Mediating proximate care in transnational families in Sweden and the UK: language practices and institutional processes

Population, Space and Place

WILEY

RESEARCH ARTICLE OPEN ACCESS

Mediating Proximate Care in Transnational Families in Sweden and the UK: Language Practices and Institutional Processes

Tony Capstick[1] | Katarina Mozetič[2] | James Simpson[3]

[1]Department of English Language and Applied Linguistics, University of Reading, UK | [2]Malmö Institute for Migration Studies, Malmö University, Sweden & German Center for Integration and Migration Research (DeZIM), Berlin, Germany | [3]Division of Humanities, Hong Kong University of Science and Technology, Hong Kong

Correspondence: Katarina Mozetič (katarina.mozetic@mau.se)

Received: 29 May 2024 | **Revised:** 28 January 2025 | **Accepted:** 4 February 2025

Funding: This study is a part of the research project "Care, Inequality and Wellbeing in Transnational Families in Europe: a comparative, intergenerational study in Spain, France, Sweden & UK (CareWell)". CareWell is an international research project funded by the JPI More Years Better Lives and carried out by the University of Reading and the University of Leeds in the United Kingdom, Malmö University in Sweden, Aix-Marseille Université in France and Universidade da Coruña in Spain. The UK part of the project was funded by the Economic and Social Research Council (grant RG.GEOG.123085) and the Swedish part was funded by Forte (the Swedish Research Council for Health, Working Life and Welfare) (grant 2020-01524).

Keywords: institutional discourse | language brokering | literacy mediation | proximate care | transnational families

ABSTRACT

The paper advances our understanding of care in transnational families by exploring how proximate family members engage in care within two institutional contexts, a school and a hospital. It considers how care processes and outcomes are shaped by the transnational character of families and by the related power dynamics inherent within families and institutions. It does so by studying language and literacy practices that people engage in when they act as language brokers and literacy mediators for family members who are accessing care. Working with two families in the United Kingdom and Sweden, our analysis draws on fieldnotes, interviews with caregivers, and interactional data. We describe the language and literacy practices and interactional events associated with our participants' institutional encounters, relating them to individuals' intersecting positionalities. Analysis demonstrates the ways in which these practices enable them to challenge inequalities inherent in health and educational systems.

1 | Introduction

This paper explores how members of transnational families provide proximate care within two institutional settings, a school and a hospital. We consider how care processes and outcomes are shaped by the transnational character of families and the power dynamics across families and institutions. Compared to distant care practices, proximate care has received less attention within the literature on transnational families. Predominantly, proximate care arrangements are studied in relation to distant care (Merla et al. 2020; Thi Nguyen et al. 2023), reflecting the established understanding that the two represent complementary forms of care (Baldassar and Merla 2013; Kilkey and Merla 2014). Merla et al. (2020) further highlight how restrictive Global South-North mobility regimes impact proximate care within transnational families.

This paper shifts the focus to the provision and negotiation of proximate care at the intersection of state care providers in destination countries and transnational family members, whilst retaining attention on the role of the transnational in these encounters. To do so, we home in on the language and literacy practices that people engage in when they act as language brokers and literacy mediators for family members who are accessing health and social care, in multilingual contexts and

across generations. The focus on language and literacy practices enables us to discern—at the level of interaction—the tensions embedded within caregiving, and the agency of particular social actors. Our material, generated through 'Care, inequality and wellbeing in transnational families in Europe: a comparative, intergenerational study in Spain, France, Sweden & UK', focuses on transnational families with members residing in the United Kingdom and Sweden, whose networks extend globally.

Grounded in sociolinguistics and literacy studies, this research examines how caring relationships are enacted and developed interactionally. It aligns with critical sociolinguistic perspectives (Blommaert 2012; Heller 2010) that view contexts as having permeable boundaries, shaped by activities, individuals, institutions and discourses. By investigating institutional interactions in schools and hospitals, our approach enables us to look across activities and family relationships by considering the ways in which positions and discourses are challenged (Bauman and Briggs 1990). We pay particular attention to the negotiation (successful or otherwise) of power and agency that relate to how family care is negotiated when family members broker and mediate on behalf of other members.

The paper begins by situating our work within discussions of care, tension, and agency before detailing our study and analytical approach. In the two analytical sections, we introduce participants and their families and analyse caregiving mediation within institutional settings. Using interactional sociolinguistics and literacy studies, we examine the challenges of institutional interactions, the agency participants exercise, and its limits. Finally, we consider the role of extended, globally dispersed families in negotiating care.

2 | Ethics of Care, Tensions and Agency

This paper adopts Tronto's (1998) ethics of care approach which defines care as a process encompassing four interrelated phases, each entailing a moral disposition. 'Caring about' relates to the perception of caring needs in oneself and others and to listening to those who need care, requiring attentiveness to notice and attune to that person's situation. After the caring need has been identified, 'caring for' assumes acknowledgement that one can act upon the identified needs. It involves the development of a sense of responsibility to address those needs, and to organise and provide resources to meet them. The 'caregiving' phase is about the actual addressing of the caring needs. It is associated with knowledge and competence about how to care, denoting competence as a key value. Fourth, the 'care receiving' phase is about the response of the person or group that received care. It is based on the idea that evaluation of care, that is, the actions of caregiving and quality of forged relations, should not be reserved only for the caregiver, but also those who receive care. More recently, Tronto (2016) has added a fifth phase to her framework. Acknowledging the gendered, classed and racialised distribution of care and the ensuing social inequalities, 'care-with' establishes that the fulfilment of caring needs should align with democratic principles of ensuring fairness, equality, and liberty for everyone (Tronto 2016: 14–16).

While these phases are heuristically distinct, they are tightly intertwined in an on-going process, co-produced by various parties and mediated by intersecting social structures (Davis 2022). Accordingly, care can foster both solidarity and conflict (Carling et al. 2012), with tensions arising within or across phases (Tronto 2016). For instance, responsibility during the 'caring for' phase may vary between actors based on social, geographical, and temporal contexts (Hoang et al. 2012). Responsibility for proximate caring can deny caring for at a distance (Bastia 2015).

Caregiving itself can be fraught with tensions, shaped by differing views of what constitutes good care and how to achieve it (Tronto 2016). In transnational families, caregiving is influenced by cultural obligations, negotiated commitments, and access to resources like mobility, communication, finances, and education (Merla and Baldassar 2011). Access to these resources is mediated by migration regimes (Merla et al. 2020), employment, and welfare systems (Kilkey and Merla 2014), as well as intersecting social factors such as gender, generation, ethnicity, and class. Discrepancies in caregiving responsibility can cause tensions. Intergenerational conflicts can arise from, for example, when significant care obligations are placed on children and young family members (Suter et al. 2025) or, as Salazar Parreñas (2008) highlights, from traditional, authoritarian transnational fathering practices that neglect emotional care.

Beyond families, states, markets, and third-sector organisations provide essential care resources for transnational families (Levitt et al. 2017). These resources form a dynamic environment that varies across time, places, and individuals. This paper focuses on interactions between transnational families and state care providers, examining how care is negotiated. Rather than exploring state provisions directly (Bilecen 2020), we investigate how power relations influence the ability to define, assume responsibility for, and evaluate care in these interactions, particularly through language and literacy mediation.

Effective caregiving that entails interactions between institutional and personal caregivers requires language proficiency, a particular challenge for many individuals on a migration trajectory. Social actors from minority linguistic backgrounds are often at a disadvantage in institutional interactions, suffering the linguistic penalty associated with this status (Roberts 2013). Pertinent in this study is the observation that the linguistic challenges faced by migrant families navigating institutional care systems in a new environment happen within specific institutional domains, requiring access to equally specific, and frequently inaccessible, knowledge. The use of specialist, insider discourse is regarded by critical sociolinguists and literacy theorists as an aspect of the discursive control that prevents those who are outside the institution from accessing 'powerful' languages, registers, genres, discourses and literacies (Capstick 2016; Wodak 2014; cf Gee 1992). Moreover, successful institutional interactions regarding care require access to knowledge of rights and specific institutional practices related to care; knowledge that migrants often do not have (Rechel et al. 2013).

Hence 'care involves power relations' (Tronto 1998: 17), as played out in interaction between unequal social actors. While recognising a generally understood power imbalance between those providing care in institutional settings and the care receivers (see, e.g., Henderson 2003), we acknowledge further complexities that relate to language and literacy mediation when members of transnational families engage with institutional provision of care (Iqbal and Crafter 2023). On the one hand, there is the relationship between

caregivers from state institutions, and the mediating family member with lay knowledge about the care needs at hand and perhaps limited destination-country language proficiency. On the other, there is a particular power dynamic between the mediating family member and the person in need of care, emerging from the divergent social locations connected to gender, age and kin relationship, as well as from differences in access to resources (e.g., communicative resources such as multilingualism).

As such, family members acting as language and literacy mediators claim agency to 'influence their contexts rather than merely react to them' (Liddicoat and Taylor-Leech 2021: 1). As our analyses demonstrate, institutionally sanctioned decisions that invoke an educational or medical policy have the potential to be rejected as a form of resistance (Giddens 1984) or as an exercise of choice (Pickering 1995). This resistance is gendered, as we shall demonstrate, when cultural practices affect the extent to which married couples are able to shape the outcomes of institutional interactions as they perform their roles as wives and husbands as well as carers (Heidbrink 2014: 16).

3 | Methods

Community researchers on the project undertook 71 interviews with members of 42 families in Sweden and 88 interviews with members of 26 families in the United Kingdom, in addition to associated work in France and Spain. The majority of the interviewees in Sweden have forced migration backgrounds. The UK family members have a range of migration experiences, both forced and voluntary. Additionally, ethnographic research was carried out by academic researchers with five families in Sweden and three in the United Kingdom. This paper draws on work with two of these families, one living in Sweden and the other in the United Kingdom. Our material comprises transcriptions of in-depth interviews, fieldnotes, transcripts of spoken interaction between the family members in the country of origin and elsewhere, social media exchanges between family members, and interactions with institutional actors in a school and a hospital.

We adopt a case study approach in this paper, enabling the detailed study of the real-world experiences of two families, and a deep understanding of their complexities. We pay close attention to the data, supporting credibility of, and confidence in, the findings. The selection of the two cases from among a larger number of possible cases suggests the applicability of the findings in other contexts (Lincoln and Guba 1985). It also points to their pertinence to practice and policy, a theme we draw out in our discussion and conclusion.

Our analysis proceeded in two steps. Initially, we scanned the larger data set of interviews conducted by the community researchers to obtain a sense of the mediation practices our research participants undertake when providing care. This enabled us to discern the relevance of such practices in institutional settings. In the second step, we explored this topic in more detail with reference to the ethnographic case study families, eventually focusing on just two. These were selected for the rich and particularly illustrative understandings of care-related mediation in institutional settings. With the family in Sweden, we refer to three in-depth interviews with a caregiving mother, Manar, and fieldwork notes from a fourth meeting. In the UK case, we examined three interviews with Shazia, whose husband is receiving care, two interviews with each of her sons, notes from ten visits to their home, and transcripts of interaction recorded when accompanying the family to hospital consultations. Informed consent was gained from all participants in the project, concerning the use of the recordings for analysis. All data in this paper are anonymised.

The analytical sections that follow are informed by two broad approaches to the study of situated language use: interactional sociolinguistics and literacy studies. In the first section we take an interactionally-oriented approach to the narratives that emerge in the interviews with Manar, analysing them as communicative practice (De Fina and Georgakopoulou 2012). We examined data on home–school interactions around the support offered to Manar's son Adnan by the education authorities. These were in Swedish, and focal extracts were transcribed by the third author and translated into English, retaining some paralinguistic detail.

In the second section our attention is also on spoken data, to which we adopt a literacy practices approach (Barton and Hamilton 2005). We brought together data on the theme of home-doctor interaction as it was experienced by Shazia and her husband Faisal, the selection of data guided also by the emergent findings from the analysis in the Sweden case. Recorded interactions, in English, were transcribed by the research assistant and the first author. Transcriptions follow a simplified version of the conventions developed by Jefferson as summarised by Holt and Clift (2007) (see appendix 1).

4 | Example 1: Manar and Adnan

Manar and family are from Syria, now living in Sweden. The family consists of the parents Manar and Bashir (born in Syria; she in her thirties, he in his fifties), and their three children, including teenager Adnan, who, according to his school, experiences learning difficulties. Project team member Ingrid conducted three in-depth interviews with the family in May and June 2022. While Manar, Bashir and Adnan were all present in the interviews, Adnan played no active verbal role, and Bashir made only an occasional comment. Our analytical focus is on the talk of Manar, and specifically how she narrates her experience of negotiating Adnan's care at his school. The analysis aims to provide enriched understanding of how a mother from a migration background navigates institutional practices around the care for her child in a school setting.

Manar arrived in Sweden in 2015, earlier than Bashir, together with the two eldest children (including Adnan). Manar and Bashir say that their migration was prompted by Adnan's diagnosis of a heart condition, and by being unable to receive appropriate health care during the war in Syria. Manar and Bashir both have siblings in Syria and elsewhere

in Europe, with whom they are in regular contact. Manar has attended Swedish language classes since arriving in Sweden. She works full-time at a children's daycare centre. Bashir, after dropping off their toddler son at his own daycare centre, goes to his own Swedish language class.

Manar appears to take responsibility for caring for everyone in the family, receiving some help from Bashir and Adnan. This primary role relates to her more developed competence in Swedish, and thus to the family's status as fairly recent migrants in Sweden. She is in contact with institutions like health care providers and schools. Bashir assists with the household chores but plays no role in tasks that involve institutional interactions outside the home. Manar says that Bashir becomes shy when he needs to talk to people such as doctors. He himself reports feeling anxiety when trying to interact in Swedish. He supports Manar with activities involving literacy, however, as Manar is dyslexic. Manar perceives Adnan as a possible source of assistance, and often mentions him as a person who could help Bashir to improve his Swedish. But this is easier said than done: according to Manar, Adnan's Swedish vocabulary is large, but not his Arabic. The two elder children also use English to communicate between themselves, privately. As Manar says with a laugh, *when they don't want us to know what they are saying, they speak English*.

Adnan has been seeing the school psychologist for several years. These psychological counselling meetings are called habilitation (*habilitering* in Swedish). Habilitation is offered to children with various kinds of disabilities, physical, intellectual (i.e., a developmental disability), neuropsychological (e.g., autism) or a visual or hearing impairment. The aim is to assist children in going about their everyday life as independently as possible. While habilitation is primarily directed towards the child, it also offers support to the child's caregivers (Region Skåne 2019).

The family has been told in a letter from the school psychologist and Adnan's teacher that he has problems with learning: Manar says they *claim that there is some kind of issue with his brain*. Manar has also recently begun to attend habilitation meetings at the school, attempting to understand what Adnan's problems are, and how they can be addressed. In the extracts we examine, we consider Manar's talk in relation to three issues. First, she narrates her experience of navigating care in the context of complex institutional decision-making processes with which she is unfamiliar. Second, she questions which people have the right to assume responsibility for her son's care. Third, she positions herself as someone responsible for proximate care in one locality while maintaining an emotional connection with distant and separate family members in another.

4.1 | Navigating Institutional Decision-Making

The first extracts are from talk near the beginning of our second interview with Manar. They point to the difficulty experienced by a migrant mother in navigating the care her child needs, in a complex and unfamiliar context. She articulates her own confusion about the teachers' interpretation of Adnan's difficulties at school, and the confusion too of those carrying out *kontrollerna [the checks]*. This confusion is coupled with a disagreement about the account she has been given of Adnan's problems. The account she herself gives is of an oppositional stance towards the support offered, indicated in particular by the contrasting use of reference pronouns *they* and *we*:

1.	M:	My son goes to the sixth
2.		but son has problem in (.) is difficult to understand
3.		that they say here
4.		I don't know that think that (.) but we have that now come they
5.		takes long time that they do check-ups to her and she
6.		they say teachers who are at the school
7.		they say that Adnan has difficulties to understand
8.	I:	ok
9.	M:	yes they think that he has problem (.)
10.		but we say ↓no that he doesn't have any problem
11.		because when we are going when speak with him
12.		he is going to explain everything (.) but maybe he
13.		I feel that he ok
14.		he maybe has difficulties learning or
15.		maybe he has same my problem
16.		that has dyslexia to difficult to read and write (.)
17.		but I don't know what they think
18.		but (.) they maybe do right but also wrong
19.		because they do check-ups since 2018
20.	I:	yes
21.	M:	until now it is now that now the decision don't come
22.	I:	yaha so it started in [2018 yes
23.	M:	[2018 yes and you know that
24.		always the staff is going to change

Extract 1 Interview 2, beginning at 0:04:06

The extract begins with Manar stating that her son *has problems in (.) difficult to understand* (line 2). There then follows a sequence (3-9) where she presents what *they* say as being in opposition to what *we* say. *They* are mentioned repeatedly (6–9). Her own position is in contrast: *but we have* (4) and *but we say no* (10). The use of the pronouns *they* and *we*, coupled with the conjunction *but*, indicates Manar's disputing stance towards the authoritative voices of the teachers giving her the information. In (10–12) she explains why she adopts this position, drawing upon her own experience of interacting with her son. In lines (12) to (15) she hedges this assertion, indicating uncertainty (*but*/*maybe*/*might*), suggesting that

Adnan could—like Manar herself—be dyslexic. The episode continues with a further comment that emphasises this uncertainty (17-18). The *long time* that she has mentioned earlier (5) is given a concrete starting point (19), and the subsequent repeated reference to *now* (21) emphasises that this is an ongoing issue. Here she mentions a *decision* that has yet to come. Ingrid's request for confirmation (22) is met with Manar's affirmation (23); and the following *and you know that* signals a shift to the next topic, the continual staff changes, which appear to relate to the delays in the decision that she has just mentioned.

The confusion she displays in this stretch of talk does not have a lack of linguistic competence at its root: Manar is a competent speaker of Swedish. But the communication in the habilitation meetings, as with all communication, is situated, happening in a particular context, with a specific setting, participants, role relations, purposes and ends (Hymes 1974), some of which might be shared and mutually understood, and others not. Manar's struggle relates not only to an uncertainty about the nature of her son's problems, but also to an unfamiliarity with the discourse around care as it unfolds in the habilitation meetings.

4.2 | Asserting Responsibility

Up to the point of the first interview, Manar and Adnan have been to three or four habilitation meetings together. The meeting planned for the next day will be between Manar and the teachers only. In the interview, her talk revolves around how Adnan should, in her view, be present:

> *I have feel that always because they are going to tell when he with me when we have the meeting I think that good that when something says about my son that he listens to know what they say about him (Interview 1)*

She talks of Adnan's presence in the meetings where his care is discussed as being to his benefit. Adnan's role in the interaction, according to Manar, would not be to interpret or act as a language broker, but to hear at first-hand what *they say about him*. She notes however that the teacher will not allow Adnan to attend tomorrow's meeting. There follows a stretch of talk where Manar appears to directly quote herself, as she argues with the teacher. She is however not reporting an actual conversation but is rehearsing one that could hypothetically take place.

1.	M:	But then (.) it is teacher decide that no (.)
2.		he could not be at meeting tomorrow
3.		ok ↑why you decide so
4.		I want that he listens what you speak about him
5.		because when you say that ok if that is true (.)
6.		he is going to quiet
7.		if not true (.) he is going to say to you
8.		↑no that is not ↑true (.) ↓ or
9.	I:	yes
10.	M:	↑yes (.) I want to ↑know that if you are that
11.		everything you tell
12.		if he if true or not (.)
13.		I don't want only you say
14.		I tell to to you ok ok ok (1.0)
15.		I don't say ok if don't know what that as true (1.0)

Extract 2 Interview 1

At line (3), marked by a rising intonation on the first word (↑ *why you decide*) there is an abrupt shift to direct speech: *they* becomes *you*, and the past—the discussion about whether Adnan should be allowed into the meeting that is about him—is intertwined with the here-and-now of the interview event. In (4) to (15) she presents her position: If Adnan attends, he will be able to validate what the teacher says in the meeting. If the teacher tells the truth Adnan will say nothing, but will speak up if an untruth is told (5-8): Adnan will say either ↑*no that is not true* (8) or ↑*yes* (10), the introduction of the direct speech within the narrative again marked by a rising intonation, and followed by further argument. This rests on the idea that Manar herself was not present at the events that the teacher will describe at the next day's meeting, but Adnan was. This appears to be a question of trust, and the teacher is not trusted (line 13: *I don't want only you say*). Manar will not confirm that she agrees with the teacher's account: she does not know if it was true or not, because she was not there (lines 14–15). Adnan's role in the coming interaction, according to Manar, will therefore be to ratify what the teacher says.

The discussion with the teacher is narrated in a way that foregrounds the immediacy of the occasion (using present tense verb forms and first and second person pronouns), bringing it and us into her immediate temporal space. The quoted speech presupposes the event in which the speech might conceivably occur. It also enables Manar to present herself as a certain type of person who might speak in this assertive way. In the interview she is the one who can act decisively, and in a way that challenges the school's position regarding who has a stake in arrangements for her son's care. It remains to be seen if that can actually happen.

4.3 | Transnational Embeddedness

A minute or so after the talk in extract 1 (above), the topic shifted to the matter of how Adnan is viewed in class by the teacher. As she speaks, Manar reveals her transnational embeddedness as a member of a family which has experienced forced dislocation, with close connections to other family members far away.

1.	Yes but they to do
2.	we think at the same time about right and wrong
3.	that they sit on () group to concentrate the right for her
4.	but not always that it comes right
5.	when the pupil thinks or ↓child I want

(Continues)

6.	when teacher thinks that the pupil who comes on another country
7.	here is war (.) that the same child who was born in Sweden
8.	there comes much difference I believe not the same
9.	yes ok he was born here he learned the language here
10.	but other boy ok (.) he doesn't show
11.	but he thinks within that what happens
12.	ok we have the life now (.)
13.	he knows what we have
14.	families whom we know for example
15.	always think about mama and family
16.	ok they have in Syria but always my feelings there

Extract 3 Interview 2

She introduces the idea that the teacher (possibly a generic teacher) considers children who have experienced war in the same way that they consider a *child that was born in Sweden* (7). She presents a contrasting account: *there comes much difference*; it is *not the same*. She elaborates with a description of the distinction between two boys, an imagined local-born boy and an *other* boy, Adnan, who *doesn't show* what happens but nonetheless thinks about it *within* (10–11). In the final lines she encompasses Adnan within the *we* of the collective family experience (12–14), and turns to her own personal circumstance. The attention is no longer on what the teachers do, or how Adnan (*he*) responds, but pivots towards herself: *always think about mama and family* in Syria. Manar is physically in Sweden, yet *always my feelings there* (15–16). Adnan's difficulties, the school's inability to address them satisfactorily, and Manar's frustration, are related, in her talk, to her own thoughts and concerns for the family back home.

Taken together, the analysis affords insights into the tensions in caring for and caregiving that arise through a migrant mother's navigation of a complex and unfamiliar system on behalf of her son, and which, according to her, can be traced back to the school's disregard for the way the family's transnational character impinges on her son's conduct in school. We develop these themes with reference to the interaction in our second example, as a family with members in the United Kingdom and Pakistan attempt to put in place care for a sick husband and father.

5 | Example 2: Shazia, Faisal and Family

This analytical section is based on ethnographic fieldwork carried out with the Hussein family in Spring 2023. Shazia is an outreach worker in a town in the south of England. She was born in Pakistan where she trained as a teacher and taught in a school for 1 year. She moved to the UK when she was in her twenties, and married her husband, Faisal, in the United Kingdom. They had two sons, now in their twenties, who live with them. Faisal was born in Pakistan but lived in the US for 5 years before coming to settle in the United Kingdom. Shazia went back to Pakistan for 6 years while her husband remained in the United Kingdom to work. Since returning to the UK, Shazia has worked in social care, for local authorities and for different charities.

In this section, we present and discuss care dynamics in relation to family members' linguistic repertoires. We quote from extracts of verbatim transcripts of the interviews in English with project team member Arwah as well as transcripts of hospital meetings between a consultant kidney specialist, Faisal and Shazia.

Shazia's mother passed away 5 years ago and her father, Abbas, lives in their ancestral home in Pakistan. He has a heart condition and was having an operation in Pakistan around the same time that the fieldwork was being carried out in the United Kingdom. Shazia also has three sisters and two brothers. Her sister Nazia lives in Pakistan. Nazia's husband holds a senior position in an institution which affords the family access to good medical treatment in Pakistan. She has an older sister who lives in the United Kingdom, Nadia, who (as Shazia reports) provides Shazia with emotional support. Another sister lives in continental Europe, and she has one brother in the United Kingdom and another in Pakistan.

Shazia's husband Faisal has chronic kidney disease. The specialist at the hospital where he is being treated had been encouraging him for 3 months to start dialysis. The family had been given the information about dialysis several years previously, but Faisal has to this point refused to start the dialysis or have a kidney transplant despite his health deteriorating. From what she reports in the interviews, Shazia appears to have taken on most of the caring responsibilities for Faisal during his current illness, though the two sons support her by helping in the home, driving and managing errands. Fahd, the eldest son, talked in detail in the interviews about the amount of support which he and his brother provide their father. This includes ferrying his father to and from hospital, as well as *helping around the house*. This caregiving is often done with little help from Faisal himself.

Shazia explained that her husband becomes shy when he needs to talk to individuals in institutional settings but is less shy when talking with friends and family. He is also mistrustful of the health professionals in the United Kingdom. As becomes apparent below, Faisal does not always provide accurate answers to questions and often lets his wife do the talking at the hospital. This is not because he does not understand what the doctors are saying. According to Shazia, Faisal speaks English well, and can read and write in English, including in work settings. Faisal and Shazia use Punjabi and Urdu at home.

We first focus on recorded interaction during visits that Shazia made to the hospital with Faisal to discuss his kidney condition, in addition to the field notes taken during participant observation of these meetings. We then turn to data from a later interview with Shazia.

5.1 | From Confusion to Agency

This extract is from the beginning of the recorded interaction between a doctor and Shazia and Faisal, where Faisal's kidney condition is discussed.

1.	D:	So the last bloods I've got are from the twelfth
2	S:	yeah he had fifth of December he had his iron infusion
3.	D:	iron infusion
4.	S	fifth of January actually
5.	D:	fifth of January
6.		December you had your iron
7.		so are you in any EPO (.) let's have a look
8.		no let me look if your folic acid level is alright
9.		it was a bit low in October
10.		did you have some folic acid in ↑October
11.	F:	yeah
12.	D:	you did
13.	S:	no no no
14.	D:	↑no
15.	S:	[*looking at husband*] did you get the folic acid in the ↑blood
16.	F:	no
17.	D:	let's have a look [*looking at screen again*]
18.	S:	I don't think he had folic acid
19.	D:	OK so we can start some folic acid

Extract 4 Consultation 3

The doctor uses medical terminology and also jargon, for example, *the last bloods I've got* (line 1) when looking at the screen. Here she also either misinterprets the information in the computer records or the records themselves are incorrect. Shazia claims agency by correcting and filling in the gaps in information that the official computer records appear not to include. Shazia can shape the outcomes of the meetings about her husband's care by drawing on knowledge that she has recorded in her own notes at home. Shazia told us that she must keep a record of her husband's medications and hospital visits. These notes, what Papen (2009) has described as health literacies, are an important part of Shazia's caring practices as they enable her to manage complex meetings with doctors.

The doctor introduces medical terminology: *you had your iron*, *EPO* and *folic acid* as questions, to which Faisal responds that he did receive the folic acid. Shazia interrupts to explain that her husband didn't get the folic acid in the blood by asking him directly; he confirms that he didn't. Shazia recasts this politely with her response to the previous question from the doctor, saying *I don't think he had folic acid*, to which the doctor decides *ok so we can start on some folic acid*. Shazia again claims agency by countering her husband and by correcting the information that he provides. She thus shapes the outcome of the meeting by speaking up to contradict her husband. Although Faisal cedes control within this particular interaction, we know from later extracts, however, that Faisal is far from an obedient patient and does not follow the advice provided by the doctors. This makes these negotiations more complex for Shazia as she is not only correcting errors in Faisal's medical records, but is also managing her relationship with her husband, who is mistrustful of what the doctors tell him.

The next extract is from interaction in the check-up meeting about Faisal's hernia, which is complicating the treatment of his kidney condition.

1.	D:	So you've got a (.) where is your hernia is it in the ↑groin
2		is it in the ↑top [*looking at patient*]
3.	F:	[*looks at Shazia but says nothing*]
4.	S:	in the (.) the (.) the they are saying um you know (.) by the belly
5.		button or something
6.	D:	[*loud as she is typing on computer*] so you have got hernia
7.		of let me just see if (.) I got a note from anaesthetist
8.		[*S and F looking nervously at D as she reads from screen*]
9.		did you have an anaesthetic assessment
10.	S:	yeah
11.	D:	when was that
12.	S:	he did assessment but I don't know whether anest (.) anest
13.		put that in the note but there was one of the consultant
14.		before doctor () but even doctor () saw him last time
15.		didn't realise that he has hernia and when I told him that
16.		one of the consultants said then he checked it again and he
17.		said yes so it's probably in one of the doctor's reports
18.	D:	ok let me have a look
19.		alright and how are you doing in terms of how are you feeling
20.		any shortness of ↑breath ↑nausea ↑vomiting ↑sickness ↑appetite
21.		everything is ↑OK [*looking at F*]
22.	F:	everything is alright [*nervously playing with fingers*]
23.	D:	alright and how are you doing in terms of how are you feeling
24.		lovely
25.	S:	his appetite is not very good
26.		he has not been eating that well he was very nauseous
27.		before which but he is OK now at the moment

(Continues)

28.	D:	that's [good
29.	F:	[but the thing is if you see me
30.		I'm look as a kidney patient [*holding arms up, questioning*]
31.	S:	that's what he says
31.	D:	he doesn't have any symptoms that's why he believes he
32.		doesn't need the dialysis

Extract 5 Consultation 3

In the extract, the doctor begins by trying to find out where the hernia is. This information has apparently not been recorded on the computer correctly. When Faisal doesn't reply, Shazia explains where the hernia is (4–5): *by the belly button or something*. The doctor speaks as she types this information onto the computer records. According to Arwah's field notes, the doctor is looking at the screen and reading the test results. Shazia then interrupts the doctor by explaining there have been several consultants and even the doctor who saw him last time *didn't realise that he has a hernia and then when I told him that one of the consultants said then he checked it again and he said yes* (15–17). This is another example of Shazia realigning the power dynamics of the doctor-patient relationship.

Next, Shazia counters her husband's comment that *everything is alright* (22) by intervening with *his appetite is not very good*, thereby alerting the doctor to Faisal's ill health when this would not have emerged from his own responses to the doctor's questions. At the end of the extract, as the doctor notes, *that's why he believes he doesn't need dialysis* (31–32), and so we return to the main topic: Faisal asserts that he doesn't need this treatment, contrary to the advice of the doctors, and to Shazia's preference that he should receive the dialysis soon.

5.2 | Brokering Advice From Pakistan and From the United Kingdom

In interviews at home with researcher Arwah, Shazia talks about the difficulties she faces managing delays in correspondence from the hospital, her husband's reluctance to take the advice from UK doctors, and—in the case of the extract below—his preference for treatment originating in Pakistan.

1.	Last Thursday he went for blood tests
2.	we have a hospital log-in where we can check on blood results
3.	to see the percentage of kidney function
4.	but now somehow this log-in has been locked and I cannot see
5.	any results and it has been some time so I tried to ring the hospital
6.	they took time till they picked up
	[*8 lines omitted*]
15.	he says in England they have a serious problem
16.	they never reply to you and they do not give appointments
17.	so why are they asking me to do that
18.	he thinks all these drug companies are bad companies
19.	he is afraid for his health
20.	he told me he searched there is a popular doctor in Pakistan
21.	so he showed me that he will take some herbal medicine
22.	one of his nieces is coming from Pakistan
23.	and she brought the medicine
24.	but I do not know how it is going
25.	he does not tell the truth all the time
26.	he lies about being ok all the time

Extract 6 Interview 4

The extract begins with Shazia explaining that they are locked out of the online hospital patient records system where they wish to find the results of Faisal's recent blood test (1–5). This indicates the textually mediated nature of their engagements with the hospital, and how dealing with online systems requires reading and writing skills in English as well as knowledge of the technologies involved. Shazia explains how the lack of response from the hospital worries her husband (15): *he says in England they have a serious problem*, which she relates to his reluctance to receive dialysis. She explains how his fear for his health leads him to search online for alternative health information (20). He has arranged for his niece to bring *herbal medicine* from Pakistan (22–23). Shazia's proximate care therefore includes brokering health information that originates, or at least is passed to Faisal, from a distance, from relatives in Pakistan. This balancing act is carried out in talk and writing, and is not simply a case of mediating across languages but requires Shazia to unpack cultural knowledge and bridge different cultural practices relating to health information, treatment and medicine. Faisal communicates with his niece via WhatsApp, and then the information is remediated, passed orally to Shazia in their home and then drawn upon by Shazia as she negotiates with the doctors on her husband's behalf when he remains silent in the hospital consultations.

6 | Discussion

In this section, we discuss the findings we have presented in relation to the conceptual framework of ethics of care (Tronto 2016), offering three main contributions. First, the focus on language and literacy practices has enabled us to foreground the role of the 'transnational' in the family members' understanding of good care (Tronto 2016). In the case of Manar,

good care requires a *recognition* of the transnational character of the family. In the case of Shazia, transnational familial ties represent a source of care (Levitt et al. 2017), propelling diverging understandings of good care. The care that both Shazia and Manar negotiate with the authorities is proximate: Faisal is in the United Kingdom, and Adnan is in Sweden. Yet the transnational embeddedness of both women is—if not foregrounded—at least evident in the interactions we examine. Faisal's reliance on medical information from what he regards as a trustworthy source, the doctors in Pakistan, leads him to contact his niece via social media, who will bring to the UK the medicine he supposes will be more effective than the treatment provided by his doctors in England. Manar's negotiation of Adnan's care is done in the face of school authorities who in her view disregard their status as forced migrants, with family in a war-torn area of the world. The geographically situated location of the caregiving, in Faisal's case, is both here, in the United Kingdom, and there, in Pakistan. For Manar, discussions about Adnan's care leads her to invoke a type of belonging that exists mainly in the memory (Butler and Spivak 2007).

Second, our attendance to language use and literacy mediation has fostered a more nuanced understanding of how agency and tensions are enacted in the assumption of responsibility during 'caring for' and 'caregiving' (Tronto 1998), and how these are informed by unequal power relations between caregivers from state institutions, as well as the mediating family member and the person in need of care. Manar's negotiation with her son Adnan's school entails an uncertain negotiation. It is not clear to her what Adnan's actual problem is, from the school's perspective, nor what precisely is the course of action the school wishes to take regarding his care. Her response is to assert her own responsibility, to claim agency of a kind, as she insists on Adnan's presence in the meetings where his care will be discussed. This agency is more an act of resistance, however, rather than an exercise of choice: she claims it in the context of a research interview, rather than in an actual institutional interaction. Shazia's agency, on the other hand, is tangible in the caregiving interactions with the NHS doctor and hence the state. She draws upon her knowledge of her husband Faisal's medical history to identify gaps in his computerised medical records, and actively corrects the doctor's error. From experience (possibly informed by her understanding of the social care system) she knows she must keep her own records of Faisal's care, to support her efforts in managing the consultations with his doctor.

Last but not least, we show that the performed agency is gendered and informed by further social locations. The position and positioning of social actors occurs within the interplay of locations that are relative to the specific temporal and social contexts where interaction takes place (Anthias 2012). Not only geography but gender, generation and migration status inform the language and literacy mediation practices in encounters between members of transnational families and institutional care providers. In both our cases, the women and not the men adopt the primary role in interactions in their respective institutional settings. Men, even when they are present, remain largely silent as their wives take on the complex negotiations over care. The care is intergenerational in both cases too, most obviously in relation to Adnan, as his mother mediates on his behalf. Faisal too, whose mistrust of the UK authorities leads him to source medicine from Pakistan, engages in transnational communication via social media with a family member from a younger generation. His sons in the United Kingdom also provide proximate intergenerational care.

7 | Conclusion

We began this paper by maintaining that it is worthwhile to pay attention to the language and literacy practices of transnational people, as they navigate institutional systems in the process of providing care for their family members. We conclude by drawing out policy implications for the settlement of newcomers needing to engage with institutional processes relating to care. A general language competence, understood narrowly as the command of a repertoire of lexical and grammatical features and functions that can be deployed in daily life, is not a particular concern for our participants, as already noted. Shazia is an expert user of English, and Manar is an advanced learner of Swedish. However, their access to the specific communicative resources required to successfully navigate an unfamiliar institutional context differs somewhat. Shazia demonstrates familiarity with the technical language of Faisal's medical conditions and can realign asymmetrical doctor-patient power relationships by using successful strategies: for getting a blood test carried out, and for filling in the gaps in the doctor's knowledge of her husband's treatment. Manar on the other hand might be a competent user of the dominant language of her new home, yet she does not have access to the specialised lexis and discourse of the domain of educational psychology. She is therefore inconclusive about the nature and source of her son's problems. There are implications for education and integration policy for the settlement of newcomers in society.

Schools and hospitals are frequently visited by new arrivals, and the kinds of communication experienced by Manar and Shazia are likewise commonplace. A clear understanding of how successful interaction happens in institutional settings could inform educational practice, for example the language education opportunities that state, regional or local authorities provide for adult migrants as part of their settlement process. We argue for a language education that draws its content and direction from authentic interaction of the kind we examine in this paper, and—following Gumperz and Cook-Gumperz (2005)—that aims to support and potentially transform the out-of-class experience of newcomers. This might involve topics that prepare people for potentially difficult interactions in health and education settings (among others) in ways that accurately reflect the nature of such discussions. This would involve educators and their students understanding the nature of this communication (see Bremer et al. 1996; Simpson 2020). This might work towards lessening the inequalities in knowledge experienced by people like Manar in particular. By extension, support for newcomers needs to recognise that misunderstanding in institutional interaction does not occur only between languages but also between discourses and registers. While policy recommendations in the United Kingdom (Casey 2016) and Sweden (Region Skåne 2018) are often focused on improved language learning and provision of interpreting services, we claim that attention needs to be paid to

empowering newcomers to develop resources for effective navigation of an unfamiliar discourse, not just a new language.

Not knowing the discourse, and not being inside the discourse community (Swales 1990)—that is, not knowing the conventions of speaking and of the literacy practices of a specific community—is of course an experience that is common to all non-insiders (for the case of patients with lower education, see for example, Smith et al. 2009). Trans-discursive, trans-cultural mediation (in addition to translation services) is needed to support anyone faced with navigating an unfamiliar context. Recognising that these issues are common for all, not just members of transnational families, might contribute to lessening the othering implicit in a study of migrants navigating a care system. The problems they encounter are met by potentially anyone, whoever they are, and from whatever background.

Acknowledgements

This study is a part of the research project "Care, Inequality and Wellbeing in Transnational Families in Europe: a comparative, intergenerational study in Spain, France, Sweden & UK (CareWell)". CareWell is an international research project funded by the JPI More Years Better Lives and carried out by the University of Reading and the University of Leeds in the United Kingdom, Malmö University in Sweden, Aix-Marseille Université in France and Universidade da Coruña in Spain. The UK part of the project was funded by the Economic and Social Research Council (grant RG.GEOG.123085) and the Swedish part was funded by Forte (the Swedish Research Council for Health, Working Life and Welfare) (grant 2020-01524).

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The research data are not shared.

References

Anthias, F. 2012. "Transnational Mobilities, Migration Research and Intersectionality: Towards a Translocational Frame." *Nordic Journal of Migration Research* 2, no. 2: 102–110.

Baldassar, L. and Merla, L., ed. 2013. *Transnational Families, Migration and the Circulation of Care: Understanding Mobility and Absence in Family Life*. Routledge.

Barton, D., and M. Hamilton. 2005. "Literacy practices." In *Situated Literacies: Reading and Writing in Context*, Edited by D. Barton, M. Hamilton, and R. Ivanič, 25–32. Routledge.

Bastia, T. 2015. "Looking After Granny': A Transnational Ethic of Care and Responsibility." *Geoforum* 64, no. 1: 121–129.

Bauman, R., and C. L. Briggs. 1990. "Poetics and Performances as Critical Perspectives on Language and Social Life." *Annual Review of Anthropology* 19, no. 1: 59–88.

Bilecen, B. 2020. "Asymmetries in Transnational Social Protection: Perspectives of Migrants and Nonmigrants." *The Annals of the American Academy of Political and Social Science* 689, no. 1: 168–191.

Blommaert, J. 2012. "Lookalike Language." *English Today* 28, no. 2: 62–64.

Bremer, K., C. Roberts, M. Vasseur, M. Simonot, and P. Broeder. 1996. *Achieving Understanding*. Longman.

Butler, J., and G. Spivak. 2007. *Who Sings the Nation State?* Seagull Books.

Capstick, T. 2016. "Literacy Mediation in Marriage Migration From Pakistan to the United Kingdom: Appropriating Bureaucratic Discourses to Get a Visa." *Discourse & Society* 27, no. 5: 481–499.

Carling, J., C. Menjívar, and L. Schmalzbauer. 2012. "Central Themes in the Study of Transnational Parenthood." *Journal of Ethnic and Migration Studies* 38, no. 2: 191–217.

Casey, L. 2016. *The Casey Review: A Review Into Opportunity and Integration*. Department for Communities and Local Government.

Davis, J. 2022. *The Caring City: Ethics of Urban Design*. Bristol University Press.

De Fina, A., and A. Georgakopoulou. 2012. *Analyzing Narratives: Discourse and Sociolinguistic Perspectives*. Cambridge University Press.

Gee, J. P. 1992. *The Social Mind: Language, Ideology, and Social Practice*. Bergin & Garvey.

Giddens, A. 1984. *The Constitution of Society. Outline of the Theory of Structuration*. University of California Press.

Gumperz, J. J., and J. Cook-Gumperz. 2005. "Making Space for Bilingual Communicative Practice." *Intercultural Pragmatics* 2, no. 1: 1–23.

Heidbrink, L. 2014. *Migrant Youth, Transnational Families, and the State: Care and Contested Interests*. University of Pennsylvania Press.

Heller, M. 2010. "Language as Resource in the Globalized New Economy." In *The Handbook of Language and Globalization*, Edited by N. Coupland, 347–365. Blackwell Publishing.

Henderson, S. 2003. "Power Imbalance Between Nurses and Patients: A Potential Inhibitor of Partnership in Care." *Journal of Clinical Nursing* 12, no. 4: 501–508.

Hoang, L. A., B. S. A. Yeoh, and A. M. Wattie. 2012. "Transnational Labour Migration and the Politics of Care in the Southeast Asian Family." *Geoforum* 43, no. 4: 733–740.

Holt, E., and R. Clift. 2007. *Reporting Talk*. Cambridge University Press.

Hymes, D. 1974. *Foundations in Sociolinguistics: An Ethnographic Approach*. University of Pennsylvania Press.

Iqbal, H., and S. Crafter. 2023. "Child Language Brokering in Healthcare: Exploring the Intersection of Power and Age in Mediation Practices." *Journal of child and family studies* 32, no. 2: 586–597.

Kilkey, M., and L. Merla. 2014. "Situating Transnational Families' Care-Giving Arrangements: The Role of Institutional Contexts. *Global*." *Networks* 14, no. 2: 210–229.

Levitt, P., J. Viterna, A. Mueller, and C. Lloyd. 2017. "Transnational Social Protection: Setting the Agenda." *Oxford Development Studies* 45, no. 1: 2–19.

Liddicoat, A. J., and K. Taylor-Leech. 2021. "Agency in Language Planning and Policy." *Current Issues in Language Planning* 22, no. 1–2: 1–18.

Lincoln, Y. S., and E. G. Guba. 1985. *Naturalistic Inquiry*. age.

Merla, L., and L. Baldassar. 2011. "Transnational Caregiving Between Australia, Italy and El Salvador: The Impact of Institutions on the Capability to Care at a Distance." In *Gender and Well-Being: The Role of Institutions*, Edited by P. de Villota and J. Eriksen, 147–161. Routledge.

Merla, L., M. Kilkey, and L. Baldassar. 2020. "Examining Transnational Care Circulation Trajectories Within Immobilizing Regimes of Migration: Implications for Proximate Care." *Journal of Family Research* 32, no. 3: 514–536.

Thi Nguyen, H., L. Baldassar, and R. Wilding. 2023. "Care Visits: Obligations, Opportunities and Constraints for Vietnamese Grandparent Visitors in Australia." *Journal of Ethnic and Migration Studies* 49, no. 4: 996–1013.

Papen, U. 2009. "Literacy, Learning and Health: A Social Practices View of Health Literacy." *Literacy and Numeracy Studies* 16, no. 2: 19–34.

Pickering, A. 1995. The Mangle of Practice: Time, Agency and Science. *Chicago*. University of Chicago Press.

Rechel, B., P. Mladovsky, D. Ingleby, J. P. Mackenbach, and M. Mckee. 2013. "Migration and Health in an Increasingly Diverse Europe." *The Lancet* 381, no. 9873: 1235–1245.

Region Skåne. 2018. *Jämlik Hälso-Och Sjukvård Ur Ett Migrationsperspektiv: Rapport Om Möjliga Indikatorer För Kvalitetsuppföljning I Region Skåne*. Kunskapscentrum Migration Och Hälsa.

Region Skåne. 2019. Habilitering. https://www.1177.se/Skane/barn–gravid/vard-och-stod-for-barn/funktionsnedsattning-hos-barn/habilitering/.

Roberts, C. 2013. "The Gatekeeping of Babel: Job Interviews and The Linguistic Penalty." In *Language, Migration and Social Inequalities: A Critical Sociolinguistic Perspective on Institutions and Work*, Edited by A. Duchêne, M. Moyer, and C. Roberts, 83–96. Multilingual Matters.

Salazar Parreñas, R. 2008. "Transnational Fathering: Gendered Conflicts, Distant Disciplining and Emotional Gaps." *Journal of Ethnic and Migration Studies* 34, no. 7: 1057–1072.

Simpson, J. 2020. "Navigating Immigration Law in a "Hostile Environment": Implications for Adult Migrant Language Education." *TESOL Quarterly* 54, no. 2: 488–511.

Smith, S. K., A. Dixon, L. Trevena, D. Nutbeam, and K. J. McCaffery. 2009. "Exploring Patient Involvement in Healthcare Decision Making Across Different Education and Functional Health Literacy Groups." *Social Science & Medicine (1982)* 69, no. 12: 1805–1812.

Suter, B., R. Evans, R. M. Giralt, and K. Mozetič. 2025. "Special Issue Young People's Caring Practices in Transnational Families in Sweden and the Uk: Care Ethics and Wellbeing." *Population, Space and Place* 31, no. e70002: 1–11.

Swales, J. 1990. *Genre Analysis: English in Academic and Research Settings*. Cambridge University Press.

Tronto, J. C. 1998. "An Ethic of Care." *Generations (San Francisco, Calif.)* 22, no. 3: 15–20.

Tronto, J. C. 2016. *Who Cares? How to Reshape a Democratic Politics*. Cornell Scholarship Online.

Wodak, R. 2014. "Critical Discourse Analysis and the Study of Doctor-Patient Interaction." In *The Construction of Professional Discourse*, Edited by B. L. Gunnarsson, P. Linell, and B. Nordberg, 173–200. Routledge.

Appendix 1

TABLE A1 | Transcription conventions (Holt and Clift 2007).

(0.5)	Timed pause in seconds
(.)	Short untimed pause
[	Overlapping turns
()	Indecipherable talk
↑	Marked rise in intonation immediately before the shift
↓	Marked fall in intonation immediately before the shift
[*comments*]	Commentary italicised, in square brackets