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Systematic review

Experiences of carriers of multidrug-resistant organisms: a systematic review

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ABSTRACT

Objectives: A comprehensive overview of the ways control measures directed at carriers of multidrug-resistant organisms (MDRO) affect daily life of carriers is lacking. In this systematic literature review, we sought to explore how carriers experience being a carrier and how they experience being subjected to control measures by looking at the impact on basic capabilities.

Methods: We searched Medline, Embase and PsychINFO until 26 May 2016 for studies addressing experiences of MDRO carriers. Twenty-seven studies were included, addressing experiences with methicillin-resistant *Staphylococcus aureus* ($n = 21$), ESBL ($n = 1$), multiple MDRO ($n = 4$) and other ($n = 1$, not specified). We categorized reported experiences according to Nussbaum's capability approach.

Results: Carriage and control measures were found to interfere with quality of care, cause negative emotions, limit interactions with loved ones, cause stigmatization, limit recreational activities and create financial and professional insecurity. Further, carriers have difficulties with full comprehension of the problem of antimicrobial resistance, thus affecting six out of ten basic capabilities.

Conclusions: Applying Nussbaum's capability approach visualizes an array of unintended consequences of control measures. Carriers experience stigmatization, especially in healthcare settings, and have limited understanding of their situation and the complexities of antimicrobial resistance. **B. Rump, Clin Microbiol Infect 2019;25:274**

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Introduction

Antimicrobial resistance (AMR) is a serious health threat associated with a substantial financial burden and estimated mortality rates as high as 23 000 deaths a year for the United States and 25 000 for the European Union [1,2]. Contact precaution measures aim to minimize direct or indirect contact with carriers of multidrug-resistant organisms (MDROs) or their environment. They are widely installed to prevent (further) transmission of MDROs into the healthcare setting [1–4]. Control measures vary by

country [1–4]. Further, the literature remains inconclusive on their effectiveness [5].

Carriage and related control measures are reported to have negative implications for the well-being of carriers in terms of health-related outcomes such as anxiety, stress and depression [6–9]. It might well be that there is more at stake for carriers when it comes to their well-being. The capability approach is a way of thinking about well-being in terms of the genuine freedom people have to achieve the things they personally value in life [10–15].

In view of a capability approach, the well-being of people depends not only on basic things like avoiding unnecessary morbidity and mortality or being in good physical and mental health. It also includes achieving more complex things like being able to connect to other people, be of worth for others or take part in community life [10–12] (Supplementary Table S1). Using the capability

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approach to look at experiences of carriers may therefore offer a better understanding of what truly is at stake for carriers and what we thus should be concerned about protecting when implementing control measures [16].

In this review, we sought to explore the experience of being MDRO carrier and being subjected to related control measures by looking at its impact on capabilities.

Methods

This review is registered at the PROSPERO register (CRD42016034055) and reported according to the PRISMA statement [17].

Eligibility criteria

We conducted an integrative review (allowing for the combination of qualitative and quantitative evidence) of the published literature to identify studies reporting on experiences of people diagnosed with MDRO colonization or infection [18]. Studies reporting on infection control measures (e.g. isolation) and studies addressing health-related outcomes (e.g. mortality or length of hospital stay) were screened full text and were included only if MDRO experiences could be separately extracted. Provided that original data were presented, all article types were included.

Information sources and search strategy

We searched Medline, Embase and PsycINFO databases (OvidSP interface) for studies describing experiences of people diagnosed with MDRO colonization or infection and published before 27 May 2016. We combined search terms addressing MDRO colonization or infection with outcome-related search terms like ‘barriers,’ ‘experience’ and ‘satisfaction’ (Supplementary Table S2). MDRO was defined according to Kluytmans-Vandenbergh et al. [3] including methicillin-resistant *Staphylococcus aureus* (MRSA).

Study selection and data collection

Abstracts and full texts were screened by one reviewer (BR); random subsets of 151 abstracts (10%) and 40 full texts (25%) were independently screened by second reviewers (AT and MH). Disagreement was resolved by consensus discussion. Studies with promising titles but missing abstracts were included in the full text screening. Reference lists of included studies were searched to identify further studies. Data regarding study specifics and experiences were extracted using an Excel-based standardized data extraction form.

Quality assessment

The diverse representation of primary sources—typical for integrative reviews—complicates quality assessment [18]. Quality assessment was performed using two criteria: firstly relevance in terms of addressing the full experience of carriage, and secondly representativeness in terms of being detailed enough (coded on a 2-point scale, limited or high) [19].

Synthesis of results

The framework of ten capabilities as proposed by Nussbaum [12] was used for categorization (Supplementary Table S1). All text fragments representing experiences of carriers were labelled and grouped into themes. Themes were then further categorized according to the capabilities they represented.

Results

The search strategy yielded 1496 unique publications; 162 were retained for full text screening. Twenty-eight publications, representing 27 studies, met the inclusion criteria (Fig. 1).

Thirteen studies scored high on relevance (addressing full experiences of carriers), of which nine also scored high on representativeness (in-depth studies). The remaining 14 studies, except for one, scored low on both relevance and representativeness, focusing mainly on quality of delivered hospital care (six studies) and anxiety and depression (five studies) (Loveday H et al., ‘The patient experience of the MRSA screening process and the impact of a MRSA positive result: a qualitative study,’ paper presented at the 2nd International Conference on Prevention and Infection Control, ICPI 2013; Mo Y, Tambyah PA, ‘Socioeconomic impact of multiresistant nosocomial infections—preliminary results of a qualitative study,’ paper presented at the 3rd International Conference on Prevention and Infection Control, ICPI 2015) [20–45]. Supplementary Table S3 lists the characteristics and quality assessment of all included studies.

In terms of heterogeneity, studies were mainly set in the United States (7/27), Sweden (6/27) and the United Kingdom (5/27), targeting mainly the hospital setting (20/27) and handling mostly MRSA (21/27) or several MDROs (extended-spectrum β -lactamase (ESBL), vancomycin-resistant enterococci and MRSA) (4/27); one study concerned ESBL and one did not specify the MDRO. Types of control measures were poorly specified. Quantitative (11/27) and qualitative (11/27) studies were equally represented (Supplementary Table S3).

A total of 277 text fragments were extracted. Eighty-seven percent (242/277) concerned negative experiences, 1% (4/277) concerned positive experiences and 12% (31/277) concerned neutral or mixed experiences (Supplementary Table S4). Impact per capability was supported by a minimum of four and a maximum of 20 studies (Supplementary Table S5). Although aim and design varied, results were consistent; any inconsistency found in the data is mentioned in the text.

Six different capabilities were affected: bodily health (capability 2), emotion (capability 5), practical reason (capability 6), affiliation, being able to laugh, play and to enjoy recreational activities (capability 9) and having control over one’s environments (capability 10). Impact on capabilities 1, 3, 4 and 8 was not observed (Fig. 2).

Bodily health (capability 2)

The capability ‘bodily health’ concerns being able to achieve good health and remain healthy. It was addressed in 20 of 27 studies (Mo Y, Tambyah PA, ‘Socioeconomic impact of multiresistant nosocomial infections’) [20,24,25,27–33,35–38,40–42,44,45]. None of these studies reports a lack of essential elements of healthcare, suggesting that basic health needs are not at stake. However, carriers have concerns about their treatment and feel they do not get access to patient care on the same terms as noninfected patients [20,27–29,36,37,39,42]. They perceive delays in care and effects on length of hospital stay [28,30,38,40,41], and they describe time-consuming trips to the infection clinic [31]. Carriage interferes with rehabilitation [29,30,44]. Carriers also reported positive aspects [34,36,37,40]: isolation ‘enabled them to sleep’ [37] and ‘helped their adjustment to the injury’ [40]. Some carriers only seek healthcare when absolutely necessary [31]. Three studies report only minor interferences with treatment and little differences in perception of care (Mo Y, Tambyah PA, ‘Socioeconomic impact of multiresistant nosocomial infections’) [24,25]. Carriers are poorly informed or are provided with information that fails to meet their needs [31,32,40]. They are left with a feeling of still wanting more information [32]; further, they are uncertain about their carriage status [31,40].

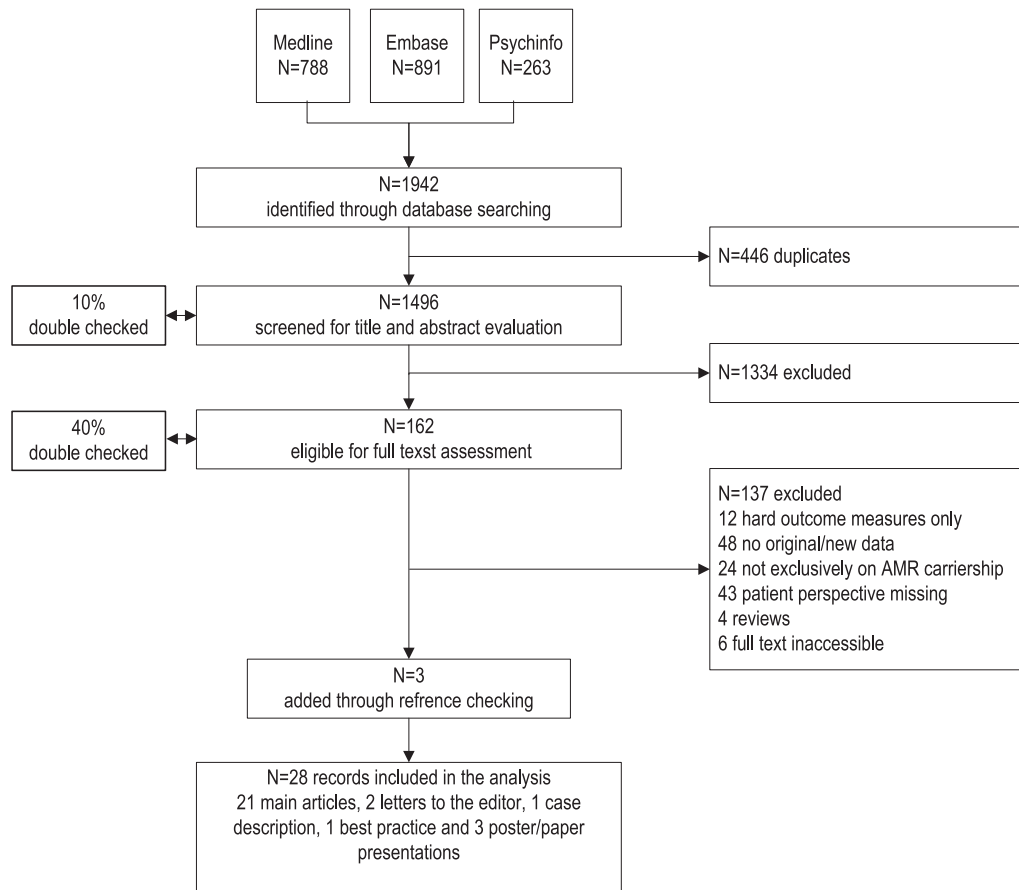


Fig. 1. Flowchart search strategy.

Emotion (capability 5)

The capability of emotion relates to how a person's emotional development can be affected by anxiety, fear or traumatic events such as abuse or neglect, and how this interferes with being able to experience the appropriate emotion for a situation. Carriage does not affect this capability in terms of experiencing the appropriate emotions, but 17 of 27 studies report on how the situation triggers certain emotions that carriers presumably would prefer not to experience (Loveday H et al., 'The patient experience of the MRSA screening process') [20–23,25,26,28,29,33,35,37,40,41,43–45]. Lindberg et al. [33] summarizes the experience as 'invaded, unsecure and alone' and Skyman et al. [40] as 'violated, unclean and scared.' Isolation is reported to be unpleasant and stressful [25,28,33,45]. Carriers placed in hospital isolation score higher on depression [21,22,35,41,44]. Andersson et al. [20], Catalano et al. [21], Day et al. [22], Soon et al. [41], Kennedy and Hamilton [29], Hartmann [28], Tarzi et al. [43] and Wiklund et al. [45] also report higher scores on anxiety and remain inconclusive on anger; Day et al. [22] and Donaldson et al. [23], however, report no differences. Emotional reaction to initial diagnosis is mostly described as 'shocking' or 'traumatic' (Loveday H et al., 'The patient experience of the MRSA screening process') [20,26,40,45], but indifference is also reported [20].

Practical reason (capability 6)

The capability of practical reason is understood as being able to form a conception of the good and to engage in critical reflection about the planning of one's life. The capability also requires having a basic understanding of one's situation and being able to reflect on

it. It appears that carriers have difficulties with comprehension: 12 of 27 studies show they have limited understanding of their situation (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [20,27,28,31,33,36–38,40,44,45]. This goes beyond a lack of knowledge—as described in capability 2—and concerns conceptualizing what it means to be a carrier. Few carriers have a complete understanding of transmission and the reasons for control measures (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [28,36–38,45]. Many feel uncertain [28,33]. 'The lack of outwards signs [of infection] makes the experience confusing and surreal' [44]. Newton et al. [37] report, 'MRSA was perceived as not serious by half, whereas others thought it was more serious.'

Some carriers question the reasonableness of MDRO control measures: MRSA is called an 'overstated problem' [20], and strict isolation practices are 'considered redundant' because 'MRSA is out of control' [44]. Others feel that 'certain rights and privileges have been limited' [27] or feel that they are 'shouldering an undue burden to follow strict isolation policies, as healthcare workers [HCW]... are not subject to MRSA testing' [44]. Others question the 'required openness' that is demanded, considering 'the potential colonization among HCWs' [33].

HCWs further complicate the situation: carriers receive mixed messages or information that is incorrect [31,33,40,45]. 'Staff-members encouraged them to apply good hand-hygiene while staff themselves do not follow this routine' [45]. Indeed, some feel confused about why some staff do not need to follow strict isolation policies or why isolation policies are not required in the community [20,44]. Protective clothing is described as 'being ready for a trip to outer space' [33].

Capability	Definition according to Nussbaum	Definition used in the review	Example of extracted data	Number of studies containing data
2  Bodily health	Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter	Having access to healthcare of good quality and being able to achieve good health	Carriers perceive delays in care and impact on length of hospital stay	20/27 [20,24,25,27-33,35-38,40-42,44,45] ^a
5  Emotion	Being able to have attachments to things and people outside ourselves, not having one's emotional development blighted by overwhelming fear and anxiety	Having emotions people presumably prefer not to have	Isolation is reported to be unpleasant and stressful	17/27 [20-23,25,26,28,29,33,35,37,40,41,43-45] ^a
6  Practical reason	Being able to form a conception of the good and to engage in critical reflection about the planning of one's life	Having a basic understanding of the situation and being able to reflect on it	Carriers lack understanding of reasons for control measures	12/27 [20,27,28,31,33,36-38,40,44,45] ^a
7  Affiliation A	Being able to live with and toward others; to recognize and show concern for other human beings, to engage in various forms of social interaction	Having the opportunity for social and physical interaction with family and loved ones	Carriers fear to harm close surroundings	12/27 [20,23,25,27,31-33,37,38,40,44,45]
 Affiliation B1	Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others	Being able to maintain self-respect and non-humiliation in normal social interaction	Carriers report social situations in which they are treated differently	16/27 [20,25,27-29,31-33,36,38-40,44,45] ^a
 Affiliation B2	Not described as such by Nussbaum	Being able to maintain self-respect and non-humiliation in the interaction with hospital staff	Carriers report that HCWs act unknowing and uncaring	13/27 [20,25,27,28,30,31,33,36,39,40,44,45] ^a
9  Play	Being able to laugh, to play, to enjoy recreational activities	Having the ability to engage in recreational activities	Carriers have questions about using public facilities	7/27 [20,32,33,36,40,44,45]
10  Control over environment	Being able to participate in political choice, hold property and hold employment on an equal base as others	Having material and professional security	Carriage creates insecurities about job opportunities in healthcare	4/27 [20,33,45] ^a

^aPaper presentations by Mo et al. and/or Loveday et al. are included in the study count

Fig. 2. Narrative figure.

Affiliation (capability 7)

The capability 'affiliation' reflects the opportunities one has to affiliation and social interaction. The studies elaborate extensively on negative consequences that are relevant for this capability (18 of 27 studies in total) (Loveday H et al., 'The patient experience of the MRSA screening process'; Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [20,23,25,27–33,36–40,44,45]. This includes capability 7A (the space available for living with and towards others) as well as 7B

(self-respect and nonhumiliation) in normal social interaction (7b1) and specifically within healthcare (7B2).

Firstly, carriage has negative consequences for physical and mental interaction with loved ones (7A; 12 studies) [20,23,25,27,31–33,37,38,40,44,45]. Carriers fear that they may harm their surroundings [20,23,33,38,44]. Some mention 'an intense fear of being a danger to their children and grandchildren' [20] and 'a fear that their children would be noted as the one with the contagion' [31]. Some carriers do not want their relatives to worry and therefore refrain from informing them about the

situation [45]. Others isolate themselves and their family in order to prevent stigma [31,33]. Hospital isolation measures can negatively affect the emotional interaction with loved ones [25,27,28,44], but these isolation measures may also have positive effects [27,37]. One study observes no worries for carriers and relatives [25].

Secondly, carriage has a negative impact on self-respect (7B1, 16 studies) (Loveday H et al., 'The patient experience of the MRSA screening process'; Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [20,25,27–29,31–33,36,38–40,44,45]. Studies by Lindberg and colleagues [31,33], Wiklund et al. [45] and Skyman et al. [40] assess the impact of carriage on normal social interaction and show how carriers feel stigmatized. This is not only a matter of perception; actual social situations in which carriers are treated differently are described [31,33]. Some seem to internalize this stigma. They can be upset for generating fear in their surroundings, and they have strong concerns over being a danger to others (Loveday H et al., 'The patient experience of the MRSA screening process') [20,27,33]. The situation comes with a feeling of being dirty and unclean, and hygiene becomes of particular concern for carriers [20,31–33,44,45]. Some actually change their behaviour, such as increasing sanitation or hand hygiene [20,32,33,45]. Some also report the absence of stigma or a 'commitment to protecting others' (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [33]. Hesitation about disclosure of one's AMR status is also reported [31,33,38,44].

Carriage seemed especially problematic for social interaction within healthcare (Extra category 7B2 'in healthcare,' 13 studies) (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [20,25,27,28,30,31,33,36,39,40,44,45]. HCWs are reported to act unknowingly and uncaringly, and carriers feel they cannot question such behaviour (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [20,31,39,45]. The interaction is described as being 'met with disrespect and humiliation' [39]; 'at the mercy of healthcare' [45]; 'treated like a plague victim' [27,31,40,45]. Further, infection is seen as part of one's identity [31] and as being 'exposed to other people's shortcomings' [20]. HCWs are perceived as unfriendly [28] and as sloppy and neglecting [28,31], and carriers are twice as likely to express greater dissatisfaction, reflected in informal and formal complaints [39]. Carriers perceive an MRSA door sign as 'a breach in confidentiality' [36]. Studies also show good experiences: some report that friendly staff is very important to them [28], some are satisfied when visits are prepared and continuity is achieved [33] and Giese et al. [25] finds only a minority reporting negative impact on interaction with staff.

Being able to laugh, play and to enjoy recreational activities (capability 9)

Carriage sets limitations to the ability to engage in recreational activities (seven of 27 studies) [20,32,33,36,40,44,45]. Carriers have questions about going to the hairdresser, going shopping, having a cup of tea with friends or using public facilities (public transport, communal shower rooms) [20,33,40,45]. Some feel that 'they are not able to live a normal life or that they adapt their needs to MRSA in order to live a normal life,' while others live their life as usual [33]. Isolation is perceived as boring [36,44]. Some feel 'that MRSA did not affect their lives, they [say] that because they neither see or feel the bacteria they forget about it' [33].

Having control over one's environments (capability 10b)

This capability reflects the people's material and political security and the opportunities they have to influence their environment

(four studies) (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections') [20,33,45]. Carriage can have a significant financial impact (Mo Y, Tambyah PA, 'Socioeconomic impact of multiresistant nosocomial infections'). It creates insecurities about job opportunities, especially for HCWs [20,33,45]. Someone describes how 'her whole future was affected because [...] there were jobs that she was not permitted to do,' and another participant describes the situation as 'something that is good' and 'as a new start' [20].

Discussion

This review shows that MDRO carriage and related control measures can have negative implications for six out of ten capabilities, thus visualizing an array of unintended consequences, even though some carriers also appreciate certain aspects, notably increased privacy [24,29,33,36,37,40]. Most included studies concerned MRSA, which is not surprising: MRSA has been around the longest and requires strict isolation—in contrast to, for example, multidrug-resistant Gram-negative bacteria, for which precaution measures are often less stringent [3–5].

An important finding is that carriers have a limited understanding of the implications of the control measures for their personal situation and how to relate these to the overall problem of AMR. This affects their sense of control. Healthcare providers should thus dedicate time to explain what is at stake and listen to and acknowledge the questions, uncertainties, fears and desires of carriers on whom control measures are imposed. Such dedication is also necessary to prevent the stigma that carriers experience, specifically within healthcare practice [46]. Control measures easily isolate patients from their social environment, and healthcare institutions should minimize these effects. Similarly, involvement of family and friends can further reduce stigma and other negative experiences.

Our findings suggest that many HCWs also struggle with understanding AMR and its implications for patient care. AMR is a notoriously complex problem, creating ethical dilemmas [47,48]. More research is needed to better understand this lack of full comprehension and to address this (ethical) complexity. This permits honesty towards carriers, but it may also be essential for acceptance of AMR control measures in the future.

Transparency declaration

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Appendix A. Supplementary data

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