

Methodological Note to accompany D5.3 national case studies

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This Working Paper was written within the framework of Work Package 5 'Justice as lived experience'

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Thanks to the country teams who responded with such patience and thoroughness



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About ETHOS

ETHOS - Towards a European Theory Of juStice and fairness is a European Commission Horizon 2020 research project that seeks to provide building blocks for the development of an empirically informed European theory of justice and fairness. The project seeks to do so by:

- a) refining and deepening knowledge on the European foundations of justice both historically based and contemporarily envisaged;
- b) enhancing awareness of mechanisms that impede the realisation of justice ideals as they are lived in contemporary Europe;
- c) advancing the understanding of the process of drawing and re-drawing of the boundaries of justice (fault lines); and
- d) providing guidance to politicians, policy makers, activists and other stakeholders on how to design and implement policies to reverse inequalities and prevent injustice.

ETHOS does not only understand justice as an abstract moral ideal that is universal and worth striving for but also as a re-enacted and re-constructed 'lived' experience. This experience is embedded in legal, political, moral, social, economic and cultural institutions that claim to be geared toward giving members of society their due.

In the ETHOS project, justice is studied as an interdependent relationship between the ideal of justice and its manifestation – as set out in the complex institutions of contemporary European societies. The relationship between the normative and practical, the formal and informal, is acknowledged and critically assessed through a multi-disciplinary approach.

To enhance the formulation of an empirically based theory of justice and fairness, ETHOS will explore the normative (ideal) underpinnings of justice and its practical realisation in four heuristically defined domains of justice - social justice, economic justice, political justice, and civil and symbolic justice. These domains are revealed in several spheres:

- a) philosophical and political tradition;
- b) legal framework;
- c) daily (bureaucratic) practice;
- d) current public debates; and
- e) the accounts of vulnerable populations in six European countries (Austria, Hungary, the Netherlands, Portugal, Turkey and the UK).

The question of drawing boundaries and redrawing the fault-lines of justice permeates the entire investigation.

Utrecht University in the Netherlands coordinates the project, and works together with five other research institutions. These are based in Austria (European Training and Research Centre for Human Rights and Democracy), Hungary (Central European University), Portugal (Centre for Social Studies), Turkey (Boğaziçi University), and the UK (University of Bristol). The research project lasts from January 2017 to December 2019.

D5.3 METHODOLOGICAL NOTE TO ACCOMPANY NATIONAL CASE STUDIES

ETHNOGRAPHY OF PHYSICALLY DISABLED CARE USERS AND PAID CARE WORKERS IN PRIVATE HOUSEHOLDS

Objectives WP5: Justice as lived experience

Work package 5 is concerned with justice as lived experience. It examines the subjective experiences of those vulnerable to injustice in three spheres of justice: political, economic and social, and has a particular focus on people's lived experiences as members of ethnic and religious minorities, and as vulnerable categories in the welfare state such as disabled adults and care workers. The welfare state is pictured as a means of inclusion (access to welfare state provisions is a fundamental benefit of national citizenship) and of exclusion. We are interested in the conflicts, tensions and contradictions between different justice claims of vulnerable groups and how these are negotiated in the day to day. While it takes the perspective of the vulnerable, it avoids a focus on victimhood, emphasising agency.

Objectives D5.3

D5.3 explores the accommodation of justice claims in the lives of adult physically disabled care users and care workers in private households. We are interested in everyday practices of recognition and redistribution and how daily conflicts of justice claims are managed (or not). Analysis will draw on a capability approach, considering people's capacity to achieve the kinds of lives that they value, and the achievements themselves. (See http://www.iep.utm.edu/sencap/).

Each national case study was designed to enable us to:

- Identify the intersections and contradictions between people's understandings, claims and experiences of recognition and redistribution;
- Identify the argumentative, practical and conceptual tools that people use to negotiate conflicting justice claims;
- Explore the contradictions and intersections between claims for and practices of justice;
- Explore the role of the national state in creating conflicts and shared interests between care workers and care users (e.g. employment, immigration and taxation laws; support for the rights of disabled people and their carers; minimum care standards; engagement in private household);
- Analyse the specific challenges and opportunities for justice in the context of the
 private Analyse the specific challenges and opportunities for justice in the context of
 home-based care, and their link to ideas of the public and private spheres.

Fieldwork Preparation

All partners began by producing a short report on law and policy on care and private households in their country. This included labour rights of professional care workers and care workers paid by cash-for-care schemes, the rights of disabled people to care, labour rights in private households and, if migration is an important source of care labour, how migrants (including au pairs in some cases) fit into this picture. This report also provided basic, easily available statistics on numbers of elder care, elder and disabled care providers in private households and, where possible, the demographics of care workers. They also provided a 'map' of the commodified relationships my ethnography will comprise care user/employer A, care worker B; family member C and D, part-time care worker E.

Because of the complexity and nuance of these relationships we used a combination of miniethnographies and semi-structured interviews. Ethnography is a useful method through which "to explore the feelings, beliefs, and meanings of relationships between people as they interact within their culture or as they react to others in response to a changing phenomenon (Fields & Kafai, 2009)" (see http://nsuworks.nova.edu/cgi/viewcontent.cgi?article=2580&context=tqr). facilitates lt understandings of norms, values and roles and is a way to capture practices and what is unsaid. It is therefore particularly useful in researching relationships and nonverbal communication. Ethnographies can last years and involve immersion into a world of practices that the researcher must familiarise themselves with, however, mini-ethnographies are much shorter and can incorporate focussed field visits rather than embedding. In a European context, embedding in a private household is likely to be regarded as intrusive and would raise financial and resource issues, moreover, it is likely to have a significant impact on the relationship we are interested in observing. Furthermore, we decided that conducting three, week-long ethnographies would enable us to compare different relationships facilitating an analysis of the private households as a specific site of justice. It was anticipated that researchers will not 'live-in' but will visit the households daily for a week and take part in activities with the worker and the care user as appropriate. Researchers were trained in the conduct and recording of research finding in a workshop during the ETHOS meeting in Coimbra (see Appendix One). They were also given readings to prepare for this (see Appendices One and Two).

Semi-structured interviews 'bookended' the mini-ethnographies. The first semi-structured interview was conducted before the ethnographic work commenced and was based on an interview schedule designed by the co-ordinators. Interviews were conducted separately with care workers and care users and will cover factual questions about people's backgrounds and employment arrangements, their understandings of justice with respect to disability and

employment relations, and how they negotiate with the care worker/care user (see Appendix Three).

Our sample

We were committed to studying five commodified care relationships, but explained that this did not have to be five separate ethnographies but could be one network of five relationships (e.g. care user, three care workers, and the care workers' employer), or two networks (e.g. care user/employer A, care worker B; care user C, care worker B, employer D). This was largely because we knew that access was likely to be challenging. To accommodate this we were flexible in the nature of the care arrangements we are engaging with, but took as a basic requirement that it will generate data on everyday practices of recognition and redistribution and how daily conflicts of justice claims are managed (or not) in the context of the private household. It was up to the national teams to decide whether they are looking at live-in or live-out care workers.

We emphasised that we were looking for examples of good practice, where relationships work and at least one party considers that different interests are successfully negotiated. We suggested that partners contact care agencies, self-organised groups of disabled people and that churches, mosques and other places of worship can also be useful sites for meeting migrant care workers and the people they care for.

Time frame (2018)

Phase 1 Feb- March

February

- Ethnographers receive training in Coimbra.
- Partners initiate ethical procedure for ethnographies and interviews.

March

- Partners produce research brief covering 'map' of commodified relationships (see above), legal rights, basic statistics if easily available, and key readings on commodified care relationships in private households in their countries.
- 26 March: Voluntary Skype discussion for partners to ask questions on research brief. Partners must send request by 22 March.

Phase 2 April- June

April

• April 2nd partners send research brief including map and legal rights

- Week of 2nd April WP5 coordinators work with partners to produce interview schedules.
- April 9th coordinators circulate interview schedules and fieldwork note template to all partners
- April 10th 11am UK time: Skype interview to discuss and finalise fieldwork template
- April 13th partners confirm fieldwork dates.
- April 16th coordinators circulate national report templates to all partners and schedule for fieldwork Skypes to share ideas and discuss second interviews.

May-June

- Partners prepare and conduct mini-ethnographies (NB data recording to be done at same time as fieldwork)
- June 11th Skype discussion for partners to give verbal feedback on their findings
- June 18th Skype discussion on coding frames

July - August

- Report writing
- August 6th partners hand in national reports.

Methodology: Austria

We first drew on legal and policy documents to produce a short report on care and private households in Austria. This was used to develop the first part of our national case study. Fieldwork combined mini-ethnographies and semi-structured interviews with users and providers of personal assistance. The service users were interviewed twice: at the beginning of the mini-ethnographies, and several times after the visits. Both the semi-structural interviews as well as the field visits followed the guidelines developed by the project coordinators (see Appendix Three). These guidelines were translated into the national language and slightly adapted along the specific context and subject of personal assistance — which is understood in opposition to 'care work'. Thus, personal assistance per concept implies self-determination (see section II on national context). Also the level of detail in the guidelines was adapted to the national context.

Access

The following strategies were applied to get access to the field: contacting individuals, who published job announcements for personal assistants. This strategy proved not successful. Later on, the Styrian Association "Selbstbestimmt Leben" was asked for support in access to the field. This association is an umbrella organisation of users of personal assistance. It was founded in 2012 for the purpose of representing the interests of persons with disabilities, particularly in the fields of inclusion and participation in society. The main tasks of this association are representing the interests of persons with disabilities before politics, public administration and the general public and supporting people with disabilities in applying for funds and services.

The executive board of this organisation was informed about the project, its embeddedness into the ETHOS project and Horizon 2020. Moreover, they were informed about the methods of data gathering, data evaluation and data protection. The board circulated the request for participation among their members. Many users expressed their interest in participating in the survey – the readiness was significantly higher than expected. The centre for integrated studies (Zentrum integriert Studieren) at the University of Graz was another successful channel for recruiting cases. A member of this centre received the call for participation via the association Selbstbestimmt Leben and distributed it among their students. In the end, more people than needed expressed their readiness to participate in the survey. Interestingly, the majority of these persons were blind. All these persons highly valued the study and research. One blind person expressed interest in participating in the study but did not give consent to the visits in her home. She only wanted to share her views in the framework of an interview. However, unfortunately, this person and others had to be refused. Criteria for refusal were: order of consent for participation, location (persons, living in too remote areas were excluded) and heterogeneity of the sample (the aim was to include people with different kinds of disabilities and experiences with service provision).

Ethics

An application for an ethical approval was requested from the University of Graz before the fieldwork started. The application followed the standardised procedure implemented by the University of Graz, containing the following information: title of the research project, persons responsible, research disciplines, funding. A description of the research project, focusing on content of research, aims and objectives, interviewees, methods of recruiting and information on personal data gathered was added based on the research guidelines. Information on specific ethical issues included that there are no interest conflicts of all scientists involved and that there are neither advantages nor disadvantages for all research participants. It was clearly described that participation in research is voluntarily and can be withdrawn at any time until the report is published. The informed consent information letter and form was attached to the application. As this research project involves persons with disabilities, information was provided on how to obtain consent barrier free, i.e. reading it out and audiotaping verbal consent in case of blind persons. Finally, information on the protection of personal data was provided. The ethic committee approved this research project within a few weeks (application submitted on 26 March approval obtained on 19 April).

Sample

The sample consists of four users of personal assistance and five assistants. Three service users are blind, two are fully blind and one is partly blind. The fourth service user is spastic and uses an electronic wheelchair. One partly blind person and one fully blind person included in the sample live together and have three children, who are not disabled. The other two live alone. Three out of four service users are female. All service users are aged between 25 and 35 and all are employed in part-time, three out of four have obtained University degree.

For further details please see the national case study, available from https://www.ethoseurope.eu/sites/default/files/5.3 austria.pdf.

Methodology: Hungary

In order to contextualise the analysis, the researcher first mapped the Hungarian background through a review of the academic literature relevant to commodified home care in Hungary, a legal and policy analysis, and presentation of a selection of available national data. Fieldwork was conducted with two households between May and July 2018. It was comprised of daily home-visits, each approximately five-hours long, for between one week and ten days, complemented by semi-structured interviews with all the participants involved in the commodified care relationships. Two semi-structured interviews were also conducted with a mediating person, who, while not directly involved in these arrangements, was central in bringing them about. The interviews lasted between 20 minutes and one and half hour. Some were conducted in the private households of the care users and others in public cafés.

Ethnographic notes were taken, but no audio recordings, during the in-house visits. Every interview was audio recorded, transcribed, and carefully analysed.

Access

Securing access to the two private households was a long and mediated process. Access was based on trust networks, friendships and work relations that had existed well before the time of the fieldwork. As a researcher I was highly dependent on these networks and my choices of families were constrained by these. Initially my aim was to observe Transylvanian Hungarian carers. This is a Hungarian minority ethnic group who live in and are citizens of Romania, and whose mother tongue is Hungarian origin and who I understood to be major providers of private care in Hungary, along with ethnic Hungarians who are citizens of Ukraine and Serbia. I contacted an acquaintance active in the Transylvanian Hungarian diaspora and who were in contact with families in Hungary employing carers from Transylvania. She readily agreed to help, already thinking of households where I could follow care relationships. However, after several attempts she informed me her contacts were reluctant to participate because of its association with the CEU. (This was at the time leading up to the April 8th 2018 national elections and CEU was under attack from the government).

I then contacted a friend who was running the Centre for Early Intervention, a service to support children aged six and under who have delayed or impaired development. It offers complex diagnostic assessment, individual and planned developmental and therapeutic programmes for children and their families. She kindly suggested some possible people I could approach. One was an active parent of an autistic child but ethical considerations required that fieldwork be conducted only with people with physical disabilities. Zsuzsa (pseudonym), a pensioner who had been connecting elderly people in need of care with care workers for around thirty year, gave me a good lead. As she told me she grew up without knowing she was Jewish, not at all a unique life course in Hungary, and after she had found it out slowly it became her mission to do something for the Jewish people and gradually became involved first in helping elderly Jewish Holocaust survivors find appropriate care. One our meeting I asked if she was working with Transylvanian Hungarians, but she was reserved about their suitability. During our post-fieldwork interview she explained that many of the elderly people she helped came from formerly prosperous bourgeois Jewish families who before the war had employed several servants, gentile people who had recently arrived in the capital city looking for work. The care relationships she knew about, she facilitated followed the same pattern, Jewish people who employed gentile care workers. It was through her that I contacted the daughter of 'Anna', my first respondent. The second care relationship was accessed through a friend of the care user's mother. I contacted Aron's mother through a friend and she talked to her son about this research. Aron quite quickly agreed to being part of this research. He was as much curious as what a researcher would do as I was about him and was looking forward to this peculiar journey. He later half-joked that I might be also part of the material, "the raw data" of his art for his next theatre play. I was

not only observing but I was being observed, which while it startled me, it also calmed me, as it made this relation more balanced, more equal. In both cases they openly stated that they were happy to take part in this research and thereby show their support of the CEU.

Ethics

This research has complied with all the ethical guidelines stipulated in the relevant documents, receiving permission to conduct it from the Central European University's Ethical Commission. All the names used here are pseudonyms and all the participants have consented to their participation in this study in writing.

Sample

The sample consists of two households. The first consists of an elderly frail woman, aged 93, 'Anna', and two female care givers, 'Maria' and 'Paula', both pensioners in their mid-sixties. Maria was from a town in Eastern Hungary, and Paula was from Budapest. They both lived in for 10 days at a time. The second is Aron, young man aged 25 (Aron), with a physical disability, a professional physical therapist - a former conductor, now working as a Shiatsu therapist, and the mother of the young man.

For further details please see the national case study, available from https://www.ethoseurope.eu/sites/default/files/5.3 hungary.pdf.

Methodology: Netherlands

As a first stage in this work the researchers undertook a literature and policy review to present an overview of care workers' and care recipients' rights and obligations in the Netherlands. This later formed the basis of the first part of the national report. Fieldwork was ethnographic with the researcher accompanying care workers in their visits to the care recipients' homes. Next to these 'trips', the researcher was also hanging around between activities at the community centre and office where the home care team is based. Because of spending so much time in the habitat of care workers, it could have been the case that the researcher is more prone to take the perspective of the care workers, as she had broader access to their everyday working lives. The researcher took this potential bias into account during the analysis and presentation of data.

<u>Access</u>

Access to a fieldwork site was difficult and consequently delayed the work. The main reasons, as far as we could trace them are work-overload, privacy of care recipients and family members not willing to cooperate. We utilized two different strategies to acquire access. Firstly, a formal path was taken through directly contacting care organisations and

organisations representing people with disabilities. Secondly, we utilized chain referral methods through our professional and personal networks.

Firstly, we did a web-search on Dutch care providers, care intermediating organisations (temporary work agencies mediating between people with home care needs and home care workers) and patient organisations representing people with disabilities and/or elderly people. Following the list, we contacted five well-known and smaller care agencies at the same time. We received little response to our initial email and a phone call round followed in which two organisations declined to participate on the grounds of a heavy workload. The third organisation never replied nor answered our follow-ups. The fourth organisation expressed their interest, but at a certain point stopped answering our emails and follow-up calls. The fifth, a publicly well-known organisation representing the interests of people with disabilities explained they were unable to help us as they did not have direct contact with people with disabilities and referred us to another organisation that they felt would be more suitable. That organisation promised to reply to our email and phone call, which never happened, also not after two reminders. Following this unsuccessful first round, we send out various new requests to care organisations. A phone-call to an autonomous team of home care workers employed by a well-known, popular care organisation seems to be more successful; the team reacted positively and soon recruited a care recipient who consented to participation. However, family members of the care recipient decided that he should not cooperate after which we had to start again. A final care organisation that had initially reacted positively then decided they could not participate, due to scheduling conflicts and heavy workload. This led to further delay in our planning. In the meantime, we were looking for another fieldwork location.

At the same time, as well as the more 'formal' access strategy we attempted a chain referral strategy by contacting colleagues, friends and relatives, asking them whether they were in contact with any care workers (organisations) or people who receive care at home. Through our personal network we acquired some leads but these proved to be unsuccessful: firstly we found the case of friends of the researcher's parents in law that have a mother who receives care at home. The friends were not very keen on participating, because the mother was very ill. Finally, there were two care workers in the personal network of the researcher, but the first care worker (female, white Dutch, in her late twenties) depended on the consent of her employer (who was coincidentally one of the organisations that we approached through the formal access strategy) and this consent took too much time to realize. The second care worker (male, Dutch Surinamese, in his thirties) was self-employed and willing to participate but explained that getting consent from his clients was very difficult, as he did not have any regular clients because he works as a substitute care worker.

The professional network would prove to be successful in the end although not all leads led directly to the realization of a fieldwork site: firstly, through a colleague within the ETHOS consortium, we got in touch with two advocacy groups that focus on migrant communities in the Netherlands. After a first very positive meeting with these advocacy groups they stopped

replying to emails and phone calls. In the end it was via a Master's student of the department of Interdisciplinary Social Science that we became successful. This student wrote her thesis on care work for which she has had contact with an autonomous home care team in Utrecht. That team was very interested in joining a care-oriented study but to their regret they did not fit in the student's framework. Immediately at the first contact they were happy to join our study and to provide us access to our fieldwork sites; they very quickly contacted the care recipients who gave consent for the observations and interviews.

The mini-ethnography took place in a short duration of a week. The final interviews also took place in the period of this week, with one exception where the person was unavailable until the following week. Because the time-period of participation was limited, there was relatively limited time for participants to get to know the researcher better and vice versa. Yet passing of time is crucial for participants to be willing to share their (private) views on and experiences with care work, to build a form of rapport. Still, when comparing the interview materials of the initial interview with the closing interview, the materials of the closing interviews show that the participants were more willing to express the in their eyes, more sensitive information. Thus, participant observation, even though it took place in a short period of a week, is of great added-value when compared to a stand-alone interview. Furthermore, the participant observation was also an added value, as it gave the researcher the opportunity to contrast practices with expressed views during the first interviews and inquire about real life examples of care practices during the final interviews.

The nature of the participant observation was that the researcher would accompany care workers in their visits to the care recipients' homes. Next to these 'trips', the researcher was also hanging around between activities at the community centre and office where the home care team is based. Because of spending so much time in the habitat of care workers, it could have been the case that the researcher is more prone to take the perspective of the care workers, as she had broader access to their everyday working lives. The researcher took this potential bias into account during the analysis and presentation of data.

Ethics

Prior to the fieldwork, we attended a team meeting. The informed consent letter was handed over and the team members were informed about fieldwork procedures of our fieldwork on which she had several questions that could be answered. The actual fieldwork started with the distribution of the informed consent letter to all study participants and all other members of the home care work team. The team also received an email asking whether any of them opposed the presence of the researcher at the home care work agency. None of the care workers within the team opposed the research. However, not all of them would themselves participate in the research. Three care workers within the team that were involved in providing care for the selected care recipients agreed to participate in the study; to be interviewed and to allow us to participate in and observe their care activities. Before the initial

interview took place, the researcher further explained the focus and aim of the study, her role in data gathering and asked all participants to sign the informed consent letter. The hard copies of the consent letters are kept in storage at Utrecht University according to the ethical protocol.

During the fieldwork different matters relating to consent arose. The first issue was the office space of the care workers' agency that is located in a community building in which also other (health)care and welfare institutions have their offices. Issues of consent relate to observing persons frequenting this building who did not sign a consent letter such as care workers from another team, social workers or people from the neighbourhood visiting the office. Because the people were visiting public space, behaviour that could be outwardly observed are included in the data, but informal talks with persons are not included because no consent was given. Furthermore, the researcher would also be present at the early morning team meetings where attended by care workers who had not signed a consent form. General information obtained from these work meetings were used as data, but personal conversations between the researcher and care workers and among the care workers that did not sign a form were omitted.

A second issue that arose during the fieldwork relates to the aspect of observing nudity in care related work such as bathing and dressing. While all care receivers gave their consent to participate, the researcher continuously checked with them whether they felt comfortable with her presence at these private care activities. When inquiring with the care receivers, they all answered that they gave their consent and more so, that being there when they received these very private care activities is crucial for understanding care work. For these reasons, the researcher did observe these very private care activities, but tried not to intrude too much by taking some physical distance by not entering the bathroom.

To assure the anonymity of the participants, all names and personal details of persons have been anonymized and only aliases have been used. Furthermore, specific information about personal details of participants have been changed where possible.

Sample

The research was conducted among three care workers (Barbara, Moniek and Selma) and three clients (Adrienne and the married couple Henk & Jannie) of a neighbourhood home care team of nine different home care workers; all female. All are employees of a large national home care organisation that has won the municipal bid for this part of the city. Although they are employed by a large nationally operating care organisation, they operate autonomously in the neighbourhood.

The mini-ethnography took place in a short duration of a week. The final interviews also took place in the period of this week, with an exception of Adrienne's final interview that was carried out a week later because she was unavailable during the last day of the mini

ethnography. Because the time-period of participation was limited, there was relatively limited time for participants to get to know the researcher better and vice versa. Yet passing of time is crucial for participants to be willing to share their (private) views on and experiences with care work, to build a form of rapport. Still, when comparing the interview materials of the initial interview with the closing interview, the materials of the closing interviews show that the participants were more willing to express the in their eyes, more sensitive information suggesting that the participant observation, even though it took place in a short period of a week, is of great added-value when compared to a stand-alone interview. It also gave the researcher the opportunity to contrast practices with expressed views during the first interviews and inquire about real life examples of care practices during the final interviews.

For more details please see the national report available from https://www.ethos-europe.eu/sites/default/files/5.3 netherlands.pdf.

Methodology: Portugal

The methodology for this case study followed the guidelines designed by the work package coordinators. The first part comprised desk research and involved a review of academic literature and the analysis of policy documents, legislation and demographic data regarding the Portuguese population, types of care and profile of care workers. This first review allowed us to obtain the background information necessary to carry out the fieldwork, that is, the second part of this case study. The methodology chosen for the fieldwork was a combination of mini-ethnographies and semi-structured interviews. The ethnography is the basis for the fieldwork, as it was designed to observe, understand and explore the relationships between care workers and care users in private households. The semi-structured interviews were used to obtain more detail to add to the ethnographies, and particularly to add information that was not possible to obtain through the observations alone. In order to respect privacy, all names were changed and when someone was referred to by the participants and/or intervened their names were redacted.

The guidelines specific to the fieldwork were adapted because of difficulties with access.

<u>Access</u>

Unfortunately, the access was never easy: sometimes the relatives and parents of the care user were not willing to have someone 'strange' in their house; other times the care user did not agree to be observed in their intimate space. Therefore, in coordination with the coordinators of WP5, we agreed to adapt the field work: one field site was established through accompanying the mobile units of a Portuguese institution that visits dependent elders and provides home care. The goal was to compare this type of care with the care provided in a nursing home of the same institution. This solution was found through personal knowledge and contacts with the caregivers of the institution and we were confident that the

relationships in this context would be interesting to observe and analyse. The mobile units would enable us to observe situations where families preferred to keep the elder at home, avoiding institutionalization for the longest time possible whether for emotional or financial reasons and we could also observe situations where although at home, elders were left alone. In the nursing home we had the opportunity to see how individuals tried to recreate the life they had at home and fulfil the idea they had in mind for their retirement age. In both situations, the care workers were very important, as they provide not only physical care but also emotional care to the dependents. All care workers were Portuguese females, as the institutions do not employ migrant workers (Wall & Nunes, 2010). Taking care of older people in Portugal is mostly carried out by Portuguese women, and it is still very rare for men to work as caregivers partly for cultural reasons — women are perceived as the responsible for care provision — but also because most of the care users are women and they do not feel comfortable with men providing them with physical care.

Although we understand and recognize the importance of looking at the private household as a specific site for claiming more redistributive justice, we do think that mini-ethnographies in this context gives a superficial overview of what can be the life of a caregiver and the life of a care user, and the claims for justice that could exist in the relationships of commodified care. During fieldwork we were able to tackle some of the themes that are common in those situations, but only the result of a longer observation could demonstrate the reality of these live experiences and certain problems that were probably diminished or ignored during the fieldwork.

Ethics

Prior to the beginning of the observations and interviews, following the guidelines of ETHOS project, the letter and consent form was sent to CES ethical commission as well as the guidelines for us to obtain ethical clearance. After the formal authorization from the commission, the same documents were presented to the administration of the institution in which the fieldwork was done for them to also approve. Also, as demanded, for each individual participant the research study was explained and their oral and written consent was collected.

It is important to mention some limitations and discomfort felt with the fieldwork. We consider one week to be too short to observe the reality of the relationship between the caregivers and care users. Although we had authorization to perform the observation in the institutions, during the fieldwork we had to adapt to the schedules of the caregivers and their own will to participate in the research. The two first days of the fieldwork served to establish a relationship of trust between the researcher and the participant, which was not easy. Most of the caregivers felt observed and judged, despite the constant reassurance by us that they were not being evaluated on their work and that they should perform as they are used to do in their everyday working life. It became difficult to go unnoticed. One way to avoid this was to choose not to take notes during the observation, since it was clear that seeing someone

writing was altering the behaviour and attitude of the participants. Care workers' lack of time and availability somehow compromised the development of the interviews, which were too short to really understand the key issues they felt regarding their profession. Regarding care users and their families, orally and written consent was given and no one refused the presence of someone who were not from the mobile unit's teams, since they assumed that the new presence to be a trainee/making an internship. However, they asked questions about the new arrival, in particular for how long the presence in the institution would last. In some cases, it was difficult to explain that the goal was to carry out a research. Personally, I (Laura) felt very uncomfortable being in someone home observing such intimate moments. Most of the time, I tried to stay outside the bedroom when physical care was provided since it was the moment who caused me more discomfort. In my opinion, I didn't have the right to invade the intimacy of the people. During the observation in the nursing home, the discomfort was exacerbated due to the emotional demands of care users, who were constantly demanding my attention, and asking why I was there — in some cases, several times a day.

<u>Sample</u>

Because of the access difficulties outlined above fieldwork was conducted in two sites. The first was through accompanying mobile units, and the sample of workers and care users is given below.

Context of	Person	Description
care		
Mobile care	Care worker 1: Maria,	Both carer has been working on the mobile care
units	aged 44	units for about 15 years.
Mobile care	Care worker 2: Ana,	
units	aged 35	
Mobile care	Care user 1: António,	Family is absent from home, António lives alone
units	aged 71	and has some mobility limitations. The mobile
		care units are the main carers and the home visits
		occurs three times a day – early morning, lunch
		and dinner/bed time.
Mobile care	family member 1:	Daughter whose mother (Inês, 82 years old) has
units	Alexandra, aged 66	mobility problems due to an accident. Since then
		they use the services of mobile care units. There is
		one person accompanying Inês during the day and
		another one during the night. The services of
		mobile care units are essentially for hygiene.
		,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,

Mobile care mei	mber of	the	João started working for the administration of the
units adn	ministration:	João,	Santa Casa after retiring from his work in
age	aged 65		engineering. He is part of the administration since 2016 and has been trying some changes in the functioning of the nursing home, principally regarding the working hours of the carers.

The second site was a care home run by the same institution. There we worked with

Context	Person	Description
Nursing	Care worker 1: Helena,	Helena was an immigrant in Switzerland, where
Homes	aged 63	she worked as a carer for about 12 years. She
		returned to Portugal in 2001 and started
		working in Santa Casa in the summer of 2013.
Nursing	<u>Care worker 2</u> – Raquel,	Raquel is the youngest carer in the nursing
Homes	aged 23	home and was hired through the employment
		centre after finishing secondary school.
Nursing	Care user 1 – Susana, aged	Susana and Paulo are a couple, and both live
Homes	74	together at the nursing home since the summer
Nursing	Care user 2 – Paulo, aged	of 2017. They decided to move to the nursing
Homes	77	home because they don't have children, and
		both have been losing some mobility due to
		health problems.
Nursing	<u>Family</u> member –	Fernanda had her father admitted to the
Homes	Fernanda, aged 59	nursing home after a cardiovascular incident
		that made him lose all his mobility. Since herself
		has been dealing with health issues and her
		mother couldn't take care of her father alone,
		the institutionalization came as the best
		solution.

For more details please see the national case study available from https://www.ethoseurope.eu/sites/default/files/5.3 portugal.pdf.

Methodology: Turkey

Using national data and academic and policy literature on care work an overview of migration and eldercare in private households in Turkey was compiled and shared with the coordinators.

The field study was conducted from May 2018 till July 2018 and participants were accessed using personal contacts. There were certain methodological difficulties in the ethnography study regarding access to households. Given that the study was going to be finished in 5-6 weeks, building trust with the families to conduct such work of ethnography that intervenes in the intimate lives was a major challenge. It was not easy to persuade care receivers and their families to conduct an ethnographic study that would last for a week where the researcher had to spend time in their homes. Elderly people and/or their families were understandably reluctant to have a 'stranger' in their house. Moreover, most of the care receivers we have worked with have mental disabilities and so could not be included for ethical reasons. Furthermore, the field study coincided with Ramadan which also affected participation. The time limitations imposed by the study made access even more challenging.

Once access was granted it was necessary to build trust with the families in order to conduct ethnographic work. Being polite, cheerful and friendly (thanks to Simla's joyful and sincere character as a young researcher) and giving accurate information about the study facilitated the establishment of the trust relationship between the researcher and participants. Almost all participants felt more comfortable after the end of the first day of ethnographic study and the trust relationship between the researcher and participants was established earlier than expected. The researcher generally left the field (house) around 6 pm. Hence, all the participants invited her to have dinner together. The researcher was invited to the lunch table and they had their meals together during the day indeed. The researcher spent one week with each family but did not attend when the care givers were off work and out of the house. In some cases care receivers did not want to participate in the study with visitors present. Apart from those interruptions in the house, the guidelines to spend a week in the house was completed over the course of the project. We should note that the design of the ethnographic study was questioned by our Ethics Committee as building trust in that short period of time was the major challenge which was also revealed by our experience as researchers.

All participants were accessed via personal contacts because of time constraints. Initially we tried to find participants from Istanbul. We live and work in Istanbul and have extensive networks of friends and personal contacts there, but factors such as ill health and bereavement meant that our initial contacts did not bear fruit. We think that this reluctance also is related to the fact that Istanbul is huge city with a dense population and comparatively difficulty living conditions making people's daily lives more isolated and more distrustful of 'strangers'. We should note that this just our sense of Istanbul, not based on scientific knowledge. Ethnographic work that demands access to the intimate lives is already contested

issue which pushes one to critically explore not just the class and cultural aspects but also spatial aspects with regard to where the research is conducted.

We decided to switch to Ankara because this is the city where the project researcher was born and her family still lives there. Her mother who has been an English teacher at an elementary school helped us to find some of our participants through her parent-school contacts. Firstly, she put us in contact with care receivers that she was already acquainted with through her students. She reached the parents whose mothers or fathers are cared for migrant care workers. Then, the researcher called the family, shared information about the ethnographic study and asked for their permission to be contacted. Here, being polite and sincere and explaining the project requirements clearly and openly were very important to persuade people to participate in the study. The care users and care workers who accepted to participate in the study and signed the informed consent form were included as research participants.

We used different routes to follow up depending on whether our initial contact was with the care receivers or care workers. Permission to access houses through the care worker was much more difficult than access through the care receiver for obvious reasons. Many care providers we contacted in the first place did not agree to be observed in their workplace since many work without valid work and residence permits. Since we were strangers coming from a public institution, some workers we did not want to participate in the study. We should note that majority of care workers who participated in our study had a work permit. When we had access to the house through the care receiver permission was much easier and this in turn affected care workers' willingness to participate in the study. As in our earlier efforts in istanbul there were cases where the care receiver agreed to participate but had to pull out because of health problems but we managed to reach the target number of cases.

In addition to the mini-ethnographies we also conducted interviews. We used the questions provided in the guidelines as guidance only, adapting them to the Turkish context. In coordination with the coordinator of WP5, we agreed to make amendments in the questions that would work better in the Turkish context. For instance, the last question of interviews concerning a vignette scenario was revised. In the scenario, we changed the wording 'racist' to 'insulting'. We also changed the phrase 'the stealing the money' to 'breaking a vase' that refers to a possible conflicting situation as stealing money could have been perceived by the care provider as an interrogation. Furthermore, some questions had not been comprehended completely as the participants were not familiar with certain concepts in the interview questions. Before starting to conduct field study, we were not sure about the question of unionization since unionization of the migrant workers was not a reality in the Turkish context; they usually do not know anything about unionization of care workers. Nonetheless, we kept this question during the interviews of the first and the second cases. After receiving the reaction of the first participants (they did not understand the question and they could not give

any meaning to it), the question on unionization was removed as it did not work in the Turkish context.

The interviews were recorded (with the written consent of the research participants) and field notes of the ethnographic study were taken throughout the research. The recorded data was transcribed and anonymized through the usage of pseudonymous names. The analysis was carried out in Nvivo qualitative analysis software; following the analysis, the quotes, the passages and other ethnographic data used in the report were translated to English from Turkish. An informed consent form for the interviews and permission for accessing the houses were prepared. The researcher thoroughly read the consent form to the participants explaining the purpose of the study and their right to withdraw at any time. Care providers and care receivers were also informed that their interviews would be anonymized.

Ethics

The study was approved by the Ethics Committee of Boğaziçi University. http://www.boun.edu.tr/en

<u>US/Content/About BU/Governance/Councils Boards and Committees/Ethics Committees</u>

A comprehensive ethical application form that includes the ethical considerations of the research and measures was taken to conduct ethical research by the project team was filled and applied to the Ethics Committee. We should note that Bogaziçi University Ethics Committee follows strictly universal rules for the ethical research and Committee demands the applicant researchers to provide accurate and detailed information about all stages of the research to be conducted. To receive the Committee's approval, we were very careful with our research design that also complies with the guidelines of the WP5. In summary, full name of the project, brief summary and methods of the project, the names of the project team (project managers and researcher) and their contact information were provided in the ethical application form. Besides, ETHOS Case study protocol-D5.3 and a sample of consent form were also shared with the Committee to ensure clear information about the research. On 2 May 2018, we have received our ethical approval. After the ethical approval was provided to us, we had start field study. No major ethical dilemmas were faced in the fieldwork as the ethical issues were considered beforehand and care receivers with mental disability were not included in the sample. The researcher took all the measures not to give any disturbance to the daily life of the families who kindly agreed to participate in the research. During the interviews, the voice recorder was used with the permission of the participants. All participants accepted the recording. Quotations of participants were provided at the final report with pseudonym names.

<u>Sample</u>

	Care giver	Care receiver	Additional Information
Case 1	Linda, female, 52 years old, coming from Kutaisi, Georgia, physics teacher, has 3 children, widow	Ragip, male, 83 years old, retired mechanical engineer, has four children, married	In this case, care giver was caring for both Ragip and his same aged wife whose name is Ayca. However, since Ayca has mental disorders she were not included in interviews.
Case 2	Remziye, female, 27 years old, coming from Bishkek, Kyrgyzstan, was working as a chef before coming to Turkey, has a son, divorced	Didar, female, 96 years old, retired bank officer, widow	
Case 3	Meryem, female, 39 years old, coming from Samarkand, Uzbekistan, elementary school teacher, has three children, married	Gül, female, 86 years old, housewife, has three children, widow	In this case, daughter of Gül, Fahriye, was the employer of the care giver. Thus, interviews were also conducted with her. Fahriye, female, 52 years old, married, has two children, housewife, living in the same apartment with her mother (but in different flat)
Case 4	Anya, female, 58 years old, coming from Telavi, Georgia, nurse, has two children, married	Hamdi, male, 96 years old, retired civil servant, has three children, widow	In this case, son of Hamdi, Ali, was the employer of the care giver. Thus, interviews were also conducted with him. Ali, male, 59 years old, married, has two children, elementary school teacher, living in the same apartment with his father (but in different flat)
Case 5	Ayda, female, coming from Bishkek, Kyrgyzstan, 49 years old, divorced, has two children, was working as a cook and salesperson before coming to Turkey	A married couple: Leman, female, 88 years old, housewife, has three children, married Şinasi, male, 92 years old, judge retiree, has three children, married	

APPENDIX ONE

ETHNOGRAPHY TRAINING SESSION FOR ETHOS

WP5: 'Mapping of everyday negotiations of conflicting claims for justice with attention to the role of gender and ethnicity'

Preparatory work

The training session in Coimbra next month will be an introduction (or refresher, depending on your background and previous experience) to ethnographic fieldwork. We will focus on the specific value and challenges of short-term or mini-ethnographies, and on doing research in private homes. Please make sure you read the study protocol and the following articles before the session (PDFs attached):

Ferguson, Harry. 2018. "Making home visits: Creativity and the embodied practices of home visiting in social work and child protection." Qualitative Social Work 17 (1):65-80. doi: 10.1177/1473325016656751.

Madden, Raymond. 2017. Being Ethnographic: a guide to the theory and practice of ethnography. Los Angeles: SAGE. ['Chapter 1: "Definitions", methods and applications'].

Pink, Sarah, and Jennie Morgan. 2013. "Short-Term Ethnography: Intense Routes to Knowing." Symbolic Interaction 36 (3):351-61.

Some questions to consider:

- In light of Ferguson's article, consider the degree to which the social worker expression 'working the house' might be applicable to both care-workers and the ethnographer (i.e. you): what instances and practices of 'working the house' do you expect to encounter during your fieldwork and what dilemmas and challenges do you expect to arise from them?
- How do you expect to 'work the house' during fieldwork? (think about spaces and interactions, how to relate to care-workers, care-receivers, and other people living in the homes). Will you be able to and comfortable moving around the house (including kitchen, bedrooms, bathrooms, hallways, living rooms, etc.) with your research subjects, and what might be gained from interactions and interviews conducted in different spaces?
- In light of Pink & Morgan's argument for the value of short-term ethnography, how will you seek to ensure that your fieldwork is 'data-intensive'? (visual images, videos, recordings, note-taking, embodied practices of care, etc.?) □

 Think about atmosphere, and sensory and embodied impressions of homes, and the role of objects; how will you aim to capture these for analysis later? How will you seek to access the experiences of atmosphere of care-workers and care-receivers respectively?

Training days

Thursday 13.45-15.45

13.45-14.00 Introductions (name, role, prior experience of and training in ethnographic methods)

14.00-14.30 What is ethnography?

- Being with and writing about people; encompassing both doing and writing up research
- Endeavours to understand emic perspective; ethnographer moving between emic and etic perspectives
- An embodied process involving creativity, craft, and improvisation; importance of 'being there'; establishing empathy and using resonance
- Interest in claims and acts / discourse and practice, and the gaps and discrepancies between them
- Rich, granular data (good for capturing complex relationships and emphasises importance of embodied and tacit knowledge / practice)
- A learning process (role of faux pas, cultural translation between potentially incommensurable worlds)
- Interdisciplinary and enduring, yet changing, social science method

Short-term or mini-ethnographies:

- Punctual & focused vs. holistic & open-ended (intensive excursions)
- Interventional and observational (close and intentional focus on details of everyday practices; interventions to make the invisible and unspoken emerge)
- Data-intensive (reflect on different data collection methods, what constitutes data, how to ensure richness for further discussion on Friday)
- Role of theory
- Interest in practice and practical activities (here: care work and care receiving)
- Inductive and deductive

14.30-15.15 Ethnography in/of the home

- 'Working the house' (Ferguson); different spaces; what happens where and when; permitted and closed-off spaces for researchers and research participants (e.g. live-in care givers)
- Atmosphere, reverberations, objects and material culture ('things do things to us'; the feel of places, smells, sounds, touch)
- Asking research participants to perform and explain everyday tasks (researchers to participate)
- Dealing with awkward situations and drawing boundaries (think about toilet and bath visits, intimate care situations, bedrooms, arguments between research participants)

Ethnography as embedded and embodied

- Using the ethnographer's body as tool: the importance of capturing the non-representational and the taken-for-granted; the challenge of articulating and translating unspoken, tacit knowledge, hidden experiences, senses, emotions, movements, embodied practice
- Inter-subjectivity
- Role of empathy and resonance
- Body techniques and habitus: thinking of care work and care receiving as learning processes (the challenge of and need to articulate everyday minutiae and detailed bodily practices); consider asking participants to perform everyday tasks for recording and discussion. Where appropriate, ethnographer to emulate (need to think carefully about situations/practices that are/are not appropriate and ethical)
- Asking intrusive / 'irrelevant' questions (can be awkward, but also revealing and open up for reflection and discussion)

15.15-15.45 Validity and comparability of data; access consent and ethics

- Validity, veracity, reliability (how to deal with incommensurable accounts)
- Systematic data gathering (how to ensure data intensity: photos, filming, audio recording, drawings/sketches, maps of rooms and the home)
- Systematic data interrogation (strategy for analysis)
- Presentation of the ethnographic story Agree a template for field notes with prompts? (e.g. timing activities, noting mobility in the house, 'atmosphere', who is present, etc. Note Ferguson's descriptions – how can you ensure same level of detail)

Friday – 45 minutes

Access, consent and ethics

- Presentation of self and research project info sheet and consent form
- Obtaining meaningful consent from all involved parties
- Dealing with withdrawal of consent (this covered in our ethics procedures)
- Dealing with disclosure of abuse [need procedure and clear guidelines that are locally relevant and links with local services] this will have to be covered in the consent procedures. I will flag.
- Interview schedule / guide
- Agree on platforms and frequency for staying in touch during fieldwork and sharing of notes
- Language issues? E.g. where care giver and care receiver have limited shared language; will care givers be interviewed in their first language? Use of interpreters?

APPENDIX TWO

Suggested readings

ANDERSON, Bridget and SHUTES, Isabel. (2014). "Conclusion". In *Migration and care labour: Theory, policy and politics*. London: Palgrave Macmillan, pp. 213-225.

BARNES, Marian. (2012). *Care in everyday life: An ethic of care in practice.* Bristol: Policy Press, pp. 61-85 [working at care].

FOLBRE, Nancy, 2006, Demanding Quality: Worker/Consumer Coalitions and "High Road" Strategies in the Care Sector, *Politics & Society*, 34 (1), pp. 11-32.

GROOTEGOED, E., T. KNIJN and B. DA ROIT, 2010, 'Relatives as paid care-givers: how family carers experience payments for care', *Ageing & Society* 30 (3), pp. 467-489

KNIJN, T. & C. Ungerson, 1997, 'Introduction: Care, Work and Gender in Welfare Regimes'. *Social Politics. International Studies in Gender, State and Society*, 4 (3), pp. 323-327

KNIJN, T. & M. Kremer, 1997, 'Gender and the caring dimension of welfare states: toward inclusive citizenship'. *Social Politics. International Studies in Gender, State and Society*, 4 (3), pp. 328-361.

KNIJN, Trudie and VERHAGEN, Stijn (2007), "Contested professionalism: Payments for care and the quality of home care", *Administration & Society 39*(4), pp. 451-475.

LUPPI, Matteo, Rosanne OOMKENS, Trudie KNIJN and Bernhard WEICHT, (2015) *Citizenship in the context of migrant care work. Regimes, Rights & Recognition*, bEUcitizen Deliverable 9.6, Utrecht University, 18-07-2015.

NAKANO GLENN, Evelyn. (2010). *Forced to care: Coercion and caregiving in America*. Cambridge: Harvard University Press, pp. 1-11 [introduction].

STONE, Deborah. (2000). "Caring by the book". In HARRINGTON MEYER, Madonna, *Care work: Gender, labor and the welfare state*, London: Routledge, pp. 89-111.

TRAUSTADÓTTIR, Rannveig. (2000). "Disability reform and women's caring work". In HARRINGTON MEYER, Madonna, *Care work: Gender, labor and the welfare state*, London: Routledge, pp. 249-269.

APPENDIX THREE

Interview guidelines

1. Initial interviews with care users/employers/family members

- 1. History of care needs and how these were met until now (including family members' history of caring for their relative)
- 2. What do they think of current law and policy with regard to care do they feel that it is just? If not, why not? What are its benefits and how could it be improved.
- 3. Thinking about your current situation, what would make it more just or more fair?
- 4. In what way does employment of someone in your house/having someone into the home differ from employing someone in a business? (i.e. how important is the *site* for relations).
- 5. In what way does paying for care differ from paying for other services like cleaning? (i.e. how important is the *nature of the work* for relations).
- 6. What are the best and worst aspects of your day?
- 7. What would be the characteristics of a good employer?
- 8. What would be the characteristics of a good care giver? Is it the same if they are paid or unpaid?
- 9. What skills are needed for care work?
- 10. In general do you think care workers are treated with respect in this society?
- 11. Do you think that paid caregivers should have the same rights as standard workers?
- 12. Some people say they treat caregivers as part of the family rather than workers. What do you think of this?
- 13. What do you think about unionisation for care givers? If think it is not a good thing, why?
- 14. Can you give me an example of where you had a disagreement with your current or a past care giver and how you worked it out? What lessons did you learn from this?
- 15. Consider this scenario:

Anna is a migrant worker who has been working as a care worker for Tom in his house for four weeks. Tom is becoming forgetful and his daughter, Maria, employs Anna to be in the house from 9-5 while she is at work. One day she comes home to find Tom very distraught. Tom says that he had set aside some money for shopping and that it has disappeared. Anna says that she has not stolen the money. She also says that Tom has been using racist words in his dealings with her.

What should Maria do?

What should Anna do?

Would it be different if Anna had worked longer for the family?

Care homes

- 16. What do you most like about this place, and what do you dislike (trying to get at whether they feel at home)
- 17. Do you think the people who work here are paid well? Do you think they enjoy their work (probe on hours and conditions)

2. Initial interviews with commodified care workers

- 1. How long they have been working in the sector/being paid for their work. What they think of this arrangement.
- 2. In their own words, how would they describe their relationship with the person/people they care for? Has it changed over time?
- 3. What do they think of current law and policy with regard to care do they feel that it is just? If not, why not? What are its benefits and how could it be improved.
- 4. In what way does working in a private house differ from working in a business? (i.e. how important is the *site* for relations).
- 5. In what way does being paid for care differ from being paid for other services like cleaning? (i.e. how important is the *nature of the work* for relations).
- 6. What are the best and worst aspects of your day?
- 7. What would be the characteristics of a good employer?
- 8. What would be the characteristics of a good care giver? Do you think that a good paid care giver gives the same kind of care as an unpaid family member?
- 9. What skills are needed for care work?
- 10. In general do you think that care workers are treated with respect in this society?
- 11. Do you think that paid caregivers should have the same rights as standard workers?
- 12. Some people say they treat caregivers as part of the family rather than workers. What do you think of this?
- 13. What do you think about unionisation for care givers? If think it is not a good thing, why?
- 14. Can you give me an example of where you had a disagreement with your current or a past employer/care user and how you worked it out? What lessons did you learn from this?
- 15. Would you prefer to work in people's private homes or in an institutional setting? Why?
- 16. Consider this scenario:

Anna is a migrant worker who has been working as a care worker for Tom in his house for four weeks. Tom is becoming forgetful and his daughter, Maria, employs Anna to be in the house from 9-5 while she is at work. One day she comes home to find Tom very distraught. Tom says that he had set aside some money for shopping and that it has disappeared. Anna says that she has not stolen the money. She also says that Tom has been using racist words in his dealings with her.

What should Maria do?

What should Anna do?

Would it be different if Anna had worked longer for the family?