# Translating Behind the Scenes: An Observational Study on Language Barriers in Childhood Cancer Care

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## Abstract

Language barriers impact patient's and families' involvement in childhood cancer care, risking the quality of care and patient safety. Despite several studies in the field, few focus on the patient/family perspective. The aim of this observational study was to explore social patterns of communication across language barriers, and to explore how children and families dealt with their main concern. Through the lens of classic grounded theory, we collected and analysed data from observations and interviews conducted at two Swedish childhood cancer centres. Translating behind the scenes is used to resolve the main concern of overcoming language barriers. The causes are varying proficiency in the languages of the conversation, and being uninitiated to the setting, and in a context of respecting the importance of the initiated people. Consequences include being left out of the communication and staying uninitiated. We argue that this leads to ineffective communication and lack of support for patients and their families, which ultimately threatens the patient safety.

**Keywords:** observational study, language barriers, childhood cancer care, classic grounded theory, translating behind the scenes.

## Background

Language barriers present significant challenges in childhood cancer care, affecting both patients and their parents with limited proficiency in a country's majority language, as well as healthcare personnel dealing with language barriers in the care meeting (Robles et al., 2024). These barriers can reduce the ability of patients and parents to engage in care, compromise the quality of care, and pose risks to patient safety (Joseph et al., 2022). Misunderstandings between healthcare personnel and patients or their families can hinder child- and family centred care and, in worst case, lead to life-threatening outcomes (Ruiz et al., 2025).

Research has shown that the use of trained professional interpreters or bilingual healthcare personnel improves communication, yields higher patient satisfaction, gives better health outcomes, and shorter hospital stays, as well as fewer clinically significant errors (Joseph et al., 2022; Karliner et al., 2007). However, healthcare personnel often rely on ad hoc translators, such as bilingual colleagues, adult family members, close relatives, or even children (either the patient or their siblings) (Granhagen Jungner et al., 2019). In the Swedish healthcare context, despite legal mandates and the availability of professional interpreters, there is a systematic underuse of interpreters, and in addition there are numerous non-linguistic barriers to communication in paediatric healthcare (Choe et al., 2019; Granhagen Jungner et al., 2021).

The involvement of an interpreter introduces a triadic relationship in consultations, adding complexity to the communication process (Pergert et al., 2007; Wadensjö, 2020). This complexity is heightened in paediatric care, where children have the right to be involved in communication (Goenka, 2016). Additionally, there may be situations where the child is more proficient in the majority language than the parents and used as an ad hoc translator in care

situations, which creates an unreasonable burden to the sick child while at the same time it affects the family dynamics (Iqbal and Crafter, 2023; Williams et al., 2018).

It is evident that communication deficiencies can lead to critical information and educational opportunities being missed for children and families with limited proficiency in the majority language. Currently, there is limited knowledge regarding the communication experiences for this group in paediatric care. While some research has been conducted on communication involving interpreters, there is a lack of studies focusing on communication without interpreter support in childhood cancer healthcare settings. To enhance child- and family centred care and ensure patient safety, it is crucial to investigate the dynamics of communication between healthcare personnel and children and families with limited proficiency in the majority language. Understanding the social patterns when communicating across language barriers, both with and without the presence of an interpreter, is of importance for the care of seriously ill children and their families. This observational- and interview study will provide valuable knowledge which will contribute to improving patient safe communication and thereby improving quality of care. Thus, the aim was to explore social patterns of communication across language barriers in childhood cancer care, and how children and families dealt with their main concern.

## Methods

In this observational and interview study, classic grounded theory was chosen as research design. On site observations were made and patients and their families were interviewed. This resulted in a data set which allowed us to explore participants main concern and to explain how participants dealt with their main concern (Glaser, 1998; Glaser & Strauss, 1967).

**Data Collection**

The data collection was made at two childhood cancer care centres in Sweden – Stockholm and Uppsala – over a period of 3 years, 2016 to 2019. Before focusing on families with little or no proficiency in Swedish, baseline observations were made, 36 hours of baseline observations on four different occasions in Stockholm and 8 hours of baseline observations on one occasion in Uppsala. The rest of the observations comprised of 80 hours on ten different occasions (six in Stockholm and four in Uppsala). A total of six families were observed and interviewed during data collection, all families had different language backgrounds. The inclusion criteria for the families were that they had little or no proficiency in Swedish, and that they had a child who was a patient at one of the centres. Only families who gave informed consent were included. Theoretical sampling was made throughout the observations and data analysis was initiated during the data collection (Glaser, 1998).

The data collection was made onsite by one observer (first author), and detailed analogue fieldnotes were taken on paper. Spontaneous as well as planned interviews were also made, and planned interviews were recorded. Professional interpreters were used for communicating with the families, but only for gathering informed consent, and for planned interviews. Many observations were made without professional interpreters being present. Exploratory observations were conducted, unconditionally observing communication situations and the families' whole context as they were present at the centre.

The observer was mostly a passive observer, i.e., not a participant in the care. However, the observer communicated with all healthcare personnel and the observed families. On some occasions the observer also took a more active role and informed healthcare personnel about

interpretation and how to book and work with interpreters. The interviews were made when there was a possibility to do so.

**Data Analysis**

Fieldnotes (in Swedish) from observations and interviews were read out loud to the co-researchers (second and last author) by the researcher who conducted the data collection (first author). Also, recorded interviews were played on loudspeakers. Fieldnotes included notes about the observations as well as codes and notes about those codes. During the reading, it was clearly stated what kind of notes were read. The two co-researchers, who had not participated in the data collection, wrote memos while listening to the data. The three researchers coded their own memos separately, using open coding line by line, as well as selective coding for the fieldnote codes identified by the first author. Codes and incidents were compared and discussed among the researchers. The codes were conceptualized and digital memos were written about each of the categories. The researchers continued writing memos in-between meetings. Memos were printed and sorted, and theoretical coding was conducted by the researchers and thus ensuring the emergent fit to the six C's (Cause, Covariance, Context, Condition, Contingent, and Consequence [Glaser, 1978], see further Figure 1). The memos were rewritten to form the basis of the manuscript and translated to English.

## Theory

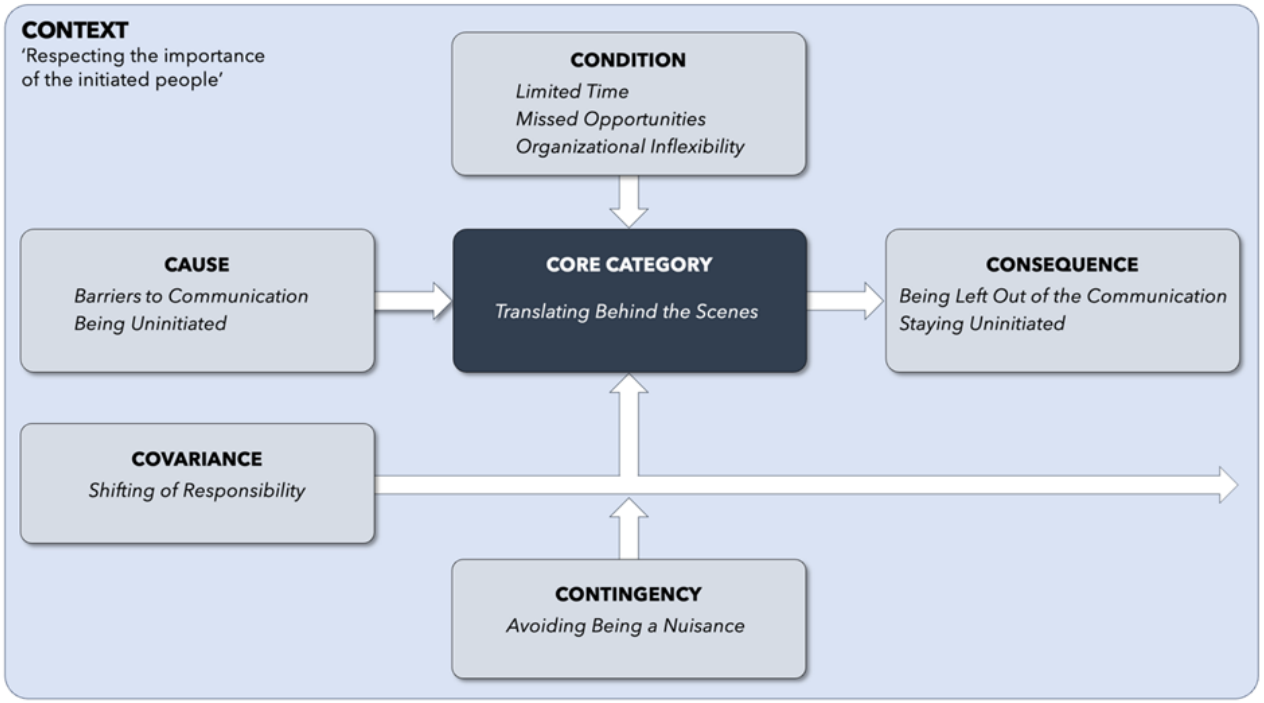
*Translating behind the scenes* is the core category in this study, used to resolve the main concern of *overcoming language barriers*. The situation causing this social pattern is that there are *barriers to communication* through varying proficiency in the majority language and not everyone present shares a common language and that the family is uninitiated in the context and culture. To address this, they translate behind the scenes. Translating behind the scenes is done in

an atmosphere of respecting the importance of the task and time of the 'initiated people' (i.e. Swedish speaking healthcare professionals) and in that context, it is vital not to bother them unnecessarily and to be courteous. In this study the families had *respect for the time of the initiated people*, who should focus on treating and caring for the child, and thus the family did not want to bother them with their needs and questions.

In a meeting with communication across language barriers, where a member of the minority speaking group does not know the majority language and/or is uninitiated in the local culture, it risks causing the communication being reproduced through translation behind the scenes. The consequence of such a situation contributes to the exclusion of that person and to them remaining uninitiated, see Figure 1

Figure 1

*The Conceptual Model (after Glaser 1978) for Explaining the Theory of Translating Behind the Scenes*.



**Translating Behind the Scenes**

This is when an informal translation takes place in the background, that is, not part of the ongoing *official* conversation. The informal translation can take place simultaneously during the ongoing conversation, after the conversation or both. When translation takes place after the conversation, it is done by the speaker understanding the two languages giving a summary of what was said to the person not included in the conversation.

When translation takes place behind the scenes, there are varying levels of awareness of this. Often, the majority language speakers (MLS) do not seem to be aware of the other language(s) spoken by those present. MLS may also be unaware that there is someone present in the conversation who understands neither the majority language nor the translated language. Translation behind the scenes may be done by a child who has learned the majority language better than the parents, by a MLS who also speaks the language of the minority language parties, or by a parent when only one parent understands one of the languages spoken in the conversation.

In our study, we observed a family where the two parents spoke different minority languages and the language spoken by the interpreter was only understood by one parent. The personnel spoke Swedish, the interpreter translated into Persian, the language of the mother, which means that the father, who spoke mostly Dari, was to some extent left out of the conversation. During our interview, he was mostly silent, but at one point he told us what happened when he sought care for the child. The mother translated very little to the father during the interview.

Another example we observed were conversations with a mother and her son who had been treated for cancer for many months. The boy knew Swedish, and the personnel told the

observer that the mother now communicated quite well in Swedish. No interpreter was present in the care conversation and the personnel spoke Swedish to the child and the mother. During the conversation, the child kept mumbling translations to his mother, unnoticed by the personnel. Sometimes the personnel spoke directly to the boy, for example, to tell him what they were going to do, whereupon the boy summarized some but not all of the information to his mother. This led to the mother not understanding everything that was said in the room, but only the information that the boy chose to retell. When questions were asked directly to the mother, the boy translated mumbling to the mother, to which she responded very briefly with single words in Swedish.

**Barriers to Communication**

The situation causing this social pattern is varying proficiency in the majority language and that not everyone present in the communication shares a common language. The language situation within a group can be very complex as different group members may have different language proficiency in the majority language and, in addition, they may have different mother tongues and language proficiency in other different languages. Furthermore, in institutional meetings, the institutional parties may not have the majority language as their mother tongue, and they may have language proficiency in other languages.

Sometimes the context can be frightening and needs to be explained, which is made more difficult when there are language barriers. An example from our data was when a child was transported in bed from the ward to the radiotherapy department. The transport went through the hospital culvert where there was a strange smell and some odd art on the walls. Without a common language it was difficult to explain and reassure the child.

There is also local jargon in the context that can be difficult for the uninitiated to understand, in healthcare it can be medical terms. The longer a person is in a local context the

more familiar they become with the local jargon. We observed an interpreted consultation where an otherwise very professional interpreter was not familiar with the term “neutropenic”, which the mother understood as it was widely used in the context. This signalled to the family that the interpreter was incompetent, and even made the mother comment “give the interpreter a dictionary.”

**Being Uninitiated**

A contributing cause to translation behind the scenes is when a person is uninitiated in the context. Communication happens constantly in any given context and gives information about both explicit and implicit rules. Much of this information is in writing, which is only understood by those who can read the majority language. Unspoken rules can be very difficult for the uninitiated to understand if they have not even understood the spoken rules. This can lead to the person breaking the spoken and unspoken rules of the context, affecting the interaction and communication.

For example, we observed that healthcare personnel wore the same clothes regardless of their profession, but had signs in different colors indicating their profession. This was important for families to understand as the various professions had different powers and responsibilities. For example, it was difficult for the family to understand why the nursing assistant, who came in when they alerted the personnel, did not mute the drip machine but just said something and left the room. Only when a nurse entered the room did she stop the noise.

Before and during procedures that are potentially frightening for the child, personnel usually interact with parents and involve them in preparing and initiating the procedure. When the parent is uninitiated, it complicates the process of initiating the child. We observed a boy being prepared for bone-marrow aspiration. The boy spoke Swedish, and the nurse

communicated in Swedish with him, but the mother's Swedish proficiency was not enough to participate in the initiation and preparation. No interpreter was present, and the boy was left alone with the responsibility to understand and prepare for the procedure.

**Shifting of Responsibility**

The shift of responsibility is related to *translation behind the scenes* and refers to the institution and its personnel, who are responsible for patient-safe communication, do not take their responsibility to enable this. It thus creates a void forcing the individual to ensure communication. In one of our interviews, a family told us that they called friends who spoke Swedish when they needed to communicate as they did not have access to an interpreter. And in one of our observations, a boy took the responsibility to report about his food intake and to translate instructions for medication because his mother did not speak enough Swedish to understand the instructions and no interpreter was present. In this particular case it was also challenging that the mother, who had started communicating more in Swedish during the long treatment of her son, was deemed to communicate well in Swedish now. Thus, she had less access to an interpreter and therefore had to rely more on her son. We also observed a nursing assistant who took a lot of responsibility for translation for the Persian speaking family, even though Persian was her third language, in situations which normally would have required the personnel to call an interpreter.

**Avoiding Being a Nuisance**

A factor influencing translating behind the scenes is the uninitiated individual not wanting to bother or be difficult and trying to take responsibility for managing the situation smoothly. Courtesy influences translation behind the scenes, in an effort to respect personnel time. It is a matter of trying to blend in, understanding their role and what is expected, and

learning without asking too much. Many people want to make every effort to speak the majority language and prefer to avoid using an interpreter unless they have to. If there are varying levels of proficiency in the languages of the conversation, it would be better to risk one member being left out of the conversation and use translation behind the scenes rather than unnecessarily take up the time of the personnel.

In one of our interviews, the mother told us how she learned what to do with her child's urine in connection with chemotherapy treatment by watching what the personnel did and showed without an interpreter. She said, “before we didn't know, but now we have learned.” In our study, we interviewed a Chinese speaking family where the father spoke English fluently but not the mother. Both parents told us, translated via the father, that in the beginning all communication was enabled by the father’s translation. The father censored the mother’s questions because he thought it was unnecessary for her to take up the personnel's time. The mother expressed that when an interpreter finally was present, she was relieved to be able to ask unfiltered questions. If dissatisfaction was experienced, it was yet considered important to be reasonable and not complain, for instance when the interpreter was perceived as incompetent, the family did not point it out to the personnel.

**Limited Time**

Limited time is a condition impacting translation behind the scenes. Time for meeting the individual in institutional encounters is often limited, also in healthcare. Interpreted conversations take longer than monolingual conversations, as one language layer is added to the conversation. In interpreted encounters there is thus an increased time requirement, which is in most cases unaccounted for. This unaccounted time requirement leads to diverse challenges for the participants in the encounter.

We observed an interpreted encounter, where the interpreter was booked for an hour, after the hour they left, although the conversation was not finished. In one of our interviews, a father described how the cancer diagnosis of his daughter was delayed, since they were asked to come back next Tuesday when an interpreter would be available, rather than being examined immediately. This had a direct impact on the time lost before accessing healthcare.

**Missed Opportunities**

The missed opportunities condition is about situations where an interpreter is available, or there are other opportunities to communicate, but due to different factors, the opportunity is overlooked and not taken by the personnel. The reasons why the opportunity is overlooked can be as simple as personnel not understanding that an interpreter is available, or personnel not knowing that they are allowed to ask for interpreter collaboration. The condition creates situations where uninitiated are kept out of the information and communication loop, and it results in them using translation behind the scenes.

In one of our observations, we observed the interpreter arriving on site and standing outside the patient's room, waiting for the encounter with the physician. While the interpreter was waiting, the nurse arrived to explain and prepare a procedure (a bone marrow aspiration). Despite the fact that she saw and passed the interpreter, she did not ask him to participate in the preparation for the procedure. Instead, she resorted to explaining to the 13-year-old patient who then served as a translator to his mother. In a similar situation, another patient and his mother were having a conversation with his physician, and a nurse was waiting outside to explain the central venous catheter, but the nurse was not invited into the room while the interpreter was there.

In another observation we saw the following situation, an interpreter was booked for a certain time and arrived for that appointment, however, as this was in clinical care, the personnel were not available at that time, and the interpreter had to wait. No one worked with the interpreter during that waiting time, and there was thus a loss of interpreting resources and communication possibilities.

**Organizational Inflexibility**

Many barriers for successful communication across language barriers lie in organizational inflexibility. The organizational setup creates the condition for communication across language barriers both in an explicit way, but also, and perhaps with an even higher impact on the successful communication, implicitly. Explicit frameworks include legal regulations and the procurement of interpreting services, as well as the routines around recruiting an interpreter. All in all, this creates a bureaucratic complexity that amplifies inflexibility.
In terms of implicit frameworks, the decision to call an interpreter should be mentioned as it highlights implicit inflexibility. In our observations we noted that interpreters were called when the physicians identified a need for themselves. Nurses would never raise the question of calling an interpreter if there was no identified need from the physician.

In our observations, nurses were the ones responsible for booking interpreters. When a nurse booked an interpreter, they called a procured interpreter agency. The agency sent the confirmation of the booking to a personal e-mail address (since the clinic did not have a shared mailbox). The nurse who made the booking was not working when the interpreter was scheduled, and therefore it was not possible to trace the confirmation and find the interpreter who did not show up.

Another implicit inflexibility, which substantiates language barriers, is the lack of information about an interpreter being on site. We observed how one interpreter arrived onsite without identifying themselves to the personnel, thereby causing the personnel to have to look for the interpreter. On another occasion, the interpreter who arrived had to search for personnel to alert them to their presence.

**Being Left Out of the Communication**

A consequence of language barriers is that one party may be left out of the communication. When the translation occurs behind the scenes the excluded party does not get access to the communication. A common reason for the individual to be left out of communication is that they lack proficiency in all of the languages in the conversation.

In our baseline observations, many of the interactions containing important information, between personnel and patient/families happened informally in the corridor. We did not observe the same type of informal conversation between personnel and families with low Swedish proficiency. However, in one case a Persian speaking nursing assistant was asked to relay information.

When we observed telephone interpreting, only the people participating in the actual conversation (the physician and the two parents) were introduced to the interpreter, not the other people in the room (nurse, sibling, the observer). This made it challenging for the unintroduced people in the room to take the floor, if they wanted to add things to the conversation.

In one observation, the impact of unintroduced people in the room was particularly salient when an unintroduced child started playing quite noisily, since the interpreter was on the phone, it was impossible to know what caused the disturbing noise. This was further complicated as a medicine list, that the interpreter did not have visual access to, was discussed.

In this case, the interpreter is left out of the conversation by not having full access to contextual information about the communication. The consequences are that the patient and family are partly left out of the conversation.

In the observations described in other categories with Persian/Dari speaking parents and with Chinese/English speaking parents, we observed, and the parents also talked about, how the parent who did not speak the language of the conversation was not included in the communication. In one observation, four of the participants spoke Swedish – two physicians, an interpreter and, the patient – and one did not – the patient's mother. The interpreter did not interpret to the mother when the physician was talking to the patient in Swedish about how he felt. The same thing happened when the two physicians talked to each other about the patient in Swedish. Thus, the mother was not included in all the communication, although the interpreter was in the room.

**Staying Uninitiated**

When translation is happening behind the scenes, the consequence is that a person being left out of the communication remains uninitiated. An individual, who lacks access to communication, will not know who to direct their questions and concern to, which hinders them to be initiated. The prerequisites to be initiated are influenced by the shifting of responsibility for translation, the desire to avoid being a nuisance, and conditions such as the limited time of personnel and organization, but also missed opportunities for interpreting, and organizational inflexibility.

An example from our observations is the Dari speaking father, who did not speak any of the languages of communication, and who was dependent on his wife for most of the information about his daughter's illness and treatment. Throughout our observations, he remained silent and

passive, also in situations where he was the main caregiver. Also, the Arabic speaking mother, who had been striving to learn Swedish, but because of the complex context of childhood cancer care, had to rely on her son's mumbling translation behind the scenes, rather than proper access to the communication.

## Discussion

The aim of this study was to explore social patterns of communication across language barriers in childhood cancer care, and how children and families dealt with their main concern. Our substantive theory shows that *translating behind the scenes* is the core category used to resolve the main concern of *overcoming language barriers*. Translating behind the scenes occurs in the current context when those present in the communication have varying levels of proficiency in the spoken languages and some have very limited proficiency which leads to them being *left out of the communication*. In addition, the person is *uninitiated*, which means that there is a very limited knowledge of the care context which further contributes to the person being left out of the ongoing conversation.

Translating behind the scenes is somewhat similar to façading which is about presenting a façade in social interactions to protect oneself and others (Pergert, 2017). Façading is a social pattern for hiding vulnerabilities and potentially disturbing emotions and information, for example staying strong and protecting professional composure (Pergert et al., 2008a). Translating behind the scenes is a way of handling a situation when one person is uninitiated and is being left out of the communication, thus, façading the failure of including everyone. Furthermore, responsibility of the situation is shifted and thereby façading the failure of the ones who should be responsible.

Being uninitiated and barriers to communication emerged as causes to translation behind the scenes. These causes lead to situations where children and families are not adequately prepared for care situations, which can create fear and uncertainty. Preparation for procedures is an important area of competence in childhood cancer care, and important for the child to help them prepare and "feel less worried and less scared" (Bray et al., 2019: p. 632). Language barriers add another layer to the complexity of the situation and the preparation.

Furthermore, being and staying uninitiated can be compared to Sandgren's (2012) grounded theory "Deciphering unwritten rules". In Sandgren's theory the main concern was the uncertainty about how to act and behave appropriately in various situations in a context with unwritten rules and unspoken expectations. In our case, the fact that patients/families did not share a common language with the healthcare personnel further hindered them from deciphering the unwritten rules, and the consequence was that they stayed uninitiated.

The shifting of responsibility emerged in this study and includes both individual and organizational responsibility. The responsibility of ensuring communication across language barriers is shouldered by the individual, which can be both the personnel and the parent/patient. The individual steps in and solves the problem themselves ad-hoc, since the organisation fails in creating a structure and system that manage language barriers. This is an ever-present social pattern in society, for example, in disasters the individual, and the local community take on a greater responsibility than could normally be expected, as this is required by the situation (Mayer, 2019). However, it can hardly be argued that communication across language barriers in Swedish health care is an emergent disaster, quite the contrary, it is a well-organized system which dates back to the 1960s, surrounded by legislation and frameworks (Tiselius, 2022). The patients and families in childhood cancer care are surely in a crisis situation, and it is thus not

surprising that they take on the responsibility for communication as well. It is all the more surprising that the healthcare organizations are unable to uphold their responsibility and cater for a functioning organization of an inclusive communication.

The consequences of translating behind the scenes are that if parents are left out of the conversation, they are denied their right to be well informed in order to participate in shared decision-making, and support their child (Boland, 2019). Furthermore, the lack of communication between parents and health personnel affects the aim of healthcare to act in the best interests of the child. Another aspect of translating behind the scenes is when children do the ad hoc translation. In these cases, they risk focusing more on solving the communication situation than on their own involvement in and shared decision-making about their own care. The conditions limited time, missed opportunities and organizational inflexibility have been identified in previous studies as main obstacle to communication across language barriers (Granhagen Jungner et al., 2021; Jaeger et al., 2019; Pergert et al., 2008b). These conditions all contribute to increasing the risk of important information being missed or misunderstood as described by Ruiz et al. (2025) and Karliner et al. (2007).

A limitation of this study is the low number of observed individuals. This might have contributed to the theory being quite descriptive. Further theoretical sampling would increase the conceptualization of the theory and further explain variations of the concepts.

In summary, the social pattern of translating behind the scenes as described in this theory, is not unique to this specific setting of childhood cancer care, or the healthcare sector, but may also occur in other contexts when someone lacks knowledge and is uninitiated in the local environments and language used. Examples of this are, on a microlevel, when a person is new to a workplace, or on macrolevel, when migrants arrive in a new country. However, further

theoretical sampling is needed to modify this substantive grounded theory to explain other contexts.

## Clinical Implications

This study has shown that there is a need for structural changes to address the challenges of communication across language barriers, and that professionals take their responsibility over the communication so that it is not shifted to patients and families. Furthermore, an awareness is needed about the vulnerable situation of children when their parents have low proficiency in the majority language. Such an awareness must include the understanding of the great complexity of language backgrounds and language use among patients and families and how this complexity leads to parties being left out of the communication.

Structural changes for meeting the challenges of communication across language barriers could include: employing interpreters with a 24/7 accessibility for minority languages with many speakers; employing coordinators responsible for communication flow across language barriers; allowing interpreted encounters to take the time necessary for ensuring patient-safe communication; including interprofessional training in working with interpreters in the curriculum at the basic training for all professions in the healthcare; ensuring proper education for healthcare interpreters; and last, but not least, increasing knowledge about how to communicate through interpreters, and also the organization's responsibility to ensure patient-safe communication.

## Conclusion

We conclude that the consequences of translating behind the scenes are that patients and families are left out of the communication, and that the person who does not speak the majority

language stays uninitiated. This leads to ineffective communication and lack of support for patients and their families in childhood cancer care, which ultimately threatens the patient safety.

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**Authors' contributions:** The first author designed the study, applied for ethical approval and collected the data and analysed the data, wrote the manuscript. The second author analysed the

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