

**Healthcare at the margins:
An ethnography of chronic kidney disease
and peritoneal dialysis in Mexico**

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Abstract

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The aim of this thesis is to document and analyse the practices and experiences of poor and uninsured patients and their families living with Chronic Kidney Disease (CKD) and using Continuous Ambulatory Peritoneal Dialysis (CAPD) in Mexico, tracing them throughout multiple contexts in the process. This study draws on a critical and interpretive social science methodology, one that takes into account the social, political, cultural, and experiential dimensions of a condition and treatment that are often regarded as exclusive to the biomedical domain. I carried out ethnographic fieldwork in Jalisco, Mexico, from September 2012 to May 2013, during which I conducted in-depth interviews with patients, family members, healthcare professionals, and charitable organisations' staff, and undertook ethnographic observations in domestic, hospital, and community settings. The ethnographic perspective adopted in this study allowed me to provide a richer account of the unequal, hierarchical, and historically rooted social relationships that underpin interactions between patients and the health professionals who represent and control access to the health system. Focusing on the socio-material conditions within which the problem is situated, the study starts off by following the trajectories of uninsured patients from their diagnosis to treatment, and the work that they are required to undertake throughout. At a public hospital for the uninsured, patients have a catheter inserted in their abdomens and they are put on peritoneal dialysis, the mainstay therapy for CKD patients in Mexico. They have to go through an admission process, which takes the form of a rite of passage, in which they are drilled in new body techniques, a part of their homes is turned into a para-clinical space, and they are transformed into productive CAPD patients to whom peritoneal dialysis can be outsourced in the home. Ultimately, this process aims to create a nexus between the body, the therapy, and the clinic. Patients and families do, however, modify, accommodate and thus domesticate CAPD by the constant practice of the therapy, although complications of the disease and therapy occur all throughout their trajectories, sometimes with fatal consequences. In the absence of proper public healthcare coverage for CKD and CAPD, a biosocial community has emerged around CKD and its therapies, characterised by exchange practices among its members, operating according to various quid pro quo logics, which I call the informal economy of renal replacement therapies. However, renal biosociality and the informal economy that arises from it cannot provide all the support uninsured patients need. I conclude that, while considered a global health concern, to fully understand the social and political implications of CKD and its therapies we need to adopt an ethnographic perspective that traces the practices of patients and families through different sites of care – the hospital, the home and the community. I argue that CAPD is a therapy situated at the margins of social welfare, which makes patients and their families directly responsible for its success and failures, a process which imposes substantial long-term financial and social costs on those already in desperate need. Although collective responses have emerged through the local biosocial community and its informal economy, those responses, I argue, are just another consequence of the problematic social context within which CKD and CAPD are embedded.

Table of Contents

Abstract	2
Acknowledgement.....	10
Declaration	11
List of abbreviations.....	12
Introduction	13
CKD: A global and local health concern.....	13
CKD and CAPD as social problems.....	19
Outline of chapters	20
Chapter 1 Problematising chronic kidney disease and its treatments in Mexico: a literature review	26
Introduction	26
1.1 Biomedical contributions to understandings of CKD and RRT.....	28
1.2 Social policy contributions to understanding the Mexican fragmented health system.....	38
1.2.1 The Public Sector.....	39
1.2.2 The Private Sector.....	43
1.2.3 Distribution of populations between institutions and its consequences	44
1.3 Qualitative health research: the individual's perspective on CKD and RRT ...	48
1.4 Ethnographic perspectives on CKD and its treatments	59
1.5 Sensitising concepts: biopolitics, biosociality and rites-of-passage.....	68
1.6 Conclusion.....	72
Chapter 2 Methods and methodology	74
Introduction	74

Introduction	154
4.1 The introductory meeting to the CAPD programme	157
4.2 Meeting the programme's requirements.....	167
4.2.1 Daniel's progress	167
4.2.2 Lucero's progress.....	173
4.3 CAPD training: learning the technique	181
4.3.1 The training set up	182
4.3.2 Learning a new technique of the body: la técnica de cambio de bolsa de diálisis	191
4.3.3 Drilling in the technique	197
4.4 Conclusion.....	201
Chapter 5 Performing CAPD in the home	209
Introduction	209
5.1 Situating CAPD in the home	212
5.1.1 Lucero: accommodating CAPD, embodying the technique	213
5.1.2 Accommodating and indigenising CAPD at home.....	220
5.1.3 Situating bodily techniques.....	230
5.2 Assignments: check-ups, follow up and healthcare support	238
5.2.1 Taking clinical tests	238
5.2.2 The follow-up consultation.....	242
5.2.3 Further assignments	246
3. Complications: the threat of peritonitis and cardiovascular disease	248
5.3.1 Dealing with peritonitis	250
5.3.2 Deterioration, death and hardship.....	254
5.4 Conclusions	259

Chapter 6 The Informal economy of renal replacement therapies	264
Introduction	264
6.1 Patients' 'bio-socialisation'	266
6.1.1 José's quest for dialysate supplies	267
6.2 Renal biosociality: the emergence of a community around CKD	276
6.2.1 The importance of asociaciones civiles	278
6.3 The informal economy of renal replacement therapies	283
6.3.1 The role of asociaciones civiles	288
6.3.2 The role of healthcare professionals	291
6.3.3 Exchanges between patients	292
6.3.4 Engaged and disengaged patients	296
6.4 Conclusions	298
Chapter 7 Discussion.....	304
Introduction: 'Leaving the field' and the death of patients	304
7.1 The socio-material conditions of CKD and its treatments	307
7.1.1 CAPD and biopolitics	308
7.1.2 The fragility of the nexus.....	310
7.1.3 Patients, families and the biosocial community.....	312
7.1.4 An informal economy that not always delivers	314
7.1.5 Stagnant trajectories.....	315
7.1.6 CAPD domesticated.....	316
7.2 Renata's wisdom.....	318
Chapter 8 Conclusion	320
Appendices	325
Appendix 1. List of topics covered during the interviews.....	325

Appendix 2. Sample of Participant invitation letter: patients and families.....	327
Appendix 3. Sample of Participant invitation letter: health professionals	328
Appendix 4. Sample of Participant information sheet: patients and families	329
Appendix 5. Sample of Participant information sheet: health professionals.....	333
Appendix 6. Sample of Consent form	336
References	338

List of tables and figures

Table 1 Proportion of the population covered by institution according to different sources	45
Table 2 Study cases	92
Table 3 Participants of the study	94
Table 4 Characteristics of patients' dialysis rooms	222
Figure 1 Fray Antonio Alcalde in Guadalajara, by Gustavo Peralta.....	117
Figure 2 Fray Antonio Alcalde, by Jorge Monroy	118
Figure 3 Mezcala's Centro de Salud.....	126
Figure 4 El Lago clinical laboratory, sample collection unit in Mezcala	127
Figure 5 Back of Daniel's prescription note, with Dr Arrayga's annotation	128
Figure 6 Material requested by the nephrology services to patients starting peritoneal dialysis at Hospital Alcalde.....	131
Figure 7 Placement of peritoneal catheter in the patient's body	132
Figure 8 José holding the Pisatek Biosafe© cycler set he had just bought	140
Figure 9 Farmacias Similares in Chapala.....	144
Figure 10 Illustration of the layout of a dialysis room.....	161
Figure 11 Photograph of a patient used to apply for CAPD training	163
Figure 12 Perspective of Lucero's family house.....	174
Figure 13 PiSA's double-bag BennY System	191
Figure 14 Snapshots of PiSA's CAPD instructive video	195

Figure 15 Lucero performing CAPD at her home after a week of continuous practice	218
Figure 16 Participants' dialysis rooms	225
Figure 17 Dialysis supplies stored in different parts of the patients' homes	228
Figure 18 Ronaldo performing CAPD in his dialysis-bedroom	233
Figure 19 Lourdes performing CAPD in his dialysis-exclusive room.....	234
Figure 20 Cristian performing CAPD in his dialysis-exclusive room.....	235
Figure 21 Bazaars at the entrance of Hospital Alcalde	270
Figure 22 José's quest for dialysate	274
Figure 23 The biosocial community of CKD and he informal economy of RRT....	287

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Declaration

This thesis and the work presented in it are my own and has been generated by me as the result of my own original research. Where I have consulted the published work of others, this is always clearly attributed. The material contained in this thesis has not been presented, nor is currently being presented, either in part or wholly for any other degree qualification.

List of abbreviations

CAPD	<i>Continuous Ambulatory Peritoneal Dialysis</i>
CKD	<i>Chronic Kidney Disease</i>
DIF	<i>Sistema para el Desarrollo de Integral de la Familia</i> (System for the Integral Development of Families).
GFR	<i>Glomerular Filtration Rate</i>
HCG OPD	<i>Hospitales Civiles de Guadalajara, Organismo Público Descentralizado</i>
IJAS	<i>Instituto Jalisciense de Asistencia Social</i> (Social Assistance Institute of Jalisco).
IMSS	<i>Instituto Mexicano del Seguro Social</i> (Mexican Institute for Social Security).
IMSS-CMNO	<i>Centro Médico Nacional de Occidente del IMSS</i> (IMSS's West National Medical Centre)
ISSSTE	<i>Instituto de Seguridad Social y Servicios para los Trabajadores del Estado</i> (Institute of Social Security and Services for State Servants)
PEMEX	<i>Servicios de Salud para los Trabajadores de Petróleos Mexicanos</i> (Healthcare Services for the workers of Mexican Oil).
SEDENA	<i>Servicios de Seguridad Social y Salud de la Secretaría de la Defensa Nacional</i> (Social Security and Health Services of the Ministry of Defense).
SEDESOL	<i>Secretaría de Desarrollo Social</i> (Ministry of Social Development)
MoHJ	<i>Ministry of Health of Jalisco</i>
SSPH	<i>System of Social Protection in Health</i>

Introduction

This study seeks to understand the complexity of a medical condition and one of its treatments in a particular place and time: Chronic Kidney Disease (CKD) and peritoneal dialysis in contemporary Mexico. I will do this by drawing on a critical and interpretive social science methodology, one that takes into account the social, political, cultural, and experiential dimensions of a condition and treatment that is often regarded to be exclusive to the biomedical domain. As the reader will see in the following pages, this study moves back and forth between the biomedical and the social, the experiential and the structural, the clinic, the home and the community, in an attempt to understand the nature of CKD and peritoneal dialysis in its contexts.

CKD: A global and local health concern

The standard picture of CKD depicted by the epidemiological and medical literature emphasises the incidence and prevalence of CKD to be rising steadily over the last fifty years worldwide. The problem is often treated as an unintended consequence of the ‘epidemiological transition’, i.e. of material development, techniques for treating previously fatal infectious diseases and the subsequent ageing of populations (Eknoyan et al., 2004; Jha et al., 2013; McClellan, 2006). Nephrology is the medical subspecialty that deals with CKD and it does so along different fronts, from its clinical definition, to its treatment and prevention. The range of the practices that nephrologists engage in are shaped by understandings of what CKD is. According to current

definitions in clinical medicine, CKD is a general term¹ that encompasses heterogeneous disorders that affect the normal functioning of the kidneys,² and hence the health of the person, which, if not treated opportunely, can lead to death (KDIGO Work Group, 2013; Levey et al., 2012). According to nephrologists, CKD can result from the complications of a pre-existing disorder, most commonly diabetes and hypertension, and can cause severe complications and damage to other organs. CKD is classified into five progressive stages according to the level of kidney dysfunction seen at each, something determined by measuring the kidneys' filtration rate.³ A person who has reached stage IV or V of CKD needs some form of medical treatment to stay alive.

In many respects, CKD is a disease that reflects the contemporary world. While non-communicable, it has become a global health problem, one which affects health systems worldwide independently of the resources at their command (Eknayan et al., 2004; Grassmann, Gioberge, Moeller, & Brown, 2005; Jha et al., 2013; S. L. White, Chadban, Jan, Chapman, & Cassa, 2008). CKD is particularly problematic because it reduces the life expectancy of the person, decreases his or her quality of life, causes high rates of hospitalisation, and is extremely costly to treat, in terms of time and

¹ According to the current definitions issued by Kidney Disease: Improving Global Outcomes (KDIGO), the leading clinical nephrology body, CKD refers to the abnormalities of kidney structure or function, present for more than three months, with implications for the person's health. KDIGO guidelines specified that abnormalities of kidney structure may exist without affecting the functioning of the kidneys, thus having no implications for the health of the person (KDIGO Work Group, 2013).

² Within the biomedical literature, the kidneys are defined, in structural-functional terms, as those two organs, located at the rear of the abdominal cavity, that perform the vital biological functions of removing waste products, toxins and excess of water from the body; producing renin and erythropoietin hormones; and helping to maintain body homeostasis and interact with all other major organs (Eckardt et al., 2013; Levey et al., 2012).

³ Clinically known as the Glomerular Filtration Rate (GFR), the GFR describes the flow rate of filtered fluid through the kidneys. It can be calculated using urine or blood tests. The stages of CKD are determined by the GFR as follows: normal or high GFR >90 ml/min/1.73 m²; stage I mildly decreased GFR 60-89; stage II mildly to moderately decreased GFR 45-59; stage III moderately to severely GFR 30-44; stage IV severely decreases GFR 15-29; stage V kidney failure GFR <15 (KDIGO Work Group, 2013).

resources, technical and human. In the absence of a cure for CKD, three different treatments have been developed, collectively known as Renal Replacement Therapies (RRT): haemodialysis, transplantation and the lesser known peritoneal dialysis.

Haemodialysis performs the function of waste removal, a function that the kidneys can no longer do, with the help of an ‘artificial kidney’, a dialyser machine. It is usually carried out at a clinic or hospital. In this therapy, a fistula is surgically created in the arm or leg of the patient that will serve as an access point to the bloodstream. The blood of the patient is drawn out to be cleansed by the dialyser and then pumped back in, a process that lasts three to four hours and has to be repeated three to four days a week. Transplantation, considered the best option for CKD, is a procedure by which the kidney of a person – dead or alive – is surgically removed and then placed in the body of another. If the transplant is successful, the patient will undergo immunosuppressive therapy for the duration of the graft, to prevent the immunological rejection of the transplanted kidney.

Peritoneal dialysis, a lesser known form of RRT, is a procedure that uses the patient’s peritoneum⁴ to filtrate waste products that the kidney no longer removes. A permanent polyethylene catheter is inserted in the abdominal cavity of the patient in order to infuse a dialysate solution into it. The catheter will remain in the patient’s abdomen for as long as the treatment lasts – although complications are very frequent and many patients experience the painful replacement of the catheter a number of times during

⁴ The peritoneum is a serous semi-permeable membrane, composed of thin layers of connective tissue, lining most of the abdominal organs. Its ability to filtrate was studied during the 19th Century and in the 1920s the first attempts of peritoneal dialysis were conducted by Georg Ganter in Germany. The development of the permanent peritoneal catheter by Tenckhoff in the 1960s allowed the use of peritoneal dialysis in the long term, but it was not until the 1970s with the development of CAPD that peritoneal dialysis was widely used worldwide (Negoi & Nolph, 2009).

their treatment trajectory. Peritoneal dialysis can be performed in the hospital with the help of a machine, which will infuse and then drain out the dialysate solution from the abdomen of the patient. But this form of dialysis can also be performed in the patient's home manually, a modality known as Continuous Ambulatory Peritoneal Dialysis (CAPD). In the case of CAPD, which is normally conducted by the patient themselves or by a family carer who has been trained at the hospital or clinic, the infused dialysate solution 'dwells' in the abdominal cavity for usually four hours, then it is drained out and new solution is infused. CAPD must be repeated several times a day, usually four to six, for an undefined period of time –until the patient gets a transplant. As a home and self-administered treatment, peritoneal dialysis is often considered to be a therapy that gives freedom and independence to patients (Tong et al., 2013), while at the same time producing the same clinical outcomes as the more expensive haemodialysis (Yeates & Blake, 2009).

Neither peritoneal dialysis nor haemodialysis replace all the functions the impaired kidneys no longer serve, and further medicines (e.g. erythropoietin, calcitriol and antihypertensive drugs) and strict dietary restrictions are needed as complements for successful treatment. A renal transplant, by contrast, does perform the kidney's lost functions and, although the recipient will never stop taking medicines to control immune system rejection of the transplanted organ. In spite of that, renal transplantation is considered a superior treatment to dialysis, for it controls the symptoms of CKD.

By the end of 2004, as reported in the epidemiological literature, 1.7 million people worldwide were undergoing some kind of RRT, with a growing annual incidence of 8%, and it is estimated that this will have exceeded 2 million by 2010 (Grassmann et

al., 2005). In line with the global trend, epidemiological studies have indicated that the incidence of CKD in Mexico has increased over recent decades to the point where it became one of the five leading causes of mortality at the beginning of the 21st century, a consequence often linked to the country's epidemiological transition, the ageing of the population and, more particularly, the rapidly rising incidence of diabetes and hypertension Mexico has experienced over time (López Cervantes et al., 2010).

The landscape of RRT in Mexico presents rather unusual characteristics. Medical researchers have shown that the majority of CKD patients worldwide undergo in-centre haemodialysis, and many live with a functioning transplant, with a minority using peritoneal dialysis in the home (USRDS, 2014).⁵ In contrast to this, leading Mexican clinical researchers have demonstrated that Mexican public hospitals have historically relied on peritoneal dialysis as the mainstay therapy to treat patients with CKD (Treviño-Becerra, 2007). Since the 1980s, despite the lack of a national dialysis registry and accurate statistics, Mexico has been one of the countries with the highest rate of peritoneal dialysis utilisation in the world, although other forms of RRT are also available (Cueto-Manzano, 2003). According to a study published two decades ago, during the 1990s the utilisation rate was higher than 90% (Su-Hernandez, Abascal-Macias, Mendez-Bueno, Paniagua, & Amato, 1996), and although the rate has decreased in recent years, it has been estimated to be more than 60% (Méndez-Durán, Méndez-Bueno, Tapia-Yáñez, Montes, & Aguilar-Sánchez, 2010). In 2012 it was reported that in the State of Jalisco,⁶ where this study was conducted, there were

⁵ In 2013, 14% of the dialysis patients in the UK were undergoing peritoneal dialysis in the home; in the United States this was roughly 9% and in Argentina, a similar country to Mexico, only 5% used this modality (USRDS, 2014, p. 201-203).

⁶ Jalisco is a state in the west of Mexico. With 7.5 million people (2010), it is the fourth most populous state of Mexico. Guadalajara is the capital of the state and the second biggest city in the whole country.

about 10,000 CKD patients undergoing dialysis and more than 50% of them using CAPD in the home (USRDS, 2014).

To complicate things further, historically and politically rooted inequalities in access to healthcare in Mexico, where less than half of the population has access to medical services through social security schemes (Valencia Lomelí, Foust Rodriguez, & Tetreault Weber, 2012), have severely restricted access to these life extending therapies for more than half of the country's population – that is, the uninsured. Garcia-Garcia et al. (2007) have reported striking inequalities in access and outcomes of RRT between insured and uninsured populations, with the uninsured having much more restricted access to these therapies, particularly transplantation.

It is within this context of health inequalities in Mexico, in terms of access and outcomes of therapies, and of reliance on peritoneal dialysis as the mainstay treatment for CKD patients, that this study is situated. However, different to epidemiological or other biomedical research that seeks to define and describe the occurrence of a disease, this study draws on critical and interpretive social science perspectives to make sense of CKD and peritoneal dialysis in the context of the State of Jalisco, Mexico, where concerns connected to the increasing incidence of CKD have been reported. Instead of looking at the biological, organic, or clinic manifestation of CKD and its therapies in isolation, this study seeks to understand the social manifestation of this disease and how it is addressed and lived by those who suffer most from it – the uninsured poor of Jalisco.

CKD and CAPD as social problems

The social world of CKD and its therapies is not alien to social scientists. Sociologists, anthropologists, and researchers from other related disciplines such as nursing, psychology, and health services research, have explored many issues related to this condition and its treatments for decades, although the focus has mainly been on haemodialysis and renal transplantation (Fox & Swazey, 2002; Ikels, 2013; Kierans, 2010). This study is situated within anthropological and sociological traditions, particularly those that adopt an interpretive and ethnographic perspective centred on peoples' practices and actions (Biehl & Petryna, 2013; Wacquant, 2003). As will be discussed in the literature review, much has been written about transplantation and its subjective and societal meanings, but still relatively little is known about the ways in which peritoneal dialysis, a marginal modality of treatment in many respects, operates in practice.

In this study, I attempt to fill this gap in the anthropological and sociological scholarship on CKD and its therapies. I do it not only to report on the experiences and practices of people undergoing this particular treatment, but also as a way to understand contemporary Mexico. As will be shown in the course of the chapters, an investigation of CKD and peritoneal dialysis highlights the ills of the Mexican healthcare system, and particularly the biopolitical consequences of health reforms in the neoliberal era (Foucault, 1978).

I develop this investigation by adopting an ethnographic perspective, one that takes into account the social, political, economic, and cultural contexts of the lives of the people who suffer from CKD and undergo peritoneal dialysis, as well as all those actors and institutions that are brought together in the course of making this modality

of treatment work. I focus heavily on the patients and their families, their stories and their practices, the trials and tribulations they face in the course of their trajectories as renal patients. I also focus on the strategies patients and other actors have devised to enable uninsured patients to sustain their treatment at the margins of the State, despite the implementation of measures supposedly designed to protect the health of all of its citizens. My aim is, then, to provide a contextualised and nuanced description and analysis of how peritoneal dialysis is practised by uninsured patients and the challenges they face from diagnosis to treatment in the State of Jalisco, Mexico.

Outline of chapters

This thesis is organised into eight chapters, starting with a review of the literature and a discussion of the ethnographic approach adopted, followed by data chapters that trace the trajectories of patients from diagnosis, through accessing treatment, and on to life with peritoneal dialysis in the home. These chapters have been organised in this way in order to highlight the trials and tribulations poor uninsured patients faced at different moments of their experiences with CKD and peritoneal dialysis and their encounters with the Mexican healthcare system.

In Chapter 1, I chart a body of work that seeks to make sense of CKD and how it is treated worldwide and in Mexico in particular. This body of work, while centred on a shared concern for understanding this condition and its treatments, is not unified but reflects four separate approaches to the problem in question – namely, biomedical approaches, social policy approaches, qualitative health research approaches and sociological and anthropological approaches, particularly ethnographic studies. I critically work through the contributions of each in turn in order to show that CKD

and its treatments are not only a problem for medicine, but expand beyond the clinical domain. I argue that if we want to understand the experience of patients undergoing any type of RRT in Mexico, we need to take into account structural forces that shape their experiences of biological infirmity, and that an ethnographic perspective is suitable for that purpose.

Chapter 2 presents the methodological approach that underpins the research project. Methodologically, this thesis draws on the sociological and anthropological tradition that is often called interpretive social science (Rabinow & Sullivan, 1979), but it is also informed by ideas of political economy, structural violence and biopolitics (Farmer, 1996; Foucault, 1978; Gupta, 2012). Particularly, this thesis takes up ethnographic contributions from anthropology, sociology and science and technology studies in order to explore medical technologies in different cultural contexts (Biehl & Petryna, 2013; Lock & Nguyen, 2010). In this chapter I discuss and describe the ethnographic approach adopted, from fieldwork methods, the analytical treatment given to the data, and the ethical implications in undertaking the research. I will argue that, in order to overcome the partiality of the medical, social policy and qualitative health research perspectives, it is necessary to study CKD and peritoneal dialysis ethnographically, in its sites – the clinic, the home, the community – and take into account their social, cultural, political and cultural contexts.

Chapter 3 starts off by focusing on the socio-material conditions that shape the experiences of uninsured renal patients. In part one, I introduce the landscape of medical services available in the State of Jalisco, Mexico, in particular the hospitals located in the city of Guadalajara, that cater for the poor of Jalisco and neighbouring states. I argue that the hospitals for the uninsured are spaces where contemporary forms

of historical relationships between the ill poor and healthcare providers have taken shape and find expression. I introduce the notion of ‘supplicatory practices’ in order to focus on the interactions these relationships are grounded in and to highlight the hierarchies and inequalities they help cement, one of the main features of the public healthcare services in Mexico and patients’ experiences of seeking care through them. In part two of this chapter, I describe the practices, routes navigated and the work of families and patients to access diagnosis and treatment. This involves descriptions of the patients’ trajectories from diagnosis to the initiation of treatment in the hospital and how they navigated through the private and public health services. In this chapter, we start to see how the infrastructure and services available to the poor are not only insufficient, but that in some ways governmental institutions fail to detect such problems, affecting particularly those who these institutions are supposedly meant to protect.

Chapter 4 turns to the experiences of patients who applied to the CAPD programme of a public hospital for the uninsured, where those who participated in the study were treated. The admission process in this hospital consists of three stages: an introductory meeting; setting-up a dialysis room in the patient’s home; and, finally, a week-long training session in the hospital. I show that this process takes the form of a rite of passage (Turner, 1969; Van Gennep, 1960), in which the patient acquires a new identity, that of the *CAPD patient*, and the family’s home is transformed into a *para-clinical space*, with the aim of creating a nexus between body, therapy and clinic. I argue that the admission process to the CAPD programme aims to transform the sick person into a competent and productive patient, one who has embodied new skills and so is capable of taking on outsourced clinical work in their home by diligently maintaining the body-therapy-clinic nexus. I use the stories of two patients and their

families to show how socio-material conditions shape the experience of patients who go through the transformations required by the admission process and how supplicatory practices reappear as part of this, particularly where family members are involved.

Chapter 5 moves from the hospital to the home, in order to explore the situated practices and the socio-material conditions of living with CKD and doing CAPD in the home, and how the supplicatory practices patients are required to engage in transform through time. In part one, I explore how families and patients accommodated CAPD in their domestic contexts. I show that the process of therapy accommodation does not end with the setup of the dialysis room, but continues through the patient's trajectory and changes over time. I argue that home and therapy modify each other. There is a process of mutual transformation: the home receives the treatment and domesticates it (Appadurai, 1990), while the treatment transforms the home into a para-clinical space. It is during this process that the patient actually embodies the techniques of CAPD through constant and continuous practice, thus establishing the body-therapy-clinic nexus in practice. In the second part of this chapter the analysis focuses on the assignments patients and their families have to carry out on a regular basis, as part of their therapeutic regimen. This includes practising CAPD four times a day, every day, but also taking pills, keeping to a strict diet, observing fluid restrictions, and attending regular medical follow-ups. Here, I focus on the 'hidden transcripts' (Scott, 1990) that enable patients to maintain CAPD in their lives. The final part of this chapter explores the contextually iatrogenic character of CAPD by analysing the experiences of patients when dealing with potentially fatal complications of disease and treatment in the context of the Mexican healthcare system. Through this

exploration, I establish what happens when therapy is moved from hospital to home in the context of Mexico.

Chapter 6 follows patients and families in their search of support into community and other institutional contexts. This chapter examines the networks for support and resources poor families draw on in order to support family members with CKD, doing CAPD in the home, in the absence of comprehensive public healthcare coverage. This chapter continues with the analysis of the socio-material conditions of CKD and its therapies in its multiple sites. In particular, I analyse how healthcare policies and the local history of a hospital for the uninsured have given rise to a biosocial community (Gibbon & Novas, 2007) around CKD and to an informal economy of renal replacement therapies (Sharp, 1999) at the margins of official and regulated healthcare services. The biosocial community is comprised of several agents – patients, family carers, health professionals, hospitals, charities and even pharmaceutical companies – but lacks formal organisation. The informal economy rests on the exchange and circulation of medicines, information, support, and influence within a wider biosocial community. I also show how supplicatory practices manifest in new spaces, with patients having to plead for different types of support from the charitable organisations that have emerged in response to the lack of appropriate support for uninsured patients. I argue that the constitutive practices of the biosocial community and the informal economy are, at the same time, consequences of, and responses to, the fragmentation of the healthcare system and the welfare policies of the Mexican government. In a very direct sense, they stand as a critique of the failures of both.

Chapter 7 draws out the insights from previous chapters to discuss the socio-material conditions within which CKD and peritoneal dialysis are practised, domestically and

institutionally, within the context of Mexico. I will particularly discuss how the convergence of biomedicine, politics and community shapes the local experiences and practices of CKD and CAPD in Mexico. Finally, in Chapter 8, I conclude that, although considered a global health concern, to fully understand the social and political implications of CKD and its therapies we need to adopt an ethnographic perspective that traces the practices of patients and families through the different sites of care – the hospital, the home and the community. I will argue that, for Mexican uninsured patients, CAPD is a therapy situated at the margins of social welfare, which makes them directly responsible for its success and failures, often incurring substantial long-term financial and social costs for those who desperately need this therapy. Although collective responses have emerged through the local biosocial community and its informal economy, such support and exchange practices are just another consequence of the problematic healthcare context within which CKD and CAPD are embedded.

Chapter 1

Problematizing chronic kidney disease and its treatments in Mexico: a literature review

Introduction

In this chapter, I examine a body of work on CKD and how it is treated, with a focus on Mexico in particular. Based upon an extensive literature review, in what follows I examine the main research fields which have contributed to understandings of CKD, its treatments and its implications. These contributions rest on four different approaches to the problem of CKD – namely, biomedical approaches, social policy approaches, qualitative health research approaches and ethnographic approaches (which draw broadly on anthropological and sociological research on issues of transplant medicine and its social and cultural contexts). I will critically examine the contributions of each in turn.

In the first part, I will review biomedical contributions and explore their relevance to understandings of CKD and RRT in Mexico. As biomedical research dominates the literature on CKD and RRT, it is important to clarify how they are approached from this perspective. I will pay particular attention to how epidemiological research carried out in Mexico has defined CKD as a public health problem for the country. In broad terms, this approach to research focuses on organic dysfunction and the measurable outcomes of therapies. Despite this narrow focus, however, Mexican epidemiologists and clinicians help us to see that CKD is a problem that extends beyond the medical realm. Once the problem of who gets CKD was examined, medical researchers quickly

realised that the disease tracks social and economic inequalities. It also became clear that patients are situated in a healthcare system that reflects those same social and economic divisions as much as the needs of those it serves.

Building on this analysis, the second part of this chapter introduces a social policy-oriented literature in order to better understand those aspects of the problem of CKD and RRT that the medical literature helps highlight: namely, how the existence of different healthcare institutions results in unequal access to therapies across Mexico. Here I will draw on the work of those Mexican sociologists and public health scholars who have conducted studies of the structure of the Mexican healthcare system. This structurally-focused literature helps us to see that, in the context of Mexico, not all patients are the same and adds greater detail to descriptions of the problem of CKD by highlighting the problematic and fragmented character of the Mexican healthcare system.

However, structural political and economic analysis has limitations too. It goes beyond the biomedical research but it cannot account for individuals' experiences of CKD. Therefore, we need to draw on other literatures that help us in this respect. In part three, I will therefore turn to qualitative health research. Here I focus on nursing and psychology as disciplines interested in focusing upon the individual's experience, perspective and attitudes to CKD and RRT.

Once again, however, qualitative health approaches have limitations. Experience is important but by focusing too much on the individual, and thematising their experiences and perspectives, this literature highlights the lives of patients but ignores their position within wider social and cultural structures—the reverse of the problem found in the social policy literature where systemic issues had priority. Neither

approach reflects C. Wright Mills' suggestion that structural and experiential issues must be dealt with together within the social sciences (Mills, 2000, p. 6).

In the fourth and final part, I therefore turn to a growing body of ethnographic research from the fields of anthropology, sociology and science and technology studies that seek to link the biological, individual, political economic and contextual dimensions of disease and therapy. These studies recognise that disease processes and therapeutic interventions, including the way in which conditions such as CKD are problematised within both biomedical and social science research, do not exist in a vacuum, but are shaped in particular cultural, political and economic contexts (Latour, 1987; Latour & Woolgar, 1986; Marcus, 1995). I will argue that an ethnographic perspective helps examine the problem of CKD and RRT beyond the medical domain and acknowledges the interconnections between the social, cultural, political and biological dimensions of disease, illness and treatment in Mexico. The first three parts of the chapter pave the way for this argument, providing an introduction to the scale of the problem of CKD in Mexico, the unequal way that the problem is distributed across the population, the structural bases of those inequalities and the implications for the lives of, in particular, poor Mexicans on RRT.

1.1 Biomedical contributions to understandings of CKD and RRT

As I have shown in the introduction of the thesis, CKD is currently considered to be a global health problem, affecting health systems worldwide (Jha et al., 2013). In line with this trend, the incidence and prevalence of CKD in Mexico has steadily increased in the recent decades, becoming one of the leading causes of mortality (López Cervantes et al., 2010). In this country, all three modalities of RRT – haemodialysis,

peritoneal dialysis, and transplantation – have been available for a long time. Although Mexico has a long history of RRT utilisation, little has been written about it.⁷ What we do know from the little historical information available is that the first successful RRT programme in Mexico operated within a peritoneal dialysis unit established in 1978 by Alejandro Treviño-Becerra at a hospital of Mexico's Institute for Social Security (IMSS)⁸ in Mexico City (Treviño-Becerra, 1981, 2007). According to Treviño-Becerra himself (2003, 2007), the original programme was widely replicated, spreading across the country, though the new programmes were often run by physicians rather than nephrologists, leading to a high incidence of complications among patients – mainly peritonitis⁹ – and poor outcomes. Since then, peritoneal dialysis programmes have become the central feature of responses to CKD, making Mexico a country that has adopted peritoneal dialysis as its treatment modality of choice, in contrast to the world trend towards haemodialysis and transplantation (Treviño-Becerra, 2007). Haemodialysis programmes were slowly established a decade later, principally in the country's largest cities, but mainly as backup services when peritoneal dialysis failed. Transplants were occasional and sporadic in most centres until the 1990s, when staff trained abroad returned to the country and new

⁷ The first attempts at in-hospital peritoneal dialysis and haemodialysis in Mexico were carried out in the 1960s, and the first kidney transplant was performed in 1964, from a living donor, just a decade after the first ever successful transplant by a medical team in Boston. Large-scale, sustainable RRT programmes were, however, only rolled out in Mexico after 1980 (Martínez Ramírez, Cortés Sanabria, & García-García, 2010; Monteon-Ramos, 2010; Treviño-Becerra, 2003, 2007).

⁸ IMSS is the largest social security institution of Mexico and one of the leading centres of biomedical research. In the second part of this chapter I will discuss the characteristics of the Mexican healthcare system, its institutions and the publics they serve.

⁹ In the context of peritoneal dialysis, peritonitis is the inflammation of the peritoneum due to an infection contracted through the catheter or its exit-site of the catheter, located in the abdomen of the patient. Most patients will get peritonitis at least once while undergoing peritoneal dialysis. The infection can be contracted either at home or at the hospital (Fried & Piraino, 2009).

generation immunosuppressant drugs became more widely and cheaply available (Monteon-Ramos, 2010; Monteon-Ramos et al., 2003).

Growing concerns about the incidence and prevalence of CKD accompanied the expansion of clinical services and the development of RRT in Mexico. As I will show, clinicians sought to convince the Ministry of Health, the national authority in health issues, of the importance of CKD as a national public health problem, arguing that greater effort had to be made to tackle growing incidence. The need to explain the scale, scope and costs of the problem provided the impetus for epidemiologists to join forces with nephrologists and clinicians by undertaking research which would guide the debate and inform health policy. The literature in question thus tells us a story, providing insights into how understandings of this problem were gradually broadened through a series of attempts to influence policy through the publication of data – often incomplete and patchy – on CKD and RRT use over a number of years (Haraway, 1991; Latour, 1987).

Notwithstanding the small number of nephrologists and limited resources for (bio)scientific, clinical and epidemiological research in Mexico, some practitioners have engaged in research into CKD and RRT over time – although the volume of research is small relative to current estimates of the scale of the problem (Obrador, Cueto-Manzano, & Garcia-Garcia, 2001). These researchers form part of a small group, one which regularly publishes on CKD and RRT and which also participates in national and international associations – such as the International Society of Nephrology, the Latin American Society of Nephrology and Hypertension and the International Federation of Kidney Foundations, among others. As well as a focus on the condition itself, this group has driven efforts to provide more accurate and reliable

estimates of the epidemiological parameters of CKD in Mexico, partly to assist them in their efforts to treat the disease but also to publicise the problem, informing and influencing national debate as well as influential figures in both the public and private sectors as a means of unlocking much needed resources.

The first significant study of this kind dates back to the early 1990s and involved a team of researchers from IMSS who reported on the first attempt to estimate the prevalence of CKD and the outcomes of peritoneal dialysis programmes at the hospitals of the institution (Su-Hernandez et al., 1996). Su-Hernandez et al. started the study in 1992, with the collaboration of Baxter, the multinational pharmaceutical company which has held the monopoly on provision of dialysis supplies to public hospitals since the introduction of the therapy in Mexico. At the time, the corporation had information on those accessing peritoneal dialysis across 120 public hospitals. Based on this data, the study found that 7,785 patients were undergoing this type of RRT. Working on the assumption that prevalence of CKD could be inferred from the number of patients on peritoneal dialysis, with 91% undergoing this therapy for CKD, the authors estimated a prevalence of 200 patients per million of population. However, the report did not include patients who were not receiving RRT at all, and they took pains to note that a more accurate figure of CKD prevalence, had more complete data been available, would have been higher.

Although Su-Hernandez et al. reported high morbidity and mortality rates among peritoneal dialysis patients – peritonitis being the major complication and cardiovascular disease the main cause of death – they argued overall CKD rates were similar to those reported in the United States.¹⁰ The authors concluded that the high

¹⁰ The risk of peritonitis, catheter exit-site infections, blockage of the catheter, and deterioration of the peritoneum are complications that have accompanied the evolution of peritoneal dialysis. For decades,

use of in-hospital intermittent peritoneal dialysis accessed via public hospitals was due to ‘nonmedical factors’ rather than greater incidence levels as it would have been in the United States. When explaining the numbers on this specific treatment, they pointed to patients’ socioeconomic characteristics, ‘lack of education’ and their living environment as making CAPD at home unsuitable for them. However, it is more likely that the main factors driving the extensive use of peritoneal dialysis in public hospitals were the lack of haemodialysis facilities and the scarce human resources deployed to manage this technology, as well as, more particularly, the budgetary restrictions and the expensive supply contract between the public institutions and Baxter (Cueto-Manzano, 2003; Cueto-Manzano & Rojas-Campos, 2007).

The next attempt to estimate the incidence and prevalence of CKD in the Mexican population was carried out in 2003 and published two years later (Amato et al., 2005). It was, again, conducted by researchers based at IMSS, the public hospital system, but this time they did not use the registries of pharmaceutical companies or work through the network of public hospitals. Instead, Amato et al. conducted a survey connected to a screening programme with 3,564 participants in the city of Morelia, in the west of Mexico. The survey was conducted by contacting patients who were making use of the primary healthcare centres that form part of IMSS’s system. Measurements of height, weight, and blood pressure were taken alongside blood and urine samples. The results of this pioneering study, one of the largest to be conducted in Mexico, showed a prevalence of 1,143 persons with some level of kidney dysfunction per million of

medical investigators have struggled to design a safer technique and prevent peritonitis. This was partially achieved with CAPD at the end of the 1970s, and then a decade later with the introduction of the Y-system (a connection device) and new disinfectants. The introduction of the Y-connection system in Mexico, at the end of the 1990s, reduced considerably the episodes of peritonitis both in public and private hospitals (Garcia-Garcia, Tachiquín-Bautista, et al., 2007; Monteon-Ramos et al., 1998).

population, a figure again very close to that of the United States. Diabetes and hypertension, as well as a range of social, economic and behavioural characteristics, were highlighted as the main risk factors associated with CKD. The authors claimed that poverty, low educational level and marginality were key problems and linked these to inadequate diet and patterns of eating leading to obesity. They also argued, ‘behaviouralising’ the problem still further (Mair, 2011), that this population was more reluctant to use high-tech medicine, less compliant and delegated decisions about treatment to others.

What we learn from these studies is that, as predicted, the prevalence of particular populations of renal patients known to be accessing RRT has grown constantly over the years (López Cervantes et al., 2010), with the most recent study conducted at the public hospital system, although it did not include all its hospitals, reported more than 31,000 patients using dialysis, 65% of them on peritoneal dialysis (Méndez-Durán et al., 2010). They thus shed some light on the spread of CKD and uptake of RRT in Mexico. However, the picture conveyed remains partial, only accounting for the population covered by IMSS, less than half of the total population of the country. Moving beyond that restricted population, and thus gaining a better sense of the distribution of CKD across Mexico, has proven difficult.

Amato et al. (2005) are one group of researchers who have attempted to generate a more complete population count. They proceeded by assuming that insured and uninsured populations might present a similar incidence of CKD, but that prevalence and access to RRT might be different. Building on this initial work, the differences between populations were then explored by Garcia-Garcia et al., who conducted studies in the State of Jalisco (Garcia-Garcia, Briseno-Renteria, et al., 2007; Garcia-

Garcia, Monteon-Ramos, et al., 2005; Garcia-Garcia, Renoirte-Lopez, & Marquez-Magana, 2010). Their study aimed to estimate the regional epidemiological parameters of CKD and RRT at the beginning of the 2000s (Garcia-Garcia, Monteon-Ramos, et al., 2005), drawing on data from the Jalisco State Dialysis and Transplant Registry, the only one of its kind in the country. The authors showed that there were serious disparities between insured and uninsured populations regarding access to renal replacement therapies in Jalisco. Social inequity, they concluded, was a major medical problem. For example, the access rate of new patients with CKD, admitted in public hospitals and put on RRT, was significantly higher in the insured population than the uninsured (327 per million of population [pmp] vs 99 pmp, respectively), and the prevalence rate was even higher (939 pmp vs 166 pmp, respectively). Notwithstanding similar dialysis reliance rates in both population (85% on CAPD and 15% on haemodialysis), the transplant rate was almost ten-times higher in the insured population than the uninsured (72 pmp vs 7.5 pmp, respectively). In a subsequent study they found that mortality rates were three-times higher in the uninsured population of Jalisco than the uninsured Hispanic population in the United States (Garcia-Garcia, Briseno-Renteria, et al., 2007). Recently, the same authors have shown that the disparities among Jalisco's renal patients remain a significant problem eight years after their first report (Garcia-Garcia et al., 2010).

Although these studies draw only on data for Jalisco, they show important differences between insured and uninsured populations with regard to access to and outcomes of RRT. Research of this kind represents a shift from concerns with disease prevalence alone, something which invites decontextualised analyses, pointing instead to a major structural problem that affects millions of people in Mexico, i.e., lack of access to healthcare among those too poor or economically insecure to have access to social

insurance. These studies thus highlight the importance of economic inequality when it comes to understanding unequal access to healthcare and unequal health outcomes, an issue seldom discussed directly in the medical literature on Mexico despite its significance.

The most recent epidemiological study relating to CKD in Mexico shares the same core focus as the rest of the medical literature from the 90s – an interest in estimating the prevalence and incidence of CKD and highlighting inequalities in access to renal care. Drawing on the studies of Amato et al. (2005), Garcia-Garcia et al. (2005), and socio-demographic and mortality national statistics, Franco-Marina et al. (2011) carried out an indirect estimation of current and future inequalities in incidence and prevalence of CKD for the whole country. In line with the findings of previous studies, Franco-Marina et al. estimate a prevalence of between 1,200 and 1,300 per million people for the year 2005, showing a future and progressive worsening among the poorer regions of the country. The high prevalence rates of diabetes and hypertension in Mexico will contribute to the rise of CKD prevalence, since those two conditions are the major causes of renal failure in the country and worldwide. According to the authors, the health services will face serious challenges in providing equitable access to RRT for the increasing number of renal patients, particularly the poor and the uninsured given available resources.¹¹

¹¹ Somewhat surprisingly, these forthright conclusions are diluted by analytical ‘flip-flopping’. Despite the clear importance placed on structural issues, the study’s authors suggest that the best way of tackling the problem of CKD would be a series of preventive measures, including early detection, patient education and modification of unhealthy lifestyles among risk populations – the diabetic and hypertensive patients. While acknowledging the presence of systemic failure within the health system, their proposals place the responsibility on individuals for dealing with them rather than advocating structural change.

Taken together, these studies show a growing concern for the increasing incidence of CKD and the expensive treatments related to it, despite their varying purposes, methodologies and outcomes – something that can be seen particularly clearly in the development of medical studies carried out across the 2000s and the conclusions drawn from them (Treviño-Becerra, 2002, 2008). The accumulated evidence of two decades of research has been used to support diverse interventions to tackle CKD and provide RRT to those in need. The interventions these researchers have proposed over time include a national RRT registry, the provision of RRT to the uninsured population, the promotion of organ donation and transplantation, the training of more nephrologists and renal nurses, and above all the prevention of CKD through early detection and patient education (Gutierrez-Padilla et al., 2010; Obrador, Garcia-Garcia, & Hernández-Llamas, 2002; Tamayo-Orozco, 2008; Treviño-Becerra, 2008).

However, the efforts of the nephrology community have had little impact as such on national health policy. While the Ministry of Health has recognised the issues at stake, nothing concrete has been done. While there have been a variety of locally driven developments, central government has been much slower to act. The Ministry of Health has not adopted a national health policy toward CKD, although it has recognised the burden this condition represents for the health system (Tamayo-Orozco, 2008). Most RRT programmes rely on the initiative of individual hospitals, usually thanks to the efforts of clinicians and often funded partially by national or international charities and philanthropists. Single hospitals discretely apply their own prevention and screening programmes, but their results fall short of an effective response to a complex problem because these measures are always small scale and frequently short-lived.

Despite the availability of haemodialysis and transplantation in public and private hospitals, their utilisation remains low compared to peritoneal dialysis and for diverse reasons – insufficient infrastructure, lack of trained staff, budgetary restrictions, specialist preferences and prohibitive contracts with pharmaceutical companies, among others (Cueto-Manzano & Rojas-Campos, 2007). It is clear that the provision of renal replacement therapies in Mexico is deeply affected by the organisation and administration of the health system and the mixed economy of welfare, which cuts across public, private and voluntary sectors in quite particular ways and with important consequences for different constituencies of patients and their families. Put slightly differently, the nature of the medical problem revealed by biomedical, clinical and epidemiological research cannot be made sense of by approaching it from those perspectives. In order to make sense of CKD and its unequal distribution and consequences, we have to look at how the health services are organised, financed and delivered in Mexico. That is the implicit conclusion of the studies reviewed above.

The epidemiological and clinical literature I have introduced here cannot, however, be dismissed. It provides us with a powerful account of CKD and RRT in the context of Mexico. It is ultimately, however, limited. Situated within a specific paradigm and way of seeing medical problems, this body of literature reflects the biomedically-informed perspectives and assumptions of those who carried out the studies. The preoccupation with estimating parameters of incidence, prevalence and outcomes for populations, as well as for the whole country and within institutions, tells us that CKD is regarded by the medical community as an important problem, one with several dimensions. Biomedical researchers understand that the problem of CKD and RRT extends beyond the biomedical domain. However, the methods they employ to identify the scale of the problem also prevent them from examining its structural basis. Given

that, in the next part of the chapter I will review social policy research conducted in Mexico that has addressed the health system from a structural point of view in order to explore CKD and RRT in wider perspective. The focus will be on the organisation, administration and delivery of health services and how they shape the provision and outcomes of therapies.

1.2 Social policy contributions to understanding the Mexican fragmented health system

There is no explicit agreement in the research literature about the formal structure and organisation of the Mexican health system. One perspective represented by Gómez-Dantes et al. (2011), assumes the existence of an official Mexican health system and claims it is comprised of institutions that form a public and a private sector, all of them with their own funding streams, facilities and human resources, with the Ministry of Health operating as the steward of the system as a whole. Valencia Lomelí et. al. (2012) challenge this idea of a formal and integrated health system. Instead, they argue, health services are configured around a host of independent systems with little or no integration. For Valencia Lomelí et al, the Ministry of Health might have a formal stewardship role, but this role is limited to setting broad clinical guidelines, with no interference in service delivery—in practice, every institution supplies their own scheme of services. In spite of this, they recognise the existence of the public-private divide in the health sector as an important axis in the system. It is worthwhile, therefore, following this analysis of the public-private divide within the system and showing its implications for problematising healthcare delivery, in particular the provision of care for CKD. In what follows, I will draw on these authors to describe the different sectors, institutions and the publics they serve, while highlighting the

fragmentation and the consequences for those publics. I will begin with the public sector before moving on to the private.

1.2.1 The Public Sector

I start with the public sector because it is the most important provider of health services in the country.¹² However, it is a far from unified system. What I want to focus on is the fragmentation that has characterised Mexican health services following ‘State modernisation’ in the mid-20th Century and subsequent waves of ‘neoliberal’ reform (Barba Solano, 2007; Mesa-Lago, 2009; Ordóñez-Barba, 2016). As things currently stand, the public sector is comprised of several institutions that can be classified into two tiers of provision: a) employment-based social security, relatively generous, aimed at salaried workers in the formal economy and civil servants, and b) the social assistance ‘safety net’ services provided by the Ministry of Health, aimed at those registered to the System of Social Protection in Health (SSPH) and all those who lack any other kind of insurance, which is under-resourced.¹³

Despite the existence of social security welfare institutions related to the labour market from the 1940s on, the Mexican State only recognised the right to healthcare for all in 1983 when it was added to the Constitution (Valencia Lomelí, 2012). Before then, the right to healthcare was an entitlement only for the salaried workers of private and public corporations who enjoyed access to social security. From 1943 to 1976, five social security institutions were created to meet that purpose: the IMSS (created in

¹² The public sector caters for the majority of the population of the country. Although there are no accurate figures, it is believed that 60%-80% of the population rely primarily on public health services. I will discuss this further in this chapter.

¹³ The social security institutions and the Ministry of Health are products of the post-revolutionary period in Mexico and the modernisation projects which followed from it in the 1940s.

1943), which serves the workers of private corporations, and is, on paper, the largest healthcare provider in the country; the Institute of Security and Social Services for the State Servants (ISSSTE, created in 1957); the Health Services for Mexican Oil's workers (PEMEX, created in 1960); and the Health Services for the Armed Forces (SEDENA, established in 1970). Each of these social security systems is funded by contributions from the employer,¹⁴ employees, and the government, and provides comprehensive healthcare services free at the point of use to all those who have recognised entitlements – entitlements which may be extended from these workers to some of their family dependants.¹⁵ Coverage provided by these social security institutions include all currently available therapies in the country recognised by the Ministry of Health, from preventive medicine and primary care treatment to tertiary level hospital and the highly complex specialist care associated with it.

Besides its stewardship role, the Ministry of Health also provides health services itself. Formally constituted in 1943, it is the country's second largest healthcare provider and offers services through a network of hospitals and clinics, unevenly distributed throughout the country, to every person who presents to them, independently of social, economic and insurance status.¹⁶ According to Valencia Lomelí et al. (2012), these

¹⁴ In the case of ISSSTE, PEMEX and SEDENA, the government is also the employer.

¹⁵ All of these services allow the right-holders to insure: a) their legal spouses; b) their children under the age of 15, or under the age of 18 if enrolled at school; and c) their parents, if they are the right-holder's dependants and live in the same house (Valencia Lomelí et al., 2012). This means that a young person older than 18 years old, not attending school, will not be insured through his or her parents. Neither can an insured single person, living with his or her parents, insure his or her siblings even when these are dependants. This means that social security services are designed on a strict generational understanding of family, and do not reflect the kin relationships and extended family arrangements typical of Mexican households. That families are organised by relations of descent life is assumed by both supporters and critics of the health system.

¹⁶ Formally and in practice, the services of the Ministry of Health cannot be denied to insured patients, either through social security or private insurance companies. Moreover, insured patients often present as clients of the services of the Ministry of Health for several reasons.

services do not constitute a national system in itself, but a loosely integrated patchwork of medical facilities at state level and health institutes at a national level. Budgets and services are restricted in the majority of Ministry of Health hospitals, and, more often than not, the patients pay a share of the costs of the services and medicines received, typically out-of-pocket. Hospital charges are negotiated, through the intermediary of the social worker,¹⁷ and some patients pay nothing. The government is not the only source of funding, and hospitals are free to reach their own agreements with whatever partners they choose, entering into collaborations with philanthropic institutions, international aid agencies, pharmaceutical companies, sister hospitals, grass-roots charities and so on.¹⁸ Tertiary hospitals in the network will not necessarily provide access to the full range of specialist medical services. Only a handful have nephrology services and fewer still provide renal replacement therapies.¹⁹

Since its creation, the Ministry of Health has delivered health services primarily to those who lack other social security entitlements. This changed in 2003, when a major health reform was initiated in Mexico, the major outcome of which was the creation of the SSPH (Barba Solano, 2010; Frenk, González-Pier, Gómez-Dantes, Lezana, & Knaul, 2006; Valencia Lomelí, 2012). The architects of the reform claimed that the SSPH was the only option for delivering health services for the uninsured and meeting the 1983 constitutional mandate (see Frenk et al., 2006). However, in contrast to other health institutions in Mexico, the SSPH does not provide health services but financial

¹⁷ In Mexican public hospitals, the social worker is the professional who, among other administrative responsibilities, sets the cost of treatment and hospitalisation in negotiations with patients.

¹⁸ This is the case for Hospital Civil de Guadalajara, where most of those who took part in my research received care at some point.

¹⁹ This is the case for the three tertiary hospitals for the uninsured in Guadalajara. While they all have nephrology services and offer peritoneal dialysis and haemodialysis services, only one of them offers transplantation services.

protection in case of disease, accidents or other health-related problems to its beneficiaries through its main programme: Seguro Popular (Frenk et al., 2006).²⁰ According to Frenk et al. (2006), the SSPH ‘buy’ health services for registered beneficiaries of Seguro Popular from Ministry of Health hospitals and medicines from private providers. As a result of this reform, the Ministry of Health has become the main health services provider for the Seguro Popular’s beneficiaries, although it hasn’t stopped providing services to the uninsured.

Since its creation in 2003, the SSPH has issued what is known as the ‘Universal Catalogue of Health Services’ – the definitive list of diseases, interventions and medicines covered by Seguro Popular. This catalogue is updated and expanded every year. Generally speaking, Seguro Popular covers first and second level interventions and a handful of specialist services for specific chronic conditions – namely, care for HIV-AIDS, breast cancer, cervical cancer and most paediatric cancers. When a required service is not included in the catalogue of financial coverage – like imaging, laboratory tests, therapeutic interventions or pharmaceutical services – the patients must find a way to pay for it themselves (Valencia Lomelí et al., 2012). This is the case for several chronic conditions, but is particularly problematic in the case of CKD, where unrecoverable patient costs are high. The situation is, however, a complex one, and it is important not to treat the divisions policymakers claim structure the system too literally. As I will show in subsequent chapters, many CKD patients are

²⁰ Seguro Popular is the main scheme or programme of the SSPH. Seguro Popular, in turn, has two main sub-programmes: Health Insurance for the New Generation (recently renamed Health Insurance 21st Century, and aimed at children under 5 years old) and the Protection Fund against Catastrophic Health Expenditures. In fact, SSPH’s Seguro Popular is a ‘voluntary’ or ‘opt-in’ insurance system, meaning that all prospect beneficiaries must register and then re-register for every year in order to claim the benefits. Failure to do so, may cause delays in medical services and unexpected expenses for the patients.

beneficiaries of Seguro Popular and, by adopting certain strategies, making alliances with health professionals and taking advantage of loopholes in the administrative system, they find ways of claiming back costs from it.

1.2.2 The Private Sector

According to Gómez-Dantes et al. (2011), the Mexican health system is complemented by the private sector which works very closely with public institutions, connecting into them in several significant ways.²¹ It is, therefore, important to consider the part private enterprise plays in the provision of care for CKD patients. As Valencia Lomelí et al. (2012) have argued, private involvement is even less unified than the public system: it lacks formal organisation and is comprised of several private medical care and insurance institutions that – in theory – provide their services to all those who can afford them whether rich or poor. The private sector provides a wide range of services. The major enterprises involved range from national and transnational insurance and financial companies (such as MetLife, AXA and Grupo Nacional Provincial among others),²² tertiary hospital networks (such as Grupo Angeles or Centro Medico Puerta de Hierro), obstetrics clinics, small speciality clinics (including clinics of chemotherapy and haemodialysis, for example), private *consultorios* (private medical practice offices, both GPs and specialists) for the wealthy and the poor, dispensaries,

²¹ Public providers, particularly IMSS, outsource many services to private providers, usually when services are unavailable or are not typically provided. Haemodialysis is one of the best examples. More importantly, public-private relationships are also sustained through the work of health professionals the majority of whom hold positions in both types of institutions simultaneously.

²² Private insurance schemes can be comprehensive or include only a limited set of services, depending on the contract between the individual and the insurance company.

clinical laboratories, medical imaging establishments, pharmacy retailers down to street vendors dealing in out-of-date medicines and samples.

1.2.3 Distribution of populations between institutions and its consequences

The share and character of the different populations served by each sector and institution is a matter of controversy in Mexico. In 2012 Knaul et al. (2012; see also 2015) claimed Mexico had achieved universal coverage in healthcare in a celebratory special article in *The Lancet*. They claimed that the SSPH had reached 52 million registered individuals to Seguro Popular by April 2012, therefore achieving universal coverage in health. However, as Valencia Lomeli et al. (2012) noted, such a claim is difficult to sustain because of the unreliability of institutional registries. These authors showed major discrepancies between the institutional records, the 2010 Census, and the 2010 National Survey of Income and Expenses of Households, all of them official sources (see Table 1). The 2012 National Survey of Health and Nutrition reported similar discrepancies between records and results from the survey (Gutiérrez et al., 2012). The authors of this survey, based at the same institution where the SSPH and Seguro Popular were created, attributed these discrepancies to cultural factors, suggesting people attached little importance to their insurance status (Gutiérrez et al., 2012). Gutierrez et al. had expected the results of the survey to match institutional records. However, as employment mobility is high in Mexico, people can enter and drop out of the formal labour market at any point in time, meaning that they switch unpredictably between insured and uninsured status throughout their lives. Labour market mobility undercuts the accuracy of institutional records, making claims based upon them unreliable. Yet, this particular problem, the nature of the mobility of the labour force across formal and informal sectors of the economy, is little commented

upon by Mexican scholars, either critics or supporters. It acquires particular importance when it comes to CKD and RRT, because that mobility, and the shifts between systems that come with it, is central, as I will show in later chapters, to the difficult paths patients and their families chart along the road to securing medical care. Even working with conservative estimates, that 20% of the population of Mexico (Table 1) has no medical coverage is a major problem, and one exacerbated in the case of CKD.

Table 1 Percentage of the population covered by institution according to different sources

Source	Institutions 2010	ENIGH ^a 2010	Census 2010	ENSANUT ^b 2012
IMSS	46.5%	28.8%	32.8%	32.19%
ISSSTE	10.7%	6.9%	6.7%	6.0%
PEMEX, SEDENA	1.3%	2.0%	1.0%	1.74%
Total of Social Security	58.5%	37.7%	40.5%	39.93%
SSPH/Seguro Popular	38.7%	30.5%	24.3%	38.53%
Insured	97.2%	68.2%	64.8%	78.46%
Uninsured	2.8%	31.8%	35.2%	21.39%

Source: Gutierrez et al. (2012), INEGI (2011) Valencia Lomelí et al. (2012). Notes: a. National Survey of Income and Expenses in Households. b. National Survey of Health and Nutrition.

Although it is important to acknowledge the accomplishments of the SSPH in providing financial protection against health related problems to under-protected sections of the population, whether that is a smaller or larger percentage, the very idea of ‘universal coverage’, as Valencia Lomelí et al. (2012) have argued, is problematic under these conditions. Moreover, even if universal coverage had been achieved in Mexico, that would not mean that all Mexicans enjoy the same entitlements and access to equivalent medical services. On this point, Barba Solano and Valencia Lomelí note that the actual arrangement of welfare institutions, and particularly healthcare institutions, produces a hierarchy of citizenship rights (Barba Solano, 2012; Valencia

Lomelí, 2012). According to Barba Solano (2012), the creation of the SSPH and Seguro Popular has added another tier to the hierarchical structure of citizenship in Mexico and further complicated the already fragmented system of healthcare in the country. As Valencia Lomelí et al. (2012) have shown, while social security provides comprehensive healthcare services to salaried workers, Seguro Popular only covers a limited set of conditions for its beneficiaries. It is important, therefore, to bear in mind that the entitlements individuals possess vary according to their socio-economic situation, geographical location and affiliation to particular institutions. Variability will not necessarily be a problem for someone affiliated to social security via his or her formal job, but it is a problem for the beneficiaries of Seguro Popular.

Exactly how this differentially affects those enrolled via Seguro Popular is worth reflecting on because it bears directly on CKD and RRT. For example, a beneficiary of the Seguro Popular can claim financial protection for diabetes treatment, like medicines and consultation to the physician or endocrinologist, because it is included in the catalogue of conditions SSPH covers. Nonetheless, while diabetes may damage the kidney and cause CKD, since this condition is *not* included in SSPH's catalogue, the same patient cannot claim for coverage of CKD-related medicines and therapies. This means that all Seguro Popular-insured patients must rely on services which charge them with a share of the costs for the services received and so incur out-of-pocket expenses all along their trajectories as CKD sufferers.

In spite of recent reforms to the hybrid Mexican public-private healthcare system, old problems persist and new ones have emerged. As has been pointed out by Asa Cristina Laurell, several basic structural problems continue to undermine equitable access to health services: high segmentation; low public health expenditure; insufficient and

deteriorated infrastructure and lack of human resources; the unequal distribution of problems and resources geographically and regionally; and the unsatisfactory regulation of the public and private sectors (Laurell, 2007). The creation of the SSPH and Seguro Popular further complicated the landscape and produced new fragmentations, as described by Barba Solano (2012). It is in this highly complicated environment of fragmented services, unequal access and under-resourced institutions that the problem of CKD takes on its shape. That is, the fragmentation of the health system not only shapes the unequal provision of healthcare services in general, but also shapes the disparities in access to renal replacement therapies between the insured and uninsured in particular. As was acknowledged by some epidemiologists (Franco-Marina et al., 2011; Garcia-Garcia, Briseno-Renteria, et al., 2007; Garcia-Garcia et al., 2010), this fragmentation affects access to healthcare services in the country, and especially to renal care. Consequently, as Cueto-Manzano and Rojas-Campos (2007) have pointed out, excluding private healthcare services, treatment of CKD in Mexico is determined largely by the limitations of the country's major institutions. As they put it:

The Social Security system is an equal opportunity system for patients but, in practice, there may be some restrictions and limitations as funding is subject to annual budgetary considerations. The renal replacement treatment provided by the Ministry of Health has the severest limitations and is very restricted due to economic constraints (Cueto-Manzano & Rojas-Campos, 2007, p. 143).

Authors like Barba Solano, Valencia Lomelí, Laurell and others thus direct attention to social structure when dealing with healthcare issues in Mexico. They show that the malfunction of the Mexican health system is rooted historically, socially and politically, and that recent attempts to improve it have failed to address fragmentation

and inequity in access to services – problems that reflect the socio-economic inequalities which structure Mexican society more broadly. In doing so, this literature helps us to situate the problem of CKD in the political economy of welfare in Mexico. This is an important advance on the biomedical literature. Yet, this body of research is also limited because it fails to account for local context and the experience of specific constituencies of people as they try to secure care. A focus on structure is not particularly useful when it comes to understanding how disparities in the provision of renal replacement therapies affect the individual, the family or the community. An understanding of the situation of patients is also required and structural approaches do not deliver that.

By overlooking individuals, the structural, political economic perspective can, at times, be overly deterministic. It provides insights about the structure of the health system and its problems, but we do not get an account of the lives of those who rely upon these institutions. To overcome these limitations, it is important to establish some understanding of individual experience. In the next part of this chapter I will therefore review contributions from scholarship that attempts to shed light on the experience and perspectives of patients living with CKD. Since no research of this kind has been conducted in Mexico as yet, this study being among the first, the studies reviewed bring in a cross-cultural perspective.

1.3 Qualitative health research: the individual's perspective on CKD and RRT

While offering ways of quantifying the scale of the problem of CKD, its distribution across the population and across institutional sites, the bodies of literatures presented above were unable to account for socially situated perspectives on kidney disease, i.e.

the perspective of those with CKD on RRT, focusing instead on the biological manifestation of the disease and, on the other side, the political economy and structural (dis)organisation of health services in Mexico. There are, however, large numbers of studies that explore what it is like to suffer from this particular disease and be on different types of RRT. These studies date back to the 1960s, when transplantation and chronic haemodialysis, as ‘medical miracles’, were on the brink of becoming routine medical procedures (Fox & Swazey, 2002). The quality of life of patients undergoing dialysis and transplantation has been a recurrent topic within this body of work over the years (see for example Al-Arabi, 2006; Atcherson, 1978; Bass et al., 1999; Simmons, Anderson, & Kamstra, 1984; Timmers et al., 2008), although quality of life studies usually take a behaviourist and quantitative perspective grounded in a narrow conceptualisation of patients’ lives (Joralemon & Fujinaga, 1997).

While research on quality of life continues to be of concern for researchers and policy makers alike, the subjective experience of living with CKD and undergoing RRT from the individual’s perspective has emerged as an area of research in several health-related disciplines. There is now a large body of literature from disciplines like nursing, health services research, psychology and sociology, covering a wide range of issues about the experiences and perspectives of living with CKD and each type of RRT. In this part of the chapter, I review studies of this more qualitatively-oriented kind and the valuable insights they offer on the issues at stake. The bulk of these studies have been carried out in a few countries with established traditions in nursing and qualitative health research and a long history of renal replacement therapies, such as the United States, the UK, Australia, Canada and Sweden, with few from other countries. The number of published articles about this particular subject is large and growing and a number of systematic reviews have been published over time which

summarise and synthesise the results of numerous previous studies (Bayhakki & Hatthakit, 2012; Low, Smith, Burns, & Jones, 2008; Polaschek, 2003b; Tong et al., 2011; Tong, Lowe, Sainsbury, & Craig, 2008; Tong, Winkelmayr, & Craig, 2014; Tong, Morton, Howard, & Craig, 2009). My aim here is not to conduct another systematic review, but to highlight how these literatures help us to understand the individual's experience of CKD and its treatments in salient ways. I will focus on those studies that have addressed perspectives on dialysis, particularly peritoneal dialysis – the preferred modality of treatment in Mexico and the focus of my research. Although no similar studies have been conducted in Mexico, studies from elsewhere offer valuable ways of thinking about the personal and subjective experience of patients with CKD undergoing dialysis, and thus, help anticipate and offer a potential point of contrast with what we might expect to see in Mexico.

The first point to note is that most studies of experiences of CKD and its treatments have been conducted within the discipline of nursing for a clinical nursing audience. In this context, one of the main objectives has been to use the perspectives of patients and those close to them to influence clinical nursing practice. A major focus is how patients experience renal replacement therapy outside the clinic, and particularly, how they adapt their individual lives to specific therapies, or fail to do so. Here, adaptation and resilience are common tropes used to highlight and promote positive adjustment, and patients' experiences acquire an instructive value for nursing practice (see for example Tong et al., 2013).

A second point to note is that studies within this body of literature recurrently find that the perspectives and experiences of patients in doing dialysis at home and at the clinic do not always agree – some patients focusing on the positive aspects of their

experiences, with others highlighting the challenges and setbacks they have faced. The work of Curtin and colleagues (Curtin, Johnson, & Schatell, 2004; Curtin, Mapes, Petillo, & Oberley, 2002; Curtin & Mapes, 2001), carried out in the United States, captures the positive side of the CKD and dialysis experience. Their articles explicitly take up, as they put it, successful long-term dialysis experiences. In their studies the authors purposively selected and interviewed individuals who had successfully used haemodialysis or peritoneal dialysis for more than a decade. In Curtin et al. (2002), for instance, the authors suggest long-term haemodialysis should be thought of as a transformative experience, involving a process of positive adjustment to chronic illness and life-long treatment. The process implies a shift from the perception of illness and treatment as an obstacle to that of a manageable challenge. As they progress, patients remember their past selves but live out new ones (Curtin et al., 2002, p. 614). As a consequence, the changes brought about by disease and treatment are integrated into a ‘new self’.

According to the authors, a successful dialysis experience is one in which patients have adjusted their lifestyles to their new situation and come to terms with the restrictions that come with illness and therapy alike. They conclude that these ‘successful’ experiences should be used by nurses to provide better care to renal patients and help them to achieve active self-management.

Similar successful experiences of renal patients using peritoneal dialysis are discussed in Curtin et al. (2004) – according to them, a self-care modality with better patient satisfaction than haemodialysis. In this study the authors again employ the idea of self-management to capture ‘patients’ positive efforts to oversee and participate in their healthcare to optimise health, prevent complications, control symptoms, marshal

medical resources and minimise intrusion of the disease into their preferred lifestyles’ (Curtin et al., 2004, p. 617). Based on their ongoing research, the authors argue that patients are able to negotiate some aspects of their treatment with health professionals, have a positive attitude toward being in charge of their treatment at home and feel empowered because of that. At the same time, they suggest that peritoneal dialysis enables the patients to restore some sense of normality in their lives by virtue of its location within the domestic setting.

The results of these studies, they argue, support previous quantitative research that suggests patients on peritoneal dialysis are more satisfied with their treatment and enjoy a better quality of life than those on haemodialysis. Reflecting on the lessons to be drawn, the authors advise nurses to guide, support and direct patients to succeed in self-managed peritoneal dialysis in order to promote patient satisfaction and better quality of life.

In a similar fashion, Polaschek (2006, 2007) reported the results of interviews with patients undergoing haemodialysis and peritoneal dialysis at home, this time in New Zealand. In contrast to Curtin and colleagues in the United States, Polaschek did not interview long-term dialysis patients, but ‘competent haemodialysis and peritoneal dialysis clients’ who had been in treatment for more than six months. He describes how patients learned to manage treatment and to minimise the complications caused by it. According to him, patients continually modify certain aspects of the treatment regime in order to accommodate it into, as he put it, their life situation – that is, their everyday lives, including family, social and work relationships. These may include variations of fluid intake, dietary restrictions, schedule and frequency of dialysis and medicines, among other things. From the ‘client’ perspective, he argues, these

modifications are necessary because they are the only way patients can integrate the therapy into their lifestyles and maintain, to some extent, normality. In this context, renal clients are motivated not by restoring or maximising their health status, but by their life situations, most importantly their relationships with family, community, work, spirituality and their general attitude towards life (Polaschek, 2003a, 2006, 2007).

These studies did not draw on the concept of compliance or adherence to treatment directly, although their results point to it. This is where the work of McCarthy, Shaban, Boys and Winch makes its contribution (2010), through an exploration of the perspective of patients on the subject of compliance with peritoneal dialysis. The authors interviewed five Australian patients, who had been identified as compliant by nurses from the clinic they attended. According to McCarthy et al., although the patients did not use the concepts of compliance or adherence in their accounts explicitly, they reported that they followed health professionals' advice as much as they could, particularly the sterility measures connected with the prevention of peritonitis. They did so, not because of a desire to 'be compliant', but because it allowed them to cope with life-threatening CKD. However, the patients also discussed how they modified or sidestepped certain procedures to adapt the therapy to their needs. According to the authors, the participants followed the majority of recommended procedures, refining only those they felt would make life easier for them without inviting complications. McCarthy et al. argue that, for patients, 'compliance [...] is a function of maintaining a relatively normal state of being' (2010, p. 249), albeit one which departs from clinicians' insistence on strict adherence to recommended procedures to enhance patients' health.

Many other studies have brought to the fore similar accounts of adjustment to therapy, self-management strategies, patient autonomy and freedom in the case of home-based modalities, satisfaction and the possibility of choosing (and altering) therapies to better fit to the patients' lives (Fex, Ek, & Söderhamn, 2009; Fex, Flensner, Ek, & Söderhamn, 2011; Lee, Gudex, Povlsen, Bonnevie, & Nielsen, 2008; Morton, Devitt, et al., 2010; Morton, Tong, Howard, Snelling, & Webster, 2010; Tong, Sainsbury, et al., 2009). But there are many other studies that show how ambivalent the dialysis experience can be, recognising its negative and disruptive side (Clarkson & Robinson, 2010; Faber, 2000; Faber, de Castell, & Bryson, 2003; Hagren, Pettersen, Severinsson, Lützén, & Clyne, 2001; Lindqvist, Carlsson, Per-Olow, & Molzahn, 2000; Martin-McDonald, 2003, 2004; Sadala & Lorençon, 2006; Sadala, Miranda, Lorençon, & De Campos Pereira, 2010; Y. White & Grenyer, 1999). In terms of the experience of living with CKD and doing dialysis, the key finding in this group of studies concerns the disruption and changes these bring to previously 'normal' lives. This group of studies thus provides a fuller picture of the dialysis experience than those that emphasise the positive side through a focus on successful experiences alone.

These studies pick out aspects of RRT downplayed in other work. Peritoneal dialysis and haemodialysis, as mentioned earlier, do not constitute a cure for CKD. Rather, these therapies can be thought of as maintenance therapies, insofar as they perform certain functions the kidney no longer do, but cannot replace its other complex and also vital roles. Dialysis must be repeated constantly to remove excess water and waste products from the body. Both dialysis and haemodialysis are examples of 'half-way' technologies in medicine: they might be efficient in controlling and diminishing bodily symptoms caused by disease, extending the life of the sick person, but do not cure organic failure (Brown, 1996; Thomas, 1977). Moreover, these therapies take their toll

by imposing serious restrictions and limitations to the patients' previous everyday routines and lives on an ongoing basis – the issues only partially acknowledged by studies focused on positive experiences.

With regard to peritoneal dialysis, Martin-McDonald has pointed out that 'dialysis demands a regime of restricted fluids, prohibited foods, myriad medications, technology management, aseptic techniques and knowledge of patho/physiology' (Martin-McDonald, 2003, p. 29). In her study in Australia, she noted that CKD patients became dependant on dialysis regimes as part of continuing to live and striving to reconstruct their individual biographies and life-worlds. In the context of peritoneal dialysis, some were able to reformulate their lives and focus on the future, while others came to feel trapped by the 'tyranny' of the dialysis regime and its accompanying restrictions. She captures the contradictions of the experience in the following way: 'a dialysis-dependent person takes control over their life to varying degrees. However, that control waxes and wanes according to physical circumstances of the illness, changes in the functioning of their renal system, or effectiveness of current dialysis regime' (Martin-McDonald, 2003, p. 32). Feelings of dependency were also emphasised by Hagren and colleagues in their studies with haemodialysis patients in Sweden (Hagren et al., 2001; Hagren, Pettersen, Severinsson, Lützén, & Clyne, 2005).

Besides the strict rules concerning diet and fluid intake, dialysis introduces a series of other restrictions to patients' lives. Shaw (2015) characterises these as restrictions of space, time and mobility. Restrictions on space are particular to home-based modalities, and derive from the invasion of the home by machines, appliances, dialysis supplies and medicines and its division into quarantined and non-quarantined zones (Giles, 2004; Martin-McDonald, 2004; Shaw, 2015). The restrictions that come with

these time-consuming therapies are mentioned frequently by many authors too. Whether using in-centre or home-based modalities, inescapable dialysis schedules take up a great deal of patients' time. Just after starting dialysis, time becomes a lost aspect of patients' lives. Patients are left with reduced opportunities to work, study or relax, and more often than not, this creates problems around maintaining their social lives, careers and or jobs, problems which may also have consequences for family finances (Giles, 2004; Lindqvist et al., 2000; Sadala & Lorençon, 2006; Shaw, 2015; Tong, Sainsbury, et al., 2009). Finally, the restrictions on mobility that come about through dialysis are also a prominent issue in studies about the experiences of CKD and dialysis. In addition to strict therapeutic schedules, both peritoneal dialysis and haemodialysis must be performed in a clean and controlled environment, which can be a clinic or the patient's house. This means that the patient must be able to return again and again to the same place for dialysis, in order to keep symptoms under control. In addition to the debilitating effects of CKD and dialysis, these new schedules disrupt the routines that had made up the normal lives of patients. Many patients have to abandon work, drop studies and stop going on holidays so as to remain close to their dialysis lifeline (Giles, 2004; Martin-McDonald, 2003). These limitations and disruptions to everyday lives are felt as keenly by partners and families as by patients (Y. White & Grenyer, 1999).

Reflecting on these issues, Molzahn, Bruce, and Sheilds (2008) argue that receiving dialysis treatment for CKD is a liminal experience, one in which the outcomes of therapies are uncertain and the patients live an in-between life of treatment and the threat of death. The authors draw on the concept of liminal spaces from the anthropological literature (Turner, 1969; Van Gennep, 1960) to call attention to the complex and ambiguous experiences of patients under the various forms of dialysis.

They argue that patients' lives are simultaneously dependent and independent, normal and disrupted. This echoes findings from the studies discussed thus far – patients struggle with the changes brought about by disease and treatment and at the same time strive to regain balance and normality in their private lives, sometimes succeeding, sometimes not. While a number of these studies suggest some patients are able to redefine themselves and restore some balance to their lives while on dialysis (Hagren et al., 2001; Polaschek, 2006), other studies present transplantation as a hope of liberation from dialysis and the return to a near normal life (Shaw, 2015; Tong, Sainsbury, et al., 2009). Either way, for the majority of patients, CKD remains an unpredictable illness 'with periods of stable health, which are interspersed with unexpected acute illnesses episodes which may be life threatening in nature' (Y. White & Grenyer, 1999, p. 1318).

While these studies make valuable contributions to our understanding of CKD and its treatments, they are limited by their excessive focus on the individual. The life of the person is back in the picture, but structure has disappeared from view – the patients' experiences are socially dis-embedded, eliminating the structural forces that work to shape their experiences. Instead of exploring and describing patients' situated experiences in their social, political and cultural contexts, these analyses search for the most common and frequent themes that emerge in interview transcripts. Although these studies also map the relationships between themes, these themes are treated without considering other contextual and structural factors not mentioned by the patients but written into the organisation of their practices. To paraphrase Marx (2004), CKD patients do adapt to the condition and its treatments but not in social, cultural, economic, political and indeed technological circumstances of their own choosing.

The constraints different patients face are not sufficiently acknowledged in the studies I have examined here.

Just as problematically, a majority of the studies discussed employ ideas of self-management, independence, autonomy and choice to frame the patient experience with dialysis, and particularly home-based modalities, based on after-the-fact reports. But performing a home-based therapy implies acquiring therapeutic skills and putting them into practice, and the majority of studies just report what patients say, not what they actually do, how they were trained to do such things, and the practical relationship this establishes with health professionals and socio-medical regimes. Because of this, they miss the fact that home-based therapy does not mean an escape from biomedical surveillance. Patients might not be hospitalised for extended periods of time, or may not attend dialysis sessions at a clinic, but regular visits to the nephrologist, laboratory and pharmacy will continue for life. Moreover, there will always be some sort of biomedical surveillance that sanctions the way in which therapy is carried out and seeks to control its outcomes.

As a final note on this form of research, the majority of these studies are conducted within the biomedical domain – their objective is to inform clinical practice and improve services. While this is without doubt positive, by virtue of their location within that domain, these studies tend to overlook issues of medical power over patients. This body of research belongs to and assumes a shared outlook, it assumes commonalities and a common cultural orientation to the values of evidence based medicine, practice and policy in the governance of patients. A growing body of literature exists that is positioned in a more critical and interpretive perspective, one that draws on ethnography to explore different dimensions of CKD and RRT cross-

culturally. This literature is the focus of the last part of this chapter and provides the starting point for my study.

1.4 Ethnographic perspectives on CKD and its treatments

The three bodies of literature reviewed thus far addressed issues related to chronic kidney disease in ways that separated out its different dimensions. In doing so, they provided partial and disconnected accounts of what CKD is, how Mexican society is stratified in terms of access to health services, the consequences of health policies and the effects of disease and therapies from the individual perspective. Each perspective makes important contributions but those contributions are limited and little is done to move beyond those limitations in these literatures. Thus, by reading these studies we learn that Mexican insured and uninsured patients have unequal access to therapies, but we do not learn about the challenges they face when trying to access health services; we learn that outcomes of therapies are worse for uninsured patients, but we do not learn about their subjective experiences of undergoing RRT and how such outcomes might come to pass in practice; finally, we learn that some patients have positive experiences of dialysis, while others struggle to cope with it, but while no equivalent research has been conducted in Mexico, these studies have little to say about the importance of context in framing the experiences of the individuals concerned.

A growing ethnographic literature exists in the areas of medical anthropology, sociology and science and technology studies which attempts to provide a more integrated understanding of medical technologies for CKD in situated contexts. This literature addresses the wider social, cultural and political contexts within which disease processes and therapeutic interventions take place. But ethnographic studies

also help us to understand human experiences and practices related to CKD and its therapies in their local contexts – social, political, economic, cultural, clinical and more (Biehl & Petryna, 2013).

As things stand, ethnographic studies of CKD and RRTs have focused heavily on transplantation. Only a few studies address haemodialysis and peritoneal dialysis is barely mentioned, with no published ethnographic study as yet conducted which focuses on this particular modality of treatment for CKD. Despite this inequality of focus in relation to other dialysis modalities, however, the ethnographic approach is uniquely suited for helping us to develop a fuller understanding of CKD and its therapies within the concrete sites and settings in which they are encountered.

Transplantation has dominated the attention of ethnographers because it has proven to be a key site for addressing biomedical technologies, bioethics, social justice, iatrogenic and State harm, cyborg constructions, gift giving relationships, kinship, conceptions of body, self and identity, life and death, and the commodification of human body parts (Crowley-Matoka & Lock, 2006; Ikels, 2013; Kaufman, Russ, & Shim, 2006; Kierans, 2010, 2011, 2015, Scheper-Hughes, 2001, 2008, Sharp, 2006, 1995, 2000). I will not review all the work done in this area but a selection of articles that are particularly useful for thinking about CKD and RRT in Mexico specifically. I focus particularly on studies that discuss issues of harm (iatrogenic and other types), clinical and institutional arrangements (and how these arrangements shape how technologies are embedded in practice and the consequences of that), and the experiences of CKD patients, along with their family and kinship networks. I will argue that a similar approach is needed in order to understand the distinctive place of CKD and its therapies in Mexican society.

There are several reasons for this. Chronic illness and suffering are linked in different ways. Indeed, CKD, like any other chronic illness, is itself a form of human suffering. While never entirely explicit, many of the studies reviewed in the previous section pointed to particular ways in which the condition and its therapies connect with the suffering of individuals – through the physical pain and discomfort caused by symptoms, side effects of haemodialysis and peritoneal dialysis, identity challenges, loss of freedom, disruptions to everyday life, and so on. However, those studies focused on immediate manifestations of suffering in individuals' lives, without considering the broader social contexts within which such experiences take place or other forms of suffering linked to CKD – i.e. long-term harm to family relationships, personal and financial security, access to housing, and the exacerbation of existing forms of socio-economic inequality.

Human suffering, in its various forms, has been at the centre of anthropological debates in the last two decades (Das, Kleinman, Lock, Ramphela, & Reynolds, 2001; Farmer, 2010; Kleinman, Das, & Lock, 1997; Robbins, 2013). In their contributions to these debates, anthropologists have shown that CKD and its therapies are often connected to harmful practices, social injustices and suffering in different parts of the world. Renal transplantation and organ trafficking is, perhaps, the starkest example. Scheper-Hughes (2001, 2008) and Cohen (1999, 2001) have studied this controversial subject from a critical and political economic perspective. They argue that concerns surrounding the scarcity of organs for transplantation are a creation of the transplant community (surgeons, pharmaceuticals, medical institutions and so forth) – a consequence of the need to expand the pool of organs brought about by advances in immunosuppression and surgical techniques. Moreover, this shortage and the resulting demand has led to the emergence of organ markets in the global south and, with this,

asymmetrical power relations and inequalities between the poor and the rich in the globalised world have deepened.

In their work, they document the stories of organ sellers, buyers, brokers and transplant surgeons involved in organ trafficking in countries like the United States, the Philippines, India, Brazil, Turkey and Moldova. In *The Last Commodity*, Scheper-Hughes (2008) critiques in particular the role of bioethics in supporting and justifying the organ trade between poor kidney donors and rich renal patients. She argues against the assumption that kidney removal, or nephrectomy, is harmless and shows that many kidney vendors experience severe post-operative complications. Moreover, post-surgery many of those who have sold a kidney are stigmatised for having done so. Scheper-Hughes uses the idea of commodity fetishism and argues that others' organs, especially those of the poor, are the 'last' commodity, sought after by rich transplant surgeons and patients from rich countries, the United States and Israel in particular. The author states that 'the global traffic in organs follows the modern routes of capital and labour flows, and conforms to the usual lines of social and economic cleavage. *In general*, the organs flow from South to North, from poor to rich, from black and brown to white, from female to male bodies' (Scheper-Hughes, 2001, p. 45, emphasis in the original). It is her broader claim that is of most relevance here, however, namely that attempts to manage CKD, including transplant biotechnologies, have led to new forms of exploitation, social suffering and structural violence layered on to existing forms of inequality and disadvantage.²³

²³ 'Structural violence' refers to the social structural processes – political, economic, historic – that put individuals and populations at risk of, but often cause, physical and psychological harm, reducing their capacity to have a fulfilling, long and healthy life. Segregation, discrimination, and disparate access to economic, educational, and health resources are examples of it (Farmer, 2010).

The work of Scheper-Hughes and Cohen is important, then, because it has drawn attention to the forms of structural violence, injustice and social exclusion that are part-and-parcel of the spread of supposedly benevolent biomedical interventions. However, Kierans (2011) points out that the way in which Scheper-Hughes and Cohen depict the world of transplantation, within the broader domain of nephrological practice, is reductionist – they present a polarised dichotomy in which bad people and good people can be easily distinguished. Kierans notes that studies of the commoditisation of organs and exploitation of the poor, while important, do not exhaust what happens in the domain of transplantation – and, by extension, other forms of treatment aimed at managing CKD. Kierans goes on to show that there are many other issues to attend to in these domain, and calls for a focus on the subtler ways in which inequalities are shaped in different contexts (Kierans, 2011).

The case of Egypt provides an illustrative example of the complex ways in which social suffering and structural violence connect with CKD and its therapies. In her work, Sherine Hamdy (2008) explored the experience of poor patients undergoing haemodialysis in Egypt, where healthcare services are limited, badly resourced and unreliable. Those Hamdy spoke to were aware that their illness was not just physical. Rather, they linked their suffering to the failures of the Egyptian State. Their experiences helped Hamdy to see how State corruption had led to the mismanagement of toxic waste and the impoverishment of land, resources and people. Through material and bodily experience, those suffering from CKD connected their bodily ailments to governmental actions: their ‘failed bodies’ were a consequence of the failed Egyptian State and its policies (Hamdy, 2008). Egyptian CKD patients knew they were vulnerable to medical mistreatment, under-resourced medical facilities, irregular power supply, polluted environments, contaminated food, water and air, and more.

They were aware, as Hamdy shows, that the causes of their illness were not only physiological but political as well (Hamdy, 2008, 2009, 2013). According to Hamdy, CKD patients understood their compromised local biologies as the product of structural violence (Hamdy, 2013). Understanding the context of their condition and treatment, patients would refuse organ donations from relatives due to the risks entailed by the loss of a kidney in the context of unreliable healthcare and the dangerous political-governmental environment of Egypt (Hamdy, 2013).

Some of the qualitative health research studies reviewed in the previous section acknowledged such issues in passing, noting that illness and therapy have consequences for the families of patients. Renal replacement therapies, as well as other highly-technologised biomedical therapies, imply the deep involvement of family in a range of different ways. Ethnographic studies, with their special attention to detail and context, provide us with nuanced accounts that show how family and kinship are implicated by the disease and its therapies (Crowley-Matoka & Lock, 2006; Heinemann, 2014; Kaufman et al., 2006; Kierans, 2011; Kierans, Padilla-Altamira, Garcia-Garcia, Ibarra-Hernandez, & Mercado-Martínez, 2013; Sharp, 1995, 2001). These issues are not a secondary but central concern. As Hamdy showed in her study, for instance, it is within the context of Egyptian kin relationships that decisions about living organ donation take place. Although live donation and transplantation have been the main focus, ethnographic work thus highlights the critical question of the family in connection to CKD and RRT.

As the ethnographic literature shows, however, the ways in which family relationships are implicated by CKD and RRT are themselves complex and contextually variable. There is no simple story to tell. While in Egypt patients refuse live kidney donation,

for example, on the grounds of the risks to their prospective kin donors, in other contexts live kidney donation is much more routine. The work of Shimazono (Shimazono, 2008) captures this difference. He explored transplant recipients' subjective experiences of receiving a live organ donation in the Philippines. Deceased organ donation is very low in this country and most renal transplants are from living donors, and Shimazono uses Mauss's theory of gift exchange (1970) to analyse what is at stake in kidney transplant reciprocity within the Filipino family context.

As Shimazono shows, transplant recipients acknowledge that donating a kidney in life implies an extraordinary sacrifice involving risks of bodily harm, health complications and the loss of income. They frequently feel guilty of causing this harm to their kin, but gratitude because of the gift received and they feel compelled to repay it. This situation creates a sense of indebtedness on the part of recipients and an obligation to reciprocate an unrepayable debt. This takes different forms and imposes a range of duties on the patient. Through Shimazono's ethnographic work, we therefore gain valuable insights into how RRT, here living organ donation and transplantation, forges new roles and responsibilities within the family and kin group. But this is just one example of the influence of the family and kinship relations to biomedical therapies. As I will show in the rest of this section, there are other ways in which family and kinship influence how therapies are perceived and put into practice.

The work of Crowley-Matoka (2005, 2016) is particularly useful in relation to this point as it focuses on different aspects of the relationship between family, kinship and transplantation. Hers is one of the few studies carried out in Mexico. She analysed the situated meanings of living with a transplant and the transplanted body, and at the same time explored what transplantation meant to patients with CKD in Mexico. According

to Crowley-Matoka, ideologies around the family and gender in Mexico shape the way in which transplantation is carried out. The author compares the contexts of the United States and Mexico in order to demonstrate that transplantation must be fostered among the patients in the latter, while in the former there is 'always a demand of organs'. In the Mexican context, patients and their family members are 'educated' by healthcare providers and convinced that a transplant is the best option to 'return to normalcy'.

Given that cadaveric organ donation is very low in Mexico, due to religious beliefs, the lack of medical facilities and a general distrust in Mexican health institutions, the patients are told that the best option is a living related transplant. Within this context, Crowley-Matoka shows that the images of 'normality' offered by transplantation are culturally potent, highly gendered and related to the value of having (reproductivity) and supporting (productivity) a family. According to her, the social value of bodies lies in the concepts of reproductivity and productivity, within the context of the Mexican family, rather than health and individuality as in the United States' cultural context. However, once the patients have received their kidneys, they realise that such promises are hollow – they must continue with a strict regime of immunosuppressant drugs and medical screening. In the end, the transplant recipients find themselves in a 'persistent liminal state' – they are not a normal healthy person, but neither an ill patient as before (see also Kierans, 2001, 2005).

The work of Crowley-Matoka shows that moral ideas around family and gender underpin the promises made by health professionals about transplantation in the context of Mexico. However, her comparisons of Mexican *vis-à-vis* North American cultures is rather simplistic. She takes for granted the assumption that the family is more important than individual health in Mexico, while in the United States the reverse

is true. Underpinning this is the assumption that orientations to RRT in North America arise naturally, while in Mexico they are created institutionally (Crowley-Matoka, 2005, p. 825). However, as Kierans et al. (2013) have shown, the structure of responses to CKD are always best treated as contextually embedded and explained as such. For Kierans (2015), CKD and its treatments are socially, culturally, politically and economically produced. The problem of CKD is one that is medically configured and how it is configured will vary depending on the complex arrangements that medical practice is connected to within and across different national and sub-national contexts (see also Kierans & Cooper, 2011).

Despite its occasionally essentialising tendencies, the work of Crowley-Matoka (2001, 2006), along with that of Crowley-Matoka and Lock (2006), Scheper-Hughes (2001, 2008), Hamdy (2008, 2009, 2013), Shimazono (2008), Kierans (2005, 2010, 2011, 2015) and others (e.g. Heinemann, 2014; Kaufman et al., 2006), nonetheless provides an important starting point for my research. What we get through the line of studies – to which Crowley-Matoka’s work belongs – is an attempt to link questions concerning the structural consequences of CKD and its therapies via ideas of suffering, harm and violence to detailed studies of medical practice, family life and social settings. Moreover, although most ethnographic studies focus on transplantation, rather than on other forms of renal replacement therapies, the perspective they offer helps us to set individual experience in economic, social, cultural and political context. The few instances where ethnographic researchers have explicitly taken up RRT, however, are especially important resources in the context of my study. Sharp’s work on the ‘underground economies’ (Sharp, 1999) that spring up around transplantation in the United States is one such study. Her emphasis in that study, on the ways in which patients build fluid networks for the exchange of immunosuppressant medications,

makes a series of useful contributions to our understanding of the often unseen ways people work to ensure RRT is sustainable. I examine equivalent networks in Guadalajara in Chapter 6 of this thesis. Even more relevant is Kierans' (2015) work on the political economy of CKD and its treatments in Mexico and Crowley-Matoka's (2016) recently published work on how Mexican patients work towards transplantation, both based on fieldwork conducted in Guadalajara and in the hospitals that provide the focus of this research too. References to these works are made throughout the body of this thesis and I will draw on specific aspects of these works as I proceed. In order to draw this part of the discussion to a close, however, it is enough at this stage to note that ethnographic research allows us to see that CKD and its treatments are not only a problem for medicine, but expand beyond the clinical domain in various ways, ways that can only be discovered through fieldwork that takes CKD and RRT in practice as its primary focus. If we want to understand these practices, we need to follow them in the field.

1.5 Sensitising concepts: biopolitics, biosociality and rites-of-passage

Before proceeding to the next chapter, I want to finish this one by explicitly drawing attention to three concepts which provided analytical touchstones for the data chapters which follow. These concepts are also resonant with the ethnographic literature reviewed in the preceding sections. Indeed, by employing them as sensitising devices or heuristics to open up questions rather than as prescriptive analytical frameworks (Blumer, 1954), it was possible for me to use them as a means to establish an analytical dialogue with other research in the process of undertaking mine.

First, is the concept of biopolitics. Over the last four decades the work of Michel Foucault, specifically his analyses of the connections between power, knowledge and life (Foucault, 1978, 2003), has been influential across the social sciences, but particularly in social studies of health and biomedicine (Fassin, 2009; Kierans, 2015; Lemke, 2011; Lock & Nguyen, 2010; Lupton, 2003). His conception of biopolitics has been a recurrent focus in this (Foucault, 1978, 2003). Foucault's thinking has been a particularly important resource for understanding how forms of knowledge, organisation and intervention centred on the body have come to be intimately bound up with the institutional apparatus of government and politics. Throughout my fieldwork and the process of writing the data chapters, the field of problems Foucault's account of biopolitics brings into view helped stimulate my thinking. Drawing on it, I have sought to explore biopolitics as a set of practices not just for managing populations but for justifying their mismanagement and neglect through various techniques of knowledge and intervention, and biopower as various modes of discipline exerted over individual bodies, both directly and indirectly (Foucault, 1978, p. 139-141).

Often considered an unfinished project by Foucault (Fassin, 2009; Lemke, 2011), the domain of the biopolitical has prompted rich discussions about the social consequences of biomedical technologies and the newly hybridised forms of experience they give rise to (Kierans, 2015). As the sociological and anthropological studies I have reviewed show, biotechnical interventions, such as organ donation and transplantation, have much to teach us about the highly differentiated life chances and challenges constituencies of patients face in highly differentiated socioeconomic settings.

The work of Foucault, is, as a consequence, particularly important in sensitising the ethnographer to identify the connections between bodies and their situation within disciplinary, social, political and economic arrangements. These arrangements, in turn, produce very different biopolitical subjects, as in the case of Mexican dialysis patients, whether they be insured or uninsured, public or private. I take up this concern throughout the data chapters, by focusing on a specific intervention of state welfare – Seguro Popular – to show varying capacities to foster both life and/or death.

The second concept – biosociality – is one developed by Paul Rabinow (1996), though heavily influenced by the work of Foucault on biopolitics. Originally, Rabinow's concept of biosociality was employed to explain the emergence of communities of patients and their related others around a shared identification with specific genetic disease risks factors. At the beginning of the 21st century, a number of sociologists and anthropologists drew specifically on the concept of biosociality to explain the developments and growth of support groups and patient activism particularly in relation to advances in genetics and the human genome (Gibbon & Novas, 2007; Novas, 2006; Valle & Gibbon, 2015). This was in turn broadened out to incorporate prior forms of disease-related sociality, which predated the biosocial groups Rabinow originally had in mind when he coined the concept, like the diverse communities which formed around conditions such as diabetes (Guell, 2011) or HIV/AIDS (Marsland, 2012), to name just a few. In a similar way to those researchers who had extended its boundaries, and as I will go on to discuss in the chapters which follow, I found the concept of biosociality helpful to think about the social relations which underpin the experience of CKD, particularly for those who have little access to forms of state support and social welfare and who are thus forced to find other means of assistance. Approached as an opening onto a field of relations, biosociality helps the ethnographer

to attend more closely to how people, who share certain biological characteristics, work practically to find ways of supporting themselves by connecting with others within wider biopolitical regimes.

Finally, although from a different and much older theoretical tradition, I found myself coming back to the concept of rites-of-passage as a potent device for considering the changes and alterations which characterise CKD and its treatments. Conceived by Arnold van Gennep (1960) to analyse those rites of transition in small scale societies which formalised the socio-cultural marked transitions between one stage of life into another, rites-of-passage were initially cast as comprised of three phases – the preliminal, liminal, and postliminal. This was further extended by the anthropologist Victor Turner (1969), whose work concentrated on the significance of ‘liminality’ – that phase within a transition when things are not as they should be, a state of betwixt and between, where one must endure ambiguity of social status and identity, something pertinent to being a patient, where patients are often excluded from normal social interactions (Varul, 2010). Though very influential in anthropology as a device for analysing diverse ritual processes as well as the human life course across cultures, rites-of-passage, has been important to scholars studying the changing experiences and consequences of chronic diseases and their treatments (see for example Goffman’s classic work *Asylums* (1961) as well as more recently Jackson, 2005; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Miles, 2013). With specific reference to CKD and the RRTs, the significance of rites-of-passage has been emphasised in newer scholarship too (Crowley-Matoka, 2005; Molzahn et al., 2008), aiding consideration of the shifting character of temporality, social roles, statuses, duties, obligations and tasks, important aspects of the renal experience that I will discuss further in later chapters.

1.6 Conclusion

I began this chapter with an examination of the biomedical perspective on CKD and its therapies, which focused on failed organs and the outcomes of therapies. In the particular case of Mexico, clinical researchers have tried to document the distribution of the disease among the Mexican population, as well as how therapies are distributed among categories of patients – the insured and the uninsured. By focusing on the biological and organic manifestation of the disease or, on the other side, population differences, these bodies of literatures do not account for the social-structural and experiential aspects of CKD. Those aspects, I have argued, are examined together in ethnographic work and, thus, in comparison with the other three bodies of literature I have examined, adopting an ethnographic perspective, as I do in this study, makes it possible to explore all the issues that arise around CKD and RRT in particular contexts. This does not put the contributions made by medicine, social policy or health services research in question but offers a more integrated approach.

However, the aim of the chapter was not just to review literatures that take up the biological, the structural, the experiential and the situated aspects of CKD and RRTs in general, important as those themes are. It also served as an introduction to the issues faced by CKD patients on RRT – particularly those undergoing peritoneal dialysis – in Mexico including the forms of inequality and stratification which define their situations, the nature of work and family obligations put under strain by the condition and life with treatment, as well as the institutional arrangements within which those problems are identified and managed in the Mexican context – from medical practice through to the hybrid public-private welfare system. This is the background within which my study was conducted and I will be developing the picture offered here in later chapters.

Finally, this chapter also sets up a discussion of my methodological orientation. One of the things that differentiates the ethnographic perspective from the others examined here is that it does not seek to define CKD and RRT in particular ways (as, e.g., a matter of biological, structural or experiential significance) but rather seeks to find out what comes to define CKD and its therapies in the contexts being studied. Instead of taking a fixed position, the point of ethnographic research is to find out what shapes the problem of CKD. How this connects to the specific way in which I conducted my study is the focus of the next chapter. Nonetheless, before moving on, it is worth pointing towards what is perhaps the key lesson from ethnographic research: if we want to better understand what makes CKD and RRT, and particularly peritoneal dialysis a problem in practice, we need to go out and look rather than assuming knowledge in advance.

Chapter 2

Methods and methodology

Introduction

As I demonstrated in the literature review, the problems that arise around CKD and RRT – particularly peritoneal dialysis – are not simply medical in character. When it comes to exploring how those problems arise, in the Mexican context as elsewhere, we are quickly drawn to issues outside the medical domain. As a consequence, researchers have had to take into account social, cultural, political and economic issues, including the way healthcare and related forms of welfare are funded, organised and delivered. They have also had to examine the personal and experiential dimensions of life with CKD, both for those with the condition and those around them. What this means is that if we want to understand who gets CKD, how they are identified and treated, on what basis, in what ways, for how long and with what consequences, we cannot take a narrow view of CKD. As shown in the previous chapter, the biomedical, social policy, and qualitative health research literatures captured just part of the complexity of CKD and its treatments. These complexities are what ethnographic research seeks to open up rather than close down. From the ethnographic perspective, when we learn about CKD we are also learning about issues of medical practice and technological development, political priorities and the work of organisations, alongside suffering, harm, structural violence and more besides. In CKD and RRT – as with any other disease and its treatments – these issues are not discrete, but are

woven together in concrete ways (Biehl & Petryna, 2013; Kierans, 2015; Lock & Nguyen, 2010).

The situation in Mexico exemplifies these points in many ways. An important initial point to note in relation to the literature is that, in Mexico, peritoneal dialysis, CAPD in particular, is by far the most used modality of RRT. This is not because patients have opted for it, but because of the complicated development of nephrology and RRT within the political economy of healthcare in Mexico. Therefore, when it comes to understanding CKD in Mexico, this particular modality of treatment is central. As I will show, this means we have to explore how peritoneal dialysis is practised not just by health professionals, but, because this is a home and self-administered therapy, by patients themselves too. Patients are central to this treatment, they embody administration of care, and thus have to be a focal point of study.

In setting out to capture a subject matter of this complexity, ethnographic research starts off at concrete sites and moves outwards, tracing the links between people, practices, objects and institutions (Latour, 1987). The approach I took to this task, what was involved in conducting the research and the approach I have taken to reporting on it in later chapters provides the focus of this chapter. In the following sections I will describe and discuss the research objectives, the methodological stance, the fieldwork I conducted, the methods used, the analytical treatment given to the data, as well as the ethical implications. This chapter establishes my approach to tracing CKD and CAPD through their socio-material and temporal contexts, the subject matter of the four data chapters which follow.

2.1 Research aim: capturing the hidden aspects of CAPD in Mexico

In my review of the ethnographic literature on CKD and RRT, I noted that CAPD was under-studied compared to other treatment modalities. My study, which takes CAPD as its focus, is thus an attempt to cast light on a form of RRT we have relatively little understanding of, through providing the first detailed ethnographic study of this treatment in Mexico.

My main objective has been to document the practices and experiences of poor and uninsured patients and their families living with CKD and using CAPD in the home, setting their practices and experiences in context in the process. More specifically, I understood this to involve:

- Documenting and examining the trajectories of patients from diagnosis through to treatment.
- Developing an understanding of how patients, families, and communities engage in the care of the ill.
- Identifying and examining the networks and resources families draw on in order to support family members undergoing CAPD.
- Linking the trials patients undergo to wider systemic issues, principally the fragmentation of Mexico's healthcare system and the structures which shape it.

The aim, in other words, was to start with the patients and move outwards from there, a simple but powerful strategy in which the patients were to be my guide to the issues involved.

2.2 Methodological approach

This thesis follows in the tradition of a body of sociological and anthropological scholarship that is often labelled interpretive social science (Rabinow & Sullivan, 1979). Research within this tradition starts off with the observation that the social world is made up of people, their relationships, their activities and their material surrounds. That world is not a brute fact but is built up by people as they go about their lives. Thinkers as diverse as Karl Marx (2004) and Ian Hacking (1999, 2015) have noted that people make their social worlds in concrete ways and have suggested that the principal aim of social scientists should be to study the activities involved. In setting out to do that, as Alfred Schutz (1972, 1976), drawing on Max Weber (1978), has pointed out, we cannot lose sight of the fact that those social worlds come already interpreted by the people who inhabit them. Thus, the role of the social scientist is to make sense of the practices – i.e. the complex sets of social activities – through which social worlds are structured and given meaning by people. These practices are, in important respects, constrained because people act within contexts defined by the actions of others. The fact that CAPD is the first-line treatment for CKD is not something CKD patients in Mexico can wish away. It is something the majority must live with and find ways of accommodating – an important focus in the chapters that follow.

Seen from this perspective, the problems that accompany CKD and CAPD do not exist in a vacuum; they are, instead, socially, culturally, politically and economically embedded phenomena. In order to understand them, we need to take into account how they are defined and responded to in particular contexts, in this case Mexico. Here I follow Hacking (1999, 2015) when he argues that in order to understand something like a medical condition and its treatments we need to study the technologies,

materials, institutions, actors, and practices related with it in its ‘sites’ – i.e. the various practical settings they are anchored in and linked across. CKD and its therapies, peritoneal dialysis in particular, have a number of sites – the hospital, the body, the home, the dialysis room, charitable organisations, and the street, and wider communities. These are the places where CKD is to be found as it in these places where it acquires a particular social and material form. As a result, a study of CKD and CAPD will need to cover those sites.

Ideas of political economy, structural violence, and biopolitics also inform this study and the perspective which frames it (Farmer, 1996; Foucault, 1978, 2003; Lemke, 2011). While my approach takes me to the local and the particular, this focus on the local and particular encompasses the political and economic. I take seriously the message from Barba (2010, 2012) and Valencia (2012) about the importance of focusing on the exclusion and marginalisation of populations, but I also take Farmer’s advice about drawing on political economy when attempting to arrive at an understanding of how lives, particularly the lives of the poor, are affected by disease (Farmer, 2003). In developing Farmer’s insight, I follow the work of Gupta (2012) on the varied ways in which bureaucracy and social policy shape the lives of the poor, making worse their situation of poverty instead of alleviating it. When looking at the stories of patients, I also look at their social and political situation: to be uninsured and living in rural communities is not a side issue but central to what it means to have CKD and what it will mean to be put on CAPD. In other words, to be uninsured in Mexico shapes the experience of illness and medical care, and medical care is, in turn, shaped by the political-economic situation of people.

However, to say the situation of those who suffer from chronic conditions like CKD is socially, culturally, politically and economically situated and, hence, will vary according to the circumstances of those whose lives are being examined is just a starting point. It does not tell us about the specific ways in which that is so. The purpose of this thesis is to begin to explore that question by attending to the stories of patients and the practical ways they are involved in the management of their own condition. Adopting an ethnographic orientation to these problems has been absolutely critical. As previous ethnographic research has shown, it is only by exploring these processes in practice that we can start to make sense of social worlds. Those studied are the social scientist's instructors in what is involved, as Schutz showed (1976). For Schutz and others, the social scientist's role is to analytically examine their practices and stories.

Methodologically, details matter in this. If we ignore the practical situation of patients, we risk overlooking the ways in which CKD and CAPD reshape their lives on all levels. In the chapters that follow, I will attempt to draw that insight out through a focus on the details of patients' lives. The fine-grained accounts I will present have not been pursued for their own sake. As I discovered in the course of my research, attention to detail is necessary to understand how CKD and CAPD feature in the lives of poor and uninsured patients. It is important to remember that the complexity of the situation is one these patients must deal with on a daily basis. The complexity of their situation is, first and foremost, their problem.

My study developed against this broad background. The details of how I proceeded with fieldwork, data collection and analysis are described in the following sections.

2.3 The ethnographic orientation

Classically understood, ethnography, as a research method, begins with the study of people in particular settings: their everyday life, routines, their interactions and practices, values and norms, beliefs and shared meanings, and so on and so forth (Wacquant, 2003). Ethnography, at least as it has traditionally been practised in sociology and anthropology, aims to capture how the micro-processes of everyday life and the macro-forces of the social, political, economic, and cultural contexts shape and transform each other. Ethnography's relevance, Fassin argues, can be seen in its capacity to 'apprehend the life of others and make sense of their ideas and actions' (2013a, p. 122), but more importantly in the ways in which it sheds light on understudied regions of society (2013b). As Pigg states, ethnographers pay 'attention to what falls out of view or falls between the cracks' (2013, p. 132). This is possible because ethnography is a flexible method that develops as a study unfolds (Hammersley & Atkinson, 2007), opening room for the discovery of issues researchers were unaware of when they began (Holmes, 2013). Adopting an ethnographic approach, therefore, requires the researcher to be aware of the potential limitations and assumptions that might turn out to have been built into their initial research questions, and be open to changing direction when confronted with the empirical reality of the social world they have set out to understand (Pigg, 2013).

Nonetheless, while ethnographic research involves studies with people it does not just involve studies of people. In recent decades, sociologists and anthropologists have extended ethnography's traditional focus on non-Western medical systems to critically examine a wide range of issues related to biomedical technologies, the outcomes of global health initiatives, the lived experiences of illness and therapy in cross-cultural contexts and much more besides (see for example Biehl, Good, & Kleinman, 2007;

Biehl & Petryna, 2013; Lock & Nguyen, 2010; Lock, Young, & Cambrosio, 2000). The anthropological research reviewed in the last chapter, which takes transplantation as its main focus, is a good example of this shift in emphasis. More broadly, as Biehl and Petryna put it, ethnography has been a ‘crucial methodological tool for achieving better comprehension of health services at all levels of analysis’ (Biehl & Petryna, 2013, p. 13).

However, while this is true, as I discussed above, the social worlds of peritoneal dialysis have tended to fall between the cracks of ethnographic and anthropological studies of CKD and its therapies. Even where it has been studied, it has often been treated as a stepping-stone treatment rather than a focus in its own right. Making the problem worse, existing studies of peritoneal dialysis experience also rely heavily on interviews, disregarding the practical contexts in which it is situated. For instance, when Crowley-Matoka (2005, 2016) studied organ donation and renal transplantation in Mexico, she did partially examine the experiences of doing peritoneal dialysis. However, by treating it simply as the phase of treatment before transplantation, she failed to flag important issues connected to life on CAPD: how patients come to accommodate peritoneal dialysis at home; how they are prepared and trained; what consequences this way of organising treatment had on the people who did not or could not pursue transplantation, and so on. More importantly, although she provided important insights regarding the importance of family, kinship and gender for transplantation, her ethnography did not capture the ways in which insured and uninsured patients on dialysis are differentiated by the healthcare system and its demands, glossing over the challenges uninsured patients in particular face throughout their illness trajectories. By bringing an ethnographic orientation to bear on CAPD, I seek to fill this gap in the anthropological literature. My aim is to provide a

contextualised and nuanced description and analysis of how peritoneal dialysis is practised and the challenges uninsured patients face from diagnosis to treatment. By building on and extending the initial work of Crowley-Matoka, I aim to show how the social, cultural, political and economic are interwoven in CAPD. In the process, I will attempt to demonstrate the ways in which wider historical forces shape the lives of Mexican people and thus, what the stories of patients tell us about their social, economic and political situation. As I will discuss in further chapters, insurance status is a critical feature of the ways in which lives are changed by CKD and treatment by CAPD.

2.4 Fieldwork and field sites: Lake Chapala and the public hospital

Ethnography is characterised by the flexible use of diverse data collection techniques (Fassin, 2013a). Nevertheless, fieldwork and extended observation provide the foundation of ethnographic practice, both in anthropology and sociology (Gupta & Ferguson, 1997). This requires the immersion of the researcher in the practices of particular communities, not just to interview people, but to live and work with them and to partake of their social and cultural reality for an extended period of time (Bourgois, 1990). As Fassin (2013a, p. 120) has said with regard to fieldwork and participant observation, ‘there [...] is a unity of time and place, which is supposed to guarantee the intimacy of the relationship with the natives.’ Following ethnographic practice, I conducted fieldwork across multiple sites, that include six communities located on the shore of Chapala Lake and a public hospital and the offices of charitable organisations, both located in Guadalajara City, from September 2012 to May 2013.

I chose my field sites based on the particular significance of CKD as a problem for patients and healthcare provision in the region,²⁴ the profound difficulties patients from that region face when accessing healthcare without social security,²⁵ as well as my familiarity with the city of Guadalajara and the wider State of Jalisco, having grown up there. What follows is a description of the fieldsites, the strategies of data collection I used and the people who took part in this study.

2.4.1 Lake Chapala's communities

Some 40 kilometres away to the south of Guadalajara City is Lake Chapala, Mexico's biggest freshwater lake. It is located in the territory of the western states of Jalisco and Michoacán, and has been the main source of water for the inhabitants of Guadalajara since the 1950s (Durán Juárez & Torres Rodríguez, 2003). According to the 2010 Census, the ten municipalities that surround the lake had 326,522 inhabitants (INEGI, 2011). Fieldwork was conducted in six communities from the municipalities of Jocotepec, Chapala and Poncitlán, on the north side of the lake.

Chapala and Jocotepec municipalities are popular destinations for national and international tourists, but more importantly for North American retirees who have emigrated in search of a cheaper way of living and a better quality of life (Sunil, Rojas,

²⁴ As discussed in the literature review, Garcia-Garcia et al. (2005, 2007, 2010) have reported profound inequities in access to and outcomes of renal replacement therapies between insured and uninsured populations in the State of Jalisco.

²⁵ According to data from the 2010 Census, the majority of inhabitants of the three municipalities where I conducted fieldwork were uninsured: 67% in Chapala, 76% in Jocotepec, and 66% in Poncitlán (INEGI, 2011). The percentage of uninsured people was even higher in the communities where fieldwork was based, between 70% and 97%.

& Bradley, 2007).²⁶ Upper and middle class families from Guadalajara have also bought properties in these gentrified regions of the lake. However, Chapala and Jocotepec are also inhabited by poor peasants, fishing communities and working class families, who have been increasingly pushed to Chapala's social and environmental margins. Today, many members of these families serve as maids, gardeners, construction workers and employees for the better off newcomers. Fieldwork was conducted particularly in Chapala Town, Huejotitán, and Santa Cruz de la Soledad.

Poncitlán, the third municipality where I conducted fieldwork, is very different to the other two. The only tourist attraction is El Presidio island, a colonial military fortification, that also served as a prison during the Mexican War of Independence between 1810 and 1821. Proud of their indigenous past, the communities of Poncitlán located on the shore of Lake Chapala have been reluctant to sell their lands to outsiders, national or foreign (Bastos, 2011; Paredes Perales & Moreno, 2010). Fieldwork was conducted in Agua Caliente, Mezcala, and San Pedro Itzicán, which are communities almost exclusively inhabited by peasant, fishing and working class families, with the majority of them living in extreme poverty.²⁷ The majority of families and inhabitants of these three communities are uninsured, and rely mainly on the services of the Ministry of Health of Jalisco (MoHJ), and particularly those covered by Seguro Popular (INEGI, 2011).

²⁶ Several hotels, spas, boutiques, handcraft, souvenir and art shops, gourmet restaurants, real estate agencies, casinos, malls, and a couple of golf courses distinguish the landscape of the corridor Jocotepec-Chapala from the rest of the lake's shore.

²⁷ Practically all families from Agua Caliente, 93% from San Pedro Itzicán, and 55% from Mezcala were enrolled in the main poverty alleviation programme run by the government, called Oportunidades (INEGI, 2011), which support families in the lowest deciles of income through conditional cash transfers (Valencia Lomeli, 2008).

What attracted me to these communities, Poncitlán in particular, was a series of events that took place in 2010, before I embarked on the PhD. During 2010, when I was participating in a related study (Kierans et al., 2013), we conducted fieldwork in a public hospital, where we found out that many CKD patients came from the communities that surround Lake Chapala. All of them shared many commonalities: they were from working class background and uninsured, were enrolled in Seguro Popular, and the aetiology of their renal failure was *unknown*.²⁸ That same year, residents of the communities of Mezcala and San Pedro Itzicán claimed that CKD was rampant in their communities and that the cause was the unsafe water supply and contamination of Lake Chapala (La Jornada Jalisco, 2010a). Their claims were dismissed by the State authorities (La Jornada Jalisco, 2010b), and although they pursued legal action, the issue was left unresolved. During fieldwork, I realised that the people from these communities were not only concerned with the high incidence of CKD, but that they were, at the same time, demanding support and free access to RRT and medicines for their patients. The majority of patients from these communities were young, uninsured and poor, and their families were struggling to afford treatment. In fact, the majority of patients I met from communities of Lake Chapala shared these characteristics – young, uninsured, and diagnosed with CKD of unknown aetiology. And almost all had turned to two public hospitals that historically have attended the

²⁸ Garcia-Garcia et al. (2007) reported an incidence of 35.9% of uninsured renal patients with CKD of unknown cause between 1998 and 2000, the majority of them young. This problem seemed to be affecting insured and uninsured populations of Jalisco and on the rise in recent years. In a study conducted with insured CKD patients who received a renal transplant at an IMSS hospital between 1994 and 2014, Solis-Vargas et al. (2016) reported an incidence of 80% CKD of unknown aetiology among this group of patients. Kierans (2015) has noted that hospital staff and patients from Jalisco speculate about the link between the failure of State regulation on environmental issues, as well as the political and economic change of the last three decades, and the rise of CKD of unknown cause.

uninsured poor – Hospital Alcalde and Hospital Menchaca, also known as the Hospitales Civiles de Guadalajara.

2.4.2 The hospitals for the uninsured

The fragmented infrastructure of healthcare services provided and available in Jalisco, and particularly in Guadalajara City and the communities of Lake Chapala, will be introduced and discussed in Chapter 3. For now, it is important to introduce the hospital where fieldwork was conducted. The MoHJ is the main institution that provides medical services for the uninsured in the State. The three tertiary hospitals of the MoHJ, where highly specialised medical services are available for the uninsured, are located in Guadalajara City: Hospital General de Occidente, Hospital Civil Juan I. Menchaca (from now on Hospital Menchaca) and Hospital Civil Fray Antonio Alcalde (from now on Hospital Alcalde).

Hospital Menchaca and Hospital Alcalde are managed and run by the University of Guadalajara, although they are part of the MoHJ's network of facilities and funded by both federal and local taxes. Together these two hospitals form a single institution—Hospitales Civiles de Guadalajara OPD (HCG OPD).²⁹ Both are named after notable citizens who contributed to their construction. Hospital Menchaca, the University of Guadalajara's teaching hospital, is named after a prominent physician and politician. It was completed and opened to the public in 1988, it currently has 500 beds and provides comprehensive services covering a range of medical specialities. The

²⁹ OPD stands for *organismo público descentralizado*, public decentralised organisation in Spanish. It is the designation for a type of public institution formally independent from the state government but which retains public funding. Both hospitals are thus part of the network of facilities of the MoHJ. OPD status was granted in 1997 as part of a wider programme of decentralisation in the Mexican health system.

nephrology department specialises in children's care and has its own paediatric peritoneal dialysis programme but haemodialysis and renal transplantation are not available in this hospital. When a patient is transferred to haemodialysis they are sent to the other MoHJ hospital or, more often, to private clinics. Similarly, if a patient is a candidate for transplantation, and they are willing and able to shoulder the cost of the protocols, they are sent to Hospital Alcalde.

Hospital Alcalde is the main hospital of the HCG OPD and the site where its general headquarters are located. Hospital Alcalde is the largest and most important hospital for the uninsured in the west of the country, with about 1000 beds and services covering a wide range of medical specialities.³⁰ The older parts of the hospital are still in use, remaining much as they were when built at the end of the 18th century, with a range of new buildings added to the hospital complex over time. Torre de Especialidades, or the Medical Specialities building, is where the nephrology department is located. It is the only public hospital for the uninsured in Jalisco with two transplantation programmes – living-related and deceased. It also has a haemodialysis clinic, the only renal health pre-dialysis programme and the largest peritoneal dialysis programme for the uninsured in the State. It was in this hospital where I conducted fieldwork, accompanying patients to take CAPD training, attending consultation and clinical appointments between September 2012 to May 2013.

The majority of uninsured renal patients in Jalisco receive their diagnosis in Hospital Alcalde and Hospital Menchaca. All but one of the 20 patients who participated in my

³⁰ Only the Hospital Juárez de México and the Hospital General de México, both public hospitals for the uninsured located in Mexico City, are larger than Hospital Alcalde. Given its size and the range of treatments it offers, Hospital Alcalde draws patients from neighbouring states, including Aguascalientes, Colima, Guanajuato, Michoacán, Nayarit, and Zacatecas.

study were diagnosed in one of these two linked sites. All were uninsured at the beginning of their illness, although some did obtain access to IMSS after-the-fact. The lives of these uninsured patients, therefore, were deeply connected to the City of Guadalajara, where these two hospitals were based, as will be described and analysed in the chapters to come.

2.4.3 Ethnographic observation and participation

To conduct fieldwork and facilitate movement between my principal fieldsites in the city and the communities in Chapala, I was based in the City of Guadalajara, where my permanent address is, for the duration of the study. From there, I visited the communities in Chapala with regularity. On average, I visited two communities every week, spending time with patients and their families in their homes. To initiate fieldwork, however, and to remain faithful to my commitment to study CKD and CAPD from the perspective of the people who suffer from it, I attended a full course of CAPD training at Hospital Alcalde in order to observe how this modality of dialysis was communicated to those who would depend on it and gain an understanding of what precisely was required in order to accommodate it into the context of both home and family life. In the course of attending CAPD training, I conducted informal interviews with those undertaking the training. This is presented and analysed in detail in Chapter 4.

As fieldwork unfolded, and I got to know the patients that participate in my study, I accompanied them on their travels across the city to obtain medicines, dialysis supplies, attend laboratory and consultation appointments, and so on. Later in my fieldwork, I also attended a private clinical laboratory and gave blood and urine

samples to be analysed, as patients do bimonthly, in order to better understand what patients had to undergo on a regular basis.³¹ This experience, and also undergoing training as patients did, helped me to understand many aspects of the embodied experience of CKD and CAPD in the context of Mexico. Also, observing the movements of patients through different institutional settings and the long waiting times many had to endure, provided many important insights into life as a CKD and CAPD patient. In the early stages of fieldwork, it also helped fine-tune my research priorities and questions.

Outside of conducting fieldwork in the clinical and institutional settings patients moved through, I made connections with a range of charitable organisations involved in supporting those with CKD. Locally called *asociaciones civiles*,³² these charitable organisations have become an important source of arbitration and support for patients. They play a major role in helping patients access medications and maintain their treatment over time, as will be described in detail and analysed in Chapter 6. I paid several visits to the offices of Una Oportunidad de Vida, Quiero Vivir, and Trasplantados en el Hospital Alcalde, three *asociaciones civiles* that supported uninsured renal patients, and was permitted to observe their daily work. These visits lasted between one and two hours, during which I interviewed their personnel, talked with volunteers, and observed how they received and offered help to patients and

³¹ I asked a doctor to prescribed me the same clinical exams as patients were and he indicated to me which private laboratories I could go.

³² In the context of Mexico, an ‘*asociación civil*’ (plural *asociaciones civiles*) is a charitable organisation that is similar to charities in the UK context. Within the Mexican context, the term ‘*asociación civil*’ means that the organisation does not pursue political goals like a political party, although there are many *asociaciones civiles* advocating for democracy, civil and human rights, the environment, the rights of indigenous peoples, the poor, the ill and so on and so forth. Throughout the thesis, I will use the singular *asociación civil*, the plural *asociaciones civiles*, and in some parts I will use just the word *asociación* or *asociaciones* to simplify.

families. I also took every opportunity to attend events organised by the hospital and the asociaciones civiles, participating where and when I could. Over the course of fieldwork, I attended four workshops and lectures aimed at patients and their families, helped with conducting a focus group with renal patients during an event, sold raffle tickets to raise money for one of the asociaciones and participated at the march in commemoration of the World Kidney Day in March 2013, organised by HCG OPD with the help of asociaciones.

2.4.4 Participants and cases

In ethnographic research, the selection of informants depends upon the research problem and the theoretical perspective adopted. Participants were selected not only because they belonged to Chapala's communities, but because of the particular type of knowledge they could contribute to the research problem (Bernard, 2006; Johnson, 1990). I was primarily interested in patients who were either training for home dialysis or already using it at home.

My first attempt to identify this type of patient was to ask the hospital and the asociaciones civiles. However, the records of both hospital and asociaciones were not reliable, because patients often did not report their full addresses. Furthermore, I found out that, at the time of my fieldwork, the asociaciones I contacted only supported a handful of patients from the communities I was interested in. It turned out to be more productive to make site-visits to the respective local MoHJ primary health centres in the communities. While there, I took the opportunity to interview local health professionals working in these centres about their views on CKD. In turn, they provided me the whereabouts (because they did not have their contact details) of

families who had members with CKD, which I then had to approach personally.³³ With the help of the families I contacted at the beginning of fieldwork, I used a system of snow-balling to establish a sufficient number of patient cases for study. Every time I contacted a participant for the first time, I introduced myself and explained the objective of my research project, and asked each of them for their consent to participate in the study, as will be explained further in this chapter. By the end of fieldwork, I had collected the life-stories of 20 such patients from the same number of families (see Table 2).³⁴ In some cases, there was more than one patient in the family, but I focused on the case of the patient who was on CAPD.

³³ As will be explained in the following chapters, CKD patients do not receive care or support for their respective treatments in this primary care centres, having to travel to the hospitals located in the City of Guadalajara for any kind of appointment or emergency care.

³⁴ All names mentioned throughout the thesis are pseudonyms to maintain the anonymity of participants.

Table 2 Study cases

Pseudonym, age ^a	Date of diagnosis	Cause of CKD	Treatment trajectory ^b	Time on peritoneal dialysis ^c
Alejandra, 22	April, 2008	Unknown	CADP-HD-TX	3 months ^d
Clara, 22	July, 2010	Unknown	CAPD	2 years, 11 months
Cristian, 31	May, 2006	Congenital malformation of the urinary tract	CAPD	7 years
Daniel, 18	December, 2012	Unknown	IPD	2 months ^e
Isabel, 45	June, 2006	Diabetes	CAPD	5 years, 7 months
Jaime, 28	July, 2008	Unknown	CAPD-TX- CAPD	4 years, 11 months
Lázaro, 28	September, 2011	Unknown	CAPD-TX	1 year, 5 months ^f
Lourdes, 21	June, 2010	Unknown	CAPD	3 years
Lucero, 19	September, 2012	Unknown	CAPD	6 months
Martin, 23	December, 2010	Unknown	CAPD	2 years, 5 months
Miguel, 23	2009	Unknown	CAPD-HD	6 months ^d
Noe, 18	2011	Unknown	HD	
Pablo, 20	March, 2009	Unknown	CAPD	4 years, 2 months
Ramon, 47	December, 2011	Hypertension	CAPD-APD	1 year, 5 months
Renata, 48	2007	Diabetes and Hypertension	CAPD-HD	5 years ^e
Ricardo, 18	2005	Unknown	CAPD-TX	7 years ^f
Rita, 64	May, 2008	Diabetes	CAPD	5 years
Ronaldo, 22	January, 2010	Unknown	CAPD	3 years, 5 months
Silvia, 22	August, 2008	Unknown	CAPD	4 years, 5 months ^e
Simón, 21	2007	Unknown	CAPD	6 years

Notes: a. Age at the time of the first interview. b. CAPD: Continuous ambulatory peritoneal dialysis; HD: Haemodialysis; TX: Transplant; IPD: In-hospital intermittent peritoneal dialysis; APD: Automated peritoneal dialysis. Current therapy in bold. c. Time on peritoneal dialysis at the end of fieldwork, unless specified. d. Transferred to haemodialysis. e. Died before the end of fieldwork. f. Received a transplant before the end of fieldwork.

I visited half of the participant patients at least twice in their homes, while I visited the other half more often. These visits lasted at least two hours each time, and in some occasions up to eight hours, during which I conducted formal interviews and had

informal conversations with patients and their respective family members. Being there also allowed me to observe and understand how CAPD was practically accommodated in their homes. Furthermore, these visits served to build trust with patients and their family carers and facilitated further introductions to many other people in the communities who had experience of CKD or were concerned about its prevalence in the area. Over time, I was permitted to take photographs of patients' homes, their dialysis rooms and the various places where they stored dialysis supplies. Spending time with families at home was critical to understanding how they put into practice what they learned about performing CAPD in the hospital but also the many different ways they modified their homes and daily routines, adapting the therapy to their lives over time. Being present and participating in the multiple settings across which CAPD is practiced allowed me to better understand the conditions under which CAPD works and, indeed, fails to work. Furthermore, it was important to bear witness to the movement of patients and their families as they made their way through very different social and institutional sites and settings (Kierans, 2015) to support their regimes of care. This made it possible to better understand what living with this condition actually involved.

Supplementing the twenty patient cases, I recruited a wide range of informants from both Guadalajara and Chapala's lake-side communities. In total, I interviewed 97 people over the period of the study – patients, carers, family members, charitable organisations' and institutions' staff and volunteers, health professionals, and local authorities and community residents (see Table 3).

Table 3 Participants of the study

Type of participant	N
Patients (cases)	20
Family members, carers and relatives	37
Charitable organisations' and institutions' staff and volunteers	17
Health professionals	12
Local authorities and community residents	11
Total	97

2.4.5 Interviews

In addition to observation, interviewing is an important component of ethnographic fieldwork (Davies, 1999; Hammersley & Atkinson, 2007) and ethnographers usually employ different types of interviews in the course of fieldwork. As part of this study, I conducted three different types of interviews, according to the type of participant I interviewed and the nature of information I required. I conducted semi-structured interviews with health professionals, asociaciones civiles's and government officials. For these types of interviews, I prepared a list of topics in advance, although I was flexible with respect to question order and responded to issues arising by introducing further questions in the course of the interview (see Appendix 1).

With patients and family members, I used three types of interviews: narrative, semi-structured, and informal, conversational interviews. In the case of narrative interviews, I usually started with 'Tell me about' questions, e.g. 'Could you tell me about your experience as a CKD patient?'; 'Please begin at any point you wish'. The use of narrative interviews, based around a 'tell me about...' structure allowed the participants to control the flow of the interview and prevented me, the researcher, from broaching issues the participant themselves did not want to discuss or which they regarded as of a personal or sensitive nature. Since most patients and family members

were visited over several occasions, I was able to continue with more focused interviews but also informal chats about their everyday lives, what it was like to live around Lake Chapala and many other issues less directly related to the research project. Using a combination of interview types, across multiple occasions, allowed me to reconstruct the patients' illness histories and trajectories from their point of view.

At the end of fieldwork, I had digitally recorded 104 formal and informal interviews – 81 interviews with patients, family carers and relatives; ten with charitable organisations' and institutions' volunteers and staff; six with health professionals; and another six with other key informants from the communities (local authorities and community residents). Interviews ranged from 20 minutes to 2 hours, culminating in 92 hours of audio-recordings. Some informal interviews and conversations with community members, health professionals and other participants were not audio recorded, and in these cases, I took notes about the main topics.³⁵

All formal interviews were carried out in the participants' preferred setting. With patients, caregivers and family members, it was essential to conduct interviews in their homes, where they felt more comfortable. I attempted to interview every participant alone, but in most cases this was not possible. In terms of questions, interviews with patients and relatives had a central focus on CAPD. Issues covered included: a) the trajectory of the condition and all associated treatment(s); b) strategies to support/find ways of paying for treatment; c) problems faced; d) perspectives on the condition,

³⁵ This is the reason why there is a difference between the number of participants (n=97, people I interviewed or talked with and obtained verbal or written consent from) and the number of digitally recorded interviews (n=104).

treatment and aetiology; e) everyday life and routines on CAPD; and f) family members and family history (see Appendix 1).

Interviews with health professionals, charities' staff and volunteers, and government staff, were carried out in their offices, although I had several non-recorded informal chats with many of them during fieldwork (especially with personnel and volunteers from the asociaciones civiles). These interviews covered a wide range of issues related to the condition, its treatments and how various forms of support for patients are organised and delivered, as well as their views on the current problem of CKD in Mexico. The interviews with non-patients throughout Lake Chapala focused on everyday-life in their respective communities and the rapid spread of CKD within them (see Appendix 1).

Throughout fieldwork, I took detailed and extensive fieldnotes, culminating in more than 120 pages of descriptions, summations of interviews, insights and further questions. I initially followed Bernard's (2006) distinction between descriptive, analytical and methodological fieldnotes by differentiating what I was writing into these separate categories. In the end, however, I developed my own style of field-noting, starting with descriptions of the scene or setting, followed by analytical and or methodological comments. Because there wasn't always a clear separation between observing, participating and interviewing, I always carried a small notebook and also my smart phone to jot down observations that I later developed into full fieldnotes of the fieldwork day. These notes became the main source of information and analysis for the write-up of the thesis.

2.4.6 Secondary sources: documents, photographs, videos and material artefacts

Documents, secondary sources of information and material artefacts also have an important role in ethnographic research as study materials. They can provide important information about the context of the problem under study as well as information that would not otherwise be available to the ethnographer (Hammersley & Atkinson 2007). During fieldwork, I paid particular attention to the kinds of texts and other material artefacts that had a direct bearing on or role to play within the settings I was being lead to. For example, I followed CKD and its treatments in the media, particularly television and the press and identified several articles from local and national newspapers (from 2005 to 2013) that addressed or covered issues related to the research problem. These provided a sense of the live public debates that surrounded the topic.

I also collected ‘working’ documents, both official and unofficial, as well as other documentary materials related to the condition and treatment. Among the documents collected, there were four CAPD manuals for patients, one cookery book for renal patients, and hospital leaflets containing information for patients due to start CAPD at home. These documents proved to be very valuable for understanding the way in which the hospitals communicated with patients and family members, as well as their expectations concerning what patients ought to be able to do. In addition, these documents helped me to add specificity to the detailed stories featured in the chapters to follow.

From asociaciones civiles I obtained leaflets, flyers and slides from presentations. Leaflets and flyers were very useful in two ways. They helped me to understand the work these charitable organisations do and the services they provide to uninsured patients. I also asked the associations whether I could distribute leaflets and flyers to

the patients from Chapala lake-side communities, who might find them useful. This, in turn, also allowed me to feel of some use beyond my role as a researcher.

I was permitted access to patients' medical records by many of the patients and their families. This was crucial to the analysis of the cases I will go on to present. As described by Kierans (2015), Mexican patients must carry their own medical 'files', a miscellaneous collection of materials, with them. These files include prescriptions, laboratory tests orders, tests results, hospitalisation summaries, receipts, and so on, all serving to chart their encounters with the healthcare system, from attendance at hospital to visits to the pharmacy. Each patient I met had their own files stored in plastic shopping bags, blue plastic envelopes (very common among both insured and uninsured hospital patients), or cardboard boxes. Among these assorted documents, the *tarjetón* – a type of patient ID and appointment timetable – was the most important, as this was their 'pass' to the hospital's services. Besides the *tarjetón*, their hospitalisation discharge summaries were very useful for reconstructing the patients' trajectories, as these contained important information about the clinical condition of the patients before and after periods of in-patient treatment.

Photographs and videos also became part of the data gathering tools as fieldwork unfolded. They were not something I anticipated being relevant, but they became increasingly useful for illustrating and explaining the things I studied, as well as for recording events and CAPD practices. I also found it useful to photograph documents, given the unavailability of photocopy services particularly outside of the city.³⁶

³⁶ It is important to note here that, as with interviews, I asked the participants' informed consent before taking any photographs. In addition, as the reader will notice, no faces were photographed so as to maintain privacy and anonymity, and all names and other identifiers were erased from photographed documents.

Finally, given the focus of the study was a form of therapeutic intervention, I paid close attention to its different material ‘set ups’, particularly the key artefacts and equipment involved, and took care to document textually and visually the way they worked.

2.5 Data analysis

When the ethnographer finishes fieldwork, he or she ends up with an extraordinary amount of material: audio recordings, transcripts, notes, photographs as well as documents and artefacts of various sorts. The different types of data they contain have to be brought into conversation with each other. While various types of data might need to be analysed, organised and stored separately, it is their capacity to be drawn into an integrated analysis that is one of the hallmarks of ethnography (Atkinson, 2013; Hammersley & Atkinson, 2007). Finding ways of doing this requires on-going work. The ethnographic fieldwork experience as well as lessons from the literature have to be brought to bear on these resources, as part of an exercise in what, adapting Charles W. Mills, might be referred to as the ‘ethnographic imagination’ (Mills, 2000). Exercising that imagination is key to producing rich, contextually grounded insights and descriptions.

In addition, I have also tried to follow some more specific analytical policies, such as those employed within thematic narrative analysis (Mishler, 1986; Riessman, 2008). Narrative analysis involves focusing on a particular event or issue through the reconstruction of the stories people tell. It is structural in character, eliciting an understanding of how people create meaning based on how stories are ordered, what is being told, who is doing the telling and what is at stake for them in the process. By

collecting the narratives of patients through the various stages of their illness and exploring the problems they recounted in relation to accessing and maintaining treatments, it has been possible to show how the realities of CKD and CAPD open up critical questions regarding the Mexican healthcare system and its failings.

Stories, as told by the individuals during interviews, are often unstructured, messy, and sometimes contradictory. Drawing on interviews, fieldnotes, and the patients' records, allowed me to reconstruct the stories of selected patients in chronological order, from the beginning of illness to its possible outcomes. As the reader will see, the data chapters that follow are organised into broad themes that relate to the stages of the trajectory of CKD and its treatments in the context of Mexico, as told in the stories of patients – for example, the onset of symptoms and diagnosis, CAPD training, accommodating and practicing therapy at home. In telling the stories this way, my hope is that the reader will gain a deeper understanding of the different challenges, trials and tribulations patients and families go through in the process.

In the reconstruction of these stories, as they are presented in the chapters to come, the reader will note that I have used few verbatim interview quotations. This decision was consciously made on the basis that the focus of the thesis is on people's actions and practices, not merely on what people say about those actions and practices. The verbatim quotations featured at key points in the chapters, translated from Mexican rural Spanish into English, are not only important to understand the stories – they were significant for the people who told them as well. Patients and families, the protagonists of these stories, had a developed understanding of the issues discussed in this thesis. In that respect, they were not merely my *informants* but my *guides* during fieldwork and helped me through the data analysis stage as well by providing these insights.

Through this emphasis on practices and practical understandings, the emphasis in this thesis has been put squarely on what people do. The only way to understand CAPD, I argue, is to go and see it in its respective sites and settings, paying attention to how it is practised and the trials and tribulations encountered along the way. In drawing together my data as part of an ethnographic analysis, my goal was to re-present those practices, trials and tribulations in as much detail as I could, in order to reflect the extraordinary work and challenges faced by Mexican families. I contend that we need to understand those details to fully understand what is going on. To that end, I have drawn on the widest range of ethnographic materials and insights in order to provide the most in-depth account possible.

2.6 Ethical considerations and reflexivity

This study was approved by the University of Liverpool's Committee on Research Ethics (reference: PSYC-1112-030, 6 July 2012). It also complies with the codes of practice of the University of Liverpool, American Anthropological Association and the European Association of Social Anthropologists, in their emphasis on informed consent, data protection anonymity, non-maleficence and beneficence.

Working with different participants – health professionals, charitable associations, government officials, patients, their families, and so on – involved reflection on situated rather than just institutional defined conceptions of research ethics.³⁷

³⁷ Institutionally defined versions of ethical conduct, monitored and overseen by universities' review boards, tend to frame ethics in a particular way. Adopting a biomedical and contractual model, institutional ethics aims to govern research with 'human subjects' with an emphasis on informed consent, anonymity, confidentiality and the principles of beneficence and non-maleficence. Social scientists, in the broad, and anthropologists, in particular, have questioned this mode of governance and

For those participants who were professionally involved in CKD, I provided them with written and verbal information about the research project in Spanish as well as what they could expect from their participation along with a consent form to sign (see Appendices 2-6).

For patients, their families and other residents of Lake Chapala's communities, information was translated into lay-Spanish, and provided in written and verbal form (see Appendices 2-6). Consent was also taken in written or verbal form depending on the literacy and preference of the participants. It is important to note that requests for signed consent, particularly when dealing with poor people, are not common practice in Mexico and can invite suspicion or raise concerns about what a signature might be subsequently used for. In all cases, therefore, I clearly explained the study, my work as a researcher and offered assurance that their participation was completely voluntary and that at any point they could stop participating or request the withdrawal of information they had provided. I assured anonymity and explained that anything I wrote would not identify any of the study's participants in any way.

Only two patients refused to participate in the study. With those who agreed to participate, I conducted at least two interviews. As relationships developed with patients and their families, I was invited to have meals with them in their homes, where they often shared stories about their lives, their children, their work and what life is like growing up around the lake. As fieldwork unfolded, many participants communicated to me that they felt I was both sensitive and sympathetic to them and

the restrictions that come with it, pointing to its inadequacies when it comes to social science research practice (Bourgois, 1990).

the difficulties they were facing. This assured me that they were comfortable with my presence, the research project and my many questions.

As a measure to avoid undue intrusion into the lives of my research participants, I made sure my visits were at a time convenient for them. I did not want to disturb their everyday routines so I made sure my visits were sensitive to the rhythms of family life. Research ethics, in the context of this study, was never going to be a one-off event, something neatly packaged into a consent form, but required constant consideration and reflection over the entire fieldwork process (Bourgois, 1990; Darling, 2014). Doing ethnographic research implies managing different expectations and understandings across very different informants, in a transparent and open manner (Robles, 2012). I am confident I achieved that in my research.

Over the course of my fieldwork, I routinely introduced myself to health professionals and local authorities as a Mexican PhD student, studying at the University of Liverpool, with a background in social science and an interest in the lives of uninsured people affected by CKD. While I introduced myself in a similar way to patients, I usually tended to disclose more personal details about myself, and also talked about own family's experiences of illness and seeking healthcare in public hospitals. As fieldwork progressed, I learned that research engagement, particularly in the Mexican context, necessitated reciprocity. In this regard, I volunteered with charitable associations and provided as much support to patients as I reasonably could; for instance, by introducing them to relevant organisation who could help them understand the processes of organ donation and transplantation and advising them on sources of financial support.

As a distinctive but fluid research approach, ethnographic research often involves moving back and forth between the roles of researcher and participant (Bourgois, 1990; Darling, 2014; Robles, 2012). Indeed, role ‘transgressions’ are often a necessary condition for producing reliable and credible ethnographic accounts. During fieldwork and my encounters with patients and their relatives, I faced dilemmas I could not have anticipated: requests to donate blood, medical information, money or other forms support which were beyond my capacity as a student or social scientist. In these situations, I directed patients to their closest medical contact, local charitable organisations or others I felt could offer help. Patients and their families were not only participants willing to answer my questions, but people who had pressing needs, who were in a difficult situation and were searching for sources of support. They were willing to draw on whoever was available, including ethnographers.

Throughout the study, I was always conscious of my own privileged position as a hybrid insider-outsider. I grew up in the city of Guadalajara, in a working class family, not unlike many of my informants. And while I did not have any direct experience of CKD and all it implies in Mexico, I had enough experience of the country’s fragmented health-care system to understand the challenges many of my informants faced and the issues most at stake for them. At the same time, I had the benefit of a third level education both and inside and outside of Mexico. The ethnographic distance created by studying in the UK was also important in learning to see my own country through a new lens. Travelling back to Mexico for fieldwork as a UK-based PhD student provided me with a unique vantage point. Undertaking CAPD training was also critical to ensuring that my twinned roles of citizen-insider and student-outsider allowed me to learn as others learn, from the perspective of the ‘stranger’ in Schutz’s terms (1976). In all of this, I was aware of the complexities of coming to the issue of CAPD as an

academic researcher. I was not an activist, nor a patient advocate but someone working with patients to produce an account of their lives and social worlds that would likely not benefit any of them directly. Having much in common with those I was studying, increased my empathy, particularly given the kindness they extended me by accepting me into their lives.

2.7 Conclusion

The general aims of this thesis is to provide a contextualised and nuanced description and analysis of how CKD is experienced and the ways in which peritoneal dialysis, as the mainstay therapy for this condition in Mexico, is practised in its sites and the challenges uninsured patients face along the trajectory from diagnosis to treatment within the Mexican context. I have argued that an ethnographic perspective, as described in this chapter, is a necessary approach to study this problem that has fallen out of view of anthropological studies about CKD and its therapies, but also as a form to overcome partiality of the medical, social policy and qualitative health research perspectives.

As I will show in the chapters to come, life with CKD and undergoing CAPD within the context of Mexico is complex and problematic for uninsured people. In order to understand such complexity, and the trials and tribulations uninsured patients have to go through, it is important to start off at concrete sites and move outwards, tracing the links between the various social actors, their practices, social relations, the objects, and the institutions involved in the problem. By adopting an ethnographic perspective, it is possible to visualise and understand who gets CKD, how they are diagnosed and treated, on what basis, in what ways, for how long and with what consequences,

bringing together the experiential and the structural. This approach, as I adopted it, required me to put the patients and their families at the centre of analysis, as they were my instructors in what was involved in life with CKD and CAPD. They were central in understanding the convergence of and mutual influence between the structural – social, political, cultural, technological – and the experiential and ordinary.

As I argued, methodologically, details matter to understand this problem. We need to pay close attention to the practical situation of patients in various ways – who they are, where are they come from, what, how, and why they do what they do, to try to solve their health problems. Chapter 3 starts off with a close examination of how a group of patients experienced the onset of CKD, and follows them through their navigation of the fragmented healthcare infrastructure of Jalisco State, until they are correctly diagnosed and initiated in peritoneal dialysis treatment at Hospital Alcalde. Describing and analysing in detail how patients come to be diagnosed with CKD and started on this particular treatment, paying attention to the trials and tribulations encountered along the way by them and their families, helps to open up critical questions regarding the Mexican healthcare system and its failings. In further chapters, we will observe and understand how this problem extends beyond the clinical setting, linking the home and the community in various ways, through the work of patients, families, and asociaciones civiles.

Chapter 3

Navigating the Mexican health system: the hard road to diagnosis and treatment

Introduction

Drawing on the methods described in chapter 2, in this chapter I will describe how people from rural and semi-urban communities begin their careers as renal patients. The aim is to provide examples of the kinds of trajectories and techniques of navigation patients adopt as they move through different healthcare providers and institutions (Bowker & Star, 1999; Goffman, 1961; Roth, 1973). I will reconstruct the stories of patients who were unexpectedly diagnosed with CKD and the journeys and struggles they undertook to get an accurate diagnosis and access the appropriate medical therapy. Focusing on their individual stories from the point at which they began their journeys as patients, I will try to convey their bewilderment when confronted with the fragmented character of the health system meant to provide them with care and the realities of CKD in the context of Mexico. Observing the experiences of people who suffer from CKD, in particular their attempts to access renal replacement therapies in public hospitals, offers a vantage point to critically interrogate how the health system functions in practice (Auyero, 2012; Gupta, 2012).

This chapter focuses on the ways in which patient trajectories begin for a series of reasons. Those trajectories are important because, in tracing how they start and develop, we come to learn about the wider healthcare context as it takes form for the patients seeking treatment within it as well as those who accompany them along the

way. Drawing on Latour (1987), I suggest that by carefully following the patients, we are thus introduced to the role, function and connections between clinics, services and insurance providers as they work not in theory but in practice from the patients' point-of-view. This way of proceeding lays the empirical and analytical grounds for the chapters that follow.

Before introducing the stories of patients, however, in the first part of this chapter I will provide the reader with an introductory map of the healthcare infrastructure available to insured and uninsured patients in Jalisco, so they can follow the moves the patients make more easily. The organisation of services, I argue, forms part of the socio-material conditions – i.e. the concrete physical, social and institutional 'matrices' (Hacking, 1999) – within which patients' experiences of care are forged. Particular stress has to be placed on those services which support the uninsured population, most significantly those based at hospitals located in the city of Guadalajara, which cater for the poor of Jalisco and neighbouring states. This is because, as I will show, hospitals for the uninsured are spaces where we see the contemporary form of the one-sided historical relationships between those who are ill and poor and the healthcare providers that frequently characterise Mexican healthcare. I will draw particular attention to the importance of what I will call 'supplicatory practices' to the functioning of hospitals, i.e. the obligatory shows of deference the system of healthcare requires of those who turn to it for help, and I will highlight the hierarchical and unequal relationships between patients and healthcare providers those practices of deference help to form (Auyero, 2012; Gupta, 2012). These practices, as demonstrations of a willingness to defer to the authority of those in official positions, are one of the main features of public healthcare services in Mexico and the extent to which they are able to engage in them shapes patients' illness trajectories. In this and

chapters to come, I focus on Hospital Alcalde where these forms of qualified assistance and conditional care can be seen in action.

With this map in hand, the second part of this chapter will begin the task of exploring these issues empirically, focusing on three specific cases which exemplify the complex and problematic experiences of uninsured patients in Jalisco. I will use patients' stories to analyse how they encountered the Mexican health system, and particularly the organisation of health services available to them. The level of detail provided in relation to each case is intentional and serves to make visible the socio-material conditions within which patients and their families are left to construct their own paths to diagnosis and treatment. The stories are recounted in all their complexity because the situations the patients had to manage were defined by those complexities. In this sense, the accounts offered here are designed to capture the unending trials the health system imposes on those who turn to it for help.

A repeated medical claim is that patients arrive late at nephrology services, giving the impression that it is the patients who bear the responsibility for delays in their own treatment. However, on the basis of the detailed reconstructions of patients' accounts I present in this chapter, I challenge this claim, showing instead that private and public healthcare services at community level struggle to identify CKD, often preventing its timely recognition. From the outset, then, and even before they know they have the condition, the difficulties CKD patients face in securing treatment are clear.

3.1 Fragmented infrastructure: medical services in Jalisco

For the people from the communities of Lake Chapala, Guadalajara city is the principal access point for the forms of highly specialised medical care chronic conditions

require. The city of Guadalajara serves as a hub for healthcare services, medical teaching and clinical research. Clinics and hospitals are run by all of the main social security institutions, the MoHJ and private providers located throughout the city. *Consultorios*, or private consultation offices, offering access to general practitioners and medical specialities, are scattered throughout the city. In less populated communities, like those of Lake Chapala, there are also many types of consultorios. It is through consultorios that physicians offer their services to those who can pay – and there are practitioners for all budgets.³⁸ Charity consultorios are also available, usually within the premises of Catholic churches, where general practitioners – and often homeopathy practitioners – provide consultation for free or for a very low fee. A wide variety of pharmacies (general, generics-only, and speciality medicines), clinical laboratories, medical equipment retailers and even, despite efforts by the authorities, a growing black market in medicines³⁹ are all at hand in the city of Guadalajara, but particularly in the areas close to public hospitals. In addition to these, a myriad of alternative and traditional medicine practitioners and shops cater for those who prefer these types of therapies.⁴⁰

³⁸ In the last two decades there has been an increasing shift to private primary care in Mexico (Hayden, 2007). Generic drug pharmacies, like the Mexican pharmacy company chain Farmacias Similares, have set up small consultation rooms next to their establishments, so that people can see a doctor and acquire medicines in the same place. People from poor backgrounds prefer these services because of their opening hours (seven days a week, from early in the morning to late in the evening) and waiting times are better than the MoHJ (whose facilities usually open only in the mornings from Monday to Friday). Consultation is usually cheap (between \$20 to \$50 pesos) and medicines are affordable for most patients. As an uninsured citizen, I had to use these services on more than one occasion during my fieldwork, to treat throat and stomach infections.

³⁹ This black market is close to the main hospital for the uninsured, in a zone called Barrio del Santuario. The poor and the well-off resort to this black market because there they can acquire medicines for as little as a tenth of the market price.

⁴⁰ Although medical pluralism is not the focus of my thesis, it is important to mention that some of the participants have used some type of alternative or complimentary therapy to treat CKD. For an ethnographic account of contemporary medical pluralism in Guadalajara see Napolitano (2002) and Napolitano and Mora-Flores (2003).

As in other cities in Mexico, the IMSS is the main healthcare provider in Guadalajara in terms of infrastructure, human resources and budget (DGIS, 2015; IIEG, 2011; Laurell, 2007, 2011).⁴¹ Three major acute hospitals, sixteen community hospitals and 102 primary health clinics cater for the medical needs of those who have access to Mexico's relatively generous employment-related social security system, IMSS⁴², most of them in the Guadalajara metropolitan area (IIEG 2011; IMSS, 2014, p. 254).⁴³ All the services and medicines provided by IMSS are free of charge at the point of service to those enrolled. Centro Médico Nacional de Occidente (IMSS-CMNO), a complex of three major acute hospitals, is the most important facility run by IMSS in the west of Mexico, offering services across all medical specialities to those who live in Jalisco and neighbouring states.⁴⁴ The IMSS-CMNO's renal transplantation programme specialises in living related organ donation, practising around 250 renal transplants a year, making it the most important programme in the country – no other hospital in the country reaches that number of transplants (CENATRA, 2015).⁴⁵ Haemodialysis and CAPD programmes are also available at many of IMSS's hospitals. Due to the high demand for haemodialysis among CKD patients, this institution has

⁴¹ Though less extensive, other social security institutions, like ISSSTE and SEDENA, also have facilities in the city. Both institutions have a tertiary hospital with a haemodialysis programme. However, these hospitals do not have the capacity, or license, to perform organ transplants.

⁴² See part 2 of Chapter 1 for an explanation of Mexican social security institutions and the publics they serve.

⁴³ The metropolitan area of Guadalajara comprises the municipalities of Guadalajara, Zapopan, Tlaquepaque, Tonalá, Tlajomulco de Zúñiga and El Salto. In 2010, the population of Guadalajara metropolitan area was about 4.4 million, making it the second most populated urban centre in México (INEGI, 2011).

⁴⁴ This includes the states that neighbour Jalisco: Aguascalientes, Colima, Guanajuato, Nayarit, Zacatecas, Michoacán, but also Sinaloa, some 700km westward.

⁴⁵ Crowley-Matoka (2016) provides a useful ethnographic analysis of the programme in its early years, at the turn of the century. However, as noted in the literature review, many things have changed since Crowley-Matoka's study and it is the situation as it stands today that my study seeks to capture.

out-sourced haemodialysis services to private clinics for their beneficiaries in recent years.⁴⁶

Private medical services are an option for the insured and uninsured alike. In the city of Guadalajara, private providers cover all medical specialities. Prices vary widely, with some more affordable than others. Renal medicine, however, is not cheap. Although there are several nephrology consultation offices, the average consultation fee tends to be expensive for the poor (on average \$400)⁴⁷ and renal replacement therapies are even more expensive still. Private hospitals, such as San Javier, Ángeles del Carmen, Puerta de Hierro and others, have their own haemodialysis clinics, which serve those who can afford the costs, even if it is just for a few sessions. There are transplant surgeons who practise transplantation in these hospitals, although the number of procedures they carry out is lower than in the public hospitals (CETOT, 2014). Over the last few years, new haemodialysis clinics have appeared around the city but CAPD is not offered in private hospitals and clinics and it remains a treatment that is mostly available through public institutions. Interestingly, many of the doctors who work in these hospitals also work in public institutions – e.g. MoHJ and social security – and most of them were trained at public universities. In their independent ethnographic studies conducted in Guadalajara, Crowley-Matoka (2005, 2016) and

⁴⁶ Fresenius Medical Care and Laboratorios PiSA's Sanefro share the haemodialysis outsourcing contracts tendered by IMSS; however, the health personnel at these clinics are not IMSS staff. In addition, both pharmaceutical companies are IMSS's main providers of medicines and equipment for renal replacement therapies (Portal de Compras del IMSS, 2015a, 2015b). Laboratorios PiSA, a national pharmaceutical company, is the main provider of renal medicine for the MoHJ's hospitals.

⁴⁷ Monetary figures referred throughout the thesis are expressed in Mexican pesos using the symbol \$. During the fieldwork period, the average currency exchange rate was \$20.01 per £1 (pound sterling) (Banco de Mexico, 2016). The average monthly income of a household located in the fifth decile of income in Mexico in 2012 was \$7,971; the average income of a household in the lowest decile was just \$2,332 per month. The average number of members in a household in 2012 was 3.7 (INEGI, 2013).

Kierans (2015) have highlighted the movement of healthcare professionals and patients through public and private hospitals and services.

The MoHJ is the second most important provider of healthcare services in Jalisco, serving, principally, the uninsured and Seguro Popular beneficiaries, although it is open to any Mexican citizen regardless of insurance status. While the MoHJ's facilities are distributed throughout the territory of Jalisco, the main hospitals are located in Guadalajara city. About 20 community hospitals are located in municipalities outside the metropolitan area of Guadalajara but most of them have limited capacity (less than 50 beds). In addition, in almost every community with more than a thousand inhabitants, there is a *Centro de Salud*, or primary health centre, which may consist of anything from a simple consultation room up to a small clinic with an obstetric delivery suite (IIEG, 2011). These centres cater principally for those who need to see a general practitioner, regardless of their insurance status. However, the majority of clients are the beneficiaries of Seguro Popular and Oportunidades,⁴⁸ the two main social programmes run by the Mexican Government. These centres provide a limited package

⁴⁸ Oportunidades is Mexico's conditional cash transfer programme. Oportunidades, literally *opportunities* in English, was launched in 1997 with the name PROGRESA, an acronym for Programa de Educación, Salud y Alimentación (education, health and nutrition programme), but also means 'progressing', 'advancing'. It is a third generation social policy programme which targets families below the poverty line (Valencia Lomelí & Padilla Altamira, 2010). The programme puts emphasis on the idea that 'human capital' is necessary to compete in the labour market (Valencia Lomelí, 2008). Therefore, poor people need to develop and enhance their own human capital in order to break the intergenerational cycle of poverty. Based on this hypothesis, Progres-Oportunidades gives the children of poor families the opportunity to improve and accumulate human capital (in the form of health and education), in order to compete in the labour market in adulthood. Monetary transfers are conditional on the fulfilment of particular actions, which are mandatory. For instance, the mother must attend a monthly health education lecture-workshop at a primary health centre; the family must attend the primary health centre every six months for health check-ups; and children in years three to nine of education must attend an appropriate school (years 10-12 are optional). Mexican academics have shown this programme's limits and meagre results in breaking the cycle of poverty (Barba Solano & Valencia Lomelí, 2011; Padilla Altamira, 2010; Valencia Lomelí, 2008; Valencia Lomelí & Padilla Altamira, 2010).

of medicines for free to the uninsured, but many medicines (which are not supported by Seguro Popular) must be bought by patients out-of-pocket.⁴⁹

Centros de Salud are staffed by general practitioners, nurses, a few clerks and *pasantes* –medical students near graduation, who are doing their mandatory social service year.⁵⁰ Centros de Salud usually lacks clinical laboratory facilities, and only a few centres are equipped with X-rays and other diagnostic technologies. Services in these hospitals and primary clinics are overloaded and they struggle to cope with demand. In most clinics and public hospitals service for the uninsured is organised on a ‘first come, first served’ basis. Patients begin to arrive as early as 5 am to join the queues for consultations. At 7 am a clerk allocates *fichas* or appointment slots, and the consultations begin between 8 and 9 am. A limited number of fichas are allocated which means a number of patients have to return the next day to repeat the process in order to be seen by a doctor. Since most primary health centres do not open in the afternoons, or on weekends, many prefer to pay for a consultation with a private physician.

When specialised medical care is needed, the uninsured and Seguro Popular’s clients will typically turn to one of the three MoHJ tertiary hospitals in the city of Guadalajara: Hospital General de Occidente, Hospital Alcalde and Hospital Menchaca. Hospital General de Occidente, better known as Hospital de Zoquipan, is a 215-bed tertiary

⁴⁹ As I will show in chapters 5 and 6, doctors in the nephrology service help CKD patients to get some of the medicines they need by concealing their status as renal patients through the use of alternative designations for their condition.

⁵⁰ The social service year, or *año de servicio social* in Spanish, is a mandatory public service work placement undertaken by all Mexican students from public universities during or just after the last year of their undergraduate studies (usually for free or for a very low salary). Medical students are often sent to primary health clinics run by the MoHJ in rural or semi-urban communities, far from the cities where universities are located.

level hospital located in the north of the city. Hospital de Zoquipan has its own CAPD programme and a haemodialysis unit – with about 15 haemodialysis stations – in association with Sanefro, which rents haemodialysis machines to the hospital.⁵¹ As already shown in the methods chapter, the other two hospitals are managed and run by the University of Guadalajara, although they are part of the MoHJ's network of facilities.

However, before moving on, the history of Hospital Alcalde deserves further discussion as its historical development plays a part in shaping contemporary practices and encounters between the uninsured and the healthcare system. It is not simply a medical or organisational site, it is also a moral and political one, and its modes of operation can be seen by examining how historical relationships between those providing services and those receiving them have been depicted pictorially. As a preface to the discussions that follow, I want to briefly discuss Hospital Alcalde's past through particularly powerful visual representations of these historical relations – the murals that adorn the hospital – before continuing with the stories of renal patients.

3.1.1 Fray Antonio Alcalde's gift to the suffering humanity of Guadalajara

Hospital Alcalde was founded in 1794 as Hospital Real de San Miguel de Belén. At the beginning of the 20th century its name was changed to Hospital Civil de Guadalajara, to signify its newly secularised status, but that did not erase its historical links to charity and the Catholic Church. It was renamed again at the beginning of the 1990s, when it acquired its current title, this time to honour Fray Antonio Alcalde.⁵² A

⁵¹ As none of the participants in my study attended this hospital, I did not conduct fieldwork there.

⁵² Because of his philanthropic actions and commitment to the ill, the poor and the helpless, Fray Antonio Alcalde remains an important symbolic figure and is considered one of greatest benefactors to

Spanish monk of the Dominican Order, Fray Antonio Alcalde is credited with the building of the hospital in 1786, after the famine and epidemics which struck the city the year before, killing more than two thousand poor and homeless immigrants (Oliver Sánchez, 2010). He laid the first stone of the hospital in 1787, but did not live to see it finished, dying in 1792 two years before its completion.⁵³

Hospital Real de San Miguel de Belén was famously dedicated by Fray Antonio Alcalde to *la humanidad doliente*, ‘the suffering humanity’ in Spanish, that is, to the ill and destitute. A stone carved with these words is in place above the main entrance of the old hospital buildings. Fray Antonio Alcalde’s philanthropy and commitment to the ill, the poor and the helpless is the subject of three murals that decorate selected walls of Hospital Alcalde. The first one, completed in 1993, is the work of muralist painter Gabriel Flores. He painted the curved ceiling of the wards, in the old part of the hospital, with scenes depicting episodes in the history of medicine but also of the epidemic which struck the city in the 18th century. A decade later, another mural was painted by Gustavo Peralta in the same hospital (Padilla Muñoz, 2004), depicting a similar scene, that of Fray Antonio Alcalde surrounded by the ill poor, who are begging for help, while he is extending his arms in a sign of benevolent welcome (see Figure 1).

the people of Guadalajara. One of the most important avenues in the city is named after him. There are also two sculptures of Alcalde in the city, one in the botanic garden next to the hospital and another in the garden in front of the Santuario de Guadalupe.

⁵³ According to Bayardo Rodríguez (2011), Antonio Alcalde not only obtained substantial funds from King Charles III of Spain for the construction of the hospital, he contributed his own money as well. Besides the hospital, many other projects were carried out in the city of Guadalajara under his leadership. He is credited with being the founder of the University of Guadalajara, with the construction of two important churches (Santuario de Guadalupe and Sagrario Metropolitano) and with the provision of housing for the poor, the homeless and new immigrants to the city (the last still a shelter, also named after him). However, the Hospital San Miguel de Belén is considered his major work.

Figure 1 Fray Antonio Alcalde in Guadalajara, by Gustavo Peralta



Source: Fundación Hospitales Civiles de Guadalajara.

In 2014 a third, larger mural (15 × 10 m approx., see Figure 2) was painted by Jorge Monroy for the new outpatient consultation building, the Torre de Consulta Externa. This third mural was conceived to sum up the history of Hospitales Civiles, but it also, whether intentionally or not, speaks to the experience of uninsured patients and the character of public healthcare in Mexico. The figure of Fray Antonio Alcalde dominates this work, with the local landscape, typical architecture of Guadalajara and scenes of the infamous epidemics serving as its background. At the bottom of the mural Monroy included portraits of about 50 people (most of them physicians, and only two women) recognised as having made major contributions to the hospital across its history.⁵⁴ Down to the right, an ill man representing suffering humanity, the destitute, is raising his hand to Fray Antonio Alcalde, in a gesture that resembles a beggar asking

⁵⁴ The list of people featured was handed to Monroy by Horacio Padilla Muñoz, a paediatrician from the hospital who had led in the commissioning of the previous two murals (Gustavo Peralta's and Monroy's). The inclusion and exclusion of notable doctors and people was hotly debated and commented upon in the press (Reza, 2014).

for help. Fray Antonio Alcalde, in turn, reaches towards him in a sign of compassion, but his gaze is directed to the viewer.

Figure 2 Fray Antonio Alcalde, by Jorge Monroy



Source: Hospitales Civiles de Guadalajara's Facebook page.

The concept for the mural was Monroy's. Monroy said in an interview that when he was looking for a model for the character of 'suffering humanity', he stumbled upon Carlos, a man who was selling religious paraphernalia and prayer cards on the streets outside the hospital. Carlos is a poor and homeless man from Guerrero State (700 km south east Guadalajara). He came to Guadalajara and was hit by a car on the streets. As he was uninsured, he was taken to Hospital Alcalde, where he received medical attention and his life was saved. He was so grateful to the hospital that he decided to stay, making a living selling religious postcards in the surroundings of the hospital, where he also sleeps (Pint, 2014).

It appears that Monroy wanted a model that resembled an indigenous man from Fray Antonio Alcalde's time, the suffering humanity the Spanish monk had in mind. The mural is not only a candid portrait of 18th century Guadalajaran society, however, but of contemporary Guadalajaran society as well. Carlos not only represents suffering humanity in Monroy's mural, he is a real person, a typical example of the uninsured and destitute in Mexico. While presented as an historical scene, the attitude to the plight of the poor and ill personified by Fray Antonio Alcalde is not something that Mexican society has left behind – it is an attitude carried over from the colonial period and cemented since. That is, healthcare for the uninsured remains largely a matter of charity rather than an entitlement of citizenship extended to all, despite the assurances in the Mexican Constitution to the contrary. Nowadays the poor and uninsured still beg for healthcare in public hospitals like Hospital Alcalde, but in a different way. Healthcare is not a right, at least not for the poor, but is treated as a gift given to the poor by the enlightened and pious men of medicine, religion, government and capital. Their benevolence is far from guaranteed or automatic, however, and the poor and

uninsured must work hard and learn how to conduct themselves appropriately if they are to qualify for such gifts, as the stories of CKD sufferers readily attest.

Public hospitals that cater to the uninsured and Seguro Popular's clients are not entirely free. Services come with social and financial strings attached. Hospitals and clinics are not, for example, fully equipped with a stocked pharmacy. As a result, patients are often required to buy medicines and medical supplies from one of the many pharmacies that surround them. In addition to the costs they incur in this way, the public hospitals also charge the patients *cuotas de recuperación*,⁵⁵ fees for service, according to the socioeconomic status of the patient's family. As I will show, some patients are able to negotiate their socioeconomic status with service specific social workers⁵⁶ so as to obtain a considerable reduction or even a fee waiver for the services received. Patients and family members, in turn, are asked to do certain things in return, over and above the monetary charges.

These negotiations take the form of *supplicatory practices* that have complex roots but are contemporary reflections of a colonial past. As the murals depict, the poor have to show deference and obedience to authority – doctors, nurses, social workers – if they want to receive much needed services. The model is not one of citizens claiming social rights, nor consumers buying healthcare services, though elements of both exist, but of a mass of petitioners seeking the favour of gatekeepers empowered by their office

⁵⁵ *Cuota de recuperación*, literally 'recovery fee' in Spanish, is a form of subsidised charge, common at Mexican public hospitals for the uninsured, but it is not clear how much of the charge is absorbed by the institution and the client. 'Cuota de recuperación' means, in the Mexican context, that the charge imposed is only to recover a part of the fee for the services provided, and that it is not intended to profit for the institution.

⁵⁶ The role of the social worker is examined in much more detail below and in later chapters.

and their place in the wider administration of health.⁵⁷ Doctors and nurses, who are in charge of treating the patients, are not the only figures of authority families have to show compliance with and make appeals to. In this institutional context, the office of the social worker functions as the primary institutional point where patients appeal for reductions in the financial cost of treatment. The social workers, when approached, assess the patient's socio-economic situation and decide, using a scale, the level of assistance to provide on behalf of the hospital for whom they officially (and unofficially) speak. This is not a one-off negotiation, but one that takes place every time the patient returns to the hospital. In this regard, Hospital Alcalde is a good example of both a past and a present where supplicatory practices make up a set of one-sided, unequal social, economic and political relationships – relationships captured in the murals that adorn its walls. Nevertheless, poor and uninsured people still come to this hospital as both a refuge and a last resort.

In the course of the following chapters of this thesis, I will further illustrate these practices in the encounters between the uninsured and the Mexican public hospitals, with particular focus on Hospital Alcalde. In the next section I begin that task by examining how patients begin their journeys as patients. My focus is provided by three exemplary cases that detail the trajectories that lead patients to public hospitals and the practices that enable their access to the appropriate therapy.

⁵⁷ It is important to note that the roles reverse when these gatekeepers have to turn to their superiors for support. Here officials become the petitioners who must conduct themselves with deference when approaching those higher up the chain if they are to secure favour. This reveals the system to be what Andrew Abbot terms a 'nested hierarchy' (2001, p. 8) where the supplicant-superior relationship is reproduced by being re-enacted at every level (Mair, personal correspondence). What differentiates the situation here from those Abbot discusses (e.g. soldier-officer) is that expectations are not formally set out but circumstantially determined. As a consequence, petitioners can never know exactly what might be asked of them in advance but have to improvise and respond as the situation dictates.

3.2 Symptoms, diagnosis, treatment: stories of seeking healthcare in Jalisco

Pathways to renal replacement therapies in Mexico are highly contingent and every patient's experience is different.⁵⁸ However, having observed numerous patient cases and the workings of medical services and charitable organisations during my fieldwork, I want to describe commonalities in the paths from diagnosis to treatment. This section focuses on what I described above as the socio-material conditions within which healthcare is sought in Jalisco. That is, it focuses on the fragmentation of the healthcare system patients encounter, their movement between services and between physically separated sites of service, the types of challenges they have to face and the types of resources they have to draw on in order to access appropriate treatment as well as the social relations that have to be negotiated in the process. These conditions are at once social and material in character, i.e. grounded in and produced by the relations between people but also carrying real costs and with real consequences.

The three cases I discuss in this section – Daniel, Lucero and Isabel⁵⁹ – have been selected because they typify the experiences of the majority of uninsured patients that arrive at Hospital Alcalde. Their stories enable us to visualise and understand commonalities in experiences of unexpected diagnosis and the dilemmas created by navigation through a fragmented healthcare infrastructure. I have selected the cases of Lucero and Daniel because I met them at the beginning of their trajectories and I had access to a great deal of detailed information about them – I met with and talked to them a great deal and had fieldnotes, interviews and their medical records to draw on.

⁵⁸ For further work on this issue see Kierans et al. (2013), Kierans (2015) and Crowley-Matoka (2016).

⁵⁹ As mentioned earlier, all names mentioned throughout the thesis are pseudonyms to maintain anonymity of participants.

The case of Isabel, although discussed in less detail, was selected because it exemplifies a different aspect of the shortcomings of primary health services.

Drawing on these three cases, I make a series of related points. First, I will show that being poor, uninsured and living in rural communities in Mexico brings cumulative disadvantages which play against the patients when it comes to seeking medical help. Second, I will highlight the fact that patients do not move alone but bring others with them, showing why, in their quest for medical care, family members are at the forefront of patients' stories. Third, by following and listening to patients in their attempts to secure care, I show that we gain important insights into the role of supplicatory practices and how petitioning is staged and enacted. Finally, all three cases make clear the organisational insistence on peritoneal dialysis as the only viable treatment option for patients. As I will show, it is a therapy which requires the cooperation of the patient and the family on many levels. Engaging in peritoneal dialysis in Mexico establishes new, unexpected and unfamiliar forms of work for families and patients to perform, forms of work which change according to the different stages in the trajectory of CKD. The rest of this chapter thus helps set the scene for more extended discussion of peritoneal dialysis by exploring the first requirements the patients are expected to meet following diagnosis and beginning with the case of Daniel.

3.2.1 Daniel

18-year-old Daniel was the second of Pedro and Bernice's seven children. The family was from Mezcala, a community in the municipality of Poncitlán, on the shore of Lake Chapala. Pedro, 45 years old, had always been the family's main provider, but he had never had the sort of formal job that would have entitled him, his wife and their

children to social security. Berenice, 43 years old, said ‘we always have been a *familia humilde*, a humble family’ – a family that struggled to make ends meet with a modest income. Like many other families of Mezcala, they were enrolled in the principal social assistance programmes for those on low incomes run by the federal government: the conditional cash transfer programme Oportunidades⁶⁰ and Seguro Popular.⁶¹ Berenice was, in fact, very disciplined when it came to performing her duties within the programmes, particularly Oportunidades, making sure, for instance, that all family members attended health check-ups every six months, as required by Oportunidades, at the community’s primary health centre. The whole family had attended a check-up appointment in September 2012, just weeks before Daniel started to experience the non-specific symptoms of CKD.

Daniel, like his oldest brother, had just finished secondary school and begun to work at the age of 12. According to his mother, he just wanted to work like most men in the community and earn his own money. After leaving school, Daniel worked with different people in the community, gaining experience as *peón de albañil*, or apprentice construction worker, fisherman, and *peón de campo*, or agricultural worker, at different times as and when work was available. These jobs did not require special skills, but a capacity for hard, physical work – starting before sunrise and working unprotected under the Mexican sun, sometimes poorly hydrated. As these

⁶⁰ See footnote 48 on this chapter.

⁶¹ 55% of households and 54% of the population are beneficiaries of Oportunidades and Seguro Popular, respectively (INEGI, 2011). Both programmes are voluntary, meaning that families have to request to be enrolled into them. However, there is a major difference between them. Anyone can enrol for Seguro Popular, irrespectively of income level, but those on the lowest levels do not pay the premium fees (Frenk et al., 2006). Oportunidades, in contrast, is a benefits providing programme aimed at families below the Mexican poverty line. Families’ income and assets are assessed and programme coordinators decide who will receive the subsidies based on several criteria. The results are discretionary and far from transparent; families are never sure why they were selected by the programme, while their neighbours were not.

arrangements were informal and discontinuous, Daniel was, like his brother and father and the majority of Mezcala's labour force, *uninsured*.

One day late in November 2012, Daniel returned home after work and explained to his mother that he had 'blacked out'. He had fainted during work and his workmates helped him recover. Prior to this incident, Daniel had experienced headaches and dizziness, but had not told anyone. The day after he fainted, Daniel's feet started to swell and he began to worry that something serious was involved. Concerned with her son's health, Berenice decided to take Daniel to a doctor in Santa Cruz de la Soledad, a town some 20 km west of Mezcala. When I interviewed Berenice, she explained that when a family member became ill, she would take them to private doctors located in Santa Cruz de la Soledad, because she does not like the service provided in the Mezcala's Centro de Salud. Being seen by a doctor in the primary health centre of the community, meant queuing as early as 6 am, although the doctors arrive at 9 am and your turn might not come until 12 pm. She preferred, instead, to pay \$50.00 to go the doctor of her choice and wait for a shorter period to, according to her, receive better medical treatment.

Figure 3 Mezcala's Centro de Salud



Source: My own.

On the 29th of November 2012, Berenice took Daniel, whose condition had worsened, to a private consultorio in Santa Cruz de la Soledad. They saw Dr Arrayga, who checked Daniel's vital signs. She noted that his blood pressure was very high and prescribed medication to control it, recommending rest for three days. The next day, Berenice took her son to have blood and urine tests at the local laboratory, Laboratorio Clínico El Lago.⁶² Dr Arrayga requested a complete blood count and urinalysis, which are the usual tests used to diagnose CKD. The cost of both tests was around \$600,

⁶² El Lago clinical laboratory is a small business owned by a chemist from Chapala Town. She opened her laboratory in the Chapala Town and later opened a small branch, a sample collection unit, in the community of Mezcala, to serve those communities of the east of the lake. In Mezcala, El Lago clinical laboratory is open from 8:40 am to 10:45 am from Monday to Friday. The samples are then taken to the laboratory in Chapala, where the analysis is carried out. The results can be collected the next working day.

almost the weekly wage of an agriculture or construction worker and how much Daniel was being paid when he was working.

Figure 4 El Lago clinical laboratory, sample collection unit in Mezcala



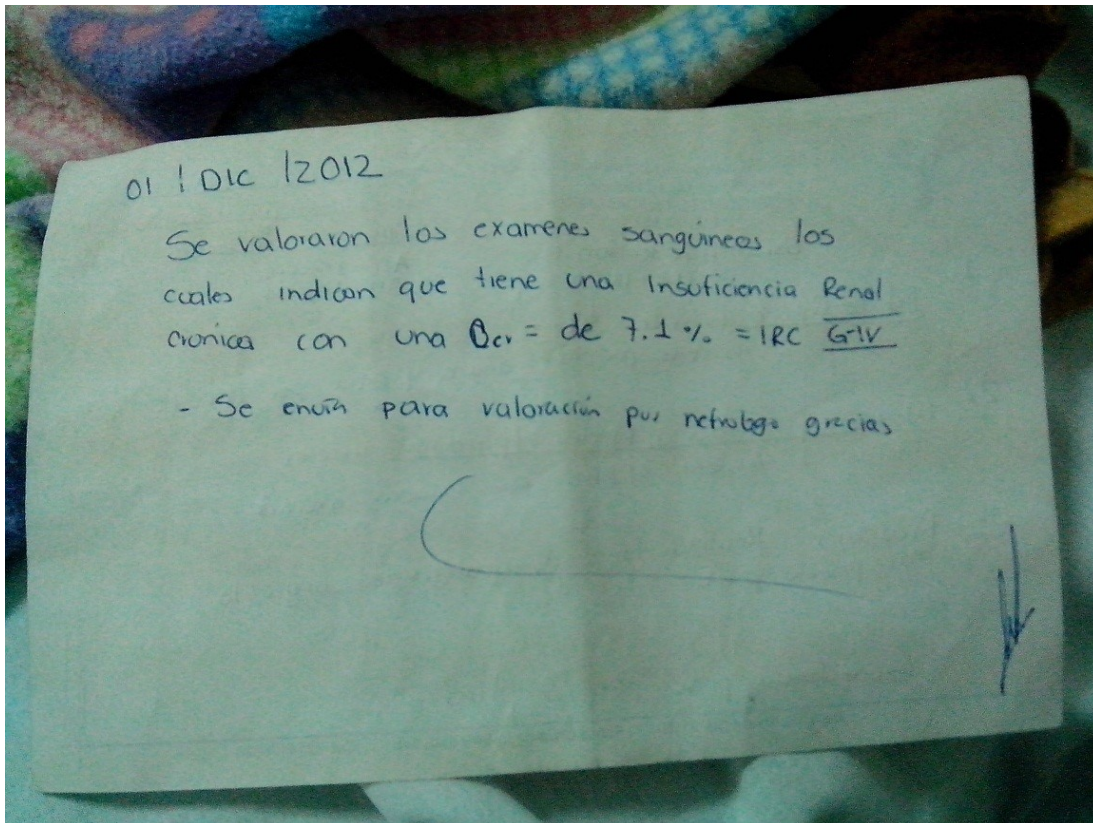
Source: My own.

Pedro collected the results of the tests the next day and Berenice took them back to Dr Arrayga. The results showed that Daniel's blood was very high in urea and creatinine, and very low in haemoglobin.⁶³ Dr Arrayga told Berenice that her son was critically ill and told her she should take Daniel immediately to the emergency service at Hospital Alcalde. Dr Arrayga used the back of the test results as a 'referral note,' and

⁶³ I had the opportunity to see Daniel's clinical results when I interviewed his parents in their home in Mezcala. Patients and families are usually made responsible for their own files (Kierans, 2015). The clinical exams showed that his serum creatinine was 14 mg/dL, more than ten times higher than the normal adult male parameters (0.8-1.3 mg/dL); his urea was 200.2 mg/dL, while the normal parameter is 10-55 mg/dL; and his haemoglobin was 11.9 g/dL, below the 14-18 g/dL normal range. Like the majority of CKD patients, Daniel, Berenice and Pedro were in no position, however, to make sense of this information. They were, thus, structurally reliant on the advice and guidance of the doctor.

wrote the following: ‘Blood test was evaluated, which indicates that the patient has chronic renal failure with a $Der^{64} = de 7.1\% = CKD\ G-IV$. The patient is to be evaluated by nephrology. Thanks’. However, this informal referral note was not addressed to a particular hospital, and the family was given very little information about how to get access to the emergency service.

Figure 5 Back of Daniel’s prescription note, with Dr Arrayga’s annotation



Source: My own.

On Saturday 1st December 2012 Pedro and Berenice took Daniel to the Servicio de Urgencias, the emergency service of Hospital Alcalde, and showed Dr Arrayga’s note to the doctors there. The family waited several hours until a doctor evaluated Daniel’s

⁶⁴ ‘Der’ seems to mean GFR, which stands for glomerular filtration rate, the parameter by which the functioning of the kidneys is evaluated. A person with a normal renal function has a GFR >95 mL/min/1.73 m². Current clinical guidelines of CKD (KDIGO Work Group, 2013) indicate that stages IV is between 15 to 29 mL/min/1.73 m², and stage V is < 15 mL/min/1.73 m². If Dr Arrayga’s calculations were right, Daniel was in CKD stage V not IV as she suggested in the note.

condition, but told Pedro and Berenice that their son's situation was not critical and they should bring him to the outpatient consultation service instead. Berenice had been very upset: as she recalled, 'Doctor Arrayga wrote 'please, attend to him because it is an emergency', but they told us he didn't need urgent medical attention.'

Two days later, on Monday 3rd December, Berenice paid a friend to take her and Daniel to Hospital Alcalde very early in the morning. They arrived before 7 am and queued for about an hour to pay the consultation fee. They waited until around 10 am, when Daniel finally was seen by a doctor. Once again, Daniel was not considered to be in a critical condition. He was sent home and given an appointment at the end of the month. Berenice was utterly disappointed with Hospital Alcalde's service and felt they were being ignored by the hospital staff – 'They don't listen to you', she told me when I interviewed her.

Three days later, Daniel's blood pressure 'sky-rocketed' and he started having seizures. However, Berenice and Daniel were reluctant to go back to the hospital, due to their recent disappointments there. Ofelia, Berenice's mother, however, convinced them it was important and volunteered to accompany them to the hospital. This was to prove important. Ofelia had experience navigating the hospital and dealing with healthcare personnel, because her son Ronaldo was also a renal patient.⁶⁵ With the help of a neighbour who had a car, Daniel was taken again to Hospital Alcalde's emergency service, where this time his condition *was* deemed serious enough to warrant medical attention. According to Berenice, her mother's involvement was key for Daniel's acceptance to the emergency service, where he was put in for observation.

⁶⁵ Ronaldo, Ofelia's youngest child, was 22 years old, only four years older than Daniel. I will discuss Ronaldo's case in chapters 5 and 6.

Hours after arriving at Hospital Alcalde's emergency service, Daniel was transferred to the hospital's nephrology ward. There, the family was informed that Daniel had end-stage renal failure, he had reached CKD stage V⁶⁶ and he urgently needed dialysis to survive. Berenice said that the doctors did not give her any option, simply that Daniel needed peritoneal dialysis. As noted in previous chapters, peritoneal dialysis is the first-line therapy offered by Mexican public hospitals to patients with CKD, either insured or uninsured. Given the lack of resources in Hospital Alcalde, the medical personnel of the nephrology service frequently ask that families buy their own materials and medications, or pay for further diagnostic tests from private service providers.⁶⁷ In this case, Berenice was told to buy three items needed to start peritoneal dialysis in the hospital – a Tenckhoff catheter,⁶⁸ a titanium connector, and a peritoneal dialysis transfer line⁶⁹ (see Figure 6). However, Ofelia and Berenice did not have enough money to buy the Tenckhoff catheter at that moment, which cost about \$1,000. They pleaded with one of the resident doctors to help them, who agreed to write a

⁶⁶ CKD is divided in five stages, according to the rate of waste product filtrated from blood (see footnote 3 in the Introduction). According to clinical guidelines, patients who reached stages 4 or 5 need some form of dialysis or a transplant (KDIGO Work Group, 2013).

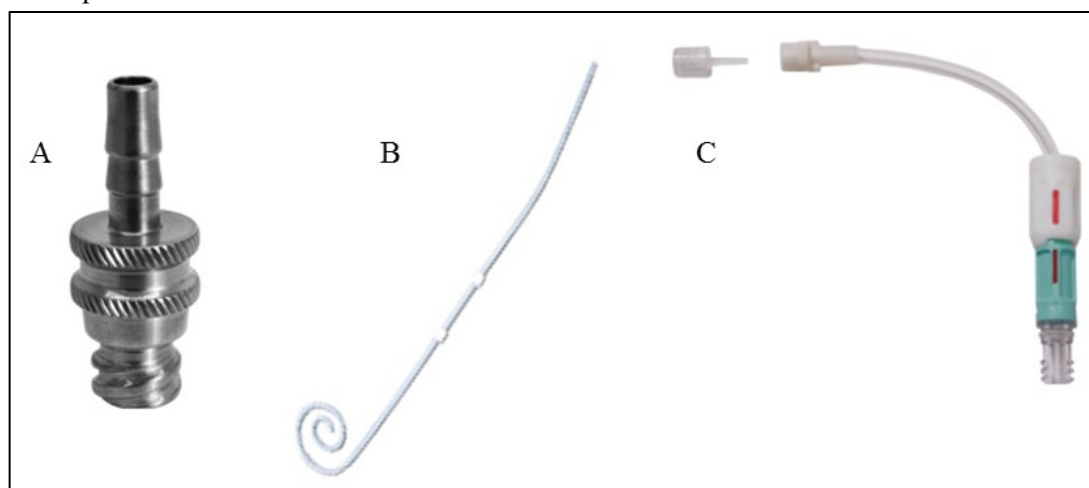
⁶⁷ Patients and their families are told to acquire medicines and surgical material from the pharmacies and medical retailers that are located outside Hospital Alcalde.

⁶⁸ A Tenckhoff catheter is a flexible silicone tube used as permanent access to the peritoneal cavity for the purpose of dialysis. It was first developed by Russell Palmer in 1964, but later modified by Henry Tenckhoff in 1968, after whom the catheter was named (Cameron, 2002). According to Negoï and Nolph (2009, p. 11) Tenckhoff's modifications were 'a major breakthrough and became the most important factor in promoting peritoneal dialysis in other centres'. Almost four decades later, the Tenckhoff remains the standard catheter for peritoneal dialysis.

⁶⁹ The three separate elements are assembled to produce a single device, which will become "the catheter", as it is experienced by patients and practitioners. The titanium connector serves as safe connection between the permanent Tenckhoff catheter and the transfer line, which is replaced every six months. Due to the use of PiSA's products at Hospital Alcalde, patients are told to buy the products from this company. The transfer line piece, in particular, is essential because it is the only type of transfer line that suits the products used in the hospital. It is a similar practice used by Baxter, whose products do not suit PiSA's and vice versa.

reference letter addressed to the social work office requesting support to acquire the catheter in question.⁷⁰ Their plea was successful and they did not have to pay for it.

Figure 6 Material requested by the nephrology services to patients starting peritoneal dialysis at Hospital Alcalde



Source: Laboratorios Pisa (2010). Notes: A. Titanium connector (3 cm approx.); B. Intraperitoneal Tenckhoff catheter (40 cm approx.); C. Pisatek© transfer line for peritoneal dialysis (15 cm approx.).

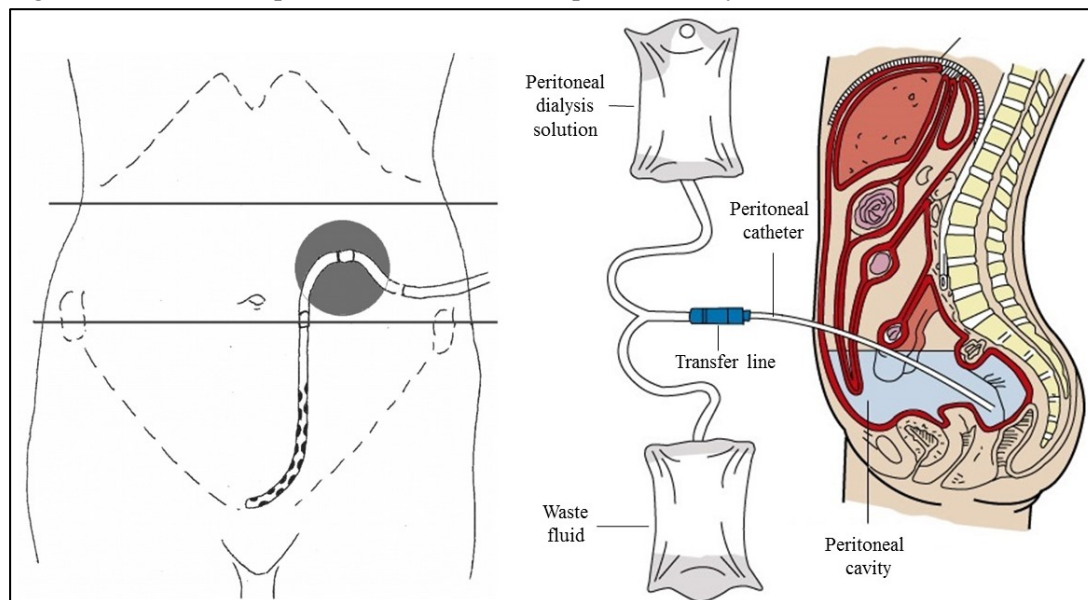
Once they had obtained it, the catheter was surgically implanted into Daniel's abdomen in order to start peritoneal dialysis in the hospital. The Tenckhoff catheter, the titanium connector and the transfer line, once connected to Daniel's body through his peritoneum, were assembled in such a way as to form a therapeutic device,⁷¹ one that would replace the kidney's functions of waste and excess of liquid removal from his body (see Figure 7). Daniel was put on intermittent peritoneal dialysis, a modality of treatment carried out in the hospital with the help of a machine called a 'cycler'. Via this modality, the machine infuses two litres of dialysate solution into the patient's

⁷⁰ Berenice had saved the letter in her makeshift files, which, like nearly all those in the public hospital system, she carried with her all the time.

⁷¹ As Mair and Kierans pointed out in personal correspondence, the assembly or 'assemblage' formed by catheter, connector, line and body is important (Law, 2004, p. 18) as it is this body-machine hybrid which enables the patients to become the embodied interface required for CAPD to work.

abdomen and drains it out every one or two hours. The cycle is repeated 20 to 30 times to complete a session.

Figure 7 Placement of peritoneal catheter in the patient's body



Source: Li et al. (2012), SehatSelalu (2010).

Daniel, Berenice and Pedro knew little about peritoneal dialysis. They were aware that Ronaldo, Berenice's brother, had been undergoing peritoneal dialysis at home for more than three years. They knew that the catheter was essential to 'wash' Daniel's body with a 'special water' (the dialysate solution), which would remove the toxins that were making him ill. But their grasp of the procedure which was now the only route to Daniel's survival was experientially 'thin', sketchy rather than filled out (Geertz, 1973), particularly its transformative implications. Nonetheless, that journey had begun and Daniel, having been made physically compatible with the treatment programme's material interfaces through surgery, was subsequently hospitalised for four days during which he received a session of intermittent peritoneal dialysis. When Daniel was discharged from the hospital, he was given an appointment for a second session of in-hospital intermittent peritoneal dialysis at the end of the month.

During Daniel's stay in the hospital the family was assessed by the *trabajadora social*, the social worker attached to the nephrology department, who recorded their details in the department's registry. Ofelia and Berenice pleaded with the social worker to reduce the hospitalisation charges they were facing, arguing that they were a poor family who didn't have enough money to pay. The social worker accepted their plea and classified Daniel's family in the lowest socioeconomic bracket on the hospital's scale, waiving the charges. She also informed them that Seguro Popular did not cover any treatment, medication or service specific to CKD. In spite of that, she recommended that they update their enrolment status within Seguro Popular, because it could be useful in the future.⁷²

In just two weeks, the lives of Daniel and his family changed drastically. Daniel was an ordinary young man, from a *familia humilde*, who was working in his community, earning his own money and contributing to his family's income. Suddenly, he found himself one of a rapidly increasing cohort of people diagnosed with a chronic disease in the communities of Lake Chapala. Moreover, unlike some of his more fortunate counterparts, he was facing the problems of being poor and uninsured in a context of a fragmented and multi-tiered healthcare system. It turned out that being a beneficiary of Oportunidades and Seguro Popular was not enough to help him: neither would secure quicker or less costly access to medical services. But private care was no guarantee of better treatment either, as Berenice had initially thought. Dr Arrayga certainly detected CKD, which was then corroborated in the hospital, but the lack of a

⁷² In chapter 5 I will discuss how doctors help patients to access some support through Seguro Popular to pay the costs of, e.g. x-rays, blood and urine tests, or hypertension medications

referral system between private and public providers prevented Daniel from receiving timely care.

The intervention of his parents and extended family proved to be critical. As we see in Daniel's case, patients in Mexico rarely stand alone. The intervention of Ofelia, Daniel's grandmother, was crucial to overcoming the bureaucratic and organisational hurdles that blocked access to the hospital. Having experience in navigating the hospital's bureaucracy and dealing with hospital personnel, Ofelia helped her grandson receive the care he needed and, just as importantly, qualify for reductions in hospitalisation charges (which he was eligible for but would not automatically have been given – little is automatic in this context). Moreover, as Daniel's case also shows, relatives are called on to provide medical supplies to the hospital and undertake diverse forms of work on behalf of the sick family member. Securing access to treatment involves the work of many people and the family is intimately involved.

Pedro and Berenice would later be summoned to an introductory meeting, where they would be informed about the home peritoneal dialysis programme the hospital runs. This process of admission, and the multiple transformations it implies, is the focus of chapter four. Despite the complexities discussed above, Daniel had just embarked on the unpredictable trajectory of CKD and its therapies; intermittent peritoneal dialysis was only the starting point. But, as I mentioned before, his case was far from unusual, many other people from the communities of Lake Chapala would receive the same fate. In the next section I introduce Lucero and her family, whose situation was similar to that of Daniel and his family in several respects, but whose experiences with the build-up of symptoms and path through public and private medical services help us to deepen our understanding of the CKD experience in Mexico.

3.2.2 Lucero

José and Úrsula, Lucero's parents, were born in Agua Caliente, a community located on the slopes of one of the mountains that surround Lake Chapala, in the municipality of Poncitlán. They married when José was 18 years old and Úrsula was 17, and over the years they had eight children. By 2013, José and Úrsula were reaching their 60s and seven of their children had already married and formed their own families. Lucero, the youngest in the family, was their only single child and still lived with them in their house in Agua Caliente.

Lucero was 19 years old when I met her in 2013. She had dropped out of school before completing her primary schooling, due to learning difficulties, and her parents had not forced her to return. She was not the only one in the family to drop out of school at an early stage. Her parents and five of her siblings had failed to complete primary education, mainly due to economic reasons. The family had always struggled to survive with a low income, and securing paid work had priority over education. José worked as a construction worker until the age of 30, when he suffered an accident. He had fallen from a 3-metre-high scaffold, injuring his left leg and foot, and limped ever since. José was barely compensated by his employer and had to find a new job elsewhere. He moved between different informal jobs and local agriculture for several years, until he got a job as a night watchman in a hotel in Poncitlán.

Having a low-salary job and being uninsured meant that all José's children had to work from their teenage years on to contribute to the family's income – the men working in construction, agriculture and fishing and the women primarily as domestic servants for better-off families. Around the age of 15, Lucero began working as a *sirvienta*, a maid, for an upper-class family in Guadalajara City. This is one of the few job opportunities

available for young girls from rural communities in Mexico. It does not require any special skills, nor a specific level of education, but simply the ability to perform domestic tasks – cleaning, cooking, ironing, taking care of children – and show appropriate deference to employers while doing so. Lucero worked Monday to Friday in Guadalajara, staying in the house of her employers and returning to her parents' house in Agua Caliente only at the weekends. 'It was an easy job', Lucero once told me. With her salary, which was a little higher than that of a typical agricultural worker from her community, she contributed to the family's income. Like the majority of *sirvientas* in Mexico, Lucero's employers did not provide her with social security. In fact, no one in her family had social security from their jobs, instead relying only on the services of the MoHJ and private doctors when needed.

Like all families from the community, Lucero's was enrolled in the two main Mexican social policy programmes, *Oportunidades* and *Seguro Popular*. Úrsula, José and Lucero, the three registered members in *Oportunidades* in the family, complied with their duties to visit the primary healthcare centre for a check-up every six months. Although the amounts involved were relatively small, the cash benefits released by participation in *Oportunidades* contributed to the family's income. *Seguro Popular* had proven particularly helpful to them as well, particularly when it came to pregnancy related care, something Úrsula had accessed in the past. On the basis of this experience, José and Úrsula had taken the government's claims at the time at face value, i.e. that *Seguro Popular* was similar to IMSS and that all medical services were covered by the programme. It was not until Lucero became seriously ill with CKD that they realised this was not in fact the case.

As with Daniel, CKD disrupted Lucero's biography (Bury, 1982). However, in her case, the symptoms appeared slowly and built up over several months, during 2011 and 2012. Lucero recalled that she experienced the first symptoms about six months before being taken to the doctor: 'I suddenly started to feel very tired and I lost my appetite when I was still working in the house of the lady in Guadalajara, but I didn't know why and I didn't care too much about it. Even if I felt tired, I had to work'. These diffuse and unspecific symptoms confused her, as she didn't think it was a serious illness, and never imagined it was related to her malfunctioning kidneys. Headaches and nausea followed the sensations of weakness and loss of appetite. The woman who employed her suggested she was pregnant, and even told her to take a pregnancy test, but Lucero replied that she knew she wasn't pregnant. Lucero made an effort not to complain too much about her ailments, because she was afraid of losing her job. The symptoms worsened and, by April 2012, her feet and face became swollen and her skin had turned a yellowish hue. At that point she quit her job, although her employer still wanted Lucero to keep working for her.

Worried because of the sudden and unexplained illness of her daughter, José and Úrsula took Lucero to a private doctor in Poncitlán, one that they could afford. They consulted a doctor in May, who prescribed her medication for high blood pressure and nausea, and recommended Lucero rest for a few days. However, the symptoms persisted and in June, José took Lucero to another private doctor in Poncitlán, who also prescribed anti-hypertensive drugs and other medicines to treat the severe anaemia she was having, which did have a positive effect on Lucero's health, although only for a short time. In August, seeing that Lucero's health hadn't improved, José and Úrsula decided to take her to Poncitlán's Centro de Salud, as a last resort, although that implied waiting for two to three hours to be seen. According to José, the doctor of the

Centro de Salud requested Lucero take blood and urine tests. Since Poncitlán's Centro de Salud did not have a laboratory, the family took Lucero to the nearest private clinical laboratory in town. A day after, by the end of August, José picked up the results and handed them to the doctor, who in turn, told José to take his daughter immediately to the hospital because her condition was life-threatening.

The doctor wrote a letter – a referral note, put it in a sealed envelope, and told José to hand it over once he arrived at the emergency service of Hospital Alcalde. José followed the doctor's instructions and took Lucero to the hospital at the beginning of September. As José's family did not own a car, he asked a friend to take them to the hospital in Guadalajara city, some 80 km from their community. Once arriving at the hospital, José, Úrsula and Lucero had to wait in the reception of emergency service. The letter was not necessary in the end because the staff recognised the seriousness of Lucero's condition. José saved the letter, in the original envelope, with other documents in his makeshift file, which he carried every time they went to the hospital. He never dared to open it.

Lucero spent several hours in the emergency service. At that point, her parents still didn't know what Lucero's problem was. Eventually, Lucero was transferred to the nephrology ward, where they were finally informed that the problem was her kidneys. She had uremic syndrome, that is, the accumulation of toxins (waste products) and liquids in her body⁷³ and she urgently needed dialysis if she was to survive. As with Daniel, Lucero's parents were told that peritoneal dialysis was the only option

⁷³ Uraemia, or uremic syndrome, is the main manifestation of kidney failure, characterised by a set of nonspecific symptoms such as fatigue, loss of weight, anaemia, nausea, and others (Meyer & Hostetter, 2007). The majority would simply learn that their damaged kidneys caused them to accumulate toxins and liquids in their bodies, but didn't understand the meaning of the word uraemia, which would feature on the discharge notes they would receive after being hospitalised.

available to her. It was September 2012, about nine months after the symptoms had first appeared.

Like all other patients who arrive in the same condition at the nephrology service of Hospital Alcalde, Lucero's parents were told to buy the materials needed for intermittent peritoneal dialysis in the hospital. But José did not have enough money and could not afford the items asked for. He had to call a relative who lived in Guadalajara to ask him for the money to buy the materials for peritoneal dialysis. This relative, a *compadre*,⁷⁴ came to the hospital and lent them enough money to buy the materials: a catheter, a titanium connector, and a transfer line (see Figure 6 on page 131). The catheter was surgically inserted into Lucero's abdomen shortly after her family secured it. In order to start intermittent peritoneal dialysis, José also had to buy four sets of tubes and drainage bags for the peritoneal cyclor machine Pisatek Biosafe© (see Figure 8). While the hospital provided dialysate solution, when it came to this specific cyclor machine, the patients had to provide the tubing and drainage bags needed to catch the used dialysate after it had been 'cycled' through the patient's abdomen.

⁷⁴ *Compadrazgo* is a form of ritual kin relationship, like that of the god parent elsewhere, common in Latin America and the Iberian Peninsula. This form of kinship is established through Catholic rites of baptism, first holy communion, and marriage. In Mexico, *compadrazgos* are usually established through the rite of baptism, where the biological parents ask a close friend or a relative to become a *compadre* or a *comadre* (Van den Berghe, 1996). This usually leads to strengthen the bonds between the parts, who call each other *compadre* and or *comadre*. This form of kin relationship can be a source of different sorts of support, especially in times of economic crisis and health related problems (Kana'iaupuni, Donato, Thompson-Colon, & Stainback, 2005).

Figure 8 José holding the Pisatek Biosafe© cykler set he had just bought



Source: My own.

While Lucero was hospitalised, José and Úrsula were interviewed and received the same ‘induction’ to the hospital’s nephrology service as Daniel’s parents did by the social worker. She assessed their socioeconomic status, informed them about costs of treatment and the issues with Seguro Popular, and summoned them to the introductory meeting to the CAPD programme in the next slot available. José and Úrsula, like many other parents and patients who relied on Seguro Popular, were taken aback to find out that the programme did not cover CKD, contrary to the government’s claims. The only thing they could do was draw on their own resources and networks of support to cover the costs of treatment. They were classified in the lowest socioeconomic level, and as such, most hospitalisation charges were waived, and they just paid \$350 that first time. However, although that sum seems very low, it wasn’t for a poor family already financially strained by Lucero’s disease.

Lucero spent three days in the hospital, after which she was discharged from the hospital and given an appointment for another session of in-hospital dialysis. A few weeks later, an ultrasonography was conducted to determine the aetiology of Lucero's kidney failure. José and Lucero remembered being told that her kidneys were *chiquitos*, literally small, that they never grew, never developed to the normal size and that was what had caused her renal failure. That explanation didn't satisfy Lucero and her parents, but they couldn't do anything but accept the doctors' diagnosis. In a matter of months, Lucero's life, just like that of Daniel's, had been radically altered.

While Lucero was the person who fell ill, it was her parents who sought medical care for her. As in the case of Daniel, we again clearly see that patients do not stand alone. Once she disclosed to her parents that she was feeling sick, they took on the responsibility of seeking medical care for her, drawing in support from friends and relatives to do that. It was their decision to first consult a private doctor, for instance, because they considered him to be a good option or, more accurately, the best option available to them under the conditions. When Lucero didn't respond to the treatment, they took her to another service and then another, until finally they arrived at the hospital. In this sense, the beginning of Lucero's illness trajectory was also one she shared with her parents.

Misdiagnosis was common among the patients who participated in my study and all patients who were misdiagnosed experienced delays in treatment.⁷⁵ However, even patients with more 'conventional' aetiological profiles – i.e. whose CKD could be

⁷⁵ Misdiagnosis is not uncommon, and can occur in lots of different ways with a range of negative consequences.

traced to hypertension – faced problems, something I will discuss next through the case of Isabel.

3.2.3 *Isabel*

Isabel was a 46-year-old woman from Chapala Town. She married Luis in her early twenties and they had three children. Their humble house, roofed with asbestos cement sheeting panels,⁷⁶ was located close to downtown Chapala. They were a fairly typical working class family from the town, employed in the informal economy of tourism. Luis worked in one of the stalls located in Chapala's promenade, selling *nieve de garrafa*, a type of locally produced ice cream and sorbet, very popular among tourists from Guadalajara. Sometimes Isabel joined Luis and helped him to attend to the customers. Luis had worked in several other informal jobs. As I showed in the previous cases, in Mexico working in the informal economy carries risks as such work falls outside protections against disease and accidents. This was the case with Isabel, who had relied upon the MoHJ services to treat the hypertension she had suffered for at least fifteen years. She also relied on private local doctors to treat other less serious episodes of disease (respiratory or gastrointestinal infections, for example), including the services of the Farmacias Similares chain, who offered medical consultation and medicines for a very low price.

Between 2005 and 2006, Isabel experienced a series of unrelated symptoms, which, when I interviewed her, she believed had been signs of her failing kidneys. At the beginning, she recalled, they came in the form of a recurrent flu, which returned almost

⁷⁶ Asbestos is not banned in Mexico, despite its known risks to human health. Many Mexican poor families use asbestos cement panels to roof their houses.

on a monthly basis. At the same time, Isabel began to have painful cramps all throughout her body. She also experienced a generalised weakness, an inexplicable feeling of tiredness that disrupted her everyday life and routines. What made Isabel seek care was diarrhoea and nausea she suffered for at least three weeks. These symptoms were, perhaps, the most difficult for her. She remembered going to the toilet and passing '*pura agua*', that is, several liquid bowel movements. Isabel could barely eat anything due to the vomiting. At that point, she had no other choice but to seek medical help. As she was uninsured, Isabel told her son to take her to 'Farmacias Similares' doctors in Chapala town. She chose this type of service just for convenience, as she thought there might be a rapid solution for her upset stomach. However, it turned out that the doctor who saw Isabel wrongly interpreted her symptoms and told her that perhaps she was pregnant. Isabel was unhappy with the service and sceptical about the doctor's diagnosis. She laughed when she told me about that experience and said 'that doctor was a real idiot'.

Figure 9 Farmacias Similares in Chapala



Source: Google Maps.

The symptoms persisted and, a few days later, Isabel's sister took her to Clínica Municipal de Chapala, which is a small surgery managed by the municipal council of Chapala, and dependant on the MoHJ. This clinic provides a few services such as emergency, obstetrics, dentistry, and also has X-ray and clinical laboratory services (for the hospital, not the public). The doctors there told Isabel that her symptoms were similar to that of pregnancy, but for her age that seemed unlikely. She was given blood tests in the clinic, and they examined her further. When the doctors got the results they told her immediately to go to Hospital Alcalde. Isabel said that the doctors in the clinic gave her a letter, which she handed over the doctors of the emergency service of Hospital Alcalde. She didn't know the content of the letter, but for her, it represented 'her pass' to the hospital. She was admitted the same day to the emergency service. Eventually she was referred to the nephrology ward, where she was diagnosed and informed about her renal failure, remaining in the hospital for about three weeks.

Isabel said that for fifteen years prior to deterioration of her health, she had been attending the primary health centre to be treated for her hypertension. She was given medicines and medical consultation there for free, but was not provided with any indication of what was to follow. She evaluated this experience and regretted that little was done to prevent further complications:

I always attended the Centro de Salud to receive treatment for my hypertension. I attended every month and I got the medicines for free. We even used to do exercises, with the hope of controlling the hypertension and not taking too many drugs. And there were talks at the Centro de Salud. But I don't remember being told that this [CKD] could happen to you. I think that they should have warned us, or at least they should have given us a less harmful treatment. But they never said anything. It [CKD] is what you get from having hypertension and for taking drugs for so long, but I wish I had been told this before.

Isabel recalled that at the hospital she was told that the mismanagement of her hypertension and the long-lasting use of anti-hypertensive drugs had caused her kidney failure. During her stay at Hospital Alcalde she was initially treated with haemodialysis, but the venous catheter, which was inserted in her chest, failed several times. Eventually, she was taken home, but was told to return to the hospital a few weeks later. When she returned, Isabel was transferred to peritoneal dialysis, although she didn't remember the reason for the change. Like all patients who are offered peritoneal dialysis, the relatives of Isabel were also asked to bring all materials necessary for this form of dialysis to the hospital. She was hospitalised again, the catheter surgically inserted and she initiated intermittent peritoneal dialysis in the hospital – the prelude to the next phase of her journey as a patient.

The three cases I have discussed, those of Daniel, Lucero and Isabel, show how public and private primary health services fall short when it comes to CKD, even when it comes to identifying new cases in populations at risk. Lucero and Daniel's stories overlap in several ways. Both had some coverage through governmental protection schemes, primarily Oportunidades and Seguro Popular, the main social programmes for low income households. However, falling ill with CKD highlighted the shortcomings of both programmes – the families learned, at their cost, that they provide little support for chronic conditions either before or after diagnosis.

Lucero's case was also, however, different to Daniel's in a number of respects. The initial onset of CKD was not as overwhelming and Lucero waited until she left her job. She did this because she didn't want to lose a regular source of income if that could be avoided, although in the end, it was inevitable. Despite being an informal job, with no social security protection, it was important for Lucero and her family. Yet, she experienced, as Daniel did, the risks of informality – their jobs and employers were not liable, neither they were willing, to provide support once they fell ill.

Unlike Daniel's case, local private doctors misdiagnosed Lucero's condition. That delayed proper diagnosis and extended Lucero's suffering. The case of Isabel is also exemplary in this respect. Having suffered from hypertension for many years, the services she had access to failed to prevent further damage to her health. Isabel is not alone. Many uninsured middle-age and elderly people suffering from diabetes and hypertension are developing renal failure because of inadequate care.

This, then, is a system that exacerbates problems at the very moments it is meant to be responding to them. An arrangement predicated on conditionalities – where patients and their families can only gain access to treatment *if* they have completed some prior

step, meet certain criteria or carry out whatever tasks might be required of them across a disconnected host of clinical and para-clinical sites – it does not facilitate the work of diagnosis but interrupts it. As all the cases above make clear, this has a range of negative consequences for patients and their families. As the next chapter will make clear, this is a sign of what is to come as they progress along their treatment journey.

3.3 Conclusion

This chapter analysed the socio-material conditions within which patients, and those who accompany them, work to access diagnosis and treatment in the context of Mexico as well as the various routes they must take to do so. I have reviewed the cases of Daniel, Lucero and Isabel in some depth, focusing particularly on the beginning of their trajectories as renal patients. By following them from their starting points, as argued earlier in the chapter, we learn a series of important lessons about social and cultural relations and the practices which ground them and give them shape in particular circumstances.

In the first part, I highlighted the fragmentation of healthcare services, but also the role of Hospital Alcalde in the care of the poor and uninsured of Jalisco. The fragmented structure of the Mexican healthcare system and the type of social relationships that characterise it, I suggested, shape the types of trajectories traced by renal patients as they move through the Mexican healthcare system. In this conclusion, I want to emphasise a series of analytical points to summarise the contributions of this chapter.

First, the progressive character of disadvantage has real consequences for health. It is well established that living in poverty leads to poor health (Whitehead & Bird, 2006). In Mexico, the majority of poor families participate in the informal economy and, as

consequence, they lack access to social insurance and comprehensive healthcare. The only services available to the poor, particularly those who live in rural areas, are limited and of low quality. The Mexican government has acknowledged these inequalities and Seguro Popular and Oportunidades, the two main social programmes of the last decades, were designed to tackle them. However, on the local level, both programmes fail to protect the health of their clients (Hernández-Ibarra & Mercado-Martínez, 2013; Kierans et al., 2013; Molina & Palazuelos, 2014), particularly when it comes to chronic conditions, as the stories of Daniel, Lucero and Isabel have demonstrated.

Oportunidades, for example, asks that family members visit the primary health centres twice a year for a medical check-up, but that is not enough to detect chronic conditions like CKD. Seguro Popular, on the other hand, constituting as it does a contemporary field of biopolitics in which some health conditions are selectively prioritised and others ignored on the basis of instrumental social, political and economic calculations (Foucault, 1978; Kierans, 2015), actually works to lock the poor and uninsured who develop CKD out of systems of formal support. As a consequence, the poor and uninsured are driven to find other forms of support in whatever ways, using whatever resources and under whatever pretexts or pre-scripts that they can make work as part of securing care. The paths taken by Lucero, Daniel and Isabel, and in fact all renal patients, show the tremendous costs this incurs, and not just financially, also at the interpersonal level. The State does still protect them through the work of hospitals devoted to the uninsured, the ill and destitute, they are not simply left to die (Gupta, 2012). But in order to qualify for that protection patients and families had to engage in a range of different kinds of supplicatory practices, practices that have historically characterised these types of hospitals, if they want to survive. Supplying proof of moral

eligibility through situated displays of compliance, whenever and however those may be demanded and whatever the costs, is the condition of entry (Goffman, 1956).

Second, the prevalence of such conditions within the public healthcare system, and the hierarchies of consideration which inform them, is one of the central reasons why patients choose to engage with those services only when they absolutely have to. Even though most patients are enrolled in Seguro Popular and Oportunidades, they will opt to consult private doctors when faced with problems unless the circumstances are truly desperate so as to avoid the waits, the costs and the demands ‘going public’ will place on them. But private services are problematic, frequently misdiagnosing patients (as is true of local public health services too, as Isabel’s case showed). Furthermore, the stratified character of the healthcare system, its division into services differentiated according to how affordable they are, exacerbates the problems of misdiagnosis, delaying accurate diagnosis and access to appropriate treatment. Even when diagnosed correctly further problems arise, as we saw in the cases discussed. The lack of an efficient referral system between private and public services, and between primary and tertiary level of attention, was clearly evidenced in the cases discussed. Thus, the community level public and private healthcare services patients turn to instead of the more comprehensive federal and state systems, are extremely problematic.

This leads us to the third point. What the cases show is that, in the context of Mexico, being sick is not enough to guarantee access to treatment. Instead, patients and families have to work to negotiate their access to healthcare services over and over again. Despite the problems that attend them, patients do begin their illness trajectories by negotiating diagnoses in community or private service settings in order to secure referrals to tertiary hospitals, where treatments for CKD are available. But upon arrival

at the hospital, they have to restart the process of access and diagnosis. This, in turn, places additional burdens on families and patients, making the experience of seeking healthcare more difficult. New conditions have to be met at every stage. If they cannot satisfy them, they cannot move forward.

Fourth, when patients arrive at Hospital Alcalde supplicatory practices become particularly important. They define the terms of relationships with the healthcare professionals who are the gatekeepers in determining their eligibility for support. As uninsured and poor patients from outside the city, they are contemporary examples of the ‘suffering humanity’ Fray Antonio Alcalde had in mind when establishing Hospital San Miguel de Belén. Daniel, Lucero and Isabel were three semi-destitute people who did not have any other option but to rely on the services of Hospital Alcalde, the hospital for the poor. As a consequence, once there, they had to engage in different forms of supplicatory practices to qualify for medical attention. As part of finding ways of providing the materials – catheters, tubing and so on – for their own treatment, a condition of access to treatment they are confronted with upon presenting to the hospital, often in desperate circumstances, patients must negotiate the ‘socio-economic assessment’ described above with the hospital’s social workers, so their income levels and hence the hospital fees they will incur can, if they are lucky, be reduced. But the supplicatory practices, and the conditional terms of access they contribute to defining, do not end there; patients have to demonstrate they deserve to be helped by showing their willingness to cooperate with healthcare personnel – social workers, doctors and nurses – in all manner of ways. As entitlement to treatment is not a right, it can be withdrawn if patients do not cooperate as they are expected to (Goffman, 1956).

Access to treatment is, therefore, far from automatic under these conditions. Patients are, instead, perpetually being asked to do things, to take on or engage in work so as to continue their treatment. There is a substantial literature on this. A large number of medical anthropologists and sociologists have contributed to our understanding of the role of patients, families and community in accomplishing therapeutic outcomes and goals (Corbin & Strauss, 1985; Kleinman, 1980; Mattingly, Grøn, & Meinert, 2011; Mykhalovskiy, McCoy, & Bresalier, 2004; Strauss, Fagerhaugh, Suczek, & Wiener, 1985). Concepts such as patient's *work* (Corbin & Strauss, 1985), *chronic homework* (Mattingly et al., 2011) and *healthwork* (Mykhalovskiy et al., 2004) have been used to conceptualise the efforts and actions of patients and families in caring for the chronically ill. According to these researchers, the work patients do as part of their treatment regimens is often ignored, sometimes denied by healthcare professionals, or simply labelled cooperation or compliance. However, in stressing the importance of supplicatory practices in the Mexican context, I am doing more than drawing attention to medical care's neglected side, i.e. the necessary part the patient plays in treatment in conjunction with medical personnel. The emphasis on supplication is deliberate, and designed to bring out the idea that the reassertion of unequal relations is a cornerstone of access to treatment. It also helps to make visible other implications of that inequality and the expectations placed on patients. As I will go on to show, the work families and patients have done at this point is just the initiation of a form of outsourced care, one which will take shape as the patients progress in the trajectory of CKD and its treatments. The following chapters will analyse the different forms of outsourced care patients and families undertake in diverse settings and at different moments in time.

The presence and indeed involvement of people other than the patients in these processes is something that, at this stage, it is important to underline. As the stories

introduced in this chapter attest, and this is the fifth point, patients rarely stand by themselves; they are always accompanied by others, typically family members, who are at the forefront of the supplicatory practices. During the early stages of the patient's trajectory, it is the next of kin – child, spouse, parent – who petitions healthcare professionals on the patient's behalf, field those healthcare professionals' requests and carry out the work according to the instructions they have been given. Other family members, kin and friends are also called into action as part of this. If the patient is to be able to progress to the next stages of the trajectory, the next of kin have to continue to fulfil these roles, as will be shown in further chapters.

The work of patients and those who accompany them is about more, therefore, than meeting one-off demands. Rather, meeting the specific demands of the moment is a condition for progressing to the next stage (which will, from the perspective of those seeking treatment, bring new demands). As Kierans (2015, p. 54) has put it, diagnosis unlocks a series of therapeutic interventions. I argue, and this is my last point, that it also inaugurates the trajectory of CKD and its treatments through an ongoing series of trials. When Daniel was diagnosed and put on intermittent peritoneal dialysis, he and his parents were drawn into such a trajectory. They came to see this based on the experience of Ronaldo, Daniel's uncle, who had been on home peritoneal dialysis for three years. But for Lucero and Isabel, and the majority of patients, subsequent stages in that trajectory had not yet been revealed, and they would learn in the following weeks and months that they had a long and unpredictable journey ahead. In the next chapters I will further explore the work implied in making that journey.

Patient's trajectories, however, are not only constituted by a series of administrative stages, but by important transformations of the body, self and family life. Diagnosis

and initiation of intermittent peritoneal dialysis in the hospital were just the first of these. Thus, the Tenckhoff catheter, the titanium connector, the transfer line and the peritoneum of the patient were brought together to form a therapeutic unit, a bodily interface with the medical system and its modes of organisation as much as with cyclor machines, that would substitute for the failed kidney's functions of waste and excess liquid removal but at the cost of making them more dependent on the good favour of those treating them. They turned out to be instruments that would mark the patient's body and identity. The assembled catheter and the peritoneum have to be reconstituted so the patient becomes compatible with the treatments they are eligible for. It is only by being made compatible that they have any chance of surviving in the long term and progressing in the trajectory of CKD. While patients receive intermittent peritoneal dialysis in the early stages of their illness, with doctors and nurses administering treatment, this changes. Ultimately, they along with their families have to take charge of the treatment at home. However, to get to that point, patient and families would have to pass the admission process to the hospital's home peritoneal dialysis programme. This process of admission and the efforts of patients and families to pass it are the focus of the next chapter.

Chapter 4

Learning to be a CAPD patient

Introduction

The previous chapter examined the starting points to patient trajectories. The cases of Daniel, Lucero and Isabel were used to illustrate the typical experience of uninsured patients from the onset of symptoms to their arrival at public hospitals, usually after seeing a number of medical practitioners. The majority of CKD patients in Jalisco arrive at Hospital Alcalde's emergency service presenting the effects of uremic syndrome, for which they have to be hospitalised for several days until their condition is stabilised. It is at the hospital where a definitive diagnosis is undertaken. Diagnosis, as Kierans (2015) has pointed out, prepares the ground for therapeutic interventions. In this context, the initiation of peritoneal dialysis in the hospital marks a turning point in the patient's and their family's lives – and it is what happens after this turning point has been reached that provides the focus for what follows.

At Hospital Alcalde, in-hospital intermittent peritoneal dialysis is initiated the day after the catheter has been inserted. The patients and their next of kin learn during the following days that peritoneal dialysis will continue at home and that they will be responsible for its practice – this is their introduction to CAPD. Active participation in CAPD care is an unexpected responsibility, a prospect they are not at all prepared for. But before taking on this responsibility, patients and their families have to be 'allowed' onto the CAPD programme of the hospital, which takes the form of a process of admission and instruction – a loosely organised series of stages, meetings, lectures,

training, paperwork, activities, and requirements that awaits every patient who arrives at Hospital Alcalde with CKD and initiates in-hospital peritoneal dialysis. As I will show in this chapter, a great deal of effort was demanded from the patients and their next of kin; getting through meant having to deal and negotiate with different gatekeepers, such as physicians, nurses, and social workers, all of whom wanted different things, at each step along the way.

In order to bring the principal features of the process out, this chapter is organised around the experiences of the patients I met as they were attempting to get through what are the three main stages of the CAPD admission process – the introductory meeting, the construction of the dialysis room and CAPD training. I argue that accessing Hospital Alcalde’s CAPD programme turns on two consequential transformations in particular. First, the house of the patient must be prepared to accommodate the therapy and the equipment it requires, transforming a part of the house into a *para-clinical space* – a dialysis room that will function as an extension of the hospital. That is the aim of the first two stages, the introductory meeting and the construction of the room. Second, the sick person must formally become a *CAPD patient*, either by learning to manage the therapy at home for themselves, or when they are able to be looked after by a family carer who has learned how to manage the treatment on their behalf. This status is achieved during the third and final stage of the admission process – CAPD training.

How these transformations are effected will be discussed at some length. In the first section of this chapter I will describe the introductory meeting, the first stage of the admission process, and how families are instructed on what they are required to do. In the second section I will present the stories of Lucero and Daniel and discuss their

efforts to meet these requirements and progress to the next stage. The third section of this chapter, in turn, is dedicated to describing and analysing how the CAPD training, the final stage, is conducted in practice. Before proceeding with CAPD at home, the patients are in a 'liminal state' (Turner, 1969): they are not healthy, but neither are they renal patients in full therapy. They only become CAPD patients by meeting the programme's requirements and passing the mandatory training programme to health professionals' satisfaction. That is, once they have learned and embodied a set of technical practices, new 'techniques of the (transformed) body' (Ingold, 2011; Kierans & Bell, 2016; Mauss, 1973), and, what is more, have been able to persuade the nursing team that they have done so correctly and in the required ways.

The admission process to CAPD, like that of diagnosis discussed in the last chapter, also highlights the social relations of healthcare more generally; in particular, the unequal relations between healthcare providers and clients (Foucault, 1995; Lupton, 2003). The admission process is, then, a further expression of the supplicatory practices constitutive of the context within which renal care is accessed in Mexico. As I will show, for healthcare personnel, the relationship with patients and their relatives within the admission process is again an asymmetric one – patients and their families should defer to them and submit to their instruction. But, as I will show, things do not always work this way; many patients actively but discretely 'push back', seeking to negotiate the terms on which they have been 'granted' treatment, articulating their own demands and asserting their autonomy in the process. Nonetheless, the stages are fixed points in otherwise variable trajectories, hence the importance of organising my account around them.

With a focus on the processes by which those with CKD become *CAPD patients* and the implications for them and their families, this chapter provides insights into the practical organisation of peritoneal dialysis as the main pillar of renal care in the context of Mexico as well as the socio-material conditions within which this form of treatment – of the failing kidneys but also of people – is produced and reproduced. The sections which follow draw on my fieldwork observations and the accounts of Lucero, Daniel and their next of kin as they went through this learning and transformational process, and provide an understanding of how they came to know and make sense of the therapy they were to be treated with. The unfamiliarity of the forms and rationales of medical practice encountered by patients is foregrounded in order to provide a nuanced account of these processes from the perspective of patients and their families.

4.1 The introductory meeting to the CAPD programme

As patients' families had already discovered, the *trabajadora social*, or social worker, is a major gatekeeper to the services of public hospitals, particularly at the MoHJ's hospitals for the uninsured. The social worker role in public hospitals is mainly administrative, and involves, for example, assessing a family's socioeconomic status⁷⁷ and determining hospitalisation charges, as discussed in the previous chapter, but also involves organising healthcare education, counselling patients as well as performing other social assistance tasks such as finding shelter for patients who come from rural communities. Given their administrative function, the social worker is someone the

⁷⁷ Every hospital uses its own method of assessing socioeconomic status and usually families do not have access to such information.

patients and their relatives come into contact with on a regular basis and must, therefore, keep on their side.

The relatives of renal patients who arrived at Hospital Alcalde would soon learn that Catalina, the social worker of the nephrology service, played a major role in the organisation of the CAPD Programme. Working with the nursing team, Catalina was directly involved in the programme's administration. One of her roles was to organise and facilitate the introductory meeting, and Catalina would distribute a seven-page document to the relatives of patients who had recently been admitted to the service and summon them to the next available meeting. At first this document seemed rather ordinary, just another bundle of printed paper sheets to be saved by the families in their own makeshift hospital files, but this document would turn out to be of great significance for the journey ahead. Simply referred to as '*las hojas*', or 'the paper sheets' in Spanish, the document contains basic information about the CAPD Programme including: the rights and responsibilities of patients and families; what CKD and CAPD are; and, more importantly, the programme's admission requirements. For many relatives of hospitalised patients, this document was the first hint of things to come in the provision of treatment for CKD. Even for those who had already heard from fellow patients what CAPD entailed, there was still much to take on board.

Informally referred to as *la junta*, or the meeting in Spanish, takes place every Wednesday morning in the CAPD office. Located next to the social worker's office, the CAPD office is a small room where Gloria, the nurse in charge, organises and oversees the training and manages registered patients' files. Two next of kin for up to five new patients are required to attend the Wednesday meeting. In what follows, I draw on my ethnographic observations of one of these *juntas* which I had the

opportunity to attend. As the description proceeds, I pay considerable attention to the social relations which characterise the meeting, the way in which it was conducted and the type of instructions the patients were given on how to proceed to the next stage of treatment.

Relatives of four patients attended the meeting on a Wednesday morning in September 2012. Six people in total sat on chairs arranged in a semi-circle, while Catalina took a seat behind a desk, making her the centre of everyone's attention. The attendees sat quietly, some of them visibly worried, preparing to listen to what the social worker had to say. Although they had been told to read 'las hojas' beforehand, Catalina nevertheless read the entire document aloud from beginning to end. Throughout the session she explained what every section of the document meant and repeatedly asked the attendees whether they had any questions or queries. Even if they had, no one said anything, the entire gathering just listened and quietly observed her while she read and explained what was expected from them as part of their participation in the programme.

In the hour-long meeting, Catalina focused on the requirements for being admitted to the CAPD Programme – the necessity of setting up a special room for dialysis at home, buying the relevant equipment, tools and supplies, the importance of training, the cost of treatment – and the duration of CAPD as a process. She focused much attention on the setting up of the *cuarto de diálisis*, or dialysis room in Spanish, transforming part of their home into a virtual extension of the hospital, a quarantined space where hygiene and safety is key. This was not, therefore, just an introductory meeting, but the first session of CAPD training, one in which patients and their next of kin began to receive instruction in how to set up a para-clinical space where CAPD could be

performed on a daily basis. Catalina emphasised the strict specifications the dialysis room had to meet: it had to be dedicated to dialysis; the patient could use it as bedroom, so long as it was only furnished with a bed; the floor had to be made of a type of material that would not gather dust, such as polished cement or tiles;⁷⁸ the walls and ceiling had to be plastered and painted with clear-colour oil-based paint; the windows had to be sealed and the door must be closed at all times to prevent draughts and the accumulation of dust; and it had to be well lit. Catalina said that the aim of these specifications was to prevent peritonitis,⁷⁹ but she did not elaborate on what peritonitis was or how it was related to CKD or CAPD. Although peritonitis is an important feature of CKD and peritoneal dialysis (Fried & Piraino, 2009), the patients and their families would not learn about it until the next stage of the admission process – ‘formal CAPD training’. Unaware that they were actually attending the first session of that training, they were instructed to make the necessary preparations to accommodate the therapy at home.

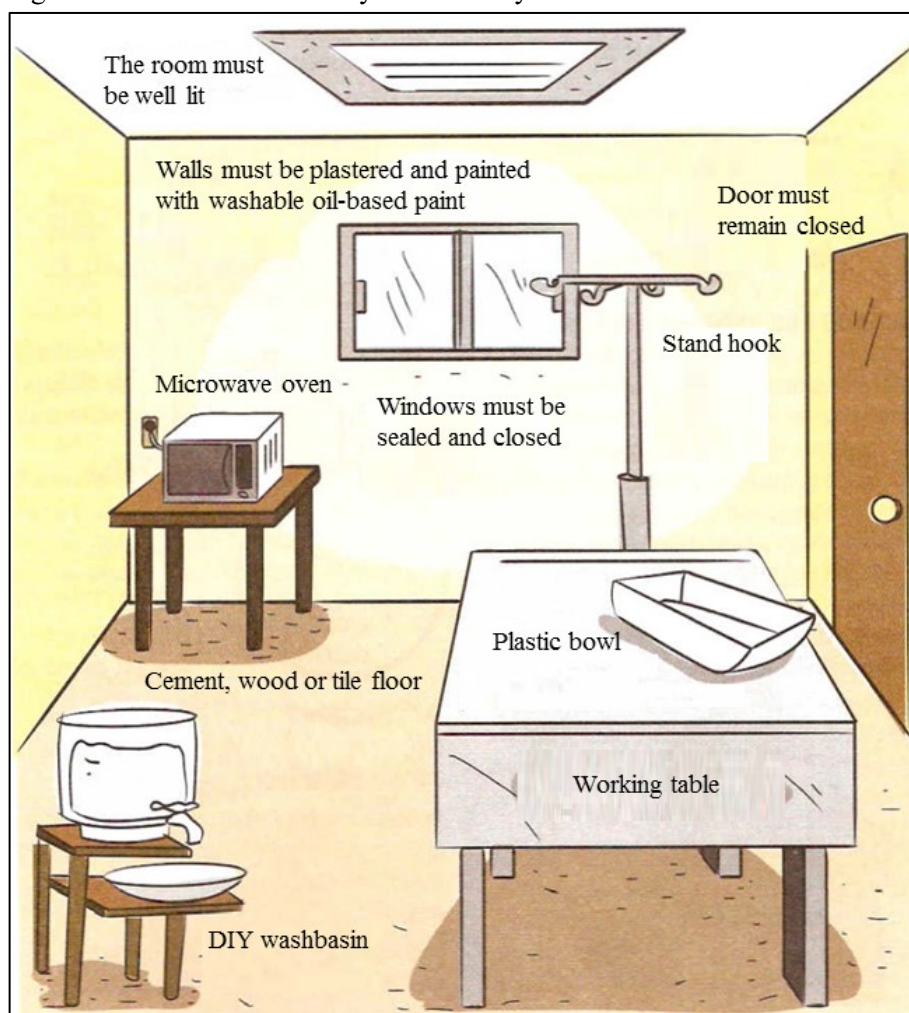
Having explained the specifications, the social worker jumped rapidly to the equipment needed to complete the layout of the dialysis room. She listed the following items: a working-table, ideally a stainless steel surgical table, but, if not, a small rectangular table (50 cm x 100 cm recommended) with a clear crystal panel (with the same dimensions) placed over it as a top surface; a DIY washbasin assembled using a large washing bowl, a 12-litre jug and a water dispenser, to be placed inside the room

⁷⁸ It is still common for the houses of the poor from rural communities to have dirt or rough unpolished cement floors which gather and produce dust. Walls and or ceiling are often not plastered and also tend to gather dust. If the space chosen for dialysis has any of these issues, families have to fix it to comply with the programme’s requirements.

⁷⁹ As mentioned earlier, peritonitis refers to the inflammation of the peritoneum caused by an infection contracted through the catheter or its exit-site. Although this infection can be contracted not only at home, but in the hospital as well (Fried & Piraino, 2009), this risk was not discussed with patients, making the patients responsible for this complication.

(as it is not permitted to wash one's hands outside the room before the procedure); a medical stand hook, a coat stand, or at least a large nail on the wall on which to hang the dialysate bags; a microwave oven, used exclusively to warm up the dialysate bags; and a scale to weigh the drainage bags at the end of the procedure (see Figure 10). Understanding the housing conditions of uninsured poor families, Catalina suggested some options for setting up the dialysis room. Ideally, the patient's bedroom should be used. If that was not possible, the family should consider building a new room or splitting an existing one.⁸⁰

Figure 10 Illustration of the layout of a dialysis room



Source: CAPD patient's manual, Laboratorios PiSA (n.d.).

⁸⁰ This could be done by using one corner of a room and using wood or cement partition panels to construct a 'cabin' which would only have to hold the items necessary for performing CAPD.

In addition to the room and the equipment needed, Catalina went on to say in concluding that the families also had to buy a list of supplies and tools they would need on a daily basis. This list included:

- 3 scrub gowns
- 3 scrub hats
- 1 pack of disposable medical face masks
- 1 plastic bowl of about 50 cm of diameter
- 1 thermometer
- 1 re-usable soft brush (to wash their hands)
- 1 pack of regular or microfiber cloths
- 1 pair of plastic clamps
- 1 bottle of povidone-iodine
- 1 bottle of hydrogen peroxide
- 1 bottle of Exsept©, a sodium hypochlorite 50% disinfectant solution produced by PiSA

The only visual aid Catalina used in her presentation was a group of photographs of already registered patients' rooms, photographs which had been requested as proof that patients had met the requirements. She explained that once they had completed the room and bought the list of supplies and tools, they would have to take three photographs similar to those she had used in the presentation: two showing different angles of the room with all the items appearing in both; in the third photograph the patient would have to appear inside the room, sitting on a chair or on a bed, and wearing scrubs, as though they were already performing the procedure (see Figure 11). In order to qualify for the next stage of the programme – CAPD training – the families

would thus have to print out and bring in the three photographs to the social work office of the nephrology service as visual evidence of their compliance with the CAPD programme. Catalina warned the attendees not to ‘cheat’ by borrowing the photographs of fellow patients. She said that they had caught patients using borrowed photographs and had to remove them from the programme. So, she continued, if they were caught doing it, they would not be allowed to continue in the programme either.

Figure 11 Photograph of a patient used to apply for CAPD training



Source: My own.

If Catalina approved the photographs, the patient or a family carer would then be allowed to attend the next available training session, for which they have to bring all the supplies and tools she listed before. She stressed that only *one* person per family could undertake the training, and that this would be the patient in most cases. She made it clear that a designated family carer would only be allowed to undertake the training if the patient was suffering from incapacitating disability and had difficulty walking, moving or seeing. If this was the case, she urged the families to talk it through at length, because if a family carer were needed, he or she would have to take care of the patient

almost twenty-four hours a day. She did not explain why only one person was permitted to undergo the training, nor did the attendees ask. As with other things, it was taken at face value as simply the way things had to be done.

Before finishing the meeting, the social worker informed the attendees about the *cuota de recuperación* or costs of the treatment within the programme. If the patient or the family carer passed the training, they would have to pay a monthly fee, of about \$2,500 pesos, to receive 120 packages of dialysate solution, which would be delivered to their home by Laboratorios PiSA, a local pharmaceutical company.⁸¹ If the family of the patient could not afford to pay the fee,⁸² they would have to negotiate a reduction or a waiver with the social work department.

Catalina concluded the meeting by explaining they would have to work to a specific timetable. She informed the attendees that they were expected to meet all the requirements of the CAPD programme within about six weeks. During that period, the patients would be given three to four appointments for in-hospital intermittent peritoneal dialysis, at least 15 days apart, while the family arranged everything as required. If they hadn't completed the room before running out of appointments, they would have to rely on the hospital's emergency services. That is, they would have to wait until the patients suffered an escalation of symptoms in order to be administered peritoneal dialysis again. After issuing this warning, Catalina asked the attendees again

⁸¹ As I mentioned before, PiSA is a local pharmaceutical company that produces generic drugs and specialises in renal medicine. PiSA is Hospitales Civiles' exclusive supplier of renal medicine, and shares 50% of IMSS's peritoneal dialysis supply contract with Baxter.

⁸² Although it was not discussed during the meeting, nor explained in the document given to the patients' relatives, since 1989 Hospital Alcalde has collaborated with Laboratorios PiSA to provide peritoneal dialysis treatment at a low cost to uninsured patients. The costs, which are subsidised, are shared between the hospital (33%), PiSA (33%) and the patient (33%) (Garcia-Garcia, Aviles-Gomez, Luquin-Arellano, Ibarra-Hernandez, & Briseño-Renteria, 2005).

whether they had any questions. None of them did. Catalina therefore closed the session and returned to her office, a few metres away. The patients' next of kin then began to leave the room. Some headed directly to the social work office to talk to Catalina in private.

Attending this first meeting provided an opportunity to observe the social interaction between patients, their relatives, and healthcare providers first-hand and, therefore, get a better sense of the form supplicatory practices take in this context. The meeting had set out the terms of the relationship between the hospital and patients, particularly what is expected from families in terms of compliance. During the meeting, the attendees paid attention but remained silent, preferring to approach the social worker in private. I am sure all of those in attendance would have had questions of some kind about the process, but they were probably reluctant to publicly air them during the meeting for fear of antagonising Catalina or making it look like they weren't paying attention. This way of interacting with the social worker, I argue, involves an understanding of the need to show deference in these contexts. That understanding of the relationship explains why patients and families rarely address healthcare personnel with direct requests in public, preferring to petition them privately instead.

Although the social worker talked about clinical and administrative issues, the programme's requirements were the main focus of her talk. The dialysis room's specifications, the equipment and the materials needed took up most of the social worker's talk. But the detail of the instructions and the visual aids were insufficient and underspecified. Being verbally instructed on how to set up the dialysis room opens up uncertainties around interpretation (how exactly were the instructions to be acted on?) and domestication (how could this be accommodated in the patients' lives?),

which result in patients doing things which do not fully comply with the hospital requirements. Doing what was expected in the required way, given the possibilities and resources available to them, was complicated and patients struggled during the admission process but also afterwards as well (as I will discuss in the next chapter).

For one thing, having just six weeks or so to set up the dialysis room and buy the necessary tools and supplies was extremely difficult for the majority of patients. If the family is, for whatever reason, unable to meet the requirements on time, the sick person would not receive peritoneal dialysis treatment until they had a flare up of symptoms serious enough for them to be first admitted to the emergency service. From the hospital's perspective, this measure was aimed at ensuring families' compliance as it blocks them from relying on intermittent peritoneal dialysis for any length of time. For patients and their families, however, as some of them told me, these expectations were unrealistic and that they were placed upon them at all was a sign of the hospital's lack of understanding of their situation.

Not all of the patients who arrive at Hospital Alcalde, however, initiate dialysis treatment. In a study conducted in this hospital, Garcia-Garcia et al. (2007) showed that 37% of cases arriving at the hospital did not go on to dialysis: with half dying in the hospital before they could be considered for treatment; a third refusing to undergo dialysis; and just under 15% deemed unsuitable. What these numbers capture is that many patients arrive at the hospital at a very late stage of their disease, particularly the elderly, and they and/or their families decide not to continue with long-term dialysis, opting instead for less aggressive forms of treatment until the patient dies (O'Connor & Kumar, 2012). Those who can make it, and are willing to continue to the following stages – 63% of patients arriving at this hospital – have to deal with real challenges in

their attempts to meet the hospital's requirements. The cases of Daniel and Lucero discussed below, who were at the beginning of their CKD trajectories, provide insights into the common challenges patients and their families face in meeting the hospital's requirements and dealing with the management of CKD symptoms before CAPD.

4.2 Meeting the programme's requirements

Since the only information the families receive is that provided by the social worker, the process of actually setting up the dialysis room relies on the financial, personal and emotional resources each family has and on the creative way they exploit them. Buying the list of materials mentioned above is not a big problem. The families are advised to buy most of the items from one of the several shops outside the hospital,⁸³ simply because of convenience. However, many families struggle to set up the dialysis room on time, and only a few can do it within a month of the introductory meeting. For the majority, completing the room takes more than six weeks and, in some cases, up to six months or even longer. Understanding why again tells us much about the socio-material context within which CAPD operates.

4.2.1 Daniel's progress

Returning to the story of Daniel, his case differs from most because in his family there was a precedent of CKD. As previously mentioned, Daniel's uncle Ronaldo was diagnosed with CKD at the age of 18, just three years before Daniel. Ronaldo and

⁸³ Outside Hospital Alcalde there are several shops selling scrubs and other clothing, but also items specially needed for dialysis (brushes, plastic bowls, fabric cloths). In many of the pharmacies that surround the hospital it is possible to acquire the specific disinfectant (Exsept), povidone-iodine, hydrogen peroxide and the plastic clamps. Not all the patients buy all the items here, but the majority approach these shops at some moment in their trajectories.

Daniel shared many childhood and coming of age experiences. For example, they attended the same primary school in the town, before working as peon de albañil, agricultural workers, and helping the fishermen of the community in their early teens. When Ronaldo was diagnosed with CKD and put on CAPD, Daniel's family came to learn about the disease and the treatment. They therefore knew something about the constant hospitalisations, the economic hardship it represented for the family, the home arrangements, and the consequences of the disease for Ronaldo's health.

However, that did not mean Daniel's parents were in a better position than anyone else. It simply meant that they had an idea of what to expect from the hospital and what they had to do in order to start CAPD at home. As I showed in the previous chapter, Berenice and Pedro, Daniel's parents, struggled to get access to Hospital Alcalde. The intervention of Ofelia, Berenice's mother, was crucial for Daniel's acceptance in the hospital. As Berenice put it, 'she knows how to navigate, "how to move" in the hospital.' After Daniel received his diagnosis, Pedro and Berenice attended the introductory meeting, where they were told about the specifics of the CAPD Programme and the timetable to complete renovations of the cuarto de diálisis and bring in the photographic evidence.

Daniel's first intermittent peritoneal dialysis appointment was three weeks post-diagnosis, at the end of December 2012. They turned up for the appointment punctually at 8 am, although Daniel was not given a bed until the afternoon. In total, Daniel was hospitalised for three days, during which 2 litres of dialysate solution were infused into his abdomen and then drained out every two hours, until he completed 30 cycles or changes. That is, during three days of hospitalisation 60 litres of dialysate

were used to remove the toxins from his body. Daniel was then discharged and sent home, his next appointment scheduled for three weeks later.

Meanwhile, José, Berenice and Daniel himself were preparing to set up the dialysis room in their home. Since Pedro's father was a *comunero*,⁸⁴ he had been given a small allotment where he had built the family's house when he and Berenice married, two decades before. Theirs is typical of the houses of the Mexican poor (and perhaps elsewhere in Latin America), whose main feature is a never-ending, ongoing construction process. The houses are always in the process of being completed, there is always something left unfinished. The majority of the houses in Mezcala are like Pedro's: one-storey house with bare-brick façades. Their house had three bedrooms, a living room and a kitchen. Only the walls of the bedrooms were plastered and the floor was made of rough concrete; the walls of the kitchen, by contrast, were not plastered and the floor was of dirt.

Already too small for the family's nine members, the family was planning to split the living room and make all the necessary arrangements for installing a dialysis 'cabin'. Berenice consulted Catalina about this option, but she rejected it and advised Berenice to build a new room from scratch. This meant that the family had to invest more money and work in building the dialysis room, with Pedro and Berenice borrowing money from their extended family and friends, and also from money lenders.

Knowing her brother Ronaldo's experience of CKD, Berenice was aware of the transplant option, thinking it meant a 'cure' for CKD (Crowley-Matoka, 2005). They knew that the best option was for a member of the family to donate a kidney to Daniel,

⁸⁴ A *comunero* is a person – usually a man – who legally owns a portion of land within the territories of an indigenous community in Mexico, and therefore, participates in the decisions over communal land.

and Bernice was the first in the family to step forward to do it. Pedro and Vicente, the oldest son, were also willing to donate a kidney to Daniel, in case Berenice wasn't compatible. Daniel himself was grateful and willing to receive a kidney from his family. Thus, amidst the tragedy of Daniel's illness, the family had a plan, but first they had to start the so called *protocolo*, as the transplant protocol is locally known. At Hospital Alcalde, transplants are carried out by the Transplant Unit, but getting access to that department is not easy, and a referral from the nephrology service is needed. At the same time, they were also working to build the additional room.

Berenice did manage to persuade a doctor from the nephrology service to give her an *interconsulta*, a referral to the Transplant Unit, so they could be evaluated and start the transplant protocol.⁸⁵ However, as soon as they reached this service, the Transplant Unit refused their request on the grounds that Daniel had not yet been established on a proper renal replacement therapy, i.e., CAPD. In other words, Daniel would only be considered a candidate for a transplant when he started CAPD at home. This disappointment refocused their minds on meeting the requirements of the CAPD Programme. However, everything changed suddenly when Daniel experienced severe complications with his illness and treatment, prior to returning for his next appointment at the hospital. This would be a turning point in his trajectory as a CKD patient.

The second appointment Daniel was given was for the 20th of January 2013, but he could not make it. Ten days after his first round of intermittent peritoneal dialysis in

⁸⁵ The transplant protocol is the official procedure every patient has to undertake in order to be considered a candidate for receiving an organ. It includes numerous clinical tests and paperwork. In the case of living organ donation, the first step is to have a donor (usually a relative). In the case of deceased organ transplantation, the patient has to complete all the clinical tests in order to be included in the transplant waiting list.

the hospital, Daniel suffered a flare up of symptoms of uremic syndrome and high blood pressure. He was taken to Hospital Alcalde's emergency service, where he was admitted due to his status as a registered renal patient of the nephrology service. After waiting for several hours, as is usual in all Mexican public hospitals, Daniel was transferred to the nephrology ward, where he was put immediately on intermittent peritoneal dialysis. After some hours connected to the cyclor machine, his catheter clogged inside his abdomen and stopped working. As is standard procedure in these cases, the doctors tried to unclog the catheter with a special needle but it didn't work. Needless to say, it was a very painful experience for Daniel, who described the procedure as if the doctor were scrambling his intestines. Over the following days, Daniel's catheter was replaced twice, and on both occasions the family had to buy the replacements from a local pharmacy. After nine days of hospitalisation, Daniel was discharged from the hospital on the 19th of January, now with a functioning catheter, because he 'showed signs of improvement', as described in his discharge note.

As Daniel and his family were recovering from his long stay in the hospital, they were preparing to continue their work on the dialysis room. According to Berenice, for a few days Daniel appeared to have recovered, almost as if he wasn't ill at all. But suddenly, a week after his last hospitalisation, Daniel's health deteriorated again. He started to have cramps during the night, and later he coughed uncontrollably and had difficulty breathing – 'I feel as if I am short of breath', he said to Berenice. But Daniel didn't want to go back to hospital. Despite his reluctance, Pedro took him again to Hospital Alcalde's emergency service the morning of the 30th of January, and later that day he was transferred to the nephrology ward.

At the nephrology ward Daniel was diagnosed with acute pulmonary oedema, and received treatment to resolve a condition which is a complication of CKD and dialysis. According to Pedro, his son responded well to the treatment, and slept well that night. But during the morning of the 31st of January, the cough and shortness of breath worsened again. ‘His face changed colour rapidly, he became very pale, even yellowish, it seemed to me as though he was *más pa allá que pa acá*, “at death’s door”, as though he was in agony’, Pedro recalled. He immediately asked the nurses and doctors for help, as he feared for his son’s life. Pedro called home to tell Berenice to come to the hospital as soon as possible because Daniel was in a critical condition. The pulmonary oedema worsened in a matter of hours, and the doctors employed increasingly severe measures to save him. Their efforts were in vain, and Daniel was declared dead at 9:30 am, two hours before Berenice arrived at the hospital. Daniel passed away only two months after being diagnosed with CKD. His family had not progressed very far with the preparation of the room, as they were interrupted by the complications of disease and treatment. Daniel was mourned by his mother and father, his siblings and his extended family.

Sadly, the tragedy of Daniel is not unusual. According to a study conducted by Garcia-Garcia et al. (2007), 20% of patients who initiate peritoneal dialysis treatment at Hospital Alcalde die within the first 90 days of starting treatment. Daniel’s case underscores CKD’s status as a life threatening condition. Even if a patient and their family complied fully and were willing to actively participate in the treatment, complications could occur at any moment. Given the healthcare context in Mexico, it is clear that the support available at public hospitals when complications do happen – particularly for the poor and uninsured – is insufficient. For example, there is no ambulance service for uninsured renal patients, or any other chronically ill patient, so

they have to arrange their own means of transportation to the hospital. In the case of patients like Daniel from the Chapala area, who lived more than 40 km from the hospital, this can also be a matter of life and death.

Pedro and Berenice were not sure whether their son's death was a consequence of him not receiving enough dialysis, contributing to the reappearance of life threatening symptoms, or whether his death was due simply to CKD. They were aware of the limitations of the Mexican hospitals, and thought the lack of resources might have had something to do with the events that had led to Daniel's death. Either way it is clear, however, that patients and families are running up against a condition so unpredictable that serious complications can flare up at any moment. Experiencing numerous problems during this stage of in-hospital intermittent peritoneal dialysis, while preparing the dialysis room, is not unusual; many of the patients I interviewed recalled being hospitalised due to various complications before completing the CAPD room and undergoing training. Many people, like Daniel, would not make it to the next stage. Others are more fortunate and, despite complications, do reach and pass the training stage after much effort struggling with the programme's requirements. The case of Lucero shows this and illustrates forcefully the kind of problems patients face during this liminal stage. Her case is the focus of the next section.

4.2.2 Lucero's progress

There are some commonalities between Lucero's and Daniel's cases. Both were young workers, making their ways into adulthood in their families and communities. Before becoming ill, Lucero was able to save enough money to build a private room in her parents' house. As was typical in Agua Caliente, José, Lucero's father, had built his

house by himself for his family. José built the first room almost three decades ago, when they were newlyweds. After that, more rooms were added to the building to house new members of the family. Today, José's house has five rooms and is home to three families, his own and the families of two of his children. Lucero's bedroom was the newest addition to the house. Almost completed before she became ill, it was just waiting for some of those finishing touches considered a luxury in the context of rural Mexico (for example, plastered walls and ceiling, paint, and tile floor). Like all other parts of the house, Lucero's bedroom was built by the men and women of the family, and she provided most of the money for its construction.

Figure 12 Perspective of Lucero's family house



Source: My own.

When José and Úrsula, Lucero's mother, were told to set up the dialysis room in their house, they had no problem deciding which room would be the most appropriate. However, there were issues to resolve. Although Lucero had a private bedroom, something many families cannot afford under the conditions of rural poverty, it was

not ready and the family needed money and time to make the changes. Specifically, the room's walls were not plastered and painted, and the floor was simply rough concrete. José borrowed money from relatives and friends to buy the necessary construction materials – sand, cement, mortar, and floor tiles.

Before starting the renovation of the room, José took Lucero to her second intermittent peritoneal dialysis appointment at Hospital Alcalde, just two weeks after she was discharged following her first stay. According to her files, she arrived at the hospital still having the symptoms of uraemia, high blood pressure, and anaemia, all consequences of chronic renal failure. The first course of treatment she had undergone had not been completely effective in controlling and reducing the consequences of renal insufficiency. During her second stay, the doctors diagnosed that she also had a urinary tract infection, and she had to remain hospitalised until it was under control. In the end, Lucero was hospitalised for thirteen days. That meant that José and Úrsula, and sometimes her sisters, had to stay with her at her bedside in the hospital.

When Úrsula and José were at the hospital, one of them would spend the night at the Albergue Fray Antonio Alcalde,⁸⁶ a shelter home for families and patients who come from rural communities far from the city, while the other would stay at Lucero's bedside. If he or she were lucky enough, a chair would be available for them; if not, the only option would be to sit or lie down on the floor to get some rest during the night. Spending time at the hospital incurred expenses they found difficult to meet; for example, for meals, for transportation, and often for buying medicines that the hospital

⁸⁶ This shelter, discussed briefly in the last chapter, is the only remaining building from the late 18th century that was constructed under the direction of Fray Antonio Alcalde while he was alive. It was refurbished in the 1990s by the municipal government, with the original architecture preserved.

had run out of or did not stock. All of these drained the family's finances and delayed the renovation of Lucero's room.

Three weeks later, Lucero returned for her third intermittent peritoneal dialysis session at the hospital. This time she arrived 'asymptomatic', that is, not showing life threatening symptoms according to her files, but only signs of 'asthenia' (weakness) and 'adynamia' (difficulty with moving). She was hospitalised for three days, that is, only for the duration of the intermittent peritoneal dialysis session. By this time, the renovation of the room had started but was yet to be completed. Her fourth appointment was at the end of October 2012, when she was again hospitalised for three days.

Being classified in the lowest socioeconomic status bracket according to the hospital's scale, Lucero's family paid the lowest cuota de recuperación for hospitalisation charges. But that does not mean they didn't incur any expenses. On the contrary, at every session they had to buy the materials requested by the service: four tubing sets for the peritoneal dialysis cyclor (the machine used in the hospital for automated peritoneal dialysis, see Figure 7 of the previous chapter), clamps and disinfectant. More than once they also had to buy erythropoietin⁸⁷ for the severe anaemia Lucero was suffering because this medicine was in scarce supply in the hospital.

By the end of November, when Lucero had her last appointment of intermittent peritoneal dialysis, the family still hadn't finished setting up the dialysis room. When

⁸⁷ Erythropoietin is a hormone naturally produced by the kidneys that controls the production of red blood cells. When a person suffers from CKD, the kidneys produce less erythropoietin, leading to anaemia. This is usually treated with a genetically engineered erythropoietin, which is subcutaneously injected (NIDDK, 2014), to stimulate the production of red blood cells. Several brands of erythropoietin are available in the market, but patients in this hospital usually buy PiSA's, because it was the cheapest.

she was discharged after four days of hospitalisation, her doctor wrote on her *resumen de alta*, or discharge note, ‘Cita abierta a urgencias’, which roughly translates to ‘open appointment to emergency service’. This statement in the *resumen de alta* informs the healthcare personnel of the emergency service that the holder is a registered patient of the nephrology service, whose health condition requires special attention and quick access to the hospital in case of an emergency. For Lucero and her family, the statement meant that they had run out of dialysis treatment programmed sessions and that they could only access treatment when her symptoms worsened. It was not long until Lucero experienced a flare up again.

Three weeks after Lucero’s last appointment, her parents took her to the hospital due to an escalation of symptoms. Her feet and face had become swollen again, she started to experience problems when urinating, she was visibly weak and had severe nausea. Lucero was admitted to the emergency service, although she had to wait for several hours until she was transferred to the nephrology ward. There the doctors diagnosed a worsening of anaemia and uraemia, in addition to a recurrence of the urinary tract infection. She received another course of intermittent peritoneal dialysis and a dose of antibiotics and was discharged after three days. Only two days later, the family took her to the hospital again because she was experiencing tonic-clonic seizures,⁸⁸ due to high blood pressure and hypocalcaemia, both consequences of kidney failure. Lucero was hospitalised for two more days and discharged the day before Christmas Eve. She was hospitalised another five times, once at the beginning of January 2013, twice in February and twice in March. During those episodes, her catheter had to be replaced

⁸⁸ A form of generalised seizures that affects the entire brain, caused in this case by hypertension and hypocalcaemia (an abnormally low level of vitamin D in blood plasma).

because it clogged inside her abdominal cavity – an experience as painful as Daniel’s. One of the worst flare ups Lucero had was in mid-February, as José recalled:

Something very serious happened. I wasn’t at home this time, it was my wife who took care of it, with the help of two friends. It was five days ago. It happened suddenly. It seemed as if my daughter was going to die at home. She was at home with everybody else and was talking with her mother as usual. All of a sudden she tried to cry out, but she couldn’t. She unconsciously clenched her hands very hard. My son tried to help her, he tried to straighten her hands, but he couldn’t. She winced in pain, so my wife took her to the hospital as soon as she could. It’s been five days since we arrived at the hospital, but she has not been controlled yet, her face is still jammed and she can’t speak.

The recurrent hospitalisations had massive consequences for the family. José was sacked from his job as watchman in November, due to his absenteeism. In one year, the family had lost two of its main economic contributors, Lucero and José, making it all the more difficult to meet the CAPD programme’s requirements. With every hospitalisation, he had to negotiate with the social worker for the lowest charge possible saying, for example, that he was carrying a low sum of money. Although Catalina, the social worker, asked him to appeal to family and friends, she tried to help him by reducing the charges as much as possible, and on some occasions even waiving them entirely. In the end, however, José became heavily indebted to many relatives and friends from his community, yet still continued to struggle to meet the demands of the hospital.

It was the end of March 2013 when the family finally completed the room. The raw cement floor was replaced with ceramic tiles and the walls were plastered and painted. José bought a table, a crystal panel, a water dispenser, and two plastic bowls in

downtown Poncitlán. To save money, José did not buy a stand hook, instead he nailed a hook on the wall next to Lucero's bed. Lucero's grandmother gave her the scale and a broken microwave, which was used for taking the photographs. The remaining items were acquired in various shops outside the hospital.

Having laid out all the items in the newly constructed dialysis room, José asked a nephew to take the photographs using an old compact camera. José brought the printed photographs to the social worker, but she rejected them on the grounds that there were missing items from the photograph where Lucero appeared seated. José's nephew had to take the photographs again, taking care everything was in its place. This time Catalina accepted the photographs, but another issue arose.

Úrsula had decided to be the carer and was eager to take the training to help her daughter perform CAPD at home. José and Úrsula felt Lucero was unable to take the training because of her debilitated condition. During her last hospitalisation, Lucero experienced a range of symptoms which drained all her strength and made her lethargic, as if she had a cognitive impairment. But Catalina thought differently, and did not allow Úrsula to take the training, arguing that it was Lucero's responsibility to look after herself. Lucero, then, was given an appointment to attend the training in April 2013. That training week is the focus of the third and final section of this chapter.

Before moving on, however, it is important to reflect back on what has been presented so far. I have chosen to focus on Daniel and Lucero's stories because they help us to understand the challenges patients and families face throughout the initial stages of the admission process. Ideally, from the perspective of the hospital, a patient and their family should be able to prepare the necessary accommodation for CAPD at home within a few weeks, and rapidly move onto training and subsequently carry out the

therapy by themselves. However, for the majority of the uninsured CAPD patients I met, it took more than two months to accomplish the setting up of the dialysis room, the main requirement to be met before undertaking training, with some patients dying before reaching this stage. Daniel's and Lucero's stories tell us of the myriad difficulties attached to preparing for dialysis at home: the constant hospitalisations, the unpredictability of complications of both disease and treatment, the hardships a condition like this mean for an uninsured family living in poverty, and the difficulties in meeting the programme's requests.

Daniel and Lucero's cases demonstrate how preparation for CAPD is a *rite of passage* (Grimes, 2000; Turner, 1969; Van Gennep, 1960) as a series of stages and trials. Passing through these stages underscores the status of the recently diagnosed renal patients as *liminal*,—a concern also taken up by other scholars (Jackson, 2005; Little et al., 1998; Miles, 2013; Murphy, Scheer, Murphy, & Mack, 1988; Turner, 1969). Liminality in this context means that the recently diagnosed are not proper *CAPD patients*, but are *initiates* who have to earn full status by completing the whole admission process – meeting the requirements, setting up the dialysis room and passing the training. Daniel's case was very clear in that respect. When he and his family requested the transplant protocol, their request was rejected on the grounds that he wasn't undergoing therapy proper. In other words, he was not yet a 'proper patient', he was an *initiate*, someone who still did not qualify as a candidate for a kidney transplant. Sadly, Daniel died striving to become a CAPD patient, but his family didn't even have enough time to complete the second stage of the admission process. With the help of her family, and particularly her father José, Lucero was able to reach the next and, as I shall show, equally challenging stage – CAPD training. Mainly due to economic reasons, it took Lucero and her family more than six months to meet the

programme's requirements, something which, despite the difficulties, gave them some hope for the future.

As I show in the following section, CAPD training deserves careful examination, not just to acquire an understanding of the patients' experiences, but also to acquire an understanding of the importance of the peritoneal dialysis process itself. CAPD training demands a lot from patients as they try to learn and embody a set of movements, practices and routines – new 'techniques of the body', to borrow from Mauss (1973; see also Ingold, 2011; Kierans & Bell, 2016) – before proceeding to carry out the therapy at home. What follows is a detailed description of how patients are taught and drilled in these new techniques of the body, techniques necessary for creating and maintaining the nexus between the surgically altered body, medical equipment and the dialysis room that CAPD depends upon.

4.3 CAPD training: learning the technique

By the time the patients and family carers finally take their place on the training course, they have learned a few things about peritoneal dialysis but still have some way to go. Every week at Hospital Alcalde up to six patients or family carers are admitted to CAPD training delivered by a nephrology nursing team. By this point, the patients have already experienced the sensation of being dialysed in the hospital – the infusion and drawing out of the dialysate liquid from their abdomens. They have lived for several weeks, and sometimes months, with the catheter protruding from their abdomen, awaiting the time when they can perform peritoneal dialysis by themselves. They have observed how the nurses handle the tubes and connect them to dialysate bags and cyclor devices, but remain outside the procedure which is done for and on

them. For family carers the training will be their first contact with the procedure, because, when the patient is hospitalised, the family carers are not allowed to be in the room when peritoneal dialysis is performed. For patients and their families, training represents the next stage in their trajectories as renal patients, but more importantly, the next trial they must undergo in order to become a full *CAPD patient*. As will become evident, this stage often raises questions about their status as patients, because they are active participants, but still remain subordinated to healthcare professionals. What follows is a description of what is, then, an important event. It is the last part of the admission process, and requires great effort. Patients will have to demonstrate their adherence to strict rules, their knowledge of the drills they have been trained in, and be able to competently stage their compliance for the nursing staff to see – this is a process where discipline will be on display (Latour, 1988). During the previous stage, patients learnt that they will depend on peritoneal dialysis and the room to survive. During training, they learn to establish a connection between their bodies, the dialysate and attendant apparatus, and the room – the nexus discussed above – through a prescribed sequence of embodied actions.

4.3.1 The training set up

Gloria was the nurse who co-managed the CAPD Programme along with the social worker and a senior nephrologist. She was in charge of CAPD training and the registry of current patients. While Catalina, the social worker, was in charge of introducing new patients to the programme, as well as managing the *cuotas de recuperación*, Gloria was in charge of training new patients and keeping an up-to-date patient registry. In addition, Gloria participated in the provision of care to patients, organised the bimonthly check-up appointments, kept hardcopies of patients' files, including clinical

exams, and coordinated the care of the patients' catheters. For the majority of patients and family carers who attend the training, she was a new face.

I attended a training week in September 2012. The training started with a sort of ceremony where the participants had to demonstrate they were ready to start by laying out the supplies and tools they had bought for their homes, as previously requested by the service. Gloria welcomed the *trainees* in her office, while she registered their details⁸⁹ and checked that everyone had brought all the items requested, even though these would not be used during the training. The trainees that week were four patients and two family carers. The patients were drawn from Jalisco and neighbouring states; Nicolás (59 years old) from the State of Michoacán; Teresa (49 years old), from the north of Jalisco; Lourdes (20 years old) and Bruno (23 years old), from the outskirts of Guadalajara. The family carers were Concepción (50 years old), from the south of Jalisco, who was preparing to take care of her cousin; and Patricia (32 years old), from Guadalajara, who would look after her brother-in-law. From the very beginning, Gloria noticed that Patricia was not aware of the responsibilities that came with being the family carer of a CAPD patient – that is, as the trainees would learn, helping the patient to perform CAPD four times a day, every day, and being close to them almost 24 hours a day. However, Gloria let her remain for the whole session.

In a manner that mirrored the introductory meeting led by Catalina, during the first session of the training Gloria lectured the attendees about the CAPD programme at the hospital. She explained that at the end of the training week there would be two exams; a written exam on Friday, and a practical one on Saturday or Sunday, which would

⁸⁹ Although the details of every patient had already been registered by the social worker, Gloria recorded their particulars again: name, age, date of birth, whether they were hypertensive or diabetic, address, telephone number (whether land-line or mobile), postcode and date of catheter insertion.

consist in performing a dialysate bag change – the technique they would learn that week. Gloria also provided them with two documents – a 35-page patient’s manual designed and published by PiSA and a 32-page cookery book for renal patients, prepared by the service’s nutritionists – that the attendees had to photocopy at the end of the session. They were not permitted to take these copies home. She told us that the patient’s manual was the most important and that the trainees should use it *to study* for the final exam. She also said that if someone failed the training, he or she would have opportunities to take it again; ‘it depends upon one’s ability to learn’ she remarked. Gloria emphasised that the trainees could ask questions and that those questions would be answered by the nursing team during the training.

In order to get things underway, she gave them a leaflet with instructions about the general and basic cleaning activities they had to undertake on a daily basis. The attendees would probably not have realised yet that much of the training would revolve around the prevention of infections – the Achilles heel of CAPD. To address that, Gloria would stress, over and over, that all the painstaking steps were aimed at the prevention of potentially fatal infections, principally peritonitis. What might have seemed a rather unimportant piece of paper, turned to be a set of *CAPD commandments* – it listed a set of practices and prescribed forms of conduct, and a daily routine for keeping the treatment working and preventing complications. As a way of driving this point home, she read the instructions written in this document aloud⁹⁰ and elaborated on every point. This is what Gloria had to say in summary form:

- *Establish a timetable of daily dialysate bag changes.* The patient’s physician usually prescribes three to six changes a day, although normally only four

⁹⁰ The translation of the list is mine. I have re-ordered the list to make it clearer.

would be needed. The changes should be performed every four hours during the day as follows: 8am, 12pm, 4pm and the last one at 8pm.

- *Dialysis bag changes to be performed only by the person who was trained by the nursing team.* The trained patients or carers were not allowed to train another person. If a patient became unable to perform the CAPD, another person would have to be trained by the CAPD Unit's team.
- *Perform the dialysis bag changes only in the designated room.*
- *Wash hands only in the washbasin inside the dialysis room.*
- *Change scrub hats, gowns and face masks every day, both patient and family carer.*
- *Take a shower every other day.* Body cleanliness was highlighted as critical for preventing infections.
- *Wash and clean the catheter exit site (abdomen) every day with 'Isodine' (povidone-iodine) and 'agua oxigenada' (hydrogen peroxide at 6%), and fix the catheter to the abdomen.*
- *Clean the whole dialysis room thoroughly just once a week.* This would involve sweeping and mopping the floor and wiping the walls using soap and chlorine. They were not to sweep more often, because sweeping produces dust that might cause an infection.
- *Mop the floor of the dialysis room every day before the first bag change of 8 am,* using soap and chlorine, and clean the plastic bowl.

- *Keep the door and windows closed to seal the room and prevent the accumulation of dust.*
- *Pets are to be banned from inside the house and especially the dialysis room.*

The last point in the leaflet, *Infections do not enter through the mouth, but because of a deficient procedure*, was not an instruction but a statement that made patients and carers responsible for any possible infection. Gloria explained, ‘It is very common for patients to claim that they got peritonitis because they ate street-food,⁹¹ but actually peritonitis and infections are caused because of a deficient procedure, like not wearing face masks, not washing the hands, allowing draughts through the room’s door or windows or carelessly allowing dust to accumulate inside the room.’ She laboured this point in order to underscore the fact that the otherwise mundane and harmless draught, primarily due to the dust it brings, would be from then one of their main enemies as CAPD patients, so the room should remain free of such threats.

Cleanliness and the prevention of infections dominated the first part of the first day of training. Gloria continued using a pre-designed flip chart, produced and provided by PiSA,⁹² to give a 30-minutes presentation about CKD, renal replacement therapies and peritoneal dialysis, where infections would again be raised as a key concern. The illustrations on the slides were similar to those in the patient’s manual. The first slide simply stated ‘Your life hasn’t finished yet.’ Because of the nature of renal failure, and the invasive character of dialysis treatments, kidney patients do face many limitations on their lives, but, as Gloria argued, ‘you can have a normal and more stable life, if

⁹¹ In the context of Mexico, street-food is often regarded as unhygienic and unsafe, and linked to gastrointestinal infections. Gloria is explaining here that, as peritonitis is experienced as excruciating abdominal pain, patients often link this to what they had eaten and not to the way they performed CAPD.

⁹² It was a set of laminated slides of about 50 cm × 1 m standing at an easel.

you prevent complications’. No one was in a position to question such a claim. During the next thirty minutes, Gloria flipped over and read another 29 slides, covering a range of medical issues,⁹³ from anatomy and the kidneys, renal replacement therapies, with particular emphasis on peritoneal dialysis, through to peritonitis infections, the most common complication associated with CAPD (Fried & Piraino, 2009; Garcia-Garcia, Tachiquín-Bautista, et al., 2007).

In her half-hour presentation, Gloria stressed the dangers of peritonitis infections, noting that peritonitis might damage the peritoneum in ways that might prevent the patients from using peritoneal dialysis longer term, resulting in them being transferred to haemodialysis. She warned the attendees that there were very few places in the hospital’s Haemodialysis Unit, that three sessions a week would be needed and that the sessions were very expensive, much more than CAPD, particularly in private clinics. As she put it, ‘this is a disease for the rich, but it also affects us, the poor’. While trying to show understanding of the hardships CKD represents for uninsured families, Gloria also reminded them that CAPD was considered to be less expensive than haemodialysis.

After a break of 15 minutes, Gloria continued the session with a demonstration of the technique of CAPD – the first time patients and family carers got to see what they were

⁹³ The following were among the topics covered: the kidney and its functions (excretion, hormonal, hemodynamic); the symptoms and causes of chronic kidney disease, its various stages; available renal replacement therapies (peritoneal dialysis, haemodialysis, renal transplant); modalities of peritoneal dialysis (continuous ambulatory peritoneal dialysis and automated peritoneal dialysis (she explained continuous means that it is an ongoing treatment [they will always have ‘water in their abdomens’] and ambulatory because they will be able to do it at home and ‘have a more normal life’); the peritoneum, its functions and why it is used in peritoneal dialysis; peritoneal dialysis requirements; PiSA’s double-bag Y-system (she described its features); dialysis room requirements and restrictions (she highlighted the need for cleanliness); personal care and cleanliness; the importance of treatment compliance; diet restrictions; symptoms of infections of the exit site; what to do in the case of line break; what peritonitis is, its causes and symptoms; peritonitis treatment and follow-up; malnutrition issues.

expected to learn. She took the group to see a dialysate bag change performed on a patient in the nephrology ward. She provided us all with face masks to wear during the procedure. Once in the room, Gloria talked through all the steps of a dialysate bag change, from beginning to end. The young patient chosen for the demonstration did not appear to have a choice in this, and was not asked whether he wanted to participate in the training. During the infusion stage, Gloria asked him if he was feeling pain or discomfort, and he reported that actually he was feeling a little pain.⁹⁴ The whole procedure lasted about thirty minutes; after which we left the room. We returned to the CAPD Unit, where Gloria finished the three-hour long session and told us that the sessions to follow would be taken up with practising the technique we had just seen.

From the beginning of the session, Gloria showed concern about Patricia, one of the family carers who was taking the training. The issue was that Patricia seemed to have been put under pressure to volunteer to be the carer of her brother-in-law. She explained that she had been asked to accompany her brother-in-law to the hospital, without being told that she was also going to take the training to become his family carer. At the end of that first day of training, Gloria and the social worker discussed the issue with Patricia. They concluded that Patricia was not the most suitable carer for her brother-in-law; because she was not the next of kin, but also because she had two children, lived far from the house of the patient and it would be difficult for her to look after him. Catalina and Gloria advised Patricia to talk about the issue with the family of her husband and choose another more suitable person for the role. Patricia accepted the decision to remove her from the training and did not return the next day.

⁹⁴ Actually, it was quite clear that the patient was in some discomfort. After 5 minutes, the young boy started to belch as a consequence of the infusion of dialysate to his abdomen. Near the end of infusion, he almost threw up.

The next day the other participants learned why Patricia had left the training. Teresa and Concepción showed surprise and were worried about being removed too, given the amount of information they had to learn and the difficulty of acquiring the skills needed to perform CAPD. In the following days, however, more participants would be removed from training for other issues. This showed us as a group that reaching the training stage was no guarantee of succeeding in it.

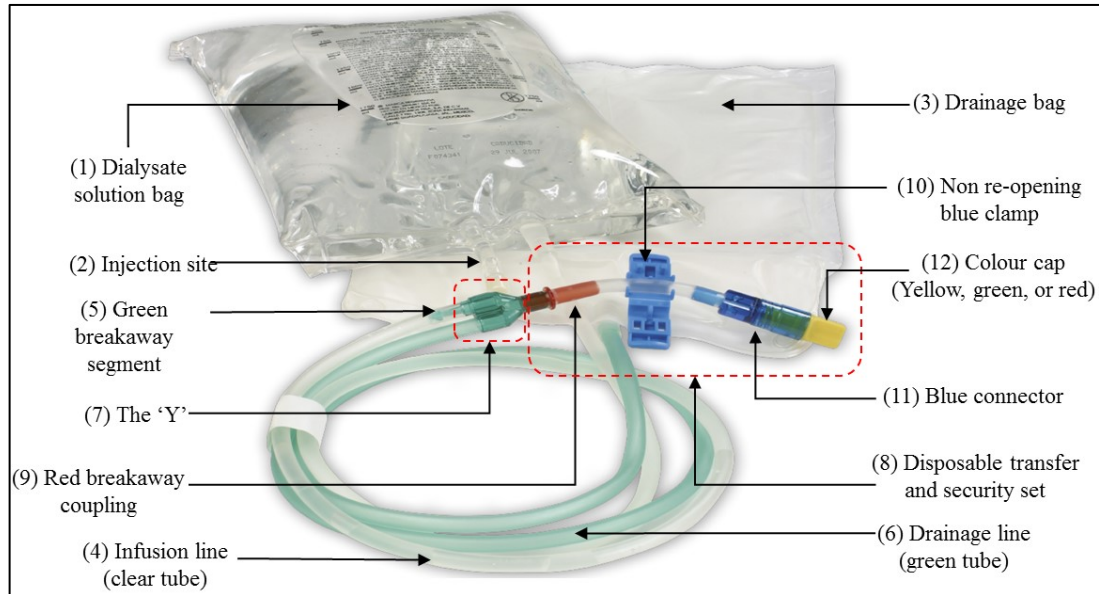
Concepción told me that the reason she was taking the training was because her cousin Manuela, who was the sister and carer of Javier, also failed the training. According to Concepción, Manuela had a difficult time during training and failed the final exam, as she couldn't tell the difference between the peritoneum and peritonitis, and so had been told to take another week of training. 'But Manuela did not want to come back to the hospital and asked me to take the training for her', Concepción revealed to me. They had agreed that Concepción would take and pass the training, but Manuela would be the actual carer of Javier. She assured me that Manuela had learned the technique and was ready to look after her brother Javier, but first Concepción had to pass the week of training. 'That's why we have to be obedient and do our best to learn everything the nurses teach us', she remarked.

The main focus of the first day of training was the issue of preventing infections. The second day of training would be equally important, because it was the first day of drilling in the *técnica de cambio de bolsa de diálisis* – the dialysate bag change technique. While the day before everybody saw the content of a dialysate package, for the majority of us this was the first time we had handled one. From this day on, the patients and carers would work to create a particular relationship between their bodies and the dialysate package, and later, when undertaking the treatment at home,

establishing a connection between their bodies, the dialysate package, accompanying apparatus and the room. The package would have a double meaning, as a means of treatment but also a reminder of ongoing illness (Peitzman, 1989). But in the meantime, they had to become acquainted with the content of the dialysate package.

A PiSA dialysis package contains a double-bag Y-system (see Figure 13): (1) a dialysate bag, containing 2 litres of dialysate solution (2 kg weight approximately), with (2) an injection site (in case additional medications are to be added); (3) an empty drainage bag, which would be filled with used dialysate from the abdomen; (4) an infusion line, which is a clear tube that connects the dialysate bag to the 'Y'; (5) a green breakaway segment in the junction of the 'Y' and the infusion line; (6) a drainage line, which is a green tube connected to the drainage bag and the 'Y'; (7) the 'Y', a green plastic connector which joins the infusion and drainage lines to the transfer and security set; (8) the disposable transfer and security set, which is a tube with a series of parts: (9) a red breakaway coupling, from which the double bag and the transfer set disconnect; (10) a non-reopening blue clamp, which works as a security lock; (11) a blue connector, filled with iodine-povidone to prevent contamination, which is the point of connection between the double bag system and the patient's transfer line; and (12) a cap whose colour would indicate the percentage of glucose concentration (yellow 1.5% the most used; green 3%; red 4.25%).

Figure 13 PiSA's double-bag BennY System



Source: Laboratorios Pisa (2010).

Before starting with the demonstration of the technique, Gloria conducted a round of questions and answers, where participants were examined about the things learned the day before and the content of the CAPD manual. She would repeat this ‘teaching strategy’ over the following days, to help participants to become familiar with the sort of questions included in the written exam. But it also served to reaffirm the hierarchical relationship between health professionals and participants – the former always asked the questions, while the role of the latter was to answer.⁹⁵

4.3.2 Learning a new technique of the body: la técnica de cambio de bolsa de diálisis

After the quiz, Gloria staged a performance of the *técnica de cambio de bolsa de diálisis*, or dialysis solution bag change technique, step by step, to instruct the attendees how to do it for themselves. This time she did not use a patient from the

⁹⁵ Such interactional asymmetries are analysed in Sacks (1995).

ward, as she had done the day before. Instead, she used a sort of dummy⁹⁶ to simulate a patient. As will be evident, the actions that comprised the steps show us that the objective of the technique is not only the replacement of used dialysate solution for fresh one, but the prevention of infections. More importantly, what she was doing was teaching them a drill, one in which they were being trained to perform a series of ‘assembled’ actions, as well as the appropriate movements for handling the objects and tools involved in CAPD therapy. These movements might seem laborious, meticulous and tedious, even unnecessary from an outsider’s perspective, but moment to moment, during the training, the participants were expected to follow and imitate them fluidly, with precision and readiness. It is important to remind the reader that, for patients and carers, passing the training is a matter of showing that they are able to naturalise this technique of the body, performing it from beginning to end without hesitation or mistakes. From the hospital’s perspective, the success of the therapy is based on the efficacy with which the patient and the carer perform the technique at home. While Gloria did not enumerate the actions or steps, I will do so in order to highlight the ordered sequence of atomic movements she intended us to learn and embody as part of ‘an ensemble of instructed action’ (Garfinkel, 2002). This is the list of steps involved in performing the technique according to Hospital Alcalde’s CAPD programme:⁹⁷

1. *Put on the scrubs (gown, hat and facemask).* The gown must be worn by the person who performs the change. If it is the patient, he or she must wear a gown

⁹⁶ The dummy was made of a stand hook, a gown and a peritoneal dialysis transfer line.

⁹⁷ While most home peritoneal dialysis programmes in Mexican hospitals involve similar techniques, there are marked differences among them, particularly with regard to handwashing. What I describe here is the particular technique used and taught at Hospital Alcalde.

with the opening at the front, in order to handle the catheter easily. If it is a caregiver, then the gown must be worn with the opening at the back.

2. *Warm up the dialysate package* in the microwave for about 2 minutes (the liquid must be at 36 degrees or body temperature).
3. *Gather the dialysate package, disinfectant, clamps and wipes near the working table.*
4. *'Normal hand washing'*: wet hands and apply regular soap, from the fingers to the elbow. Rinse one hand at a time, do not rub or use both hands. Dry up one hand at a time, beginning by the fingers (one finger at a time), using a fabric towel. Do not rub hands or fingers. Go to the working table with both arms raised like surgeons do.
5. *Clean the working table.* Spray disinfectant to the surface at five points: at the centre and each of the four corners. Use a wipe to clean in one direction, doing clock-wise movements from the centre to the edges of the table. Throw the wipe away from the table. Lay the spray and clamps in the left top corner of the working table.
6. *Clean the dialysate package.* Take it and raise it with one hand. Use the other hand to spray disinfectant to the package. Dry the package using a wipe using top to bottom movements. Throw out the wipe. Once the package is dried, lay it on the left-hand side of the working table, with the opening towards the person who is carrying out the procedure.
7. *Surgical hand-washing technique.*

- a. *First time:* wet the brush and apply a little of soap. Scrub ten times between the fingers and thumb of one of the hands, in one direction. Close the fingers and scrub the nails 20 times, in the same one directional movement. Open the hand and scrub from the finger tips to the elbow. Repeat the whole procedure on the other hand. Rinse with water in one directional movements by introducing the hand and arm into the water stream, one hand at a time (avoid rubbing using both hands).
 - b. *Second time:* repeat the whole scrubbing procedure, but this time until mid-arm and rinse until the elbow.
 - c. *Third time:* repeat the whole scrubbing procedure, but this time until the wrist and rinse up to the elbow.
 - d. *Dry hands with the fabric towel,* starting with the fingers, one at a time. Do not rub. Go to the working table with the hands raised.
8. *Open the package.* Tear open the wrapping plastic at the opening site and dispose of it. Lay the content of the package on the left-hand side of the table, near the spray and forceps, over the tubing. Check the expiration date of the bag and the glucose concentration. Squeeze it gently to identify any leaks. Turn it over in the same place, so the tubing is over the solution bag. Cover the line's cap with one hand and detach the tubing with the other hand. Remove the wrap that protects the drainage bag and throw it out.
9. *Check the transfer line of the patient's catheter is closed.*

Figure 14 Snapshots of PiSA's CAPD instructive video



Source: Laboratorios Pisa (2013). The video was released on July 2013, after I finished my fieldwork; it is intended to be a support for patients, not a substitute of training.

10. *Disinfect hands.* Apply disinfectant to one of the hands, rub both hands and wait five seconds.
11. *Connection phase.* To connect the double-bag system to the patient's transfer line, hold the top of the patient's transfer line with index and middle fingers, and the top of the double-bag's line with the thumb and the index finger of the same hand. Remove the cap of the double-bag's line and apply disinfectant. Remove the security and transfer set from the patient's transfer line and apply disinfectant. Connect the double-bag to the patient's transfer line.
12. *Drainage phase.* Hang the solution bag on the stand hook and place the drainage bag in the plastic bowl on the floor. Squeeze the infusion line with the clamps and break the seal of this line. Open the patient's transfer line and wait until all the liquid is drawn out from the abdomen, between 10 to 30 minutes (it depends on each patient's case).⁹⁸
13. *Infusion phase.* Close the patient's transfer line when the drainage has finished. Remove the clamps from the infusion line, wait five seconds and squeeze the drainage line, to purge air from the dialysate solution bag. Open again the patient's line to infuse fresh dialysate solution into the patient's abdomen. It will take between 5 to 10 minutes.
14. *Disconnection phase.* Once the solution bag is empty, close the patient's transfer line. Close the blue lock. Squeeze both infusion and drainage lines with the clamps. Unhang the solution bag and place it in the plastic bowl.

⁹⁸ This is related to the nature or the condition of the patient's peritoneum. For example, before, during and after peritonitis infection, or any other complication of the catheter, the infusion and drainage of the dialysate solution could be slower.

Disconnect the double-bag system by breaking the red breakaway coupling (leaving the disposable transfer and safety set).

15. *Weighing used dialysate.* Weigh the drainage dialysate bag on the scale. It should weigh between 2300 and 2500 grams. Subtract 50 grams (the weight of the empty bag) to get the actual weight and write it down in a note book.⁹⁹

16. *Disposal of the used dialysate.* Introduce 10 cm of chlorine, using a syringe, into the drained dialysate and let it wait 30 to 60 minutes. Dispose of the liquid into the drainage.

4.3.3 Drilling in the technique

Gloria's flawless performance and skilful handling of the dialysate package, the tubing and the hand washing, made the procedure seem straightforward. When she finished, Gloria said 'now you have seen how to do it, it is your turn to drill.' Because none of us volunteered, Gloria chose Teresa to do it first, which she did without saying a word, because in such situations nobody wants to contradict the nurses. Teresa made many mistakes, especially when washing her hands. Gloria pointed out her mistakes, and at various points told her to start again when she didn't do it right. The other trainees were also trying to help by pointing out her mistakes and telling her what to do next. Teresa seemed upset and nervous, and kept saying 'it's difficult, I forget what follows'. Although Gloria gave feedback and advice to all of them, she also warned that they had to learn as quickly as possible. The warnings added to the general discomfort of

⁹⁹ Patients must weigh the used dialysate to monitor the functioning of peritoneal dialysis. If lesser liquid is drained than infused, it is an indication that CAPD is not working properly.

the situation, especially for Teresa, because at some points Gloria was close to supervising all her movements. While Gloria had performed the technique in around 20 minutes, it took more than 30 minutes for Teresa to complete her first practice.

All the participants were drilled in the technique as part of the second day of training, which lasted about three hours. It was a challenging experience and every one of the trainees made mistakes throughout the procedure, although Gloria supervised and gave them feedback. However, it was more challenging for Nicolás, who in the end was considered unable to perform CAPD for himself. Aside from being illiterate, and so someone who could not read the expiration date of the solution, he was diabetic and hypertensive, conditions that had led him to gradually lose his sight. More importantly, he had problems of mobility in both arms, so he could not easily hold the 2 kg dialysis bag (apparently he had suffered injuries in both arms some time ago, though he did not say anything about those injuries). Gloria noticed these problems, but decided to let him finish the exercise. She told him ‘do it now and later I will talk with you and with the social worker about your situation.’ Nicolás was obviously upset because of this situation and replied ‘that’s why I proposed my daughter-in-law should do it, but the social worker said I should be responsible for my treatment; I have problems with my arms and hands too.’ He continued, but at some points he said ‘I cannot move my hands well, it’s too difficult.’ The situation was uncomfortable for the other trainees too. At the end of his turn, Gloria took him to the social worker. Eventually, they convinced him to leave the training and recommended that he discuss the designation of a carer for him with his family.

Teresa would be the next person to be removed from training. This took place during the third day of training, when a new nurse coordinated the session. Teresa still had

problems with the hand washing, but it was her short-sightedness that was picked up by the nurse. Teresa acknowledged that she had sight problems, but said that she could use glasses. The nurse felt this was enough to consider her unsuitable for taking care of herself. She and the social worker talked to her and they agreed that her husband would be her carer and would take the training in the following weeks. Later, I had the opportunity to talk to Teresa and her husband. She told me that she was upset at being removed from training, and felt her sight was not such a big issue. Moreover, she and her husband had invested money and time to attend the training, and, like many other patients who are unexpectedly removed from training for diverse reasons, these costs were not easily recovered. However, Teresa and her husband had a plan: he would take the training, but she would perform CAPD at home and take care of herself. It was a similar strategy to that of Concepción and her cousin. That is, even when it seemed that patients didn't have control over the training, they were able to recover their autonomy and find ways of passing the last stage of the admission process by showing outward compliance while proceeding in ways that departed from its strict requirements – a form of 'hidden transcript' underlying their surface displays of compliance (Scott, 1990).

Over the following days Concepción, Lourdes and Bruno, the remaining participants, went through the drill several times. The nurses also dedicated time to asking them questions about the technique and the tasks they would have to perform to keep the dialysis room sterile. It was a way of helping patients to keep focused on the topics that would come up in the exam. The three remaining participants passed both exams at the end of the week.

For Lucero, the training week was another challenge in her trajectory as a renal patient. As Lucero recounted, she felt that the nurses in charge of the training were very strict with her. She had been hospitalised the week before training. Her mother had proposed she would take the training and act as the carer for Lucero, but the social worker thought differently and did not allow her to take it. Lucero was weak and lethargic, as a result of constant hospitalisations, complications and the symptoms of CKD. Given her fragile condition, José had to take her to the training sessions in a wheelchair, which he borrowed from the shelter, when Lucero was given an appointment to attend the training in April 2013.

As Lucero told me, she was scolded by the nurses because she repeatedly made mistakes washing her hands. As Lucero recalled, ‘the nurse told me ‘If you don’t learn, you will have to attend another week of training or more, until you learn how to do it correctly’. But I don’t want to be here, I just want to go home, I am very tired of being in the shelter. I am so tired.’ At one point, she was even thinking of leaving the training. Lucero told her mother that she did not want to continue because it was too difficult for her. But her mother convinced her to carry on. During training, she had to undertake drills in the hand washing over and over again until the nurses felt she had it right. The nursing team made her attend one more day than her fellow trainees, to continue drilling in the hand washing and the dialysate bag change technique.

Lucero also had difficulties with the ‘theory’ part of the training. Not only because all her energies were sapped by treatment and disease, but also because she was almost illiterate – she had barely completed six years of education. She found it very hard to read the patients’ manual, and had to rely on what the nursing team explained to her during training. It was particularly difficult for her to differentiate peritoneum from

peritonitis – a question that the nursing team asked several times during training. I visited Lucero in the shelter, where she and her father were staying during the training week, and knew about the hard time she was having. The day before her examination, I helped Lucero to revise the content of the exam, in order to help her improve her chances of passing it. She sat the exam on Saturday, instead of Friday as the other participants did. She eventually passed both exams, the written and the practical, and was allowed to proceed with CAPD at home. For Lucero and her family, it was a major achievement; she had become a proper *CAPD patient*, ready to start therapy at home.

4.4 Conclusion

This chapter has focused on the challenges connected with gaining access to CAPD, in particular the difficulties of meeting the CAPD programme's requirements, preparing the home to accommodate a complex therapy and completing the appropriate training. Based on what I have shown above, I want to draw out a series of related analytical points that help us to think about the socio-material conditions of the situated experience of CKD and peritoneal dialysis, as the mainstay of renal replacement therapies in Mexico.

As this chapter has shown, diagnosis unlocks a series of therapeutic interventions (Kierans, 2015). However, for uninsured CKD patients, as I demonstrated, diagnosis didn't mean automatic access to home peritoneal dialysis. I showed in Chapter 3 that, shortly after receiving a diagnosis of CKD in the hospital, patients found themselves with a catheter and undergoing intermittent peritoneal dialysis in the hospital, having little option but to continue on this path. Over the course of days and weeks following the first hospitalisation, they learnt that intermittent peritoneal dialysis was just a

temporary therapy, and that they had to apply for a place in the CAPD programme of the hospital. However, getting access to this programme meant enduring a whole process of admission – a series of meetings, training sessions and other requirements patients and families, as *applicants*, must satisfy.

The events following diagnosis described in this chapter resemble the ritual processes analysed by anthropologists like Gluckman, Turner and Van Gennep (Gluckman, 1962), but also analyses of ‘initiation’ and reconstructed subjectivity offered by Goffman (1961) and Foucault (1995). As was evident, the stages prior to performing CAPD at home are a process of probation, during which the patients and their families undergo tests and trials, and if they succeed, they acquire a new identity, a new status, that of the *CAPD patient* – one who is officially recognised as capable of undertaking medical work in their own home. In short, they have to remake themselves in important ways in order to qualify as *CAPD patients*.

Thus, I argue that the admission process is a ‘liminal’ stage in the patients’ trajectories (Turner, 1969). After diagnosis with CKD and the initiation of intermittent peritoneal dialysis, sick persons can be considered *renal patients* – as in need of some form of renal replacement therapy – but not *CAPD patients*; they are caught between the two. The characteristics of the renal patients during this stage are ambiguous, and until the transition has been completed, they do not gain their new identity, nor are they able to perform the roles and responsibilities related to that new status (Turner, 1969). Before achieving it, the initiate patients stand at a threshold, in a betwixt and between position – outside treatment proper, despite official recognition of their medical needs. Their status before becoming a proper CAPD patient is indeterminate – dependant on the hospital, which, in turn, demands they meet a series of criteria designed to filter out all

but extreme cases due to the overloading of hospital services. For the hospital, a trainee patient is a burden, and they are required to complete training as soon as possible. If they do not, the patient will be ‘punished’, left in a risky situation without dialysis until their condition is critical and they have to be admitted to emergency service, as the cases of Daniel and Lucero illustrated. The admission process seems arbitrary and contradictory from the outsiders’ perspective, but reflects the organisation and operating ethos of the hospital, predicated as both are on control and the management of scarce resources. Only when all those stages are completed is the patient allowed to proceed with peritoneal dialysis at home. As this chapter has shown, getting access to the CAPD programme is a significant part of the trajectories of uninsured people with CKD in the context of Mexico.

Becoming a CAPD patient requires undergoing testing that demonstrates a willingness to learn to perform a procedure that is normally a responsibility of well-trained healthcare professionals. Gaining the status of CAPD patient is challenging for the majority of patients and family carers, because it demands effort and discipline from them – they undergo yet more trials in different forms. They have to learn to perform the therapy during a training week at the hospital, as if they were becoming adjunct clinical workers. In a sense, the whole admission process prepares the patients and their families for the outsourcing of medical work and, at the same time, it makes them responsible for the eventual success or failure of the therapy.

CKD is an unpredictable life-threatening condition whose symptoms can flare up at any moment, and this can affect the admission process. The case of Daniel, who unexpectedly died two months after being diagnosed – well before his family were able to complete the dialysis room – is a reminder of that unpredictability. For those

who can make it onto the training, it is a learning process in many ways, where supplicatory practices feature throughout: the sick person and his or her relatives have to learn how to be patients, how to submit to medical procedure, and how to comply correctly (Goffman, 1956). At the same time, they learn how to look after themselves and how to perform complex clinical tasks, from keeping the room sterile, washing their hands, to changing a bag of dialysate. Undertaking training is no guarantee that the patient will pass, and a number fail and have to retake it. This is in part due to the contingencies which affect the whole admission process, as described in this chapter.

Being a renal patient in peritoneal dialysis thus implies not only being compliant to some degree when directed by the health professionals, but being disciplined, submitting to authority, and above all, learning and embodying the set of skills needed to perform the various tasks required by peritoneal dialysis in the home safely. Such skills – negotiating with stakeholders, handling dialysis related objects and tools, the hand washing – and practices – such as attending medical appointments, keeping to the timetable of dialysate changes, maintaining the routine of keeping the room sterile – are picked up progressively from the time of their first arrival at the hospital. From that moment on, the patients and their family have to adjust to a new reality and begin to learn how to deal with different stakeholders, that is, how to be a supplicant in the context of the Mexican healthcare services. This continues through training, when they learn the skills to perform CAPD at home, how to keep the dialysis room clean and free of dust, and the domestic routinisation of CAPD (as far as that is practically possible). The prescriptive and rule bound training serves not only as an instructive procedure, but as a disciplinary device, the means for establishing a new practical subjectivity (Foucault, 1995) – the sick person is transformed into a productive CAPD patient capable of undertaking medical work responsibly.

Getting a place in the CAPD programme means submitting to a disciplinary apparatus put in place by the hospital to turn the sick person into a CAPD patient – the rules, the training, and the staging of local ‘theatres’ of, here, photographic proof (Latour, 1988).¹⁰⁰ The house must be transformed to accommodate the therapy. The patient’s body – and sometimes a carer’s – must be trained to handle a series of objects, to minimise the risk of infection, and to inculcate a clinically-approved regime of care. In other words, patients and carers are required to learn new body techniques (Ingold, 2011; Kierans & Bell, 2016; Mauss, 1973), that is, a series of assembled movements and actions aimed at the achievement of particular goals, in this case, to dialyse the body. However, training is difficult for several reasons: it is unsupportive, unhelpful manuals are used and almost everything must be learned by viewing and drilling. The nurses in charge of training are strict, and patients must endure their oversight, submit to their orders and accept punishment without complaint. As I described at some length in the second section of this chapter, CAPD training aims to create a nexus between the surgically modified body, therapeutic objects and the dialysis room (Foucault, 1995; synergy in the words of Ingold, 2011). The patients, and sometimes the family carers, will learn how to manipulate and to practically co-exist with new objects and transformed spaces – catheter, bags, table, disinfectant, the room, and so on – in order to recover and maintain some stability in their lives. Catheter, dialysate and the equipped dialysis room are three elements upon which the life of the patient will depend from then on.

In this chapter I have attempted to open up these processes, showing the different kinds of activities patients and their families have to engage in at different points during the

¹⁰⁰ I owe this point to my supervisors who drew my attention to the idea of ‘theatres of proof’ in the STS literature.

admission process. In the previous chapter I argued that patients do not stand alone but are always accompanied by their next of kin and draw on wider networks of support. Such accompaniment takes the form of work. In this chapter their work also featured heavily during the whole admission process; in the first stages it was the family that was in charge of many of the changes to the home and responsible for attending meetings; during training, it is usually the patient who is called upon. But the admission process also had another objective, that of the outsourcing or ‘putting out’ of clinical work to the home, the family and the patient.

The outsourcing or ‘putting out’ of clinical work is not unusual. Medical anthropologists and sociologists converge in considering cooperation and compliance – or the subversion of it – as itself a form of work in which the patient contributes to their treatment in a range of ways (Corbin & Strauss, 1985; Mattingly et al., 2011; Mykhalovskiy et al., 2004). Thus, for patients and their families the set of tasks related to the medical regime – from the more familiar elements, such as exercise, diet and timing of medications, to the more unfamiliar elements, such as monitoring and managing symptoms, or changing a dialysate bag, either followed to the letter or modified – are aimed at maintaining a certain level of balance between chronic illness and everyday life. In other words, they try to create sustainable ways of living in the face of the deep problems posed by chronic conditions like CKD. As shown above, however, what is more unusual in the context of CAPD in Mexico, the intensity, frequency, and complexity of clinical tasks that patients and their families are required to carry out means that the hospital hands responsibility for clinical care to patients and families by making them transform their house into a para-clinical space in circumstances that are especially challenging, financially and socially. In order to do this, the patient must be made capable and disciplinary techniques are the means used

to achieve this. Chapter five will explore the actual outsourcing of care in domestic contexts and how the dialysis room, as a para-clinical space, is actually used.

Before continuing with that account in the next chapter, however, it is important at this stage to underscore the contradictory character of peritoneal dialysis, as it was discussed during training. In order to do good, to replace some renal functions, peritoneal dialysis damages the peritoneum and puts the body at risk of life threatening infections and other serious problems. Long term peritoneal dialysis carries many clinical complications that threaten the continuation of the therapy and the life of the patient – for example, catheter failure, cardiovascular disturbances, atherosclerosis, hernias, vasculitis, and oedema caused by leaks (Bargman, 2009). However, infections of the peritoneum are the most common complications of peritoneal dialysis, and these have their epicentre in the catheter (Fried & Piraino, 2009; Garcia-Garcia, Tachiquín-Bautista, et al., 2007).

The catheter, perhaps the most significant mark of peritoneal dialysis, serves as the conduit through which the dialysate solution is infused into and then drained out from the abdomen, replacing some of the functions the kidneys no longer do. As noted in the previous chapter, the assembled parts that constitute the catheter and the patient's body also function as a bodily interface with the medical system and its modes of organisation. The catheter makes the patient compatible with CAPD, at home and at the hospital, but at the same time, it makes them vulnerable to the previously innocuous environment of the home. A literal opening of the body, the catheter is a major site of concern, because it is the point of entrance for infections. Having a catheter exposes the body to bacteria and fungi that in normal situations are harmless, but which become very dangerous in the delicate environment of the peritoneal cavity (Fried & Piraino,

2009). This is the reason why we see such efforts put into training aimed at preventing contamination during bag changes.

As a clinical therapy, peritoneal dialysis helps to remove water and waste products from the body, but it carries a series of risks that the patients and their families are not always aware of. In other words, peritoneal dialysis therapy involves an ‘iatrogenic’ gamble patients are participating in without full knowledge (Illich, 1976). Thus, the admission process is not necessarily a process of deciding who deserves to be accepted onto the programme, but more a process of ensuring that the patients will be able to replicate, as best as they can, a safe environment and that they have learned and embodied the sterile preparation to perform a risky therapy at home.

In sum, what we can see from the descriptions offered in this chapter is that becoming a CAPD patient requires great discipline, work and adherence to the rules, not just in spirit but to the letter and by both the hospital and the patients and their families. The admission process is a space and time for learning. It is a stage where the hospital tells patients and families what is expected from them and what they will have to do to meet its requirements. The next chapter will explore if and how such expectations are met, and to what extent patients depart from the programme’s strict prescriptions. It will also explore the situated manifestations of harm through the complications related to this therapy.

Chapter 5

Performing CAPD in the home

Introduction

The previous two chapters have tracked the trajectories of patients from the onset of symptoms and the search for medical care through to the initiation of in-hospital peritoneal dialysis and the process of becoming a proper CAPD patient. Particular attention has been given to the challenges, trials and tribulations patients and families encounter along the way. This chapter will focus on the situated ways in which CAPD is practised in the context of domestic life (Lave, 1996; Suchman, 2007). I will focus on what might be termed the ‘hidden transcripts’ (Scott, 1990) that shape how CAPD is practised in domestic settings, including the accommodation of care in the home (Heinemann, 2015; Hodgetts et al., 2011) and the work families do to keep the therapy going (Corbin & Strauss, 1985; Mattingly et al., 2011). The aim is to provide a clearer picture of the problems and challenges of living with CKD and performing CAPD in a poorly resourced context.

The chapter has three main sections – dealing with practices, relationships and outcomes in turn. In the first part, I will describe patients’ ways of practising CAPD at home, treating them as instructed and situated actions (Garfinkel, 2002; Suchman, 2007). I will look specifically at how the techniques of dialysis bag change are embodied by the patients who practise CAPD and I will show how the body techniques, drilled into the patients during training, are reinterpreted and adapted to the particular circumstances each patient finds themselves in. How the body-therapy-

room nexus is ‘continuously’ re-enacted by individual patients is a central part of this process of reinterpretation and adaptation and it reshapes the therapy in several respects. Despite these reinterpretations and adaptations, however, the need to perform the therapy remains a constant. That it does have to be undertaken ‘continuously’ means that the person will dedicate his or her life to dialysis, something which limits them enormously when it comes to doing anything else. CAPD becomes full-time work and it is work on which their lives depend.

Patients are not, however, the only ones engaged in this work. For that reason, in this first part of the chapter I also explore how families and patients manage the demands of CAPD with limited resources. I show that the process of accommodating the therapy does not end with setting up the dialysis room but continues through the patient’s trajectory and changes over time. Nor can CAPD be confined to the dialysis room; instead it ‘overspills’, spreading out into other parts of the family home. Home and therapy thus modify each other; there is a process of mutual transformation. The household makes provision for the treatment and ‘indigenises’ or ‘domesticates’ it (Appadurai, 1990), while the treatment ‘medicalises’ the home, transforming it into a para-clinical space. This is the home as a space of hybridisation (Haraway, 1991).

Proceeding from this account of the practice of CAPD, the second part of the chapter describes and analyses the long-lasting relationship between patients, families and healthcare personnel. A major feature of this relationship is ‘home-work’: healthcare professionals regularly assign patients and families with certain tasks which they have to accomplish as part of CAPD. In examining the organisation of home-work, this section explores another manifestation of supplicatory practices. Accomplishing the various tasks they are assigned requires the families and patients to invest time, effort

and money in the maintenance of the therapy. In this, they are supporting the life of the patient. This is not a one-way relationship however: families show compliance with healthcare professionals' demands, who in turn, offer help with hospital services. The presence of hidden transcripts again becomes important here. For example, patients are told they are expected to abide by dietary restrictions, medication regimens, strict scheduling, and so on. However, these can be difficult to follow through. Patients thus develop ways of demonstrating compliance even though they are not doing so to the letter. Doctors also operate with hidden transcripts, helping patients to access Seguro Popular benefits that would otherwise be restricted to them as CKD patients.

The final section of the chapter explores the possible outcomes of CAPD in the long run. While some uninsured patients, with great effort, are able to get a transplant, for the majority their treatment trajectories ended with CAPD. Since its beginnings in the 1970s, CAPD has been known to give rise to many related complications, some of which can have serious consequences. One complication in particular has haunted CAPD programmes around the world, and particularly in Mexican programmes: peritonitis. Many patients I came into contact with who experienced peritonitis were able to resume CAPD, others were transferred to haemodialysis, bringing other problems. Many other patients also experienced other complications, besides peritonitis, that in some cases led to death. While every medical therapy is linked to undesired effects, I will conclude the chapter by arguing that CAPD is in itself harmful in many respects – it is an iatrogenic form of therapy (Illich, 1976). Crucially, however, CAPD's iatrogenic character is as much a product of the socio-material conditions in which it operates as the therapy in itself – it is, thus, *contextually* rather than *intrinsically* iatrogenic.

5.1 Situating CAPD in the home

Chapter four demonstrated that completing the process of admission to the CAPD programme was a challenging experience. Families and patients had to learn the practical role they would play in stabilising and delaying the progression of CKD – for CAPD does not constitute a cure for CKD. It was assumed that patients would follow instructions in an idealised environment – the dialysis room – where they would become agents in the production of their own health. However, although families were instructed in specific routines and patients were drilled in techniques of sterilisation, they still had to work out how to practise CAPD and sustain the therapy structurally and financially in the long run.

I will take up the next phase of Lucero's story to illustrate some of the key challenges associated with accommodating and practising CAPD just after passing the admission process. As I will show, it was during those first weeks when they began practising CAPD on their own that patients actually came to embody the sterile technique – a process that was influenced by the place and arrangement of the dialysis room in the domestic context. However, these body techniques were not stable but changed over time in line with personal circumstances and socio-material situation. To illustrate this, I will also draw on the cases of more experienced patients to explore how they practised these techniques as well as the ways in which they sought to domesticate the therapy.

As I will show, as CAPD novices, Lucero and her family tended to comply with most of the instructions given to them during training. However, from the beginning, like most patients and families, they also introduced a series of modifications that deviated from those instructions. They did this, as I will show, in order to make the therapy

‘work’ in their domestic contexts. While not ‘medical’ as such, the example of patients with more experience of conducting CAPD at home shows that these adaptive practices are what enable patients to carry on with the therapy and survive in the long term.

5.1.1 Lucero: accommodating CAPD, embodying the technique

It took Lucero and her family six months to progress from diagnosis to the point where they had met all the CAPD Programme’s requirements. Everything was almost ready for Lucero to start CAPD at home, she only needed one last thing – a supply of dialysate solution packages. Just two days after she passed training, José managed to obtain a donation of ten boxes of dialysate solution packages¹⁰¹ from an asociación civil in Guadalajara. The story of how José obtained this donation deserves further treatment and analysis, and I will return to it in the next chapter. Suffice it to say at this stage that I had accompanied José and helped him transport the boxes from the city of Guadalajara to his community on the east side of Lake Chapala. Once in their home, José and Úrsula asked me to help their daughter perform her first *cambio de bolsa*, or dialysis bag change. Knowing the difficulties Lucero had during training, I felt obliged to assist.¹⁰²

Lucero’s room was above her parents’ (see Figure 12 on page 174), the only room suitable for CAPD in a five-room house that accommodated three families. When I

¹⁰¹ A box contains eight packages of dialysate solution, each containing a double-bag system, required for every dialysis bag change. See Figure 13 on page 191, Chapter 4, for an example of the content of a dialysate package.

¹⁰² As discussed in the previous chapter, I also learned the technique, taking the same training as the patients, and I had the procedure written down in my notes, which I could access through my smartphone.

first saw her room, it didn't look very different to a normal bedroom. It was 3 m × 4 m, the walls were recently painted and it had a window looking out onto Lake Chapala. The room was clean and tidy because Lucero and Úrsula had prepared it for the first dialysis that day. Lucero's bed was at the end of the room, pushed into the wall at the bottom right corner. Lucero's double-layer working table was arranged against the wall on the left (see Figure 15 on page 218). José had mounted the washbasin over the table, placing the water dispenser on the left side and a plastic bowl on the floor.¹⁰³ Barely enough space was left for Lucero to handle the double-bag system during the connection phase. In front of the working table, against the wall on the right of the room, was another triple-layer table holding the microwave and a mechanical balance-beam scale. Next to this table was Lucero's wooden wardrobe, and above it, there were small sculptures of the Virgin of Guadalupe, a Niño Dios (Baby Jesus) and a Niño Doctor de los Enfermos (Baby Jesus, Doctor of the Sick) alongside other dolls and teddy bears. Besides the water dispenser, the scale and the rest of the medical equipment, this was a typical young woman's room.

Lucero was both nervous and excited about initiating dialysis at home and the chance to finally put into practice the techniques she had struggled to learn during the training week. As soon as she closed the door, this domestic space was transformed into a *dialysis room* – the para-clinical site on which her life was now dependent. Once inside the room, we wore the obligatory dialysis attire – hospital gown, surgical facemask and scrub hat (step 1, see list in Chapter 4, Section 4.3.2). She had tied up her long hair, making a braid with it which hung behind her head underneath the scrub hat. I also put on a surgical facemask, and stood away from her. Lucero still seemed lethargic

¹⁰³ That is, it was not a DIY wash basin as suggested in the training and depicted in the PD manual.

and frail – renal failure and constant hospitalisations had sapped her energy. Her face was still swollen, which contrasted with her thin arms, and her brown skin tone was a little yellowish. She walked and moved with difficulty, but she was determined to carry on with the treatment.

I was expecting Lucero to warm up the dialysate package (step 2), but she didn't. I asked her why, and she said, rather lamenting, 'the microwave is broken, it doesn't work. My grandma gave it to me, but we only used it to take the photographs. But, it is broken.' Later I learned from José that, during the setting-up of the dialysis room, the family couldn't afford even a second-hand microwave – a domestic appliance uncommon in the homes of the rural poor. Fellow patients advised them to borrow one for staging the photographic evidence because it was not essential for the therapy.¹⁰⁴ That is why Lucero did not warm the dialysate bag, as required in the training, one of the first of many 'ad hoc' modifications patients introduce over time.

Apart from the absent microwave, Lucero followed the instructions as best she could. She started with the hand washing as soon as she had dressed up. Given the way they had set up the wash basin, she had to bend over a little when washing her hands. It took Lucero about fifteen minutes to complete the handwashing, clean the working table and clean the package, but she did it following the procedure as she had been trained (steps 4-7). During the connection phase (step 11), she was visibly nervous and hesitant; her moves were cautious and slow, but she did it right. The connection phase, which she performed in about 30 seconds, is the most critical point in the whole CAPD procedure because it is when the body of the patient on CAPD is most exposed to

¹⁰⁴ The microwave is used to warm up the dialysate solution to a temperature close to that of the body. This is done to prevent discomfort for the patient – some might feel cold, chills and even a little pain if the solution is colder than body temperature – but it does not affect dialysis functionally.

infections. Nurses told patients to strictly adhere to the procedure and safety measures and to perform it as quickly as they could, as this would reduce the risk of infection.

Once Lucero connected the double-bag system to her body through the permanent catheter, she took the fresh dialysate solution bag and hung it on a nail on the wall, next to her working table, José had provided since the family couldn't afford the recommended stand-hook (see Chapter 4, section 4.2.1). She opened the transfer line of her catheter and initiated the drainage phase (step 12). Lucero then sat down on her bed and put the drainage bag on the floor because she had used the plastic bowl to catch the water she had used during the handwashing. At this point, she had missed two minor steps – squeezing the infusion line with the plastic clamps and breaking the green breakaway segment of the infusion line. I mentioned this to her, and she did it immediately, although these steps didn't affect the procedure at that point.¹⁰⁵

Lucero had been discharged from the hospital with about a litre of dialysate solution in her abdomen, according to what she had been told, which was drained out of her in a few minutes. The used dialysate came out in a dark colour, but she said it was the same colour as when she was in the hospital on intermittent peritoneal dialysis. She continued with the infusion phase (step 13), which lasted another ten minutes. Lucero said 'it feels cold when it's getting in (the dialysate solution)', but it was a minor discomfort she could bear. Once her abdominal cavity had filled with fresh dialysate solution, Lucero proceeded with the disconnection procedure without any great problems (step 14): first, she closed the transfer line, then squeezed the infusion and

¹⁰⁵ The green breakaway segment (see Figure 13 on page 191) is a seal that prevents the fresh dialysate solution from mixing with the used dialysate during the drainage phase. The formal procedure requires the patients to squeeze the infusion line before breaking the green breakaway segment, in order to hold the fresh dialysate flow until the infusion phase. Since Lucero did not break the seal, it was not necessary to squeeze the infusion line.

drainage lines, and closed the blue lock, and finally disconnected the system by breaking the red breakaway junction. After introducing a little chlorine, she made a knot with the lines and disposed of the used dialysate down the toilet. Although it took her more than 40 minutes to complete her first dialysate bag change – almost double the time that it would have taken a nurse – it was an important milestone for Lucero and her parents: Lucero had become a CAPD patient.

A week later, I returned to Lucero's home and I had the opportunity to observe her performing the bag change once again. Lucero had been doing CAPD on her own – four times a day, every day for a week – strictly following the timetable prescribed by the CAPD programme. In addition, she had been taking her prescribed medications and was adhering to the dietary and fluid restrictions that were also part of her therapeutic regimen. Lucero had reduced liquid intake and stopped her consumption of salt, potassium and other substances that her kidneys no longer processed. She started this strict, bland, and sometimes unbearable and challenging diet soon after she was diagnosed. However, it was not until this diet was combined with continuous dialysis that she and her family saw the positive results. It seemed to me that Lucero's health had improved greatly after just one week of continuous peritoneal dialysis. She was much more talkative, and she could do things that a week earlier she was unable to do. The swelling of her face and feet had reduced considerably and her energy had returned, but she was aware that her health was still delicate. However, Lucero's body had changed, she developed a bulging, bloated belly – a bodily change all CAPD patients experienced – caused by the constant presence of two litres of dialysate solution in her abdominal cavity.

Figure 15 Lucero performing CAPD at her home after a week of continuous practice



Source: My own. Notes: Photo A taken during the first week; photos B to H taken the second week. A. Triple-layer table, with the broken microwave, balance beam scale and bag with medicines. B. Lucero washing her hands. C. Connecting the double-bag system to her catheter. D. Hanging the fresh dialysate bag. E. Waiting for the used dialysate to drain out of her abdominal cavity. F. Weighing the used dialysate. G. Preparing to dispose of the used dialysate. H. Lucero's wardrobe with religious figurines.

Lucero and her mother had kept the room clean and tidy, as they had been told to by the programme. More like a normal bedroom, however, the broken microwave had by

this stage been replaced by an old television (see Figure 15, photographs A and F, on previous page). Nonetheless, when the time arrived, the door was closed, medical attire was put on and the room again became a site for dialysis. This time Lucero performed the whole procedure much quicker than the week before – completing it in just about 30 minutes without any mistakes. More importantly, she performed the connection of the double-bag system and her catheter in less than 20 seconds, compared to 30 seconds the week before.¹⁰⁶ Continuous practice resulted in the technique becoming ever more familiar, ever more directly and unhesitatingly embodied – Lucero's activities formed and stabilised the nexus between body, therapeutic objects and the room. While being drilled in the technique during training was a necessary precursor to this, it was not until Lucero had acquired experience in the home through continuous practice that she actually embodied the sterile technique, as evidenced by her movements and confidence in performing CAPD a week later.

Lucero was beginning her trajectory as a competent CAPD patient, and although she adhered to the spirit of the instructions, she and her family had already modified aspects of CAPD to fit to their particular domestic and familial situation. The long-term implications of the practice of CAPD on the family had still to become clear, however. Their awareness of what this change meant for them was taking shape at the moment when I conducted fieldwork. Nonetheless, Lucero's case points to two broad issues that cut across the experience of CAPD in the context of Lake Chapala's communities – the accommodation of CAPD and the situated character of practising CAPD in home contexts. I address both these themes in the following subsections.

¹⁰⁶ This is important because the less time the patient exposes their catheter to the environment, the less risk of infection.

5.1.2 Accommodating and indigenising CAPD at home

Over the course of fieldwork, I had the opportunity to observe the dialysis rooms of most of the patients I interviewed. Families addressed the problem of how to accommodate the therapy at home and fit it into wider patterns of domestic life in various ways and they often demonstrated a great deal of creativity in doing so. The family's residential circumstances were a key factor: whether the family owned a house or rented one, whether they had a suitable room or could only dedicate a space in the house for the purpose of CAPD, whether the house was well-built and spacious enough for all those who lived there or poorly built and cramped, were all issues that affected how CAPD became a part of their lives. Nor were the issues restricted to the inside of the home: equally important were the families' financial situation and their networks of support, which influenced the type and quality of the equipment that could be used to maintain the dialysis room.

Although each dialysis room was different and had its own particularities, they can be classified into two main types. The first type was what I call the *dialysis-exclusive room*, which was normally either a former bedroom or a new room constructed solely for the purpose of performing dialysis. This was the type of dialysis room the programme treated as the ideal, i.e. a room containing nothing else but the dialysis set up (see Figure 10, on page 161), although the majority of the actual dialysis-exclusive rooms I observed departed in many ways from the programme's ideal. The second type was what I call a *dialysis-bedroom*, a room used for both dialysis and as private accommodation – Lucero's was typical in this respect. As discussed in chapter four, although Hospital Alcalde would formally request that patients set up a dialysis-exclusive room, during the introductory meeting the social worker would introduce the possibility that a bedroom could be used. While they insisted it should only be

furnished with a bed, patients would surround themselves with a range of items, such as Lucero's religious ornaments and toys.

Inevitably, the homes of patients who were under treatment of CAPD were changed in ways that affected family life as a whole. With part of the house transformed into a para-clinical space, a borderland between home and hospital (Mattingly et al., 2011), the presence of CAPD could be seen in almost every corner of the house. Extending the points made in the last two chapters, the permanent catheter in the patient's abdomen did not just create the interface for dialysis and organised medical care, it also made the home compatible with this medical technology by establishing an interface between the medical and the domestic in the space of the home via the body of the patient – the patients were the bridge between the two.

Table 4 shows some of the characteristics of participants' dialysis rooms at the time of fieldwork. Given that the majority of patients remained months and even years on this therapy, the rooms changed over time. Some patients were able to set up new dialysis-exclusive rooms, a few moved to other dialysis-bedrooms, while many remained in the original dialysis-bedroom. Patients usually would not report these shifts and alterations to Hospital Alcalde, although they would try to comply with the programme's specifications.

Table 4 Characteristics of patients' dialysis rooms

Case	Type and dimensions	Comments
Jaime	Dialysis-exclusive room 1.5 x 3 m	Jaime had used two dialysis rooms. His first was made of wooden panels partitioning off a space in the living room of his home. It was a dialysis-bedroom. Later, the family moved to a bigger house, and there Jaime had a dialysis-exclusive room and a separate bedroom.
Ricardo	Dialysis-exclusive room 4 x 4 m	Ricardo's dialysis-exclusive room was one of the biggest I saw. It was possible for him to have an exclusive room for dialysis because his older siblings had already left home. He slept in his own separate bedroom. He washed his hands at a toilet located a few steps from his room.
Rita	Dialysis-exclusive room 3 x 3.5 m	Rita's dialysis-exclusive room was located in the house of her daughter, Helena, who lived next door. It was the former bedroom of Helena's daughter, but had been transformed into a dialysis room when Rita was diagnosed.
Julio	Dialysis-exclusive room 1 x 2.5 m	Julio's dialysis-exclusive room was made of wooden panels partitioning off one of the corners of his family's living room. He carried out the hand washing and connection inside the room, but spent the drainage and infusion phases in the living room. The microwave was in the living room too.
Lourdes	Dialysis-exclusive room 1 x 2 m	Lourdes' was the only dialysis-exclusive room made of brick and mortar from scratch that I saw during fieldwork. It was located on the <i>azotea</i> , the flat roof of her house, just next to the clothesline where the family hung up their clothes. It was her second dialysis room. The previous room had also been her bedroom and was on the ground floor. Her father built the new one for her as a private space to separate clinic from bedroom. The microwave was in the dining room, downstairs.
Cristian	Dialysis-exclusive room 4 x 4 m	Cristian's dialysis-exclusive room was adjacent to his bedroom. It was a former bedroom reconditioned to accommodate CAPD. He carried out the hand washing and connection inside the room, but usually spent the drainage and infusion phases in his bedroom.
Silvia	Dialysis-exclusive room	Silvia's aunt lent her a room in her house that was just across the street. There she practised three to four changes a day. It was not possible for me to see her dialysis room.
Clara	Dialysis-bedroom 2 x 3 m	Clara's bedroom was turned into a dialysis-bedroom when she was put on CAPD. She took some furniture out of her bedroom to comply with the programme's guidelines.

Table 4 Characteristics of patients' dialysis rooms (continues)

Case	Type and dimensions	Comments
Artemio	Dialysis-bedroom 2 x 3 m	Artemio's dialysis-bedroom was previously his and his wife's bedroom. When he was put on dialysis, the couple did not have any option but to sleep in separate beds. Since then, Socorro, Artemio's wife, slept with their 12-year-old child. Artemio was the only patient using automated peritoneal dialysis.
Lázaro	Dialysis-bedroom 4 x 4	Lazaro's bedroom was turned into a dialysis-bedroom when he was put on dialysis. He took some furniture out of the room, but later introduced a television and an oscillating pedestal fan.
Martín	Dialysis-bedroom 4 x 4 m	Martin used his parent's former bedroom and turned it into a dialysis-bedroom. It was furnished with a bed, a wardrobe, and the dialysis equipment.
Ronaldo	Dialysis-bedroom 2.5 x 3.5 m	Ronaldo's dialysis-bedroom lacked a proper washbasin, because it had broken months before I conducted fieldwork. He washed his hands using a couple of bowls. His dialysis-bedroom was furnished with a cabinet, television, stereo and other items.
Lucero	Dialysis-bedroom 4 x 4 m	The construction of Lucero's bedroom was nearly finished when she was diagnosed with CKD. After that, it became her dialysis-bedroom. A wardrobe, where she keeps her clothes and personal items, was left inside the room. The microwave oven, as discussed, never worked and was replaced by a television.
Simón	Dialysis-bedroom	I could not observe Simon's room, due to his grave health condition. At the time I conducted fieldwork, he was experiencing serious complications. According to his mother Verónica, he used his bedroom for dialysis.
Miguel	Dialysis-bedroom	His first room was in the house of a relative who lived nearby his house. The family home was unsuitable for CAPD because it had a dirt floor. After a time, the relative changed her mind and complained about him doing dialysis in her home. Miguel and his mother decided to continue CAPD in their own home, and arranged a room for this purpose, despite the dirt floor and the lack of glass in the windows. Miguel got peritonitis soon after using his dialysis-bedroom.

The *dialysis-bedroom* was a frequent type of dialysis room set up by families with CKD patients undergoing CAPD. This was due to the residential situation of each family – the majority of poor families lived in overcrowded homes and rooms were shared by several members,¹⁰⁷ with few able to exclusively dedicate a room for dialysis. Some patients I met, who initiated CAPD at home using *dialysis-bedrooms*, were eventually able to set up alternative *dialysis-exclusive rooms* in their homes. The formal rules against having anything but a minimum number of additional items in such rooms were part of a general set of measures designed to prevent the accumulation of dust. For several reasons, this was something that most patients found it difficult to comply with and they often had forbidden items like cabinets, wardrobes, electric fans, televisions, radios, dolls, and other items in their rooms that would be normal for ‘healthy’ people to have (see Figure 16). Forbidden items which had been removed for the official photographs were returned to dialysis-bedrooms, not in a conscious violation of hospital’s rules, but because those objects made life and therapy easier (for example, a television or a stereo). The reintroduction of these items was part of regaining some privacy and drawing a line between clinic and bedroom. As discussed above, this was all part of the process by which patients and families adapted the strictures that surrounded CAPD to better reflect their particular circumstances, tastes, preferences and options.

¹⁰⁷ According to the Mexican census of 2010, the average number of occupants per room in two of the communities I visited was above 2 (Agua Caliente 2.75, San Pedro Itzicán 2.1, Mezcala 1.72, Santa Cruz de la Soledad 0.97), while the average for the municipalities as a whole was around 1.2 (Poncitlán 1.26, Chapala 1.02) and the Jalisco State average was 1.01 (INEGI, 2011).

Figure 16 Participants' dialysis rooms



Source: My own. Notes: A. Hugo's dialysis-exclusive room in the living room, viewed from the outside. B. Clara's dialysis-bedroom. C. Cristian's dialysis-exclusive room. D. Rita's dialysis-exclusive room in the house of her daughter. E. Lázaro's washbasin at the entrance of his dialysis-bedroom. F. Jaime's former dialysis-bedroom.

There were some cases, however, in which it proved impossible to make room for dialysis at home. This was the case with Rita, Miguel and Silvia, who were unable to accommodate CAPD in their own homes. However, that did not stop them from carrying on with the therapy. They got support from close relatives, who allowed them to use spare rooms in their homes as dialysis rooms. In the case of Rita (64 years old),

for example, her daughter Helena, who lived next door with her family, set up a dialysis room to care for her mother. Helena, as well as her father Mateo, were Rita's caregivers, but only Helena was trained to perform CAPD for her mother.¹⁰⁸ Dialysis supplies were also stored in this room. Mateo and Rita lived in a very small house next to their daughter's. Their house only had two rooms; one was occupied by their son Beto, the other was Mateo and Rita's bedroom, which also served as the kitchen. That is why they had to ask Helena to make room for CAPD in her home and become Rita's caregiver. The room Helena prepared for her mother and CAPD was previously occupied by her 14-year-old daughter, who now had to share a room with her older sister. Helena's family understood Rita's situation, and welcomed her in their house where she could be cared for by Helena.

In the case of Miguel, family support was short lived. His family lived in a shanty house in Santa Cruz de la Soledad and they could not afford to make the necessary changes and upgrades to their home to accommodate CAPD. Miguel's mother asked a relative, who lived a few doors away and had a more suitable house. She accepted, and Miguel carried out the therapy there for a couple of months in a room he and his mother prepared for CAPD. However, his aunt became uncomfortable with him going to her house three to four times a day to perform dialysis. Eventually, Miguel and his mother had to prepare a makeshift dialysis room in their own home, even though it had a dirt floor and lacked appropriate windows and roofing. Eventually, Miguel got peritonitis a number of times, his peritoneum stopped filtrating and he was transferred

¹⁰⁸ It is common in Mexican families that the daughters become the caregivers of their parents, when they age and get ill (Robles, 2012). Helena, for instance, had previously been the caregiver of her grandmother, but when she died, her mother Rita fell ill almost immediately and she then became her caregiver too.

to haemodialysis. As the case of Miguel shows, having an appropriate dialysis room was essential for carrying out the therapy safely.

The storage of dialysis supplies was another important issue that arose when it came to accommodating CAPD at home. However, this issue was only briefly discussed during the training meetings. The patients and their relatives were told simply that they would need a clean and dry space to store the boxes which contained the dialysis packages, but they weren't told how much space the boxes would occupy in the home. This meant patients and their families only came to confront this issue when they received the boxes at home. Usually the boxes were stored in whatever free space was available, sometimes inside the dialysis room, sometimes in someone else's room, in the living room or even in the *cochera*, or garage, usually not the cleanest space in the home (see Figure 17). Eventually, the dialysis boxes would become part of the home, part of the furniture or decoration. The therapy was thus not confined to the dialysis room but overspilled into the home.

Figure 17 Dialysis supplies stored in different parts of the patients' homes



Source: My own. Notes: A. Ronaldo's supplies in his brother's bedroom. B. Clara's supplies in her parent's bedroom. C. Ramón's supplies in his family's kitchen. D. Lázaro's supplies in the garage. E. Lourdes' supplies in the corridor, behind the front door. F. Rita's supplies in her dialysis room in her daughter's home.

Every time I visited a patient's home I was surprised by the amount of dialysate boxes they were storing. Living with dialysis supplies was not unusual for families with renal patients. Estela and Fidencio, from San Pedro Itzicán, shared their bedroom with the boxes of dialysate that their 22-year-old daughter Clara needed for CAPD (see Figure 17, photo B). Numerous boxes were kept in the corner of their bedroom, next to the

couple's *juguetero*, or shelf, mixing with ordinary objects like religious images, candles, personal care products, and documents kept in bags and envelopes. Empty boxes were also littered around the house, and the children used them for play.

The family of Artemio, a 47-year-old father of three from Ajijic, was in a similar position. In his house, which only had three bedrooms, the boxes were stored in the kitchen behind the dinner table, as shown in photo C, Figure 17. Again this shows us how peritoneal dialysis had a tendency to 'leak out' into the home – medicines and dialysis supplies sharing space with more 'ordinary' domestic objects. This photograph shows a dinner table with many mundane kitchen items: a can of Nido formula (powdered milk), a bottle of salt, a bottle of Salsa Valentina, a vase with a plastic sunflower and a clay bowl with eggs, limes and assorted medicines, syringes and cotton buds. Standing out in this photo is a sculpture of the Virgin of Guadalupe. In the background more than 20 boxes of dialysate solution testify to the presence of peritoneal dialysis.

The boxes were not only the objects related to the therapy the family had to live with and find space for. Erythropoietin, a drug that stimulates the production of red blood cells and treats anaemia caused by CKD, was kept in the families' refrigerators along with their food, because it was important to keep this drug cool. The characteristics of the diverse dialysis rooms and how therapy overspilled into the home, thus provide direct illustrations of the ongoing processes through which families accommodated CAPD in their own homes over time. However, these were not the only areas in which these processes could be seen: the manner in which patients performed CAPD in their dialysis rooms also sheds light on the domestic life of the therapy.

5.1.3 Situating bodily techniques

Earlier in this chapter I suggested that the embodiment of the CAPD technique did not take place during training at the hospital, but when the patient was confronted with the responsibility of carrying out dialysis at home. Lucero's experience was an example of this process, a process in which these techniques become second-nature through constant practice. As was the case with Lucero, the majority of patients tried to comply with the instructions fully at the beginning. However, as time went by, these body techniques would be adapted to the ever-changing domestic context and the dialysis rooms themselves. Particularly important was the manner in which patients collected together the various implements needed for the dialysis room.

I have shown that patients' dialysis rooms differed in various ways, that their characteristics were determined by the residential situation of the patient's family and their networks of support, and that there were two types of dialysis rooms – dialysis-bedrooms and dialysis-exclusive rooms. Here I am more concerned with the way in which patients equipped the dialysis room and how this affected the techniques central to practising CAPD.

As I have discussed before, CAPD involves a series of preparatory steps and safety measures designed to prevent peritonitis infections. By body technique in the context of peritoneal dialysis I refer to the series of actions and movements that constitute the sterile technique that patients are drilled in during training, described in chapter four. The process starts with the donning of clinical attire – hospital gown, surgical facemask and hat. Lucero, a 'beginner', complied fully with this instruction. Other patients who had been practising CAPD for more than a year, by contrast, tended to relax this safety measure. Julio and Lourdes, for example, often just wore the surgical

facemasks, although they had all the garments. Some, like Ronaldo, reverted back to the complete attire after suffering from peritonitis.

The hand washing technique was particularly affected by the way in which patients set up their dialysis rooms and their washbasins. As noted earlier, the washbasin is one of the central elements of the dialysis room. The hospital's recommendation was to buy a water dispenser, placing it over a table with a plastic bowl or a bucket beneath it to catch the water used to wash their hands. Ideally, it should be separated from the working table. However, as many patients struggled to construct a dialysis room according to the strict guidelines presented by the hospital, they often set up the washbasin at the same table where they carried out the handling of the dialysate package – the working table (see Figures 16 and 18 to 20). Other patients did have enough space to keep them separate, but not always in the most appropriate ways. A good example was Lázaro, who ingeniously set up the washbasin using a DIY stool, a water dispenser and a bucket, which were secured with a wire attached to the wall. This allowed him to wash his hands without much difficulty.

In contrast, Lourdes' washbasin was set up differently and affected her technique. In her former dialysis-bedroom, Lourdes had a washbasin connected to her working table, an old desk. When she moved to her new built-from-scratch dialysis-exclusive room, the desk didn't fit. She and her father had to set up the washbasin differently, placing the water dispenser over a chair and a plastic bowl on the floor, with the working table replaced by a plastic stool. The water dispenser was at a height that meant Lourdes had to crouch down every time she had to wash her hands, making the whole procedure more exhausting. Eventually, she washed her hands less often than the rules stipulated, especially when she was experiencing the fatigue commonly associated with CKD.

Julio, another patient from Mezcala, faced the same issues when washing his hands. There were also patients who did not have a washbasin inside their dialysis room. Ricardo, for example, had a dialysis-exclusive room, which was one of the more spacious I saw. However, he didn't have a washbasin inside his dialysis room and washed his hands in the washbasin of the toilet next to his room, something which was prohibited in the hospital's instructions.

Less fortunate was Ronaldo. He did have a washbasin inside his room but in mid-2012 the water dispenser broke. Ronaldo had been doing CAPD since 2010, when he was 17 years old, and when I met him he used two plastic bowls to wash his hands, because his family couldn't afford a new water dispenser. For Ronaldo, doing CAPD four times a day, every day, was a boring and tiring task, one that at times had become unbearable. CKD had not only stopped him working, CAPD had reduced his social life to a minimum. Loss and boredom had led him to neglect his handwashing technique even before the washbasin broke. He washed his hands just once or twice a day, and sometimes he didn't even bother to put on the dialysis attire. But that neglect had very serious consequences – Ronaldo got peritonitis in October. The story of Ronaldo's experience with peritonitis deserves further treatment, and I will return to it in the last part of this chapter.

Figure 18 Ronaldo performing CAPD in his dialysis-bedroom



Source: My own. Notes: A. Closing the dialysis-bedroom's window. B. Warming up the dialysis bag in the microwave oven. C. Preparing the items on the working table. D-E. Preparing the dialysis double-bag system. F. Connecting the double-bag system to his catheter. G. Placing the drainage bag in a plastic bowl. H. Hanging the fresh dialysate bag on a stand hook. I. Lying on the bed, waiting for the used dialysate to drain out of his abdomen. J. Disconnecting the double-bag system from his catheter. K-L. Disposing the used dialysate.

Figure 19 Lourdes performing CAPD in her dialysis-exclusive room



Source: My own. Notes: A-B. Washing her hands in her DIY-wash basin. C. Preparing the double-bag system. D-E. Connecting the double-bag system to her catheter. F. Squeezing the lines with plastic clamps. G. Draining used dialysate out of her abdominal cavity. H. Fresh dialysate bag hanging on a stand hook, finishing the infusion phase. I. Leaving her dialysis-exclusive room.

Figure 20 Cristian performing CAPD in his dialysis-exclusive room



Source: My own. Notes: A. Dressing up the dialysis attire. B-D. Washing his hands on the DIY wash basin. E. Applying disinfectant on his hands. F. Connecting the double-bag system to his catheter. G-H. Draining used dialysate out of his abdomen. I. Hanging the fresh dialysate bag on the stand hook. J. Disconnecting the double-bag system from his catheter. K. Applying chlorine to the used dialysate. L. Disposing the used dialysate down the sink.

I began this chapter with the story of Lucero doing her first dialysate bag change, and I showed that she followed the instructions almost to the letter. The other patients I observed had relaxed their techniques. They had learnt proper surgical hand washing, how to rinse hands, apply soap, scrub, and dry. However, the experience of following this same technique four times a day, every day, for months and even years, led them

to skip certain elements of the routine, especially when they didn't experience peritonitis infection.

However, there was another equally important part of the CAPD body technique that patients didn't neglect, nor relax – the connection phase, including the handling of the double-bag system, the tubing and their catheter-transfer lines. This required confidence with the equipment as well as with timing and movement. As discussed above, Lucero was nervous and hesitant the first time she performed CAPD and carried out the connection phase in about 30 seconds, partly because she lacked confidence. More experienced patients, like Ronaldo, Lourdes, Cristian and Julio, were not only more confident in handling the tubing and catheter, they performed the connection phase in under 10 seconds. All applied disinfectant to their hands before proceeding with the connection and handled the disinfectant bottle with a skill first acquired through initial drilling and developed through continuous practice.¹⁰⁹

Departures from the formal script provided by the hospital's rules were also visible in alterations to the dialysis timetable in light of changes to patient's circumstances. The majority followed the prescription of four changes a day, every day, but not all of them followed the timetable of 8-12-16-20 hours. Instead, they created flexible schedules that fit better with their preferences and the rhythms of their domestic lives. They tended to perform the four changes with a 'dwell time'¹¹⁰ of three to six hours during the day, and more hours during the nights. They came to learn that missing one change would not affect their health considerably, knowledge often gained as a result of

¹⁰⁹ Although it seems banal to mention that patients handled the bottle skilfully, the truth is that novice patients found it difficult to do it during training and, as was the case with Lucero, when first practised at home.

¹¹⁰ 'Dwell time' refers to the time the peritoneal solution dwells inside the peritoneal cavity of the patient, where the dialysis process takes place, before being drained out.

missing changes when attending the hospital. As a consequence, some patients missed one of the scheduled changes every now and then, because they were exhausted or bored with the whole process.

Not following the instructions in a strict manner was thus one of the ways patients used to maintain some normality in their lives and regain an element of control (Goffman 1961; Scott, 1990). But often, these hidden transcripts – the forms of conduct patients actually engaged in while showing compliance with the hospital's strict rules – reveal something else; these ad hoc adaptations were necessary if patients were to make the therapy compatible with their lives. Sometimes these adaptations were necessary and inevitable, due to the limited financial and material resources the families had at their command. In the end, how CAPD was performed depended on each patient's socio-material circumstances. But most patients were able to improvise in ways that allowed them to make CAPD work even with the restrictions they faced.

However, making home CAPD work was not the only assignment patients had as part of their therapeutic regimen. Essential to this regimen was a regular monitoring of the progression of their renal ailments, the effectiveness of peritoneal dialysis treatments and the outcomes of the therapy as a whole. CAPD not only demanded diligence, adherence and effort from patients in their home, it also required them to be compliant with regular monitoring, through consultation and laboratory testing. Following patients to the hospital revealed these further aspects of the experience of CAPD in the context of Mexico. They are the focus of part two of this chapter.

5.2 Assignments: check-ups, follow up and healthcare support

Performing CAPD at home did not take away the need for further hospital visits and ongoing medical surveillance. Being in a CAPD programme involved continuous monitoring and checks on compliance. As I will show in this section, Hospital Alcalde's CAPD programme requires patients to accomplish four kinds of 'assignment' on a regular basis: they had to attend consultations, take clinical tests, bring used dialysate to be analysed, and undertake transfer line replacement. Although these assignments might initially seem to pose few problems, following patients in their attempts to accomplish them reveals the difficulties they posed. To understand those difficulties, I will draw on two cases: Lucero and Ronaldo.

5.2.1 Taking clinical tests

Clinical blood and urine tests are essential for adequate medical follow-up care for CKD. They provide the basis for assessments of disease progression and the biochemical outcomes of dialysis. Patients had to provide results from these tests for follow up appointments. Patients were given two options – they could take the tests at a private clinical laboratory or at the hospital's laboratory. Either way, the service instructed the patients to take both tests, ideally one week prior to the medical appointment but not more than four weeks before. If the patient decided to take the exams at Hospital Alcalde, they first had to request an appointment at the laboratory, usually one week before the follow-up appointment. Although it was considered cheaper, the exams at Hospital Alcalde brought with them the extra costs of waiting and queuing, navigating the hospital's bureaucracy and arriving very early in the morning. The case of Lucero vividly illustrates the experience of patients who opted to use the public hospital's services.

Lucero's first medical follow-up appointment was the 27th of May 2013 at 9 am at Hospital Alalde's outpatient consultation service. For this appointment, she also had to take additional clinical tests – blood and urine. Given Lucero's frailness, José was given a clinical tests request form, which listed the tests requested in an abbreviated form: *BH* (complete blood count), *QS* (biochemical analysis), *ES* (serum electrolytes test), *perfil renal* (kidney function test), *perfil oseo* (calcium metabolism test), *perfil lipidico* (lipid profile), *Ac Urico* (uric acid test), *albumina* (serum albumin test) and *EGO* (urinalysis). The form stated Lucero's diagnosis, but instead of CKD her doctor wrote down *HAS*, the Spanish for systemic arterial hypertension. Although José did not understand at first why he had written down HAS instead of CKD, the reason was that it allowed Lucero to claim Seguro Popular's coverage for most of the clinical tests requested.¹¹¹

José was told that Seguro Popular would not pay for some of the tests requested so he would have to pay for them. He was given two options: pay at Hospital Alalde's laboratory or at a private laboratory. José found out that the cost of the tests at a private laboratory in Poncitlán was \$1,460. For a poor family like his, the tests were expensive – more than a week's salary – but affordable if he made the necessary sacrifices and appealed to relatives and friends. The problem was that if he decided to bring Lucero to take the tests at a private laboratory, he would still have to take her to the hospital's laboratory for the tests covered by Seguro Popular, making it harder and more exhausting for Lucero. In the end, they decided to take all the tests at Hospital Alalde's laboratory and he was given a time a week before the follow up appointment. They knew that taking the tests at Hospital Alalde meant enduring long hours of

¹¹¹ I will further analyse these practices in the next chapter when I discuss the underground economy of CKD and renal replacement therapies.

queuing, moving between departments and services and filling out the lengthy paperwork required but it was the only realistic route open to them.

José couldn't accompany Lucero, however, because he was undertaking a pilgrimage to a sanctuary in the north of Jalisco. This was because he had previously made a *manda*, that is, he had promised that if his daughter made it through and got better, he would visit the sanctuary. A week before the appointment in the laboratory, José asked me to accompany Lucero to the hospital because no other family member was confident enough to do it alone.

The morning of the 20th of May 2013, Enrique, Lucero's older brother, accompanied her to the hospital, something he had not done before. Lucero had to wake up very early, getting up at 4:30 am to perform a dialysate bag change and collect a urine sample, in order to be on time to take the 5:00 am transportation from Agua Caliente to downtown Poncitlán with her brother. From there, they took the 5:40 am bus to Guadalajara and arrived around 6:45 am at Central Vieja, the old bus station, to take another bus to Hospital Alcalde. They finally got there at 7:05 am when I met them.

Like the rest of the family, Enrique was not used to visiting the city and he did not know how to navigate the hospital's bureaucracy. For that reason, he waited in the main area of the hospital as Lucero and I set off to get the tests. Most Mexican public hospitals operate on the same first-come, first-served basis, so we headed to the hospital's laboratory immediately. It was 7:10 am when we joined the queue. A few minutes later a clerk addressed all in the queue, explaining that everyone had to pay in order to be attended. He also explained that Seguro Popular might pay for some if not all of the studies requested, and recommended that everyone should queue at Seguro Popular's office. We then went to Calle Tenerías, where the queue for Seguro Popular

started. It was 7:30 am and about 400 people were queuing before us, all of them expecting to get a subsidy for different kind of services – clinical tests, consultations, hospitalisation, operations, and so on.

As was common practice, Lucero was carrying all her files in a plastic folder – prescription notes, hospitalisation discharge summaries, clinical exams, her patient ID card, and more. Among the documents was her Seguro Popular contract along with two extra copies.¹¹² After 50 minutes in the queue, we arrived at the front desk of Seguro Popular's office, where Lucero was asked for a copy of her contract. The office was staffed by three people who received patients' documents and checked them against the system's records. Once they had completed their checks on Lucero, which lasted about three minutes, the clerk returned the copy stamped, signed and annotated with a list of the services covered by the programme, and told us to join the queue at the payment desk, shorter than the previous one but very disorganised. After 15 minutes, we arrived at the desk and the clerk gave us a receipt stating which tests were covered by Seguro Popular – six out of the seven were covered, at a total cost of \$2,664. The person also told us that Lucero would have to pay for the remaining test at the *ventanilla de pago*, the hospital's payment desk. We thus queued again, for about 10 minutes this time, to pay for the serum albumin test which cost \$560. Had Lucero's exams form stated she was suffering from CKD, Seguro Popular would have not covered the cost of the services. But support was provided thanks to the intervention of health professionals, who were aware of the financial situation of uninsured families and the hardships renal replacement therapies place on them, helping them to take advantage of loopholes in the programme. As a result of this creative recategorisation,

¹¹² We did not know but a copy of this document was needed to receive the subsidy. Failure to provide a copy would have meant refusal.

Seguro Popular covered 83% of the total cost of all the tests Lucero was required in order to access her regular medical follow up.

Having received the subsidy and paid for the remaining test, we then returned to the laboratory. It was 9 am, almost two hours after we had first arrived. The queue was far longer than it had been earlier – about 200 people were now before us. At 10:40 am we arrived at the laboratory's front desk and Lucero handed the personnel her receipts. She was given a pass that allowed her to give her urine and blood samples. After waiting a few minutes more in a last queue, a medical laboratory technician attended to Lucero in one of the laboratory's many cubicles and received her urine sample and collected blood samples. More than three and half hours since first arriving at the hospital, and five hours since they had left home, Lucero finally accomplished the task of giving bodily fluid samples for analysis, but someone from the family still had to return two days later to pick up the results. Moreover, to complete just this first *assignment*, she had to return on the 27th of May for the follow up medical consultation. These were the conditions under which uninsured patients accessed critical support, conditions that imposed a whole range of additional costs on them which it is only possible to gain an appreciation of by following them through the process.

5.2.2 The follow-up consultation

Taking blood and urine tests regularly and submitting them at the follow up consultation is the main *assignment* patients have to complete in order to continue in the hospital's CAPD programme. These tests must be carried out every two months by all patients undergoing CAPD.

While not always the case, one consequence of this is that many patients strengthen their bonds with their caregivers – parents, spouses, children, siblings – as a result of going through the process so regularly together, with the caregiver always at the side of the patient during hospital and laboratory appointments. Caregivers come to share responsibility for completing the assignments. This can be seen particularly clearly in the case of Ronaldo and his mother Ofelia.

As with all other CAPD patients, Ronaldo had a scheduled consultation every two months, an appointment for transfer line replacement every six months, and check-ups on the used dialysate three times a year. That meant that Ronaldo had to visit the hospital at least 15 times a year. As in the case of Lucero, he also had to visit the hospital for clinical tests. However, Ronaldo didn't have to pay for his tests because the nursing team requested the tests on his behalf, as if he were hospitalised. The nursing team does this to help patients like Ronaldo whose families are stricken by poverty. In these cases, patients did not have to return to the hospital to pick up the test results as these were sent directly to the CAPD Unit. Nor did Ronaldo have to queue for two or three hours to give blood and urine samples. Nonetheless, he did have to demonstrate compliance and arrive punctually for these appointments.

When it came to appointments at the hospital, Ronaldo and Ofelia would have to dedicate almost half of their day for the 20-minute consultation appointment. Travel time, queuing and the rest, as in Lucero's case, meant this was a complex logistical exercise. Every appointment required at least a couple of days of preparation, sometimes more. As part of this, Ofelia would ask her other children in advance to help cover the out-of-pocket costs involved – for travel, fees, prescriptions and meals. Transportation from Mezcala to Guadalajara cost around \$250, with \$50 on meals, and

another \$100 for medications not covered by Seguro Popular. On those occasions when they had to pay for the exams, it meant another \$400. That is, it cost them at least \$400 for a consultation appointment and \$800 for a visit to the laboratory, almost the entire weekly salary of a labourer from Mezcala.

As with Lucero, the day of the appointment would begin very early for Ronaldo and Ofelia. Ronaldo would wake up just before 5 am, in order to perform a bag change before taking the bus to Guadalajara¹¹³. They would arrive at the hospital around 7 am and would then have to queue to get the subsidy for consultation from Seguro Popular. Consultations for CAPD patients usually began around 9am. If Ronaldo was lucky, he would be among the first to be seen by a resident or a senior nephrologist – otherwise, he might have to wait for up to two hours. Consultation is also always first come, first served. First, Ronaldo had to provide his tarjetón and the receipt of consultation fees to the nursing team. Once the tarjetón and the receipt were received, a nurse would check his blood pressure and measure his weight. He would then have to wait in the corridor until he was called to see the consultant. During the consultation, Ronaldo was questioned about his health, whether he had experienced any complications, adverse side effects of medications or problems with dialysis, how much liquid he was draining, its texture and colour, how long it took to infuse and drain, and so on. The doctor reviewed his tests and copied the results to another chart, which formed part of the internal files kept on every patient in the CAPD Unit (no computers were used at the time of fieldwork, only hard copies). Occasionally, he was asked about his daily routine, what he did with his free time, whether he had considered returning to school or work, and his family relations. When Ofelia was at his side during consultation, she

¹¹³ They occasionally took taxis in the city but only when Ronaldo was too unwell to take the bus.

also answered some of the questions. Some patients are told about transplantation options during consultation, but it was not something Ronaldo was particularly at ease with. The doctors always concluded the consultation with a quiz about the medication regimen – the name of the drugs used, dose, timetable, and how he had been feeling. At the same time, they would write down new prescription notes. At this point, patients were allowed to ask questions. Before leaving the consultation office, patients were seen by a dietician, who would provide them with new dietary instructions based on the directions of the attendant nephrologist. These were written down on a form that listed weekly portions of allowed foods – but almost no information was provided as to how to prepare them.

Consultations typically lasted between 15 and 30 minutes, after which Ronaldo and Ofelia headed to Seguro Popular's pharmacy to claim for medications, again working in conjunction with the doctors to take advantage of loopholes in Seguro Popular. Claiming for HAS or diabetes on patients' prescription notes, conditions they actually had but which stemmed from CKD, meant costs could be covered through the scheme. No rules as such were broken, because they were prescribing medications or requesting tests that Seguro Popular did cover. That most of the patients I interviewed suffered from hypertension, often as a consequence of CKD, proved to be invaluable when it came to bypassing restrictions.

There was, however, no way of bypassing the need to queue. Queues in Seguro Popular's pharmacy took at least 30 minutes to get through. Once at the front desk, Seguro Popular's staff never questioned the diagnosis, they were just concerned with the validity of the patient's documents. However, as Ronaldo and Ofelia put it, 'Seguro Popular only gives us the cheapest drugs. We still have to pay for the most expensive

ones, particularly “*las vacunas*” (erythropoietin)’. Erythropoietin was the most sought after medication among CAPD and haemodialysis patients. As erythropoietin was a drug applied subcutaneously, resembling the vaccinations people receive during childhood, it was given the nickname of ‘*las vacunas*’. Given its cost, around \$600 for the generic produced by PiSA and more than \$2000 for the brand name medicine, many patients struggled to pay for it and for some it was simply unaffordable. Some patients were able to get it through *asociaciones civiles* who supported uninsured renal patients or through insured patients willing to share. These exchanges will be discussed in more detail in Chapter 6.

After all this, Ofelia and Ronaldo finally had time to eat something, usually near noon. Sometimes they were lucky and were given food by one of the charitable organisations that provide meals for families and patients at the hospital. More often than not, however, Ofelia and Ronaldo ate *tacos al vapor*, or steamed tacos (not the cheapest but considered the least unhealthy), in one of the many eateries located outside the hospital.

Having accomplished the assignment and grabbed some food, they would return home exhausted by the same route. They would get there normally between 2 and 5 pm, which meant that they had spent between 9 and 12 hours completing the consultation.

5.2.3 Further assignments

Two other assignments are required from patients. First, there is the *cambio de línea*, or transfer line replacement. As described earlier, the transfer line is the upper part of the catheter, through which the patients connect themselves to the dialysate bags. It is a small tube with a lock that enables the infusion and draining of dialysate to and from

the abdomen. In order to prevent infections, the transfer line is replaced every six months by a nephrology specialist nurse at the CAPD Unit. For this, the patient is summoned to an appointment at the Unit early in the morning, usually at 7:30 am, but the patients have to arrive at least 10 minutes earlier. It is usually performed at no cost, and the patients simply turn up at the waiting room of the Nephrology Service. In order to help the patients, however, the nursing team of the CAPD Unit try to make sure this appointment coincides with the follow up consultation, so that the patients do not have to come to the hospital on different dates. While this is of material benefit to the patients, it does mean the day becomes more complicated.

Second, the patients have to take four bags filled with used dialysate, drained the day prior to the appointment, to the hospital every three months. Most patients do not know what this is for or what the doctors do with the dialysate bags, they simply follow the instructions. The aim is to conduct further clinical tests on the used dialysate, referred to as Kt/V or dialysis adequacy in the medical jargon (Burkart & Bargman, 2009). The results are used to assess the efficiency of peritoneal dialysis in removing waste products – particularly urea – and excess of water. If specified clinical thresholds are not being met, doctors will consider changing something in the treatment – increasing dialysis, altering glucose concentration, drug prescription or dietary regimen, or, in extreme cases, making the shift to haemodialysis. However, the result of the dialysis adequacy assessment is usually not disclosed to patients.

This particular aspect of home-work consists of collecting the drained, used dialysate over 24 hours. The patients are told to collect the bags from the previous day, making a knot with the lines and burning the tips. Patients usually put the four dialysate drainage bags in a large black plastic bag – a garbage bag – and deliver them to the

nephrology service. The task itself is straightforward, but, again, it is time consuming for patients who live far from the city and who have to wake up very early in the morning to carry the bag to the hospital on the bus.

As Suchman notes (2007), following Garfinkel (Garfinkel, 2002), rules do not interpret themselves. Instead, those who have been instructed to act in accordance with rules have to work out how to follow them in the situations and circumstances they find themselves in. As we have seen, in the context of CAPD following the rules and completing assigned tasks can impose considerable burdens on those least able to shoulder them. While medical staff work to ensure their circumstances are taken into consideration, this reduces but does not remove the difficulties uninsured patients face in a system organised around queues and out-of-pocket expenses.

3. Complications: the threat of peritonitis and cardiovascular disease

As shown by sociologists and anthropologists who have studied chronic conditions and its therapies (Corbin & Strauss, 1985; Kleinman, 1980; Mattingly et al., 2011; Mykhalovskiy et al., 2004; Strauss et al., 1985), the work of families does not end with therapy-related tasks, such as regularly performing dialysis through to attending the hospital for medical tests and follow ups, it also includes one crucial additional job – monitoring signs of acute complications. Once dialysis is initiated, acute complications may not be related solely to CKD but to the therapy as well. In peritoneal dialysis, and CAPD in particular, peritonitis is the most common complication and the most frequent cause of therapy failure (Fried & Piraino, 2009), although cardiovascular disease constitutes the main cause of mortality (Stenvinkel & Ritz, 2009). Hence, acute complications, those that need hospitalisation, are an

important element of the dialysis experience. This section discusses the experiences of patients when dealing with acute complications.

Since the development of CAPD in the mid-1970s by Popovich, Moncrief, Nolph, and Oreopoulos, peritonitis was considered the main drawback of this ‘promising’ and ‘affordable’ technology. In the early days of CAPD, a patient could get it once every 10 weeks in the course of treatment in the United States (Negoi & Nolph, 2009). It was known that peritonitis was contracted during the process of connection and disconnection, hence the insistence on adherence to the sterile technique (Bender, Bernardini, & Piraino, 2006; Fried & Piraino, 2009; Moncrief, Nolph, Rubin, & Popovich, 1978). This issue was partially solved by the introduction of new connecting methods, most notably the introduction of the double-bag system and the Y-set connecting device (Dombros & Liakopoulos, 2009; Negoi & Nolph, 2009).¹¹⁴ This double-bag system is still widely used, although with variations in the connecting parts.¹¹⁵ Partly as a result of these innovations, peritonitis rates have been reduced considerably, and in Mexico it has fallen to around once every 24 months (Garcia-Garcia, Tachiquín-Bautista, et al., 2007; Monteon-Ramos et al., 1998). However, while the risk lies in the technology, from the early days of CAPD responsibility for peritonitis has been attributed to patients. In their first report, Oreopoulos and his colleagues (Oreopoulos, Robson, Izatt, Clayton, & DeVeber, 1978, p. 486) asserted that ‘[it has been] demonstrated that peritonitis occurs only when the patient has been guilty of a gross breach in sterile technique’. In Chapter 4, I showed that the same claims were employed by the CAPD Unit staff during the training – ‘peritonitis does

¹¹⁴ PiSA’s double bag system is an example of Y-set system. See Figure 13 on page 191.

¹¹⁵ In Mexico, for example, the two main providers of peritoneal dialysis, Baxter and PiSA, used double bag systems, but the connection parts were different. Interestingly, Baxter did not introduce the double-bag system until the 1990s, more than 10 years after it was developed by Bazzato et al. (1980).

not get in through the mouth, but because of a deficient technique’ as the patients’ leaflet declared. No matter who might be ultimately considered responsible for peritonitis, this complication was an important aspect of the experience of CAPD for all of the patients I interviewed during fieldwork. What follows is a description of Ronaldo’s experience. My intention is to show the challenges patients face when dealing with complications, and how during these episodes, supplicatory practices are important again.

Peritonitis underscores the stark reality of peritoneal dialysis. In order to stabilise the patient, help the body to maintain a certain balance and provide a certain quality of life, it is a therapy that puts the body at risk of infections. These infections are contracted during the connecting procedure. The infectious agents are usually harmless in normal conditions. For instance, the most frequent agent is a commensal of the skin – bacteria that lives with us when we are healthy without causing any harm. But when these bacteria enter the delicate environment of the peritoneal cavity, they induce inflammation of the peritoneal membrane.

5.3.1 Dealing with peritonitis

After more than three years of performing CAPD, Ronaldo got peritonitis for the first time in early October 2012. It was a painful experience. Three days before going to the hospital, Ronaldo started to see the characteristic symptoms of peritonitis: the drained dialysate changed in colour and he had abdominal pains, fever and diarrhoea. He couldn’t move without excruciating pain. Knowing that an ambulance service

wasn't available for an emergency like theirs,¹¹⁶ Ofelia decided to take Ronaldo to the hospital by bus.¹¹⁷ This was also a very painful experience for Ronaldo – the bus jolted him around all the way to Guadalajara.

Ronaldo was hospitalised for three days, during which he was treated with antibiotics added to the dialysate solution. He was discharged with the infection in remission. However, the family couldn't afford the full course of the prescribed antibiotics and the symptoms of the infection returned in less than a week. They returned to the hospital and Ronaldo remember being scolded by one of the doctors who warned him that if he ever got peritonitis again, he would be sent to haemodialysis. This time he was hospitalised for two weeks until the infection was completely resolved.

Two hospitalisations in very close succession put a great deal of financial strain on the family. Spending fourteen days in the hospital worried Ofelia, who knew that the hospitalisation charges would be unaffordable for her family. When Ronaldo was discharged, Ofelia had to negotiate the hospitalisation charges with the social worker. Ofelia's recollections of that encounter offer a good example of the arbitrary character of support in this context. Ofelia first asked Dr S, the attendant doctor, to help them to get a reduction in hospitalisation charges, but she received a negative answer and had no other choice but to directly ask the social worker for help. Ofelia said

Our attendant doctor was Dr S, but there was another doctor, a blondie one, whose name I don't remember, who was on our side. He told him 'Look Dr S, they are very poor, they don't have any money', but Dr S replied 'Well, It's

¹¹⁶ Ambulance services in Jalisco are mainly available for accidents. Most patients I interviewed during fieldwork knew this and preferred to ask a neighbour, to take a taxi or the bus during an emergency.

¹¹⁷ They usually asked a neighbour to take them to the hospital during an emergency but this neighbour was not available.

not up to me'. And I told him, 'Please doctor, you have to see that there are people who have [money] and others, like us, who don't. You see, this disease is attacking everybody, rich and poor'. But, sometimes I think this disease is affecting us the poor more because if you have money and pay, you are attended to and discharged more quickly. With my son spending two weeks in hospital, I had to beg the social worker for a reduction because it was \$10,400 pesos. Do you think that we can afford that? It is a lot of money; money we don't have. So I went to the social worker and told her that we couldn't afford it and she said 'Well, I can only reduce it [the total charge] by \$900', and I told her 'Dear me! Sorry, we don't have any money, we'd better never leave the hospital, because we can't afford to be discharged'. She said 'Well, pay only \$1,000 then'. I told her 'I am very sorry, but we can't even afford that'. Finally she said 'Pay only \$500 instead, but I really can't reduce the charges anymore, so you better find a way to afford it'. And that was that. I had to ask a relative in the city to lend me some money to pay, because we really were penniless. Leaving the hospital wasn't easy. My son was discharged at 9 am but I had to do paperwork here and there, bouncing from one office to the other throughout the hospital, until we finally left around 2 pm.

Complications like peritonitis almost always had the same effect – financial hardship. Most families struggled to afford the treatment, and, when complications occurred, families' suffered dramatic loss of income.

When I interviewed Ronaldo about peritonitis, he accepted it was his fault. He had been performing CAPD for more than three years without any major complications. However, Ronaldo was having a difficult time coping with the boredom of CAPD – he didn't see a way out of it. He was not being considered for transplantation because

he lacked a suitable living donor,¹¹⁸ and more importantly, because he was poor and his family couldn't afford the costs. Feeling trapped in CAPD led Ronaldo to neglect the sterile technique – complicated by broken equipment, as discussed above. He stopped washing his hands as he had been taught, and didn't use the surgical facemask during the procedure. Ronaldo admitted he was practising CAPD the wrong way and that it would just be a matter of time before he developed peritonitis.

Ronaldo recovered from his first bout of peritonitis in a couple of weeks. However, two months later, he experienced the same symptoms and returned to the hospital. He got peritonitis again. It was not clear to him whether he had done it wrong again, or whether the previous peritonitis hadn't been properly treated. He was hospitalised for three days and discharged with instructions to add antibiotics to the fresh dialysate. Over the next few months Ronaldo suffered diverse complications with hypertension, and in June 2013 he got peritonitis for the third time in less than a year. His peritoneum was damaged to the point of being unable to filtrate. There was no other choice but to transfer Ronaldo to haemodialysis. Luckily, Ronaldo was accepted into the hospital programme and he paid the minimum.

Despite being more cautious than Ronaldo, most patients I interviewed got peritonitis at least once during their time on CAPD. The majority recovered and continued in the programme, at least for the time I conducted fieldwork. Others, like Ronaldo, lost their peritoneal capacity to filtrate and were transferred to haemodialysis. Although the medical community treated patients as responsible for peritonitis, this is an over-

¹¹⁸ Ronaldo was told several times to start the protocol for living related transplantation. One of his sisters was identified as a potential donor, but her blood type didn't match his and the protocol didn't progress. His mother was considered unsuitable, due to her height, weight and age and his father was unsuitable due to his hypertension.

simplification. CAPD is not a neutral intervention but puts the delicate environment of the peritoneal cavity at risk. Indeed, peritoneal dialysis itself damages the peritoneal membrane (Bargman, 2009; Méndez-Durán, 2009) and turns ordinary aspects of human biology, primarily the presence of otherwise harmless microbes, into infectious, life-threatening agents. Peritoneal dialysis also carries other risks, particularly the threat of secondary cardiovascular complications (Stenvinkel & Ritz, 2009). In the course of their treatments, most patients will therefore experience a series of problems, including hypertension and more. Some experience other more dangerous complications, like hernias and leaks into the lungs or the scrotum. However, as we will see, the convoluted and fragmented character of the Mexican health system exacerbates the consequences of such complications. These issues will be exemplified with an examination of one last case.

5.3.2 Deterioration, death and hardship

Simón was a 21-year-old man from San Pedro Itzicán, community of the municipality of Poncitlán. He was diagnosed at the age of 15 and had undergone CAPD ever since. His health had been declining since June 2012 and, by the time I was conducting fieldwork, he was so ill I didn't have an opportunity to talk directly with him. I interviewed his mother Verónica instead, his main support since he fell ill. She was a middle-aged single mother of four. When still in her teens, she married Juan, who emigrated to the United States while their children were still very young. Years later, he returned to San Pedro Itzicán with a new partner, and was estranged from his former wife and kids. Verónica was the head of the family and the main breadwinner and she had worked for many years as a *sirvienta* in Guadalajara, while her children were taken care of by her mother. In June 2012, when Simón's health began to decline, Verónica

had to quit her job and passed it on to her 19-year-old daughter Yolanda, in order to take care of him.

When Simón was a teenager, he learned how to perform CAPD at Hospital Menchaca (he was one of the two patients I came across who had attended this hospital and not Hospital Alcalde). He took care of himself for many years, while Verónica made sure that he never missed an appointment at the hospital and that he had most of his medicines, although it was sometimes impossible to buy erythropoietin. She also tried to keep up with payments in the hospital to ensure the regular delivery of dialysis supplies. According to Verónica, Simón got peritonitis twice in six years, but his declining health was not due to this. Instead, as she saw it, he had been debilitated by the condition and peritoneal dialysis. She had noticed that Simón had started to lose his energy by the end of 2011.

Between June 2012 and January 2013, Simón was hospitalised on a number of occasions. CKD and CAPD caused him many problems, particularly cardiovascular complications, and he was also hospitalised several times due to hypertensive emergencies – his blood pressure rose way above normal levels, causing him to lose consciousness. Seeing the deterioration in his health, Verónica had no other choice but to take him to the hospital's emergency service. However, for people living in a rural community without access to an ambulance service, taking someone with a health emergency to the hospital was a major challenge. Poncitlán's municipal medical services, managed by the MoHJ, provided the only ambulance service available locally, but it wasn't reliable. Verónica recalled her experience when her son had needed emergency care at the end of October 2012, just a couple of days after being discharged from Hospital Menchaca:

I called the municipal medical services to request an ambulance, but they told me they couldn't come down to the community, that I had to take my son to the crossroads (3 km from the community) if we wanted the service. So, I paid a neighbour to take us to the crossroads, where the ambulance picked us up. But then more problems came up. They didn't want to take my son to Hospital Menchaca, because, they said, they needed a report or something, like a medical order. But I told them 'my son is a dialysis patient of Hospital Menchaca; he doesn't need a pass because he is registered and because of his condition, he will be admitted to the emergency service without a medical report. I just need you to take us there.' But they didn't want to and the ambulance took us to a Red Cross clinic in Ocotlán instead [a municipality in the opposite direction to the city]. There, the attendant doctor told me that he would send my son to La Barca's Hospital [another municipality farther out than Guadalajara], even though I told him that my son needed to go to Hospital Menchaca in Guadalajara. In the end, I had to sign off a voluntary discharge and paid a friend to take my son to Guadalajara, from Ocotlán, because the ambulance didn't want to take us there. So, I just feel helpless every time my son has an emergency. There is no ambulance service for us.

Having used peritoneal dialysis for many years had consequences – Simón's peritoneum reduced its capacity to filtrate. Because of that, Simón was prescribed dialysis solution with a higher glucose concentration – 2.5% and later 4%. The higher the glucose concentration percentage, the higher rate of fluid extracted through dialysis. Patients are usually prescribed 1.5%, and it is considered the standard dose. When the patient is prescribed a dialysis solution with a higher concentration it is usually an indication that something is not quite well, particularly because the patient has been building up fluids (mainly water) in the body. Patients understood this is a sign that something is wrong, that peritoneal dialysis is not working properly, and that it may mean being transferred to haemodialysis. Verónica feared Simón's doctors

would transfer him to haemodialysis because of the related expenses. She knew it was much cheaper to remain on CAPD, although she knew that it was causing more harm than good by this point.

Simón was found to have been building up fluids for almost a year, causing him serious problems. According to Verónica, ‘his parts had swollen as a consequence of fluid build-up’, that is, he developed what is clinically known as scrotal oedema. This is one of the many and serious non-infectious complications of peritoneal dialysis (Bargman, 2009). Peritoneal dialysis increases intra-abdominal tension, which causes changes in the shape of the patient’s abdomen. While this might not cause more than body image issues, in some patients the intra-abdominal tension can cause hernias and, more seriously, leaks to the genital area. Intra-abdominal tension also causes what is clinically known as hydrothorax or lung oedema, the presence of dialysis fluid in the pleural cavity. Patients like Simón experienced this as shortness of breath. The treatment for this complication is called a thoracentesis, or a pleural tap, a procedure in which the patient’s back is punctured and a cannula¹¹⁹ inserted to remove the fluid accumulated in the pleural area. These complications were not related to the patient’s way of conducting CAPD – they were caused by the treatment itself.

Between November 2012 and January 2013, Simón’s health declined severely. He was hospitalised for almost a month. He was discharged from hospital just to be re-admitted less than a week later, due to a recurrence and worsening of symptoms. This was a period of great strain for Verónica and her family. She and Yolanda looked after him while he was in the hospital. It was Verónica’s former employers, for whom Yolanda

¹¹⁹ A cannula is a thin tube that can be inserted into a vein or a body cavity (in this case the pleural area) to administer medicine, insert a surgical instrument, or, as in this case, drain off fluid.

now worked, who financially supported them during this period. Verónica always asked for reductions to the social worker, but in the end she always paid a considerable sum – between \$1200 and \$2600 for each spell in hospital.

By January 2013, Simón was bedridden because of the disease and the complications caused by CAPD. While he was at home, Verónica looked after him and performed CAPD for him. He could barely breathe, and his mother had to rent an oxygen tank but it was of little help to him. Simón was hospitalised for the last time at the beginning of February. At that point, Verónica was informed that his peritoneum was lost and he needed haemodialysis, for which she had to pay about \$1000 each session. She accepted, as she said, because she just wanted him to recover. But Verónica and Simón knew the end was coming. During that last week, Verónica remembers that Simón told her ‘I don’t want to live anymore. I just want to have a deep sleep and never wake up.’ Although she encouraged him to stay positive, Verónica was seeing her son dying.

After just five sessions of haemodialysis, ‘Simón had to be “intubated”¹²⁰ because dialysis would not work anymore’, Verónica recalled. It was very painful for Verónica to see her son in that situation, but she accepted it: ‘The doctors told me that he was very delicate and the only thing we could do was wait until he dies. And I accepted it, they did what they could. But nothing could be done,’ she said. Simón died the night of the 17th of February of 2013. As Verónica recalled, Seguro Popular was of little help, she and her family had to pay the haemodialysis, hospitalisation and funeral bills.

¹²⁰ Endotracheal intubation, or simply ‘intubation’, is a medical procedure in which a flexible tube is placed into the trachea through the mouth, and often it is connected to a breathing machine (or ventilator). In the case of CKD, it is indicated to help critically ill patients to ventilate their lungs (MedlinePlus Medical Encyclopedia, 2014). In the context of Guadalajara, in particular, patients and families consider it as a form of extreme measure that is mainly conducted on agonising hospitalised patients.

The most fortunate CKD patients move on from CAPD to access transplantation. Switching treatment modalities means they do not have to run the risks that come with long-term CAPD use. However, for the majority of uninsured CKD patients, their trajectories as renal patients end with CAPD. In this final section of the chapter I've shown that claims that patients are responsible for the failure of treatment do not take into account the complexities of living with CKD and undergoing CAPD, particularly in the context of Mexico. CAPD does not constitute a cure for CKD, it is a treatment that can control its symptoms and provide a certain quality of life to patients but complications are a real threat and it is often only a matter of time until the patient experiences them, whether infectious or non-infectious. In the long term, and without proper support for patients and their families, CAPD can itself generate harm. In other words, not only is CAPD not a cure, it can also be an iatrogenic agent in its own right (Illich, 1976).

5.4 Conclusions

Heinemann (2015) argues that home care is on the rise, a consequence of a neoliberal reconfiguration of the organisation of healthcare. While Heinemnan speaks for the United States experience, Crowley-Matoka (2016) also points to something similar in the Mexican context, arguing that the familial character of transplantation in Mexico, the burden imposed on families, and so on, is part of wider neoliberal trends. In the context of Mexico, I argue, something different is at work. In Mexico, caring for the chronically ill has always been a family matter – and the ascendancy of the package of economic, political and governmental measures usually grouped under the label of neoliberalism has not altered that materially. CAPD was not created as a form of neoliberal therapy but as a form of treatment that liberated the patients from the

hospital and the clinic. It was designed to make patients more productive, to put them in charge of their own treatment. Prior to CAPD, there were some efforts to bring machinery into the home of patients, but the associated costs were too high (Negoi & Nolph, 2009). CAPD achieved efficient dialysis at a low cost, but it depended upon the involvement of patients and families, enrolling them as para-clinical agents. CAPD works by outsourcing treatment to patients and families and trades upon the resources they deploy to meet its requirements. This chapter has shown the realities and consequences of the movement of therapy from clinic to home.

In the context of Mexico, we cannot assume that healthcare is confined to what happens in medical institutions, hospitals for example. Mexico has never had a universal system nor has it come close to it in recent years. The home and the family have always been important sites of care. The neoliberal influence on medicine, health and illness, can be seen not in the involvement of patients' families but in the terms in which they are involved. More specifically, and as I argue the above shows, it lies in the responsabilisation of patients and families for their own misfortunes and an emphasis on educating patients about how to deal with failures in the system on the system's behalf.

One of the things that we can conclude from the stories I examined in this chapter is that patients follow rules and instructions, but rule following implies adapting those rules to the socio-material contexts of their families' lives. The ideal dialysis room, what I have called the dialysis-exclusive room, is a luxury for many poor patients, something unattainable for those living in overcrowded houses. The solution many families must thus adopt is to merge clinic and home, by setting up dialysis-bedrooms. For the majority of patients, CAPD takes place in these spaces, but it also overflows,

spreading out into other parts of the home, with scattered boxes of dialysate and other medicines a particularly visible sign of its presence, part of the furniture of their domestic worlds.

As I also showed, the home is also a training ground. Body techniques are not entirely acquired in the clinic – they need to be continuously practised if they are to be fully embodied (Foucault, 1995; Ingold, 2011; Kierans & Bell, 2016; Mauss, 1973). The case of Lucero illustrated this. It took her some time to complete her first bag changes, but she became much quicker after just a week of practice. Other experienced patients reduced the time further, acquiring skills in working between therapeutic items, their own bodies and the room that became second-nature to them. Their body techniques however changed over time, as did their rooms. Working to accommodate the demands of CAPD within the home influenced their body techniques. But they would also cut corners and modify movements, or elements of the technique, in order to adapt the therapy to their own socio-material circumstances. The continuous practice of CAPD is also, as I showed, haunted by boredom. It is exhausting, existentially and physically, partly because it formally admits of no variation and has no foreseeable end.

While the CAPD regimen could be seen as the main work assigned to patients and family carers, they are constantly monitored and given further tasks to accomplish. This monitoring is a form of surveillance, and requires them to engage in various forms of supplicatory practices. It is this wider context of monitoring and direction, and the forms of homework that go with it, that are often invisible from the outside. In the context of Mexico, patients engage in a series of negotiations, zigzagging between services, filling out paperwork, and engaging in shows of deference and supplication. The informal economy of renal replacement therapies discussed at greater length in

the next chapter relies on these practices. The unspoken agreements between patients and health professionals that make it possible to take advantage of loopholes in Seguro Popular as discussed above is just one of its clearer expressions.

CAPD is an archetypical example of a half-way technology, as discussed by Cameron (2002) and Thomas (1977). In medicine, a half-way technology is one that is unable to cure the ailments that it was developed to treat. As I have shown in this chapter, the CAPD regimen – dialysis, diet and medications – restores the health of the patients only partially. However, as part of that, CAPD uses the peritoneum for a purpose that it was not designed for – dialysis. In the long term, dialysis damages the peritoneum to the point where it will atrophy and become unable to filtrate. CAPD also has the imminent risk of peritonitis, as we saw in the case of Ronaldo, a painful infection that can damage the peritoneum. But CAPD also brings several other complications. The case of Simón showed us that. CAPD and its unforeseen complications also have another consequence – financial hardship. Being uninsured carries the risk of what economists have termed catastrophic expenses (Sesma-Vázquez, Pérez-Rico, Sosa-Manzano, & Gómez-Dantés, 2005; Sosa-Rubí, Salinas-Rodríguez, & Galárraga, 2011). While useful, what analyses of catastrophic expenses, or expenditures, do not capture is the dramatic consequences for families and the patients themselves – something I have tried to convey in more detail here.

Overall, patients needed the spaces they had created to become productive in a very particular way. Their bodies were unproductive in one key sense, their kidneys had stopped working, and they needed to make extraordinary efforts as well as employ medical technology to make dialysis work. This is not entirely out-of-step with other forms of healthcare in Mexico. Patients and families have always participated in

different ways and to different degrees in the care of the sick. But the traditional image of familial care of the sick is not clinical; that is, the general image of care is being with the sick, administering medications, and taking charge of the 'low-tech' aspects of therapies. CAPD is different because of the frequency of dialysate changes and the training the patients and the family have to go through. In CAPD they become clinical workers who perform tasks otherwise reserved to nurses and doctors. The type of preparation involved in connecting the dialysate double-bag system is not something just anybody can do; you need to be trained and drilled in it to understand and embody CAPD. Taking a pill is not that difficult; the individual takes it and the pill does the rest. In the case of CAPD, the environment has to be prepared to produce the controlled conditions needed to administer the therapy safely. Most people do not need to know how their treatment works. In CAPD, the situation is different. It requires active participation on the part of the patient, or a caregiver. It is active participation, and all that involves, which singles CAPD out. It is also what generates the difficulties the poor and uninsured face in making it work.

Chapter 6

The Informal economy of renal replacement therapies

Introduction

In the course of the previous chapters I have examined how patients presented to the hospital with CKD and the difficulties they encountered in getting access to services. After looking at processes of (mis)diagnosis and identification in Chapter 3, in Chapter 4 I explored the requirements patients had to meet in order to be allowed to perform CAPD at home. These processes involved a series of important transformations, starting with the person becoming a renal patient and then preparing a part of the home – usually a bedroom – for CAPD. In Chapter 5 I showed how specific parts of the home were actually transformed into para-clinical spaces through the outsourcing of medical work via CAPD, how this changed patients' lives over time, how they dealt with complications, and the possible outcomes of CKD for them in the long-run. In following the trajectories of patients, these chapters traced their journeys from home to hospital and back. In this chapter, I want to broaden things out further, focusing on collective ways of managing CKD in the context of Mexico. The chapter has three parts and will examine community and (bio)sociality, informal economy and external contexts of supplication. As the focus is on a wider community of people than in previous chapters, these issues will be dealt with more schematically than has been the case thus far.

In part one, I begin by showing how uninsured patients initially and gradually become involved with a community around CAPD and that community's associated forms of exchange. I argue that supplicatory practices reappear in this context, particularly in the interactions between patients and those who they turn to for support. In order to demonstrate this, I will return again to the case of José and Lucero, to illustrate how a novice patient and her father engaged in a form of sociality, in this case a form of renal *biosociality*, and the informal economy of renal replacement therapies it was connected to (Gibbon & Novas, 2007; Sharp, 1999). The example will help draw out the serious challenges posed by maintaining treatment at home after the training process, challenges which lead patients to make links with others and practise sociality in new ways.

In part two, I move outwards from the experiences of people like José and Lucero to show how these ways of practising renal biosociality provided the foundation for a community in Jalisco, organised around CKD and its therapies (Crowley-Matoka, 2016; Gibbon & Novas, 2007; Rabinow, 1996). Studies of biosociality have tended to focus on risk factors and disease profiles in the formation of new communities. However, the renal community in Jalisco was not formed on the basis of identification with genetic biomarkers, disease risk profiles or the search for new treatments. Instead it was organised around a common need to survive, and created solidarity and connections via shared attempts to deal with the problems posed by living with dialysis and the unreliability of the healthcare system.

In part three, I show how membership of this highly mobile and fluid biosocial community was linked to joint participation in an informal economy of renal replacement therapies. I will describe the types of exchanges that take place in this

economy as well as the kinds of actors who participate within it. As I will show, this informal economy operates on the margins of the Mexican healthcare system. However, while marginal in a formal organisational sense, i.e. operating at the edges of institutional structures, it was central to patients' attempts to maintain care for themselves but was also acknowledged and capitalised upon by others, from medical personnel to private sector actors both big and small.

In the conclusion, and based on the previous sections, I will argue that renal biosociality demands a lot of patients and families besides therapeutic work, and that the community and informal economy are a consequence of and response to national healthcare policies. In other words, and echoing previous chapters, renal biosociality was another reflection of the socio-material conditions which shape the problem of CKD and its treatments.

6.1 Patients' 'bio-socialisation'

I want to begin by drawing attention to a series of arrangements and practices that help us to better understand how patients and families were able to maintain their access to peritoneal dialysis – and, in fact, other forms of RRT too – after completing the transition to treatment at home. Lucero's case is again useful here. In Chapter 5, I noted but did not expand on the fact that Lucero's father, José, had managed to secure a number of boxes of dialysate, essential to CAPD, shortly after Lucero returned home after completing training. Analysing the routes José had to follow to acquire these boxes is revealing and shows how a novice patient and her family became gradually engaged in a form of sociality that I will call *renal biosociality* by participating in an economy organised around different kinds of informal exchange.

6.1.1 José's quest for dialysate supplies

As discussed in Chapter 4, during the introductory meeting to the nephrology department (see Section 4.1) José was informed about the cuota de recuperación, the fee the family would have to pay to receive dialysis supplies at their address through the hospital programme. Patients had to pay a maximum fee of \$2,500 and then bring the receipt to the hospital before a specified date at the end of each month. Four weeks after submitting the receipt, the dialysis supplies would be delivered to the patient's address by PiSA. However, this fee could only be paid *after* the patient had completed the training. That meant a wait of between four to eight weeks. Until then the programme would provide four boxes at a cost of \$580 on site once a week, but getting them meant that patients had to return to the hospital to take the dialysate home themselves every week until they received PiSA's delivery.

José had anticipated this issue and planned a strategy while waiting for PiSA's delivery – he would get the dialysis supplies from one of the asociaciones civiles that supported renal patients at Hospital Alcalde he had made contact with and from which he had received an offer. Lucero's parents learned about these charitable organisations thanks to the networks of support they had been building while she was hospitalised for intermittent peritoneal dialysis appointments or for her various acute complications. Over the course of six months, José in particular had come to befriend relatives of other hospitalised patients. They offered him help when he needed it, not monetary, but of another sort – information. He learned a great deal about CKD and its treatments from these new friends, although he spoke with them on only a few occasions. They told him, for example, that the best treatment, perhaps a cure, for Lucero's condition was to receive a transplant from a living organ donor. From those fellow patients, who came from many parts of Jalisco and neighbouring states, José also learned about the

various asociaciones civiles who supported patients suffering from CKD. One of those was Una Oportunidad de Vida. José first came to learn about this asociación following one of Lucero's periods of hospitalisation when he had been asked to buy erythropoietin. Knowing the family was almost penniless, when José explained the situation to them a relative of another hospitalised patient recommended he approach Una Oportunidad de Vida and told him where to find them. He made contact with this asociación based on that recommendation and they donated a pack with a number of doses of the sought-after medicine to him.

Later in the process, during the CAPD training week, José met Rosario, a woman who volunteered for Trasplantados en el Hospital Alcalde, another asociación based at the hospital. Rosario had approached José and Lucero, who were resting in the waiting area at the main entrance of the Torre de Especialidades, and asked José whether his daughter suffered from CKD. At the time, Lucero's face had been particularly swollen and José was transporting her around in a wheel-chair. Rosario, who had received a transplant some years before, knew the tell-tale signs of renal failure well. José told her about his daughter's case and explained that Lucero was about to complete training so she could start CAPD at home. Understanding how the CAPD programme worked, Rosario offered José up to 15 boxes of dialysate packages for only \$100-150 and José agreed. This meant Lucero was theoretically in a position to start CPAD at home as soon as she passed the exam, although the problem of getting the supplies home had yet to be resolved.

The Monday after Lucero passed the training, José gave me a call to tell me the good news, but also to ask me to lend him some money to pay for the dialysate. He told me

about Rosario's offer and that he had arranged transportation. I accepted and we agreed to meet up the next day at 9 am at the entrance to the hospital.

I arrived on time on the Tuesday at the entrance of Torre de Especialidades on Calle Coronel Calderón. All along this street, from Calle Tenerías to Calle Hospital, it was possible to buy all kinds of goods and services aimed at those attending and working in the hospital, whether from established businesses¹²¹ or street sellers.¹²² At the main entrance to the Torre de Especialidades, however, only two stands had been given permission to set up in the waiting area: the stands of Una Oportunidad de Vida and Trasplantados en el Hospital Alcalde.¹²³ Both stands were staffed with volunteers – patients and relatives of patients who had been supported by them in some way and were fulfilling *quid pro quo* agreements entered into with the asociaciones in return for their help. They sold second-hand clothes and toys and new underwear to the people who attended the hospital (see Figure 21).

¹²¹ Ranging from restaurants, pharmacies, groceries, funeral services, health professionals' garment shops, parking lots and clinical laboratories.

¹²² Despite attempts by municipal and hospital authorities to keep them under control, by the time I conducted fieldwork, many street sellers were offering food, plastic envelopes, women's purses, pillows, children's toys, religious items, herbs, creams and infusions, even loose cigarettes, on the streets around Hospital Alcalde.

¹²³ Although both charitable organisations supported CKD patients they worked separately and did not collaborate with each other.

Figure 21 Bazaars at the entrance of Hospital Alcalde



Source: My own.

José met me at 9:30 am, explaining that he had been at the social worker's office in the nephrology ward trying to arrange the payment for the dialysate supplies. Considering the family's socioeconomic status – according to Hospital Alcalde's scale – the social worker reduced the fee by 70%: José would pay \$750 for 15 boxes, containing 120 packages of dialysate in total, the amount needed for a month of treatment. The market price of a single PiSA's double-bag Y-system package (see Figure 13 on page 191), containing 2 litres of dialysate (1.5% glucose) was \$48. A box containing 8 dialysate packages would therefore cost \$384. If a patient needed 15 boxes a month, or 120 packages, the cost would be \$5,760, which was about the average monthly income of a household like José's (INEGI, 2013).¹²⁴ This meant that a patient who paid the full charge requested by the hospital was receiving a reduction

¹²⁴ According to official statistics, in 2012 Mexican poor families, located in the bottom three deciles of income, had an average monthly income of \$5,245 (INEGI, 2013).

of 56.6% on the market price. In José's case he was receiving a reduction of 87%, taking into account the market price, or 70% taking into account the cost of the programme's fees.

However, José wasn't able to secure the dialysate for the month of May – it turned out that he had missed the deadline, which was the day before. José pleaded with the social worker, who was responsible for recording payments, to allow him to pay the next day but the decision was out of her hands. José would have to pay and bring the receipt in before the next deadline at the beginning of May in order to receive dialysis supplies in early June, a delay of a month. José was extremely disappointed: he had not been able to secure these crucial supplies for Lucero. He had no other option but to seek dialysis supplies for April and May through another route. He thus turned to the asociaciones civiles, something which entailed extra work.

He also told me about another problem that had come up before coming to the hospital that morning – he hadn't been able to arrange transportation to carry the dialysate to Agua Caliente either. His son-in-law's truck had a mechanical problem and he didn't want to put anyone at risk by driving it. The next person he turned to, a friend from the village, wasn't able to help him either: he didn't have a driver's license and the last time he helped another patient he had been pulled over and had to bribe a police officer in Guadalajara at a cost of \$500. He wasn't willing to risk driving to the city again. José didn't give up. The next best option was to take a taxi from the hospital to Central Vieja, the old bus station in Guadalajara, from there take a bus to Poncitlán, and then get a lift from Poncitlán downtown to Agua Caliente. It was a long and laborious journey, but it was the cheapest option.

After explaining his plan to me, José approached Rosario at the Trasplantados en el Hospital Alcalde's stand and asked her whether her offer still stood. Rosario gave him more bad news: the organisation had run out of dialysate and wouldn't have any until further donations arrived. Rosario apologised and promised to call José once they had dialysate to share. José did not know where else to go. I told him that Una Oportunidad de Vida might have dialysate supplies they could donate to him. I knew some of the people who worked for them and I offered to ask them on his behalf. He agreed and we walked to their offices, half a mile from the hospital. When we arrived, José talked to Sarah, who was the receptionist and the initial point of contact for the charity. José explained his situation and the difficulties his daughter and family were dealing with. Luckily, Sarah was in a position to help. As José had approached them for support before, when trying to secure erythropoietin, this asociación had already assessed the socioeconomic situation of the family and had a file on Lucero so could release supplies to him that day. Once Sarah had found the file in her records, she went through the standard donation procedure: she asked José some questions to fill up a proforma for the organisation's records, requested the dialysis prescription from José and asked him to sign off a 'donation receipt'. The boxes José was given were stored in one of the rooms of the building that served as the asociación's offices (see Figure 22). On behalf of Una Oportunidad de Vida, Sarah gave José eleven boxes for free, containing 88 dialysate packages, enough to start CAPD at home. According to her, the boxes were donated by an insured patient some weeks before. The quid pro quo arrangement was fairly explicit in this case: in the months to come, José would have to volunteer for Una Oportunidad de Vida and attend their monthly lecture at Hospital Alcalde. Given the circumstances, José was happy to agree to the terms of the exchange.

Once Jose had the dialysate, we took a taxi to the bus station. We put the boxes into the taxi's boot and passenger seat, leaving just enough room for us to squeeze in. The taxi driver tried to convince us to hire him for the trip to Poncitlán for \$600, but José stuck to the original plan. The trip to the bus station was only for \$50 and we arrived at the bus station at 10:50 am with the next bus to Poncitlán leaving at 11 am. José asked the bus driver's permission to put the boxes in the boot and the bus driver agreed, and at no extra charge. Tickets cost \$50 per person and, once we'd bought them and were on the bus, we were quickly underway, arriving in downtown Poncitlán at noon. We retrieved the boxes and piled them up in the hallway of Poncitlán's bus station. José then left me with them while he went downtown to find a lift.

About 15 minutes later, José came back in the company of Pedro, a neighbour with a pickup truck. Pedro had come to town to do some shopping with his wife and see a doctor while there. José had spotted him and asked for a lift, as had another local man. Pedro and this other passenger helped us load the boxes into the back of the pickup and the three of us took our seats there too. After Pedro finished what he needed to do in town, we left Poncitlán at 12:40 pm. It was another 40-minute trip to Agua Caliente from Poncitlán; 20 minutes on a paved road and another 20 bone-shaking minutes on a dirt road, full of potholes and throwing up a lot of dust. Whether PiSA's delivery service could reach this village was an open question. We finally arrived at José's house around 1:15 pm where the family gave us a warm welcome. Lucero and her mother Úrsula were very happy to see the boxes of dialysate and even the children knew they were needed for Lucero's treatment. While there, Lucero's parents asked me to assist her with her first dialysate bag change, which I did – with the results described in chapter five.

Figure 22 José's quest for dialysate



Source: my own. Notes: From left to right, top to bottom: A) Dialysis supplies in the storeroom of Una Oportunidad de Vida; 2) José loading the boxes into the taxi's boot and backseats; 3) José helping to put the boxes into the bus's boot; 4) Pedro's pickup truck with the boxes in the back, ahead of the lift to Agua Caliente; 5) The dirt road that connects Agua Caliente to the paved road to Poncitlán; 6) Having lunch: fried charales, hand-made maize tortillas and salsa, with the boxes in the background on the patio of José's family home.

Throughout the six-month process of admission to the CAPD programme, from the point of diagnosis to completing training, Lucero and her parents had been becoming gradually more aware of different aspects of her status as a renal patient and what supporting her entailed. They came to realise they were not alone but belonged to a

wider community made up of uninsured patients and their families all in similar situations and facing similar difficulties – medical, social, political and economic. They came into contact with other members of this community as a result of the treatment process and learnt that they could rely on some of them for help and support. This was a population organised around managing kidney failure. The nephrology ward was a critical site for this community: not only was it a space for medical care, where highly specialised medical treatments were practised upon their bodies, it was a space where they were brought together with others like them. Not only were social relations established between health professionals and patients there, then, they were also established between different sets of patients and family members. The socio-material conditions of the hospital setting thus facilitated the formation of a community of renal patients.

Among other things, moving through the hospital provided opportunities for interacting with other patients and their relatives, and learning from their experiences. This often involved the exchange of (not always accurate) information of many kinds and from many (not always reliable) sources. What some of the healthcare professionals referred to as *radio pasillo*, literally the ‘radio corridor’, close to the ‘grape vine’ in English, was one of the main sources of information patients had about the nature of the disease, its possible causes, its treatments, its costs, natural remedies and ‘miraculous’ products, but also about the *asociaciones* and related services that support uninsured renal patients. *Radio corredor* might not always have been accurate, but for many patients, like José, it was of crucial help when it came to learning about these charitable organisations. It was also the entry point to the informal economy of RRT for José and Lucero. José came to understand that he could rely on informal forms of exchange to maintain access to dialysis supplies and keep his daughter’s therapy

going. He was thus willing to participate in the community by taking on the obligations that came with the kinds of relationships and exchanges that underpinned it. How this biosocial community and its informal economy was organised and worked in practice are taken up in turn in the sections that follow.

6.2 Renal biosociality: the emergence of a community around CKD

The issues addressed in this chapter resonate with recent discussions of the concept of biosociality. Biosociality is a concept introduced by Paul Rabinow to capture the emergence of new identities and communities in the light of the discoveries of the Human Genome Project from the mid-1990s onward (Rabinow, 1996). Many sociologists and anthropologists have gone on to employ the concept to explore the emergence of the new social identities which have formed around shared identification with specific disease risks (Gibbon & Novas, 2007; Novas, 2006; Valle & Gibbon, 2015). These studies have dealt mainly with patient support groups, with a particular focus on those that have been politically active and have advocated for such things as the development of new genomic therapies or specific kinds of policy change. Ian Hacking has noted that ‘currently, the genetic imperative – the drive to find biological, but above all genetic, underpinnings for all things human, in sickness or in health, in success or in strife – is fuelling fascination with this concept’ (Hacking, 2006, p. 81). Hacking has also pointed out that the concept is difficult to restrict: we can all be viewed as participating in different biosocialities – with the family seen as constituting one of the ‘primary’ biosocial groups in various contexts (Hacking 2006). In light of comments by Hacking and others, Rabinow has also acknowledged that older forms of disease-related socialities, involving the sharing of experiences and organised collective advocacy for better understanding of diseases and treatments but without a

focus on genetic medicine, still retain a great deal of significance (Rabinow, 2007, p. 188).

Many other studies that have drawn on the concept of biosociality have focused on these more established forms of community, analysing the subjectivities and practices of groups whose members share identities in terms of the particularities of non-genetic diseases (Guell, 2011; Marsland, 2012; Nguyen, 2010; Petryna, 2004). Marsland (2012), for example, suggests sociality should be taken as seriously as biology, arguing one should not be privileged over the other. For Marsland, it is important to recognise the importance of 'non-bio' relations that may support the formation of particular biosocialities and be aware that not all biosocial groups pursue political goals. Guell (2011) has also noted that some of the biosocial groups that form around particular conditions may share other non-biological traits, such as a collective experience of inequality in a particular context. Importantly, these studies show that the social, political and economic context of disease are crucial for understanding the emergence and possibilities of local forms of biosociality.

I am interested in how a biological condition, in this case CKD, along with its related forms of medical intervention and the welfare provisions which support (or fail to support) access to them, linked people together in the context of Jalisco. What I have begun to describe here is a very particular biosocial community, connected in terms of a renal biosociality, whose major aim was not to promote medical research and the development of new treatments but to ensure survival within the socio-material contexts that defined their situation. What characterised this biosociality, I argue, were the specific types of exchanges that took place among its members, which I will call an informal economy of renal replacement therapies. But before discussing this

particular economy, however, I will further discuss how it was possible for these people to form as a community.

6.2.1 The importance of asociaciones civiles

Like other chronic illnesses explored in studies of biosociality such as HIV, cancer, diabetes, and so on, CKD is a disease that brings people suffering from this condition, their families and friends together. Once brought together, they form self-help associations, support groups and charitable organisations – locally known as *asociaciones civiles*, as mentioned above. Large numbers of such organisations, dealing with all manner of conditions, can be found in countries worldwide. Mexico is no different. At the time I conducted fieldwork, there were hundreds of patient support organisations throughout the country covering a wide variety of conditions. These often had quite different agendas, with many of them pursuing explicitly charitable goals – principally helping the uninsured poor.

As discussed in Chapter 3, charity in Mexico has a long history, at least that dated back to colonial times (Verduzco, 2001), when groups connected to the Catholic Church provided diverse forms of assistance to the poor, destitute and ill. Religious groups remain prominent providers of charity, but they have been joined by a different type of non-religious charitable group which emerged at the end of the twentieth century. Since the 1970s, a large number of voluntary sector groups have been formed which aim to provide relief to those in need, particularly the poor and the ill. The number of *asociaciones civiles*, has increased exponentially since the 1990s (Charry, 2003; Verduzco, 2001). Many of these organisations were created with the explicit objective of supporting uninsured patients with specific health conditions (see for example

Cuadra-Hernández, Zarco-Mera, Infante-Xibillé, & Caballero-García, 2012; González Vázquez, Márquez Serrano, Treviño Siller, Gómez-Jauregui, & Pelcastre-Villafuerte, 2010; Maza-Fernández & Vecchi-Martini, 2009). Many were set up by relatives of patients, usually the mothers or wives of patients, or by patients themselves, individuals who had experienced the hardships of illness and the difficulties associated with securing adequate healthcare and medicines. Usually, these groups would hold back from public debates about health policy,¹²⁵ although some of them do campaign for the improvement of health services and the right to access healthcare. Within this context, numerous *asociaciones civiles* now provide different types of support to insured and uninsured renal patients across Mexico.

The consolidation of renal replacement therapy programmes in the 1990s contributed to the growth of *asociaciones civiles* supporting renal patients. In her study, Crowley-Matoka, for instance, noted the formation of informal collectives of transplanted patients, who worked together to pool medications and monetary resources, as well as the growth of advocacy groups aiming to raise awareness about organ donation and transplantation (though usually with little success) (2016: 173-174). Crowley-Matoka also discussed the formation of biosocialities around transplantation (Crowley-Matoka, 2016: 175). Useful as her discussion is, however, it is important to recognise, contra Crowley-Matoka, that these biosocialities pre-date transplantation, emerging as they do once patients are diagnosed and recognise themselves as belonging to the renal patient population. At the time Crowley-Matoka conducted her fieldwork, these forms of biosociality around CKD were still in their infancy. When I conducted fieldwork a

¹²⁵ In the State of Jalisco, IJAS (Instituto Jalisciense de Asistencia Social, or Jalisco State Institute for Social Assistance), the institute that regulates the work and activities of charitable and philanthropic organisations, forbids them from participating in politics or political demonstrations. Members of charities can do it, but not on behalf of organisations.

decade later, they were more robust, stable, with a more defined institutional shape and greater scope – these biosocialities were not only restricted to transplanted patients but included CAPD and haemodialysis patients, their families, friends, health professionals and other related actors, all of whom participated in the informal economy of renal replacement therapies. As importantly, by the turn of the century many new asociaciones had been set up specifically to support uninsured patients receiving treatment for CKD at Hospital Alcalde and Hospital Menchaca adding a new set of organisational actors to the picture. As José's efforts to secure the dialysate supplies showed, their interventions were often critical for patients.

In contrast to charities in the UK and United States, who raise money to provide social support, promote research, influence policy or campaign for new frameworks of biological citizenship (Novas, 2006; Rose, 2007), the asociaciones civiles that have emerged around CKD in Guadalajara have tended to have more restricted agendas. Most importantly, charitable organisations in Guadalajara have not tended to function as a form of collective representation. Instead, they raise money to support uninsured patients to partially fund renal replacement therapies, particularly haemodialysis and transplant surgeries. I will return to these practices, but first, it is important to understand how these asociaciones civiles came to form in Jalisco specifically.

The majority of renal patient support groups in Jalisco were founded at the beginning of the 2000s through the initiative of parents, especially mothers, of patients with CKD who had just received a transplant. They had come to identify with the problem of CKD before setting up their organisations. It was usually in the hospital, the medical setting, where patients and their families made this identification. As I showed in earlier chapters, although the sick person acquired the identity of renal patient just after

being diagnosed, it was not until they had passed the rite of passage that constituted the admission process that they were recognised as a specific class of patient – a CAPD patient. Crowley-Matoka (2016, pp. 115–117) has also noted that acquiring the identity of renal patient is no easy matter, involving a complicated process reliant on time, resources and medical knowledge as well as diagnostic and therapeutic technologies. Those whose peritonea were damaged to the point of being unable to filtrate, and were transferred to haemodialysis, stopped being CAPD patients and became haemodialysis patients. Those who were able to access transplantation, became transplant patients. Each of these new identities also implied their own specific rites of passage and the transition from one to the other was usually far from smooth or easy.¹²⁶ However, this picture remains too abstract. New identities were not formed in a void but by virtue of common experience in physical places. Hospital Alcade was one such place and was thus an important crucible for the emergence of renal-specific asociaciones.

As discussed in chapter 3, Hospital Alcalde had historically been a refuge for the destitute ill, ‘suffering humanity’ in Fray Antonio Alcalde’s terms. Today, the uninsured poor and ill constitute the contemporary expression of that suffering humanity, coming from across the west of the country to Hospital Alcalde in search of medical care. Once there, the hospital is also a place where they become members of a community which has organised itself around CKD and the identities associated with its various stages and modalities of treatment. As this is where patients and their families come together, Hospital Alcalde has been a key site of charitable activity, with all the asociaciones that supported uninsured renal patients at the time I conducted

¹²⁶ For ethnographic analyses the life after transplantation in the Mexican context see Crowley-Matoka (2005; 2016) and Kierans (2013, 2015).

fieldwork working from there. Besides sharing the same illness, it was their unprotected status, being uninsured, which led patients to contact asociaciones and join together with others. Indeed, it was what had led many of those who formed the asociaciones civiles, through personal experience of CKD, to start them in the first place.

Over the years, these asociaciones have helped hundreds of renal patients undergoing peritoneal dialysis, haemodialysis and transplantation in different ways. One of their most important contemporary functions, however, is as major providers of medicines for renal patients. These charities receive donations of surplus medicines from insured and uninsured patients, and then distribute them among those who need them most. Three asociaciones, in particular, became the main formal biosocial groups providing support and medicines to uninsured patients at the hospitals for the uninsured – Una Oportunidad de Vida, Trasplantados en el Hospital Alcalde, and Quiero Vivir.¹²⁷

Although asociaciones civiles are characteristically biosocial groups, in the terms defined above, renal biosociality in Guadalajara did not, however, revolve solely around their activities. Many patients, families, and wider networks engaged in exchanges of support, information, money and medicines but did not participate in patient support groups. The intensity, frequency and scope of these exchanges constituted an independent economy, albeit informal, unofficial and so ‘off-the-books’, centred on renal replacement therapies. The third part of this chapter discusses this economy and the actors and exchanges that constitute it.

¹²⁷ There were many other registered charitable organisations, one of them linked to the pharmaceutical company PiSA, and informal and loosely organised groups of patients who carried out the same sharing practices, but these were the three main asociaciones civiles that collaborated with the public hospitals for the uninsured.

6.3 The informal economy of renal replacement therapies

It was not just asociaciones civiles and patients/families who engaged in different types of exchange in order to help uninsured patients secure renal replacement treatments. Rather the kinds of practices of exchange that characterised patients' interactions with asociaciones civiles – as a distinctive biosocial community – formed part of an even wider informal economy of renal replacement therapies.¹²⁸ Here I am drawing on the concept introduced by Leslie Sharp (1999) who has described similar practices among poor transplant patients in the United States. In introducing it, Sharp was concerned with examining what she referred to as the 'survival paradox': how it was possible for poor patients to stay alive and remain compliant with treatment regimes in the absence of insurance and hence access to high-cost immunosuppressant medications – something which led to economic hardships and bankruptcy. As a way of dealing with these problems, Sharp pointed to sharing practices among insured and uninsured patients, often out of the sight of healthcare staff. These practices constituted what the author called an *underground economy of medical survival*. It was not an analysis Sharp elaborated further, focusing on other aspects of organ transplantation instead (Sharp, 2006, 2009), and, more generally, the issue of drug sharing and the underground economy has not been taken up and developed further by social scientists who study CKD and the various modalities of RRT. This is something I seek to do in this section, drawing on but also adapting, broadening and extending Sharp's idea of underground economies of medical survival by situating them in the context of renal

¹²⁸ I have already discussed the existence of a healthcare black market based primarily in the area around Hospital Alcalde, where illegally acquired medicines are sold on at very low prices. Black markets such as these are different from informal economies as the concept is being used here, however, because they are explicitly profit driven and do not aim to support a particular constituency of patients.

biosociality in Mexico. Where Sharp uses the term ‘underground’, I use the term ‘informal’ for reasons that will become clear below.

The sorts of practices Sharp points to are commonplace in Mexico, particularly in the State of Jalisco and Guadalajara specifically. Recent studies focusing on the case of uninsured CKD patients in Guadalajara give empirical support to Sharp’s analysis of the importance of these practices among the poor, although these studies did not draw on the concept of the underground economy explicitly (Kierans, 2015; Kierans et al., 2013; Mercado-Martínez et al., 2014; Mercado-Martínez & Correa-Mauricio, 2015). Nonetheless, there are some differences. While Sharp describes undercover practices of drug sharing conducted ‘out of sight’, in Jalisco these exchanges were conducted openly in public and regularly featured in the press, radio, television and the internet. In contrast to the United States situation, in Jalisco such practices were not, therefore, underground. However, despite taking place in plain view, they were not officially sanctioned but were tolerated and thus informal. Most of the exchanges took place around the edges of the formal health system and formal health services, and were sustained by interactions between insured and uninsured patients, their families, charitable organisations, health professionals and many other related actors who would operate outside explicit organisational structures and procedures. Given their *informal* status, these exchange relations could not always be guaranteed and were often far from reliable.

Recent qualitative and ethnographic studies have shed some light on what is involved. Mercado-Martínez and Correa-Mauricio (Mercado-Martínez & Correa-Mauricio, 2015), for instance, documented the difficulties families and uninsured patients face in trying to secure and comply with haemodialysis treatment. They underlined the

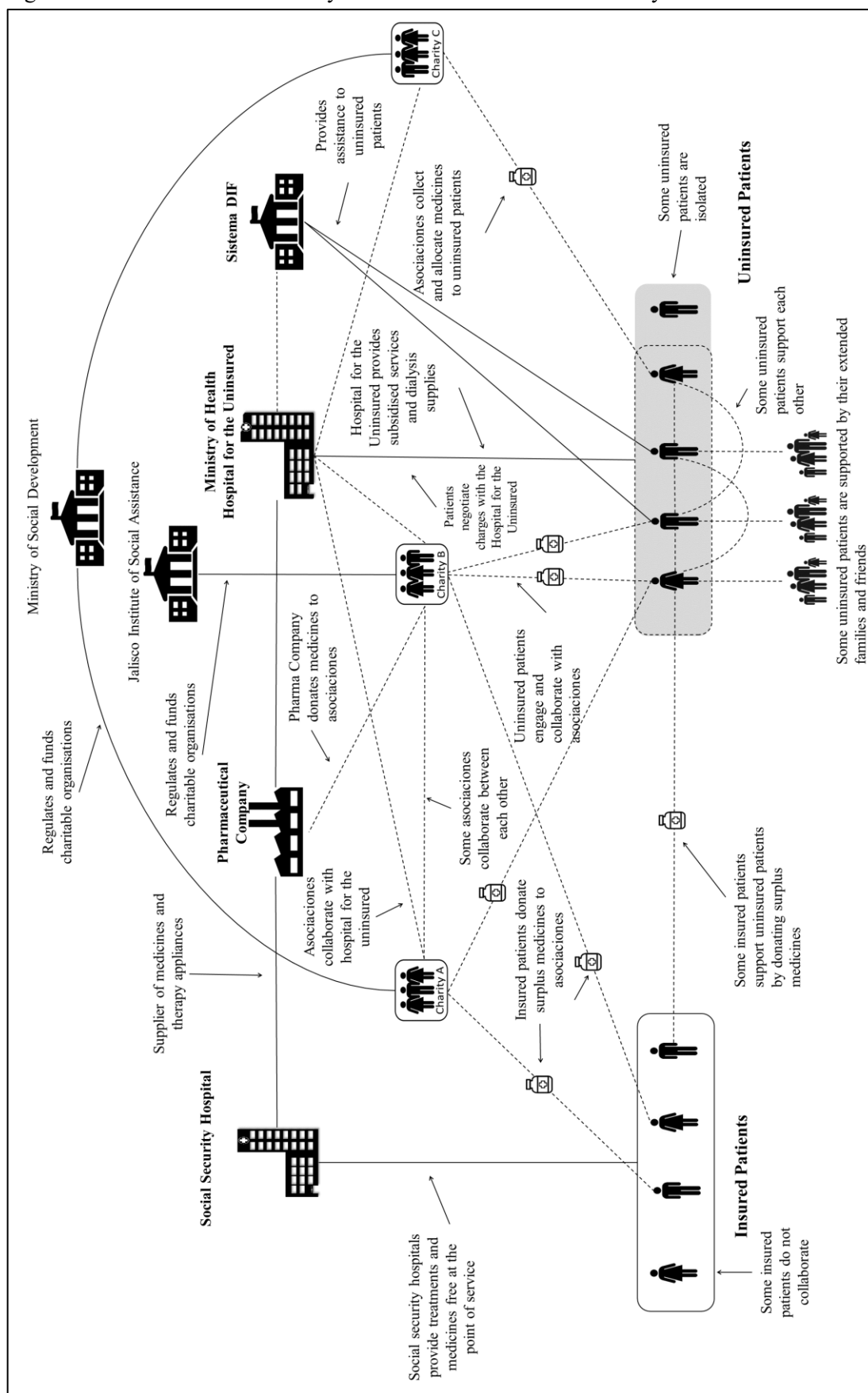
problems working class families face in paying for expensive treatment in the context of the fragmented and multi-tiered Mexican health system – much as I have done in previous chapters – and pointed to the strategies families employed to gather the necessary resources to support haemodialysis. One of these strategies involved approaching local asociaciones civiles and other governmental institutions for specific types of support. For example, the offices of Sistema DIF,¹²⁹ a governmental social assistance institution, and Caritas, the international Catholic social welfare charity, were increasingly common stopping-off points for uninsured patients on haemodialysis because these institutions provided financial support for a number of sessions in private clinics. They also noted that local charitable organisations, set up by other renal patients, were an important source of information and medicines, especially the more expensive ones. In Kierans et al. (2013), the research team showed that renal care in Mexico requires a lot from families and patients and documented a series of practices patients engaged in when attempting to access renal replacement therapies. Among those practices, the negotiation of treatment and costs, as well as the financing and resourcing of healthcare, were particularly important. Families had to rely on their own extended families, when possible, alongside networks of support. When these were exhausted, charitable organisations became a critical resource, a route by which it was possible, for example, to secure medicines donated by families who had lost members to CKD. Mercado-Martínez and Correa-Mauricio (2015)

¹²⁹ Sistema para el Desarrollo Integral de la Familia (Sistema DIF, for short), or the National System for the Integral Family Development, is an institution that provides a variety of services for, in the main, poor families in Mexico: primary care, pharmacy, dentistry services, physical therapy and support for people with disabilities, and financial help to partially cover treatments for chronically ill patients, among other things. Sistema DIF has representation at national, state and municipal levels. Renal patients usually approach the state level Sistema DIF Jalisco and their municipal DIF in turn. Sometimes the state and municipal level DIFs collaborate to provide support for patients, although that requires that patients move back and forth from one institution to the other doing paperwork at both institutions at the same time.

argued that these practices were cyclical, with patients and family members mapping possible sources of support – primarily but not solely charitable and governmental institutions – approaching each in turn and then starting again once they had worked through the list. Kierans (2015) has argued that this mobilisation of patients through interactions with public and private healthcare providers, local charitable organisations, State institutions and diverse networks of support, is what makes renal transplantation possible. That is, it is not medicine and the healthcare system that constitute the conditions of possibility for renal replacement therapies but the wider sets of social, cultural, economic and political relations which medicine and healthcare establishes in structuring access to treatment in the ways that it does.

Thus, patients and their families, charitable organisations, health professionals, governmental institutions and, as I will show, pharmaceutical companies, were involved in different types of ‘unregistered’ but not illicit exchanges that helped uninsured patients secure renal replacement treatments in the short and long term – the informal economy of renal replacement therapies. In what follows, I discuss how three of the main groups of actors – patients and families, asociaciones civiles and health professionals – engaged in these exchange practices, exchange practices which the hospitals for the uninsured, and therefore the wider health system, relied on to provide care for uninsured renal patients. Figure 23 is a graphic representation of the renal biosocial community and the informal economy of renal replacement therapies. It has been designed to help the reader to visualise these exchange practices, the social relationships they were linked to and the movement of medicines through different spaces and among the different groups involved.

Figure 23 The biosocial community of CKD and the informal economy of RRT



Source: My own. Note: Dashed lines represent *informal* relationships between the actors, while solid lines represent *formal* relationships.

6.3.1 The role of asociaciones civiles

Over the years, the three asociaciones civiles I mentioned before – Una Oportunidad de Vida, Trasplantados en el Hospital Alcalde, and Quiero Vivir – had become important actors in the informal economy of renal replacement therapies. Aware of the shortages of medications in public hospitals and families' struggles to afford them, these patient support organisations started to accumulate and distribute a large volume of medicines. The majority of these medicines were donations from other patients or the families of patients who had passed away, both insured or uninsured. But asociaciones would also use some of the money they raised through donations, collections and other activities to buy much needed medicines (particularly immunosuppressants for transplanted patients). Among the most valuable of the medicines they distributed to dialysis patients, as has already been discussed, was erythropoietin and peritoneal dialysis solution – medicines that José obtained through the asociaciones at different stages of Lucero's trajectory. Cheaper medications, such as antihypertensive medications and related drugs, were also distributed to patients through these charitable organisations. Hence, these asociaciones operated as centres of exchange through practices of donation and distribution.

The exchanges they engaged in were not monetary in character. The asociaciones did not usually charge the patients, or, if they did, they asked them to pay what they could rather than a set price. Instead, they asked patients to register with them, participate in monthly meetings and undertake volunteer work with them, for example, by staffing their 'bazaars' or selling raffle tickets to raise money. Uninsured transplant patients, reliant on immunosuppressive drugs, and their relatives, mostly their mothers, made up the majority of 'volunteers'. By volunteering they were given priority access to drugs when they needed them. In this way, patients and their families sought to

demonstrate to asociaciones civiles that they mattered, that they were worthy, and so deserved to be supported by them when it came to securing a transplant (Crowley-Matoka, 2016).

But patients undergoing CAPD or haemodialysis also had to work to make themselves matter enough to the asociaciones to secure their support. As with transplant patients, those who approached the asociaciones in search of erythropoietin or dialysate solution had to show deference and a willingness to volunteer. Through specific practices of exchange, then, another form of supplicatory relationship was enacted. The asymmetry was not the same as in the hospital but patients still had to prove their poverty, show their willingness to work with the asociaciones and thus demonstrate their worth by doing whatever might happen to be asked of them.

By the time I conducted fieldwork, between 2012 and 2013, the three asociaciones civiles I have discussed were being treated as partners within the healthcare system. Most importantly, they were part of the organisations the hospitals relied on when they needed to help a patient. Given this, they were regularly invited to public events related to CKD, organ donation and transplantation.¹³⁰ Yet these charitable organisations were not part of any formal structure – they were at the margins of the healthcare system. In spite of that, they received funding from State institutions like IJAS, the Jalisco State Institute of Social Assistance, and SEDESOL, the Federal Ministry of Social Development, to provide support and relief to the disadvantaged.

¹³⁰ Organ donation and transplantation have been the focus of recurrent promotion campaigns, usually organised by the hospitals, the Council for Organ Donation and Transplantation of Jalisco and the MoHJ, with asociaciones civiles invited as part of the events.

Asociaciones civiles that supported renal patients not only received money from the State, they also collaborated with Hospitales Civiles and pharmaceutical companies. From pharmaceutical companies they received donations of medicines but the relationship with Hospitales Civiles was different. By the early 2010s, it was clear that the asociaciones civiles had become an indispensable link in the provision of renal replacement therapies. However, the asociaciones did not operate like the hospitals but wrote themselves into the picture in quite specific ways. Trasplantados en el Hospital Alcalde, for example, had bought a haemodialysis machine which was donated to the hospital. This machine, according to the director of the organisation, was dedicated exclusively to patients supported by them. In terms of transplantation, Una Oportunidad de Vida and Quiero Vivir played an important role in increasing access, negotiating important reductions in costs and partially funding the rest. This was the case with Ricardo, who was supported by Quiero Vivir to get through his transplant protocol. They also negotiated the cost of the surgery for a deceased organ transplant on his behalf. For that to happen, however, his mother had to become a virtual worker of the asociacion. She volunteered three days a week for more than two years before the transplant and had to continue to do so after the procedure to secure access to immunosuppression. This was routine and it was common to find patients and their family members, like Ricardo and his mother, volunteering several days a week in the bazaars, attending lectures and meetings, and engaging in public displays of respect for the asociación's directors.

These practices of exchange and the relationships they established meant patients were not all treated equally by the asociaciones civiles and, through them, the hospitals. Those who showed enthusiasm, initiative, compliance, and who demonstrated they would work hard for support, received the most. Those who did not – or could not –

received little if anything. This inequality of attention is the outgrowth of the situation Crowley-Matoka (2016) observed in relation to the city's transplantation programmes more than a decade earlier, where patients had to find ways of showing that they were worthy of being supported. Since then these practices have spread outwards to more aspects of renal care, with patients having to demonstrate their worth to both the hospital and the asociaciones civiles in order to get access to therapies and medicines, not just transplantation.¹³¹

6.3.2 The role of healthcare professionals

As already noted, renal biosociality linked more than patients. Health professionals also played a very important role within the community and in the informal economy it was linked into. Importantly, and as has already been discussed, doctors and nurses formed partnerships with patients in different ways. Although they were figures of authority, and patients tended to rely on and submit to their authority, doctors and other health professionals not only worked on them, they also worked with them to help them access medicines, tests or other related services at reduced or no cost. These forms of assistance also helped patients to commit to their treatments.

Some nurses, for example, helped patients to get clinical exams for free at Hospital Alcalde. Clara, in a manner similar to Ronaldo (see Chapter 5, section 5.2.2), got her

¹³¹ This was the case of Ronaldo, for instance. In 2015, when I visited Mexico, I visited Ronaldo and found out that he was transferred to haemodialysis. Ronaldo struggled with recurrent peritonitis, which ultimately damaged his peritoneum, losing its capacity to filtrate and, thus, he had to be transferred to haemodialysis. Trasplantados en el Hospital Alcalde ultimately helped him to get a place in the overburdened Haemodialysis Unit of Hospital Alcalde, but this support was not automatic. He and his mother had to try a large number of charitable organisations before their petitions were heard and accepted by Trasplantados en el Hospital Alcalde and Ronaldo was supported to get the place. The demands placed on patients and their families are high and charitable organisations are under no obligation to hear their case let alone extend them support.

clinical exams every two months with the help of one of the nurses in the nephrology ward. Clara was asked to come to the nephrology ward two days before the consultation. She had to arrive very early in the morning, before 8 am, in order to give blood and urine samples to this nurse, who would then submit them to the laboratory on her behalf. In this way, Clara did not have to pay for the clinical exams nor did she have to return for the results the day after. The nurse helped Clara, as she did others, because she was committed to helping impoverished patients in whatever ways she could.

Well aware of their patients' impoverished conditions, as well as the economic hardships that were a consequence of CKD and its treatments, the doctors also tried to help patients. Stories of patients whose doctors had helped them get a catheter, a particular drug or had requested reductions to hospitalisation charges on their behalf were common. But perhaps the most frequent assistance offered was to help patients get access to benefits through Seguro Popular by not disclosing their status as CKD patients, instead presenting them as 'hypertensive patients' – discussed in an earlier chapter. Using loopholes in Seguro Popular's rules – which treated bodies and conditions as discrete rather than as complex and categorisable in multiple ways – was a way of helping patients to get access to medicines and services. These practices created a reputation for helping the poor among the hospital's staff. When patients moved between treatment modalities, the support would continue in different forms.

6.3.3 Exchanges between patients

Finally, there were other types of exchanges, perhaps more frequent, that were carried out without the participation of charitable organisations – exchanges between patients,

both insured and uninsured. The exchange of medication between patients in Mexico has occurred for a long time, although it is a practice that has not been studied. People exchange surplus medication they consider appropriate for any type of ailment, or in other cases, for specific conditions that both parties share (for example, anti-hypertensive medications shared between hypertensive patients).

It is likely that what I am calling the informal economy of renal replacement therapies had first begun to take shape in the 1990s, when these treatments were established in public hospitals. These exchanges intensified when PiSA, the Mexican manufacturer of dialysis solutions, entered into partnership with the IMSS system. The fact that both institutions used the same dialysate supplier enabled insured patients to support uninsured fellow patients with dialysis supplies of the same kind. While this would not be an issue with many medicines, where different brands or generic versions would do, it was an issue in relation to CAPD supplies. In CAPD, the different types of connecting devices used by different manufacturers, and so the corresponding bag change techniques, had to be equivalent. A patient using PiSA's system is not able to use Baxter's, unless they have undertaken further training and the transfer line, which connects the catheter and the double bag system, is replaced. That both institutions opted for the same brand of dialysate, however, meant that insured and uninsured patients could exchange dialysis supplies.

During fieldwork, I came to learn that exchanges of medicines and dialysis supplies between patients were common in the communities of Lake Chapala. This was particularly true when it came to dialysate supplies. For the majority of patients from the Lake's communities it was very difficult, for some almost impossible, to secure dialysate from asociaciones civiles based in Guadalajara. Transporting the boxes from

the city to the Lake was simply too expensive and required a lot of effort, as the experience of José at the beginning of the chapter shows. Instead, the majority of patients from the Lake turned to the asociaciones only when they absolutely had to, as was often the case when they needed erythropoietin. They found other ways of getting dialysate.

Uninsured CAPD patients from the communities I visited mainly relied on other patients for dialysate. Insured patients showed a great deal of solidarity with the uninsured, to whom they would donate boxes of dialysate on a regular basis. Some were able to donate several boxes at a time, having accumulated them when they had experienced complications and had been hospitalised, building up unneeded stock in the process. The social security institutions and PiSA did not monitor the stock of dialysate at each patient's disposal particularly closely. As a consequence, insured patients were able to donate surplus dialysate to asociaciones civiles or, in the case of communities outside the city, to the uninsured patients they were in contact with.

This was the case with Cristián. At the beginning of his trajectory, Cristián was an uninsured patient with Hospital Alcalde for about two years. Later, his wife got a job at a maquiladora and he qualified for IMSS. After that, whenever possible, he helped other patients from his community, sharing spare dialysis supplies and medicines. As Cristian once told me 'we do it because we understand each other, we know what is like to be uninsured, not having money to buy food, not even to buy medicines. So, we donate dialysate and medicines thinking *hoy por ti, mañana por mi*, "today for you, tomorrow for me". That's why we do it.'

It was also common for the families of patients who tragically passed away to donate unused dialysate left in their homes. As I showed in chapter five, the majority of CAPD

patients in Jalisco ended up dying from CKD or from complications connected with CAPD. In the case of Simón, who passed away after almost six years on CAPD, his mother donated the unused dialysate solution to Clara, her neighbour. Patients who were transferred to haemodialysis, after suffering irreversible damage of their peritoneum, also donated their surplus dialysate to other uninsured patients. In more fortunate situations, patients who got transplants would donate all their surplus medicines to patients and charitable organisations. Erythropoietin was not commonly shared between patients, however. It was simply too expensive and so was seldom left unused.

As can be seen in Figure 17 (page 228, photos A, B, D, and E), uninsured patients tried to collect extra boxes of dialysate packages whenever they could, so they had more than those needed for a month. This enabled them to save money by not paying the *cuota de recuperación*, the CAPD programme's monthly fee. Some families were able to rely on donations of dialysate for several months, paying only when they knew they couldn't get a donation. This, however, came with its own set of risks. In some cases, the dialysate was close to its expiration date, so the patients and their families had to be very careful about what supplies they were using.

These sharing and exchange practices were known to the CAPD Unit's staff, particularly the social worker and the nursing staff. The social worker, for example, was aware that many of the patients who were registered for CAPD would not regularly pay the monthly fee but were still on the programme. This practice was thus unofficially tolerated by the hospital, an implicit acknowledgment that the monthly fee, even when subsidised, was unaffordable for most uninsured poor families.

Most exchanges between CAPD patients, and also between asociaciones civiles and patients, were non-monetary. Between patients, in particular, money rarely passed hands. That said, although most exchanges between patients, and between asociaciones civiles and patients, did not involve monetary transactions, there were many patients offering medicines, dialysate and even catheters below the market price. Pinned to the walls of the corridors and waiting areas of Hospital Alcalde, especially on the walls of the waiting area and outpatient consultations of the nephrology ward, it was common to see handwritten adverts for medicines and surgical material. However, while visible, these monetary exchanges were on the fringes of the informal economy I have been discussing. For the most part, it relied on the other forms of exchange I have described.

6.3.4 Engaged and disengaged patients

It is important, finally, to stress that the biosocial relations and practices of renal biosociality I have been discussing, as well as the informal system of exchanges and obligation they connected to could take stronger or weaker forms – some patients were reliant on these processes of give and take, while many others – both insured and uninsured – only rarely engaged in these exchanges, if at all, particularly with asociaciones civiles. Not all insured patients, for instance, were willing or able to donate medicines to asociaciones or to other patients. At the same time, only a handful of uninsured patients that participated in this study were engaged in exchanges with asociaciones, mainly because it was difficult for them to reciprocate by volunteering. As Leticia, the mother of Lourdes, told me, ‘I never approach the asociaciones, because they always ask you to work (as a volunteer) for them, and I don’t have the time to do so. I have to work in my job (as a sirvienta) to buy the medicines my

daughter needs and pay the programme's fee.' When they did not have money to buy erythropoietin, she simply did not take it, although that meant that the anaemia, a consequence of CKD, would flare up and Maria would feel very weak. Nonetheless, they were engaged in exchanges with other patients, mainly through the sharing of medicines, although not with the same frequency as others.

Other patients, like Ronaldo and his mother Ofelia, were more engaged. Ofelia was always looking for a donation, asking insured and uninsured patients from other communities whether they had anything to share. Sometimes they received offers from families that had lost a member due to CKD, and who had been on CAPD. She tried to make sure that Ronaldo would always have enough supplies while avoiding the payment to the programme. However, Ofelia, like everyone else, struggled to get erythropoietin through patients from the communities of the Lake. This was a particular problem in Ronaldo's case as he had been directed to take erythropoietin two to three times a week. But that cost more than the programme's monthly fee, and was thus unaffordable – financial constraints meant Ronaldo could mostly only take one dose a week, sometimes just one a month. Securing even a reduced supply for Ronaldo meant Ofelia had to travel to Guadalajara to petition the asociaciones she knew, working through them until she was able to secure a package or two.

In contrast to Ronaldo and Ofelia, some patients had to rely on their own resources. Rita exemplifies the cases of elderly patients who were taken care of, and who were more vulnerable to being isolated. Almost blind and bedridden, as a consequence of many years suffering from diabetes and lately from CKD, Rita was cared for by her husband Mateo and her daughter Helena. They had to pay the programme's monthly fee, but when they couldn't, they had to ration their supplies in order to avoid running

out. They were not engaged in the informal economy like other patients because neither Mateo nor Helena had the time or the networks of support others were able to call upon to enable them to do so. Rita's case is important, then, because it shows the limits of renal biosociality and informal exchange. Petitioning others, establishing relationships and building support networks was itself a time and energy consuming task, often involving taking on new obligations in return for help. Getting support carried costs. However, those who could not secure dialysis supplies in any other way had no choice but to become active participants and enter relationships with others through the local systems of exchange that had developed around CKD and RRT over time. Where that was not an option due to the constraints on patients and their families, where they could not carry the extra interpersonal costs, it became impossible to access what was in practice a vital source of support. This informal economy of exchange was one which thus both reflected and reproduced inequalities and socio-material stratification among patients.

6.4 Conclusions

In this chapter I have argued that particular forms of renal biosociality have emerged in the context of Mexico with groups of renal patients becoming linked together by virtue of their shared problems. Grounded in CKD and the need to secure access to RRT, biosocial relationships have been established between insured and uninsured patients, charitable organisations, and health professionals committed to supporting the poorest and most vulnerable through various practices of exchange. The informal economy that has emerged out of these situated exchanges is one in which medicines, information and other goods are circulated on the basis of *quid pro quo* arrangements in which patients pay not with money but with time, energy, commitment and by

showing the appropriate forms of deference and gratitude. These exchanges were not disinterested but they did help many uninsured patients to continue their treatments in the short and, sometimes, the long term.

In reflecting on this informal economy and the practices it is organised around, it is important to stress that the existence of a particular community around CKD and replacement therapies is a product of the problems surrounding the provision of renal care in Mexico. The failings of the system make the forms of renal biosociality I described above necessary. This was not just a patient support community, one that gathered together to share experiences and provide moral support to recently diagnosed patients and their families (Guell, 2011). Nor was it an advocacy community formed to raise awareness and influence health policy (Gibbon & Novas, 2007). Instead, it was a diffuse, fluid and multi-stranded community, whose boundaries were difficult to locate and which was characterised by the variable nature, level and degrees of interaction among its members as well as the types of exchanges that took place between them. It worked to provide support where the healthcare system would not or could not. The identity of its core members was medical, indeed nephrological: they came together as renal patients and related to one another on that basis. Although this wasn't a self-identification but something which defined them externally, the status of renal patient enabled them to negotiate with different stakeholders, form alliances, network with different actors, and so on in a wider web of biosocial relations. Within this community there were sub-communities, marked by such things as the type of renal replacement therapy but also the economic situation and resources of families. What this chapter has done is focus on the relationships and practices that linked those undergoing peritoneal dialysis, adding to the literature on haemodialysis and transplantation in the region as explored in great detail in the works of Mercado-

Martínez and Correa-Mauricio (2014), Kierans (2015) and Crowley-Matoka (2005; 2016).

These practices of exchange involve patients and their families taking on new obligations and thus, as I showed, new forms of work (Corbin & Strauss, 1985; Mattingly et al., 2011; Mykhalovskiy et al., 2004; Strauss et al., 1985). In previous chapters I argued that navigating the private and public local level health services and hospitals demands immense effort from families and patients. Later, when they are admitted in the CAPD programme, clinical work is outsourced to patients and families in the home context. An understanding of the informal economy reveals another strand of work patients and their families engage in, one that aims at garnering and allocating medicines, as shown in this chapter. This form of work takes place in a range of community and organisational contexts – charitable organisations, in and around hospitals, and the homes of other patients. It is a form of work that is not regulated and is not clinical, but unregulated, interpersonal and ‘voluntary’ in the sense of self-initiated. Through this, as Kierans (2015) noted with transplanted patients, the State passes further aspects of responsibility for care onto patients and families. Under these socio-material conditions, the health system, as an agent of the State, reallocates its work to *asociaciones civiles* and patients alike.

Although often presented in the context of charity as altruistic in character, the forms of exchange the informal economy of renal replacement therapies was organised around has some of the same characteristics of gift exchange explored by classic anthropologists (Kierans, 2016; Malinowski, 1932; Mauss, 1970). While donations are not gifts, and are not given freely but are petitioned, as with gifts receipt carried the expectation of reciprocation. This was explicit in the case of *asociaciones civiles*, who

would donate medicines for free or for a very low price but asked the receiver in return to reciprocate through volunteer work. It was the *quid pro quo*, the set price, of engaging with asociaciones. Here supplicatory practices were very much in evidence again too. Patients had to demonstrate their need and that they deserved to be supported. They also had to demonstrate that in the right way, by showing the appropriate respect and deference. Benevolence was conditional and patients had to prove themselves worthy of it on an ongoing basis.

The exchanges between patients also carried their own expectations, although in a different form. As Cristian said, it was based on a feeling of gratitude. The giver did not expect something directly in return from the gift, but that the receiver would behave likewise – turning giver – were they to find themselves in the reverse position in the future. When patients donated medicines to the people they came into contact with, they saw it as a way of repaying those patients who had supported them in similar ways in the past.

Extending the analyses presented in previous chapters, what this chapter shows is that by doing little, the State places the burden of care within the system not just on patients and their families individually but collectively. They are compelled to support one another to survive and this unacknowledged, informal work enables the healthcare system to continue. This activity benefits the healthcare system as much as if not more than the patients. As it does keep going, it is possible to claim the system functions as intended. Nonetheless, the practices that constitute the informal economy highlight the healthcare system's clear failings. That the practices of exchange documented above take place at the margins of the health system rather than being central to it is indicative of the deeply problematic way in which CKD and RRT are managed within it.

Although *asociaciones civiles* are increasingly recognised as partners within the system, by dedicating themselves to the movement of resources from the entitled (the insured) to the supposedly unentitled (the uninsured), their very existence shows the need for forms of exchange that according to official claims ought to be unnecessary. In this sense, their work too represents a situated critique.

The other area of subversive practice touched upon in this chapter was that carried out by health professionals. As shown, doctors are using medical labels such as ‘hypertensive’ in order to allow patients to obtain some benefits from Seguro Popular. In this way, they would take advantage of loopholes in the programme but without breaking the rules – patients do suffer from hypertension, but as a consequence of CKD rather than a cause. Like other aspects of the informal economy of renal replacement therapies, these practices were unregulated, situated and emergent. They subverted and took advantage of the current configuration of the healthcare system but, again, only to make up for its deficiencies. These practices, and the ‘hidden transcripts’ they involved (Scott, 1990), were, in this sense, responses to and consequences of the inequalities written into and reproduced via the healthcare system.

Finally, renal biosociality and its informal economy also had their limitations. Not all patients could engage in its practices and establish networks of support, nor could patients rely solely on these – the resources of the informal economy were very limited even where they could be accessed. Those in rural communities tended to relate to and draw on each other, engaging less often with *asociaciones* based in the city of Guadalajara. They, therefore, had more direct bonds of solidarity to draw upon but less support when it came to the most expensive aspects of treatment. Elderly patients also faced significant challenges when it came to engaging in exchanges. Although the

renal community and its informal economy had emerged as a spontaneous, self-organised response to the lack of support from the State, and charitable organisations had been established with the explicit goal of helping patients to access medicines and therapies, there were still zones and constituencies of patients excluded from this type of support. Being part of the community meant extra work, being outside it meant being unable to access a vital lifeline in deeply insecure conditions.

Chapter 7

Discussion

Introduction: ‘Leaving the field’ and the death of patients

The last time I saw José was a week before finishing fieldwork in May 2013. I accompanied him as he returned the stubs of 10 raffle tickets that he had been commissioned to sell as part of volunteering for Una Oportunidad de Vida, a task he had undertaken in return for the latest support they had given to his daughter and the family. Each ticket cost \$25 and the prizes were a brand new sofa and a microwave oven. José had not sold the tickets as such; they had instead been bought by his extended family as part of ‘giving something back’. Before going to the offices of Una Oportunidad de Vida, we stopped by at a local park and he wrote down the names and addresses of his relatives on the stubs of the tickets he had supposedly sold. For José this was simply one of the obligations that came with engaging with the asociaciones in Guadalajara, and he hoped that by showing his willingness to volunteer he would continue to enjoy access to CAPD supplies for Lucero. If all went well and they could secure further support from the asociaciones, José felt Lucero might even be able to start the transplant protocol.¹³² I wished them all the best in this.

As we said our goodbyes, José asked me not to forget about them and, when I returned to Liverpool, I kept an eye out for news of how they were getting on. In July 2015,

¹³² As mentioned in Chapter 6, besides Una Oportunidad de Vida, José had also connected with the charitable organisation Trasplantados en el Hospital Alcalde, as multiple contacts had been needed to secure supplies for Lucero.

José approached Una Oportunidad de Vida, this time not to ask for support, but to tell them that Lucero had died at the beginning of June. José thanked them for all they had done and asked if they could let me know the bad news, news passed on to me by the director of the asociación via email. Knowing that Lucero had died from CKD was extremely upsetting, as were the deaths of the other patients I came into contact with over the years of my PhD. In 2016, through a chance encounter back in Guadalajara with another person who had met them, I found out that Lucero had spent two years on home dialysis but had not had the opportunity to pursue a transplant. Lucero's family struggled to maintain and sustain her treatment and, eventually, she died from CKD while still on CAPD.

Four patients I interviewed passed away during the period of my fieldwork, all of them from complications related to CKD and its treatments. Silvia died just a month after I interviewed her for the second time, in December 2012. According to another patient, who was a friend of hers, she had not been able to recover from a peritonitis infection and other complications which had accompanied her move to CAPD. Renata, from Mezcala, died in May 2013, just six months after she began undertaking haemodialysis. She had previously spent several years on CAPD, but because of recurrent peritonitis and cardiovascular complications, she had been transferred to haemodialysis, a treatment she struggled to pay for, and so only received sessions once a week or less. She received some support from DIF, Caritas and other charitable organisations, but her treatment was unsustainable through charitable funds alone and her family struggled to find the extra money needed to continue more regular sessions. I have already described the cases of Daniel, who died even before completing the admission process, and of Simón, who died from complication of the disease and treatment after several years of carrying out dialysis at home, in earlier chapters.

When I visited Mexico in March 2015, I learned that another two female patients had died from CKD. Lourdes, from Mezcala, died in July 2013, just a few months after I finished fieldwork. The last time I saw her she was recovering from her first peritonitis infection in three years. In that March of 2015 I also visited Fidencio, the father of Clara from San Pedro Itzicán, and he told me that his daughter had passed away in 2014. After struggling with recurrent peritonitis and lung oedema, she was eventually overcome and died in the hospital. He summed up the sentiment of many patients aware of their situation as CKD patients, uninsured and poor:

It is not fair that the government constantly brags that Seguro Popular has millions of pesos to spend on medical care for the ill and poor, but in the end it doesn't cover conditions like this [CKD]. So, what's the point? My daughter was supported by an asociación civil from Guadalajara, and I was grateful, but their help was not enough. I realised that the demand of [charitable] support is very high, there are many patients like my daughter, poor and uninsured. But asociaciones civiles can't help with everything, they just can't. I felt helpless. Sometimes I think that my daughter suffered unnecessarily all these years.

These unnecessary tragedies are not isolated cases, they are the norm, and to understand why families must go through them, the personal, social and political circumstances of the deaths of these patients must be kept front-and-centre. CKD, as an incurable disease that requires continuous expensive treatment, lays bare the ills of the Mexican healthcare system. However, while dying from this condition is 'normal', each of those deaths remains profoundly shocking. Learning that Lucero had died was certainly a shock – I had thought she would have the opportunity to move towards a transplant. But I was wrong. Although Lucero and her family were engaged in Guadalajara's biosocial community and its informal economy, they lacked the

financial resources and social support to get a transplant. Being connected was not sufficient, as Fidencio was well aware.

In the course of the previous chapters, I have attempted to show that gaining an understanding of the problem of CKD and its treatments in Mexico from a social science perspective means understanding the socio-material conditions within which it is embedded. As I have attempted to show, these conditions include, minimally: the healthcare infrastructure of the country and its regions; the socio-political configurations of welfare, particularly the terms of differential access to specialised healthcare; the types of technologies used; the social, cultural, and living standards of the people affected by this disease; and the myriad actors involved as well as the social relationships that connect them together. Ethnography is crucial to achieving such an understanding, for its emphasis on actors situated within their particular contexts makes it possible to explore these layers of complexity and the human stories that unfold across them (Biehl & Petryna, 2013). Understanding is not a consolation, however, and it does not in any way lessen the losses experienced by those who I encountered during my research. What it does do at least is help to uncover the deep problems with a system that routinises personal tragedies – including all those that take place without anyone to document them.

7.1 The socio-material conditions of CKD and its treatments

CAPD was originally developed in the United States and Canada, but has subsequently become a global technology, a therapy that has been exported everywhere. Nephrologists, clinicians, biotechnological engineers from all around the world – including Mexico – have contributed to the advancement of CAPD over its four

decades of existence, bringing it to the people of their countries but also adapting it in the process (Negoi & Nolph, 2009; Peitzman, 1989).

Some elements of the therapy do not change much from place to place. Wherever CAPD is rolled out the patient must be made compatible with the therapy and the healthcare system that therapy is delivered by through the implantation of the peritoneal catheter, the home has to be transformed into a para-clinical space, and the patient or a family carer has to be drilled in the new body techniques required to perform it. In other words, a nexus between the social-structural, the clinical and the domestic settings has to be established through the patient's peritoneum, the peritoneal catheter and disciplined practices.

7.1.1 CAPD and biopolitics

However, these 'standard' elements work in very different ways depending on the context. What gives CAPD in Mexico its specific character is the particular socio-material conditions within which these elements have to be brought together and their connections maintained. In the Mexican context, CKD is a condition that reveals the biopolitical contradictions of healthcare policy and especially its recent reforms (Barba Solano, 2010; Kierans, 2015). Before 2003, there were two main constituencies in the welfare landscape of Mexico – the insured and the uninsured. Since the creation of Seguro Popular, the Government's claim has been that the country has achieved universal coverage (see Knaul et al., 2012, 2015), conveying the image of a unified biopolitical collective (Foucault, 2003). However, Seguro Popular is a financial scheme that only covers a limited list of conditions and treatments, making a biopolitical distinction between those who deserve and will receive protection and

those who do not and will not – that is, between those whose biological constitutions are considered worthy of care, and those whose ailing bodies are not. CKD is a stark example of the biopolitical distinctions at the centre of Seguro Popular – no treatment related to CKD is financially covered by the scheme. Thus, Seguro Popular did not mean the universalisation of healthcare in Mexico but a further fragmentation and the widening and complication of existing hierarchies and inequalities. Seguro Popular's rules are, in some circumstances, open to more sympathetic readings. As I showed in chapters 5 and 6, for instance, the nephrologists who cater for the uninsured take advantage of loopholes in the programme to allow patients to gain coverage for some medicines and clinical tests. Nonetheless, these informal practices also reaffirm hierarchy and inequality: unless patients engage in the kinds of displays of deference I have also outlined in previous chapters, those charged with their care will not engage in this work on their behalf.

The Mexican healthcare system has always been ridden by structural problems, hierarchies of concern and social inequalities, and has never had the healthcare infrastructure, human capital and technological resources to adequately meet the needs of the Mexican population. Analysts of the Mexican welfare system have underscored such problems (Ordóñez-Barba, 2016; Valencia Lomelí et al., 2012), problems which effect those who lack social insurance the most – half of the Mexican population. Within this context, Hospital Alcalde is a powerful example of the type of hierarchical, asymmetrical and historically rooted relationships the healthcare system is grounded in, exemplified in the iconic figures of Friar Antonio Alcalde and the suffering humanity – the destitute poor. I have suggested this relationship, vividly depicted in the murals of Hospital Alcalde, rests on supplicatory practices, those acts of deference conducted with the 'correct' demeanour that characterise interactions between the

uninsured poor and the healthcare professional. It is by engaging in these practices that patients are able to gain access to treatment and obtain reductions in hospital and treatment charges, both key to survival with CKD without insurance.

As the stories of all the patients recounted above show, renal replacement therapies in Mexico are practised within a complicated, problematic and unequal healthcare environment. Widely regarded as a ‘suitable’ technology for a low-income country like Mexico, because of the low costs associated with it and its suitability for use in the home, CAPD became the mainstay of renal replacement therapy in Mexico in the 1980s (Cueto-Manzano & Rojas-Campos, 2007; Treviño-Becerra, 2007). However, as the evidence of previous chapters demonstrates, it is a therapy that makes serious, often unmanageable demands of patients and their families. CAPD in Mexico turns treatment into a form of outsourced (and often under or unfinanced) clinical work, one that implies significant transformations for the patients and their homes without any guarantee of positive outcome.

7.1.2 The fragility of the nexus

The creation of a nexus between the body of the patient, the therapy and the clinic is crucial to understanding the situation of patients within a wider web of economic relationships, welfare institutions, technologies and medical practices. As in other national contexts, in Mexico the peritoneal catheter features as the point of interface at which this nexus is initially established, making the patient compatible with the therapy and the Mexican healthcare system. Yet in Mexico, unlike other places, even reaching this stage is a significant feat, a complicated process in which the patients and their families have to – successfully – navigate the fragmented healthcare

infrastructure they encounter in their search for help. Many do not manage to make it that far. Those that do, discover peritoneal dialysis is a therapy that is outside the social safety nets established to supposedly protect them. In Mexico, peritoneal dialysis, as well as haemodialysis and transplantation, are therapies situated at the margins of social welfare – provided by public hospitals for the uninsured, but incurring substantial long-term financial and social costs for those who desperately need them.

Patients and their families, because patients rarely have the resources to secure and maintain treatment alone, face trials throughout their journeys. After diagnosis, the fitting of the catheter and the creation of a therapeutic space in the home, the next stage is meeting the formal requirements of the admission process to the CAPD programme of the hospital. At Hospital Alcalde, this takes the form of a rite of passage (Turner, 1969; Van Gennep, 1960) in which patients and their families are drilled and tested in new body techniques (Mauss, 1973). Although the patients have been made compatible with the therapy, through the catheter, that is not enough to sustain the therapy. For that, they have to learn how to establish the body-therapy-clinic nexus in practice. The accommodation of therapy and training is an important stage in the trajectories of patients and it reveals the fragility of peritoneal dialysis in new ways. This is because it is at this point that the patients learn what it means to be made responsible for their own care via the outsourcing CAPD involves.

The peritoneal catheter, in all this, is at the same time a source of stability and instability. On one side, it makes it possible for patients to replace some of the functions the kidneys no longer perform, that is, to filtrate blood and remove waste products from the body. But on the other side, it is a site of concern and instability, for it is the main entrance point for potentially fatal infections as well as other life-

threatening complications. Before conducting this therapy at home, patients and families are introduced to peritonitis – a drawback of the therapy itself – although it is presented as something the patients themselves are responsible for. The other serious complications inherent to the treatment itself are not explained to the patients but are left for them to discover and experience in the course of their trajectories. Nor is on-site support provided to them once they have established the therapy at home. The iatrogenic gamble that is built into CAPD is not something patients and families are initially fully aware of although its unstable character emerges as treatment goes on.

7.1.3 Patients, families and the biosocial community

Families are important in helping patients deal with CKD from the onset of symptoms. Parents, children, siblings and other relatives are engaged in different ways and moments throughout the trajectory of patients, accompanying them, caring for them, connecting with other patients and families, and so on. Family members feature at the centre of supplicatory practices – they are the ones who plead with health professionals and who are assessed by social workers. It is also family members who typically first establish contact with relatives of other patients and, albeit incrementally, start to engage in what I have called the biosocial community of renal patients. The interaction between relatives of different patients in hospital settings allows information to flow and, eventually, families realise the importance of the *asociaciones civiles* that support renal patients in different ways. With all the challenges they face, they soon come to see that this biosocial community will be crucial for patients' survival (Sharp, 1999). They have little choice but to engage and those who cannot, encounter problems. Because of this, renal biosociality has become a major informal – but often acknowledged – support for Hospital Alcalde, and, thus, the wider healthcare system.

Engagement has its own demands and its own costs. Patients and their families learn that they have to approach such asociaciones civiles with the same deference they approach the hospital's staff. Supplication is ubiquitous, required wherever they, the uninsured poor, look for support.

Within this context, it is the convergence of a myriad of actors, and not only the hospital or the healthcare system, that enables the uninsured to keep the therapy going. Insured and uninsured patients, family members, asociaciones civiles, social assistance institutions and other healthcare professionals contribute to this renal biosociality (Gibbon & Novas, 2007; Rabinow, 1996) through informal (often off-the-books) interactions and networks of ongoing exchanges. In light of this informal economy, the marginal status of RRT for the uninsured within the Mexican healthcare system could be thought of as having triggered what at first sight looks like charitable action, where members of the biosocial community help uninsured patients access much-needed treatments. But, seen in another way, these actions are also collective ways of outsourcing care for and by the uninsured. This outsourcing work is marginal in the sense that the informal economy very much operates on the fringes of the primary institutions of the healthcare system. However, at the same time the informal economy and its exchanges are a consequence of and a form of half-hidden, tolerated but not an endorsed response to the failures of the State in providing care for those who need it most. Understanding the marginal character of the informal economy, in other words, means simultaneously understanding the failures at the very centre of the system which give rise to it.

7.1.4 *An informal economy that not always delivers*

The informal economy and the exchanges it revolves around operate according to a *quid pro quo* logic, in which the receiver is expected to give or do something in return for the support – usually medicines and dialysis supplies but also prescriptions, documents, equipment and more – given by members of the wider renal community. The goods that circulate among them and the services of various kinds provided by members of this community are not given for free. Between patients, exchanges are usually undertaken in response to gifts received in the past under the expectation that the receiver on one occasion will do the same when they can with other patients in need, so perpetuating the chain of exchanges (Mauss, 1970). Between patients and other actors including asociaciones, health professionals and social assistance institutions, the *quid pro quo* requires the patients to demonstrate they are in need, to display the appropriate deference by complying, often through volunteering, with what they are required to do – they have to demonstrate that they matter as patients. It is through the constant enactment of these gift-giving and supplicatory practices that renal replacement therapies for the uninsured, CAPD in particular, are sustained to the degree that they are in the context of Mexico.

Although it already operates at the margins, this biosociality with its informal economy also has *its* margins and countless patients, who for many reasons cannot adequately engage with others, are left outside these networks of exchanges. These patients, often elderly, poor and living in rural communities, face the disease and therapy with the minimum social and governmental support. They constitute a suffering humanity unable to meet the entrance price for care or show to asociaciones civiles and others that they also matter as patients. In the end, all uninsured renal patients seem not to matter much to the State.

7.1.5 Stagnant trajectories

In the literature on the experience of CKD patients, a particular trajectory is often assumed, one that starts with diagnosis, followed by dialysis and then transplantation. Another assumption of these studies is that all dialysis patients pursue a transplant, or that all can access one. Heinemann (2014), for example, treats haemodialysis and peritoneal dialysis as part of ‘transplant technology’. The picture assumed here is that these therapies are merely preliminaries to a transplant and that they do not operate as stand-alone treatments for renal patients. According to much of the social science literature, the trajectory invariably ends in transplantation, no matter that a transplanted person is still a patient (Crowley-Matoka, 2005, 2016; Crowley-Matoka & Lock, 2006; Heinemann, 2014; Sharp, 2006). This might be true for countries in Europe or for North America, although even in these places there are reasons to question these assumptions (Kierans, 2005, 2011). In the context of Mexico, however, the situation is completely different. Although dialysis technologies are, mostly, a precedent to transplantation, because the two technologies work in tandem, in Guadalajara patients have to gain their access to transplantation, they have to demonstrate that they matter in still more ways and deserve access to a form of treatment that only a few will receive.

In Chapter 3 I showed how patients began their trajectories as CKD patients, not by consciously opting into treatments but by doing as they were directed. In terms of the end points of those trajectories, at least for the uninsured, transplantation is beyond most and can only be reached if they have been able to invest considerable resources to build a wide network of support, including friends and relatives, other patients, asociaciones civiles and health professionals. Only a handful of the patients I met were able to get a transplant and so conformed to the idealised version of the CKD

trajectory. For the majority, their trajectories started and ended with peritoneal dialysis. Nor was being transferred to haemodialysis a success. Instead it meant that CAPD had failed and the patient's life was at risk. In the context of Mexico, dialysis technologies, and particularly CAPD, are the only treatment options the majority of patients will ever have access to and they will spend the rest of their shortened lives on this therapy. Living life at the margins of the healthcare system on peritoneal dialysis is to live a marginalised life, to be marginalised.

Patients are not alone and work is performed by others all along their illness trajectories. These trajectories imply transformations, not only changes in the self (Curtin et al., 2002; Giles, 2004), but important transformations of their socio-material conditions – the home, their bodies, their relationships, and so on. These are the socio-material conditions within which disease and therapy are experienced and practised in Mexico, conditions under which much is asked of patients and those around them and little care and concern is ultimately given in return.

7.1.6 CAPD domesticated

As the above suggests, the adoption of CAPD as the primary therapy for CKD patients, insured and uninsured, has involved its adaptation or domestication, in Appadurai's (1990) terms, to fit the Mexican context. For hospitals for the uninsured, like Hospital Alcalde, the result was the establishment of a process of admission in which patients are trialled and trained to perform CAPD in the home. But it has also resulted in the formation of a biosocial community, organised around an informal economy, although this community operates at the fringes of formal care and its contributions are not fully recognised.

In the home context, CAPD is also domesticated in creative ways, although sometimes such domestication fails and puts the patient at risk of infections. Without proper support, patients and families set up dialysis rooms in various ways, not always complying with the strict specifications outlined by the hospital. Dialysis-exclusive rooms, as required by the hospital, usually represent a challenge for patients and families because their residential situation means they are often not able to accommodate a para-clinical space. Setting up a dialysis-bedroom is, in many cases, the only feasible and sustainable way of accommodating CAPD in the home for uninsured poor patients and, even then, the process typically involves difficult rearrangements of family life. Setting up the dialysis room – exclusive or bedroom – marks the initiation of a process through which CAPD is adapted to home life, just as the patient's body and practices were previously adapted to and for it. This unfolds over time and is an open-ended process.

It is in the home context, and by putting into practice what was drilled in the hospital, that patients come to embody the techniques required to perform CAPD. Once these techniques become second nature, the dialysis room is brought into life as a para-clinical space. At first, patients follow the instructed actions they were drilled in during training but eventually they adapt their body techniques and relax the instructions to make them fit with their everyday lives and domestic routines. CAPD is repetitive, boring and restrictive and patients do their best to make it work for them. But CAPD is not confined to the dialysis room, it overflows to other parts of the house, transforming further aspects of the domestic context into an extension of the hospital. CAPD and the home, therefore, transform each other through the – sometimes risky – practices of patients.

Patients and their families have to adjust their lives to the timetable of dialysate changes and other exigencies of CAPD. Patients, particularly, have to adjust to the limits it places on lifestyles and social interaction. But it seems that for uninsured patients it gives little in return. Without proper support, patients are fettered to this therapy for the rest of their lives, and it doesn't extend their lives considerably. Heinemann (2015) has said that the return of home care is a symptom of 'neoliberal intromission' in healthcare more generally – the tendency of State to hand over care responsibilities to families as a form to reduce costs. Although I have mentioned that CAPD developed even before the rise of neoliberalism, we see that this therapy has affinities with wider trends in healthcare under the neoliberal agenda. This is particularly true when it comes to the responsabilisation of patients, the process of making them responsible for their own health and for their own care in the case of CAPD. And within this context, as I showed in the previous chapters, patients are not only made responsible for their treatment, but for its failure as well. Peritonitis and all other complications related to CAPD and CKD are treated as the fault of the patients. They are frequently blamed for the problems that arise from it and, eventually, for their own deaths. In this regard, the State and the health system, by doing little to support patients in their communities and their homes, is maximising the potential harm of CAPD for those patients it was meant to help.

7.2 Renata's wisdom

The first time I interviewed Renata, from Mezcala, she was struggling with peritonitis and other cardiovascular complications as well as with securing a regular supply of dialysate solution and erythropoietin. From the moment Renata fell ill her family had been under terrible economic strain. They had to sell some of the few appliances they

had in order to raise the money they need to pay her medical bills and buy the medicines she needed. Eventually, the family was left with a bare minimum to survive, living in deep poverty.

During that first interview, she told me something that I think summarised the experience of many uninsured patients who, like her family, suffered considerable hardships due to CKD and its treatments in Mexico: 'I tell my children that this disease doesn't let you die soon, it just wears you down and strips you off of everything you have before killing you'. Renata died on May 2013.

Chapter 8

Conclusion

This study sought to understand the complexities of CKD and peritoneal dialysis in contemporary Mexico by documenting the practices and experiences of poor and uninsured patients and their families living with CKD and using CAPD in the home, tracing them throughout multiple contexts in the process. In the course of the previous chapters I have provided a contextualised and nuanced description and analysis of how peritoneal dialysis is practised and the challenges uninsured patients face from diagnosis to treatment within the Mexican context. In doing so, I have contributed to the initial work carried out in Mexico by Crowley-Matoka (2005, 2016), Kierans (2013, 2015) and Mercado et al. (2014, 2015), but also to wider scholarship on CKD and its therapies, particularly those drawing on similar perspectives and methodologies. My study has, in particular, shown how the social, cultural, political and economic are interwoven in CAPD.

My aim was never simply to study CKD and CAPD for its own sake. Rather, a study of this condition and this particular therapy provided a way to explore the contradictions and failures of the Mexican healthcare system. Other scholars have already underscored the problematic character of the Mexican healthcare system, but from a structural perspective that, although important in its own right, tells us very little about how that system, and the society it operates within, work in practice or how it confronts the people it is supposed to serve. The ethnographic perspective adopted in this study allowed me to provide a richer account of the unequal, hierarchical, and

historically rooted social relationships that underpin interactions between patients and their families and the health professionals who represent and control access to the health system for those with CKD. Equally important, this perspective helped me to show the multiple trials and tragedies that a fragmented healthcare system continually inflicts on uninsured patients and their families.

The study has also hopefully demonstrated that the last wave of reforms to the Mexican healthcare system, reforms which led to the creations of the SSPH and Seguro Popular, have had important biopolitical consequences for Mexico's most vulnerable populations. By providing coverage only for a limited number of diseases, medicines and therapeutic interventions within the parameters of the scheme, Seguro Popular is an acknowledgement that, for the State, some people with particular biological constitutions matter more than others. Although enrolled in Seguro Popular, among those whose bodies and lives matter the least, are the uninsured renal patients. These patients and their families are made painfully aware of their marginal status once they begin to confront life with CKD.

The ethnographic perspective adopted in this study was crucial to drawing this out. By starting with patients and then showing how their stories require us, methodologically, to move outwards to much wider sets of concerns, it was possible to capture the fragmentation of the healthcare system and its biopolitical consequences from the point of view of those who do not matter to the State. In this, the patients themselves were critical guides to the issues involved. The specific problems posed by CKD and CAPD in the Mexican context are not easy to grasp unless approached in this way.

This ties back to a point I have returned to throughout the thesis: if we want to better understand what makes CKD and RRT, peritoneal dialysis in particular, problematic

in practice, we need to go out and look to find out what shapes those problems in their sites. This means studying people in their concrete social, political, cultural and economic situations and the activities that they engage in within and as part of them. Once this is done it becomes clear that, in many respects, uninsured CAPD patients are situated at the margins of social welfare as a result of being made directly responsible for their treatment's successes and failures, a situation in which substantial long-term financial and social costs are incurred by those who desperately need this therapy, with new burdens thereby continually added to the problems they already face.

As I was shown in the course of fieldwork, dealing with CKD in a situation of this kind requires work that goes far beyond complying and adhering to the treatment. Patient, family and community work starts when the symptoms first appear, and then continuously evolves throughout the illness trajectory. What makes CKD and CAPD a special case is the kind of transformations the patient and the family have to go through. New body techniques are important, but more important is the nexus which those techniques are subordinated to, one that has to be created between body, therapy and clinic, where the catheter works as an interface with the health system.

However, patients and their families come together with others too in dealing with CKD and CAPD and it is important not to overlook the responses and strategies that have been adopted by multiple actors to support and allow uninsured patients to continue in treatment. Nonetheless, although collective responses have emerged through this local biosocial community and its informal economy to support some (but by no means all patients), these support and exchange practices, while an important lifeline for many, are another consequence of the problematic healthcare and social

contexts within which CKD and CAPD are embedded. As renal biosociality and its informal economy are relatively new phenomena, it would, again, be difficult to study except ethnographically. More importantly, unless properly situated, it would be easy to miss the point that people's engagement in these practices is predicated on the understanding that support will come from no other source.

Finally, and to return to themes first broached in the literature review, although this is a social science study, that does not mean that it has sought to downplay clinical-medical matters or treat them as somehow secondary or of only background importance. As shown in the previous chapters, the bio-physiological manifestations of the disease and its medical interventions are critical for understanding the experiential, the practical, and also the structural in CKD and CAPD. As quickly becomes clear when these issues are investigated ethnographically, the researcher does not encounter the bio-physiological and the medical, on the one side, and institutional, social, and political contexts, on the other. Instead, these are encountered together.

As a consequence, understanding how biomedical and epidemiological researchers have sought to frame that problem and open up it up for practical interventions of many kinds over time is important, providing crucial insights into the profile of the disease and its treatments in Mexico. Nonetheless, we cannot stop there. Here lies one of the main contributions of this study. By adopting an ethnographic perspective, following those who suffer from CKD and are responsible for their own care with CAPD, it has been possible to show that while CKD and CAPD are indeed medical problems they are not just medical issues – as they are not just social, cultural, political, economic, historic or affective either, but all and more at once.

By following the patients and their family carers through different sites of care and negotiation, this study has demonstrated that the bio-physiological, structural, experiential, and practical dimensions of CKD and CAPD are not discrete, separable phenomena, but problems that are intimately interwoven and mutually shaped. As shown in the previous chapters, CAPD as the mainstay therapy for treating CKD in the Mexican context, is a 'half-way technology', a treatment that cannot cure the disease, but can only lessen its effects temporarily. In the context of Mexico, this constitutes a problem because medical care for the uninsured poor is not a right but conditional on forms of institutional and interpersonal benevolence/supplication. Moreover, as the experiences of those who participated in this study have shown, CAPD constitutes an iatrogenic gamble. But we cannot understand any of this unless we go out and look. The ethnographic perspective, therefore, proves to be a potent way of grasping the complexities of CKD and CAPD, rather than trying to reduce them to one of their several aspects at the expense of an understanding of the others. Only in this way is it possible to bring to the fore the multi-stranded character of the tragedy of CKD and CAPD in contemporary Mexico.

Appendices

Appendix 1. List of topics covered during the interviews

Patients and family members

Narrative interviews with patients and family members started with the following question:

- Could you tell me about your experience as a CKD patient? Please begin at any point you wish.

If they needed prompting, I asked specific questions such as:

- Please, could you tell me how your illness began?
- When did you start to feel ill?
- How did you realise that you needed to see a doctor?
- What happened next?

Further interviews, either narrative, semi-structured or informal, focused on the following topics:

- a) The trajectory of the condition and all associated treatments.
- b) Medical follow-up and tasks requested by the medical services (assignments).
- c) Strategies to obtain support/find ways of paying for treatment.
- d) Problems faced throughout his/her trajectory as renal patient and as a family.
- e) Patients' and families' perspectives on the condition, treatment and aetiology.
- f) Everyday life and routines on CAPD.
- g) Ways of accommodating CAPD in the home.
- h) Ways of engagement with other patients and or asociaciones civiles.
- i) Family history and general information (number of members, employment, income).

Asociaciones civiles's staff

Semi-structured interviews with asociaciones civiles's staff covered the following topics:

- a) The history of the asociación civil.
- b) Their aims as asociación civil.
- c) Forms of support offered to uninsured patients.
- d) Forms in which patients are asked to reciprocate (what is asked in return?).

- e) How the asociación obtains its funding, medicines, and dialysis supplies donations.
- f) How patients and family members collaborate/volunteer with the asociación.
- g) The challenges faced as an asociación civil that supports uninsured patients.
- h) Collaboration with public hospitals, other asociaciones civiles, and governmental institutions.
- i) General views about CKD in Mexico and in Lake Chapala in particular.

Health professionals

Semi-structured interviews with health professionals based at community primary health clinics covered the following topics:

- a) Perspectives on the alleged high incidence of CKD in the community/region.
- b) Medical services and support available for uninsured renal patients on any type of renal replacement therapy at the primary health clinics.
- c) Medical services available for the general population of the community.
- d) Guidelines or procedures to detect CKD.
- e) Referral procedures and their relation to higher level medical services or hospitals.

Semi-structured interviews with health professionals based at public hospitals covered the following topics:

- a) Organisation of medical services available for renal patients.
- b) Admission procedures for new/recently diagnosed patients with CKD.
- c) Forms of support available for uninsured renal patients (medical and financial, formal and informal).
- d) Admission procedure to the CAPD programme.
- e) CAPD follow-up procedures.
- f) Collaboration with asociaciones civiles.
- g) General views about CKD in Mexico and in Lake Chapala in particular.

Community members

Semi-structured and informal interviews with community members covered the following topics:

- a) What everyday life is like in the community.
- b) What most people do for a living in the community.
- c) Whether a community member knows renal patients from their community.
- d) Perspectives on the alleged high incidence of CKD in the community/region.

Appendix 2. Sample of Participant invitation letter: patients and families



Chronic Kidney Disease and its controversies: local knowledge in Lake Chapala, Mexico¹³³

Dear

This research study is being conducted by Cesar Padilla-Altamira, who is a PhD student in the Department of Public Health and Policy, The University of Liverpool. The aim of the study is to explore the experiences of patients and families from Lake Chapala who lack social insurance, suffer from chronic kidney disease and are undergoing continuous peritoneal ambulatory dialysis at home.

We would like to invite you to take part in this study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please find enclosed an information sheet which explains what the study is about in more detail, and what your role in the research will be if you choose to take part. Please take the time to read through this carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. Please also feel free to discuss this with your friends, relatives and doctor if you wish. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Kind Regards,

Cesar Padilla-Altamira, PhD Student

¹³³ This was the title of the project when it was submitted to ethical approval at the beginning of the PhD programme. However, when I finished fieldwork and started to analyse the data, I decided to change the title to better reflect the problem.

Appendix 3. Sample of Participant invitation letter: health professionals



Chronic Kidney Disease and its controversies: local knowledge in Lake Chapala, Mexico

Dear

This research study is being conducted by Cesar Padilla-Altamira, who is a PhD student in the Department of Public Health and Policy, The University of Liverpool. The aim of the study is to explore the experiences of patients and families from Lake Chapala who lack social insurance, suffer from chronic kidney disease and are undergoing continuous peritoneal ambulatory dialysis at home.

We would like to invite you to take part in this study. Before you decide whether to participate, it is important for you to understand why the research is being done and what it will involve. Please find enclosed an information sheet which explains what the study is about in more detail, and what your role in the research will be if you choose to take part. Please take the time to read through this carefully and feel free to ask us if you would like more information or if there is anything that you do not understand. We would like to stress that you do not have to accept this invitation and should only agree to take part if you want to.

Kind Regards,

Cesar Padilla-Altamira, PhD Student

Appendix 4. Sample of Participant information sheet: patients and families



Chronic Kidney Disease and its controversies: local knowledge in Lake Chapala, Mexico

Participant information sheet

Who is doing the research?

Cesar Padilla-Altamira (PhD student) Department of Public Health and Policy, at the University of Liverpool, UK.

Dr Ciara Kierans (PhD Supervisor) Department of Public Health and Policy, at the University of Liverpool, UK.

What is the purpose of the study?

The purpose of this study is to explore the experiences of people living with Chronic Kidney Disease (CKD) and using peritoneal dialysis in the home. We are interested in understanding its impact on the lives of patients and their families.

Why have I been chosen to take part?

You have been asked to take part in this study because you or your family member is a renal patient using dialysis at home (Continuous Ambulatory Peritoneal Dialysis). Your experiences are therefore very important to us.

Do I have to take part?

It is completely up to you. If you do decide you would like to participate, you will be asked to sign a consent form when you first meet the researcher. If you decide later on that you no longer wish to take part then you can leave the study at any time and do not have to give a reason. Your decision to participate or not to participate will not compromise your treatment in any way.

What will happen if I take part?

This research study will be asking for your involvement in two ways, depending upon what you feel comfortable with:

- (1) In-depth interviews: You will be asked to take part in at least one interview and potentially a follow-up interview. You can choose to be interviewed on your own, or with your family/a friend present. The interviews will involve you talking about your experiences of being a renal patient or having a family member with this condition. These interviews will last for approximately one hour or longer if you wish. With your permission, these interviews will be audio-recorded and then transcribed.
- (2) Fieldwork and informal interviews: If you agree to it, the researcher may also spend some time with you to chat informally about your experiences and your life in general. From this he will take field notes.

Where will the research take place?

The research will be carried out at a time and place of your choice. You may like this to be your home or a public setting (e.g. a cafe). It is up to you to decide.

Are there any disadvantages or risks in taking part?

We do not expect there to be any risks associated with participating in this research study. However, we realise that the topic is very sensitive, so if you feel uncomfortable or distressed at any time then you can stop the interview. You can also leave the study without having to give a reason. I can also provide the numbers for renal support organisations to aid in obtaining further support.

Are there any benefits in taking part?

You will be helping with a new area of research. Your experiences will help us to better understand how chronic kidney disease and peritoneal dialysis affect the lives of patients and their families.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the researcher, **Cesar Padilla-Altamira on +52 3336 1742 12 (in Mexico), +44 0151 794 5418 (in the UK) or by email cesarpa@liverpool.ac.uk, or his supervisor Dr Ciara Kierans on +44 0151 794 5594 (in the UK) or by email ciarak@liverpool.ac.uk** and they will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the **Research Governance Officer, Sarah Fletcher, at the University of Liverpool on 0151 794 8290 or by email ethics@liv.ac.uk**. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

Will my participation be kept confidential?

All the information that you give us will be kept strictly confidential. The procedures for handling, processing, storing and destroying the data will comply with the Data Protection Act of 1998 of the UK.

This means that only the researcher and his supervisor will see what you have said. All the information which you provide us with during the study will be stored in locked filing cabinets or password protected computers. Anything about you, including any quotes which are used in the write-up of the study, will have your name removed and a different one put in place, so that you will remain anonymous. At the end of the study the research data (consent forms, anonymised interview transcripts, field notes, and your contact details) will be kept in locked filing cabinets and/or password protected university computers. The data will be kept for ten years, and then will be destroyed.

What will happen with the results of the study?

After the study has finished, the results will be put together as part of the researcher's PhD dissertation. The research will be stored at The University of Liverpool. The research will also be published in academic journals and presented at conferences.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this. You can also ask for your data to be

destroyed if you decide to stop being in the study. Withdrawing from participating in the study will not affect in receiving your treatment in any way.

Who can I contact if I have further questions?

Just get in touch with the researcher, Cesar Padilla-Altamira: in

Tel. In Mexico: +52 3336174212, +52 10585200 (ext 33765); In the UK: +44 01517955418

Email: cesarpa@liverpool.ac.uk

Or his Supervisor, Dr Ciara Kierans in

Tel: +44 0151 794 5594 (in the UK)

Email: ciarak@liverpool.ac.uk

Appendix 5. Sample of Participant information sheet: health professionals



Chronic Kidney Disease and its controversies: local knowledge in Lake Chapala, Mexico

Participant information sheet

Who is doing the research?

Cesar Padilla-Altamira (PhD student) Department of Public Health and Policy, at the University of Liverpool, UK.

Dr Ciara Kierans (PhD Supervisor) Department of Public Health and Policy, at the University of Liverpool, UK.

What is the purpose of the study?

The purpose of this study is to explore the experiences of people living with Chronic Kidney Disease (CKD) and using peritoneal dialysis in the home. We are interested in understanding its impact on the lives of patients and their families.

Why have I been chosen to take part?

You have been asked to take part in this study because you have particular expertise in understanding this condition and/or an interest in it. Your opinion is therefore very important to us.

Do I have to take part?

It is completely up to you. If you do decide you would like to participate, you will be asked to sign a consent form when you first meet the researcher. If you decide later on that you no longer wish to take part then you can leave the study at any time and do not have to give a reason.

What will happen if I take part?

If you do decide you would like to take part, we would like to interview you. The interview will involve you talking about your experience of providing care for renal patients. The interview may take up to one hour. With your permission, the interview will be audio-recorded and then transcribed.

Where will the research take place?

The research will be carried out at a time and place of your choice. You may like this to be your office or a public setting (e.g. a cafe). It is up to you to decide.

Are there any disadvantages or risks in taking part?

We do not expect there to be any risks associated with participating in this research study. However, you can leave the study without having to give a reason.

Are there any benefits in taking part?

You will be helping with a new area of research. Your experiences will help us to better understand how chronic kidney disease and peritoneal dialysis affect the lives of patients and their families.

What if I am unhappy or if there is a problem?

If you are unhappy, or if there is a problem, please feel free to let us know by contacting the researcher, **Cesar Padilla-Altamira on +52 3336 1742 12 (in Mexico), +44 0151 794 5418 (in the UK) or by email cesarpa@liverpool.ac.uk, or his supervisor Dr Ciara Kierans on +44 0151 794 5594 (in the UK) or by email ciarak@liverpool.ac.uk** and they will try to help. If you remain unhappy or have a complaint which you feel you cannot come to us with then you should contact the **Research Governance Officer, Sarah Fletcher, at the University of Liverpool on 0151 794 8290 or by email ethics@liv.ac.uk**. When contacting the Research Governance Officer, please provide details of the name or description of the study (so that it can be identified), the researcher(s) involved, and the details of the complaint you wish to make.

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What will happen with the results of the study?

After the study has finished, the results will be put together as part of the researcher's PhD dissertation. The research will be stored at The University of Liverpool. The research will also be published in academic journals and presented at conferences.

What will happen if I want to stop taking part?

If you decide at any point that you no longer wish to be part of the study, then you can stop and do not have to give a reason for this. You can also ask for your data to be destroyed if you decide to stop being in the study.

Who can I contact if I have further questions?

Just get in touch with the researcher, Cesar Padilla-Altamira: in

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Appendix 6. Sample of Consent form



Chronic kidney disease and its controversies: local knowledge in Lake Chapala,
Mexico

CONSENT FORM

**Please initial
box**

1. I confirm that I have read and have understood the information sheet dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected.
3. I understand that quotes from what I say during the study may be used where necessary, on the condition that my identity will remain anonymous.
4. I agree to being audio-recorded during the study interviews, on the condition that my identity will remain anonymous.
5. I understand that, under the Data Protection Act 1998 of the UK, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish.
6. I agree to the research data being stored. I understand that the anonymised data (interview transcripts and notes) may be shared with other researchers in the future.
7. I agree to the researcher taking my contact details (name, telephone number etc.) and contacting me during the study to arrange interview times.

☐☐☐☐☐☐☐

1. I agree to take part in the above study.

☐

_____ Name of Participant	_____ Date	_____ Signature
Cesar Padilla-Altamira _____ Name of Researcher	_____ Date	_____ Signature

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