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Tinkered care: Assembling Medicine Consumption in Grey Zones

Liu, Rui

2023

Total number of authors:
1

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RUI LIU

DEPARTMENT OF SERVICE STUDIES | FACULTY OF SOCIAL SCIENCES | LUND UNIVERSITY
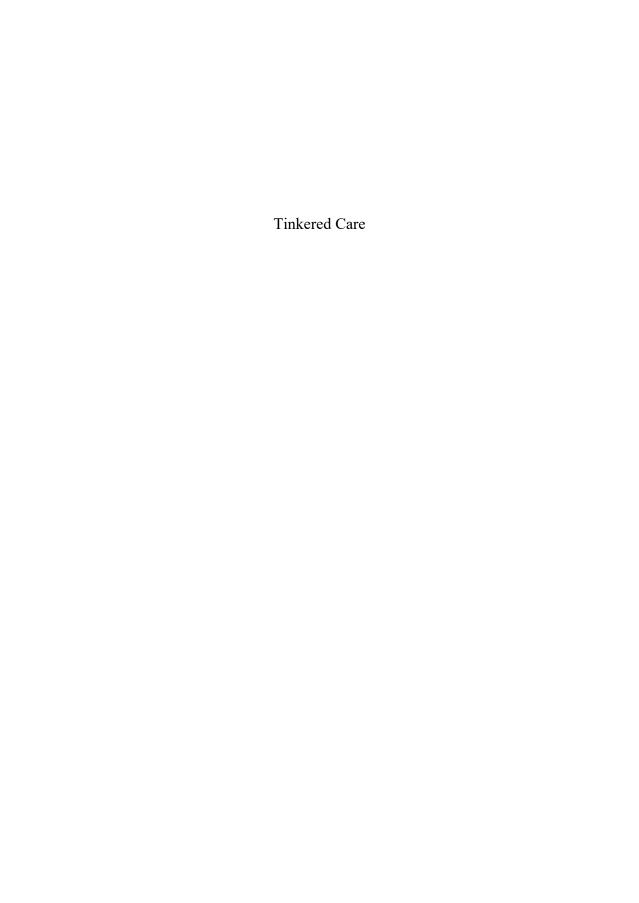
Tinkered Care

The aim of this dissertation is to advance knowledge about care as situated practices within and beyond medical institutional settings. It addresses the phenomenon of substandard and falsified medical products, an issue that concerns state governments globally and organisations including the World Health Organization. While legal sanctions and technological innovation are strongly advocated to protect legal pharmaceutical markets, this study looks at ambivalences and ambiguities in the provision and experiences of health services.

By drawing on the concepts of assembling and tinkering, and using empirical data collected from care seekers, physicians and pharmacy staff, the analysis suggests that the individual agency of care seekers is enacted and enabled in a context where an ability to adapt to a changing environment increasingly becomes a social norm. Medical professionals are well aware of people's evolving medicine consumption, but find it challenging to respond to these changes. Furthermore, observations conducted at pharmacies suggest that, in this semi-institutional and semi-retail setting, medical authority is carefully managed through embodied and routinised engagement with store environments and by attuning to customers' emotions. All these findings lead to a conceptualisation of care as a tinkered practice, with attentiveness and flexibility being two essential characteristics. However, tinkered care involves risks, especially in relation to medicine access and use.

Tinkered care: Assembling medicine consumption in grey zones provides an empirical account of health services as a multi-actor network. It adds knowledge to the spatial-temporal dimension of care practices and offers a conceptualisation of care as tinkered practices. It argues for a need for alternative understandings of care and health services other than institutionally scripted ones.

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UNIVERSITY

Organization	Document name
LUND UNIVERSITY	DOCTORAL DISSERTATION
Department of Service Studies	**Date of issue** 2023-02-28
Author: Rui Liu	Sponsoring organization

Title and subtitle: Tinkered Care – Assembling medicine consumption in grey zones

Abstract

The aim of this dissertation is to advance knowledge about care as situated practices within and beyond medical institutional settings. I use grey zones as a lens through which to study how medical professionals and care seekers negotiate different perceptions and care practices in relation to medicine access. The investigation is grounded in the Swedish context, where healthcare is informed by patient choice and there is considerable emphasis on individual responsibility. Simultaneously, service logic infiltrates the health sector and reframes relationships between medical professionals and care seekers. These circumstances affect care-seeking and challenge the authoritative role of medical professionals.

This dissertation addresses the phenomenon of substandard and falsified medical products, an issue that concerns state governments globally and organisations including the World Health Organization. There are diverse opinions among stakeholders and academia on how to define a medical product that is not manufactured or distributed according to legal standards, hence complicating policy responses and health interventions to tackle this issue. While legal sanctions and technological innovation are strongly advocated to protect legal pharmaceutical markets, this study looks at ambivalences and ambiguities in the provision and experiences of health services.

I collected empirical data from care seekers, physicians and pharmacy staff. My analysis suggests that the individual agency of care seekers is enacted and enabled in a context where an ability to adapt to a changing environment increasingly becomes a social norm. Medical professionals are well aware of people's evolving medicine consumption, but find it challenging to respond to these changes. Furthermore, observations conducted at pharmacies suggest that, in this semi-institutional and semi-retail setting, medical authority is carefully managed through embodied and routinised engagement with store environments and by attuning to customers' emotions. All these findings lead to a conceptualisation of care as a tinkered practice, with attentiveness and flexibility being two essential characteristics. However, tinkered care involves risks, especially in relation to medicine access and use.

This dissertation provides an empirical account of health services as a multi-actor network. It adds knowledge to the spatial-temporal dimension of care practices and offers a conceptualisation of care as tinkered practices. I therefore argue for alternative understandings of care and health services other than institutionally scripted ones.

Key words
Care practices, medicine consumption, tinkering, grey zones, health services, medical professionals, substandard and falsified medical products, Sweden

Classification system and/or index terms (if any)

Supplementary bibliographical information	**Language:** English

ISSN and key title	**ISBN** 978-91-8039-548-9 (electronic) 978-91-8039-549-6 (printed)

Recipient's notes	**Number of pages** 188	Price
	Security classification	

Tinkered Care

Assembling Medicine Consumption in Grey Zones

Rui Liu

LUND UNIVERSITY

To my family

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Acknowledgements

Throughout the years of doing a PhD, I am grateful for being surrounded by supportive and encouraging colleagues, friends and family.

My thanks first go to my brilliant supervisors. Thank you, Cecilia Fredriksson, for keeping me on track and staying in focus. Thank you, Henrik Loodin, for introducing me into fascinating sociological theories. And thank you, Susanne Lundin, for generously sharing your insights, networks, and, during the last stage of writing up this dissertation, your office. An idea will not spark without challenges or critiques, neither will it turn concrete or real without encouragement or nourishment. I appreciate, sincerely, the patience, sharpness and kindness all three of you provided for me.

Next, I thank Christian Fuentes, Erika Andersson Cederholm, Rachel Irwin, Kristofer Hansson and Johan Alvehus for carefully reading my manuscripts at various stages and providing valuable feedback. My gratitude also extends to Gabi Louisedotter for helping with survey layout and distribution, and to Karin Salomonsson and Carina Sjöholm for showing interest in my work. Eerika Saaristo, Annette Svingstedt, Malin Zillinger and, especially, Elin Bommenel, if I can claim having developed any pedagogical skills, this is because of you. Veronica Åberg, Matilda Yourstone, Carina Carlsson, Linda Lavin, Annika Persson, Gunilla Steen and Christel Anderberg, thank you for sorting out practicalities for me.

Over the years, I am fortunate to be part of several research groups. I have learned so much more than I can give back to the research teams. Olof Sundin, Cecilia Andersson, Cecilia Lenander, Amelie Persson, Emma Eleonorasdotter and Kristofer Söderström, thank you for showing me the best side of working across disciplines. Particularly, my gratitude is given to Margareta Troein, Talieh Mirsalehi and Anja Smith. Thank you for your dear friendship and professionalism. I look forward to collaborating with you again.

The lively PhD communities mean a lot to me. Your companionship will always be memorable. Thank you, Emma Samsioe, Malin Andersson, Josefine Östrup Backe, Devrim Umut Aslan, Stuart Reid, Ida Wingren, Carin Rehncrona, Micol Mieli, Anna Spitzkat, Aurimas Pumputis, Marthe Nehl, Annabell Merkel, Réka Ines Tölg, Marcus Persson and Joel Nilsson. I also thank Zhao Hui, for being an attentive friend and colleague next door. Furthermore, a big thank you to the PhD collective at the Department of Arts and Cultural Sciences. The not-so-structured yet super

committed writing Wednesday at Lux is definitely a weekly highlight, not to mention the International PhD Food & Drink Party. Extra thanks go to David Bowling and Alma Aspeborg for organising those events and making them so inclusive.

It is hard to pinpoint an exact moment of when I decided to go for an academic training, but I am quite certain that the Master programme of Applied Cultural Analysis played a key role. I started to see the strangeness of the familiar, thanks to a team of wonderful teachers including Tom O'Dell, Håkan Jönsson, Markus Idvall, Robert Willim and Jessica Enevold. Special thanks are given to Charlotte Hagström. Lotta, thank you for guiding me through my master thesis. There were some moments that I thought to myself, perhaps doing research was something I could do.

Lastly, this dissertation will not be possible without the love of my family. I am indebted to my parents for teaching me the value of knowledge. Mom, you raised me up to be independent and tenacious. Dad, it is a pity that you did not get to see this dissertation, but it has always been my goal of making you proud wherever you are. Settling down in a new environment is not always easy. Today I call Sweden home; this owes much to Winnie Hew, Alex Hew and the rest of the Hew family and the Hansson family.

Two creatures, Edvin and William, joined me just in time for this journey, one at the beginning and one towards the end. You have brought me sleepless nights and restless days. But I love you, my children, for refreshing my eyes to a world of wonders, for teaching me to be patient and living in the moment. Last but not least, Jun Khan, you keep the kids from disturbing me when I am in the writing bubble; you remind me that there is more in life than simply research; and, most importantly, you accept me as I am. Thank you.

Helsingborg, 2 February 2023

List of papers

Paper 1   Liu R and Lundin S. Substandard and falsified medical products as infrastructural objects: Synthesizing illegality in extra-legal domains (Manuscript unpublished)

Paper 2   Liu R and Lundin S (2020). Medicines in the grey markets: A sociocultural analysis of individual agency. In: Hansson K and Irwin R (eds) *Movement of knowledge: Introducing a medical humanities perspective on medicine, science and experience*. Kriterium. https://doi.org/10.21525/kriterium.24.j

Paper 3   Liu R, Lundin S, Mirsalehi T and Troien M (2022). "I'm not a jukebox where you push a button and then I sing": Negotiating medicine access in physician-patient encounters. *Ethnologia Europaea*, 51(2). https://doi.org/10.16995/ee.9055

Paper 4   Liu R (2022). Care in the air? Atmospheres of care in Swedish pharmacies. *Journal of Material Culture*. https://doi.org/10.1177/13591835221133289

Introduction

In 1949, an evocative British film – The Third Man – was released. It told a pharmaceutical story about illegal trading in penicillin. Being a scarce and valuable medicine in post-war Europe, penicillin was stolen from a military hospital, diluted and then sold on the black market. It caused the death and hospitalisation of many children. This fictional plot was believed to be inspired by the actual circulation of fake penicillin after World War II (Newton and Timmermann, 2016). Such tragedies continue to occur in contemporary times. Each year, the World Health Organization (WHO) issues multiple alerts warning against substandard medical products, based on reported incidents from countries around the world.[1]

To address the spread of poor-quality medicines, the WHO proposed a working definition of substandard and falsified (SF) medical products in 2017, following more than two decades of debate among its member states and academia. The term is used to refer to medicines that do not meet quality standards, or that deliberately misrepresent their identities, compositions or sources (World Health Organization, 2017a: 6). This definition is recognised by the pharmaceutical industry, academic scholars and state governments. Despite this, different views exist among stakeholders on how to define a medical product that is not manufactured or distributed according to legal standards. Diving into the academic field, it does not take long to collect a variety of descriptions such as spurious, fake, degraded, falsely labelled and – not least – counterfeit (Liu and Lundin, 2016). These diverse opinions and the difficulty in reaching an agreement reflect the ambivalent and malleable nature of medicines in different societal circumstances. Knowledge is therefore important in order to unpack how people closely engaged with health services perceive medicines and practise care.

This dissertation has evolved from my deep engagement with the academic field of SF medical products since 2016. Over the years, the intellectual body develops from being highly medical-oriented to now receiving knowledge input from both medical and social sciences. A multi-level approach emerges by examining not only mechanisms on the macro level but also mundane care practices on the micro level, although the latter receives considerably less attention than the former. My approach

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[1] https://www.who.int/teams/regulation-prequalification/incidents-and-SF/full-list-of-who-medical-product-alerts (accessed 31 January 2023)

to the phenomenon of SF medical products is to study negotiations about medicine access between care seekers and medical professionals.

In this introduction, I begin with the societal and scientific significance of researching SF medical products. Next, I present the aim and research questions, followed by an account of the Swedish context in which the study is grounded. After this, I introduce the notion of grey zones as a research lens. This chapter ends with an outline of the dissertation.

SF medical products: What are the problems?

Since the beginning of the 21st century, the phenomenon of SF medical products has been increasingly recognised as a public health threat (Sweileh, 2021; Hamilton et al., 2016; Newton and Bond, 2019). The manufacture and distribution of pharmaceuticals involves extensive international networks before they reach the shelves of local pharmacies. This concerns policymakers, academic scholars and healthcare practitioners when formal supply chains are disrupted and therapeutic quality is presumably compromised. One direct consequence, as exemplified above, is that medicine users are exposed to medical risks and can even lose their lives. Additionally, there is evidence suggesting a link between the consumption of poor-quality medicines and antibiotic resistance (Venhuis et al., 2016; Suthar et al., 2019). The spread of poor-quality medicines may also lead to an enormous economic burden on national healthcare (Ozawa et al., 2018). On top of all the above, it also risks eroding the public's confidence in formal healthcare services (Ratanawijitrasin and Phanouvong, 2014). Studying this phenomenon thus has clear societal significance.

Without denying the presence of poor-quality medicines and their negative impacts on people and society, scholars have begun to question whether it is possible to distinguish between what is fake and what is not (Kingori and Gerrets, 2019; Hornberger, 2019). Medical anthropologists have long argued that medicines are not fixed or value-free objects, but are fluid and value-laden (Russell and Widger, 2018; Lock and Nguyen, 2010). Pharmaceutical efficacy can, to a certain extent, be stabilised in strictly controlled settings such as laboratories. However, when medicines are mobilised through different regimes of value (Appadurai, 1986), they become a subject between medical professionals and care seekers, and eventually an object of consumption. In this trajectory, efficacy and quality become socially embedded concepts (Hardon and Sanabria, 2017; Whyte et al., 2002; Quet, 2017). An in-between space thus appears where oppositional categories are challenged, such as legal and illegal medicine access, appropriate and inappropriate self-care practices, lay and professional medical knowledge, as well as formal and informal health services (Hall and Antonopoulos, 2016; Nordstrom, 2007; Koenraadt, 2018; Kingori and Gerrets, 2019).

Limited attention, however, is paid to how medicines and health services are approached and provided in everyday life (Hamill et al., 2019). Policymakers tend to label illegitimate access to and use of medicines as risky and deviant (Sugiura, 2018). In turn, those who access and use medicines outside formal healthcare are often portrayed as vulnerable victims, either lacking access to good-quality medicines and healthcare services or lacking awareness of the potential harm of such an act (Hall and Antonopoulos, 2016; Sugiura, 2018). This view of medicine users and their medicine consumption can be justified under some circumstances. For example, a disproportionately large number of reported incidents came from low-income countries and resource-poor settings, where dysfunctional formal healthcare coupled with informal markets are commonly identified as major factors that lead to the spread of poor-quality medicines (Liu and Lundin, 2016; Ravinetto et al., 2018). Nevertheless, even in such materially constrained conditions, people do not make decisions based on purely economic calculations but navigate the medical market partly by relying on social ties such as kinships and connections with religious groups (Hamill et al., 2019; Liu et al., forthcoming). In other words, imagining medicine users as vulnerable and naïve consumers suggests a simplified understanding of choice-making and ignores the situatedness of care practices.

In resource-rich settings – including Sweden, where this study is grounded – national and international efforts are made to keep people away from poor-quality medicines and unauthorised pharmacies. The European Commission's Falsified Medicines Directive introduced a logo for authorised internet pharmacies,[2] which has been adopted by all EU member states. However, a pilot study I co-conducted showed that nearly two thirds of respondents from Sweden did not recognise the logo (Lundin and Liu, 2020). A similar pattern was found in a survey of Swedish residents searching for Covid-19 protection on the Internet, where half of the respondents did not check the legitimacy of online pharmacies in their searches (Liu et al., 2021). One possible explanation for the low recognition of the logo can be connected to the fairly well-established pharmacy market in Sweden. The highly digitalised medicine dispensing system works as a way to safeguard medicine access, because medicine users need to log in with their personal BankID[3] to order prescription-only medicines (POMs) from Swedish authorised internet pharmacies. By comparison, however, over-the-counter medicines (OTCs) and health supplements are not as strictly controlled. No personal identification is required when making purchases, and these products can be ordered from websites registered

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[2] https://www.lakemedelsverket.se/sv/handel-med-lakemedel/apotek/att-starta-apotek/apotekssymbolen (accessed 31 January 2023)

[3] BankID is a widely adopted electronic identification system used by Swedish residents. It is issued by Swedish banks and is used to verify user identity when using services provided by state organisations, banks or digital businesses, including internet pharmacies. Only individuals with a Swedish personal identity number can obtain a BankID. https://support.bankid.com/sv/bankid/vad-aer-bankid (accessed 31 January 2023)

in and outside Sweden. In spite of this, low recognition of the pharmacy logo hints at certain perceptions that care seekers have towards medicine access and Swedish healthcare.

Furthermore, the provision of formal health services is rarely studied in relation to SF medical products (Liu and Lundin, 2016). In this academic field, close attention is paid to strengthening legal sanctions of informal markets and illicit actors on the one hand, while on the other protecting legal supply chains through technological innovation (Attaran, 2015; Nayyar et al., 2019; Rebiere et al., 2017; World Health Organization, 2017b). By contrast, knowledge is scarce on how formal health services and frontline healthcare professionals in the formal sector perceive and relate to this issue (Funestrand et al., 2019; Liu and Lundin, 2016). Such a lack of insights is particularly pertinent for resource-rich settings such as Sweden. Medical professionals are viewed as key players for informing and assisting care seekers in connection with safe medicine access and use (Fittler et al., 2018; Persson et al., 2022; Ferrario et al., 2019). Additionally, health service studies and consumption studies – which this dissertation partly builds upon – suggest that medicine consumption is affected by a redefined relationship between care seekers and medical professionals as one between customers and providers of health services (McColl-Kennedy et al., 2017; Ostrom et al., 2015; Nordgren, 2010). Care seekers in particular are viewed in health policies as value co-producers who can be empowered by freedom of choice to decide on their own medical treatments. Healthcare professionals are therefore facing challenges to their authoritative role of educating care seekers on safe medicine access and use. Hence, taking SF medical products in the Swedish context as an empirical entry point, a renewed understanding is needed about the provision and experiences of health services, as well as the relationships between medical professionals and care seekers.

At this point, two concepts need to be clarified. The first one is care. The notion of care covers a broad range of activities performed in different circumstances. It spans from professional work carried out by trained caretakers to more mundane work such as childcare or elderly care by family caregivers (Milligan and Power, 2009). It also extends from care for humans to care for animals and the natural environment (Puig de la Bellacasa, 2017). In this study, the empirical layer of care relates to medicine access and use, in both self-care and professional care settings. Theoretically, I align with a research stream that views care as situated practices emerging from a constellation of affective and material relations (Schillmeier, 2017; Mol, 2008).

The second concept is consumption. Its definition develops along with the growing research field of consumption studies (Wherry and Woodward, 2019). My take on consumption is that it covers a range of material practices embedded in everyday life, through which people organise daily activities, social worlds and relationships (Woodward, 2018). Consumption of medicines goes beyond the point of purchase. It includes a series of activities that lead to a final decision to buy or not to buy. In

this respect, consumption is a process where objects acquire or lose meanings and (re-)establish relations with people and other objects within particular contexts (Woodward, 2018; Shove and Araujo, 2010). During the interactive process, learning takes place as people acquire skills and employ strategies to achieve certain goals (Shove and Araujo, 2010). Thus, medicine consumption involves both the doing and the knowing. It points to two interrelated aspects: How medicines and health services are accessed and provided, and how these practices are informed by different understandings of medicines and care.

Aim and research questions

This dissertation aims to advance knowledge on care as situated practices within and beyond medical institutional settings. I investigate how medical professionals and care seekers negotiate their perceptions of medicine access. I also look at how such negotiations shift boundaries between professional and lay knowledge, and between healthcare as public services and as market-oriented businesses. Insights produced in these enquiries can be useful to understand the phenomenon of SF medical products from a micro-level. They may also shed light on promoting more effective engagement between medical professionals and care seekers about safe medicine access and use.

Throughout this research process, I have often found myself moving between two huge bodies of literature. On the one side are medical and public health studies with a great emphasis on medical risks and rather rigid views on good versus bad medicine quality, and legal versus illegal medical markets. On the other side is socio-cultural literature that highlights contextualised care practices and fuzzy boundaries surrounding medicine access and use. While reading up on these two roughly divided research communities, I have come to realise that the complexity of the phenomenon is what informs my research. I started off with a conceptual analysis of the phenomenon of SF medical products and moved on to empirical investigations of care practices. Along the way, I kept returning to review the complexity of SF medical products. To some extent, SF medical products have gradually become more than just an empirical entry point, also constituting an analytical reference.

Care seekers and medical professionals are two important stakeholders in the health systems. In this study, I look at two interrelated domains: care seekers' self-care and medicine consumption strategies on the one hand, and the provision of health services on the other. Many primary care services are provided by private sectors in Sweden, just as elsewhere such as the UK (Vengberg, 2022; Goodair and Reeves, 2022). This means that formal care provision extends beyond physician-patient encounters. In terms of medical professionals, I therefore refer to two professional groups, namely physicians and pharmacy staff. The empirical data used in the

appended papers were in turn derived from three groups of research participants: care seekers, physicians and pharmacy staff.

To develop the idea of care as situated practices, three research questions are developed:

1. What insights have been produced regarding SF medical products, and how can we comprehend the often-associated illegality of this phenomenon?
2. How do care seekers navigate through healthcare services and make choices about where to access medicines?
3. How do medical professionals perceive care seekers' self-care practices, and how do they engage with care seekers in care services?

Empirical data were collected from multiple sources. I used surveys with both care seekers and physicians. I also conducted ethnographic observations at a range of sites, including pharmacies, customs clearance offices and online chat forums. Additionally, I conducted interviews with pharmacy customers. Furthermore, this research was informed by continuously monitoring health policies and academic discussions on the subject of SF medical products. My intention in using various data sources and methods is to delineate how those engaged in health services on an everyday basis negotiate their views and practices concerning medicine access.

The research questions are designed and presented in chronological order, corresponding to the research path I briefly outlined above. The first question demands a conceptual investigation that is addressed in Paper 1 by mapping insights from existing literature on SF medical products. The second and third questions are addressed in Papers 2 to 4, which are grounded in empirical examinations on care seekers, medical professionals and their encounters. Some empirical material is reused in multiple papers, but different analytical and methodological approaches are applied, thus producing insights from different angles to address these research questions.

The Swedish context

All research is conducted in specific contexts that have an impact on research design and research outcome (Adams et al., 2014). The Swedish healthcare sector is relevant, both empirically and analytically, for situating the phenomenon of SF medical products and investigating practices of care. In this section, I sketch out major changes in the Swedish pharmacy market in relation to medicine access.

The Swedish pharmacy market has undergone several structural changes, most recently in 2009 when 40 years of a state-owned monopoly, Apoteket AB, and its

nationwide control of drug supply came to an end in Sweden. This has been replaced by a pharmacy market that private actors are allowed to enter. Many restrictions on establishment and ownership have been lifted. Pharmacies are no longer the only places that sell medicines; some types of OTCs can now be bought in retail outlets such as grocery stores and fuel stations.[4] In a study on the political rationale behind this structural reform, Wisell (2019) argues that the reform does not achieve the expected political goals such as becoming more cost-effective or better incorporating pharmacies into formal healthcare. The availability of medicines is also compromised to some extent, as new pharmacy establishments are not evenly distributed across the country and are mostly located in large cities instead. This issue goes hand in hand with the closure of pharmacy agents that function as medicine collection points in less populated communities, and the difficulty of recruiting pharmacists in smaller towns across the country.[5] In addition, the availability of less frequently prescribed medicines seems to have decreased in many small and rural pharmacies in the opinions of policymakers, pharmacy practitioners and patient organisations (Wisell, 2019). These elements are not conclusive to evaluating the performance and accessibility of pharmaceutical services. Nevertheless, they indicate a need for more investigations into care provision and medicine access, particularly in connection with the liberalised Swedish pharmacy market.

Another change that greatly impacts healthcare services is digitalisation. Starting in autumn 2015, all authorised Swedish pharmacies began to sell medicines and offer medical advice over the Internet. Since then, several internet pharmacies have been established (Sveriges Apoteksförening, 2018). Digital primary care services have also grown in popularity among Swedish residents (Ekman et al., 2019). It is particularly notable that the number of users of major private digital care providers increased by around 60% within a couple of months of the beginning of Covid-19 pandemic.[6] On top of this, according to EU parallel trade policies, Swedish residents can legally purchase medicines for personal use from other EU countries.

Following these changes, the availability of medicines from formal healthcare is, to a certain extent, limited – at least for certain populations in Sweden. Simultaneously, the digitalisation of health services seems to have made medicines and health services more accessible from alternative channels. While digitalisation provides benefits, it also dissolves national borders and allows for the unauthorised provision of medicines (Lavorgna, 2015). Unlicensed internet pharmacies spring up, and the majority – if not all – of them offer unrestricted access to all kinds of medical

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[4] http://apotekswiki.se/index.php/I_mataffären (accessed 31 January 2023)

[5] http://www.sverigesapoteksforening.se/wp-content/uploads/2021/05/2021-Annual-Report-1.pdf (accessed 31 January 2023)

[6] https://lakartidningen.se/aktuellt/nyheter/2020/05/kraftig-okning-av-digital-vard/ (accessed 31 January 2023)

products, including POMs with uncertain therapeutic quality (Clark, 2015; Mackey et al., 2015). A survey conducted by the Swedish Medical Products Agency (MPA) in 2015 showed that 40% of respondents were considering buying some kind of POM without a prescription (Swedish Medical Products Agency, 2015). A 2020 Swedish study of the acquisition of antibiotics suggests that 4.3% of a total of 4243 respondents would consider buying antibiotics without having a prescription from a Swedish physician (Munthe et al., 2022). These figures alert policymakers to the potential harm of accessing and using medicines of questionable qualities.

Zooming out to a broader societal context, Swedish healthcare has been informed by the choice discourse (Nordgren, 2010; Vengberg et al., 2019). The state no longer functions as the ultimate care provider, and individuals are expected to take responsibility for managing their own health (Michailakis and Schirmer, 2010). This shift in responsibility affects the identity of care seekers in and beyond institutional care settings. It also affects the role of medical professionals in giving advice on safe medicine use and delivering health services (Funestrand et al., 2019; Persson et al., 2022). Relating these changes to the phenomenon of SF medical products, an empirical challenge is how health professionals can engage with care seekers more effectively in their services, particularly regarding safe medicine access. Analytically, it merits academic attention to understand what underpins medicine consumption and care practices that evolve alongside a shifting healthcare landscape.

A note on grey zones

SF medical products carve out an in-between space where dichotomised notions – such as legal and illegal, professional and lay, and formal and informal – become blurred. The idea of grey zones as a reference to shifting boundaries and ambivalence forms the starting point for my research.

Introducing choice into health policies puts a strong emphasis on individual responsibility (Gabe et al., 2015; Fotaki, 2007). At the same time, global connections diversify access to alternative health systems and beliefs to a greater extent than ever before. In parallel with this, a liberalised market allows health services to be offered by a mixture of public and private actors. All these seem to indicate that plenty of options exist to choose from. Yet, choices are very context-dependent. Following Schneider-Kamp and Askegaard (2020: 17), consumer autonomy is "an unavoidable by-product of the increasing focus on patient and consumer choice and the on-going marketisation of healthcare". While people in some circumstances are willing and able to exercise their rights to choose, in other situations they may be left with no option but to choose (Mol et al., 2010). Taken together, these different threads suggest that how to choose and how to care are configured by material and social contexts, where medical technologies encounter discourses such as health consumerism, individual responsibility and freedom of

choice (Merrild et al., 2016; Alftberg and Hansson, 2012; Lupton, 1997; Kristensen et al., 2016; Schneider-Kamp and Askegaard, 2020).

Meanwhile, studies show that people increasingly take a consumerist approach, albeit to different degrees, to access medicines and healthcare services (Ewert, 2013; Gabe et al., 2015; Schneider-Kamp and Askegaard, 2020). Relatedly, studies on SF medical products and other phenomena such as stem cell travel and organ trafficking point out there is a blurred space where people, intentionally or not, apply medicine consumption strategies which are not always considered appropriate or rational in the view of medical professionals or health policy makers (Lundin et al., 2016; Gunnarson and Lundin, 2015; Hall and Antonopoulos, 2016; Sugiura, 2018). These acts may lead to unwanted and unexpected consequences without reaching the threshold of being defined as illegal (Lavorgna, 2021). Linking to consumption studies on consumer choice, Schneider-Kamp and Askegaard (2020) identify a "liminal space" where people navigate between expert authority and consumer autonomy (Schneider-Kamp and Askegaard, 2020: 2). The abovementioned studies denote a context where boundaries are constantly transgressed and where such transgressions are seldom articulated verbally, and may thus easily go unnoticed. I refer to this context as grey zones. I use the term to track moving boundaries between professional and lay knowledge, as well as practices of care in and beyond medical institutional settings.

The metaphor of grey as a reference to ambiguities and uncertainties is not new to social scientists. Frederiksen and Knudsen (2015) point out that grey zones are not outcomes of temporary crises. They signal a sense of ordinariness and "thus may even become backdrops from which something new emerges" (Frederiksen and Knudsen, 2015: 5). This coheres with Nielsen and Langstrup's (2018) argument that ambiguities are needed to make space for emerging practices and ideas (Nielsen and Langstrup, 2018). These statements reinforce that grey zones can be so embedded in everyday life that they may become invisible, unheeded and rarely articulated verbally. Bubandt (2015) challenges scholars not to be satisfied by simply pointing out the ambiguities, but to be more specific about where and how to locate the greyness, and to understand ambivalence and paradoxes in specific analytical contexts (Bubandt, 2015). I interpret this challenge as a need to attend to the temporality and spatiality of grey zones in order to unpack how boundaries are negotiated in care practices.

A growing body of literature from the field of medical materialities draws attention to spatiality and temporality of care (Buse et al., 2018). A relational view of place and care (Martin et al., 2015; Martin, 2016; Brown et al., 2020) perceives place as both open and bounded, whereas care is "carefully layered through practices of place-making" (Ivanova, 2020: 1299). Adding to this, temporality of care emphasises that care is connected to past and present, materialised as memories and anticipations (Sumartojo et al., 2020; Buse et al., 2018). Linking this body of knowledge to anchor grey zones in everyday medicine consumption, grey zones

provide a lens through which to examine choice-making about where and how to access medicines, as well as how care is done. In turn, by looking at care as situated practices, this may tell us something about the taking-place of grey zones in particular socio-material arrangements. Through the lens of grey zones, the phenomenon of SF medical products serves a pertinent case that foregrounds diverging understandings of care and choice. A relevant enquiry is when and where negotiations happen and boundaries start to move.

The exploration of grey zones is thus grounded in discussions on how to choose and how to care in a changing healthcare landscape. These discussions are embedded in the re-defined relationships between medical professionals and care seekers, where the former become service providers and the latter are addressed as service users or health consumers. This prompts us to build up a dialogue, by looking at both how care seekers manifest self-care and how medical professionals as frontline health service providers perceive and react to care seekers' self-care. By reframing healthcare as services, we are additionally invited to rethink what configures care practices within and beyond medical institutional settings, especially when health is becoming commodified in the form of medicines (Henderson and Petersen, 2002). To this end, the idea of grey zones forms the starting point of this study. It has stayed with me during the journey. All the appended papers have been developed through this lens.

Disposition of the dissertation

In the introductory chapter, I have presented the empirical phenomenon of SF medical products. A research context is outlined to show the relevance of studying this phenomenon in Sweden. I also introduce grey zones as a lens through which to examine care and choice. In the following chapter, **_Previous studies_**, I review literature that is relevant to practices of care and medicine consumption. In the chapter **_Theoretical framing_**, I propose to conceptualise medicine consumption as an assemblage, and care as having an emergent quality. To understand the emergence of care practices, I introduce the notion of tinkering. While discussing these two concepts – assemblage and tinkering – I map out how the theories used in the appended papers stem from a relational approach.

The idea of assemblage also inspires my choice of methods. I perceive the research process as an assemblage, composed of different relationships and events. Hence, the process is non-linear and multi-targeted. Data collection and data analysis will be presented in the chapter **_Methods and material_**, followed by a discussion on research reflexivity.

In the **_Findings_** chapter, I summarise four independent research papers, each addressing specific research questions. They are compiled interrelatedly, meaning that the arguments made in each paper build up to fulfil the aim of this dissertation.

In the final chapter, ***Concluding discussion***, I discuss my findings on concepts, assembling and tinkering. I also re-visit the notion of grey zones. This chapter ends with my study's contributions to the scientific community.

Author contributions

Papers 1–3 are co-authored. Author contributions are clarified according to Elsevier's CRediT author statement.[7]

Paper 1:

Rui Liu: Conceptualisation, methodology, formal analysis, investigation, data curation, writing – original draft. **Susanne Lundin**: Conceptualisation, methodology, writing – original draft.

Paper 2:

Rui Liu: Conceptualisation, methodology, formal analysis, investigation, data curation, writing – original draft, writing – review and editing. **Susanne Lundin**: Conceptualisation, methodology, writing – original draft, writing – review and editing.

Paper 3:

Rui Liu: Conceptualisation, methodology, formal analysis, investigation, data curation, writing – original draft, writing – review and editing. **Susanne Lundin**: Conceptualisation, methodology, writing – original draft, writing – review and editing. **Talieh Mirsalehi**: Writing – original draft, writing – review and editing. **Margareta Troein**: Data curation, writing – original draft, writing – review and editing.

Previous studies

In this chapter I review literature in connection with the research topic of care practices and negotiations in choice-making. My intention is to position this study at the convergence of multiple research fields, namely consumption studies, medical materialities and health service studies. This chapter is structured as three sections. I first problematise the notion of choice. Next comes a discussion on reconfigured care practices, wherein choice is viewed as an everyday act that is socially and materially conditioned. Lastly, I present the notion of service as a way to frame healthcare.

Choice in healthcare

As a central concept in market liberalism, the notion of choice was introduced to healthcare in many Western countries – including Sweden – in the 1980s. It was intended as a way to improve healthcare services, and as a response to demands for more equal relationships with medical professionals (Fotaki, 2013; Fredriksson et al., 2013). These choice reforms were followed by a linguistic change, whereby care seekers began to be addressed as customers rather than patients (Nordgren, 2010). Simultaneously, value co-production appears a recurrent term to endorse the implementation of many health policies (Fusco et al., 2020). Scholars argue that such a discursive change transforms the relationship between care seekers and medical professionals, and shapes self-care as well as the provision of health services (Henderson and Petersen, 2002).

Since its introduction to healthcare, choice has attracted considerable criticism. Evidence shows that it neither improves service quality nor sustains equality, which are central principles of many public services (Fotaki, 2013; Burström, 2009; Fredriksson et al., 2013; Vengberg et al., 2019). Fotaki (2013) points out that the idea of choice is rooted in the economic framework, where people are reduced to *Homo economicus* (Fotaki, 2013). A more sociological understanding of choice relates it to the late-modern notion of reflexivity, where people are viewed as reflexive individuals (Giddens, 1991; Beck et al., 2003; Lupton, 1997). In consumer studies, scholars have argued that an emphasis on choice is part of the responsibilisation process that constructs consumers as "free, autonomous, rational, and entrepreneurial subjects" (Giesler and Veresiu, 2014: 841-842). What emerges

is an empowered individual, who is able and willing to make informed decisions if provided with relevant information and adequate support. This coheres well with the view of health service users as value co-creators and beneficiaries of the health system (Danaher and Gallan, 2016). Hence, in the logic of choice, healthcare is largely dependent on active patients (Mol, 2008).

However, health services can be characterised as a type of expert service, meaning that the provision of care is based on specialised knowledge (Azzari et al., 2021). There are huge potentialities that knowledge and power asymmetries will exist between medical professionals and care seekers. Adding to this, care seekers often have varying capacities in terms of making choices or utilising resources. Thus, without addressing these intrinsic elements in health services, choice does not empower people as intended, but risks producing weak patients and exacerbating inequality between different socioeconomic groups (Nordgren, 2010; Burström, 2009; Merrild et al., 2017).

Through a discourse analysis of governmental documents in Swedish healthcare, Nordgren (2010: 120) argues that patient choice does not offer much practical benefit to care seekers, and that it remains "a policy document that expresses a desirable political order". Along the same lines, but taking a semantic approach, Michailakis and Schirmer (2010) argue that the changing definition of health from physical well-being to bio-psycho-social well-being allows the public to claim a wide range of health services. It then forces the state to rearrange health resources in order to ease the burden for public-funded healthcare. As a consequence, the relationship is reoriented between the state – which faces a potential lack of financial capacity to provide sufficient public services – on the one hand, and citizens – with increasing demands for health services and social benefits – on the other hand. Hence, the ideas of choice and empowerment can be viewed as a political response to a more inclusive concept of illness. Following this line of reasoning, choice reforms mark a strategic shift from state responsibility and collective care to individual responsibility and self-care. Those who fail to take care of themselves may receive downgraded healthcare, and may even be denied access to social services in general (Michailakis and Schirmer, 2010). To this end, choice and self-care are strongly associated with morality (Giesler and Veresiu, 2014). In practice, it is not simply about making a choice; people are obliged to make a good choice and behave in a certain way, as promoted by the health system (Alftberg and Hansson, 2012; Henderson and Petersen, 2002).

Apart from critical readings of health policies, there is empirical evidence showing that choice is a context-specific act. A long-term ethnographic study (Merrild et al., 2016) shows that middle-class care seekers are more active in using healthcare and more willing to take responsibility for their health, while people from a lower working class, despite often suffering from poor health conditions, appear rather passive when it comes to care seeking or following medical professionals' advice. On the surface, these differing care-seeking practices seem to correlate with

economic conditions, but a closer examination of the rationales behind these choices shows that how people deal with bodily discomfort and seek healthcare is socio-materially conditioned. Middle-class people, with their relative affluence and higher social positions, are able to maximise the desired lifestyle and life quality, whereas working-class people usually need to deal with other problems such as unemployment, poverty or difficult family relationships, besides health. This finding is in line with Dumas and colleagues (2014), who demonstrate that care practices are based on a "hierarchy of incentives". This leads to a situation where other concerns such as economic stability or family needs are prioritised over one's own health. The authors therefore argue that care practices are "less a function of knowledge of health", and more an outcome of negotiating responsibilities imposed by different social norms (Dumas et al., 2014: 151). Care seeking, therefore, is more than a visit to a physician. Practising care requires the mobilisation of a range of social and material resources. However, healthcare reforms guided by patient choice and empowerment produce and prefer one singular type of care seekers: those who are active, capable and self-regulating (Irvine, 2002). In turn, it would be hard for health interventions to have an effect if little attention were paid to people's lived experiences or socio-material contexts that enable care practices (Beckmann, 2013).

Empirical studies also identify a spectrum on which people oscillate between being needy patients and active health-seeking individuals. Mol's (2008) study on diabetes patients includes cases where patients actively participate in making informed choices, whereas in other situations the same patients are heavily dependent on medical professionals (Mol, 2008). This finding is echoed in other studies on self-care practices (Lupton, 1997; Merrild et al., 2016; Kristensen et al., 2016; Maslen and Lupton, 2019). They suggest that care seekers are increasingly taking a consumerist approach, in the sense that they are more attentive to their bodies, actively look for health information and try to make informed decisions. All these factors indicate that people consume healthcare in a similar fashion to how they consume other services and commodities in the market. Nonetheless, this does not mean that care seekers deny or refuse the role of passive patients. Quite the contrary; they are still inclined to invest in a trusted relationship with medical professionals (Lupton, 1997). At times, they want medical professionals to take over. A study conducted in the UK has examined the marketisation of an OTC medicine (Will and Weiner, 2015). Whereas policymakers and medical professionals expect there to be a market for the new drug previously classified as a POM, care seekers who fall into the target group turn out to be "anything-but pharmaceutical" consumers. The authors find that people actively make purchasing choices regarding food and other health products. At the same time, these medicine users prefer to consult physicians for advice on medications to manage their heart disease. The authors conclude that demand for medicines is not constrained by the economic conceptualisation of choice in healthcare (Will and Weiner, 2015).

Schneider-Kamp (2020) proposes a concept of health capital, and defines it as a combination of the actual or potential resources one possesses and is able to utilise to influence one's health (Schneider-Kamp, 2020). These resources are categorised into economic, social, cultural and symbolic dimensions. Although health capital seems to be an all-inclusive concept, it highlights that choice-making is a process along which factors other than economic ones come into play. Accordingly, the rationality that underpins the choice discourse is contentious. What is emphasised here is the ambivalence and contextuality in choice-making. Health services guided by the logic of choice may thus fail to connect with care seekers who, for various reasons, distance themselves from formal healthcare and medical professionals.

To unpack choice-making processes, choice therefore needs to be viewed not only as a cognitive behaviour, but also as a process of moral negotiations with and within social and material resources. This is where the logic of care (Mol, 2008) comes in. A focus on care rather than choice shifts attention away from *who* decides and *what* choices are available to *how* care can be achieved collaboratively and *how* negotiations are made. In connection with this, care practices place less emphasise on results and more on attentiveness to emotional needs in addition to physical ones. Put differently, good care is collaborative and requires shared doctoring (Mol, 2008: 64). It acknowledges different forms of knowledge and focuses on the processual aspect of choice-making by attuning to various elements that are available in particular situations. Rather than viewing choice as a prerogative of certain people, following Mol (2008), choice can be alternatively viewed as a mundane activity and a characteristic of specific situations, where people may or may not want to engage in certain aspects of their care-seeking.

Reconfigured care practices

The previous section shows that the choice discourse risks sustaining the status quo because the physician-patient relationship is intrinsically imbalanced on the knowledge-power nexus and people have varying capacities to choose. However, people are increasingly obliged to choose, whether they want to or not (Ewert, 2013). In addition, with an emphasis on individual responsibility, choice opens up multiple possibilities where people can "imagine new ways of acting and choosing in their relationships with health care" (Nordgren, 2010, p. 121). A large number of studies, including the ones mentioned previously, imply that people have somehow internalised the idea of taking individual responsibility when choosing medical products and services (Schneider-Kamp and Askegaard, 2020; Maslen and Lupton, 2019; Schneider-Kamp and Askegaard, 2019). This indicates that the idea of health as a reified commodity and the free choice discourse have, to some extent, shaped social norms and configured care practices. In relation to this, drawing on the

societal context where many public services are provided by private actors,[8] care delivery is not confined within institutional care settings, but is extended to the daily domains where medical professionals tend to be removed from care practices.

In a study on patient empowerment among Danish residents, scholars identify a range of ways to approach and use formal care services (Schneider-Kamp and Askegaard, 2019). At one end of the spectrum is a traditional approach, characterised by a paternalistic physician-patient relationship and no clear signs of patient empowerment. At the other end is a resisting approach, where physicians are excluded from the decision-making process as people abandon medical advice or decide on treatments without medical consultations. In between is a consuming style, where patients are active in selecting and evaluating the available treatments included in, but not limited by, formal healthcare. The authors find that people use a mixture of these identified approaches, rather than sticking to one (Schneider-Kamp and Askegaard, 2019). Drawing on de Certeau's distinction between strategies and tactics, the authors argue that patient empowerment should be viewed as tactical empowerment rather than simply strategic top-down empowerment, in the sense that it emerges from "a bricolage of tactical interactions with a multitude of social environments" (Schneider-Kamp and Askegaard, 2019: 640). Similar observations are made in Phillimore and colleagues' studies (2015, 2019), where care seekers living in superdiverse and transnational social settings mobilise different kinds of material resources within their networks to overcome the difficulty of accessing local formal health services. In their studies, the idea of bricolage is employed to highlight people's creative use of resources to acquire health services locally and globally (Phillimore et al., 2015; Phillimore et al., 2019).

The creative use of resources in enacting care practices is found elsewhere. For example, Guell (2012) studies Turkish migrants living in Germany who self-manage their diabetes (Guell, 2012). These people acquire support from self-help groups, where abstract health recommendations from medical authorities are translated by group members into accessible and practical informational materials to support diabetes-friendly food practices. People then flexibly incorporate this health advice into everyday cooking to manage diabetes. Although in formal healthcare these Turkish migrants are considered socially marginalised, Guell (2012) finds that they are skilled and capable self-carers, and in some cases even expert patients. Thus, the author argues that self-care is about more than choosing the healthy options; it is also about transforming biomedical knowledge from multiple sources to make life habitable (Guell, 2012; Cf. Mirsalehi, 2021). This study coheres with the

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[8] Although healthcare is partly provided by private actors, in Sweden as in the UK, private actors are financed by tax transfers. See e.g. Bartlett W and Harrison L (1993) Quasi-Markets and the National Health Service Reforms. In: Grand JL and Bartlett W (eds) *Quasi-Markets and Social Policy*. London: Palgrave Macmillan UK, pp.68-92.

observation made by Azzari and colleagues (2021) that health consumers learn to translate and transform specialised knowledge to suit specific life situations.

Translating knowledge into care practices involves both human and nonhuman entities (Mol et al., 2010). In their study on people with chronic diseases, Danholt and Langstrup (2012) show that managing chronic conditions involves not only healthcare professionals, but also technologies that allow for the administration of care outside clinics, as well as a material rearrangement of the home to accommodate self-care. The authors then challenge the idea of self-care as centred on the self as a reflexive and capable individual. They argue that it is a de-centred practice where the self is inevitably interconnected with other actors and entities in a care infrastructure (Danholt and Langstrup, 2012). Following this conceptualisation, care practices are constantly configured rather than prescribed, contingent on arrangements of people, objects and spaces (Langstrup, 2013). Likewise, in a study on heart failure self-care, McDougall and colleagues (2018) show that self-care is not simply affected by contextual factors such as one's socioeconomic background or domestic conditions. Its enactment requires constant calibration among various elements such as people, technologies and expertise. Thus, the authors propose that self-care should be viewed as an assemblage constitutive of changing relations between different entities (McDougall et al., 2018). The abovementioned studies represent a growing body of literature which draws attention to the material contexts of care in addition to social ones. They call for a need to address the temporal-spatial dimensions of care to understand how care practices are collectively configured (Fox et al., 2016; Brownlie and Spandler, 2018; Buse et al., 2018; Lupton and Lewis, 2022; Weiner and Will, 2018; Parkhurst and Caroll, 2019).

Recent decades have witnessed an advancement of digital technologies. Social media platforms offer virtual spaces where people can access and share health information with their peers, and self-tracking appliances have been developed that allow people to monitor their health state (Lupton and Jutel, 2015; Maslen and Lupton, 2019). These technological advancements further shape self-care (Lupton, 2013). Maslen and Lupton (2019) study women's use of Facebook when accessing and sharing health information. The authors identify different modes of knowledge production and consumption. Some respondents self-identify as lay experts, taking an authoritative role and generating knowledge through personal and embodied experiences. By comparison, the majority view themselves as consumers participating in the form of lurking and observing other group members' online activities. On the surface, such behaviours seem rather passive compared to self-proclaimed lay experts. Nevertheless, the authors suggest that this should be viewed as another type of engaging (Maslen and Lupton, 2019). Silent observers actively update themselves on ongoing discussions and critically assess the shared information, before cautiously applying it to their own situations. It is particularly worth noting the various strategies these lurkers develop to enact the technological

affordances of Facebook in order to avoid sensitive discussions or to protect privacy. The enactment of Facebook as a space for producing and consuming health knowledge is thus "emergent and contextual rather than fixed" (Maslen and Lupton, 2019: 1648). One insight drawn from this study is that the way respondents connect or disconnect with one another is affective and relational. The idea of the "expert patient" is therefore redefined as a person who not only actively seeks information, but also learns the rules of engagement and understands the particular affordances of the technological platforms they are using (Maslen and Lupton, 2019). This finding coheres with the notion of McDougall and colleagues' (2018) self-care assemblage, where care practices are enabled or constrained in socio-material configurations (McDougall et al., 2018). Within these assemblages, health knowledge is not fixed facts, and nor are medical products or devices static objects. Rather, both health knowledge and medicines are fluid entities affected by a range of interrelated factors such as personal interests, needs and subjective feelings.

Healthcare as services

The scholarship reviewed above focuses on different health arenas, including a mixture of online and offline practices among care seekers with or without chronic diseases. A consensus can be drawn that new forms of medicine consumption and self-care practices in a digitalised age reshape the boundaries between the production and consumption of various forms of knowledge. The relationship between medical professionals and care seekers is challenged on this account, particularly regarding the role of physicians as the ultimate possessors of medical authority and expertise.

Following the introduction of patient choice and empowerment to healthcare, the influence of service logic is becoming discernible in this sector. Medical professionals are referred to as service providers and care seekers as service users, with the latter being placed at the centre of services (Osborne, 2018; Skålén et al., 2018). This framing denotes a view of care seekers as not only recipients of health services, but also value co-producers. In many ways, this coincides with what is mentioned above about the imagination of an active, capable and responsible health consumer. However, a bibliometric review of literature on co-production in healthcare shows that little is known about how health service providers have responded or adapted to the service mindset (Fusco et al., 2020). This finding reinforces a need for knowledge on how medical professionals perceive changing medicine consumption and how they can engage with care seekers who tend to manage their sickness or health without professional services or outside medical institutional settings.

While much is known about changes in self-care, insights are limited concerning medical professionals' perspectives on people's evolving self-care practices and

choice-making (Vengberg, 2022). In a study among Belgian physicians (Gabriels and Moerenhout, 2018), respondents express their concerns about the reliability of self-care technologies, data overload, incorrect self-diagnoses and a possible change in their professional role to become patients' self-tracking data interpreters. However, respondents also acknowledge the potential benefits that digital self-care technologies may bring in improving patients' health management. Similarly, in a study among physicians in Germany (Fiske et al., 2020), respondents are – to various degrees – supportive of patients' use of digital technologies to monitor their health. However, these medical professionals also emphasise that digital self-care should be conducted under professional guidance. The studies indicate that physicians want – and feel the need – to play a guiding role in people's (digital) self-care. Specific to the Swedish context, where patient choice has a strong presence in primary care, resulting in a kind of quasi-market as in the UK (Bartlett and Harrison, 1993), medical professionals have found it difficult to adjust their services to meet the demand of care seekers due to a lack of information about how care seekers select and access health services (Vengberg et al., 2019).

Furthermore, scholars from service studies have argued that the scope of services as a scholarly field should be broadened, particularly by extending the research focus from merely for-profit private sectors to also include public sectors such as healthcare (Subramony and Groth, 2021). This has two implications. First, there is a need to re-conceptualise the idea of service in order to understand how value is created and how to innovate public services (Skålén et al., 2018; Berry, 2019). Berry and colleagues (2007, 2019) point out that there are fundamental differences between services in conventional for-profit businesses and services in healthcare (Berry and Bendapudi, 2007; Berry, 2019). For example, in health services customers often suffer from bodily or mental illnesses, and they may also feel reluctant to approach health services or comply with medical advice. In addition, there are inherent risks in all medical treatments. Health service users usually need to shoulder those risks in order to continue receiving certain services. All these factors make healthcare a service highly emotionally charged for both medical professionals and care seekers (Berry et al., 2020).

Second, despite the abovementioned differences, care provision faces a similar situation to other services, whereby the role of service workers needs to be re-examined (Subramony and Groth, 2021). The provision of health services needs to be studied within particular social and material contexts. Investigations thus demand a move beyond simply looking at care seekers or care providers towards a conceptualisation of services as networked constellations involving multiple actors (Ostrom et al., 2015).

Situated at the convergence of consumption studies, medical materialities and health service studies, the above-reviewed literature has offered the following insights. First, the choice discourse is closely linked to an emphasis on individual responsibility. Yet people are empowered not simply as a result of top-down health

policy, but also in connection with the reflexive and creative mobilisation of available resources. Second, practices of care are constantly reconfigured and enacted, both socially and materially. This becomes even more the case alongside the use of digital technologies such as social media. This insight pushes a shift of focus from choice to care, and suggests that care provision is not confined within medical institutional settings. Finally, in close relation to the first two insights, understanding the provision and experiences of health services requires a broader approach to attend to both social relations among human actors and the impact of material conditions.

Drawing upon these insights, I conclude that more knowledge is needed to account for multiple ways of enacting care practices. To do so, my investigation moves beyond a singular focus on care seekers or medical professionals to investigate the relationships and negotiations of multiple actors in healthcare systems.

Theoretical framing

Theoretical framing is processual and discursive. My theoretical perspectives have evolved with the research process, both informing and informed by my engagement with multiple research fields. In the initial stage of this study, I was most attracted by the complexity of the empirical phenomenon of SF medical products. The strong representation of scholars from global health and medicine on this subject led me to explore how my research could fit into those academic discussions and fill some knowledge gaps. A close reading of the literature pointed to a lack of attention to the situatedness of care practices and an assumed illegal nature of illegal and informal domains. This explorative process is partly reflected on in Paper 1. In Papers 2 to 4, I empirically examine care practices and medicine consumption in everyday life. I lean towards consumption studies, particularly the notions of liquid consumption (Bardhi and Eckhardt, 2017) and prosumption (Comor, 2011; Ritzer, 2018), to understand the enactment of individual agency and how care seekers can be viewed as health knowledge prosumers (Paper 2). I use anthropology of things with social lives (Appadurai, 1986) and materialities as negotiated processes (Ingold, 2012), to explore how physicians and care seekers make sense of diversified medicine access (Paper 3). The fourth and last paper appended to this dissertation studies the affective and embodied aspect of care services, using the concept of atmosphere. Although each paper takes a different theoretical angle, they all stem from a relational approach that attends to social relations and material resources, as well as human and nonhuman entities.

The ambivalent quality of medicines has stimulated my interest in socio-material and post-human approaches to understand care practices (McDougall et al., 2018; Andrews and Duff, 2019). Socio-materialism raises awareness of the role played by material contexts in addition to social ones, whereas post-humanism directs attention to the temporality and spatiality of care. These two theoretical orientations do not necessarily de-centre human actors. I read them as reminders of the capacities of nonhumans in enabling changes and co-producing values with humans. To some extent, they respond to Latour's (2007) call to unpack the "black box" of the social, instead of taking the social as a self-explanatory concept (Latour, 2007). They also dovetail with Ingold's work on materialities as emergent and processual (Ingold, 2007; Ingold, 2012; Ingold, 2015). These research streams point to a shift in focus from being object-oriented to process-oriented, by attending to the emergent, heterogeneous and affective forces.

Two ideas which are cross-fertilised in both social-material and post-human approaches are influential in framing my theoretical perspectives. One is assemblage and the other is tinkering. Guided by assemblage thinking, I conceptualise medicine consumption as being configured in dynamic socio-material arrangements, and care as a relational practice emerging from those configurations. To investigate the relationality of care practices, I use the concept of tinkering. In the following, I elaborate on these ideas.

Assembling

The term "assemblage" gains prominence in relational thinking, as a way to address the fluid boundaries between nature and culture, body and mind, and human and nonhuman, particularly in the midst of technological advancement (Fox and Alldred, 2015; Andrews, 2018). It has been used as a word to describe the coming together of relations, as a tenet to pinpoint how relations are temporarily formed, and as a concept to understand the stability and changeability of relations (Anderson et al., 2012). Nail (2017) offers a reading of Deleuze and Guattari's assemblage, and defines it as "an arrangement or layout of heterogenous elements" (Nail, 2017: 22). Müller and Schurr (2016: 219) present a similar view that assemblage is "a collection of relations between heterogeneous entities to work together for some time". Venn (2006) perceives assemblage as a "relay concept, linking the problematic of structure with that of change and far-from equilibrium systems" (Venn, 2006). This perception links back to Nail's (2017) reading that assemblage emphasises multiplicity over unity and continuous changes over static outcomes. These definitions and readings point to prominent characteristics of assemblages such as fluid, affective, emergent and always becoming, making assemblage a useful concept to address the issue of "the heterogeneous within the ephemeral" in ordered social lives (Marcus and Saka, 2006: 102). In connection with this, Anderson and colleagues (2012: 180) argue that a strength in assemblage thinking lies in it being more than "a concept aimed at understanding how a set of relations emerge and hold together across differences", but also "an ethos for thinking the relations between durability and transformation".

Anderson and colleagues (2012) emphasise the exteriority of relations as a significant proposition in assemblage thinking. This means that relations are not pre-existing or inherent in the entities; they need to be worked on. This leads to the idea that relations can be formed and stay relatively stable, but they may also change, break and be re-formed differently – even among the same constituent entities. Thus, assemblages are always singular and particular. Following this line of reasoning, entities are not defined by the relations they are in, but are relatively autonomous and have the capacity to change existing relations or form new ones with other entities. Agency, understood as the capacity to act, is thus not simply distributed

among entities but is enacted by the interrelations between entities (Bennett, 2010). As Nail (2017) points out, no assemblages can exist without agents or relations between them, and, likewise, no agents would exist beyond assemblages.

Marcus and Saka (2006: 106) hold the view that assemblage can be a "strategically deployed and passing term". This perception might have correctly pointed out that the term "assemblage" and its verb form, "to assemble", risk becoming a routinised conceptualisation of relations when explaining social phenomena. However, viewing "assemblage" as a verb and a formation, rather than a noun or a form, invites a rethinking of relationalities and how each of the constituent entities, with different capacities or different natures, can relate to one another. Thus, examining the establishment or disruption of a relation can provide a pathway to understand how heterogeneous entities exercise capacities to mobilise social and material resources, and the consequences of such dynamics. It can also be viewed as a process of learning through continuous negotiations to effect change and intervene. As proposed by Sandberg and Alvesson (2021), assemblage thinking is not, perhaps, the most suitable way to explain social phenomena, but it can be characterised as a theory for unpacking "the processes through which they emerge, evolve, reoccur, change and decline over time" (Sandberg and Alvesson, 2021: 502).

Furthermore, assemblage thinking is linked to the research lens I use, namely the grey zones. To recap, this study sets out to do more than simply pointing out ambiguities; it also aims to understand how moving boundaries are negotiated between different forms of health knowledge and different practices of care in various settings. Assemblage, by treating entities that differ in nature as having the same ontological status, suggests a sense of unpredictability in forming potential relations. Thus, to think with assemblage, I take boundaries as a construct, which may be reinforced or over-written, dissolve and re-emerge depending on time-space arrangements.

Empirically, assemblage has been used in a growing number of health-related studies and has been proven to generate insights (Duff, 2015; McDougall et al., 2018; Fox et al., 2016; Lupton and Lewis, 2022; Ivanova et al., 2016). I will give a few examples. McDougall and colleagues (2018) view self-care as an assemblage. The authors show how bodies are affected by ongoing, dynamic social and material relations and that human bodies are fluid and open to changes (McDougall et al., 2018). Duff (2015) conceptualises health as an assemblage and examines the process of recovering from mental health problems. The author demonstrates that recovery is a "particular condition of becoming well", where human bodies gradually gain the capacity to affect and be affected by other human and nonhuman bodies. Recovery, thus, is not quantifiable by setting milestones of physical achievements, as is often formulated in medical guidelines. It happens incrementally, subtly and tangibly through everyday practices enabled by social and material factors in time-place settings (Duff, 2015).

Fox and colleagues (2016) use assemblage to study obesity. The authors explore how bodies are affected by a variety of material factors in becoming fat or becoming slim. A wide range of human and nonhuman agents at both local and global levels, as well as affective forces, are identified within the obesity assemblage. The authors argue that the becoming-fat or becoming-slim bodies are produced at the intersection between food consumption on the local level and food production, distribution and retailing on the global level (Fox et al., 2016). This insight challenges public health interventions, which are often focused on individual responsibility. Another example comes from a study on how people with pre-existing diseases cope with the Covid-19 pandemic and understand risks (Lupton and Lewis, 2022). Although respondents express different feelings and take different self-care strategies, the authors identify recurring elements across all narratives that have affected these experiences, such as online and offline social networks, and previous illness experiences. Spatiality appears important in assembling feelings of safety and security, which in turn affects how people assess risks and manage well-being. The authors thus argue that the situated contexts of experiences and care practices can be examined by looking at human-nonhuman entanglements (Lupton and Lewis, 2022).

Building upon the abovementioned literature, practices or identities are not isolated, but are deeply embedded in other practices and infrastructural relations on a local-global nexus. This scholarship demonstrates that entities of different natures can relate to one another and form assemblages while retaining their own capacity to form new relations and new assemblages. Hence, assemblage thinking is useful to understand how relations are sustained and how they change (Anderson et al., 2012).

In this dissertation, medicine consumption is viewed as an assemblage composed of changing relations between heterogeneous entities. Medicines, care seekers and medical professionals are among the key entities in such arrangements. Following the idea that assemblages are always singular and particular, studying the formation of relations and enactment of agency requires attentiveness to local particularities. This leads to an epistemological enquiry that asks for more than a description of identifying different elements or the effects of their relations. The investigation instead needs to "illuminate a logic underlying the way these processes are configured and interact with each other in continually (re)producing the phenomenon in question" (Sandberg and Alvesson, 2021: 503). To get close to the underlying logic in the medicine consumption assemblage, I lean on the idea of tinkering.

Tinkering

Mol and colleagues (2010) point out a tendency to use the term "care" as an object. The way we refer to medical professionals as care providers and patients as care seekers, for example, seems to suggest that care is something to be exchanged,

sought after, and outside the body (Mol et al., 2010). My conceptualisation of care, as clarified in the Introduction chapter, is in agreement with the statement that care is an embodied practice, something people do on a daily basis by coordinating time, space, objects and available resources in their surroundings (Pink et al., 2014; Sumartojo et al., 2020; Brownlie and Spandler, 2018; Mol et al., 2010; Mol, 2008; Warin et al., 2015; Mol and Law, 2004). This means that care is contingent upon shifting relations between these elements.

In several of her publications, Mol (2008, 2010) theorises the idea of tinkering. A concise definition of this is "attentive experimentation" (Mol et al., 2010: 13). This brings a focus on the processes of how spatial and temporal elements, and human and nonhuman entities, are brought together to make things work. To operationalise this concept, we must first acknowledge that there are specificities about each individual, being individual bodies, or various capacities to access and mobilise available social relations and material resources (Mol, 2010). Being attentive to the specificities makes it possible to examine the tinkerability of care practices (Broom et al., 2020). Second, there must be an awareness that knowledge about how to care, particularly self-care, can be fragmented (Guell, 2012). Tinkering, thus, involves continuously looking for ways to accommodate co-existing and often competing health beliefs, and negotiate them into a relatively coherent experience (Mol, 2008).

Kleinman and van der Geest (2009) write that there are two basic aspects of care, one being emotional and the other technical and practical. Depending on the context, one aspect of care may overrule the other. In medical institutional settings there is a sharp focus on the technical aspect, whereas in everyday life it is the emotional dimension that prevails (Kleinman and van der Geest, 2009). This is exemplified in a study on mundane care, where Brownlie and Spandler (2018) examine how people support their community members and give low-level help such as shopping for groceries and offering childcare. These seemingly trivial moments of care are the results of careful choreographies of time and space, with special attention being paid to retaining the dignity of those being cared for (Brownlie and Spandler, 2018). Here, the emotional and material aspects of care converge, bringing about a smooth experience of caring for others and being cared for by others. Tinkering can therefore be read as the work people undertake to negotiate emotional sensitivities and material constraints in order to resolve emergent tensions and move life forward.

Care as a negotiated practice also indicates that tinkering is inherently experimental, adaptive and innovative. To recall previously mentioned examples, respondents in Guell's (2012) study found ways to access alternative health services, adapt medical advice and experiment with everyday cooking to manage their diabetes, whereas people in Phillimore and colleagues' (2019) study creatively mobilised local and international resources within private networks to make medications accessible. At the same time, tinkering is configured along with changing material settings. The use of digital technologies in self-care, for example, allowed respondents in

Kingod's (2018) study to actively seek ideas on social media to adapt medication into daily life without compromising too much of their current lifestyle (Kingod, 2018). All these cases show that tinkered care involves a range of activities such as identifying and mobilising available resources, and translating fragmented knowledge to manage complex and often challenging everyday life. Adding to this, it is important to note that such translations often happen tactically (Guell, 2012). This resonates in Broom and colleagues' (2020) study on antibiotic access in India. The authors characterise people's antibiotic consumption as an employment of "contextual creativity", in the sense that antibiotics are accessed and used in a goal-oriented manner to "work with constraints" and serve one's interest (Broom et al., 2020: 24). This understanding of tinkering, thus, helps to illuminate the enactment of agency in particular time-space dimensions.

In a study about rearranging the home into a place of treatment for people suffering from chronic diseases, Langstrup (2013) shows that there are constant negotiations among entities such as medicine dispensing systems, nurses' routine check-up phone calls and patients' making space to store medicines at home (Langstrup, 2013). While negotiating these elements, the author identifies a tension between the home as a place of treatment and the home as a place of living and maintaining social life. Care practices are therefore not isolated activities or merely done for medical reasons, but are embedded in people's lifeworld. In connection with this, the idea of tinkering extends the notion of care beyond its institutional connotations to everyday life. Such an extended domain of care, however, is rarely acknowledged in health interventions (Langstrup, 2013; Beckmann, 2013).

Care for one's health can be interpreted as handling a portion of one's daily life to make it more liveable. In some cases, one has to prioritise things and relations in life other than one's health, as exemplified in Langstrup's (2013) study. In this regard, tinkering is not only about patching together available material resources, but requires continuously seeking ways to form and accommodate relations with other people and things. Such processes entail activities contingent on available material, emotional and social resources (Winance, 2010). Hence, tinkering brings together meanings and actions. It offers a pathway to understand translations of knowledge into concrete care practices.

Following Mol, tinkering also ties into an ethics of care, in the sense that care is not only judged by the results or effects on bodily improvement (Mol, 2008; Mol et al., 2010). It is also valued as a determination to keep trying while acknowledging that failed treatments are not always unavoidable (Mol et al., 2010). In this respect, tinkering is focused on the moralities rather than the rationalities behind choices or decisions. Doing care has its emotional dimension, that is the morality of not giving up and a devotion to making life more liveable and sufferings more bearable. One presumption becomes clear at this point: that the outcomes of healthcare can be unpredictable, for better or for worse. This is one of the key differences between health services and some conventional services such as retail (Berry and Bendapudi,

2007). A focus on tinkering, then, steers discussions on the value of care away from asking whether a medicine would work as expected to asking about the circumstances in which a medicine is sought after and used, and, equally importantly, what else one can do when medicines do not always take expected effect. To this end, tinkering makes it possible to view care in its multiplicities and in settings beyond medical institutions (Mol, 2002).

To summarise, as attentive experimentation, tinkering does not presume a coherent or fluid whole constituted by heterogenous entities, but acknowledge frictions and changeability within any relations (Mol et al., 2010). This conceptualisation corresponds to the exteriority of relations and agency as distributed and enacted, two highlighted propositions in assemblage thinking. In addition, viewing care as a tinkered practice points to grey zones wherein medicine access hinges upon negotiations among different forms of knowledge, different legal systems and non-medicine-related everyday concerns.

Methods and material

Fox and Alldred (2018) propose to view research processes as assemblages in that research design is affected by both human and nonhuman entities. A research assemblage includes (albeit not exclusively) the phenomenon of being researched; research tools such as interview guides; technologies for analysis such as computer software; the physical space where data are collected; the intended audience and the research institute; and not least researchers' intellectual interest. These elements and the relations among them affect data collection and ultimately shape knowledge production (Fox and Alldred, 2018). Methods, data and findings are therefore produced through relations, rather than being constructed solely by researchers or research participants (Feely, 2019). The idea of research assemblages reinforces that methods are performative research practices to enact realities in particular time-space arrangements (Law, 2009).

The research path I have taken is far from linear. I started by reviewing literature on SF medical products, trying to figure out what the problem was about (Paper 1). A prominent similarity was identified between SF medical products and other phenomena such as organ trafficking and surrogacy, whereby in the majority of medical research medicines tend to be viewed as fixed and inert technologies, whereas in social and cultural sciences they are generally viewed as ambivalent and fluid (Russell and Widger, 2018; Whyte et al., 2002; Hardon and Sanabria, 2017; Lock and Nguyen, 2010). To attend to the fluid nature of medicines, I take up Marcus' (1995) idea of following objects (Marcus, 1995). Here, following is not simply moving from one setting to another, but involves paralleling, sorting out different relationships in the research assemblages, and being led by the phenomenon while being prepared to go after what is happening in the field (O'Dell and Willim, 2017). Following objects can thus be understood as following emerging tensions where the realities are multiple (Mol, 2002). In this study, the research design has been informed by the perception of co-existing multiple realities, which is also in line with assemblage thinking that emphasises plurality over unity.

To capture human-medicine inter-relations, I collected material in various empirical fields where medicines were talked about, handled and exchanged. The material was derived from surveys and ethnographic methods. Two digital surveys were conducted, among Swedish physicians and Swedish residents, to explore their views on medicine access. In addition, I carried out participant observations at a customs clearance office at Arlanda Airport to observe how customs screened packages sent

from abroad to detect suspicious purchases of medical products. I also lurked in two Swedish online chat forums and followed discussion threads where people sought medical advice and shared personal experiences of medicine access. Finally, I conducted an ethnographic study at pharmacies in southern Sweden to study care provision and used methods including semi-structured interviews, participant observations at physical pharmacy stores, and observations of Swedish pharmacies' social media accounts and official websites.

I perceive my field site as a heterogenous network that cuts across digital and physical spaces, and across public and private domains, rather than a bounded space that researchers can enter and leave to retrieve research material (Burrell, 2009; Krieg et al., 2017). In the remainder of this chapter, I start by presenting methods used for data collection. My intention here is to show how these methods and the generated material have collectively allowed me to probe into care as situated practices. I then describe data analysis. Lastly, I reflect on research ethics, both as a pre-designed institutional procedure and as an ongoing reflexive process.

Surveys

The subject of SF medical products had rarely been reported in the Swedish media at the time when I started this research project. An immediate question that concerned me was people's awareness of the issue. During informal conversations with some of my Swedish acquaintances, this subject surprised and somehow confused them, as they seldom thought about possible medical risks associated with any forms of medicine access. This reaction made sense to some extent, given the relatively robust and regulated pharmaceutical market in Sweden. However, taking into account increasingly diversified ways of accessing medicines thanks to digital platforms and international travel, the low awareness of medical risks appeared intriguing. As for medical professionals, their recognition of SF medical products was also unclear in the existing literature (Liu and Lundin, 2016). Against this backdrop, two digital surveys were conducted with Swedish physicians and the Swedish public.

Surveys are seldom considered a mainstream research method in qualitative studies (Braun et al., 2021). There are drawbacks with surveys, such as the lack of conversational interaction between researchers and respondents. Surveys also risk generating thin data as respondents tend to answer questions briefly (Braun et al., 2021). Despite these drawbacks, Braun and colleagues (2021) argue that digital surveys have strengths in their openness and flexibility. Digital surveys allow respondents to take some control of the research process, as people can decide when, where and how they want to participate (Terry and Braun, 2017). These advantages make surveys particularly suitable when studying health-related phenomena, as questions may be related to sensitive topics and respondents may feel reluctant to

share their views or personal experiences in face-to-face conversations. In addition to these benefits, digital surveys can possibly reach a wide range of respondents who might otherwise be difficult to recruit due to practical limitations such as geographic distance and financial cost. In this respect, digital surveys offer a wide-angle approach so that a diversity of viewpoints, sense-making and experiences can potentially be collected. This diversity of voices is important, especially when studying under-explored phenomena (Braun et al., 2021) such as SF medical products in the Swedish context. For this study, digital surveys were therefore particularly suitable during the scoping and explorative stage, to map out the level of knowledge and awareness among prospective respondents. Insights distilled from the survey data were then used to inform the subsequent research design. To be specific, they guided me to pharmacies, where medicines were transacted and where institutional and commercial care services were intertwined.

Survey of Swedish physicians

The survey of Swedish physicians was designed through my collaboration with researchers from medicine and cultural sciences, and was distributed by TNS SIFO, a Swedish market research institute. Respondents were recruited from TNS SIFO's own database, which was regularly updated. Answers from 200 physicians were collected, including 100 general practitioners (GPs) and 100 emergency practitioners (EPs). In total, 260 GPs and 900 EPs from TNS SIFO's database were randomly selected and contacted by email. Respondents were recruited continuously until the first 200 responses had been collected. All potential respondents were introduced to the research topic with written information before they agreed to participate. Once consent had been obtained, a link to the survey was sent out to respondents. Demographic information including age, gender, and the region where they worked was collected, in addition to ten main questions (see Appendix I). This survey included a mixture of multiple-choice and open-ended questions. The answers were collected during May and June 2016. This data set was used in Paper 3. Part of the material was quantitatively analysed and reported in another publication that is not included in this dissertation (Funestrand et al., 2019).

It is worth noting that we, the research team I was part of, used the Swedish term "olagliga och förfalskade läkemedel" in the survey. This Swedish term does not entirely correspond to the WHO term "substandard and falsified medical products". However, the survey was designed before the WHO launched its term. We therefore chose a more colloquial expression in Swedish. The choice of word had an impact on how respondents answered the survey, as it might implicitly reduce the complexity entailed in the phenomenon of SF medical products to medicines of an illegal nature. However, in the analysis of the survey data, we were able to identify ambivalences in physician respondents' reasoning about care seekers' medicine

access from alternative channels (Paper 3). In this regard, the possible reduction of meanings in the choice of terms is limited in diverting the actual analysis.

Survey of Swedish residents

The survey of the Swedish public was designed through my collaboration with a researcher from cultural sciences. We used LimeSurvey, an open-source online survey platform, with the help of the Folklife Archives at Lund University. We pilot-tested the survey with five respondents from our private networks. Some questions were reformulated based on the feedback received. We then distributed the final version of the survey (see Appendix II) through the Folklife Archives' own digital database, a selection of Swedish patient organisations and the research team's networks. Demographic information was collected including age, gender, occupation, nationality, place of residence and level of education. The survey contained 14 main questions consisting of multiple choice and open-ended questions, in both English and Swedish. The link to the survey was open for four weeks in May 2016. 155 samples were collected, including 152 in Swedish and three in English. This data set was analysed qualitatively in Papers 2 and 3. Some findings were reported in a publication that is not included in this dissertation (Lundin and Liu, 2020).

It is worth clarifying a methodological issue regarding the recruitment of respondents. The Folklife Archives at Lund University does not actively recruit respondents. People who are interested in participating in surveys register their email addresses, and then receive alerts when new surveys are published. This practice follows the legal requirements of protecting personal information. However, it may lead to people who are not aware of or have not registered with this database being excluded. As well as distributing surveys through the Folklife Archives, we therefore also used other distribution channels. The Folklife Archives selected 34 relatively large patient organisations from a list compiled by Region Skåne, a regional council in Skåne, Sweden. We then emailed these organisations, describing the background information to the survey and asking for opportunities to disseminate it to their members. A digital link to the survey was also attached. Four patient organisations replied with a confirmation that they would distribute the link to their members, while the others did not respond. A third distribution channel was the research team's personal networks. To some extent, the recruitment process resembled convenience sampling where respondents were selected based on their ready accessibility (Waterfield, 2018). My colleague and I were aware that this method would amount to the issue of representativeness. This issue was reflected in the collected samples, as respondents appeared to be rather homogeneous with regard to education level and place of residence. In spite of this drawback, the material generated was analytically relevant to the topic of medicine access. Hence, the methodological shortcomings of convenience sampling were moderated.

Ethnographic methods

Ethnographic methods are another key approach in this study. They are "qualitative techniques for collecting or producing material on social life in different settings", including "interviews, observations, and other fieldwork procedures where the researcher is personally present in 'the field' of study" (Ehn et al., 2016: 2). In many ways, ethnographic approaches resemble the notion of research assemblage, as they also attend to the emergent aspect of research processes, the contingency of the produced knowledge and researchers' reflexivity. The idea of being in the field indicates an intimate relationship between the researcher and the field, making ethnographic approaches especially promising when investigating the situatedness of care practices and everyday medicine consumption. Ehn, Löfgren and Wilk (2016) point out that research processes are inherently messy and non-linear. Researchers should therefore actively weave a field site by staying alert to potential references in relation to the phenomena or research questions at hand (boyd, 2016).

As everyday life is increasingly mediated by communication technologies, researchers are required to attend to people's seemingly effortless shifts between physical and digital spaces and between different times (Soukup, 2012). Such shifts tend to be sedimented into daily routines which further blur temporal and spatial boundaries. In addition, it is important to recognise that, in any given research context, researchers and research participants are "co-constructing moving boundaries moment to moment in the performances of everyday life" (Soukup, 2012: 234). This delivers two messages. First, it means that researchers can only capture fragmented moments of everyday life which are produced in specific time-space arrangements (Wästerfors, 2018). Second, doing ethnography involves juxtaposing research material composed in various forms. In my ethnographic engagement, the accumulated empirical material took the form of written fieldnotes, sketches, photos, screenshots, saved weblinks, pharmacy product brochures and audio recordings of interviews. For this study, ethnography is more than a collection of qualitative research methods used at a particular stage, and is instead a methodological approach and mindset to get close to care practices in situ. Thus, ethnographic methods have been used more or less throughout the process, both in the broadest sense as a complement to surveys, and as an entirety on its own. I elaborate on this in the following.

Observation at a customs clearance point

Following a conference presentation of initial research output about SF medical products, my colleague – with whom I collaborated on the survey of Swedish residents – and I were invited by Swedish MPA to participate in the Pangea operation in September 2018. Pangea is an annual International Criminal Police Organisation (INTERPOL) operation to tackle SF medical products. It specifically

targets the illegal online sale of medical products. Sweden has participated in Pangea on a regular basis. During the participant observation, we followed Swedish customs officers and observed how they scanned incoming postal packages from abroad to identify potentially poor-quality medicines. The experience allowed me to see how illicit medical products were packaged to pass off as ordinary mail and avoid being detected. It also inspired me to apply theories of materialities to approach SF medical products. This observation was documented in Paper 3.

Observation in the digital space

To get a feeling of a research field in the initial stage, an important strategy is to search for any potentially related information (Ehn et al., 2016). I started with online arenas, lurking in two major online chat forums in Sweden: Familjeliv and Flashback. These chat forums provide spaces for discussions on nearly any topic, from opinions on policies to very personal and private issues. They are open to anyone living in and outside Sweden who wants to start, join or simply follow a discussion. According to my observation, the discussions take place mostly – if not exclusively – in Swedish. Forum users can choose to disclose or anonymise their identities. Opinions and statements expressed in these forums can be very subjective. My goal of lurking in such digital spaces was to become familiar with how people, primarily in Sweden, discussed health-related issues online and what information was shared in these open spaces. I searched archived discussion threads using keywords including "köpa mediciner" (buy medicines), "internetapotek" (internet pharmacies) and "köpa utan recept" (buy without a prescription). The data generated from this observation were rich in their variety, but lacked clear research focuses (Smith et al., 2017). I did not initiate any form of interaction with thread participants during the observation, leaving me in a rather passive position, particularly considering the co-productive perspective of knowledge production (Costello et al., 2017). However, used in combination with survey data as presented above, it functioned as a way to triangulate and produce more generalisable arguments. This data set was used in Papers 2 and 3.

As I moved to studying care services at retail pharmacies, pharmacies' digital presence provided rich background information. I regularly visited all major Swedish pharmacies' websites and their social media accounts. I took written notes and screenshots about the types of products they advertised, as well as the semiotic and visual presentations of digital promotions. My intention was not to systematically study pharmacies' digital services or marketing strategies, but to keep up with their marketing activities in order to prepare for my visits to physical stores. This data set was used in Paper 4.

Interviews with pharmacy customers

In parallel with ethnographic fieldwork at pharmacies, which will be presented in the next section, I conducted semi-structured interviews with pharmacy customers. Two selection criteria were set: over 18 years old and self-identified regular pharmacy customers. Nearly everyone has visited a pharmacy at some point, so to some extent the range of potential interviewees was broad. The first interviewee was recruited from my private network, and was then asked to put me in touch with to two potential interviewees. Using this snowballing method, I carried out six interviews between April 2019 and July 2020.[9] An interview guide was designed at the preparation stage, with a long list of questions divided into different topics (see Appendix III). This guide was highly explorative, which largely reflected my then limited knowledge about how people perceived pharmacies and how pharmacy staff worked. I later revised it after the first two interviews by re-ordering and re-grouping questions. It was clear to me that my aim with these interviews was not to produce a thematic analysis of interviewees' opinions about pharmacy services, but to use their narratives to identify possible references to inform my observation at pharmacies. This data set was used in Paper 4.

Ethnography at pharmacies

Ethnography, understood in its entirety, entails a bricolage approach (Ehn et al., 2016). As mentioned earlier, to follow is to be led (O'Dell and Willim, 2017). And being led is not passive, but active, in the sense that tensions can be developed into multiple directions. Researchers therefore need to make decisions about where to continue (O'Dell and Willim, 2017). Each decision made at a particular moment of research affects the path that follows. As my knowledge about the phenomenon of SF medical products grew deeper, the aim of the research project became more streamlined and concrete. Insights gained from Papers 2 and 3 led me to retail pharmacies, to examine care services in a setting where the commercial and the institutional are intertwined.

I did ethnography at two retail pharmacies. I was introduced to two pharmacy managers by two researchers I have collaborated with on another research project on the subject of SF medical products.[10] These researchers were trained as clinical pharmacists, and had colleagues working at retail pharmacies. I first emailed my contacts at these pharmacies, to introduce myself as a doctoral student and to explain my research interest. This was followed by a short conversation over the phone and a few rounds of text messages between me and the contact at each pharmacy. A date

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[9] The interview process was temporarily paused during spring 2020, due to the Covid-19 pandemic.

[10] https://portal.research.lu.se/sv/projects/falsified-medicines-in-a-multicultural-society-importance-of-know (accessed 31 January 2023)

and time were agreed for my first visit. During the first visit, I was required to sign a confidentiality form, stating that I would not disclose customers' personal information. I was also given a tour of both the pharmacy store and the staff area, and was introduced to all pharmacy staff working on that day.

This ethnographic immersion in pharmacies was described in detail in Paper 4. An observation protocol is attached to this dissertation as Appendix V. Here, I want to provide a brief description of the division of labour in Swedish pharmacies. This issue was specifically raised by anonymised reviewers during the peer-review process. I did not have the space to elaborate in the paper, but I was aware that pharmacy regulations varied from country to country. Hence, a clarification is needed on why I did not distinguish in the paper between pharmacists and staff who mainly work in the retail area. In Sweden, pharmacy staff consist of pharmacists (apotekare in Swedish, with a master's degree), presciptionists[11] (receptarie in Swedish, with a bachelor's degree) and pharmacy technicians (apoteksteknik in Swedish, with vocational training). There are differences in their assigned work tasks. One major difference is that pharmacists and presciptionists are authorised to dispense POMs, whereas pharmacy technicians can only dispense under the supervision of pharmacists and presciptionists. This division of labour legitimises a more powerful position held by pharmacists and presciptionists. Nevertheless, according to my observations in both pharmacies, when the customer flow in the retail section was high, both pharmacists and presciptionists were encouraged to leave the dispensary areas and work with retail customers. To quote a pharmacy manager I talked to during the fieldwork, the hierarchy was "rather flat". This statement about their organisational culture should not be taken as an objective description. However, it does indicate a quite distinct working environment in Swedish pharmacies compared to those in the UK or the US, where – by law – dispensary areas are strictly gated and pharmacists' authoritative roles are explicitly granted.

Data analysis

Surveys and ethnographic methods involve divergent operational procedures. Surveys can be said to follow a relatively linear process from designing to distributing. Once surveys have been sent out, researchers can rarely modify or influence the collection process. By comparison, ethnographic methods appear to be more flexible as researchers can potentially adjust approaches during the process. In spite of this difference, my analysis of material derived from these methods was consistently inspired by Braun and Clarke's thematic analysis (Braun and Clarke,

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[11] https://www.sverigesfarmaceuter.se/omsverigesfarmaceuter/vad-ar-en-farmaceut/ (accessed 31 January 2023)

2006; Braun and Clarke, 2019; Braun and Clarke, 2022). Data analysis is understood in a broader sense that includes analysis of both the collected data and the coded data (Braun and Clarke, 2006).

Following Braun and Clarke's (2006) thematic analysis, I started by reading and re-reading the free texts in surveys, my fieldnotes and interview transcripts. Initial ideas were noted down, alongside some original quotations which I judged to be representational. The initial ideas were then used to identify reoccurring patterns and shared meanings, which were later grouped into themes. As more themes were generated, I reviewed and refined them all by drawing on theoretical concepts and existing literature relevant to the research aims proposed in each of the appended papers. At this point, my analysis explicitly supported Braun and Clarke's argument that themes are "*actively* created by the researcher at the intersection of data, analytic process and subjectivity" (Braun and Clarke, 2019: 594, emphasis in original).

Three issues need to be clarified here. First, my analysis of data was recursive. I went back to the collected material constantly, to refresh my understandings and to spot any missing perspectives. This resulted in new themes emerging or previously identified themes growing in prominence in relation to other themes. Second, the surveys generated both qualitative and quantitative data. The analysis of the qualitative part followed the analytical process outlined above. The quantitative data were transformed into statistical figures. Working with these two types of data means that I moved between them, seeking to contextualise statistical data in qualitative material. Finally, writing constituted an important part of my data analysis, not only in terms of jotting down ideas, but also with regard to forming coherent narratives and refining arguments. To a large extent, my analysis was carried out through writing.

Research reflexivity

Ethical review

An essential step in my research process is ethical approval. Ethical review is designated to protect research participants from negative impacts of research. It requires scientific studies to be carried out "within locally-defined cultural expectations surrounding research conduct" (Fox and Alldred, 2018: 198). To this end, ethical review has the capacity to affect how flexible research design can be and how experimental and innovative researchers can be throughout the process (Pink, 2017). Whereas ethical review institutions seek to ensure some kind of certainty in the research process, the world where both researchers and research participants live is "processual, continually emergent and uncertain" (Pink, 2017: 30). Flexibility and preparedness in encountering the unknown are essential

characteristics of research, while the temporality and spatiality of everyday life are highly mediated by digital technologies (Soukup, 2012). In this regard, there is a difference between the ethics conceptualised in ethical review institutions and that practised in the actual research processes. Following Pink (2017), ethics in the former setting is ethics in advance, whereas in the latter it is ethics as ongoing. I do not suggest that either should be prioritised over the other. My argument is to acknowledge the value of both types of ethics, because ethics needs to be forward-looking as much as being reflected on. In other words, it needs to be continuously contemplated before, during and after a research project.

This study was reviewed and approved by Swedish Ethical Review Authority.[12] However, obtaining approval from an ethical review authority does not mean that the subsequent research process will be smooth. There are many negotiations in which researchers are unavoidably involved. This became particularly relevant when reviewing my experiences of conducting ethnographic observations in pharmacies. In some sense, this was also a way of practising care, that is, being sensitive to research participants' emotions. While applying for ethical approval, I was more concerned about evaluating the good and ills my research would bring to participants in a presumptive manner. It was rather researcher-centred at that stage. When I stepped into the actual field and reached out to my contacts in pharmacies, it immediately became clear that ethics stood on a shifting ground where multiple actors were involved. Pharmacies, as primary care institutions, are guided by a set of ethics where customer confidentiality is strongly emphasised. As mentioned earlier, on my first visit to pharmacies, I was asked to sign documents declaring that I would follow and respect their ethical guidelines. Signing these documents signalled that both pharmacy managers and I had to reach a kind of common ground that my presence and conduct in the field would not disturb their working environment or infringe on their commitment to protecting customer privacy. It also became very tangible to me that there were different ethics at play.

Language and data in the field

Doing fieldwork involves learning the language, both literally and metaphorically (Crang and Cook, 2007). In my situation, as a non-Swede, I was learning Swedish in order to communicate with research participants. Simultaneously, as a person with zero training in either medicine or pharmacy and who rarely used any pharmaceutical services, I needed to acquaint myself with the particular linguistic and bodily expressions used by the professional group of pharmacists. My outsider position in the field therefore became very obvious. An interesting observation was

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[12] The surveys of Swedish physicians and Swedish residents were approved with the case number 2016-238. Observations of online chat forums, participant observations of pharmacies and interviews with pharmacy customers were approved with the case number 2019-02226.

that the people I encountered opened up fairly quickly to share their views on the Swedish health system and to explain their work routines. My interpretation was that the relationship between me as a researcher and pharmacy staff as the researched could be characterised by me as a learner and them as possessing the knowledge and, thus, the autonomy to fill me with their understandings. The role of being an outsider was quite beneficial, especially at the beginning. As my engagement with the field continued, I began to strategically and cautiously use my lack of Swedish-ness and medical expertise to connect to research participants.

Language learning in the field worked in both directions. While I was busy learning research participants' language, I could sense a growing interest in my academic language from their side. For example, one pharmacy manager asked me from time to time what I thought about their service delivery to customers and whether I had any suggestions for improvements. I believe such questions were related to my academic field in service studies. Apart from this, I felt that research participants were not familiar with my methods, particularly ethnographic ones. This resulted in a certain degree of uncertainty among them. For example, I was approached by pharmacy staff several times asking what I was looking for, what information I needed and how they could help. I took these as generous gestures. However, after I explained that I was observing the store layout and the way they provided health services, I encountered a sense of confusion or even disappointment that they could not provide any form of immediate help. Research participants' willingness to contribute to my work was also shown during an interview. The moment the interviewee was seated, he asked: "So, how can I help?". I was not expecting such a question, which made me wonder what attitudes and positions it might have entailed. Interviews, in my understanding, are collaborations between interviewees and researchers to co-produce knowledge and treat interviewees as active meaning-makers (Holstein and Gubrium, 1995). However, the question of how to help seems to suggest a tendency whereby interviewees or the public in general are viewed as repositories of opinions and attitudes, and that their opinions and attitudes can simply be collected and used as unfiltered findings.

This led me to think how I could have engaged with research participants. A lesson learnt from the field is that ethics is not always predictable or something that can be pinpointed by the researcher alone or ahead of fieldwork. Apart from seeking to mitigate negative impacts on research participants, good research practices also involve communicating research design and research methods in a more accessible way. Ethics can be precautionary, but it is also negotiated between researchers and the researched in the field.

In an archaeological reading of Eurobarometer surveys, Law (2009) argues that surveys, like all other research methods, are performative. They do not simply bring realities into life, but create and reinforce certain realities supported by an established network of knowledge production practices (Law, 2009). In this respect, data generated from surveys and other methods should not be treated as objective

opinions or inherently meaningful. They are outcomes of a particular arrangement within a research assemblage, and cannot be entirely reduced to self-explanatory evidence (Braun and Clarke, 2019). Put differently, data are emergent, alive and not innocent (Koro-Ljungberg et al., 2018; Pink et al., 2018; Pink and Lanzeni, 2018). The generated knowledge is therefore always partial. This statement is a reminder of being reflexive throughout the research design. Wyatt and colleagues (2013: 142) propose that technology "mediates and structures researchers' interactions at all stages of the research process" in the same way as it mediates the feeling and doings of the researched. It means that data do not exist independently or isolated from other aspects of social lives. In this regard, so-called naturally occurring data such as those I acquired from online chat forums did not occur naturally. They were enacted by certain realities that chat forum members lived in. Thus, data are mediated, and are only meaningful in particular contexts, as are interpretations of them (Wyatt et al., 2013).

Interdisciplinary work

Before moving to the next section, where my findings are presented, I reflect on my collaboration with researchers from the disciplines of medicine and ethnology. My understanding of interdisciplinary work is still at an early stage of development. The following reflections should therefore be read as more of a learning outcome than a critical discussion of interdisciplinary work.

The collaboration started with a common interest in the phenomenon of SF medical products. When surveys were chosen as a suitable method to reach as many physicians as possible in Sweden, my collaborators from medical sciences provided their expertise in formulating survey questions (Paper 3). There were some aspects I would not have thought about, such as framing questions in a concise and precise manner and the logics of designing multiple-choice questions. These details distinguish surveys from face-to-face interactions, which I was more familiar with. Furthermore, it was the medical researchers in the team who pointed out the need for pilot testing before sending surveys to the public.

Another strength of such collaborations lies in the research team sharing analytical perspectives and updating the team with relevant insights within one's academic field. Specific to my case, collaborators from medicine prepared me for entering the pharmacies and learning pharmacists' professional language, whereas the ethnologists alerted me to being reflexive. Additionally, I became more aware of my own academic discipline. A telling example was that the use of services and value creation as analytical approaches to healthcare was a perspective that I brought to the research team.

Findings

This dissertation consists of four papers. Paper 1 synthesises insights from existing literature on the phenomenon of SF medical products. Papers 2–4 set out to empirically examine care practices, using data collected from surveys and ethnographic methods. These four papers collectively demonstrate a progression of my analytical perspectives. Step by step, they help me to achieve the research objective, that is to understand how medicine access is negotiated between care seekers and medical professionals. In this chapter, I summarise the papers and discuss how each of them responds to the research questions presented in the Introduction.

Paper 1. Substandard and falsified medical products as infrastructural objects: Synthesizing illegality in extra-legal domains

This paper addresses the first research question: *What insights have been produced regarding SF medical products and how can we comprehend the often-associated illegality of this phenomenon?*

Adams and colleagues' (2014) slow research approach takes local particularities as a starting point to investigate global health issues. My co-author and I find this argument inspiring. Reflecting on our own research and deep immersion in the academic field of SF medical products, we identify that illegality and extra-legal domains are rarely problematised in the extensive literature on this subject. Macro-level and global interventions are heavily advocated in medical and global health studies. They underlie certain assumptions that legal and extra-legal domains can be clearly separated and that the latter is deemed to be the problem area, threatening and polluting the former. In this paper, we aim to unpack the notion of illegality. To do so, we draw on a selection of studies from existing literature and use infrastructure as our research lens. In particular, we draw on the performative and relational aspects of infrastructures.

We argue that the phenomenon of SF medical products needs to be contextualised in a local-global nexus. The state and the pharmaceutical industry are powerful

stakeholders with the capacity to regulate and manipulate the pharmaceutical markets. Meanwhile, individual traders and consumers are important agents, who work with available material resources and social relations, seeking to mobilise personal networks to achieve their goals. The complexity of this phenomenon is, thus, unveiled when global interventions are implemented locally. Following this argument, we examine how infrastructural relations are formed and reformed among local and global actors in various socio-material arrangements. For example, the pharmaceutical industry works with state regulations, but also works above them to accommodate corporate strategies in a globalised market. Rather than simply attributing corporate strategies to their profit-driven nature, these strategies are outcomes contingent upon state policies, economic speculations and local production capacities. We thus underline Peterson's (2014) argument that these strategies are built into the capitalist systems (Peterson, 2014). Furthermore, our synthesis of existing literature suggests that a shadow economy does not exist entirely outside the legal structures (Hall et al., 2017; Nordstrom, 2007; Pisani et al., 2019; Hodges and Garnett, 2020; Peterson, 2014; Baxerres and Le Hesran, 2011). In many ways, it utilises the same social and material resources within an infrastructure where ordinary people practise care, live everyday life and negotiate different forms of responsibilities imposed by social norms (Beckmann, 2013).

Another key, related finding is the shift of regime from health safety to health security, evidenced in the state responses to the phenomenon of SF medical products. This shift is materialised in both policy-making and policy implementation. Regarding this shift, it is important to underline the slipperiness of the term "SF medical products". On the one hand, an ambiguous understanding of this phenomenon helps to form collaborations among stakeholders such as state governments and the pharmaceutical industry; on the other hand, the ambiguity risks diverting efforts from ensuring public health to serving the interests of multinational pharmaceutical companies. Thus, re-configured infrastructural relations seem only to reinforce the status quo, without achieving expected improvements in public health.

Based on these findings, we propose viewing SF medical products as infrastructural objects. The diverse ways of describing a medical product that falls outside the legal domains point to a need to attend to local particularities without simply attributing illegality to extra-legal domains. Market activities within the legal domains do not automatically denote legality. Likewise, illegality needs to be examined in the moral and material tensions emerging from shifting arrangements between people, objects and processes.

Paper 2. Medicines in the grey markets: A sociocultural analysis of individual agency.

This paper zooms in on care seekers in health services. It addresses the second research question: *How do care seekers navigate through healthcare services and make choices about where to access medicines?*

This paper investigates how care seekers mobilise, produce and consume knowledge to navigate within the health system. The material used in this paper comes from the survey of Swedish residents and observations in Swedish chat forums.

A key finding is that care seekers produced knowledge by drawing on both embodied and subjective experiences and institutional knowledge. The analysis shows that people employed a range of available resources within their reach. Medical professionals were not deemed by care seekers to be the sole medical authority, but one of the many. Care seekers felt the need to navigate among a range of competing authoritative voices in online and offline, personal and social networks. In the navigation process, experiences and skills gained from other consumption practices were transferred to medicine consumption. This led to different responses among respondents, some of whom were in favour of the diversified purchasing channels, while others resisted buying medicines online. Regardless of this ambivalence, it was rather clear that people became knowledge prosumers. In relation to this, medicines became a tool with which to calibrate the body according to societal expectations about being active and responsible health consumers.

When designing the survey, we intentionally wanted to push the limit by asking respondents to imagine a circumstance where they would go beyond the formal health system to search for alternative medications. Many respondents suddenly appeared very calculative in their reasoning. They started to weigh up the pros and cons of such an act, and tentatively came to a conclusion. We argue that this calculative attitude indicates a certain level of dependence people would like to have on medical professionals. Our material echoes Mol's (2008) finding that bad care is often associated with a feeling of being neglected. When such a feeling is coupled with diversified access to alternative health systems and health beliefs, some of our respondents stated that they had no other option but to go beyond formal healthcare. At this point, the question of legal or illegal medicine access was transformed into a moral negotiation. Thus, individual agency is enacted in relation to alternative health systems and beliefs beyond geographically defined jurisdictional boundaries, and with regard to the emergence of multiple authorities who provide competing opinions.

Another key finding is that respondents seem to have internalised the idea of taking individual responsibility. This is quite explicit in their active searches for advice and

information within a knowledge network. Here, it is important to note that such networks do not exist separately from everyday life, but are entangled with daily consumption practices. Hence, knowledge flows from one setting to another. Lastly, linking back to the tendency that people are viewed as naïve and vulnerable consumers in the majority of literature on SF medical products, we argue that victimhood is an inherent element of agency. Our respondents, intentionally or otherwise, become health agents when healthcare is marketised and significant emphasis is placed on individual effort. A possible consequence is that people are exposed to risks they themselves may not be aware of, such as the use of poor-quality medicines.

Paper 3. "I'm not a jukebox where you push a button and then I sing". Negotiating medicine access in physician-patient encounters

Paper 3 continues with the empirical enquiry on care practices. It looks at physician-patient relationships and mainly draws on data from two digital surveys and observations at a customs clearance office at Stockholm's Arlanda Airport and in online chat forums. Additional empirical material was derived from fieldnotes taken at a primary care centre by a co-author who worked as a physician. The findings from this paper illuminate the second and the third research questions: *How do medical professionals perceive care seekers' self-care practices, and how do they engage with care seekers in care services? How do care seekers navigate through healthcare services and make choices about where to access medicines?*

In this paper, we aim to contribute to an understanding of physician-patient relationships in the shift of healthcare models from cure-oriented to patient-oriented, and in an increasingly digitalised health market in Sweden. Given disparate legalisations of medicines and diverse health systems across countries, medicine access in legal grey zones points to a need for insights into what constitutes good care and how physicians can engage with care seekers in a meaningful way. These issues are particularly pertinent in the Swedish context, as national health insurance does not cover unwanted medical effects if they are caused by medicines obtained outside Swedish formal healthcare. Bearing this background in mind, we investigate the views and attitudes of care seekers and medical professionals on medicine access in medical grey zones.

Our analysis suggests that care seeking is an emotional involvement, not only because of physical or mental suffering due to the diseases in question, but also due to care seekers' expectations for their subjective feelings to be respected and taken seriously. We find that our lay respondents both acknowledged medical

professionals' expertise and emphasised the importance of sharing responsibilities at the same time. This suggests that the meaning and value of medical consultations hinge on how medical professionals handle care seekers' emotional state. Zooming out and linking to societal changes, such as the diversified purchasing channels and the digital social space for people to share personal experiences, we identify a push-and-pull effect. The feeling of being neglected by medical professionals pushes care seekers away from formal healthcare, whereas existing alternatives including self-proclaimed medical experts online pull them in. This finding echoes an argument made in Paper 2, that the one who chooses becomes an authority in the act of choosing between multiple options.

Our analysis about physicians shows that physicians found it challenging and difficult to intervene in people's medicine access and self-care practices. One reason for this, according to physician respondents, was a lack of information about care seekers' purchasing scenarios, as the latter tended to withhold their medicine access strategies. Another reason, which we want to highlight here, was that physicians did not simply follow medical protocols, but made medical diagnoses based on a number of considerations apart from their expert knowledge. For example, physicians acknowledged different prescription traditions and pharmaceutical regulations in countries other than Sweden. They also stressed the importance of considering one's medical history to determine the type of treatment. These findings indicate that professional judgement of appropriate or inappropriate medicine access is produced contextually. Furthermore, physician respondents had an understanding of the impact of social media and digital technologies in shaping people's medicine consumption and self-care. However, there was much uncertainty among these professionals regarding how to react to it.

Moving between the views of care seekers and those of physicians, the analysis suggests that health paternalism remains in medical encounters. Physician respondents, however, rarely reflected upon this issue. Instead, they tended to question how care seekers could make responsible choices given the liberalised and globalised market structures. In this respect, we argue that professional knowledge is not opposed to lay knowledge. Physician-patient encounters are meeting points where partly overlapping knowledge networks are negotiated into an agreed medical treatment. Thus, drawing on the analysis, we suggest medical professionals to be proactive during medical consultations. An active and meaningful health service encounter can start by asking care seekers about their medicine consumption practices in a skilful way, in order to avoid a situation where physicians do not ask and care seekers do not tell.

Paper 4. Care in the air? Atmospheres of care in Swedish pharmacies

Papers 2 and 3 point to a tension between care practised in the logic of a liberalised market and that in the logic of medical institutions. Following this lead, Paper 4 sets out to investigate care services in pharmacies. In Sweden, as in many other countries, pharmacies are positioned as an important sector in formal health systems. However, Swedish pharmacies have undergone several structural changes, with the latest one being privatisation since 2009. This means that pharmacies also operate as retailers. This semi-institutional and semi-retail setting makes it possible to explore whether care can be provided beyond institutionally scripted forms. Paper 4 therefore looks at medical professionals and specifically addresses the third research question: *How do medical professionals perceive care seekers' self-care practices, and how do they engage with care seekers in care services?*

Drawing on the concept of atmosphere, I show that care is carefully staged in material settings. It is embodied and practised through pharmacy staff's routinised engagement with the environment and customers. A telling example is the maintenance of a deodorant space in pharmacies to signal care and safety. Furthermore, I demonstrate that care services involve more than simply dispensing medicines and offering medical advice. They are affective activities. To some extent, pharmacy staff undertake a form of atmospheric labour that fills pharmacies with senses of care. Linking back to the literature on care services in pharmacies, working as healthcare professionals and working as retailers are often characterised as being opposed to each other. My analysis suggests that these two roles are intertwined. Pharmacy staff balance between being medical professionals with duties to promote safe medicine use on the one hand, and being retailers transforming health products into attractive commodities on the other. It is in these balancing acts that pharmacies become and sustain places of care. My analysis then points to pharmacies being socio-material assemblages where senses of care are enacted and enabled.

Considering structural and regulatory changes in Swedish healthcare, where public services are increasingly provided by private actors, Paper 4 provides an alternative conceptualisation of care beyond institutionally scripted understandings. With this paper, I want to emphasise a need to re-think what constitutes good care and how practices of care evolve alongside societal transitions. Taking one step further, pharmaceutical ingredients have therapeutic effects, which at best turn them into health products. However, it takes attentiveness to the material environment and a sensitivity to customers' emotions to transform medicines into products of care and pharmacies into caring places.

Concluding discussion

The aim of this dissertation is to advance knowledge on care as situated practices within and beyond medical institutional settings. I have followed and been led by emerging insights at different stages to examine care seeking and care provision. A conceptual reading of the existing literature on SF medical products (Paper 1) sets the stage for empirical investigations on care, where the knowledge and practices of physicians, pharmacy staff and care seekers are analysed, respectively in Papers 2–4. This chapter begins by discussing findings in relation to the overarching theoretical perspectives, assembling and tinkering. These concepts have been in my analytical repository throughout the research. They enabled me to examine and develop the idea that care is a relational practice. Reflections on the notion of grey zones are also intertwined into the discussion of findings. I end this chapter by describing the contributions of this dissertation.

Care as tinkered practices

In the choice discourse, care seekers are addressed as empowered and capable customers of health services rather than patients who passively receive diagnoses or treatments. My analysis shows that taking responsibility for one's health has sedimented into everyday choice-making, including where and how to access medicines. Agency is thus enabled in a situation where the ability to be flexible and adaptable to any form of change increasingly becomes a social norm. This point is explicitly supported when care seekers actively build up their knowledge networks and transfer knowledge gained from other consumption scenarios to accessing and using medicines (Paper 2).

In the translation from knowing to doing, digital technologies play an enabling role. They do not function simply as tools for people to get information or make purchases; they also help re-define self-care in the digital age. The online chat forums provide an arena where people can articulate and share personal experiences of care and form communities with those who have similar health concerns. In addition, both my empirical data and previous studies point to the emergence of self-proclaimed medical authorities in digital spaces (Maslen and Lupton, 2019). Hence, lay expertise is not merely about acquiring health knowledge, but extends to producing and mediating it. Understanding self-care and lay expertise in this way

depicts a continuous learning process where people negotiate multiple ideas and health beliefs to eventually form judgements that suit individual conditions. In such processes, the boundaries between the production and consumption of health knowledge are transgressed. In turn, I argue that people are crafted health knowledge prosumers (Paper 2).

Additionally, time and space are important elements that configure care seekers' judgement and decisions on medicine access. Choice-making hinges on available material resources, previous experiences with healthcare and anticipations for a liveable life (Papers 2 and 3). Simultaneously, health systems in other jurisdictions and alternative health claims beyond biomedical regimes also come into play. These temporal and spatial elements are assembled to rationalise whether care seekers approach medical professionals and – if so – when, where and how they do so. I characterise the formation of lay knowledge and its translation into care practices as tinkering; that is, being adaptive and making the best of the current situation.

Tinkering is far from being a newly discovered practice. The term is used in everyday language. The Cambridge Dictionary defines it as "to make small changes to something, especially in an attempt to repair or improve it".[13] My emphasis here is that the tinkered aspect of care, specifically self-care, needs to be situated within a broader context, where the idea of being experimentative and innovative is widely endorsed in many aspects of everyday life (Resnick and Rosenbaum, 2013). A telling example is that people share experiences of fabricating or hacking medical devices on social media (Kingod, 2018). While tinkering entails the creative use of resources, it may also lead to unforeseen risks. One such risk is what this study concerns: exposure to poor-quality medicines. Tinkered care, therefore, suggests that victimhood and agency inherently constitute one another. This statement challenges the prevailing perception in literature of SF medical products where care seekers are viewed as vulnerable victims or naïve consumers.

Yet, a paradox lies in the fact that tinkered self-care is often performed to fix the problems that happen in the here and now, while health risks communicated in many public health interventions are future-oriented. In these temporal disjunctions, grey zones become visible. Building upon this point, medicine access outside formal healthcare should not simply be attributed to the liberalisation of health markets or the digitalisation of pharmaceutical services, despite these being important elements in shaping medicine consumption. In health policies, lay knowledge is increasingly recognised as a legitimatised form of expertise. It coheres with the shift in healthcare models from cure-oriented to patient-oriented. My analysis points to some ambivalences in this shift. Lay respondents are well aware of their rights as patients to choose care providers and decide for themselves on medication. However, care seekers acknowledge that they lack medical expertise, and thus competence, in

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[13] https://dictionary.cambridge.org/dictionary/english/tinker (accessed 31 January 2023)

making informed decisions. In many ways, the knowledge discrepancy between the lay and the professional is deemed an important reason for care seekers to visit physicians. To some extent, this is where the value of medical consultations lies. It therefore disappoints care seekers when physicians are perceived as strictly following institutionalised protocols and do not seem to do more than is required by regulations. Thus, care seeking has to be understood in relation to the ways care is provided.

Viewpoints from physicians, on the other hand, suggest that this professional group faces difficulties accessing people's self-care strategies. Although they recognise care seekers' changing medicine consumption, this change is not reflected upon in relation to the knowledge-power imbalance inherent in physician-patient relationships. Rather, these medical professionals express their worries about the impact of liberalised pharmaceutical markets and digitalised experience-sharing within social groups. On top of this, they also express a sense of uncertainty, even hesitancy, to intervene in people's self-care when potentially risky medicine access is identified. For one thing, these findings indicate that communication skills are needed to effectively engage with care seekers, as pointed out by the physician respondents themselves. For another, a point I want to highlight – based on my analysis and my reading of existing literature – is that health services are emotionally charged, not only for those being cared for, but also for those who provide care (Berry, 2019). Following this line of reasoning, tensions in physician-patient encounters do not necessarily arise due to incompatibilities between lay and professional knowledge, but reside in different standpoints taken by both parties and in different ways of relating to the choice-informed health system. Relatedly, medicine consumption in grey zones does not essentially arise from conflicting interests between care seekers and medical professionals, but possibly emerges from a lack of common ground on which to initiate dialogues. So, the question is what constitutes good health services?

With this question in mind, I moved to pharmacies where profit-oriented businesses are strongly represented in health services. At the intersection where the commercial and the institutional are often positioned as being opposed to each other, my analysis points to care provision not always following prescribed instructions (Paper 4). The power hierarchy, as identified in physician-patient encounters, is not entirely eliminated in the pharmacy setting. Pharmacists still function as medicine gatekeepers. However, this power imbalance is carefully managed through pharmacy staff's embodied engagement with pharmacy customers and the store environment. Here, good care can be defined as attentiveness to both the physical surroundings and care seekers' emotions. Such ways of providing care fulfil, at least to a certain extent, lay respondents' desire to be treated with respect regarding both their sickness and their presence as a person with feelings and other social relations.

Until the point when I had finalised Papers 3 and 4, I began to feel more optimism in light of medicine consumption in grey zones. Medical professionals, including both physicians and pharmacy staff, have explicitly demonstrated their reflexive use

of expert knowledge to make judgements about safeguarding care seekers' medicine access. They seek ways to reinstate their medical authority in a health market full of competing voices. They also rely on both medical knowledge and understandings of societal changes to negotiate the ambiguities between the categories of good and bad self-care. To some extent, professional expertise can be defined as covering both biomedical facts and skills of attuning to specific emerging situations. On the care seekers' side, efforts are made to navigate within the plural health systems. People have learned to work with proliferating health information to scaffold their final decisions. However, the dependence on expert knowledge and a desire to share responsibilities are explicit. Drawing on my analysis of both care seekers and medical professionals, there is room to build a more engaging relationship between these two parties, and hence for collaborations that allow different degrees of dependence.

Tinkering is more than just a coping strategy or patching up available resources. Its essence lies in attentiveness and flexibility. Specific to the study on care practices, tinkering involves attuning to emerging material opportunities such as digital technologies, multiple health systems and – broadly speaking – social trends. In this regard, conceptualising care as a tinkered practice and medicine consumption as assemblages re-defines lay and professional health knowledge and disrupts the assumed tensions between them. Furthermore, such conceptualisations point to healthcare involving multiple actors. While paternalism still seems to prevail in the encounters between care seekers and medical professionals, an over-emphasis on the experiences of care seekers might obscure other aspects of health services, such as care providers' professional experiences and knowledge. Drawing on my analysis, physicians and pharmacy staff also seek ways to work reflexively and flexibly, albeit being constrained by legal and professional regulations.

Taking these insights to re-visit the notion of grey zones, an additional layer to acting as a research lens is that grey zones carve out a field where frictions and divergences are made visible. The spatiality and temporality of grey zones evolve in a web of social and material relations where societal shifts and technological advances have a tangible impact on everyday medicine consumption, resulting in constant negotiations. Grey zones become therefore temporarily visible when frictions and divergences become explicit, and then resume their invisible nature when issues are temporarily resolved. Following Hardon and Moyer (2014), understanding the constellations of care requires a focus on the specificities of local practices (Hardon and Moyer, 2014). If we take the commodification and marketisation of health as a known setting, then we need tools to account for multiple enactments of care, and hopefully to locate the ephemeral yet deeply embedded grey zones in everyday medicine consumption. This dissertation has therefore been such an attempt to delineate the formation of grey zones in the provision and experiences of health services.

Contributions and final remarks

This dissertation adds knowledge to relationalities of care by conceptualising care as tinkered practices. My material and analysis have also provided an empirical account of health services as multi-actor networks. They cast light on how frontline medical professionals and care seekers negotiate medicine access by reflexively and creatively working with social and material resources. Apart from demonstrating how relations are formed and change to configure medicine consumption, I additionally delineate the processual, emergent and situated formation of professional and lay expertise in everyday handling of medicine access.

Another contribution lies in the investigation of experiences of health service providers. Service logic is not only confined to commercial and profit-driven sectors, but has been extensively used to guide reforms in public sectors (Subramony and Groth, 2021). Healthcare is one such example. This dissertation provides insights concerning not only care seeking, but also care provision within medical institutions and between institutional and commercial settings. I have introduced to the field of service studies a well-established and growing research stream that emphasises the multiplicities and materialities of care. As my analysis shows, what is needed for a meaningful engagement between care seekers and medical professionals is to identify a common ground for dialogues while recognising the uneven distribution of knowledge and power in these relations.

Linking back to the phenomenon of SF medical products that this research has been concerned with since the beginning, my study provides insights into micro-level investigations of care seeking and care provision, to supplement macro-level and global approaches to public health issues. Global interventions – including top-down policies and market surveillance mechanisms – are needed, and have had some effects. Yet, building on my conceptual reading of existing studies on SF medical products and empirical analyses of health services, this dissertation has offered evidence to show that medicine consumption is embedded in the dynamics of social and material infrastructures and that choice-making needs to be understood at the intersection where macro societal transitions encounter individual situations.

Finally, I want to end this dissertation on an optimistic note. Before new service concepts or healthcare models are innovated, it might worth looking at good care practices that are already happening. Rather than emphasising differences or incompatibilities between cost-efficient public services and profit-oriented private services, between so-called objective and systematic professional knowledge and experiential and fragmented lay knowledge, I argue that frontline healthcare service workers are reflexive in handling changes. I have identified some good care practices, such as the way pharmacists balance seemingly contradictory elements of being retailers and medical professionals. More examples of such practices will emerge if interviews and observations are also conducted in physician-patient

encounters. This certainly points to a further research direction. Putting that aside, I underline the importance of taking a step back to examine existing knowledge and practices of care service providers at work. I also highlight a need to understand health services as neither customer-centred nor provider-centred, but centred on care as tinkered practices. The focus therefore moves from individual actors to the relations between them. Hence, in a societal context where care is increasingly practised beyond the reach of medical professionals, and in a research context where consumer autonomy and customer agency are well-researched, I hope this dissertation has been able to suggest bringing the professionals back for dialogues.

Appendices

I. Survey of Swedish physicians

Introduktion

Olagliga och förfalskade läkemedel är ett samlingsbegrepp för farmaceutiska produkter som framför allt

- är bedrägligt förfalskade med avsikt att framstå som äkta
- säljs fastän produkten för länge sedan har passerat utgångsdatum
- säljs genom förmedlare som inte är auktoriserade t ex på Internet eller i butiker/ marknader där tillstånd saknas.

Olagliga och förfalskade läkemedel kan vara verkningslösa eller skadliga. Försäljningen via e-handel ökar allt mer i Sverige, Europa och övriga världen med preparat som bantningsmedel, antidepressiva medel, potensstimulerande medel, sömntabletter, antibiotika mm. Även i de fattigare delarna av världen där livshotande sjukdomar som malaria, aids och tuberkulos härjar, är olagliga och förfalskade läkemedel ett tilltagande problem. Sjukvården, ideella organisationer och enskilda människor sätter sina förhoppningar till en förväntad effekt som uteblir eller som i värsta fall leder till ett handikapp eller snar död.

Olagliga och förfalskade läkemedel är relaterade till läkemedelsbedrägeri och bekämpas av bl.a. WHO och av Interpol. Enligt WHO utgörs 10 % av den globala läkemedelsdistributionen av olagliga läkemedel. Det svenska Läkemedelsverket anger att 3 % av den svenska befolkningen någon gång har köpt medicin på internet och 35 % av befolkningen uppger att de är intresserade av att göra så. Europeiska läkemedelsmyndigheten liksom andra läkemedelsmyndigheter världen över varnar för att olagliga och förfalskade mediciner kan vara förödande för såväl enskilda individer som för samhället i stort. I Sverige ser Läkemedelsverket, de polisiära myndigheterna och tullmyndigheterna mycket allvarligt på situationen som förutom mänskligt lidande får allvarliga socioekonomiska konsekvenser.

I denna undersökning är vi intresserade av att undersöka:

- Hur mycket läkare på akutmottagningar och i primärvården känner till kring olagliga och förfalskade läkemedel
- Vilken erfarenhet läkare har av dessa läkemedel
- Vilken (ytterligare) kunskap som behövs för att tackla detta problem

Resultaten från undersökningen kommer att användas som en basis för att utveckla relevant utbildningsmaterial för läkare kring olagliga och förfalskade läkemedel.

Resultaten från undersökningen kommer att användas i projektet *Olagliga läkemedel – informationsinsamling från allmänhet och läkare* som leds av professor Margareta Troein Töllborn (medicinska fakulteten) och professor Susanne Lundin (humanistiska fakulteten) vid Lunds universitet.

Demografisk information

Kön, ålder, akutmottagning eller primärvård, region/län

Frågeformulär

1. Har du hört talas om termen "olagliga och förfalskade läkemedel" innan du fick meddelande om denna undersökning?

   - Nej

   - Ja. → Varifrån har du hört talas om termen? **Multiple choice**

     Från kollegor

     Från patientrelaterade händelser på arbetet

     Från media → vänligen ange vilka media:

           i. TV
          ii. Dagstidning
         iii. Medicinsk tidskrift
         iv. Sociala medier
          v. Annat, vänligen ange:_____
     Från mina privata kontakter

     Annat, vänligen ange:_____

2. Har du personligen träffat på patienter som du misstänkte hade tagit olagliga eller förfalskade läkemedel? **Single choice**

   - Nej
   - Ja. → Varför misstänkte du detta? Vänligen beskriv: _____

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3. Har du personligen träffat på patienter som har tagit emot
    läkemedelsbehandling utomlands och där personen i fråga inte svarade
    som förväntat på behandlingen? **Single choice**

    -   Nej

    -   Ja. →
        Tänk på den senaste patient du träffat där detta gäller!

        Är det din bedömning att patienten fått en korrekt diagnos
        utomlands? **Single choice**

        i.   Ja.
        ii.   Nej. Vänligen ange vad som inte var korrekt: _____
        iii.   Vet ej.

        Är det din bedömning att patienten fått en korrekt behandling
        utomlands? **Single choice**

        i.   Ja.
        ii.   Nej. Vänligen ange vad som inte var korrekt:
        iii.   Vet ej.

        Är det din bedömning att patienten varit följsam till den förskrivna
        behandlingen? **Single choice**

        i.   Ja.
        ii.   Nej. På vilket sätt? Vänligen ange: _____
        iii.   Vet ej.

        Fick patienten oväntade biverkningar eller uteblev effekten av
        behandlingen patienten fått utomlands? **Single choice**

        i.   Ja. På vilket sätt? Vänligen ange: _____
        ii.   Nej.
        iii.   Vet ej.

        Har du några andra synpunkter på patienter som fått behandling
        utomlands? **Single choice**

        i.   Ja. Vänligen ange: _____
        ii.   Nej.

4. Om du har starka misstankar om att din patient tagit olagliga eller
    förfalskade läkemedel: hur agerar du då? Vänligen ange:
    _____ **Open question**

5. Har det hänt att patienter har kommit till dig med läkemedel som du inte känner till? **Single choice**

    -   Nej.

    -   Ja. →

        i.   Vilken typ av läkemedel handlar det då om? Vänligen ange: _____

        ii.   Hur och var har patienten fått dessa läkemedel? Vänligen ange: _____

        iii. Hur agerade du? Vänligen ange: _____

6. Har du någonsin gett din patient råd om var han/hon bör handla läkemedel? **Single choice**

    -   Nej.

    -   Ja, enbart när patienten frågar om råd. → Var rekommenderar du att de handlar läkemedel? **Multiple choice**

        i.   Apotek i Sverige (Butik)
        ii.   Internetbaserade svenska apotek
        iii. Andra butiker i Sverige
        iv.   Svenska internetbutiker förutom apotek
        v.   Utländska apotek (Butik)
        vi.   Internetbaserade utländska apotek
        vii. Annat, ange vänligen: _____

    -   Ja, jag ger råd om detta. → Var rekommenderar du att de handlar läkemedel? **Multiple choice**

        i.   Apotek i Sverige (Butik)
        ii.   Internetbaserade svenska apotek
        iii. Andra butiker i Sverige
        iv.   Svenska internetbutiker förutom apotek
        v.   Utländska apotek (Butik)
        vi.   Internetbaserade utländska apotek
        vii. Annat, ange vänligen: _____

7. Har du själv någonsin köpt läkemedel utomlands eller på internet?
Single choice

- Nej.

- Ja. →

    i. Utomlands: Vilken typ av läkemedel?
    ii. Internet: Vilken typ av läkemedel?
    iii. Kontrollerade du kvaliteten på något sätt? I så fall hur?

8. Behöver du mer kunskap om olagliga och förfalskade läkemedel? **Single choice**

- Nej.

- Ja. → På vilket sätt vill du få kunskapen? **Multiple choice**

    - Gruppdiskussioner
    - Utbildning på nätet
    - Föreläsningar
    - Skriftligt material (tidningsartiklar, riktlinjer etc.)
    - På annat sätt, vänligen ange: _____

9. Övriga synpunkter på fenomenet "olagliga och förfalskade läkemedel" eller synpunkter på enkäten? **Open question**

Projektet avser att genomföra intervjusamtal med läkare för att få fördjupad kunskap. Det är ännu inte bestämt när detta ska ske. Om du har intresse av att delta, vänligen kontakta Rui Liu, Institutionen för Kulturvetenskaper vid Lunds universitet, rui.liu@kultur.lu.se

Tack för din tid.

II. Survey of Swedish residents

Survey title: Where and how do you buy medicines?

1. Vad gör du när du känner dig sjuk? **Multiple choice**
   - [Ringer sjukvårdsupplysningen 1177]
   - [Försöker själv ställa en diagnos]
   - [Bokar tid på vårdcentralen eller kontaktar annan sjukvård]
   - [Annat]

2. Känner du till följande symbol? **Single choice**

Apotek med tillstånd av
Läkemedelsverket

3. Var brukar du köpa receptbelagda läkemedel? **Multiple choice**
   - [Apoteksbutik]
   - [Apoteksbutik på internet]
   - [Annan butik på internet]
   - [Annat]

4. Skulle det kännas tryggt att handla receptbelagda läkemedel från internet? **Open question**

5. Symbolen visar att ett apotek är legalt godkänt och auktoriserat. Spelar denna symbol någon roll när du handlar på internet? **Open question**

6. Vad har betydelse när du köper receptbelagda läkemedel? **Multiple choice**
   - [Pris]
   - [Tillverkningsland]
   - [Förpackning, t ex tidigare okänd förpackning, förpackning som endast har information på främmande språk, etc.]
   - [Läkemedel som du aldrig tidigare hört talas om]
   - [Annat]

7. Anser du det nödvändigt att konsultera sjukvården/läkemedelsexpertis innan du köper och använder receptbelagda läkemedel? Om ja, vem ska konsulteras: läkare, sjuksköterskor, personal på apoteken, e-läkare eller mobilappar? Om nej, beskriv varför. **Open question**

8. Har du haft vänner eller släktingar som bor utanför Sverige som skickar mediciner till dig? Om ja, beskriv situationen. (T ex varifrån skickar de mediciner? Vilka typer av läkemedel? Receptbelagda eller receptfria? Varför de gör så? Gör de det ofta etc.?) **Open question**

9. Brukar du ta mediciner med dig när du reser utomlands? Är de receptbelagda eller receptfria? Vad är det för sorts mediciner? **Open question**

10. Vad gör du när du är sjuk och i behov av medicin på resa utomlands? **Open question**

11. Har du köpt receptbelagda mediciner utomlands? Om ja, var köpte du mediciner? Beskriv kort en situation du varit med om och i vilket land det var. **Open question**

12. Om du fick/har en allvarlig sjukdom mot vilken det inte finns några effektiva läkemedel, exempelvis en neurologisk diagnos som Parkinsons sjukdom eller Huntingtons sjukdom, skulle du överväga att köpa behandlingar och/eller läkemedel som framställs lovande men som ännu inte haft bevisad vetenskaplig effekt eller genomgått en vetenskaplig prövning? **Open question**

13. Under vilka omständigheter skulle du själv söka efter behandlingar eller läkemedel som varken är lagligt godkända i Sverige eller vetenskapligt fastställda? Skulle du kunna tänka dig att göra det i Sverige, utomlands eller genom internet? **Open question**

14. Har du någonsin ifrågasatt kvaliteten och effektiviteten hos läkemedel som du har köpt via internet eller utomlands? Om ja, när och hur, och har du diskuterat detta med din läkare? **Open question**

III. Interview guide

Att söka vård

1. När var sista gången du sökte vård? Av vilken anledning? Hur gick det? Har du upplevt några svårigheter under processen?
2. Hur ofta söker du vård och av vilken anledning?
3. Hur ser en vanlig medicinsk konsultation ut för dig?
4. Förbereder du dig innan du söker vård? Varför eller varför inte? Om ja, hur brukar du förbereda dig?
5. Om läkare skriver ut läkemedel till dig, följer du alltid receptet? Varför eller varför inte?
6. Finns det några mediciner som du skulle vilja ha men läkarna inte förskriver? Har du haft sådana erfarenheter? Om ja, kan du beskriva det?
7. Diskutera du ofta medicineringsfrågor med vårdpersonal?
8. Har du provat e-läkare? Om ja, hur upplevde du det, i jämförelse med att träffa läkare personligen?

Att köpa läkemedel

1. Var brukar du köpa läkemedel eller hämta ut mediciner? Brukar du diskutera ditt hälsotillstånd och medicinering med apotekspersonal?
2. Finns det några läkemedel som du vill bunkra upp om du behöver dem? Om ja, är de receptbelagda eller icke-receptbelagda?
3. Har du delat läkemedel med någon? Med vem? När var sista gången du gjorde det? Kan du beskriva situationen?
4. Har du köpt mediciner från Internet? Om ja, finns det några specifika internetapotek som du brukar besöka? Vilken typ av läkemedel brukar du köpa från Internet?
5. (Jag presenterar EU:s logotyp som symboliserar auktoriserade internetapotek inom EU) Känner du till logotypen? Hur ser ett bra internetapotek ut för dig?
6. Har du köpt mediciner eller hälsoprodukter från butiker som inte är apotek? Om ja, kan du beskriva dina erfarenheter? Om nej, skulle du kunna tänka dig att göra det?
7. Har du köpt läkemedel eller hälsoprodukter från utlandet eller fått dem från bekanta som bor utomlands? Kan du beskriva situationerna?
8. Jämför olika sätt att handla läkemedel (på Internet, fysiska butiker, eller från bekanta, etc.). Vilket sätt brukar du använda?

Om egenvård

1. När du är sjuk, hur avgör du om du behöver besöka en läkare eller inte?
2. Har du upplevt någon oväntad effekt genom att konsumera mediciner? Anser du att det är nödvändigt att diskutera med läkarna om detta?
3. Har du provat några alternativa medicinska behandlingar eller medicinska produkter? Till exempel, vissa typer av kost, eller akupunktur, örtmediciner, osv. Hur var din upplevelse? När och hur började du med dessa alternativa mediciner?
4. Var brukar du få hälsoinformation?

IV. Consent form for interviewees

Information och samtycke

Detta medgivandeformulär innehåller två delar:

- Informationsblad (för att dela information om studien)
- Samtyckesformulär (för signaturer om du väljer att delta i studien)

Del 1: Informationsblad

Jag heter Rui Liu och är doktorand vid institutionen för service management och tjänstevetenskap, Lunds universitet. Jag genomför en studie av människors medicinkonsumtion. Du får detta informationsblad eftersom du har visat intresse för att delta i den här studien och uppfyller urvalskriterierna.

Detta formulär innehåller viktig information om syftet med studien, hur den går till och hur jag kommer att använda informationen om dig om du väljer att delta. Läs gärna informationen noga så att du är helt införstådd med vad studien innebär innan du undertecknar samtycke på sida 3.

Bakgrund och syfte

Jag studerar hur och var människor handlar sina mediciner. Eftersom den svenska läkemedelsmarknaden har omreglerats och vården blivit alltmer digital finns idag flera olika inköpskanaler. Vi vet väldigt lite om var och hur människor handlar läkemedel och vad detta innebär. I den här studien har jag för avsikt att undersöka detta.

Hur går studien till?

Du kommer att:

- Delta i en individuell intervju med mig
- Dela med dig dina erfarenheter av medicinkonsumtion
- Dela med dig av hur du upplever sjukvårdstjänster

Intervjun kommer att ta cirka 60 minuter. Du får bestämma datum, tid och plats som passar dig. Om du inte har särskilda preferenser, kommer intervjun utföras under arbetstid i ett mötesrum vid Lunds universitet (antingen i Lund eller på Campus Helsingborg).

Jag kommer att spela in intervjun så att jag minns exakt all information som du delar. Inspelningar kommer att lagras på en säker plats enligt Personuppgiftslagen GDPR (General Data Protection Regulation, Dataskyddsförordningen på svenska) och en kompletterande svensk lag, Dataskyddslagen. Om du föredrar att inte bli inspelad tar jag skriftliga anteckningar i stället.

Vilka är de möjliga riskerna?

Att delta i studien innebär inte risk för någon fysisk skada. Emellertid kan det leda till följande situationer:

- Du kanske känner dig känslomässigt påverkad när du svarar på några av frågorna. Låt mig då veta detta så att vi kan pausa intervjun.
- Du kanske känner dig obekväm med några av frågorna. I så fall behöver du inte svara och vi går vidare till nästa fråga.

Som med all forskning finns det risk att sekretessen kring den information som vi samlar in om dig kan brytas. Emellertid kommer jag att följa Personuppgiftslagen för att minimera sådana risker.

Finns det några fördelar?

Ja, ditt deltagande i studien kan innebära flera olika fördelar för dig. Du får möjlighet att reflektera över dina upplevelser av att vara vårdsökande och över dina erfarenheter av medicinanvändning. Du kan också få viss kunskap om säker medicinanvändning. Resultaten från den här studien kan även ge värdefulla insikter som på sikt kan förbättra kvaliteten på den offentliga sjukvården.

Hantering av data och sekretess

Data som samlas in från den här studien kommer att analyseras i min doktorsavhandling. Informationen som samlas in från dig kommer att användas i publikationer, konferenspresentationer och i framtida forskningsansökningar. När resultaten av studien offentliggörs eller presenteras, kommer enskilda namn och annan personligt identifierbar information inte att användas. Dina svar kommer att behandlas så att obehöriga inte kan ta del av dem. Om forskare eller andra myndigheter begär ut materialet gör Lunds universitetet en sekretessprövning i varje enskilt fall.

Finansiell information

Du kommer inte att få betalt för att delta i den här studien.

Vilka rättigheter har jag som forskningsdeltagare?

Deltagande i studien är frivilligt. Du behöver inte svara på några frågor som du inte vill svara på. Du kan när som helst avbryta din medverkan utan att ange några skäl. Om du väljer att dra dig ur studien, måste du ange om informationen som redan samlats in från dig ändå kan användas. När studien är avslutad kan du få ta del av resultatet (min doktorsavhandling) genom att kontakta mig, Rui Liu, per telefon 073-766 63 76 eller e-mail rui.liu@ism.lu.se.

Vem kan jag kontakta om jag har frågor eller funderingar kring forskningsstudien?

Om du har frågor är du välkommen att kontakta mig, Rui Liu, via e-post: rui.liu@ism.lu.se eller per telefon 073-766 63 76.

Del II: Samtyckesformulär

Härmed intygas att jag väljer att deltaga i studien.

Jag har erhållit muntlig och skriftlig information angående intervjustudien om medicinkonsumtion.

Alla personuppgifter samt inspelningen av intervjun kommer att behandlas konfidentiellt. Jag har haft möjlighet att ställa frågor och är medveten om att jag när som helst har möjlighet att avbryta mitt deltagande.

_____   _____

Ort   Datum

_____

Namnteckning

_____

Namnförtydligande

V. Observation protocol

Observationsprotokol på tullverket

Specifik tid och datum för observationen kommer att beslutas tillsammans av Liu och anpassade tjänstemän. 1-2 besök under hela projektet kommer att planeras.

- Observationsfokus: Hur identifierar och hanterar tjänstemän misstänkta paket skickas till Sverige som kan innehålla olagliga medicinska produkter?

Observationsprotokol på butiker

Tid och datum för observationen kommer att beslutas tillsammans av Liu och butikspersonalen. För att generera rik data, sker det i synnerhet observation under högtiderna vid vissa dagar i veckan. Observation planeras att hålla i 40-60 minuter per besök, 2-4 besök på varje vald plats. Följande aspekter kommer att observeras:

- Butiksmiljö, t ex storleken på affären, typer av produkter och tillgänglig service, visning av produkterna och pågående marknadsföringskampanjer. (Exakt plats för butikerna kommer att anonymiseras i kodnings- och analysprocessen för att undvika identifiering)

- Arbetsfördelning och kommunikation mellan personalen.

- Interaktion mellan kunder och personal

    o Hur hälsar personalen kunder och erbjuder service?

    o Behöver kunderna råd i butiken? Om ja, hur?

Observationsprotokol på interntapotek

- Utformning av internetapotek, sortiment av produkter och service som erbjuds av dessa apotek

- På vilket sätt skiljer sig internetapotek från, eller liknar, fysiska apotek eller hälsobutiker?

Observationsprotokol på nätforum

- Vilka hälsovårdsrelaterade och medicinrelaterade ämnen diskuteras ofta av forummedlemmar?

- Hur är hälso- och sjukvårdsrelaterad eller medicinrelaterad information delad mellan forummedlemmar?

- När vissa ämnen identifieras som mycket relevanta för forskningsfrågor, kommer de att undersökas närmare. Aspekter som gruppdynamik, ordval, nivå av deltagande och känslor kommer att undersökas ytterligare.

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