Chapter 13
Conceptualizing the Impact of MDRO Control Measures Directed at Carriers: A Capability Approach

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Abstract Many countries have implemented specific control measures directed at carriers of multidrug-resistant organisms (MDRO) in order to prevent further introduction and transmission of resistant organisms into hospitals and other healthcare related settings. These control measures may in many ways affect the lives and well-being of carriers of MDRO, resulting in complex ethical dilemmas that often remain largely implicit in practice. In this chapter, we propose to conceptualize the impact of MDRO control measures on the well-being of individual carriers in terms of capabilities and functionings. A capabilitarian framework for the ethical treatment of MDRO carriers commits us to conceptualize the harm done to carriers in terms of the impact that MDRO control measures have on what they are able to do or be. Adopting and adapting Nussbaum's list of ten central human capabilities, we present a taxonomy of capabilities and functionings that are normatively relevant for the design and evaluation of MDRO control measures.

Keywords Bioethics · Moral philosophy · Public health · Drug resistance

13.1 Introduction

Antimicrobial resistance (AMR) has been described as one of the major threats to individual and public health (WHO 2014). This threat has justified extensive restrictions on the freedom of individuals (Krom 2011; Littmann 2014; Littmann and

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Viens 2015). Many countries have implemented control measures in order to prevent further introduction and spread of MDRO. Some more general, as addressed in Chap. 6 by Gilbert et al., and some more specific, like those targeting the individual who is found to carry an MDRO. Measures directed at MDRO carriers aim to limit the introduction and further transmission of multidrug-resistant organism (MDRO) in hospitals and other healthcare-related settings. The measures vary per micro-organism and include for instance isolation and quarantine; contact precaution; eradication treatment; restrictions in the workplace; refusal of access to important activities; or contact restrictions at the one's family farm. They may in many ways affect the lives and well-being of carriers, resulting in complex ethical dilemmas that often remain largely implicit in practice.

Within the literature, little attention has been paid to how we treat carriers of MDRO, however, and Littmann et al. (2015) includes it as one of four ethical issues that needs further examination when addressing MDRO. In this chapter we aim to start filling this lacuna by proposing to conceptualize the impact of MDRO control measures on the well-being of individual carriers in terms of capabilities and functionings. A capabilitarian framework for the ethical treatment of MDRO carriers commits us to conceptualize the harm done to carriers in terms of the impact that MDRO control measures have on what they are able to do or be. Adopting and adapting Nussbaum's list of ten central human capabilities, we present a taxonomy of capabilities and functionings that are normatively relevant for the design and evaluation of MDRO control measures. Chapter 16 addresses the implications of AMR for child development and adult capabilities.

The chapter is structured as follows: In Sect. 13.2, we shortly present the issue of treating MDRO carriers as an ethical problem before we turn, in Sect. 13.3, to propose a capabilitarian framework for the conceptualization of the impact that MDRO control measures have on the well-being of carriers. In Sects. 13.4 and 13.5, we adapt Nussbaum's list of ten central human capabilities in order to develop a taxonomy of normatively relevant capabilities and functionings in the context of MDRO. In Sect. 13.4, we first present Nussbaum's list of capabilities before we argue that this list needs further specification when applied to the case of MDRO. In Sect. 13.5, we proceed to propose a taxonomy of ethical domains and normatively relevant capabilities and functionings in the context of responsible care for MDRO carriers. In Sect. 13.6, we finally argue that and show how this capabilitarian taxonomy can provide a crucial input to procedures for ethical decision-making on appropriate MDRO control measures.

13.2 The Ethical Treatment of MDRO Carriers: A Neglected Issue

Treating MDRO as an ethical issue is a double-sided coin. On the one side, it involves a concern for public health and how we can ensure that everyone, now and in the future, have access to antimicrobial treatment while minimizing the risk of further spread of MDRO. From this side of the coin, addressing MDRO is primarily an issue of global distributive justice (Littmann 2014; Littmann et al. 2015, 360): how can we distribute antimicrobials in a way that, on the one hand, adequately protects public health by ensuring that everyone has access to antibiotics while, on the other hand, ensuring that antibiotics do not become useless? In the following, however, we shall not primarily be concerned with this distributive question.[1]

The distributive focus has often been accompanied by a discussion of what kinds of control measures we can take to prevent the further spread of MDRO (Selgelid et al. 2009; Coleman et al. 2010): how can we treat carriers in a way that minimizes the risk that they contaminate other individuals? An important element in the fight against MDRO is to adequately treat infections with multi-resistant microbes in patients and to prevent that these persons are re-infected or will infect others with a resistant organism. Due to the threat that MDRO poses to individual and public health (WHO 2014), many countries have implemented specific MDRO control measures in order to prevent further introduction and spread of MDRO. Measures to prevent and control the spread of MDRO may include isolation and quarantine; eradication therapy; restrictions in the workplace; refusal of access to important activities; or contact restrictions with one's family (Verweij and Dawson 2010).

Many of these control measures threaten to seriously affect the lives of individual carriers, however, and as important as such prevention and control is, it may have burdensome implications for infected patients and healthy persons in whom a resistant organism has been colonized: they may feel stigmatized, face restrictions in their work or private life, or might be refused access to certain institutions. For example, in a healthcare context, control measures may mean that surgeons should refrain from operating due to carriership, that infected nurses should not perform patient-related activities, or that we ask infected residents of a nursing home to keep away from social activities.

In some extreme cases it is almost impossible to eradicate the resistant organism and then it may be impossible for the person to return to what used to be his/her normal life. Consider, for example, the case of a medical student who was repeatedly diagnosed as carrier of Methicillin-Resistant Staphylococcus Aureus (MRSA) (Rump 2011; Rump et al. 2016). In line with the MDRO control guidelines, the student was not allowed to be involved in patient-care, which is an implicit part of completing the internships necessary to graduate. Because of this, the student had to

[1] For a discussion of different approaches to the distribution of antimicrobials, see especially Anomaly (2010, 2013), Daulaire et al. (2015), Littmann (2014), and Selgelid (2007). For an introduction to and overview of distributive justice in general, see Lamont and Favor (2016).

eventually discontinue his studies. Whether this outcome was indeed necessary or not remains unclear, though, since the risk of further contamination could have been minimized through proper hygiene and guidance.

The consequences of MDRO carriership certainly have the potential to affect the lives and well-being of not only carriers themselves, but also their social connections, such as family members, friends, and colleagues. Yet, it is unclear in what ways MDRO and MDRO carriership affect these individuals. In the remainder of this chapter, we will offer a novel conceptualization of how MDRO control measures can harm carriers and other affected individuals and further reflect on how this conceptualization, and the normatively relevant issues that are thereby revealed, influences the design and evaluation of MDRO control measures. We argue that adopting a capabilitarian framework for the conceptualization of 'harm' done to (potential) carriers can help us make better and more informed decision about what control measures to implement. According to a capabilitarian framework, MDRO control measures may harm individual carriers by negatively affecting their capabilities and functionings.

13.3 A Capabilitarian Framework for Conceptualizing the Impact of MDRO Control Measures

What is the capability approach and how can it be used to conceptualize the (negative) impact that MDRO control measures have on the lives and well-being of individual carriers?[2] Originally conceived by the Indian philosopher-economist Amartya Sen (1979) and further developed by a number of theorists, such as Martha Nussbaum, David A. Crocker, and Ingrid Robeyns, the capability approach is a normative framework for the conceptualization of human well-being (Robeyns 2016a). According to this framework, human well-being should be conceptualized in terms of *capabilities* and *functionings*. Capabilities are the real freedom that people have to do or be certain things, such as falling in love, getting an education, being politically active, riding a bike, reading a book, and so on. Functionings are

[2] It is possible that the capability approach can also be used to conceptualize 'harm' within three other related domains of application, which we will not discuss in this chapter. First, we can conceptualize the risk that the spread MDRO poses to the well-being of members of the public in terms of their capabilities and functionings. For a discussion of how to conceptualize public health in terms of the capability approach, see Prah Ruger (2010), Venkatapuram (2011), and Nielsen (2014). Secondly, the capability approach can be used to conceptualize the 'harm' of control measures within infectious disease control in general. While the taxonomy that we provide in Sect. 13.5 may also apply within infectious disease control in general, more research needs to be done in this regard as different capabilities may be relevant in relation to different diseases. Thirdly, the capability approach has been used to conceptualize the idea of 'person-centered healthcare,' what it means to treat patients as persons (Entwistle and Watt 2013).

capabilities that have been realized either by choice or by chance. A person's *capability-set* refers to all the capabilities and functionings that that individual has.[3]

Real freedom in this sense means that there are no restrictions on achieving a particular functioning. Whether or not one has such real freedom crucially depends on certain *conversion factors*. Conversion factors are personal, social, and environmental circumstances that affect the extent to which one can achieve certain doings and beings. For example, whether or not one has the real freedom to be healthy – that is, whether or not one has the capability of achieving the functioning of being healthy – depends on one's physical health, for example the strength of one's immune defense system (personal conversion factors), the extent to which one can rely on family and social relations for care (social conversion factors), and where one lives and whether there are adequate infrastructures, such as accessible health care facilities (environmental conversion factors).[4]

Through the notion of conversion factors, the capability approach captures the fact that human beings are diverse: different people living in different societies would have different needs and capabilities. As we shall see in Sect. 13.5, the different conversion factors are relevant when we consider how MDRO control measures affect the lives and well-being of individual carriers.

The capability approach moves the focus from the means that people have to their ends – what they are able to do or be with these means, such as goods, resources, and formal freedoms. As Sen (1979) argues, this shift in focus is justified because resources and goods alone do not ensure that people are equally able to convert them into doings and beings. Consider, for example, two persons – one disabled, the other able-bodied – with the same amount of resources. According to Sen, the disabled person is disadvantaged relative to the able-bodied person in two regards. First, she is disadvantaged in terms of what she can do or be with her means and resources. She may, for example, be less able to move around because she is confined to a wheelchair. Secondly, she may even be doubly worse off because she only receive the same amount of resources as the able-bodied person, even though she has more expenses in order to correct for her disability, whereas the able-bodied person, *ex hypothesi*, can spend all of her resources to pursue her valued ends. Hence, when evaluating the well-being of individuals, we cannot merely compare the amount of resources that they have without also looking at what they are able to do or be with these resources.

[3] Capabilities and functionings can be both positive and negative, as well as neutral (Robeyns 2016b). Positive capabilities are what we consider valuable for someone to do or be. Examples of positive capabilities are good health, adequate nutrition, falling in love, and getting an education. While most applications of the capability approach are primarily concerned with positive capabilities, there are also cases where we want to consider their negative capabilities. When evaluating a person's well-being, for example, it is relevant whether her capability-set include the capabilities to be murdered or raped. Insofar as we, usually, do not consider these capabilities to be valuable, a capability-set that allows for the risks of being murdered or raped would be less valuable than a capability-set that protects the individual from these risks.

[4] This example is adapted from Crocker and Robeyns (2010).

The concepts of capabilities and functionings can help us to better understand how MDRO control measures can 'harm' (potential) carriers of MDRO in terms of how MDRO control measures influence the real freedom that MDRO carriers have to do or be certain normatively relevant things. MDRO control measures can affect the capability-sets of (potential) carriers in at least two ways. First, they may impose certain requirements on (potential) carriers. This is, for example, the case when we subject nurses to strict hygiene regimes or demand that carriers undergo mandatory screenings and eradication therapies. In terms of the capability approach, MDRO control measures thus impose certain doings and beings – that is, functionings – on carriers. Secondly, MDRO control measures can reduce the choices that carriers have to choose from (i.e., the capabilities that they can choose to turn into realized functionings). This is, for example, the case when we place carriers in isolation or ban them from social activities.[5]

Rather than merely focusing on whether or not the autonomy of carriers is being respected (Beauchamp and Childress 2001), by conceptualizing the potential impact of MDRO control measures in terms of capabilities and functionings, we get a broader picture of the many ways in which carriers are affected. In other words, it allows us to move from a singular basis for evaluation, namely in terms of their autonomy, to a multi-dimensional one. The same carrier may be impacted in many different ways by a particular control measure. For example, restricting a resident of a nursing home from participating in the weekly bingo nights not only restricts her capability for participating in social activities, but may also take away an important source of pleasure and happiness or may even lead to stigmatization. Likewise, a particular control measure may impact different carriers in different ways. For example, a child who is at a crucial stage in her social and cognitive development would arguably be negatively affected to a greater extent from being taken out of daycare (even for a short period of time) than a child who is not in this crucial stage of development (Piaget 1971).

Moreover, the capability perspective gives substance to carriers' autonomy: it allows us to identify in which ways MDRO control measures have the potential to (negatively) impact the capabilities of (potential) carriers. We are not merely concerned with the limitation of options that carriers can choose from. Rather, the capability perspective tells us that carriers are concerned with *particular* opportunities for choice (Sen 1991), such as access to day care centers, nursing homes, and physiotherapy; participation in social and leisure activities; opportunities for education and employment; freedom from stigmatization and discrimination; and possibilities

[5] That is, there might still be good normative reasons to override this concern for carriers' capabilities, for example out of a concern for the public health. While we do not engage with the discussion on how to weigh the violation of carriers' capabilities against concerns for public health in this paper, do see Sect. 13.6 for an example of how such weighing can take place within an open-ended decision-making framework. The point here is, rather, that there are certain capabilities that are so normatively relevant that we should take them into consideration when deciding on appropriate MDRO control measures – again, even if we do not consider them to have overriding normative status.

for forming and sustaining relationships to friends, family, and pets. Indeed, by employing the capability approach to conceptualize the 'harm' done by MDRO control measures to individual carriers we gain a greater, more in-depth, and more specific understanding of this impact.

As noted, this focus on particular opportunities for choice – rather than freedom or autonomy, in general – moves the discussion away from the singular dichotomy between public health versus the freedom of the individual carrier. The restriction of freedom is not necessarily a bad thing on the capabilitarian view.[6] The restriction of an individual carrier's freedom out of concern for public health is perfectly compatible with the protection of her valued capabilities. What the capability perspective does highlight, though, is that the restriction of some freedoms and opportunities, however *prima facie* insignificant, may affect capabilities that we do find normatively valuable. For example, restricting an MRSA positive child from attending kindergarten for just a few months may not seem like a big deal. However, that restriction may negatively affect a normatively crucial aspect of a person's life, namely the opportunity for a normal social, cognitive, and physical development if the MRSA positive child were, at the moment of isolation, at a crucial stage of her development.

To see how MDRO control measures can (negatively) affect the lives of MDRO carriers, it is crucial to identify what capabilities and functionings that are normatively relevant for carriers in the context of MDRO. In the following two sections, we present a taxonomy of capabilities and functionings that may be normatively relevant when deciding on appropriate control measures. This taxonomy builds on one prominent instantiation of the capability approach, namely Nussbaum's list of ten central capabilities. We first discuss Nussbaum's list in Sect. 13.4 and argue that it needs further adaptation and specification when applied to the context of deciding on appropriate MDRO control measures before we explain the taxonomy in greater detail in Sect. 13.5. In Sect. 13.6, we finally show how this capabilitarian taxonomy can help us make better and more informed decisions when deciding on appropriate MDRO control measures.

13.4 Nussbaum's Ten Central Capabilities: A Starting Point

What capabilities should we be concerned about protecting when implementing certain measures to prevent the spread of MDRO?[7] A good starting point is Nussbaum's influential list of ten central capabilities that, she argues, every

[6] See, though, Carter (2014) for a dissenting view.

[7] We have employed what Byskov (forthcoming) refers to as a *synthesizing method* to identify the relevant capabilities. Synthesizing methods compare and reconcile two or more lists of capabilities derived from different theoretical and empirical sources. We have here reconciled Nussbaum's (2000) list of central human capabilities with (i) other lists of relevant normatively domains in healthcare literature, such as Entwistle and Watt (2013) and Huber et al. (2016), (ii) empirical

government should provide for their citizens. While Nussbaum's list is thus derived from a discussion on global justice, it can nevertheless be useful for conceptualizing what kinds of capabilities that are important because it helps us to identify how well-off individuals truly are.[8] The most influential version of Nussbaum's list of capabilities can be found in her book *Women and Human Development* (Nussbaum 2000)[9]:

1. *Life:* Ability to live to the end of a normal length human life, and not to have one's life reduced to not worth living.
2. *Bodily health:* Ability to have a good life, which includes – but is not limited to – reproductive health, nourishment, and shelter.
3. *Bodily integrity:* Ability to change locations freely, in addition to having sovereignty over one's body, which includes being secure against assault (e.g., sexual assault, child abuse, and domestic violence) and the opportunity for sexual satisfaction.
4. *Senses, imagination, and thought:* Ability to use one's senses to imagine, think, and reason in a 'truly human way' informed by an adequate education. The ability to produce self-expressive works and engage in religious rituals without fear of political ramifications. The ability to have pleasurable experiences and avoid unnecessary pain. Finally, the ability to seek the meaning of life.
5. *Emotions:* Ability to have attachments of things outside of ourselves, including being able to love others, grieve at the loss of loved ones, and be angry when it is justified.
6. *Practical reason:* Ability to form a conception of the good and critically reflect on it.
7. *Affiliation:*
   (a) Ability to live with and show concern for others, empathize with and show compassion for others, and the capability of justice and friendship. Institutions help develop and protect forms of affiliation.
   (b) Ability to have self-respect and not be humiliated by others (i.e., being treated with dignity and equal worth). This entails at least protections from being discriminated on the basis of race, sex, sexuality, religion, caste, ethnicity, and nationality. In work, this means entering relationships of mutual recognition.

analysis of a database of ethical and practical questions concerning MDRO raised within the Dutch healthcare system as well as (iii) participatory case discussions with practitioners working with infectious disease control. For overviews of the various methods for the selection of capabilities, see Ballon (2013) and Byskov (forthcoming).

[8] Several scholars have taken build on Nussbaum's list and made changes to it, as necessary, when applied in practice (e.g., Alkire 2002). Thus, to be clear, we do not take Nussbaum's list at face value but rather hold that we can compare and specify this list to the particular case of MDRO.

[9] See also Nussbaum (1992, 2011) for similar iterations of her list, albeit based on different normative justifications.

8. *Other species:* Ability to have concern for and live with other animals, plants, and the environment at large.
9. *Play:* Ability to laugh, play, and enjoy recreational activities.
10. *Control over one's environment:*
    (a) Political: Ability to effectively participate in the political life, including having the right to free speech and association.
    (b) Material: Ability to own property, not just formally but materially. Furthermore, having the ability to seek employment on an equal basis and the freedom from unwarranted search and seizure.

Nussbaum's list of central human capabilities provides a good starting point for our attempt to identify what capabilities and functionings that are relevant for evaluating the extent to which MDRO control measures excessively interfere with the lives of MDRO carriers. However, when Nussbaum specifies a list of capabilities she is not concerned with the case of MDRO control measures and the well-being of individual carriers of MDRO but rather with setting out a partial theory of justice. For this reason, when adapting Nussbaum's list to the context of MDRO carriership, we still need to ask (a) whether all items on her list are relevant and (b) to what extent they need to be further specified and/or supplemented by additional capabilities.

First of all, while some of the items on Nussbaum's list may also be relevant for the evaluation MDRO control measures other capabilities are clearly not applicable. For example, while the capability for bodily integrity, seems to be of utmost importance for this discussion, the capability for senses, imagination and thought do not seem to be at stake here. The reason for this is not that being able to use one's senses, imagination, or thoughts are not important human characteristics. Rather, the reason that these capabilities are of little importance in the context of MDRO is that it can be argued that there are no control measures that have the potential to restrict one's use of the senses, imagination, and thoughts. Likewise, it is questionable whether the capability for practical reason – one's ability to form a conception of the good and critically reflect on it – would be thwarted or under threat by any conceivable measure we can take to control MDRO. (However, do note that we suggest to subsume (and expand) the capability for education, which is part of the capability for practical reason, under the capability for life as the capability for proper social, physical, and cognitive development.)

This leaves us the following list of capabilities that we can tentatively assume are relevant for the context of MDRO: Life, bodily health, bodily integrity, affiliation (in both senses), other species, play, and control over one's environment (in both senses). Now, we still need to ask whether these seven items are sufficient for our present purpose. This is so in two ways. We need to ask, first, whether these seven capabilities are comprehensive in the sense that we do not need to add additional capabilities and, second, whether they are sufficiently specified to capture what is at stake in the context of MDRO.

In the first case, are the seven capabilities that we retain from Nussbaum's list sufficient to capture all relevant ethical aspects of the context of MDRO? Do we need to add any further capabilities? In order to answer this, let us first distinguish

between Nussbaum's *categories* of capabilities and the more *specific* capabilities that are included within the categories. Thus, for example, the category of 'bodily health' includes the more specific capabilities of adequate health, nourishment, shelter, and reproductive health. Though all of these specific capabilities support the more general categorical capability of bodily health, they can neither be reduced to each other nor to the general category. In other words, the more specific capabilities are distinct capabilities in themselves.

Are the seven categories of capabilities sufficient to capture all ethical aspects of MDRO? In general, the categories on Nussbaum's list seem comprehensive. However, it may be helpful to distinguish carriers' mental well-being from Nussbaum's category of bodily health. Many of the MDRO control measures have little impact on one's physical or bodily health. Even decreases in bodily health – for example, the displeasure caused by eradication therapies – are only temporary. The mental impact, however, may be just as profound and long lasting. Being subject to isolation measures, for instance, is known to increase the levels of perceived stress and anxiety and the stigma of having been a carrier can continue long after carriage has ceased. Thus, the mental impact of MDRO control measures can and should be seen independently from their physical impact. Let us therefore add an additional category, namely *mental health*.

How about the more specific capabilities on Nussbaum's list? Does Nussbaum identify all relevant capabilities to adequately capture what is at stake within the seven general categories in relation to the context of MDRO? Given the particular focus of her own list, Nussbaum naturally leaves off many capabilities that are relevant in the context of MDRO. For example, when deciding on how to treat children and adolescents, a major concern is how the control measure affects their physical and mental development. Prolonged isolation of children in certain age groups may cause setbacks in speech or reading that will disadvantage them later in life. Moreover, Nussbaum does not explicitly address concerns related to healthcare, such as access to timely and effective treatment and protection against intrusive and excessive examinations and therapy.

Nor are Nussbaum's capabilities sufficiently specified to the context of MDRO carriership and MDRO control measures. For example, the way Nussbaum defines sovereignty over one's body (a part of bodily integrity) seems overly abstract. In the context of MDRO, what we mean by bodily integrity and sovereignty concerns not being subjected to unnecessary, intrusive, or excessive examinations and eradication therapies. Likewise, since a large issue in relation to MDRO is how it might contribute to the stigmatization of carriers (Rump et al. 2015), we need to include protection from stigmatization along with the protection from discrimination (a part of the capability for affiliation).

Thus, we can also answer the second question that we asked above, namely whether Nussbaum's capabilities are sufficiently and adequately specified to capture the context of MDRO. There are good reasons to argue that Nussbaum's list needs to be further specified and supplemented with additional capabilities when setting out a taxonomy of normatively relevant capabilities and functionings in the

context of how MDRO control measures and carriership may affect the lives and well-being of carriers.

In sum, although Nussbaum's list of ten central capabilities provides a useful starting point for identifying the normatively relevant aspects of how MDRO control measures have the potential to impact the lives of individuals, it still needs to be adapted and specified to this particular context. This is so in several ways: first, some capabilities on Nussbaum's list are irrelevant for the case of MDRO; secondly, Nussbaum's list does not distinguish all relevant capabilities, such as mental health; and, thirdly, Nussbaum's capabilities must be specified to the context of MDRO. In the following section, we proceed to present a taxonomy of normatively relevant capabilities and functionings that we need to take into consideration when deciding on and evaluating MDRO control measures.

13.5 A Taxonomy of Normatively Relevant Capabilities in the Context of Addressing MDRO Carriership

What does a taxonomy of normatively relevant capabilities and functionings look like in the context of MDRO? How can it help us understand what is at stake when deciding on measures to contain the spread of MDRO? Building on Nussbaum's list of central human capabilities, in this section we present a taxonomy that adapts and specifies Nussbaum's list to the particular context of assessing and evaluating MDRO control measures. The taxonomy supplements Nussbaum's list through an analysis of empirical literature and studies on what practitioners and MDRO carriers express as normatively relevant and divides the relevant capabilities into four ethical domains.

Table 13.1 presents a systematic overview of how MDRO control measures can potentially affect the lives and opportunities of individual carriers. The table is divided into three columns, which, from left to right, moves from four general domains of human life (the personal, the social, the institutional, and the environmental) to the more specific capabilities and functionings that are relevant in the context of MDRO.

On the right-hand side of the table, we find a list of the various capabilities and functionings that are (a) normatively relevant for living a decent or flourishing human life, as revealed by Nussbaum's list of capabilities, and (b) specifically relevant within the context of MDRO, as revealed by our empirical analyses.

In the first case, capabilities such as nourishment, shelter, the right to association, and being treated with dignity and equal worth are relevant for human life regardless of whether it involves MDRO or not. In the second case, there are capabilities that only or primarily come become relevant when combined with MDRO, such as protection against stigmatization and pathologization, protection against unnecessary or intrusive examinations and therapy, and the ability to engage in recreational activities.

Table 13.1 Ethical domains and normatively relevant capabilities and functionings for the evaluation of the impact of MDRO control measures on (potential) carriers, partly adapted from Nussbaum (2000). Additional items and specifications in **bold**

Domain	Category	Specific capability
Personal	Life	Not having one's life reduced to not worth living **(especially for elderly)**
		Proper social, physical, and cognitive development (especially for children and adolescents)
	Bodily health	Adequate health **(e.g., to fight off infections)**
		Nourishment
		Shelter
		Reproductive health
	Mental health	**Happiness and peace of mind**
		Self-respect **and self-esteem (e.g., being able not to see oneself as sick or as merely a patient)**
		Protection against internalized pathologization
		Future prospects (e.g., of a speedy recovery)
	Bodily integrity	Sovereignty over one's body **(e.g., not being subjected to unnecessary, intrusive, or excessively costly examinations and intensive eradication therapy)**
		Appearance (i.e., being able to appear in public without shame)
		Freedom of choice and opportunity, both in life and in relation to one's body
		Choice in matters of reproduction
		Protection against internalized pathologization
	Play	Ability to enjoy social and recreational activities

(continued)

Table 13.1 (continued)

Domain		Category		Specific capability
Social and community		Bodily integrity		Protection against assault **(e.g., not being seen as merely a threat), also in the case of relatives of carriers**
		Affiliation	A	Ability to live with others
				Friendship
				Family (incl. reproductive rights)
			B	Being treated with equal dignity and respect
				Social status and prestige
		Play		Ability to **engage and participate in** social and recreational activities
		Control over one's environment A		Right to association
				Ability to form and engage in social relations
Institutional	**(Health) care related**	Bodily health		**Access to adequate (i.e., timely and effective) health care**
		Bodily integrity		Security against assault **in the form of intrusive and excessive examinations and eradication therapy**
		Control over one's environment	A	**Access to just and fair healthcare treatment**
			B	Freedom from unwarranted search and seizure **(e.g., having to pay oneself for excessively expensive examinations)**
		Affiliation	A	Institutions help develop and protect forms of affiliation, **self-respect, and dignity**
			B	Being treated with dignity and equal worth
				Protection from discrimination **and stigmatization**
	Public life	Control over one's environment	A	Ability to effectively participate in political **and public** life (incl. free speech and association)
				Access to just and fair institutions
			B	Ability to seek employment on an equal basis
				Decent working environment (incl. protection against discrimination and abuse)
				Freedom from unwarranted search and seizure **(e.g., having to pay oneself for excessively expensive examinations)**
				Economic security

(continued)

Table 13.1 (continued)

Domain	Category	Specific capability
Environmental	Bodily integrity	Ability to change locations freely**/freedom of movement (incl. the ability to live where one chooses to)**
	Other species	Ability to live with other animals **(i.e., pets and livestock)**, plants **(incl. crops)**, and the environment at large
	Control over one's environment B	Ability to own property **(e.g., livestock)**

The eight categories of capabilities can, in turn, be relevant within one or more of four domains of human life, identified on the left-hand side of the table: the personal, the social, the institutional, and the environmental. Within the personal domain, MDRO control measures influence the relationship that a carrier has to herself, her own body, and her mental satisfaction. In particular, this includes her bodily health, in the sense of being healthy, well-nourished, and having access to adequate accommodation, her mental health, including being happy, feeling dignified, and being free from stigmatization, and her bodily integrity, most importantly not being subject to excessive and intrusive examinations and eradication therapies.

The social domain concerns individual carriers' relationships to friends and family and the ability to participate in social activities. Human well-being to a large degree depends on well-functioning social relationships, both instrumentally and intrinsically. Not only do we count on friends and family to help us realize certain ends and goals in life; we also attribute intrinsic value to social relationship: we engage in and enjoy social relationships for their own sake and not because they help us fulfill personal goals.

Hence, whenever our social relationships break down it is likely to harm our well-being. Social relationships are especially vulnerable to MDRO and MDRO control measures. Stigmatization and pathologization are social mechanisms by which we respond to perceived threats. In this way, the case of MDRO has a lot in common with the plight of AIDS carriers in the 1980s. However, stigmatization and pathologization are only two ways in which MDRO measures can harm our well-being in a social context. More generally, since we derive pleasure from engaging in social relationships, MDRO measures that restrict the extent to which we can engage in social relations have the potential to lead to a decrease in our well-being.

On the institutional level, we are interested in the carriers' relationship to and standing within institutions, primarily (but not limited to) health care facilities. MDRO is primarily an issue when it comes into contact with a healthcare setting. That is, MDRO is primarily a risk when it comes into contact with already vulnerable individuals who depend on effective antimicrobial treatments for their health and survival. Such individuals are more often found within care facilities, such as hospitals, nursing homes, and rehabilitation centers. Moreover, healthcare settings also provide more fertile breeding grounds for the emergence of multidrug-resistant organism because of the increased exposure to antimicrobials and, hence, the risk that organisms will evolve resistance to these antimicrobials.

Within the environmental domain, we are primarily concerned with carriers' relations with their environments. To what extent, we ask, are carriers able to connect with their environment? Are they able to exercise any control over their environment? We can talk about a person's relationship to their environment in both literal and figurative terms. Literally, we talk about the environment as something that is *there*: a physical presence that we can interact with and influence. In this sense, our relationship with the environment concerns our ability to interact with physical entities such as plants, including flowers, trees, fungi, and so on, as well as animals, including both pets and livestock. In a figurative sense, the environment is a more abstract and indefinite entity. This is so in two ways. First, we can talk about the environment at large, including in the senses of nature and the climate without referring to specific plants or animals. This way of understanding the environment is of little relevance to the context of MDRO. However, secondly, the environment can also be understood as the indefinite but physical space that surrounds us and which we can move around within. In other words, in this sense we understand one's environment as something within which she (can) has control over herself and her choices. Given that two of the primary MDRO control measures – quarantine and isolation – aim to restrict (potential) carriers' ability to move around, this second figurative understanding of the environment is highly relevant to the context of MDRO.

Crucially, a category of capabilities can be specified differently within different domains. For example, the capability for control over one's environment in the context of the social domain concerns one's right and freedom to form social relationships, while in the institutional domain it rather concerns one's institutional status, such as the freedom to participate in political and public life and access to just and fair institutions. Thus, although the different categories of capabilities can be relevant within different domains, the more specific capabilities that they contain depend on the domain.

It is important to stress that the taxonomy here does not make any claims about which capabilities and functionings that cannot be violated by MDRO control measures. Rather, it provides a structural overview of how MDRO control measures may affect the lives and opportunities of individual carriers. We still need to engage in a weighing of the relevant capabilities and functionings in individual cases in order to determine whether they provide overriding normative reasons not to implement a particular control measure. Such weighing would take place on a case-by-case basis because each case includes contextual circumstances that influence what the best course of action would be. Hence, it is not possible to *a priori* determine what control measure (if any) to implement.

However, by offering a taxonomy of relevant domains and capabilities we do make a claim about what is normatively important and relevant when addressing MDRO. First, as argued in Sect. 13.3, MDRO control measures affect carriers in terms of their capability-sets – what they have the real freedom to do or be. Hence, it is claimed that we ought to conceptualize and describe the impact that MDRO control measures have on individual carriers in terms of capabilities and functionings.

Secondly, however incomplete and underspecified, we make a claim about the kinds of capabilities and functionings that are normatively important for (potential) carriers of MDRO and which should be taken into account when deciding on the best course of action. That is, there are good reasons to claim that *these* particular capabilities have the potential to be normatively relevant when dealing with cases of MDRO. There are both normative and empirical reasons for this claim. Normatively speaking, Nussbaum's list of capabilities provides a normative philosophical grounding of the capabilities: these are capabilities that can be subject to an overlapping consensus. Moreover, there is empirical evidence that (some or most of) these capabilities are of relevance to practitioners and carriers when dealing with cases of MDRO in a healthcare setting. The comparison with real-life queries about how to ethically address MDRO – as represented by our database and deliberations with carriers and practitioners[10] – provide empirical basis for the claim that these are the kinds of capabilities that are of concern when deciding on control measures.

How can this taxonomy be implemented in practice to analyze particular cases of MDRO and decide on appropriate control measures? In the final section, we show how our taxonomy can provide an input into ethical decision-making procedures on the appropriate measure to address MDRO carriership.

13.6 Applying the Capabilitarian Taxonomy in Practice

We have in the previous section repeatedly argued that the more general categories of capabilities that Nussbaum identifies – life, bodily health, mental health, bodily integrity, play, affiliation, control over one's environment, and other species – can and should be specified to the particular context of how MDRO control measures impact the lives and freedoms of individual carriers. We further argued that we can and should specify these categories of capabilities differently according to whether they relate to either of four domains of human life, namely the personal, the social, the institutional, and the environmental. While the taxonomy that we have presented in Table 13.1 provides an overview of how the different categories of capabilities can be specified in relation to the different domains, how it contributes to the practice of implementing appropriate MDRO control measures is still unclear.

The above taxonomy can provide a useful input to ethical decision-making procedures on the implementation of MDRO control measures, such as the frameworks developed by Verweij et al. (2012; Krom 2014) or Grill and Dawson (2015). How does the capabilitarian framework help us make decisions about how to address MDRO? How can our taxonomy help us make better and more informed decisions about what kinds of MDRO control measures that are preferable, acceptable, or justifiable? In this section, we briefly consider how the capabilitarian taxonomy can be applied in practice to ethical deliberations on MDRO and what issues that are left unaddressed.

[10] See footnote 7.

The capabilitarian taxonomy presented in this chapter is especially useful in two regards. First, it can help professionals better describe cases of MDRO by making explicit what is at stake for the individual carriers and relevant stakeholders. Secondly, it can help us to identify and evaluate possible courses of action by showing how various MDRO control measures may impact the capabilities and functionings of affected carriers and stakeholders. Let us, by way of a case study, briefly show how the taxonomy of normatively relevant capabilities can be put into practice in these two ways.

To illustrate how the capabilitarian taxonomy can be applied in practice, consider, for example, the case of a young, 19-year-old mother with no income or higher education who shares a household with her own mother. The father of her newborn child is unknown or absent and the woman therefore relies on her own mother for economic assistance and care help. However, the grandmother of the child turns out to be MDRO positive and there are concerns that she is a threat to the health of the newborn child. If there is close contact, it is very likely that the grandmother would transmit the resistant organism to the newborn. To make matters worse, the child in case has a heart valve condition and needs to go to the hospital for regular check-ups. Because of the likelihood that the child will become an MDRO carrier if the grandmother is involved in the post-partum care of the child, the hospital insists that the grandmother cannot provide this care or that she should take far-reaching protection measures, such as wearing gowns and masks, that would interfere with the bond between child and grandmother.

How can our taxonomy contribute to the understanding and resolution of this case? What capabilities are at stake in this case? While this case involves a lot of different capabilities within several domains, the primary concern here is the ability to live with others, including family (part 'affiliation A' within the social domain). This capability is restricted not only for the young mother but also for the newborn child as well as the grandmother. However, although we can assume that they value this relationship intrinsically – and hence contributes to the capability of happiness and peace of mind (a part of the capability for 'mental health' within the personal domain) – in this case there are at least two instrumental reasons why this capability is important.

First of all, bonding with relatives may be considered an important part of a child's development (a part of the capability for 'life') and restricting the newborn child's relationship to the grandmother risks harming this development. Secondly, in this case, the social relationship between the young mother and her own mother can also be seen as a proxy for more formal institutional care-relationships. That is, not allowing the grandmother to care for the newborn child is mainly problematic insofar as the mother does not have alternative opportunities for care assistance. Within the taxonomy this is represented by the institutional capabilities for 'bodily health' (access to timely and effective healthcare) and 'affiliation A' (institutions help develop and protect forms of affiliation).

In the described case we have multiple courses of action, which can be employed either independently or in conjunction. How can the capabilitarian taxonomy help us identify and evaluate possible measures? Some of the measures would be directed

solely or primarily at the grandmother. First of all, in order to minimize contamination, we could demand that the grandmother undergoes eradication therapy and subsequently attends regular screenings. Secondly, we could demand that the grandmother adhere to a strict hygiene regiment, including the donning of a gown, mask, and gloves when tending to the child. Other measures would be directed at the other stakeholders, in particular the newborn child. For example, thirdly, we could subject the newborn to regular screenings to test for MDRO and, when positive, to eradication therapy.

However, as the case describes, these measures have potentially negative consequences for not only the mother's abilities to engage in social relations and to care for her child, but also the child's well-being, especially in relation to her early childhood development as well as her capability to form an affiliation with her grandmother. From a capability perspective, then, we would do well to look for alternative courses of action that provide better protection of these normatively valuable capabilities.

The analysis of the case from the capability perspective shows that a major issue is that the mother is reliant on *informal care* for her child. Informal care is – usually unpaid – care that is provided by family members or social relations. In contrast, formal care is institutionalized and usually performed by trained professionals. By applying the taxonomy, our analysis shows that the case extends beyond the personal and social domains to reveal a lack of normatively relevant capabilities and functionings at within institutional domain. In the present case, then, a possible solution to the issue could be to increase the access to *formal institutional* healthcare for the young mother and her infant, so that she does not have to rely so much on informal care, thereby avoiding many of the negative consequences that follow from limiting the analysis to focus solely on the informal care-relation between the child, the mother, and the grandmother.[11]

While the proposed course of action in this case might be intuitively clear, in general, a major issue of applying the capabilitarian taxonomy in practice, especially when evaluating the various MDRO control measures, concerns the question of how to weigh different capabilities against each other. That is, we need to ask, when does the reduction of a carrier's capability-set provide an overriding reason to dismiss or provide compensation for a particular control measure? When applying the capabilitarian taxonomy in practice to evaluate different control measures, we should weigh capabilities on at least three levels, namely the intrapersonal, the interpersonal, and the public health level.

The first level at which we need to weight the importance or value of different capabilities against each other when evaluating potential MDRO control measures is at the intrapersonal level. At the intrapersonal level, we ask whether a person is better off within one scenario *as compared to other scenarios*. That is, we can ask, is the person's capability-set more valuable as a result of a particular control

[11] A possible objection, also based on the capabilitarian taxonomy, to the proposed solution is that it would negatively affect the grandmother's capability for affiliation with her grandchild.

measure (or combination of control measures) than it would be if we implement another (combination of) control measure(s)?

At the interpersonal level, second, we are concerned with comparing the capability-sets of different stakeholders *within one particular scenario*. Here we should ask: does a particular control measure diminish the value of the capability sets of one or more of the relevant stakeholders to the extent that it outweighs the positive impact on the value of the capability sets of other relevant stakeholders?[12] Finally, thirdly, we should weigh the positive or negative impact to the value of the capability-sets of individual stakeholders against the estimated benefit to public health that the implementation of a particular MDRO control measure has.

It is beyond the scope of this chapter to consider how such a weighing may be done. Since this decision must eventually be made on a case-by-case basis, it must be a subject for further research to set out normative (or pragmatic) principles for the weighing of capabilities. Such principles might include a threshold level of capabilities and functionings: do we really need to compensate someone for a lost job-opportunity if she already has ample opportunity to find alternative employment? Other principles are principles of proportionality and acceptable risk, that can help us determine when a particular MDRO control measure is (dis)proportionate to the harm, conceptualized in terms of capabilities and functionings, that it does to the individual carrier. In this regard, possible connections could, for example, be made between our capabilitarian taxonomy and the approaches of Viens et al. (2009), who set out a principle of reciprocity, Krom (2011), who discusses the shortcomings of the harm principle in infectious disease control, and Grill and Dawson (2015) who propose a value-based approach.

Moreover, the weighing of capabilities and capability-sets should be done in consultation with the relevant stakeholders in order to identify relevant capabilities and their normative weight. This leaves quite a bit of space for professional autonomy in ethical decision-making. It is simply quite impossible *a priori* to determine the normatively relevant capabilities and their relative, normative weight. In this regard, the taxonomy of normatively relevant capabilities and functionings presented in this chapter should be taken as an open-ended and underspecified basis for further deliberation between the various stakeholders (carriers, relatives, professionals, and possibly policy-makers) on a case-by-case basis. Again, how much room to leave for professional autonomy and how exactly to conduct such deliberative exercises must be subject to further research. We have here proposed two promising frameworks for ethical decision-making, namely Verweij et al. (2012; Krom 2014) or Grill and Dawson (2015).

Finally, it might be objected that, while intuitively attractive, the capabilitarian taxonomy presented in this chapter does not add to professional practice on MDRO. That is, it is not clear that the capability perspective would change what professionals already do when addressing cases of MDRO. This objection holds

[12] Conversely, this could also be framed as: does a particular control measure increase the value of the capability sets of one or more of the relevant stakeholders to the extent that it outweighs the negative impact on the value of the capability sets of other relevant stakeholders?

that one of the supposed advantages of adopting the taxonomy of capabilities, namely its intuitive appeal, at the same time makes the contribution of this chapter trivial. However, even if the taxonomy largely corresponds to existing practice, there are at least four benefits to making the tacit or implicit assumptions of professional practice explicit through the language of the capability approach and the taxonomy that has been presented in this chapter.

First of all, the taxonomy provides a substantive – yet underspecified and open-ended – view of carriers' well-being. Rather than a person's autonomy, generally speaking, we are, on this view, concerned with protecting carriers' normatively relevant or valuable capabilities and functionings. This allows us, secondly, to provide a structured way of discussing how MDRO control measures impact the lives and well-being of carriers, namely by influencing their normatively relevant or valuable doings and beings. In this sense, the proposed taxonomy could serve as a basis for consultation among professionals and with relevant stakeholders. Third, the capability view presents a multi-dimensional view of the impact that MDRO control measures can have. Different individuals might be impacted in different ways by similar control measures and one individual might be affected in many different ways by a particular control measure. Fourth, by conceptualizing the impact of MDRO control measures in terms of people's capabilities and functionings, it possible to see how affecting one aspect of an individual's life may affect other, less immediately obvious, capabilities and functionings.

In sum, the capability framework to MDRO and the accompanying taxonomy of normatively relevant capabilities does contribute to both the literature on the ethical aspects of MDRO as well as, potentially, to real practice of addressing cases of MDRO.

13.7 Concluding Remarks

In this chapter, we have presented and discussed a capabilitarian conceptualization of how MDRO control measures can (negatively) impact the lives and well-being of individual MDRO carriers. According to the capability approach, we should measure and evaluate this impact in terms of how MDRO control measures (negatively) influence what they are able to do or be. Building on Nussbaum list of central human capabilities, we introduced a taxonomy of normatively relevant capabilities and functionings in the context of MDRO. This taxonomy proposes that measures to contain the spread of MDRO may potentially affect carriers in one or more of four domains human life, namely the personal, social, institutional, and environmental domains. We identified eight categories of capabilities – life, bodily health, mental health, bodily integrity, affiliation, other species, play, and control over one's environment – that can and should be specified differently within the four domains of human life when applied to the context of analyzing how MDRO control measures impact the lives of individual carriers. An overview of this taxonomy can be found in Table 13.1.

The taxonomy, we finally argued, should be used as an ethical input to a decision-making framework when deciding on the best measures to take when dealing with cases of MDRO. As such, the taxonomy is both underspecified and open-ended: it still needs to be expanded and adapted when applied to particular, individual cases of MDRO. It does not, by itself, determine when the infringement of a particular capability or range of capabilities is unjust and should be supplemented with a notion of when the reduction of a carrier's capability-set provides an overriding reason to dismiss a particular control measure.

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