher to ensure the comprehensiveness of the codebook. Code categories were extracted, relations identified and abstracted in networks and graphs to generate a coding tree. Reporting was guided by the consolidated criteria for reporting qualitative research (COREQ; **Supplementary data 4**) [40]. The analysis was done using atlas.ti (ATLAS.ti 8 Scientific Software Development GmbH, Berlin). The entire study process was accompanied by the interdisciplinary Migration Research Group at the University of Basel.

Patient and Public involvement

During pilot interviews caregivers' feedback was obtained to improve the interview guide and the way the interviews were done. After the pilot phase all participants were asked if the method was suitable and how they felt about expressing their opinion at the end of the interview. An interim expert panel discussion consisting of staff from the asylum-seeking reception center and the University Children's Hospital Basel was organized, to evaluate results. In addition, one interview participant reviewed the entire paper.

Ethics

As a quality assessment project of the University Children's Hospital Basel, there was no ethical approval required for this study. This was confirmed by the Ethics Committee of Northwest/Central Switzerland on October 4th 2017. We strictly adhered to international research

standards rigorously including information about entirely voluntary participation of the interviewees and the possibility to withdraw consent without any negative consequences, separation of research and clinical staff and data confidentiality.

Results

A total of 13 interviews were performed and included in the analysis, conducted in Tigrinya, English, Arabic, Dari, Farsi and German (**Figure 1**). In all interviews, the professional interpreters ensured a smooth dialogue between the participant and the interviewer and helped to establish a pleasant atmosphere. The baseline characteristics of participating caregivers and the interview context are summarized in **Table 2**.

Table 2: Baseline characteristics of participating caregivers and interview context

	1	2	3	4	5	6	7	8	9	10	11	12	13
Participant characteristics													
Country of origin	Tibet	Eritrea	Afghanistan	Eritrea	Syria	Afghanistan	Syria	Iraq	Albania	Syria	Macedonia	Syria	Syria
Age child	1-5	1-5	< 1	> 10	1-5	1-5	1-5	6-10	1-5	<1	1-5	1-5	6-10
Main department visited	OPD	OPD	OPD	OPD	OPD	OPD	OPD	Emergency	Emergency	Emergency	Emergency	Emergency	OPD
Age caregiver	40-49	30-39	20-29	30-39	20-29	10-19	20-29	30-39	30-39	30-39	30-39	30-39	40-49
Sex caregiver	Male	Male	Female	Female	Female	Female	Female	Female	Female	Female	Male	Female	Male
Education level caregiver*	4	3	3	3	3	3	3	4	2	3	3	4	3
Years in CH	6-10	1-5	1-5	1-5	1-5	< 1	< 1	1-5	6-10	< 1	< 1	1-5	< 1
Mother tongue	Tibetan	Tigrinya	Dari	Saho	Arabic	Farsi	Arabic	Kurdish	Albanian	Arabic	Macedonian	Arabic	Arabic
Other language (level)**	English (C)	English (A)	German (A)	Arabic (C)	Kurdish (C)	-	-	German (B)	German (B)	-	German (C)	English (C)	-
Interview context													
Interpreter present	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	Yes
Gender preference	n/a	No	Female	No	No	Female	No	n/a	n/a	Female	n/a	n/a	No
Interview location***	2	2	3	3	3	1	3	3	3	1	1	3	1
Interview duration (min.)	49	36	70	92	68	50	57	52	59	79	44	64	77
Number and (type) non-participants	2 (wife and child)	0	3 (husband, children)	4 (husband, children)	2 (coach, child)	0	3 (husband, children)	1 (child)	1 (child)	0	0	2 (child, student)	1 (wife)

* Education levels: 1 = illiterate, 2 = primary education, 3 = secondary education, 4 = university degree

** Language levels: A = basic user, B = independent user, C = proficient user

*** Interview location: 1= accommodation and provisioning center 2= hospital 3= participants' apartment

CH = Switzerland; n/a = not applicable; OPD = outpatient department other than emergency

The results are presented in two sections, focusing on challenges and good practice reports.

Mismatch of competences and organizational challenges

Caregivers described mismatches between their personal sociocultural and language competencies and the situation of health care. In addition, they faced organizational challenges, e.g. orientation to new surroundings after relocations. They described that this created stressful situations leading to feelings of disorientation, dependency and anxiety. This was felt strongest early after arrival and for those who had not previously lived in a cultural context like Switzerland. It became more pronounced if there was an urgent threat such as the illness of their child.

> I was frightened. I didn't know the language, I didn't know anybody. I took care of my children and I didn't know where I was. […] I was extremely worried about [my sick child]. And I didn't know: what happens? Whom should I ask? Where should I go? I had no money with me. In fact, I didn't know where I was. (4; 2:21)

Caregivers who were unable to speak or understand a local language described communication as a challenge. The inability to sufficiently explain the medical history and complaints of their child was reported to be frustrating. Being highly dependent on interpreters, one caregiver recalled feelings of fear when the interpreter was late for the appointment.

> At my second visit I was a bit frightened as the interpreter was not there. I thought: oh my God: how can I understand now [what they say]? How can I talk to them? I was a bit nervous in this moment, this was a bit difficult. (13; 14:31)

Mismatch of health concepts

Caregivers explained that their own health concepts were shaped by their culture and previous experiences. They arrived with certain expectations about Swiss health care based on stories they had heard. One important topic was the use of medication. Two caregivers stated that they had wished to receive a prescription for medication.

> In Afghanistan […] doctors have limited resources. We don't have many options. But if you go to the doctor […] you get medication and you get antibiotics if you have an inflammation or something like that. Here, that's not the case. You continue to be sick, after four or five consultations it gets better, yes, but maybe it would have been better anyway. (3; 29:46)

> In Syria, when my son or my daughter was sick, I just went to the pharmacy. It‘s like a supermarket. And then I buy […] antibiotics too, that's completely normal. (10; 7:24)

Some health concepts such as preventive services were reported to be unfamiliar. For one caregiver the detailed examination of the child during tuberculosis screening suggested to her that the child was seriously sick. The caregiver was unable to imagine why this was required when no obvious health problem was present. She explained that the idea of going to the hospital with an apparently healthy child was completely new to her.

> I knew my children were not having tuberculosis. However, I was frightened. Because they work so thoroughly [at the hospital] and they have done examinations, and that is why I was really frightened. (7; 4:40)

For some caregivers, the way in which physicians would communicate about health was unfamiliar. One caregiver mentioned that bad news was disclosed to her by five physicians which was a shocking and unpleasant experience. In addition, the information was given faster and much more directly than she was used to. She had wished that only one person had given here the information in small steps. Other caregivers, too, wished that physicians would explain more about the disease, causes and resulting treatment.

Limited personal resources

For caregivers being part of a family was considered a resource and being separated from loved ones was a psychological challenge. In many instances mothers described arriving in Switzerland with their children but without their husbands. They were reported to have been forced to stay as soldiers or prisoners or had been killed before the family left. In case of limited financial resources, priority was given to the mother and children leaving the country. The lack of communication with them or other family members was contributing to the feeling of loneliness. This was aggravated if a child was diagnosed with serious health problems and had to be admitted to the hospital.

> I had no clue about a health insurance, no clue about the law, the law here and the rules. I just endured these days there [on the ward]. […] I felt very lonely. My husband was not here at that time. That was very difficult. (3; 29:16)

Being a single caregiver had practical implications. For example, attendance to medical appointments was challenging as child care for healthy siblings is usually not available for asylum-seeking families. Another example was that the caregiver refused admission as she was unable to stay with her sick child.

> [The doctor] said you have to stay 7 to 10 days here with your son. That's what he told me just like this. And then I answered: I can't, I have [six] children and their father is not here. (4; 2:11)

Caregivers described how family members residing in neighboring countries could have been of psychological and practical support. However, as their asylum process was pending, they were not allowed to cross borders. One caregiver reported crossing the border to see family members for support in a desperate situation and being caught by police.

One caregiver reported being the single parent present made it difficult to give her child the prescribed medication. When she reported this to the physician she was treated disrespectfully and asked to leave.

> That's what made me angry: we told the truth to him. We can't just lie […]. Maybe the medication doesn't taste good, doesn't smell good. I thought: […] if I tell it to him we could maybe change it. But he was angry and just left. He said: go home! So I went home. (5; 13:32)

External challenges

Caregivers also expressed difficulty accessing health care, particularly if the asylum process was prolonged. In stations with pending asylum decision some participants reported that a health insurance card was not issued, which caused delays, additional administrative work and made caregivers feel inferior.

One caregiver described that the official person in charge brought the sick child to the hospital in a private car, took care of the administrative tasks and stayed with the family during the consultation. Another caregiver reported that the official person in charge was reluctant to address the family's health needs.

> Three years here. My chief [official in charge] said that I'm only parked here. But I'm not a car! We are parked here, 7 years by now! With F status [provisionally admitted refugees]. Tell me, why does it have to be like that? Parked! (9; 6:98)

Caregivers also described insufficient coordination between the asylum reception centers and the hospital. Two recently arrived mothers of admitted children did not have cash money. Unfamiliar with the system that they must buy their own food and unable to communicate that they had no money, the mothers fasted during several days or were eating from their children's meals.

Some caregivers explained that after the consultation they did not know how to return to their asylum center/home center. One caregiver had recently moved and did not recall her new address. Others reported to have been driven home by the interpreter or a taxi. One caregiver living in a rural area was worried not to be able to get home and therefore left the emergency department before the end of the consultation.

Understanding and responding to medical needs

Twelve out of 13 caregivers expressed a deep gratitude for the health care their child received at the hospital. They also appreciated when help was offered in various situations by interpreters, officials in charge of the asylum process, taxi drivers, engaged citizens, receptionists, social workers, nurses or doctors.

> It is impossible to describe, I can't describe it. Doctors or social workers, everybody supported and helped me. (4; 2:86)

Caregivers appreciated the fact that an interpreter was used, and this led to trust as they felt understood in their most urgent need.

> I swear, if I can talk there, I have the feeling that I'm safe! (5;13:58)

All but one caregiver explained that they were impressed by the medical help their child received. They mentioned that in the past, they never experienced such a high level of medical care, neither at their home nor in transit countries.

> I don't think you see this facility in any other country. It was around half past 10 at night. We thought he swallowed something. […] We got really scared. […] The doctor said: he will call the lady who is doing the x-ray, from home. Wonderful! This is service to the King! She came from her home to do x-ray to our son. This is fascinating! (1;12:31)

When asked why they were satisfied with the quality of care, they emphasized the immediateness of medical care. They were used to long waiting hours extending up to days. Understanding and rapidly addressing the child's health needs lead to trust and the feeling of being understood and safe.

> I like the support. The quick treatment, everything included. Not like at home, really. [..] I'm so thankful, that the child is in good hands. (11; 8:54)

Access to good quality health care was for some caregivers one important reason why they lodged an asylum-application in Switzerland.

> Sometimes I get nervous, I say: I'm dead, I have to leave. […] But then I think: I have to be thankful. I have a room and my child gets an immediate check-up if he is sick. (9; 6:91)

Showing respect

Almost all caregivers greatly appreciated that they were treated in a respectful way. Respect was even more important, if they had had negative experiences with health care providers in the past.

> In Iran, they don't treat […] people from Afghanistan with respect. […] It is not like here. For example, at the reception: maybe they don't even give you a registration code, they don't listen to you. We are very satisfied and thankful, that we came to this country because we were always treated with respect (6; 3:18)

Simple and routine practices were acknowledged as good practice such as the physician coming to the room of the patient and not vice-versa. Caregivers recalled that the physician helped to undress the patient or approached the child in an appropriate and friendly way. One caregiver appreciated that the nurse was playing with the child during the consultation. This allowed her to concentrate on the treating physicians explanations. A caregiver from Iraq appreciated that the staff directly addressed the eight-year-old daughter and therefore respected the child's opinion. A further caregiver appreciated that the staff adapted to the individual reactions of the children.

> What I liked: my children had two different behaviors. One cried and refused to cooperate. The nurse helped us. […] We helped each other. By the end both children received what they needed. (2;11:10)

Building trust through relationship

A trustful relationship to health care providers was central to all caregivers when evaluating the quality of health care. Two caregivers of children with chronic diseases visited the hospital frequently and described a family-like relationship with the hospital staff.

> If I go [to the Children's hospital] I don't see it like a hospital. The nurses, the doctors and everything, they are like my family. (4; 2:90)

As verbal communication was frequently limited, non-verbal communication was important for building a trustful relationship. Two caregivers explicitly highlighted how they appreciated when the medical staff was smiling.

> If somebody smiles at me, a beautiful smile, that makes me really happy. Then I get a very beautiful feeling. And the doctor was nothing but happy and friendly and smiled all the time at me. (9;14:52)

A trustful caregiver-provider relationship allowed caregivers to accept unfamiliar health concepts. For example, one caregiver was upset about not receiving a prescription for her child, but she explained how this changed after a medical consultation at the emergency department.

> I thought she would get a lot of medication, as she had fever. But no: they only gave this suppository to her. […] They said: don't be frightened, your daughter will be fine. She just needs time to recover. And that was the right way. I went back, and that was right. So that is an ideal doctor to me: Who knows exactly what happens, without giving too many drugs. (10; 7:40)

Another caregiver had the concept that she should never leave her infant alone in hospital. Her daughter was admitted with a chronic disease and the medical staff recommended that she go home to rest while her infant remained admitted.

> It was a shock. We […] don't have this in our culture that mum leaves the baby. But later, I said it's very helpful to go out, really because the nurses were […] very, very good. Then I understood that: If I'm good, she will be good. […] […] We have to know that. That the doctor works for us, not against us. (12; 9:27)

Discussion

To our knowledge, this is the first study investigating the perspective of asylum-seeking and refugee caregivers on the quality of health care provided to their children in Europe.

The detailed analysis of the interviews displayed a range of challenges for asylum-seeking and refugee caregivers and their sick children. However, despite including a diverse group some universal challenges were noted. This included the development of a trusting relationships, communication including interpreter services and coordination between the health care and the asylum systems. These findings confirm results from a recent systematic review which identified communication, continuity of care and confidence as the three main factors influencing health care provision to migrants [29]However, our study also highlights important additional aspects for this group of patients specifically regarding confidence and continuity of care.

First, confidence was the key factor contributing to satisfaction of the study participants. Confidence was achieved through a trustful caregiver-provider relationship. This finding is also supported by other studies, e.g investigating mental health care delivery to migrants [17 26]. In some instances confidence has been described as being an integral part of the treatment [41]. It is remarkable that small actions such as a smile by the treating physician, being helpful to undress and interacting in a playful way with the sick child, were helpful in the process of trust-building. This highlights that simple and easy measures may have important benefits for the health of asylum-seeking and refugee children and such knowledge needs to be included in transcultural training of health care workers.

Second, caregivers explained that challenges regarding the continuity of care were occurring at the intersection of the medical and the asylum-seeking systems. Challenges included the asylum-process itself, transport and access to money. Our study identified that for a positive perception of health care delivery, these areas required optimal coordination. This result is also echoed in a recent publication describing health care delivery models for refugees, which suggested including specialized case managers as one option to improve cooperation between services [42]. Connecting services may be facilitated by other interventions such as involvement of social workers and predefined referral pathways and specialized migrant health teams.

Third, communication is important in all health care encounters and has been identified as a key barrier or facilitator in this study. Numerous earlier studies have investigated the negative influence of language barriers on patient experience, health literacy and patient-provider relationship [43]. Communication was also described as essential for the adoption of new health concepts, for example, the rational use of antibiotics [44] . Although the requirement of interpreters is not debated, most health care systems in Europe do not have established payment policies for interpreter services. This results in frequent use of ad hoc non-professional interpreters, which is associated with considerable risk of translation errors leading to clinical consequences [45]. It is therefore important that coverage for interpreter services is included in health care insurance plans, which is currently advocated by a position paper published by the Swiss Hospital for Equity network (https://www.hospitals4equity.ch/).

Generally, the caregivers expressed very positive feelings about the medical care their children had received. Nearly all caregivers expressed their gratitude by giving detailed examples of individual support, fast and adequate medical care and a respectful and trustworthy approach by health care providers. A recently published study explored expressions of gratitude in women with migrant background whose health needs were not or only partially met and raised questions in how far this speaks to current normative expectations and attempts to restrict welfare. Gratitude might thus be expressed in order to “avoid being identified as excessively needy, undeserving newcomers” [46].. . It is important to take such logics and power relations into account, yet, in our study, none of the participants perceived a failure of the specific hospital or health care system. In one case, a person expressed gratitude regarding the overall care, even though she was not satisfied with one of the consultations. This could be part of the general expectations and discourse of gratitude, yet, we also interpret it as a differentiated picture of judging different parts of the same health care facility differently.

There is a possibility that through selection bias only satisfied caregivers had agreed to participate in this study. However, only one caregivers meeting the inclusion criteria refused to take part in the study. The approached caregivers were keen to be interviewed and appreciated the opportunity to express their opinion. In contrast, the hospital’s earlier efforts to assess patient’s satisfaction in asylum-seeking and refugee families using translated satisfaction questionnaires had a low response rate. This suggests that patient satisfaction inquiries using interviews instead of questionnaires are more acceptable to asylum-seeking and refugee caregivers.

A potential limitation of the study is the small number of interviews performed. However, the interviews were rich in content and included a diverse study population regarding cultural and social background, years of residence in Switzerland and reasons for seeking care. The information gathered started to repeat after 11 interviews, signaling saturation regarding the major themes. Nevertheless, we acknowledge that minor aspects might not have been sufficiently covered, or that other participants from different contexts may have differing views. The strengths of this study are the inclusion of a cross-language concept, a solid theoretic background, a thoroughly validated interview guide and the rigorous analysis, supported by an interdisciplinary research team. Therefore, we believe that our findings are relevant to health services in many host countries caring for asylum-seeking and refugee families from various backgrounds.

Conclusion

A mismatch of personal competencies and external challenges importantly influences the caregiver-provider relationship. To overcome this mismatch establishment of confidence was identified as a key factor. This can be achieved by availability of interpreter services, sufficient consultation time, and transcultural trainings for health care workers. Coordination between the family, the asylum and the medical system is additionally required to facilitate this process.

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Author’s contribution

JB and NR study conception; JB data acquisition; JB, KS, CD and NR data analysis; JB wrote the first draft, JB, KS, CD, FJ, BP and NR revised the manuscript. All authors had access to the data and gave intellectual input. JB and NR affirm that this manuscript is an honest, accurate and transparent report of the results and that no important aspects have been omitted.

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Competing interests:

None declared.

Disclaimer:

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Ethics approval:

As quality control project, this research project does not fall under the remit of the cantonal or federal law of the Human Research Act (HRA). The EKNZ (Ethikkommission Nordwest- und Zentralschweiz) has reviewed the submitted documents and confirms that the research project fulfills the general ethical and scientific standards for research with humans (see Art.51 Abs 2 HRA).

Patient consent:

Oral informed consent obtained.

Data sharing statement:

No additional data available.

Figure 1 Legend:

Flow-chart, depicting the different phases of the patient recruitment and the cross-language concept including transcription, translation and understanding of language

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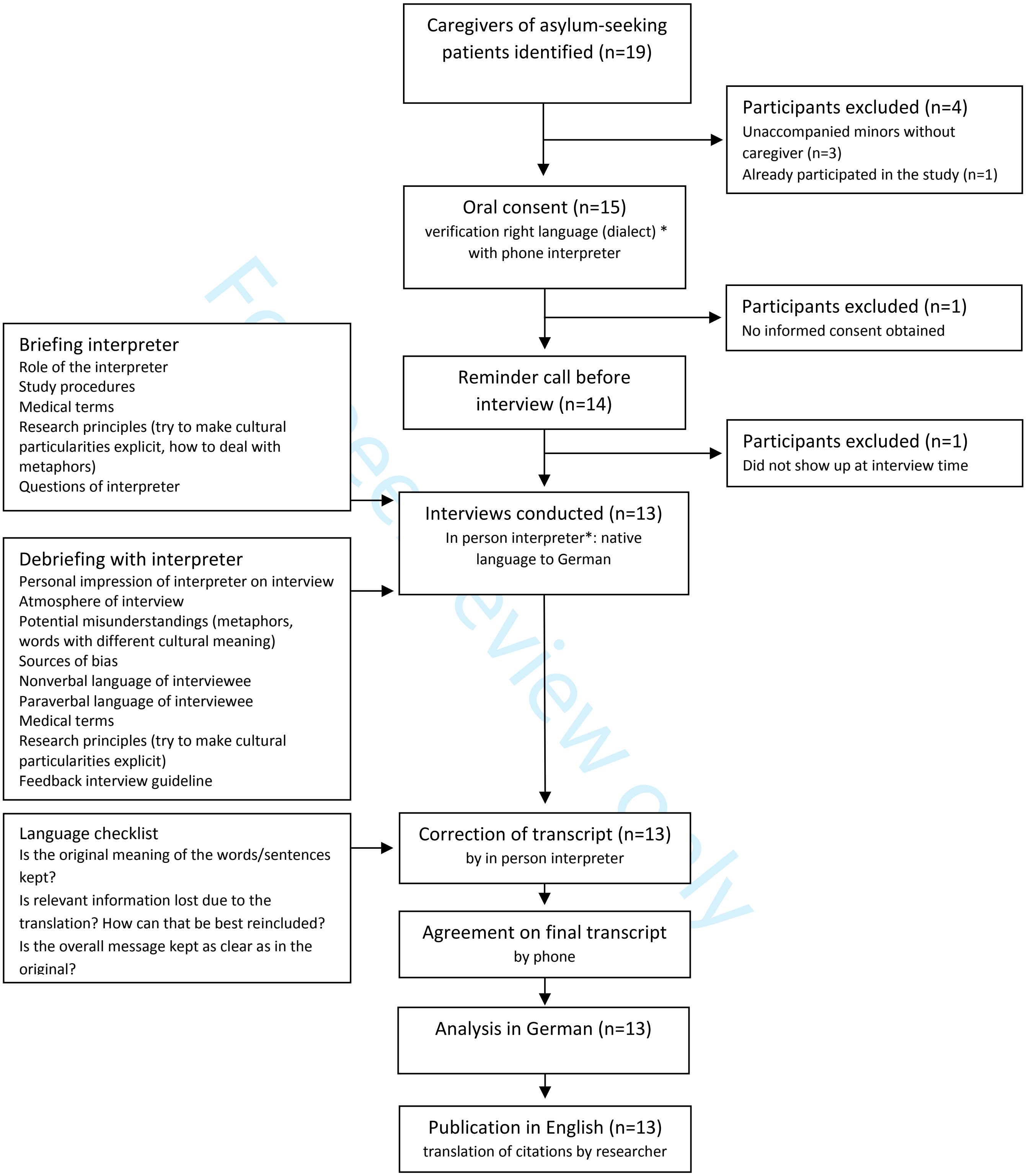
Figure 1: Flow chart of participant recruitment and integration of cross language concept



*= If communication in German/English not adequate

Supplementary Material

Supplementary Data 1: Interview guideline – theoretic design

1. Context (ice breaker oder am Ende erfragt)

- Könnten Sie uns erzählen, wo sie geboren sind, gelebt haben und wie Sie in die Schweiz gekommen sind?
  - **Waren Sie auf Ihrem Weg hierher mit Ihrem Kind in anderen Krankenhäusern / Einrichtungen?**
    - **Wenn ja im Ausland (welches Land)?**
    - **In der Schweiz?**
- Was hat Sie veranlasst ins UKBB zu kommen?
    - **Hat man Sie in das Kinderspital geschickt? Warum?**
  - **Haben Sie das Spital gut gefunden?**
- Welches Verkehrsmittel haben Sie benutzt?
  - **War es teuer herzukommen?**
- Sind sie in einem Migrationsprogramm das Sie unterstützt? Haben Sie einen persönlichen Betreuer?

2. Communication

- **Können Sie erzählen, wie die Konsultation am UKBB verlaufen ist?**
  - Sie kamen mit Ihrem Kind an die Anmeldung und dann?
    - Wie verlief die Kommunikation an der Anmeldung?
  - Welche Erkrankung hatte Ihr Kind?
    - War die Erklärung verständlich?
  - Wieviel medizinisches Personal haben Sie gesehen? War(en) ein Arzt(e) dabei? Wenn ja wieviele?
  - Was hat der Arzt gesagt, sollen Sie tun?
  - Welche Sprache(n) wurden mit Ihnen gesprochen?
- **Hat der Arzt einen Dolmetscher verwendet? Hat ein Bekannter für Sie übersetzt?**
    - Wenn ja per Telefon oder persönlich? Wie empfanden Sie das?
    - Wie konnten Sie mit dem Personal sprechen?
      - War es einfach? War es schwer? Warum?
- **Wie war die Kommunikation mit allen Angestellten des UKBB für Sie?**
  - Was fanden Sie gut?
  - Was fanden Sie schwierig?
  - Was könnte man besser machen? Was soll so bleiben?

3. Continuity of care

- **Nach der Vorstellung im UKBB, was haben Sie gemacht?**
  - Mussten Sie Medikamente zu Hause geben?
    - Wenn ja: haben Sie ein Rezept erhalten?
    - Wie haben Sie das Medikament besorgt?
  - Waren Sie bei einem anderen Arzt?
  - Hat Ihr Kind einen Kinderarzt? Wie haben Sie den gefunden?
  - Sind weitere Arztbesuche geplant?
- *Wenn sich der caregiver für ein anderes Procedere als das verordnete entschieden hat*:
- Können Sie erklären, weshalb Sie sich anders entschieden haben?
  - Denken Sie, dass das was der Arzt vorgeschlagen hat nicht hilft?
  - War es schwierig, das zu machen was Ihnen vorgeschlagen wurde?
- **Hat ihr Kind einen Kinderarzt in Basel?**
  - Wenn nein, weshalb nicht?
  - Wenn ja: wie haben Sie den gefunden?

4. Confidence

- **Beschreiben Sie: was wäre der perfekte Arzt für Sie? Was der perfekte Krankenpfleger?**
  - Wie würde man Sie behandeln? Was würde man tun?
- **Wie haben Sie sich während der Behandlung gefühlt?**
  - Waren Sie traurig, verärgert? Verunsichert?
    - Falls ja warum?
    - Was hätte man in Ihrem Herkunftsland anders gemacht?
    - Hatte nur eine Frau/nur ein Mann ihr Kind untersucht?
    - Was für eine Rolle spielt Ihre Religion im Krankenhaus für Sie?
- **Was denken Sie von den Personen, die sich um ihr Kind gekümmert haben?**
  - Gab es jemanden der es besonders gut gemacht hat? Was hat er gemacht?
  - Gab es jemanden der es nicht gut gemacht hat? Was hat er gemacht?
  - War die Betreuung so, wie Sie es sich gedacht haben?
    - War es besser/schlechter als Sie gedacht haben?
    - Was hätte besser sein sollen? Was war gut?
- **Würden Sie nochmal ins UKBB gehen?**
  - Wenn Sie nochmal dorthin gehen würden, was hätten Sie gern anders?
  - Was hätten Sie gern wieder genau so?

Supplementary Data 2: Case report form

bei der Rekrutierung ausfüllen:

Am UKBB vorstellig geworden am (dd/mm/yyyy):____

Department (NF/ MS/ Poliklinik) :____

ID-Nummer Interview care-giver (initi.Departm.&Nummer): _____-__________________________________

Alter des betreuten Kindes(Jahre & Monate/12): __________________Jahre ______________/12 Monate

Bekannte Erkrankungen des betreuten Kindes:____

mündliches Einverständnis Studienteilnahme erteilt (nein0 /ja1) ___________________________________

Sprachen des Care givers & Niveau(fliessend4 /gut3 /ausreichend2 /einzelne Worte1):________________

____

Dialekt____Interpreter

nein0/ja1___________________________Präferenz egal0/männlich1/weiblich2_____________

Berufliche Tätigkeit caregiver im Heimatland____

Berufliche Tätigkeit in der Schweiz____

Bildungsniveau des Caregivers (Höchste Ausbildung angeben: Analphabet1, Grundschulabschluss2, Abschluss

weiterführende Schule3, universitärer Abschluss4,)____________________________________

Geschlecht des care-givers (m1 /w2)____

Alter des care-givers (Jahre):____

Geburtsort des care-givers (Stadt & Land):____

In der Schweiz seit(Monate &Jahre):____

Beim Interview ausfüllen:

Aktueller Tag (dd/mm/yyyy)_________________ Uhrzeit (hh:mm)_________________________________

Ort Interview (EVZ1; Studienzentrum UKBB2;eigene Wohnung3)__________________________________

Zudem anwesende Personen beim Interview (Funktion): _______________________________________

Supplementary data 3: Code book including code definitions and frequency of appearance

	Kommentar	**Häufigkeit**
Abhängigkeit	= Beschreibung, in welcher der Caregiver von anderen Personen/Dingen abhängt	54
Adaptation Gesundheitskonzept	Veränderungen des eigenen Konzepts von Gesundheit/Gesundheitsversorgung aufgrund von Erfahrungen in schweizer Gesundheitseinrichtungen	19
Akute Krankheit Patient	= Erkrankung, die plötzlich aufgetreten ist / plötzliche Verschlechterung einer bereits vorhandenen Erkrankung, die mehr Hilfe benötigt als im sonstigen Zustand	9
Andere Kantone	= Aussagen über Kantone, in welchen der Caregiver sich aufgehalten hat ausserhalb von Basel-Stadt	32
Angestellte Wohnheim	= Aussagen, die Angestellte im Wohnheim betreffen	33
Angst Caregiver	= Emotionaler Zustand der Furcht des Caregivers im Hier und Jetzt	22
Ärger UKBB	= Beschreibung eines Gefühls der Unzufriedenheit und leichter Wut über das Kinderspital	4
Asylstatus	= rechtlicher Status, der die Möglichkeit im Land zu bleiben bestimmt	15
Ausdrücken der eigenen Meinung	= die Möglichkeit, uneingeschränkt seine persönliche Meinung kund zu tun	9
Beruf Caregiver	= Tätigkeit mit Lohnerwerb des Caregivers	12
Beziehung Caregiver - Patient	= das Verhältniss zwischen dem Patienten und seinem Caregiver	22
Bildung Caregiver	= Studium/Ausbildung des Caregivers	3
Chronische Krankheit Patient	= lang andauernde Krankheit, die nicht vollständig geheilt werden kann	21
In vivo	D: ja ich schwöre, wenn ich da ein bisschen sprechen kann	1
Dankbarkeit gegenüber UKBB	= Ausdrücken des Bedürfnisses, sich beim Kinderspital zu bedanken.	46
Dolmetscher: Amateur	= nichtprofessioneller Dolmetscher (ohne strukturiertes Training und entsprechendes Zertifikat)	14
Dolmetscher: prof.	= strukturiert ausgebildeter, zertifizierter Dolmetscher	31

Präsenz		
Dolmetscher: Telefon	= zertifizierter Dolmetscher, der über das Telefon übersetzt	16
Engagement Einheimischer	= intensiver Einsatz / Anstrengung von Menschen, die schon lange im Host-country des Asylsuchenden wohnen	20
Enttäuschung UKBB	= Beschreibung eines Gefühls der Traurigkeit aufgrund von nichterfüllten Erwartungen gegenüber dem Kinderspital	5
Erwartungen Caregiver	Leistungen, die der Caregiver vom UKBB/der Gesundheitsversorgung der Schweiz erwartet	22
Fachliche Kompetenz Administration UKBB	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Administration UKBB	13
Fachliche Kompetenz Ärzte	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Ärzte des UKBB	61
Fachliche Kompetenz Pflege	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Pflegenden des UKBB	28
Familie: getrennt	Beschreibung der Familie / familiären Struktur des Caregivers	19
Familie: zusammen	Beschreibung der Familie / familiären Struktur des Caregivers	8
Familiengefühl	= Beschreibung für Menschen die keine Verwandten sind familiäre Gefühle zu haben	5
Finanzen	= Finanzielle Situation Caregiver	44
Fluchtdauer	= Zeit vom Heimatland bis in das Hostcountry	12
Fluchtursache	= Gründe, die der Caregiver nennt, die dazu geführt haben, dass er und der Patient das Heimatland verlassen haben	13
In vivo	für mich sind König Kinderspital	1
Geschlechterrolle	= Beschreibungen des Caregivers, die die Unterschiedlichen Rollen von Geschlechtern aus seiner Sicht beschreiben	7
Geschwisterkinder	= Beschreibungen, die die Rolle der Geschwister betreffen	7
Gesundheitsinformation: gewusst	= Aussagen, die wichtige Hinweise für die Gesundheit des Patienten beinhalten welche dem Caregiver erklärt wurden	40
Gesundheitsinformation: nicht gewusst	= Aussagen, die wichtige Hinweise für die Gesundheit des Patienten beinhalten welche dem Caregiver NICHT erklärt wurden	17
Haltung Caregiver --> med. Personal	= Haltung, die der Caregiver gegenüber dem medizinischen Personal bzgl der sozialen/beruflichen Stellung hat	32

Haltung med.Personal --> caregiver	= Haltung, die das med. Personal gegenüber dem Caregiver bzgl der sozialen/beruflichen Stellung hat	32
In vivo	I think being a patient, our only duty is to bring our body to the hospital	1
In vivo	ich bin froh wenn im Kinderspital	1
In vivo	Ich denke dass Doktor nicht denke das ist fremde Kind	1
Informationsfluss	= Weitergabe von für die medizinische Betreuung relevanten Informationen	24
Infrastruktur UKBB	= Aussagen zur Ausstattung des UKBB	12
Integration	= Beschreibungen, die den Vorgang beschreiben, ein lokales Beziehungsnetzwerk aufzubauen	11
Kinderbetreuung	= Beschreibungen über die Organisation/ Möglichkeit der Aufsicht des Patienten / von Geschwistern	8
Kompetenz Sozialarbeiter	= Beschreibungen zu Fähigkeiten der Sozialarbeiter	8
Konzept Primärprävention	= Beschreibungen, die das Konzept der medizinischen Vorsorge beschreiben, welche darauf hinzielt Erkrankungen zu vermeiden	5
Kooperation Kanton – UKBB	= Zusammenarbeit der Kantone mit dem Kinderspital	10
Kooperation med. Personal - Caregiver	= Zusammenarbeit zwischen dem medizinischen Personal UKBB und dem Caregiver	11
Kooperation med. Personal - Patient	= Zusammenarbeit med. Personal und Patient	17
Kooperation SEM - UKBB	= Zusammenarbeit Angestellter des Bundes (vor allem EVZ/MIZ) und Verfahrenszentrums und des Kinderspitals	21
Koordination UKBB	= Beschreibung der Absprache von verschiedenen Organisationseinheiten innerhalb des UKBB	12
Krankenkasse	= Beschreibungen, die die Krankenkasse betreffen	26
Kulturelle Unterschiede	= Beschreibungen, die Unterschiede zwischen der Kultur in der Schweiz und anderen Ländern aufzeigen	56
Lächeln		2
Medikamente	= Beschreibungen, die Informationen zum Umgang mit Medikamenten beinhalten	53
Motivation medizinisches Personal	= Beschreibung der Motive des medizinischen Personals zur Handlungsbereitschaft	12

Niedergelassener Kinderarzt	= Beschreibungen, die die ambulanten Kinderärzte betreffen (nicht UKBB)	24
nonverbale Sprache	= Beschreibungen die die Kommunikation betreffen, die nicht mit Sprache zu tun hat, sondern mit allem was man sieht	13
Notfall	= Beschreibungen zur Notfallstation UKBB	17
paraverbale Sprache	= Beschreibungen, welche die Kommunikation über den sprachlichen Austausch, aber nicht deren Inhalt betreffen	4
Persönliche Kompetenz Administration UKBB	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Administration betreffen	7
Persönliche Kompetenz Ärzte	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Ärzte betreffen	50
Persönliche Kompetenz Pflege	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Pflegenden betreffen	25
Poliklinik	= Kommentare, die die Poliklinik betreffen	2
Religion	= Kommentare, die religiöse Auffassungen beschreiben	10
Rezeption	= Aussagen, die die Hauptrezeption (Eingangshalle UKBB) betreffen NICHT Administration	5
Schock Caregiver		12
Selbstständigkeit	= Beschreibungen, in welchen besonders hervorgehoben wird, dass etwas unabhängig von anderen durchgeführt wurde	7
Sicherheit	= Aussagen, die sich auf das Gefühl beziehen, sich in einer geschützten Umgebung zu befinden	28
Sorge Caregiver	= das Gefühl der Furcht vor negativen Ereignissen in der ZUKUNFT	30
Station	= Aussagen, die explizit die Stationen des UKBB betreffen	4
Transitländer	= Aussagen zu Ländern, in welchen der Caregiver sich zur "Durchreise" aufgehalten hat, die aber kein endgültiger Zielort waren.	22
Transport Flucht	= Verkehrs/ Mittel, mit welchen der Caregiver von der Heimat bis in die Schweiz gekommen ist	16
Triage	= Aussagen zur Station auf dem Notfall, in welcher Patienten der Schwere der Erkrankung nach klassifiziert werden	4
Überweisung	= Aussagen, die eine offizielle Zuweisung des Patienten an das Kinderspital betreffen	14

In vivo	Und Chef kommen, sagen nur holen vor Chef	1
UNHCR / NGO	= Aussagen über UNHCR / nicht Regierungsorganisationen	7
verbale Sprache	= aussagen, die die Kommunikation von verbalen Inhalten betreffen (NICHT von der Art und Weise der Sprache / der nichtverbalen Sprache)	56
Verständnis Gesundheit	= Beschreibungen der Perspektive des Caregivers auf das Gesundheit	32
Verständnis Gesundheitssystem	= Perspektive des Caregivers auf das Thema Gesundheitssystem	28
Vertraulichkeit	= Umgang mit der Diskretion bezüglich persönlicher Informationen	0
Vorerfahrung Gesundheitseinrichtung: anderer Kanton	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	13
Vorerfahrung Gesundheitseinrichtung: Heimat	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	30
Vorerfahrung Gesundheitseinrichtung: Transitland	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	21
Wartezeit	= Dauer vom Eintreffen im UKBB bis zur medizinischen Konsultation	24
In vivo	we have to know that. That this doctor works with us	1
Weg UKBB	= Beschreibungen der Anfahrt des Caregivers von seinem Aufenthaltsort zum UKBB	25
Weitere Behandlungen	= Beschreibungen von weiteren geplanten Behandlungen	16
In vivo	wenn ich da hingehe sehe ich das […]wie Familie	1
In vivo	Wenn jemand sich selbstbewusst ist, dann hat er Vertrauen	1
Wohnsituation	= Ort sowie Beschreibung des Ortes, an welchem der Caregiver lebt	26
In vivo	You don't have to ask, they are taking care	1
Zuständigkeit	= Beschreibungen die das Zuordnen von Aufgaben zu bestimmten Einrichtungen / Personen beschreiben	6

Supplementary Data 4: Consolidated criteria for reporting qualitative research 32-item checklist

No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7
3. Occupation	What was their occupation at the time of the study?	7
4. Gender	Was the researcher male or female?	7
5. Experience and training	What experience or training did the researcher have?	7
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7-8
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	6
12. Sample size	How many participants were in the study?	6
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Figure 1
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	6 and Table 2 (12)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Table 2 (12)
16. Description of sample	What are the important characteristics of the	Table 2 (12)

	sample? e.g. demographic data, date	
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6 and , Table 1 (7)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	8
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	8
20. Field notes	Were field notes made during and/or after the inter view or focus group?	8
21. Duration	What was the duration of the inter views or focus group?	8
22. Data saturation	Was data saturation discussed?	6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	8 and 9
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	9
25. Description of the coding tree	Did authors provide a description of the coding tree?	9 and Supp. Data 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	9
27. Software	What software, if applicable, was used to manage the data?	9
28. Participant checking	Did participants provide feedback on the findings?	9
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	13-21
30. Data and findings consistent	Was there consistency between the data presented and the findings?	13-21
31. Clarity of major themes	Were major themes clearly presented in the findings?	13-21
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	13-21

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

The perspective of asylum-seeking caregivers on the quality of care provided by a Swiss paediatric hospital –a qualitative study

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The perspective of asylum-seeking caregivers on the quality of care provided by a Swiss paediatric hospital –a qualitative study

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Word count: 4579

Abstract

Objectives:

This study investigated the perspective of asylum-seeking caregivers on the quality of health care delivered to their children in a qualitative in-depth interview study.

The health of asylum-seeking children is of key interest for health care providers, yet knowledge of the perspective of asylum-seeking caregivers when accessing health care is limited.

Setting:

The study took place in a paediatric tertiary care hospital in Basel, Switzerland.

Participants:

Interviews were done with thirteen asylum-seeking caregivers who had presented with their children at the paediatric tertiary care hospital. Nine female and four male caregivers from Tibet, Eritrea, Afghanistan, Syria, Iraq, Albania, and Macedonia were included. A diverse sample was chosen regarding cultural and social background, years of residence in Switzerland, and reasons for seeking care.

A previously developed and pilot tested interview guide was used for semi structured in-depth interviews between 36 and 92 minutes in duration. Data analysis and reporting was done according to consolidated criteria for reporting qualitative research (COREQ). The number of interviews was determined by saturation of data.

Results:

The interviewees described a mismatch of personal competencies and external challenges. Communication barriers and unfamiliarity with new health concepts were reported as challenges. These were aggravated by isolation and concerns about their child’s health. The following factors were reported to strongly contribute to satisfaction of health care delivery: a respectful and trusting caregiver-provider relationship, the presence of interpreters and immediate availability of treatment.

Conclusions:

A mismatch of personal competencies and external challenges importantly influences the caregiver-provider relationship. To overcome this mismatch establishment of confidence was identified as a key factor. This can be achieved by availability of interpreter services, sufficient consultation time, and transcultural trainings for health care workers. Coordination between the family, the government’s asylum system and the medical system is required to facilitate this process.

Strengths and limitations of this study

- The inclusion of a cross-language concept and theoretical background.

- A thoroughly validated interview guide.

- A rigorous analysis, supported by an interdisciplinary research team.

- As in-depth qualitative study, this study comprises a relatively small sample.

- Due to the heterogeneity of the study population minor, culturally specific aspects might not have been sufficiently covered.

Background

The recent increase of the global refugee population to 22.5 million people is the highest level ever recorded and poses challenges to health care systems and public health of host countries [1]. In 2017, European countries recorded 209,756 asylum claims by children [2]. Despite decreasing overall numbers of refugees arriving in Europe, national asylum services still registered over 115,000 asylum applications by children from January to September 2018 [3]. In Switzerland over 45, 000 asylum applications were registered in 2016 and 2017 [4]. The age of asylum-seekers has dramatically decreased in the last decade with 82% of asylum-seekers in Europe being aged below 35 years and approximately one third being children and adolescents below 18 years of age in 2017 [5].

Many refugees have had limited access to health care for years and therefore arrive in host countries with neglected health conditions [6-8]. The health of asylum-seeking children and adolescents is of key interest, as these represent an increasing refugee population in recent years and are a particularly vulnerable group [9-11].

Access to quality health care for asylum-seekers and refugees remains challenging and it is critical to identify underlying reasons [12 13]. This needs to be done from the perspective of health care providers as well as patients and their caregivers alike as the perception of challenges and expectations on quality of care provided may vary substantially [14 15].

Current understanding and evidence regarding challenges for the health care provision to asylum-seekers and refugees is growing. A recent systematic review focussed on qualitative studies investigating challenges and facilitators in providing health care to asylum-seekers and refugees. It identified three main fields influencing health care: the asylum process, the health care system and the health care encounter [16]. An important limitation of the review is that all included studies reported on the providers' perspective [16]. A recent review by our group on challenges in health care delivery to asylum-seekers and refugees in high-income countries included several studies assessing the asylum-seeking patients' perspective [17-28] and identified financial, legal, geographical and cultural challenges as additional external factors influencing access to health care [29] .

Very few studies have explored the perspectives of migrant caregivers and, to date, there have been no studies performed exclusively including asylum-seeking and refugee caregivers. Two Australian studies investigated their perspective on the quality of antenatal and early child health care [24 28]. One study from the US focused on health beliefs of migrant parents, working on farms [23] and one European study investigated migrant caregivers perception on how to maintain their children's health[30]. Therefore, studies assessing the perspective of asylum-seeking and refugee caregivers on quality of care provided to their children beyond the neonatal period and in the European context are lacking. To reduce this important knowledge gap, the aim of our study was to explore the perspective of asylum-seeking caregivers on the quality of care provided in a Swiss paediatric hospital.

Methods

Study design and setting

The study was designed as qualitative in-depth interview study at the University Children's Hospital Basel. The hospital is located in the city of Basel, which hosts the largest reception center for asylum-seekers in the area of Northwest Switzerland, where asylum-seekers are accommodated immediately after arrival for a maximum of three months [31]. The city of Basel also has various accommodations for accepted refugees and those in a prolonged asylum-seeking

evaluation process. The hospital receives referrals for children from the asylum reception centre and the various regional accommodations and asylum centres.

Study population

Caregivers of asylum-seeking children who presented to our hospital on working days were eligible for inclusion. We aimed to include a heterogeneous group of caretakers and performed purposive sampling using the following criteria to cover different perspectives: a) recent and distant (> 2 years) arrival in Switzerland; b) first and regular attendance to the hospital; c) presentation at the emergency department and at outpatient clinics; d) origin from different regions.

Potential participants were approached by the interviewer supported by a phone interpreter. Following oral consent, a separate appointment was scheduled with a face-to-face interpreter. Study participants' preference regarding language, dialect and gender of the interpreter was followed.

Sample size

Sample size determination was based on recommendations by the National Centre for Research Methods in the United Kingdom [32]. We aimed to achieve data saturation, expecting to include12 interviews until new data would mainly repeat information that was collected in previous interviews [33].. Saturation of the study results was discussed and determined by the interdisciplinary study team.

Data collection

A semi-structured interview guide (**Table 1 and Supplementary data 1**) was designed consisting of open questions mandatorily to be covered, followed by prompts to clarify given answers and allow for exploration of emerging, not-previously specified topics [34].

Table 1: Interview guideline – practical design (translated version)

Introduction	it is more a conversation, not a strict interview; everything important and correct; present interviewer and role; confidentiality; maximum one hour; Audio recording ok?	Small-Talk Conversation, no interview; everything important and correct Answers also summarized by other parents confidentiality Maximum one hour Is audio recording ok?
Think about the moment before you came to the UKBB – what made you come?	Referrers? Presentation: basic Information? Communication? waiting times? Uncertainties?	How was it before you came? Has anyone signed up for you or did you do it yourself? first time at hospital? Referring? Did you know exactly what you need to do? (Information) Why did you come up to date, what illness did your child have? What was helpful when signing up or where did you need more support? Language? (Communication) Were there moments when you were not sure what to do?
Tell us what happened when you arrived at UKBB	arrived at reception and then? accompanying persons? felt understood in your concerns? what happened next? Doctor and nurse? did you think that what they did with your child is right? How did you feel?	You went to the reception / registration and then? Was someone there? Did you know how to proceed? Waiting times? Were you informed? Did you have an interpreter? Was this the first time? Did you need that before? What was helpful when signing up or where did you need more support? Did you understand you and your concerns? What happened then? Tell about the doctor and the care. Did you understand her? Was there an interpreter? Did you trust that what you did with your child is right? Did you feel safe at home? (Confidence)
How was the further care?	was the care as intended? what is different in your country of origin? would you go back to this hospital?	Was the care as you thought it would be? Were there situations where you thought it should be different or faster? Did you trust the doctors / other medical persons at the hospital? how did you feel? (sad, insecure, angry). What was especially great? What did you tell your friends? Concrete persons? What would have been different in your country of origin? What would you like to introduce here from your home country? What would you like to introduce in your home country from here? What role does religion play in the hospital for you? Would you go to the hospital again? Recommend it to your compatriots? If you would go there again, what would you like to be different? What should remain the same? Describe: what characterizes the perfect doctor for you? What the perfect nurse?
What was your general impression?	drugs received? did you receive further instructions / therapies from the doctor? do you think that what the doctor has suggested helps? If not, why? are more doctor visits planned? does your child have a pediatrician? know where to go for health issues?	Medication received? Recipe? How to take? How bought? Did you receive further instructions / therapies from the doctor? Do you think that what the doctor has suggested helps? If not, why? Did you do it differently? Did you have a contact person in case of uncertainty and questions after the hospital consultation? Are more doctor visits planned? Does your child have a pediatrician in Basel? If not, why not? If so, how did you find him? Do you know where to go for health issues (continuity of care)?
Wrap up	additions? was it easy to express your opinion? give phone number from interviewer for inquiries	From my point of view, we have addressed all topics. Many thanks for the valuable hints. Are there any additions from your point of view? How do you feel after the conversation? Do you have anymore questions? Was it easy to express your opinion? How could we best ask the opinion of their compatriots? How do you do that in your country? What else can we help you with? Give phone number from interviewer for inquiries
Context	where were you born? How did you come to Switzerand?	Where were you born? Where have you lived? How arrived in Switzerland? Already experiences with hospitals?
Back up	experiences at home with hospitals? what's better, what do you miss here? what tips for other parents, before they come to the hospital?	What experiences did you make with hospitals in your home country? / On the way to Switzerland? what is different here? what is better, what do you miss here? What tips for other parents, before they come to the hospital?

First row: mandatory to be covered in open questions; second and third row: prompts as sub-questions

The interview guide was reviewed by an external organizational psychologist with extensive experience in qualitative research. After external revision two pilot interviews were performed to test intelligibility, acceptability and extensiveness. A further revision was done based upon feedback from the caregivers involved in the pilot interviews. To address the challenges in cross-language qualitative research [35-37] and minimize the language barrier, a cross-language concept was developed, describing steps of translation and quality control (Figure 1). The cross-language concept was developed using the guidelines on interpreter use of the Qualitative Forum of Social Science [38].

Baseline data was collected using a case report form (**Supplementary data 2**). The in-depth interviews were done according to participants' preference at their home, asylum residence or at the hospital. Interview duration was scheduled for 60 minutes and done once only. All interviews were audiotaped and transcribed as pure verbatim protocols [39] in either English or German with anonymization of all patients. The transcriptions were reviewed in detail by the interpreter present during the interview according to the cross-language concept. Para-verbal reactions, interactions between family members, other observations and cultural aspects were documented in field notes and discussed by the interviewer and interpreter during debriefing.

The role of the interviewer

The interviewer (JB) is an experienced female clinician-scientist (MD) and conducted all pilot and study interviews. During the study period she was employed by the University Children's Hospital Basel in the migrant health service research group. She is experienced in qualitative research, received trainings in interview-techniques and qualitative research methods and has a special interest in global health. Not knowing JB beforehand, the interviewer's background, the

purpose and goals of the study were explained to the participants during the oral consent and repeated during the introduction phase of the interview.

Data analysis and reporting

Data analysis was done according to the qualitative content analysis of Mayring [39].A codebook (**Supplementary data 3**) was prepared and refined in several steps, involving team discussion with JB, KS and CD. Four interviews were coded in parallel by each researcher to ensure the comprehensiveness of the codebook. Code categories were extracted, relations identified and abstracted in networks and graphs to generate a coding tree. Reporting was guided by the consolidated criteria for reporting qualitative research (COREQ; **Supplementary data 4**) [40]. The analysis was done using atlas.ti (ATLAS.ti 8 Scientific Software Development GmbH, Berlin). The entire study process was accompanied by the interdisciplinary Migration Research Group at the University of Basel.

Patient and Public involvement

During pilot interviews caregivers' feedback was obtained to improve the interview guide and the way the interviews were done. After the pilot phase all participants were asked if the method was suitable and how they felt about expressing their opinion at the end of the interview. An interim expert panel discussion consisting of staff from the asylum-seeking reception center and the University Children's Hospital Basel was organized, to evaluate results. In addition, one interview participant reviewed the entire paper.

Ethics

As a quality assessment project of the University Children's Hospital Basel, there was no ethical approval required for this study. This was confirmed by the Ethics Committee of Northwest/Central Switzerland on October 4th 2017. We strictly adhered to international research

standards rigorously including information about entirely voluntary participation of the interviewees and the possibility to withdraw consent without any negative consequences, separation of research and clinical staff and data confidentiality.

Results

A total of 13 interviews were performed and included in the analysis, conducted in Tigrinya, English, Arabic, Dari, Farsi and German (**Figure 1**). In all interviews, the professional interpreters ensured a smooth dialogue between the participant and the interviewer and helped to establish a pleasant atmosphere. The baseline characteristics of participating caregivers and the interview context are summarized in **Table 2**.

Table 2: Baseline characteristics of participating caregivers and interview context

	1	2	3	4	5	6	7	8	9	10	11	12	13
Participant characteristics													
Country of origin	Tibet	Eritrea	Afghanistan	Eritrea	Syria	Afghanistan	Syria	Iraq	Albania	Syria	Macedonia	Syria	Syria
Age child	1-5	1-5	< 1	> 10	1-5	1-5	1-5	6-10	1-5	<1	1-5	1-5	6-10
Main department visited	OPD	OPD	OPD	OPD	OPD	OPD	OPD	Emergency	Emergency	Emergency	Emergency	Emergency	OPD
Age caregiver	40-49	30-39	20-29	30-39	20-29	10-19	20-29	30-39	30-39	30-39	30-39	30-39	40-49
Sex caregiver	Male	Male	Female	Female	Female	Female	Female	Female	Female	Female	Male	Female	Male
Education level caregiver*	4	3	3	3	3	3	3	4	2	3	3	4	3
Years in CH	6-10	1-5	1-5	1-5	1-5	< 1	< 1	1-5	6-10	< 1	< 1	1-5	< 1
Mother tongue	Tibetan	Tigrinya	Dari	Saho	Arabic	Farsi	Arabic	Kurdish	Albanian	Arabic	Macedonian	Arabic	Arabic
Other language (level)**	English (C)	English (A)	German (A)	Arabic (C)	Kurdish (C)	-	-	German (B)	German (B)	-	German (C)	English (C)	-
Interview context													
Interpreter present	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No	No	Yes
Gender preference	n/a	No	Female	No	No	Female	No	n/a	n/a	Female	n/a	n/a	No
Interview location***	2	2	3	3	3	1	3	3	3	1	1	3	1
Interview duration (min.)	49	36	70	92	68	50	57	52	59	79	44	64	77
Number and (type) non-participants	2 (wife and child)	0	3 (husband, children)	4 (husband, children)	2 (coach, child)	0	3 (husband, children)	1 (child)	1 (child)	0	0	2 (child, student)	1 (wife)

* Education levels: 1 = illiterate, 2 = primary education, 3 = secondary education, 4 = university degree

** Language levels: A = basic user, B = independent user, C = proficient user

*** Interview location: 1= accommodation and provisioning center 2= hospital 3= participants' apartment

CH = Switzerland; n/a = not applicable; OPD = outpatient department other than emergency

The results are presented in two sections, focusing on challenges and good practice reports.

Mismatch of competences and organizational challenges

Caregivers described mismatches between their personal sociocultural and language competencies and the situation of health care. In addition, they faced organizational challenges, e.g. orientation to new surroundings after relocations. They described that this created stressful situations leading to feelings of disorientation, dependency and anxiety. This was felt strongest early after arrival and for those who had not previously lived in a cultural context like Switzerland. It became more pronounced if there was an urgent threat such as the illness of their child.

> I was frightened. I didn't know the language, I didn't know anybody. I took care of my children and I didn't know where I was. […] I was extremely worried about [my sick child]. And I didn't know: what happens? Whom should I ask? Where should I go? I had no money with me. In fact, I didn't know where I was. (4; 2:21)

Caregivers who were unable to speak or understand a local language described communication as a challenge. The inability to sufficiently explain the medical history and complaints of their child was reported to be frustrating. Being highly dependent on interpreters, one caregiver recalled feelings of fear when the interpreter was late for the appointment.

> At my second visit I was a bit frightened as the interpreter was not there. I thought: oh my God: how can I understand now [what they say]? How can I talk to them? I was a bit nervous in this moment, this was a bit difficult. (13; 14:31)

Mismatch of health concepts

Caregivers explained that their own health concepts were shaped by their culture and previous experiences. They arrived with certain expectations about Swiss health care based on stories they had heard. One important topic was the use of medication. Two caregivers stated that they had wished to receive a prescription for medication.

> In Afghanistan […] doctors have limited resources. We don't have many options. But if you go to the doctor […] you get medication and you get antibiotics if you have an inflammation or something like that. Here, that's not the case. You continue to be sick, after four or five consultations it gets better, yes, but maybe it would have been better anyway. (3; 29:46)

> In Syria, when my son or my daughter was sick, I just went to the pharmacy. It‘s like a supermarket. And then I buy […] antibiotics too, that's completely normal. (10; 7:24)

Some health concepts such as preventive services were reported to be unfamiliar. For one caregiver the detailed examination of the child during tuberculosis screening suggested to her that the child was seriously sick. The caregiver was unable to imagine why this was required when no obvious health problem was present. She explained that the idea of going to the hospital with an apparently healthy child was completely new to her.

> I knew my children were not having tuberculosis. However, I was frightened. Because they work so thoroughly [at the hospital] and they have done examinations, and that is why I was really frightened. (7; 4:40)

For some caregivers, the way in which physicians would communicate about health was unfamiliar. One caregiver mentioned that bad news was disclosed to her by five physicians which was a shocking and unpleasant experience. In addition, the information was given faster and much more directly than she was used to. She had wished that only one person had given here the information in small steps. Other caregivers, too, wished that physicians would explain more about the disease, causes and resulting treatment.

Limited personal resources

For caregivers being part of a family was considered a resource and being separated from loved ones was a psychological challenge. In many instances mothers described arriving in Switzerland with their children but without their husbands. They were reported to have been forced to stay as soldiers or prisoners or had been killed before the family left. In case of limited financial resources, priority was given to the mother and children leaving the country. The lack of communication with them or other family members was contributing to the feeling of loneliness. This was aggravated if a child was diagnosed with serious health problems and had to be admitted to the hospital.

> I had no clue about a health insurance, no clue about the law, the law here and the rules. I just endured these days there [on the ward]. […] I felt very lonely. My husband was not here at that time. That was very difficult. (3; 29:16)

Being a single caregiver had practical implications. For example, attendance to medical appointments was challenging as child care for healthy siblings is usually not available for asylum-seeking families. Another example was that the caregiver refused admission as she was unable to stay with her sick child.

> [The doctor] said you have to stay 7 to 10 days here with your son. That's what he told me just like this. And then I answered: I can't, I have [six] children and their father is not here. (4; 2:11)

Caregivers described how family members residing in neighboring countries could have been of psychological and practical support. However, as their asylum process was pending, they were not allowed to cross borders. One caregiver reported crossing the border to see family members for support in a desperate situation and being caught by police.

One caregiver reported being the single parent present made it difficult to give her child the prescribed medication. When she reported this to the physician she was treated disrespectfully and asked to leave.

> That's what made me angry: we told the truth to him. We can't just lie […]. Maybe the medication doesn't taste good, doesn't smell good. I thought: […] if I tell it to him we could maybe change it. But he was angry and just left. He said: go home! So I went home. (5; 13:32)

External challenges

Caregivers also expressed difficulty accessing health care, particularly if the asylum process was prolonged. In stations with pending asylum decision some participants reported that a health insurance card was not issued, which caused delays, additional administrative work and made caregivers feel inferior.

One caregiver described that the official person in charge brought the sick child to the hospital in a private car, took care of the administrative tasks and stayed with the family during the consultation. Another caregiver reported that the official person in charge was reluctant to address the family's health needs.

> Three years here. My chief [official in charge] said that I'm only parked here. But I'm not a car! We are parked here, 7 years by now! With F status [provisionally admitted refugees]. Tell me, why does it have to be like that? Parked! (9; 6:98)

Caregivers also described insufficient coordination between the asylum reception centers and the hospital. Two recently arrived mothers of admitted children did not have cash money. Unfamiliar with the system that they must buy their own food and unable to communicate that they had no money, the mothers fasted during several days or were eating from their children's meals.

Some caregivers explained that after the consultation they did not know how to return to their asylum center/home center. One caregiver had recently moved and did not recall her new address. Others reported to have been driven home by the interpreter or a taxi. One caregiver living in a rural area was worried not to be able to get home and therefore left the emergency department before the end of the consultation.

Understanding and responding to medical needs

Twelve out of 13 caregivers expressed a deep gratitude for the health care their child received at the hospital. They also appreciated when help was offered in various situations by interpreters, officials in charge of the asylum process, taxi drivers, engaged citizens, receptionists, social workers, nurses or doctors.

> It is impossible to describe, I can't describe it. Doctors or social workers, everybody supported and helped me. (4; 2:86)

Caregivers appreciated the fact that an interpreter was used, and this led to trust as they felt understood in their most urgent need.

> I swear, if I can talk there, I have the feeling that I'm safe! (5;13:58)

All but one caregiver explained that they were impressed by the medical help their child received. They mentioned that in the past, they never experienced such a high level of medical care, neither at their home nor in transit countries.

> I don't think you see this facility in any other country. It was around half past 10 at night. We thought he swallowed something. […] We got really scared. […] The doctor said: he will call the lady who is doing the x-ray, from home. Wonderful! This is service to the King! She came from her home to do x-ray to our son. This is fascinating! (1;12:31)

When asked why they were satisfied with the quality of care, they emphasized the immediateness of medical care. They were used to long waiting hours extending up to days. Understanding and rapidly addressing the child's health needs lead to trust and the feeling of being understood and safe.

> I like the support. The quick treatment, everything included. Not like at home, really. [..] I'm so thankful, that the child is in good hands. (11; 8:54)

Access to good quality health care was for some caregivers one important reason why they lodged an asylum-application in Switzerland.

> Sometimes I get nervous, I say: I'm dead, I have to leave. […] But then I think: I have to be thankful. I have a room and my child gets an immediate check-up if he is sick. (9; 6:91)

Showing respect

Almost all caregivers greatly appreciated that they were treated in a respectful way. Respect was even more important, if they had had negative experiences with health care providers in the past.

> In Iran, they don't treat […] people from Afghanistan with respect. […] It is not like here. For example, at the reception: maybe they don't even give you a registration code, they don't listen to you. We are very satisfied and thankful, that we came to this country because we were always treated with respect (6; 3:18)

Simple and routine practices were acknowledged as good practice such as the physician coming to the room of the patient and not vice-versa. Caregivers recalled that the physician helped to undress the patient or approached the child in an appropriate and friendly way. One caregiver appreciated that the nurse was playing with the child during the consultation. This allowed her to concentrate on the treating physicians explanations. A caregiver from Iraq appreciated that the staff directly addressed the eight-year-old daughter and therefore respected the child's opinion. A further caregiver appreciated that the staff adapted to the individual reactions of the children.

> What I liked: my children had two different behaviors. One cried and refused to cooperate. The nurse helped us. […] We helped each other. By the end both children received what they needed. (2;11:10)

Building trust through relationship

A trustful relationship to health care providers was central to all caregivers when evaluating the quality of health care. Two caregivers of children with chronic diseases visited the hospital frequently and described a family-like relationship with the hospital staff.

> If I go [to the Children's hospital] I don't see it like a hospital. The nurses, the doctors and everything, they are like my family. (4; 2:90)

As verbal communication was frequently limited, non-verbal communication was important for building a trustful relationship. Two caregivers explicitly highlighted how they appreciated when the medical staff was smiling.

> If somebody smiles at me, a beautiful smile, that makes me really happy. Then I get a very beautiful feeling. And the doctor was nothing but happy and friendly and smiled all the time at me. (9;14:52)

A trustful caregiver-provider relationship allowed caregivers to accept unfamiliar health concepts. For example, one caregiver was upset about not receiving a prescription for her child, but she explained how this changed after a medical consultation at the emergency department.

> I thought she would get a lot of medication, as she had fever. But no: they only gave this suppository to her. […] They said: don't be frightened, your daughter will be fine. She just needs time to recover. And that was the right way. I went back, and that was right. So that is an ideal doctor to me: Who knows exactly what happens, without giving too many drugs. (10; 7:40)

Another caregiver had the concept that she should never leave her infant alone in hospital. Her daughter was admitted with a chronic disease and the medical staff recommended that she go home to rest while her infant remained admitted.

> It was a shock. We […] don't have this in our culture that mum leaves the baby. But later, I said it's very helpful to go out, really because the nurses were […] very, very good. Then I understood that: If I'm good, she will be good. […] […] We have to know that. That the doctor works for us, not against us. (12; 9:27)

Discussion

To our knowledge, this is the first study investigating the perspective of asylum-seeking and refugee caregivers on the quality of health care provided to their children in Europe.

The detailed analysis of the interviews displayed a range of challenges for asylum-seeking and refugee caregivers and their sick children. However, despite including a diverse group some universal challenges were noted. This included the development of a trusting relationships, communication including interpreter services and coordination between the health care and the asylum systems. These findings confirm results from a recent systematic review which identified communication, continuity of care and confidence as the three main factors influencing health care provision to migrants [29]However, our study also highlights important additional aspects for this group of patients specifically regarding confidence and continuity of care.

First, confidence was the key factor contributing to satisfaction of the study participants. Confidence was achieved through a trustful caregiver-provider relationship. This finding is also supported by other studies, e.g investigating mental health care delivery to migrants [17 26]. In some instances confidence has been described as being an integral part of the treatment [41]. It is remarkable that small actions such as a smile by the treating physician, being helpful to undress and interacting in a playful way with the sick child, were helpful in the process of trust-building. This highlights that simple and easy measures may have important benefits for the health of asylum-seeking and refugee children and such knowledge needs to be included in transcultural training of health care workers.

Second, caregivers explained that challenges regarding the continuity of care were occurring at the intersection of the medical and the asylum-seeking systems. Challenges included the asylum-process itself, transport and access to money. Our study identified that for a positive perception of health care delivery, these areas required optimal coordination. This result is also echoed in a recent publication describing health care delivery models for refugees, which suggested including specialized case managers as one option to improve cooperation between services [42]. Connecting services may be facilitated by other interventions such as involvement of social workers and predefined referral pathways and specialized migrant health teams.

Third, communication is important in all health care encounters and has been identified as a key barrier or facilitator in this study. Numerous earlier studies have investigated the negative influence of language barriers on patient experience, health literacy and patient-provider relationship [43]. Communication was also described as essential for the adoption of new health concepts, for example, the rational use of antibiotics [44] . Although the requirement of interpreters is not debated, most health care systems in Europe do not have established payment policies for interpreter services. This results in frequent use of ad hoc non-professional interpreters, which is associated with considerable risk of translation errors leading to clinical consequences [45]. It is therefore important that coverage for interpreter services is included in health care insurance plans, which is currently advocated by a position paper published by the Swiss Hospital for Equity network (https://www.hospitals4equity.ch/).

Generally, the caregivers expressed very positive feelings about the medical care their children had received. Nearly all caregivers expressed their gratitude by giving detailed examples of individual support, fast and adequate medical care and a respectful and trustworthy approach by health care providers. A recently published study explored expressions of gratitude in women with migrant background whose health needs were not or only partially met and raised questions in how far this speaks to current normative expectations and attempts to restrict welfare. Gratitude might thus be expressed in order to “avoid being identified as excessively needy, undeserving newcomers” [46].. . It is important to take such logics and power relations into account, yet, in our study, none of the participants perceived a failure of the specific hospital or health care system. In one case, a person expressed gratitude regarding the overall care, even though she was not satisfied with one of the consultations. This could be part of the general expectations and discourse of gratitude, yet, we also interpret it as a differentiated picture of judging different parts of the same health care facility differently.

There is a possibility that through selection bias only satisfied caregivers had agreed to participate in this study. However, only one caregivers meeting the inclusion criteria refused to take part in the study. The approached caregivers were keen to be interviewed and appreciated the opportunity to express their opinion. In contrast, the hospital’s earlier efforts to assess patient’s satisfaction in asylum-seeking and refugee families using translated satisfaction questionnaires had a low response rate. This suggests that patient satisfaction inquiries using interviews instead of questionnaires are more acceptable to asylum-seeking and refugee caregivers.

A potential limitation of the study is the small number of interviews performed. However, the interviews were rich in content and included a diverse study population regarding cultural and social background, years of residence in Switzerland and reasons for seeking care. The information gathered started to repeat after 11 interviews, signaling saturation regarding the major themes. Nevertheless, we acknowledge that minor aspects might not have been sufficiently covered, or that other participants from different contexts may have differing views. The strengths of this study are the inclusion of a cross-language concept, a solid theoretic background, a thoroughly validated interview guide and the rigorous analysis, supported by an interdisciplinary research team. Therefore, we believe that our findings are relevant to health services in many host countries caring for asylum-seeking and refugee families from various backgrounds.

Conclusion

A mismatch of personal competencies and external challenges importantly influences the caregiver-provider relationship. To overcome this mismatch establishment of confidence was identified as a key factor. This can be achieved by availability of interpreter services, sufficient consultation time, and transcultural trainings for health care workers. Coordination between the family, the asylum and the medical system is additionally required to facilitate this process.

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Author's contribution

JB and NR study conception; JB data acquisition; JB, KS, CD and NR data analysis; JB wrote the first draft, JB, KS, CD, FJ, BP and NR revised the manuscript. All authors had access to the data and gave intellectual input. JB and NR affirm that this manuscript is an honest, accurate and transparent report of the results and that no important aspects have been omitted.

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Disclaimer:

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Ethics approval:

As quality control project, this research project does not fall under the remit of the cantonal or federal law of the Human Research Act (HRA). The EKNZ (Ethikkommission Nordwest- und Zentralschweiz) has reviewed the submitted documents and confirms that the research project fulfills the general ethical and scientific standards for research with humans (see Art.51 Abs 2 HRA).

Patient consent:

Oral informed consent obtained.

Data sharing statement:

No additional data available.

Figure 1 Legend:

Flow-chart, depicting the different phases of the patient recruitment and the cross-language concept including transcription, translation and understanding of language

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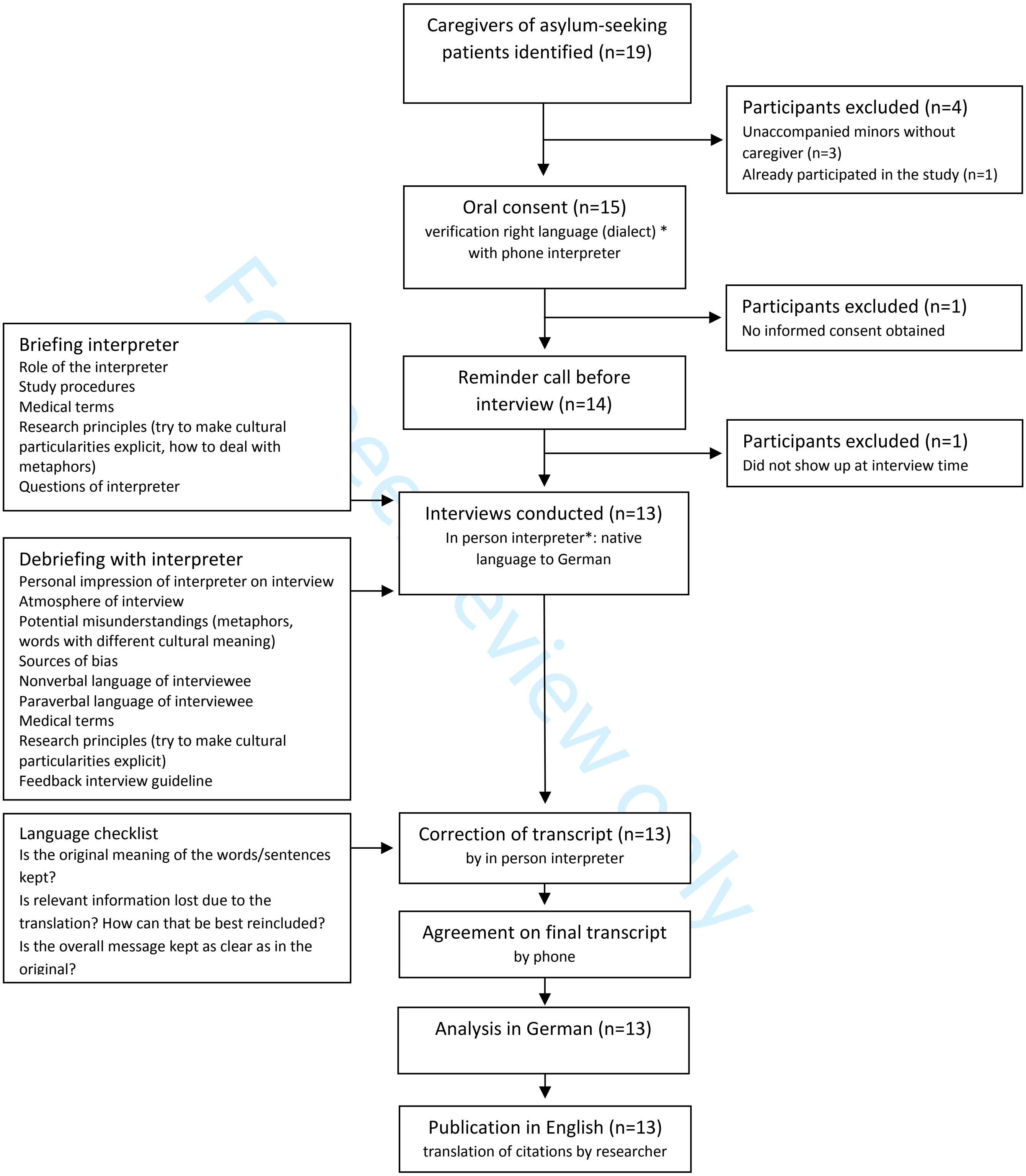
Figure 1: Flow chart of participant recruitment and integration of cross language concept



*= If communication in German/English not adequate

Supplementary Material

Supplementary Data 1: Interview guideline – theoretic design

1. Context (ice breaker oder am Ende erfragt)

- Könnten Sie uns erzählen, wo sie geboren sind, gelebt haben und wie Sie in die Schweiz gekommen sind?
    - **Waren Sie auf Ihrem Weg hierher mit Ihrem Kind in anderen Krankenhäusern / Einrichtungen?**
        - **Wenn ja im Ausland (welches Land)?**
        - **In der Schweiz?**
- Was hat Sie veranlasst ins UKBB zu kommen?
        - **Hat man Sie in das Kinderspital geschickt? Warum?**
    - **Haben Sie das Spital gut gefunden?**
- Welches Verkehrsmittel haben Sie benutzt?
    - **War es teuer herzukommen?**
- Sind sie in einem Migrationsprogramm das Sie unterstützt? Haben Sie einen persönlichen Betreuer?

2. Communication

- **Können Sie erzählen, wie die Konsultation am UKBB verlaufen ist?**
    - Sie kamen mit Ihrem Kind an die Anmeldung und dann?
        - Wie verlief die Kommunikation an der Anmeldung?
    - Welche Erkrankung hatte Ihr Kind?
        - War die Erklärung verständlich?
    - Wieviel medizinisches Personal haben Sie gesehen? War(en) ein Arzt(e) dabei? Wenn ja wieviele?
    - Was hat der Arzt gesagt, sollen Sie tun?
    - Welche Sprache(n) wurden mit Ihnen gesprochen?
- **Hat der Arzt einen Dolmetscher verwendet? Hat ein Bekannter für Sie übersetzt?**
        - Wenn ja per Telefon oder persönlich? Wie empfanden Sie das?
        - Wie konnten Sie mit dem Personal sprechen?
            - War es einfach? War es schwer? Warum?
- **Wie war die Kommunikation mit allen Angestellten des UKBB für Sie?**
    - Was fanden Sie gut?
    - Was fanden Sie schwierig?
    - Was könnte man besser machen? Was soll so bleiben?

3. Continuity of care

- **Nach der Vorstellung im UKBB, was haben Sie gemacht?**
    - Mussten Sie Medikamente zu Hause geben?
        - Wenn ja: haben Sie ein Rezept erhalten?
        - Wie haben Sie das Medikament besorgt?
    - Waren Sie bei einem anderen Arzt?
    - Hat Ihr Kind einen Kinderarzt? Wie haben Sie den gefunden?
    - Sind weitere Arztbesuche geplant?
- *Wenn sich der caregiver für ein anderes Procedere als das verordnete entschieden hat*:
- Können Sie erklären, weshalb Sie sich anders entschieden haben?
    - Denken Sie, dass das was der Arzt vorgeschlagen hat nicht hilft?
    - War es schwierig, das zu machen was Ihnen vorgeschlagen wurde?
- **Hat ihr Kind einen Kinderarzt in Basel?**
    - Wenn nein, weshalb nicht?
    - Wenn ja: wie haben Sie den gefunden?

4. Confidence

- **Beschreiben Sie: was wäre der perfekte Arzt für Sie? Was der perfekte Krankenpfleger?**
    - Wie würde man Sie behandeln? Was würde man tun?
- **Wie haben Sie sich während der Behandlung gefühlt?**
    - Waren Sie traurig, verärgert? Verunsichert?
        - Falls ja warum?
        - Was hätte man in Ihrem Herkunftsland anders gemacht?
        - Hatte nur eine Frau/nur ein Mann ihr Kind untersucht?
        - Was für eine Rolle spielt Ihre Religion im Krankenhaus für Sie?
- **Was denken Sie von den Personen, die sich um ihr Kind gekümmert haben?**
    - Gab es jemanden der es besonders gut gemacht hat? Was hat er gemacht?
    - Gab es jemanden der es nicht gut gemacht hat? Was hat er gemacht?
    - War die Betreuung so, wie Sie es sich gedacht haben?
        - War es besser/schlechter als Sie gedacht haben?
        - Was hätte besser sein sollen? Was war gut?
- **Würden Sie nochmal ins UKBB gehen?**
    - Wenn Sie nochmal dorthin gehen würden, was hätten Sie gern anders?
    - Was hätten Sie gern wieder genau so?

Supplementary Data 2: Case report form

bei der Rekrutierung ausfüllen:

Am UKBB vorstellig geworden am (dd/mm/yyyy):____

Department (NF/ MS/ Poliklinik) :____

ID-Nummer Interview care-giver (initi.Departm.&Nummer): _____-________________________________

Alter des betreuten Kindes(Jahre & Monate/12): _________________Jahre _____________/12 Monate

Bekannte Erkrankungen des betreuten Kindes:____

mündliches Einverständnis Studienteilnahme erteilt (nein0 /ja1) _________________________________

Sprachen des Care givers & Niveau(fliessend4 /gut3 /ausreichend2 /einzelne Worte1):_______________

____

Dialekt____Interpreter

nein0/ja1__________________________Präferenz egal0/männlich1/weiblich2____________

Berufliche Tätigkeit caregiver im Heimatland____

Berufliche Tätigkeit in der Schweiz____

Bildungsniveau des Caregivers (Höchste Ausbildung angeben: Analphabet1, Grundschulabschluss2, Abschluss weiterführende Schule3, universitärer Abschluss4,)___________________________________

Geschlecht des care-givers (m1 /w2)____

Alter des care-givers (Jahre):____

Geburtsort des care-givers (Stadt & Land):____

In der Schweiz seit(Monate &Jahre):____

Beim Interview ausfüllen:

Aktueller Tag (dd/mm/yyyy)________________ Uhrzeit (hh:mm)________________________________

Ort Interview (EVZ1; Studienzentrum UKBB2;eigene Wohnung3)_________________________________

Zudem anwesende Personen beim Interview (Funktion): ______________________________________

Supplementary data 3: Code book including code definitions and frequency of appearance

	Kommentar	**Häufigkeit**
Abhängigkeit	= Beschreibung, in welcher der Caregiver von anderen Personen/Dingen abhängt	54
Adaptation Gesundheitskonzept	Veränderungen des eigenen Konzepts von Gesundheit/Gesundheitsversorgung aufgrund von Erfahrungen in schweizer Gesundheitseinrichtungen	19
Akute Krankheit Patient	= Erkrankung, die plötzlich aufgetreten ist / plötzliche Verschlechterung einer bereits vorhandenen Erkrankung, die mehr Hilfe benötigt als im sonstigen Zustand	9
Andere Kantone	= Aussagen über Kantone, in welchen der Caregiver sich aufgehalten hat ausserhalb von Basel-Stadt	32
Angestellte Wohnheim	= Aussagen, die Angestellte im Wohnheim betreffen	33
Angst Caregiver	= Emotionaler Zustand der Furcht des Caregivers im Hier und Jetzt	22
Ärger UKBB	= Beschreibung eines Gefühls der Unzufriedenheit und leichter Wut über das Kinderspital	4
Asylstatus	= rechtlicher Status, der die Möglichkeit im Land zu bleiben bestimmt	15
Ausdrücken der eigenen Meinung	= die Möglichkeit, uneingeschränkt seine persönliche Meinung kund zu tun	9
Beruf Caregiver	= Tätigkeit mit Lohnerwerb des Caregivers	12
Beziehung Caregiver - Patient	= das Verhältniss zwischen dem Patienten und seinem Caregiver	22
Bildung Caregiver	= Studium/Ausbildung des Caregivers	3
Chronische Krankheit Patient	= lang andauernde Krankheit, die nicht vollständig geheilt werden kann	21
In vivo	D: ja ich schwöre, wenn ich da ein bisschen sprechen kann	1
Dankbarkeit gegenüber UKBB	= Ausdrücken des Bedürfnisses, sich beim Kinderspital zu bedanken.	46
Dolmetscher: Amateur	= nichtprofessioneller Dolmetscher (ohne strukturiertes Training und entsprechendes Zertifikat)	14
Dolmetscher: prof.	= strukturiert ausgebildeter, zertifizierter Dolmetscher	31

Präsenz		
Dolmetscher: Telefon	= zertifizierter Dolmetscher, der über das Telefon übersetzt	16
Engagement Einheimischer	= intensiver Einsatz / Anstrengung von Menschen, die schon lange im Host-country des Asylsuchenden wohnen	20
Enttäuschung UKBB	= Beschreibung eines Gefühls der Traurigkeit aufgrund von nichterfüllten Erwartungen gegenüber dem Kinderspital	5
Erwartungen Caregiver	Leistungen, die der Caregiver vom UKBB/der Gesundheitsversorgung der Schweiz erwartet	22
Fachliche Kompetenz Administration UKBB	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Administration UKBB	13
Fachliche Kompetenz Ärzte	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Ärzte des UKBB	61
Fachliche Kompetenz Pflege	= Beschreibung der Asylsuchenden, bezüglich der fachlichen Qualifikation der Pflegenden des UKBB	28
Familie: getrennt	Beschreibung der Familie / familiären Struktur des Caregivers	19
Familie: zusammen	Beschreibung der Familie / familiären Struktur des Caregivers	8
Familiengefühl	= Beschreibung für Menschen die keine Verwandten sind familiäre Gefühle zu haben	5
Finanzen	= Finanzielle Situation Caregiver	44
Fluchtdauer	= Zeit vom Heimatland bis in das Hostcountry	12
Fluchtursache	= Gründe, die der Caregiver nennt, die dazu geführt haben, dass er und der Patient das Heimatland verlassen haben	13
In vivo	für mich sind König Kinderspital	1
Geschlechterrolle	= Beschreibungen des Caregivers, die die Unterschiedlichen Rollen von Geschlechtern aus seiner Sicht beschreiben	7
Geschwisterkinder	= Beschreibungen, die die Rolle der Geschwister betreffen	7
Gesundheitsinformation: gewusst	= Aussagen, die wichtige Hinweise für die Gesundheit des Patienten beinhalten welche dem Caregiver erklärt wurden	40
Gesundheitsinformation: nicht gewusst	= Aussagen, die wichtige Hinweise für die Gesundheit des Patienten beinhalten welche dem Caregiver NICHT erklärt wurden	17
Haltung Caregiver --> med. Personal	= Haltung, die der Caregiver gegenüber dem medizinischen Personal bzgl der sozialen/beruflichen Stellung hat	32

Haltung med.Personal --> caregiver	= Haltung, die das med. Personal gegenüber dem Caregiver bzgl der sozialen/beruflichen Stellung hat	32
In vivo	I think being a patient, our only duty is to bring our body to the hospital	1
In vivo	ich bin froh wenn im Kinderspital	1
In vivo	Ich denke dass Doktor nicht denke das ist fremde Kind	1
Informationsfluss	= Weitergabe von für die medizinische Betreuung relevanten Informationen	24
Infrastruktur UKBB	= Aussagen zur Ausstattung des UKBB	12
Integration	= Beschreibungen, die den Vorgang beschreiben, ein lokales Beziehungsnetzwerk aufzubauen	11
Kinderbetreuung	= Beschreibungen über die Organisation/ Möglichkeit der Aufsicht des Patienten / von Geschwistern	8
Kompetenz Sozialarbeiter	= Beschreibungen zu Fähigkeiten der Sozialarbeiter	8
Konzept Primärprävention	= Beschreibungen, die das Konzept der medizinischen Vorsorge beschreiben, welche darauf hinzielt Erkrankungen zu vermeiden	5
Kooperation Kanton – UKBB	= Zusammenarbeit der Kantone mit dem Kinderspital	10
Kooperation med. Personal - Caregiver	= Zusammenarbeit zwischen dem medizinischen Personal UKBB und dem Caregiver	11
Kooperation med. Personal - Patient	= Zusammenarbeit med. Personal und Patient	17
Kooperation SEM - UKBB	= Zusammenarbeit Angestellter des Bundes (vor allem EVZ/MIZ) und Verfahrenszentrums und des Kinderspitals	21
Koordination UKBB	= Beschreibung der Absprache von verschiedenen Organisationseinheiten innerhalb des UKBB	12
Krankenkasse	= Beschreibungen, die die Krankenkasse betreffen	26
Kulturelle Unterschiede	= Beschreibungen, die Unterschiede zwischen der Kultur in der Schweiz und anderen Ländern aufzeigen	56
Lächeln		2
Medikamente	= Beschreibungen, die Informationen zum Umgang mit Medikamenten beinhalten	53
Motivation medizinisches Personal	= Beschreibung der Motive des medizinischen Personals zur Handlungsbereitschaft	12

Niedergelassener Kinderarzt	= Beschreibungen, die die ambulanten Kinderärzte betreffen (nicht UKBB)	24
nonverbale Sprache	= Beschreibungen die die Kommunikation betreffen, die nicht mit Sprache zu tun hat, sondern mit allem was man sieht	13
Notfall	= Beschreibungen zur Notfallstation UKBB	17
paraverbale Sprache	= Beschreibungen, welche die Kommunikation über den sprachlichen Austausch, aber nicht deren Inhalt betreffen	4
Persönliche Kompetenz Administration UKBB	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Administration betreffen	7
Persönliche Kompetenz Ärzte	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Ärzte betreffen	50
Persönliche Kompetenz Pflege	= Beschreibungen, die die psycho-sozialen Fähigkeiten der Pflegenden betreffen	25
Poliklinik	= Kommentare, die die Poliklinik betreffen	2
Religion	= Kommentare, die religiöse Auffassungen beschreiben	10
Rezeption	= Aussagen, die die Hauptrezeption (Eingangshalle UKBB) betreffen NICHT Administration	5
Schock Caregiver		12
Selbstständigkeit	= Beschreibungen, in welchen besonders hervorgehoben wird, dass etwas unabhängig von anderen durchgeführt wurde	7
Sicherheit	= Aussagen, die sich auf das Gefühl beziehen, sich in einer geschützten Umgebung zu befinden	28
Sorge Caregiver	= das Gefühl der Furcht vor negativen Ereignissen in der ZUKUNFT	30
Station	= Aussagen, die explizit die Stationen des UKBB betreffen	4
Transitländer	= Aussagen zu Ländern, in welchen der Caregiver sich zur "Durchreise" aufgehalten hat, die aber kein endgültiger Zielort waren.	22
Transport Flucht	= Verkehrs/ Mittel, mit welchen der Caregiver von der Heimat bis in die Schweiz gekommen ist	16
Triage	= Aussagen zur Station auf dem Notfall, in welcher Patienten der Schwere der Erkrankung nach klassifiziert werden	4
Überweisung	= Aussagen, die eine offizielle Zuweisung des Patienten an das Kinderspital betreffen	14

In vivo	Und Chef kommen, sagen nur holen vor Chef	1
UNHCR / NGO	= Aussagen über UNHCR / nicht Regierungsorganisationen	7
verbale Sprache	= aussagen, die die Kommunikation von verbalen Inhalten betreffen (NICHT von der Art und Weise der Sprache / der nichtverbalen Sprache)	56
Verständnis Gesundheit	= Beschreibungen der Perspektive des Caregivers auf das Gesundheit	32
Verständnis Gesundheitssystem	= Perspektive des Caregivers auf das Thema Gesundheitssystem	28
Vertraulichkeit	= Umgang mit der Diskretion bezüglich persönlicher Informationen	0
Vorerfahrung Gesundheitseinrichtung: anderer Kanton	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	13
Vorerfahrung Gesundheitseinrichtung: Heimat	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	30
Vorerfahrung Gesundheitseinrichtung: Transitland	= Vorerfahrungen des Caregivers mit anderen Gesundheitseinrichtungen als dem UKBB	21
Wartezeit	= Dauer vom Eintreffen im UKBB bis zur medizinischen Konsultation	24
In vivo	we have to know that. That this doctor works with us	1
Weg UKBB	= Beschreibungen der Anfahrt des Caregivers von seinem Aufenthaltsort zum UKBB	25
Weitere Behandlungen	= Beschreibungen von weiteren geplanten Behandlungen	16
In vivo	wenn ich da hingehe sehe ich das […]wie Familie	1
In vivo	Wenn jemand sich selbstbewusst ist, dann hat er Vertrauen	1
Wohnsituation	= Ort sowie Beschreibung des Ortes, an welchem der Caregiver lebt	26
In vivo	You don't have to ask, they are taking care	1
Zuständigkeit	= Beschreibungen die das Zuordnen von Aufgaben zu bestimmten Einrichtungen / Personen beschreiben	6

Supplementary Data 4: Consolidated criteria for reporting qualitative research 32-item checklist

No. Item	**Guide questions/description**	**Reported on Page #**
Domain 1: Research team and reflexivity		
Personal Characteristics		
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	7
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	7
3. Occupation	What was their occupation at the time of the study?	7
4. Gender	Was the researcher male or female?	7
5. Experience and training	What experience or training did the researcher have?	7
Relationship with participants		
6. Relationship established	Was a relationship established prior to study commencement?	7
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7-8
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: study design		
Theoretical framework		
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	8
Participant selection		
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	6
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	6
12. Sample size	How many participants were in the study?	6
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Figure 1
Setting		
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	6 and Table 2 (12)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	Table 2 (12)
16. Description of sample	What are the important characteristics of the	Table 2 (12)

	sample? e.g. demographic data, date	
Data collection		
17. Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	6 and , Table 1 (7)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	8
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	8
20. Field notes	Were field notes made during and/or after the inter view or focus group?	8
21. Duration	What was the duration of the inter views or focus group?	8
22. Data saturation	Was data saturation discussed?	6
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	8 and 9
Domain 3: analysis and findings		
Data analysis		
24. Number of data coders	How many data coders coded the data?	9
25. Description of the coding tree	Did authors provide a description of the coding tree?	9 and Supp. Data 3
26. Derivation of themes	Were themes identified in advance or derived from the data?	9
27. Software	What software, if applicable, was used to manage the data?	9
28. Participant checking	Did participants provide feedback on the findings?	9
Reporting		
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	13-21
30. Data and findings consistent	Was there consistency between the data presented and the findings?	13-21
31. Clarity of major themes	Were major themes clearly presented in the findings?	13-21
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	13-21

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357