CHAPTER 9

Medicines in the grey market

A sociocultural analysis of individual agency

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> Therefore, I prefer to get medicines myself so I have the opportunity to check the quality… In this way, I can ensure that no dangerous chemical stuff is used in the production process. My doctor knows I'm using cannabis, instead of the one he can prescribe which only worsens my condition.

This quote comes from our study *Where and how do you buy medicines?*[1] The respondent has been consuming cannabis for twelve years, claiming it works well to manage his pain. One way to obtain cannabis is to get family to send it from abroad. Cannabis consumption is not a common healing practice among our respondents. However, between the lines, this respondent articulates a complex yet increasingly common view of medicines and how to access them in contemporary society. Somehow, it hints at a desire to gain some control over one's body, by skilfully distinguishing what are considered as good medicines from bad ones. Such practice is often characterized as self-care, as opposed to care provided by medical professionals. Furthermore, suggested in this quote is the emergence of an array of relations: markets entering institutions, self-care constituting public care, and lay perspectives encountering professional ones. Alongside, individual agency is taking shape.

Health systems, in Sweden as elsewhere, are often conceptualized as 'knowledge economies that produce and mediate access to health

knowledge embedded in people, services and commodities' (Bloom et al. 2008, 2077). Although medicines are commonly perceived as desirable and valuable things to transform the body, they may cause harm if handled improperly. The consumption of medicines is thus usually subject to many legal restrictions. Between people and medicines, there often stand medical professionals, whose institutional expertise allow them to act as medicine gatekeepers. Therefore, in the interaction of people and medicines at various stages from production to consumption, during and beyond clinical encounters, knowledge is materialized and mobilized in the form of the medicines. It means that knowledge can also be understood as a praxis or a form of doing. Following this line of thought, in the case of medicines knowledge does not merely represent awareness about how to take care of one's body, but it denotes a set of skills obtained through everyday consumption praxis. In this chapter, we use this to investigate how knowledge as a praxis is intertwined with consumption in everyday life. We situate our discussion in the Swedish setting, while remaining attuned to the global phenomenon that is the spread of poor-quality medicines on the market.

Setting the scene

In 2009, Sweden witnessed a shift in its retail pharmaceutical landscape. A liberal pharmacy market replaced forty years of state-owned monopoly, Apoteket AB, and its nationwide control of drug supplies. Private suppliers were allowed to enter the market, and some over-the-counter (OTC) medicines can now be bought elsewhere than pharmacies. To further increase service efficiency, many kinds of digitalized healthcare services are now available to the public. Take an example, as of autumn 2015 all authorized Swedish pharmacies can sell medicines and medical advice online. Although online medicine purchases are much easier than ever before, this loosely regulated virtual market dissolves national borders and opens up for unauthorized provision of medicines. Unlicensed online pharmacies spring up, and a majority of them, if

not all, offer consumers unrestricted access to all kinds of medical products, including prescription-only medicines (POM), whose therapeutic quality cannot be guaranteed (Clark 2015; Liang & Mackey 2012). Even more worrying for the Swedish authorities, at the other end of the supply chain there are signs showing that increasing numbers of Swedish residents are buying medicines from unauthorized channels (Swedish Medical Products Agency 2015). On the global scale, the trade in illicit medicines in the grey market is expanding tremendously, harming individuals and society (Newton et al. 2016). This affects all countries in the world and infiltrates all marketplaces, whether online or offline, formal or informal (Nayyar et al. 2019). To tackle this public health threat, national and international stakeholders have called for collaboration. To facilitate collaborations, in May 2017 the WHO launched a working definition of these dangerous medicines—substandard and falsified (SF) medical products (WHO 2017).

In the current literature on the phenomenon of SF medical products, studies in medicine, law, and public health have led the way. Much of the focus is on the supply side, advocating technological innovation and harmonized international legal frameworks (Attaran 2015; Liu & Lundin 2016; Rebiere et al. 2017). Consumer perspectives, however, are usually omitted. When individuals are mentioned, they are often portrayed as either vulnerable victims or naïve consumers who risk their lives to buy medicines outside the legal market. Certainly, practical issues such as accessibility and affordability are important determining factors in the decision-making process, especially among populations with financial constraints (Alfadl et al. 2013; Nordstrom 2007). For this reason, welfare states like Sweden, with an established and functioning public healthcare system and nationwide healthcare insurance coverage, the increasingly common practice of buying medicines illicitly is intriguing.

A number of criminological studies in the British context provide some insights which account for this illicit act. They point to the direct link between the demand for medicines in general, the

widespread availability of illicit medical products, and often invisible grey markets (for example, Hall & Antonopoulos 2016; Sugiura 2018). Nonetheless, the transition from demand to practice, meaning here the consumption of medicines, is not always straightforward. For example, buyers' trust in informal drug sellers could be interpreted as a guarantee of medicine quality, as shown in a study of migrant buyers in South Africa (Hornberger & Cossa 2012). Or, as found in a UK study (Sugiura et al. 2012), a sense of entitlement may become the consumers' argument for moving to the extra-legal market, regardless of the medicines' legal status. Implied in these studies is that demand is expressed through different forms of consumption strategy. And essentially, all such strategies are relational and contextual. Linking back to the portrayal of consumers in the literature on SF medical products, we argue that dichotomizing between passive victims and autonomous agents neither helps to explain *why* people buy medicines illicitly, nor does it elucidate *how* grey markets take form (see Gunnarson & Lundin 2015). On this account, by tracing the connections between knowledge as a form of doing and everyday consumption, we offer an alternative analysis of individual agency and various expressions of demand.

Researching medicines

Our primary source material is a survey comprising 155 answers from Swedish residents, collected by the authors in April and May 2016 with the assistance of Lund University's Folklife Archives. We also draw on results from netnographic observations conducted by another project member shortly after the survey (Brissman 2016). The data were coded as themes emerged and then categorized accordingly. Respondents have been anonymized to avoid identification. We would argue that the respondents' answers serve as a keyhole to a larger research stream about grey markets. Notably, the patterns we identify in this chapter are not unique in the phenomenon of SF medical products. The search for alternatives in the grey zones and the victim–agent dichotomy are not unusual

themes in studies of other socio-medical phenomena such as medical travel. In our analysis, we thus draw on insights from those studies to strengthen our arguments.

We begin by introducing two analytical concepts—liquid consumption and prosumption—with which we explore how consumption strategies reveal the enactment of agency and the movement of knowledge. The presentation of our findings and analysis is organized around three medicine-purchasing scenarios, each centred on a specific type of object: prescriptions in medical consultations, the logo of legal online pharmacies, and medical solutions that seem promising but are only available outside the legal market.

Liquidity and prosumption

Essentially, medicines are things attributed with social and symbolic meaning (Whyte et al. 2002). Their thinginess not only gives medicines a tangible shape and texture, but concretizes various types of dysphoria so that both healthcare receivers and providers can focus their efforts. This thinginess thus also allows medicines to stand on their own, independent from medical professionals and their expertise. This means they are not only the subject of medical consultations; they can also stay with patients afterwards in the form of prescriptions (Whyte et al. 2002). This independency leads to another layer of the thinginess, which lies in that medicines can move, locally and globally, beyond clinical settings to be exchanged as commodities. In that movement, they may enter and exit various forms of markets, transcend national borders, and bridge dialogues with people and between people.

Starting off as manmade objects with the potential to cure, medicines are treated with a variety of contrasting, yet coexisting, attitudes and health beliefs such as hope and fear, trust and distrust, safe and dangerous, demand and resistance—even as generally good and bad. In turn, they also influence and shape people's experiences and expectations in terms of how and where they should be accessed and consumed (Lock & Nguyen 2010). During this interactive

process, agency—the power to act—is enacted. Ideological notions of how people understand knowledge and authority need to be revisited. Liquidity, or rather the potential to become freer agents in loosely bonded relationships, emerges as a very relevant aspect.

The first concept is *liquid consumption*, proposed by Fleura Bardhi and Giana Eckhardt (2017). Rooted in Zygmunt Bauman's theory of liquid modernity (2000), liquid consumption is characterized as access-based, ephemeral, and dematerialized, in contrast to solid consumption, which is ownership-based, enduring and materialized. These two kinds of consumption coexist on a spectrum in the consumption experience. They intertwine yet remain distinguishable. In liquid consumption, the accessibility to products or services is attributed greater value than their possession. This fluidity 'enables individuals to be flexible and highly adaptable to the unpredictable demands of global mobility, economy, and labour markets' (Bardhi & Eckhardt 2017, 589). Quick circulation and immediate access are therefore emphasized in this form of consumption process. The use value and practical benefits of a product or service are prioritized over any social value. This redefined value-creation process implies that individuals may relate to social structures temporarily or only in a specific context. Another distinctive quality of liquid consumption practice is that individuals are inclined to form networks and mobilize resources within them. It differs from solid consumption, where one is more dependent on a particular channel to access services, products, or information.

The second concept is *prosumption*. Originally coined by Alvin Toffler in his book *The Third Wave* (1980), prosumption blurs production and consumption, and is historically framed by technological advances and the adoption of a neoliberal political-economic philosophy (Comor 2011). However, prosumption, like its derivative prosumer, remained unproblematized until very recently. Duly packaged, it has been embraced by marketers as a new form of civilization that frees individuals from immobility, heavy dependence on human relations, and suppression by explicit power relations. Prosumers are assumed to be imbued with creativity

and autonomy by dint of their participation in such activities as self-surveillance, self-help, and sharing. Nonetheless, as Edward Comor (2011, 322) argues, without fundamental changes in the political, cultural and economic structures, individuals who actively participate in any form of prosumption will almost always 'serve status quo interests' and remain exploited by what George Ritzer (2015) terms 'prosumer capitalism'.

The concepts of liquid consumption and prosumption have useful implications for understanding why people buy medicines illegitimately. They provide us with the language and analytical angles to chart emerging consumption practices and the formation of grey markets in relation to the spread of illicit medicines. We apply these concepts here to examine how assumedly solid social norms which order everyday consumption are fluid in actual social conditions.

Multiple authorities and networked knowledge

A medical prescription is an important object that amplifies the division of roles between medical professionals and lay individuals (Whyte et al. 2002). On the practical level, it often is the tangible outcome of a medical consultation, and a legitimate proof to access certain restricted medicines. When asked about whom to consult when a prescription is needed, 'doctors' is the answer from the majority of our respondents.[2] But then this is followed by some confusion. To the rhetorical question 'How would you get a prescription-only medicine otherwise?', our respondents acknowledge not only doctors' authoritative status, but also the unavoidable part doctors play if one wants to obtain POMs legally. What is also implied is a recognition of the asymmetries between patients and doctors, in the sense that respondents position themselves as being dependent on doctors' expertise and institutional legitimacy for access to medicines. One respondent further explains:

> The very meaning of the word 'prescription' is associated with some regulations of access to medicines, right?… No matter

> what, it is important, I think, to contact doctors, especially if it is about, for example, antibiotics whose use should be restrictive. In other situations, it is still important to discuss things like side effects and interaction with other medicines.

This respondent understands that one should be careful with antibiotics and taking several medicines at the same time. By articulating this, she demonstrates a certain level of medical knowledge, precisely by admitting a lack of expertise in drug use. Quite a number of respondents also mention that doctors can check up on patients' allergies and medical history to ensure the safe consumption of certain medicines. Accordingly, it is the patients' expectation that doctors act as gatekeepers, applying their expertise to minimize the potential risks and to select the right medicines for patients.

However, being dependent is not equivalent to taking a less powerful position. Whenever a respondent talks of having discussed a medical condition with their doctor, an equal and interactive relationship is depicted. A medical consultation is then turned into a conversation about the body and its subjective emotions. Thus, the doctor–patient dialogue is transformed into one between two forms of knowledge—the lay and the professional—and between two forms of care—self-care and public care (see Idvall in this volume). Instead of one party to the conversation automatically being in possession of absolute knowledge and power over the other, each contributes what they know about the body in order to formulate a treatment (although the body may have different meanings in this context, from a medical body for the doctor to an experienced body for the patient, see Mol 2002). On this account, a prescription is not simply an instruction, issued by doctors to tell patients what medications to take; it is also an individualized plan to treat the illness, and a type of contract endorsed by both patient and doctor. Thus, prescriptions can be thought of as the outcome of an embodied and emotional negotiation; a negotiation underpinned by the individual's self-reflexivity, in Anthony Giddens's term (1991, 218), accepting and presenting one's own

body as 'a site of interaction, appropriation and reappropriation' where different forms of knowledge convene.

Some respondents take a relatively active part in medical consultations. For example, one respondent says that she usually prepares before visiting a doctor: 'I often first read on my own and then leave a request for a medicine.' Another respondent reflects on what happens after the visit, explaining that 'I want to know what the doctor recommends, but then I'm not sure I'll do exactly as he or she advises. But I consider it before I make my decision.' Seeing a doctor is thus thought a legitimate approach, but there is a tendency to view doctors as counsellors, whose medical advice functions as an additional input or a second opinion. In this context, prescriptions do not hold much authority as contracts any more, because they leave so much room for patients to appropriate the knowledge for their own ends. In shaping a final consumption decision, information from various sources is brought into the process to evaluate doctors' expertise. For instance, one respondent says 'I like it when the pharmacist says the same thing as the doctor. Then one knows the information is reliable'. The opinions of family and friends also play a role, as many respondents note, as do the so-called medical experts on the Internet (Brissman 2016). Gustav Brissman's netnographic observation (2016) finds that in online chatrooms some anonymous people are often regarded as medical experts, whose opinions are much valued by other members of the forum.

In the case of our survey respondents, we do not know whether they consulted people in these virtual chatrooms, but what is clearly mapped out nonetheless is a network where multiple authorities coexist. In this network, there is a range of online and offline, formal and informal actors, mediated by medicines. In our material, these actors include doctors, nurses, pharmacists, anonymous online medical experts, even non-fiction books and social media. Rather than selecting one trusted authority, what our respondents are trying to do is to evaluate and integrate different types of knowledge gained through consumption praxis before they make a decision.

Going one step further, what emerges is a dispersed yet relational network where knowledge is mobilized and prosumed. Bauman (2000) points out that the expression of numerous authorities itself presents a contradiction, in that these authorities tend to compete and counteract one another's power and influence. In the end, it is 'by the courtesy of the chooser that a would-be authority becomes an authority' (64). In the context of healthcare, laypeople are often framed as oppressed or passive, largely due to an imbalance in the possession of medical insight. Knowledge possessed by the (medical) authorities is usually deemed naturally superior. However, the respondents in our study do not merely take in knowledge from multiple sources in a network, they also synthesize it with their own understanding of the body. In this process, the information asymmetries in doctor–patient encounters are what motivates laypeople to approach the professionals for their expertise. Through the enactment of individual agency, knowledge becomes the object of prosumption.

In contrast to the majority who believe it is necessary to consult medical professionals for POMs, some respondents, however, feel disappointed with the current healthcare system. One respondent still goes to doctors' appointments for medical consultations and prescriptions, but her trust in medical expertise is low. She describes one instance when a doctor let her down.

> The doctor offered to give me penicillin 'if I wanted', even though that doctor had found a viral infection in my body. Strange but true. It lowered my trust in the profession's capabilities, not least about antibiotic resistance.

Such an experience forces her to re-evaluate the healthcare service and how to relate to doctors, not only because that particular doctor wanted to treat a viral infection with antibiotics, but because the doctor was ready to prescribe whatever medicines the respondent asked for. The doctor may feel they are doing the patient a favour, but from the patient's viewpoint the doctor is being negligent by

passing responsibility to the patient, and even abusing their medical authority to prescribe. A similar incident happened to another respondent, whose reaction is even more critical:

> Have experiences with doctors who on several occasions prescribe medicines that have conflicted with other medicines I usually take. Don't trust the system we have in Sweden when it comes to supervision of patients' drug use.

For this respondent, every time a doctor prescribes a medicine with the potential for an adverse drug interaction, his trust in doctors, even the Swedish healthcare system, is further reduced. As seen, a prescription materializes authority and expertise on the doctors' part, but also trust on the patients' part. Aware of the intrinsic institutional hierarchy and knowledge gap in any medical consultation, people approach doctors for their expertise and expect a certain quality of care. When prescribing is neither professional nor attentive, the quality and accountability of the service, together with the prescriptions, may arouse suspicion: the value of the official healthcare service will be reconsidered, and people may turn to alternative service providers. Individual freedom and liberal market logic are advocated across Swedish society. Paternalism, embedded in the once relatively solid doctor–patient relationship, no longer determines how people process medical knowledge or conform to expertise, nor does it mandate how people should obtain their medicines. When healthcare services are increasingly digitalized, how then do people relate to institutional legitimacy on the Internet?

The logo

Turning from offline encounters to the online setting, our analysis starts with a logo. According to the annual report by the Swedish Pharmacy Association (2018), online retail sales by Swedish pharmacies increased from SEK 80 million a month in 2015 to SEK 250

Figure 9.1.

million a month by the end of 2017. In 2017, e-commerce accounted for over 90 per cent of the volume growth. To regulate the online pharmaceutical market, the European Commission launched a logo (Figure 9.1) in 2014, representing the authorization of online pharmacies. All online pharmacies that operate legally in EU must display the logo on their homepage, and that includes the authorized Swedish pharmacies. Yet little empirical data is available regarding its effectiveness among the public (Sugiura 2018).

Two-thirds of respondents in our survey did not recognize the logo, which echoes what the Swedish Medical Products Agency (MPA) (2015) reported. Nearly half of our respondents do not feel safe purchasing medicines online. In response to whether the EU logo would matter when shopping online for medicine, attitudes range from full support to total negation. Some respondents believe having a logo like this would ensure the quality of medicines sold in online pharmacies, 'especially after the deregulation of the pharmaceutical market, it is important to know one is shopping in a real pharmacy'. But this logo alone does not seem persuasive enough for many respondents, because 'it is possible to have this logo without being a real pharmacy. Together with other quality measures it would feel more legitimate'. At the other end of the scale, there was strong scepticism. The logo does not seem accountable because 'it feels too easy to plagiarize and misuse logos on the Internet'. In between the two opposite attitudes, some respondents reacted with varying degrees of uncertainty, still planning to do some sort of quality control on online pharmacies, but doubting whether the EU's logo counts as useful validation. Agency is

manifested in different strategies to discern which medicines might be safe to be consumed, such as checking 'if it is the same active ingredients' or looking for 'something on that website that I feel is reliable'.

Given the various responses, we would argue that the assumed association between the EU logo and authorization of online pharmacies is problematic. The logo was introduced with a clear political intention of flagging medicine quality and legal business operations, the assumption being that it would assist consumers in telling reliable online pharmacies apart from rogue ones. However, whether an online logo like this will be deemed valid hinges on other factors. For example, as one respondent explicitly stated, 'If I bought medicine online and needed it cheap and fast, I would probably buy from the first website that offers it'. Further, despite some respondents embracing this top-down political initiative, the suspicion and resistance of many others is worth particular attention. In a dematerialized digital environment, the absence of tangibility or corporeality can lead to higher levels of uncertainty and perceived risk (Bardhi & Eckhardt 2017), in contrast to the traditional form of medical consultation, which is often characterized as material, embodied, and sensual (Lupton 1997, 2018). In this scenario, the accumulation of trust in products or services rapidly dissipates, even as the consumer remains fully dependent on recognizing individual objects visualized on a flat computer screen. Our respondents, who in other respects have crafted at least some skills in everyday digital consumption, find it difficult to accept the logo's institutional legitimacy. This also suggests that respondents form a multifaceted knowledge repertoire, which amounts to a knowledge network. Its scale extends beyond the consumption of medicines to tie into a much larger setting—everyday consumption praxis. Market offerings, including the logo, are not taken passively. Instead, their value, and especially their practical benefit, is carefully reflected on by transferring information and skills learned from other consumption practices to the activity of online medicine shopping.

Although the authorities frame the act of shopping for medicines outside the legal market as risky and deviant (Sugiura 2018), respondents present themselves as digital consumers—indeed, as craft digital consumers (Campbell 2005)—capable of identifying the pitfalls in the virtual market. Whereas in liberal market thinking this skill is desirable as it produces empowered individuals, one side effect appears to be an ephemeral, fluid attachment to authority. People are increasingly expected to take care of their own health; failing to do so may lead to downgraded healthcare, and even a denial of access to welfare services in general (Michailakis & Schirmer 2010). Self-care is associated with strong morality, as responsibility falls on individuals to not just make a choice, but to make a right choice to perform the duty of good citizens (Alftberg & Hansson 2012). Yet as virtual platforms lift the restrictions on the provision of and access to medicines, it to some extent raises the bar to manifest individual responsibility in a more flexible and reflexive manner. We have previously found that many people believe the level of self-care should be measured against whether one should be prioritized to receive care (Funestrand et al. 2019; Lundin 2008). This is the backdrop to our respondents demonstrating complex attitudes towards the EU logo or liberal virtual markets. Although respondents claim that some kind of quality certification of online pharmacies is needed, the authority embodied by this specific logo seems limited, even invalidated. In other words, the effect of the logo's assumed empowerment is countered by the enactment of individual agency, which enables people to 'express themselves in ways that reify their individualism' (Comor 2011, 322).

Some respondents simply dismiss this way of buying medicine alternative out of hand. Neither supportive nor critical, they claim they would only shop in the bricks-and-mortar pharmacies, so they 'don't feel the need to check the authorization' and the online authorization mark does not speak to them either. To understand this, we draw on the analytical concept of refusal. Refusal is rarely performed in the same way as resistance, nor does it have to involve

active non-conformity or strong criticism (Weiss 2016). Rather than focusing on structural reforms, refusers may put an emphasis on the 'health and vitality of immediate social relations' (Sobo 2016, 343). It is evident that our respondents are well aware of the online alternative, but some choose to ignore or stay away from it. As a social act, refusal in the form of avoidance can thus be seen as privileging certain social relations over others (Sobo 2016). The respondents who refuse to shop for medicines online, regardless of logos and other types of quality control, choose to vest their trust in the more solid relations with physical pharmacies and more personal interactions. They also appear reluctant to transfer their established trust from physical pharmacies to digital shopping channels that seem dematerialized and less personal. Here refusal can be conceptualized as an exercise in individual agency, designed to reduce risk by attributing authority to specific information channels. While agency is shaped and enabled by processes and structures, it also co-evolves with consumption practices (Fuentes & Sörum 2019). In the act of refusal, rather than just rebuffing new consumption alternatives, people intentionally disenable authority by shunning it. It is difficult to tell from the survey data exactly which worries discouraged the respondents from buying medicine online, but we can still conclude that respondents used their knowledge networks to make what they believe are sensible choices when it comes to shopping for medicines. Under the surface of quiet abstention (Weiss 2016), agency is practiced as a no to liquid social relations, but a yes to individual responsibility.

Is there a cure out there?

To capture the point at which respondents would consider leaving formal healthcare, we asked them in which situations they would consider buying medicines or treatments that are neither legal in Sweden nor scientifically proved. Most respondents comment that this is a difficult question, as they have never encountered such situations. However, the act of formulating an answer and imagining

a breaking point where they would move away from the legal zone uncovers any ambivalent feelings towards biotechnology.

There is consensus among respondents that being affected by a detrimental disease leaves people desperate. It therefore is understandable that they will try every possible treatment, because if 'one has a serious disease, one would be willing to do everything to become healthy again'. Here, the underlying message is that a healthy life is the norm that every person should aim for. In Swedish society, people are increasingly expected to live up to the ideal of having a healthy lifestyle (Michailakis & Schirmer 2010), which somehow legitimizes the hunt for a cure. Further, as we have argued in earlier studies on the cultural meaning of biotechnology, the notion of health is elastic, because modern technologies are ascribed an enormous potential to heal and strengthen the body—'Old truths about nature's inflexibility are replaced by an understanding of its changeability' (Lundin 2002, 339). Rather than being a solid form of existence, the body is increasingly conceptualized as an atomized object, modified to adapt to ever-emerging cultural ideals. Medicines then become one of the desired-for tools with which to calibrate the body to those ideals. National borders, coinciding with the legal boundaries, may give a sense of safety, signalling the quality assurance of the Swedish national health service. However, when 'doctors say no more alternatives are available', or when 'one doesn't get help but is tossed back and forth like a ball', many respondents consider this a legitimate reason to step outside the system and turn to the extra-legal market. This transition is not without its hesitations. It takes time, energy, bravery, and knowledge to deal with the dilemmas and uncertainties, and ultimately the optimism of envisaging a healthy life.

> I think some medicines are illegal for a reason, so I would only do that in desperation, if I didn't have other choices. In this case I would study the medicines as well as I can before I bought and used them.

Desperation is highlighted in many comments. When health professionals announce the end of a search for cures and decide to withdraw treatment, the search for the patients' part is far from over. To be desperate in no way equates to hopelessness or irrational choices; on the contrary, as the quote shows, it implies a determination to find the cure in a strategic manner, such as by studying the medicines very carefully. What can also be taken from this quote is a reluctance to leave formal healthcare for a market of unknown medicines. Medical expertise is still much needed and appreciated by the majority of laypeople, whose medical knowledge is rather limited, especially when their health is deteriorating. Even so, when all the possibilities of formal healthcare are exhausted, it leaves individuals little choice but to feel obliged to take responsibility on their own. In the dispersed, multidimensional knowledge network we conceptualized earlier, 'authority is no longer an alternative to doubt' (Giddens 1991, 195). This differs from the paternalistic doctor–patient relationship where doctors possess the authoritative power of giving orders to patients. Faced with serious diseases where no treatment or medicines are legally available, patients experience dependence on medical authority just as much as doubt towards it. The hunt for a cure continues, although reluctance persists.

Sometimes what holds together the search for a cure is a belief in medical pluralism. It is mediated through the increased mobility of people, goods and information across national boundaries.

> Absolutely! I think there are different ways to look at medication in other countries and it's not to be underestimated in serious situations. What we have in Sweden feels safe and (scientifically) proved, but not in the forefront. If I were diagnosed with a disease with no treatment in Sweden, I would look for alternatives on the Internet and abroad.

It is obvious that this respondent conceives of a boundary, or more specifically limitations on the Swedish national healthcare system. She also exhibits an awareness of alternative medical systems in

other countries. Lack of legally available treatments in one system is not the end of the story, since cures might be found in other places where medical approaches are more aggressive or inclusive. Lay understanding of medicines may be insufficient, but identifying where and how to source information is already a crafted skill for many individuals. Further, clearly put by one respondent and echoed by many others, medicines and treatments that are illegitimate in Sweden 'may actually be legally approved or scientifically established in other countries'. This view points at a blurred line between legality and illegality. It also illustrates an adaptive, fluid interpretation of medical knowledge.

'Try googling various healing properties of cannabis. You may start wondering why it is forbidden', a respondent suggests, a confusion arising from a mismatch in information on the Internet and from medical authorities. One can choose to follow the advice of medical professionals who do not have much to offer at the moment, while out there, somewhere in the extra-legal market, there seems to be hope (see Brown & Michael 2003; for hope, see also Idvall in this volume). Who to believe and how to choose? At this crossroads many people, including but certainly not limited to our respondents, cast about for a moral standpoint, between taking individual responsibility on the one hand and assuming the role of ethical citizen-consumer on the other. In searching for a possible cure, national borders and the laws that define them are contested. More tellingly, it enables individuals to justify their transgressions without feeling morally wrong. This is the point at which the legally grey market is transformed into a moral market, which lessens the paradox of exercising individual agency without neglecting the duty of being a righteous citizen.

Whereas some respondents say they would be perfectly willing to grasp at straws, many adopt a calculating mindset, weighing up the worth of buying medicines illicitly. 'There must be something that really convinces me that it's worth trying', says a respondent. Whether the treatment will outweigh its side effects; whether the medicine comes from a country one can trust; whether one can

financially afford such a medical solution: all these uncertainties are pondered over by respondents. Between the lines of the imagined presuppositions, their resistance reveals how tempting it is to shift the moral boundaries. What is more, technological advancements pave the way for it. To some extent, technologies are evocative objects (Turkle 2011). Many respondents are positive towards technological innovations, but are caught in the dilemma of choosing between doctors and markets. Worth here seems to be a question with a mathematical answer, but much more than that: many uncertainties might worsen the present situation, yet that risk is balanced by a strong desire to live what is perceived as a normal, healthy life. Far from a simple calculation of pros and cons, this is also about now and then. As one respondent says, 'Now I would never consider doing so, but if I were dying?'. With a future full of uncertainties, risk-taking is an essential and inescapable aspect of everyday life (Giddens 1991). What is left to leverage the final decision of leaving, or not, for the extra-legal market, is perhaps how much faith one has in biotechnologies, and how much confidence one can afford to live with a disease. These are variables on a spectrum, engineering a variety of social realities which are then materialized as different consumption strategies. As a result, the value of medical products and healthcare services becomes fragile, particularly when doctors' sole authority, together with their medical knowledge, is faced with competition.

Nonetheless, before making for the grey zone, one respondent leaves a final remark.

> Doctors nowadays are constrained by rules and do not dare to seek in a scientific way for new knowledge; but often resign themselves (in my experience in recent years) to diagnosing and prescribing medicines. If the diagnosis can't be made, the activity = zero and the answer is just Oh well… Oh yeah. That means there are gaps in the medics' role in constantly improving medicine.

There is a hope here, or rather an expectation, that doctors will take the lead. For many laypeople, doctors still play an important role in their healthcare. And people are willing to invest in a functioning doctor–patient relationship (see Brown & Michael 2003). Following instructions on what to do and what not is regarded as obstructing doctors from fully utilizing their expertise and medical knowledge. Doctors' inflexibility, as our respondents experience it, their refusal to step outside the safety zone, makes doctor–patient collaborations difficult. Furthermore, as skilled prosumers, our respondents claim equal power relationships with doctors—but while attempting to fit into the role of responsible citizens. The notion of taking care of one's own body, however, does not indicate a dramatic overturning of the power hierarchy. In a society where medical knowledge, products, and services are far more accessible through multiple channels than ever before, marketplaces outside the official healthcare system appear more attractive to laypeople (see Hansson, Nilsson & Tiberg in this volume). One explanation might be that such marketplaces signal their potential to meet people's basic needs for medical care. Perhaps more importantly, though, the grey zones in the market offer people tangible tools with which to conform to the image of an ethical, healthy citizen–consumer (Kristensen et al. 2016).

Becoming a health agent

In a society saturated with digital products and services, with a strong emphasis on individual responsibility, and instilled with political strategies to introduce market logic to the public sector, seeking healthcare and medication takes on new forms. The Internet is transforming how the pharmaceutical market is organized and how knowledge moves (Sugiura 2018). This is seen in many societies with neoliberal politics, and not least in Sweden from where our empirical material is taken.

In considering the empirical problem of the widespread availability of SF medical products and the increasing number of people

buying medicines illegitimately, we examine both the online and offline scenarios which may lead to the purchase of medicines in extra-legal markets. One observation is the emergence of a network where knowledge from a variety of sources is collected and synthesized, produced and consumed. Rather than being confined to a healthcare context, we find that this network also expands and becomes entangled with daily consumption praxis. It enables knowledge to flow seamlessly from one context to another. Many respondents are well aware of the risks of removing themselves from formal healthcare, and this explains why many of them feel dependent on medical professionals' expertise to access the right medicines. But simultaneously, they maintain their right to doubt authority. This implies that the reliance on medical authority should be interpreted differently from that in the traditional, paternalistic doctor–patient relationship. As authority no longer comes from a single source, knowledge can be understood as constructed using diverse channels. Although knowledge possessed by medical professionals is still deemed important, it increasingly becomes part of a 'personalized repertoire' (Kristensen et al. 2016, 496). There is a pattern to our findings, where respondents prosume knowledge and craft their skills before they decide which medicines to buy and where. In this prosumption process, individual agency is performed in various ways: by equipping oneself with necessary medical knowledge, by doubting medical diagnoses, or even by refusing to use authorized online pharmacies. All these suggest an ephemeral or loosening attachment to the authorities and their expertise.

While laypeople may have turned themselves into skilled prosumers—active, empowered, free agents, making choices according to a market logic—they may also risk becoming 'an agent of increasingly complex forms of possessive individualism' (Comor 2011, 322), only entrenching the status quo. As studies of the phenomenon of medical travel remind us, agency and victimhood constitute one another. People who seek organ transplants, fertility treatments, or stem cell treatments in the grey markets or even black markets are

actually driven by a desire to conform to normalized images. These images—having a healthy body or accomplishing parenthood—are imposed by society on individuals (for example, Humbracht et al. 2016; Lundin 2015; Pande 2014). These deeply rooted normalities in sociocultural structures enact agency in those people who are commonly considered as victims. Our study of illegitimate medicine purchases aligns with this argument; it is especially apparent when respondents are asked to consider when they would leave formal healthcare. Our findings further demonstrate that victimhood also inherently resides in the enactment of agency. Becoming prosumers, people are tasked with anchoring themselves with a moral standpoint to fit with the constantly shifting imagery of a healthy body. However, as our respondents said, at times they experience the formal healthcare system as inflexible and bureaucratic. It is not surprising, then, that people begin to oscillate between institutions and markets, in search of an authoritative and trusted voice.

Care, after all, is a collaborative practice (Mol 2008). Even in a society that endorses the rise of consumerism, advocates individual empowerment, and is increasingly informed by market thinking, a balanced doctor–patient relationship is still much desired among respondents. However, this particular service encounter has to be a relational one that allows for different degrees of dependence as well as the negotiation of power (Trnka & Trundle 2014). To do so, we have to acknowledge the multistability of knowledge production. Applied to the phenomenon of SF medical products, failing to perceive knowledge in its multifaceted forms may lead prosumers to seek healthcare and medication elsewhere, even outside the formal public health system. A legal grey market then comes into sight where low-quality medicines can circulate and cause harm.

Notes

1 All quotes in this chapter are taken from our study 'Where and how do you buy medicine', part of the research project 'Illegal drugs: Gathering information from the public and doctors: A preliminary evaluation of the implementation of knowledge in society', supported by the Erik Philip Sorensen Foundation 2017 (H2016-015)

and VINNOVA (VLU14-1006, V16-0307). Another part of the research was focused on physicians' attitudes towards a liberal pharmaceutical market and evolving consumption patterns in Sweden (see Funestrand et al. 2019).

2 Digital care has grown dramatically in Sweden after we conducted our study, and a growing number of people are turning to e-doctors (Ekman et al. 2019).

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