American Journal of Infection Control 47 (2019) 1077–1082

Contents lists available at ScienceDirect

American Journal of Infection Control

journal homepage: www.ajicjournal.org

Major Article

Evaluation in general practice of the patient's feelings about a recent hospitalization and isolation for a multidrug-resistant infection

Ophélie Hereng, Aurélien Dinh MD, MSc, Jérôme Salomon MD, PhD, Benjamin Davido MD, MSc *

Service de Maladies Infectieuses, Hôpital Raymond Poincaré, Garches, France

Key Words:
MDR
Decolonization
ESBL
Carriage
Fear

Background: Isolation precautions used against multidrug-resistant (MDR) organisms are responsible for many emotional side effects. We evaluated patient's feeling after a hospitalization for an MDR infection.

Methods: We conducted a qualitative study that included 11 interviews from August 2017 to June 2018. We used phenomenology and verbatim transcription analysis was performed using NVivo software.

Patients reported mainly negative feelings. Among them, 4 main themes were expressed: a desire to "be free from carriage," self-questioning regarding its nosocomial origin, the reduction of the therapeutic arsenal, and the expression of many fears especially relapse.

Results: For most of the participants (n = 6/11), the type of bacteria that colonized their digestive tract was precisely known including the MDR characteristics of the infection. Participants were convinced that the infection was strongly linked to the hospital and considered it as nosocomial that led to anxiety, especially regarding the origin of the infection and the absence of formal source of infection.

Conclusions: MDR infections are negatively impacting patient's lived experience even after hospital discharge, partly owing to prior implementation of isolation precautions. We need to improve communication between specialists and general practitioners to reassure the patient and his surroundings regarding the anxiety resulting from such hospitalization.

The European Centre for Disease Prevention and Control report published in 2015[1] reveals a global increase in the prevalence of multidrug-resistant (MDR) infections in Europe, especially extended-spectrum β-lactamase (ESBL) *Escherichia coli and Klebsiella pneumoniae*. In France, the Burden report published in June 2015[2] estimates approximately 158,000 MDR infections, with a mortality of 12,000 cases per year (7.6%). In addition, the prevalence of extensively drug-resistant (XDR) bacteria, including carbapenem-resistant Enterobacteriaceae and vancomycin-resistant enterococci in France, has increased 10-fold since 2000, and are responsible of numerous hospital outbreaks in different regions of France.[3,4] To prevent dissemination of these organisms, patients are placed in isolation in hospital wards and "quarantined" until the XDR they carry has cleared.

A review of the literature issued in 2009[5] reported the side effects of isolation precautions for patients carrying an MDR organism (MDRO). These side effects include anxiety, depression, and other behavior disorders such as fear of stigmatization, less contact with nurses, and other avoidable adverse events. More recently, a prospective matched study conducted in France showed that health care workers assistance with daily activities and interactions with other individuals were significantly lower for patients in isolation precautions than those that were not.[6] Nevertheless, the literature is mainly composed of quantitative studies based on closed survey questionnaires. The aim of the present study is to describe the patients' feelings and knowledge after a hospitalization for an MDR infection. Deciphering and understanding patients' emotions might help provide better answers to some questions that may be latent and shameful for colonized patients.

* Address correspondence to Benjamin Davido, MD, MSc, Service de Maladies Infectieuses et Tropicales, Hôpital Raymond Poincaré, APHP, 104 Boulevard Raymond Poincaré, 92380 Garches, France.

E-mail address: benjamin.davido@aphp.fr (B. Davido).

Conflicts of interest: None to report.

Authors contributions: All authors have approved the final article and participated in the study. O.H. and B.D. wrote the protocol, B.D. performed study analyses, J.S. and A.D. proofread the article.

Ethics approval and consent to participate: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

As part of a qualitative study with interviews, oral consent was obtained for all the included patients according to ethical standards.

https://doi.org/10.1016/j.ajic.2019.03.018

METHODS

Settings

We conducted a qualitative study through interviews of patients previously hospitalized for an MDR infection in the Infectious Disease Department of Hôpital Raymond-Poincaré located in Garches (a suburb of Paris), France from August 2017 to July 2018.

Hôpital Raymond-Poincaré is a tertiary teaching hospital with acute care facilities, 255 beds, including 43 beds in the adult intensive care unit, and a 108-bed rehabilitation unit in Garches (France). There are approximately 8,400 admissions per year for complete hospitalization. The hospital is a center of expertise in neurologic impairment, including patients with spinal cord injuries, who often develop infections because of their neurologic disabilities involving complications such as urinary bladder dysfunction and pressure sores. They are also frequently colonized by MDROs, with an incidence that can reach up to twice what is observed in other French health care facilities. In 2013, testing swabs used to detect methicillin-resistant *Staphylococcus aureus* (MRSA) and ESBL-producing Enterobacteriaceae colonization revealed an incidence of 0.71 and 1.1 per 1,000 patient-days respectively, compared with 0.30 and 0.55 per 1,000 patient-days in other health care facilities.[7]

Study participants

We screened all patients admitted during this period that were infected by an MDR or XDR organism and treated by antibiotics and placed in isolation precautions in a single occupancy room. Patients constituted a varied sample of the population admitted in an infectious diseases ward. Minimum duration of hospitalization was fixed to 3 days to evaluate psychological impact. Asymptomatic carriers were excluded from the study.

The study enrolled 19 patients, but only 11 interviews were conducted. The 8 missing interviews were due to patient refusal for vocal transcription or admission in a rehabilitation center. Participants consisted of 3 women and 8 men. Median age was 58 (26-81) years. Median duration of hospitalization was 10 (5-21) days.

Patients had been previously infected by an ESBL urinary tract infection including 3 pyelonephritis, 2 epididymitis, 4 cystitis complicating a neurologic bladder, and 1 MRSA osteomyelitis. One patient experienced a skin and soft tissue infection due to XDR bacteria (*K pneumoniae* OXA-48).

Data collection and procedure

We gathered usual variables such as age, sex, type of MDRO, and site of infection. Patients were contacted by telephone weeks after their discharge to schedule an appointment within 1-3 months.

We used a qualitative study to describe precisely the patient's behavior and emotions felt after the admission once returned back home. Qualitative studies can help to catch unexpected sentences or feelings that are hard to note in regular quantitative studies. Two interviews considered as "pre-tests" were performed to ensure the efficiency of the final interview and study.

The interview was performed by a general practice intern through a questionnaire of 17 questions (Fig 1). This person has been considered by its university (Université de Versailles Saint-Quentin en Yvelines, France) to have enough expertise and knowledge to conduct such qualitative interviews after a 3-month training.

After a short presentation of how the interview will take place, oral consent was collected, and data were transcribed later on. The interview was recorded using a tape machine and interviews took place in a quiet place namely a consultation room. Thereafter, the verbatim transcription was anonymized before being encoded using keywords for a thematic analysis during 2 months.

Data analysis

We used phenomenology for this qualitative approach to evaluate the patient's behavior after a recent admission in isolation precautions. This method has the advantage to require few participants (often 10 or less) and is centered on the participants' experiences with no regard to social or cultural norms and focuses on these 4 aspects of a lived experience: lived spaced, lived body, lived time, and lived human relations.

Analysis of the findings was performed using NVivo software (QSR International Pty Ltd, Victoria, Australia) that can plot a triangulation of data. The software allows users to classify, sort, and arrange information; examine relationships in the data; and combine analysis with linking, shaping, searching, and modeling. Results are presented in Figure 2.

Process of analysis

Median duration of the interview was 12 minutes, 8 seconds, ranging from 10.10-32.35 seconds.

No interview was interrupted by any participant. Median time between discharge from the hospital and the interview was 12 weeks (4-13).

Using the NVivo software, verbatim analyses revealed that 4 main themes were expressed: a desire to "be free from carriage," self-questioning regarding its nosocomial origin, the reduction of the therapeutic arsenal, and the expression of many fears especially contagion and relapse (Fig 3).

Compliance with ethical standards

As part of routine care, without any intervention, data were collected as natural history of the disease and filed in the medical chart.

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

RESULTS

Data that express patients' knowledge about multiresistance

For several participants (n = 6/11), the type of bacteria that colonized their digestive tract was precisely known; they could name it and expressed the MDR characteristics of the infection. They had already heard of this type of "nosocomial" infection through the media and the Internet.

These participants were also convinced that the MDR characteristic of the infection was strongly linked to the hospital and considered it as nosocomial, "*It's nosocomial for sure. In my case I am sure of it, because I was infected after a biopsy.*"

Data that express patients' feelings

Patients clearly expressed fear against these MDROs, "*I've been on the internet, you have at least an hour search, because there are so many cases. [...] I learned many things that I did not know*"; "*It's more via the newspapers, on television, what we see commonly.*" There was also a real threat concerning the risk of relapse, "*It worries me*"; "*Well it scares me a lot.*" "*I do not want to live with a sword of Damocles hanging over my head!*"; "*It's coming back, it's coming back all the time!*" Consecutively, most patients (n = 6/11) want to "be free of carriage."

"Hello, my name is Ophélie Hereng, I am a general practice intern. With the help of Dr. Davido, I am doing a thesis concerning patients who have been hospitalized at Raymond-Poincaré Hospital. My work is focusing on your communication with your family doctor, your knowledge about the infection you have been recently admitted for and your living experience, particularly your feelings about your infection. Our interview should last around fifteen minutes and will be recorded with your agreement for further anonymous analysis. Do you agree to participate to this study?"

1. Which doctor did you see within the weeks following hospitalization?
2. Have you discussed about your hospitalization with your family doctor?
- If "Yes", go to questions 4 and 5.
- If "No" go to questions 3 and 5.
3. Why haven't you talked about it?
4. How did the subject appear during the consultation?
5. Do you feel that your family doctor has changed his medical care practices following your hospitalization? (including hygienic measures or antibiotic strategies for instance)
6. If so, which hygiene advices did he give you?
7. If so, did you apply them?
8. What do you know about the bacteria that infected you while you were hospitalized?
9. What information did you received during the hospitalization?
10. What is your current thinking / feeling about the bacteria that you were infected with?
11. How did your family react about your recent admission due to a multidrug-resistant bacterium?
12. Which researches have you done concerning this bacterium (medical websites, discussion forums, association ...)?
13. Since your hospitalization and you returned back home, what have you changed in your hygiene measures (hand washing, hydro-alcoholic gel ...)? Unless already discussed in question 6
14. Since your hospitalization, do you understand the link between taking antibiotics and the existence of antibiotic-resistant bacteria?
15. What do you think about prevention campaigns (like "antibiotics are not automatic?")
16. Do you think you have been sufficiently informed by your general practitioner about the risks of taking prolonged or repeated antimicrobial therapies?
17. At the end of our interview, do you have any comments or questions you would like to share with me?

Fig 1. Survey asked of the patient to evaluate his feelings about isolation precautions induced by their multidrug-resistant bacterial infection.

Moreover, some patients (n = 5/11) expressed anxiety because of the lack of information regarding the origin of the infection. Patients want to find out where the bacteria came from and understand the "source of contamination." "*Basically, we do not know at all how it happened [...] Although I live very well with Escherichia coli, I will continue to find out where it comes from*; *because I want to know when I've been contaminated."*

In addition, most of the interviewed patients (n = 6/11) considered their infection required a salvage therapy that can only be obtained in health care facilities. Also, they were conscious that physicians are dealing with a reduction of therapeutics and had fears about the next episode of infection, "*Those antibiotics should be used starting using the broader ones. [...] To keep the strongest ones for further usage*"; "*My body does not longer respond favourably to all those mixtures of antibiotics. It will be difficult to find the appropriate antibiotic in my case.*"

DISCUSSION

First, patients had some notions regarding the MDR characteristics of their infection, but it must be considered that most of them were patients presenting with recurrent infections (n = 7/11), and were previously admitted in our department of infectious diseases. It could have led to precise information regarding resistance development and isolation precautions. Therefore, our findings might not be applicable to other departments of internal medicine.

Second, our patients expressed major fears regarding colonization and their recent hospitalization in isolation precautions for an MDR

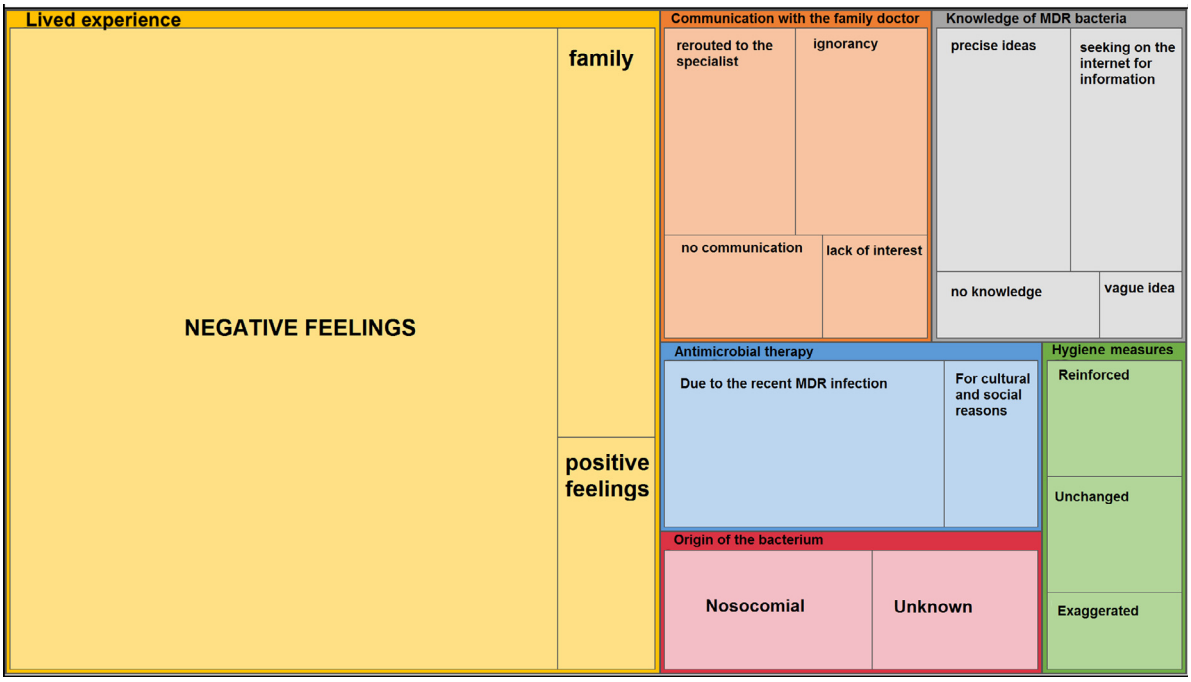

Fig 2. Hierarchy chart of the expressed feelings and knowledge during the interviews. The size of the squares reflect proportionally to patient concerns. *MDR*, multidrug-resistant.

infection, whereas the literature reported effects of isolation on patient and staff were only associated with depression and not anxiety.[8] In fact, their fears are mainly owing to the lack of information concerning the differences between colonization and its risk of contagion because of the recent infection. This feeling of anxiety might be surely accentuated by the due precautions during hospitalization. This idea has been previously studied among primary caregivers in pediatrics, after a close contact with a child suffering from a MRSA skin and soft tissue infection.[9] Indeed, it changes their behavior with anxiety to be infected or asymptomatic carriers responsible for relapse. The study concludes that there is a need for community interventions and education to prevent the negative psychosocial repercussions associated with MRSA. However, Day et al[10] showed that patients under contact precautions do not appear to be more

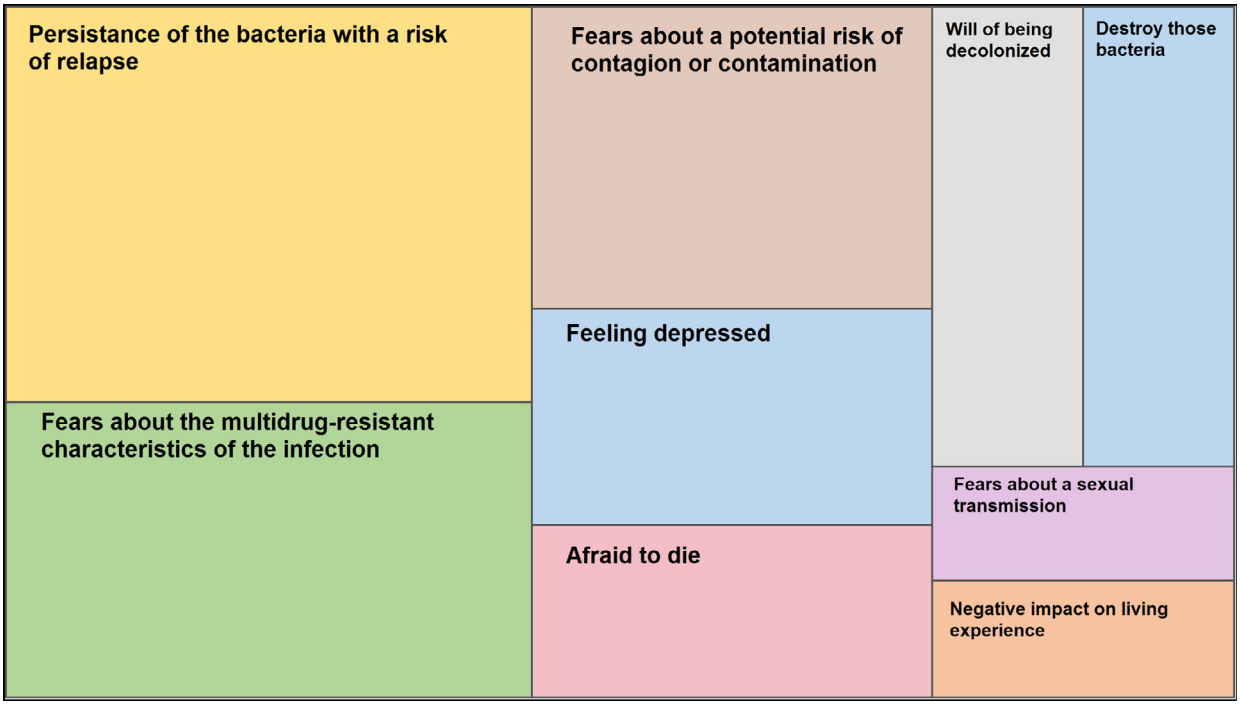

Fig 3. Hierarchy chart of the negative feelings expressed through verbatims that depicts the 4 main themes: a desire to "be free from carriage," self-questioning regarding its nosocomial origin, the reduction of the therapeutic arsenal, and the expression of many fears, especially contagion and relapse.

likely to develop depression, anxiety, or negative moods, and stated that physicians should not limit the appliance of these isolation measures.

Concerning the idea to "be free from carriage," some patients are asking for a specific therapy, which may explain why some general practitioners are urged to wrongly prescribe antibiotics for unnecessary indications, contributing to the development of resistance.[11] One possibility could be to educate people regarding the actual national plan of antibiotic sparing and its global stake, that aims to reduce the number of MDROs. Regarding the fear of being infected by a nosocomial germ, if we look closer at the definition issued by the French Infection Control Committee,[11] we can assume that most of the patients were truly suffering from a nosocomial infection considering the MDR characteristics of the microorganisms. However, patients should be informed that there are other risk factors responsible for the acquisition of MDR or XDR organisms, including antibiotic selective pressure inside the community, especially if they do have recurrent infections such as urinary tract infection, as in our facility. Even if MRSA[12] is deemed to be highly prevalent in the United States in contrast to France, ESBL are unfortunately spreading in the community in France (6% of ESBL *E coli* in laboratories).[13] It should be noted that the analyses of the different diagrams using our software revealed that most of the patients expressed a will to "be free from carriage," especially for the patients conscious about the limitation of therapeutics and the nosocomial origin of their infection. Maybe those findings would differ if the study concerned patients who had acquired MDROs from the community. In a complementary work, it could be interesting to compare the feeling of the patients infected by nonresistant bacteria in general practice to the ones infected by MDR or XDR bacteria. Nevertheless, we decided to focus our work on MDR bacteria because of their endemic level, with a high social media impact, as seen with HIV during 1980s.

A qualitative study performed by Wiklund et al[14] concerning ESBL carriers in 2013, showed that it was important that patients receive adequate information from the attending doctor. Furthermore, the same authors recently confirmed that when the information from the attending doctor was insufficient, patients often used the Internet to obtain additional information,[15] which could lead to wrong beliefs as described in our work. However, in practice, it seems that nothing really changed in physician's attitude concerning the delivered information to the patients regarding MDROs, as highlighted in our study. Considering that the interviews took place in our department, we started to deliver systematically a brochure issued by the Infection Control Committee of Paris as soon as the patient is known to be carrying an MDR of XDR organism. This brochure explains the usual precautions to limit the transmission of such microorganisms and explains that there are only few theoretical risks for those in close surroundings unless they are immunocompromised.

Another possibility could be to reinforce the link between the specialists from the hospital and general practitioners after hospital discharge, to ensure that the patient has understood the challenge of infection prevention owing to an MDRO, and, when appropriate, answer to his questions or fears. Indeed, this study supports the fact that there is a gap between patient's beliefs and the real knowledge he or she has of MDROs.

The main limitation of this work is because of the nature of such a qualitative approach. Unlike other studies using close-ended questions, the employed method does not strive for quantitative representativity. Moreover, it is a monocentric study with a small sample size (n = 11), as is usual in qualitative studies. In addition, some patients contacted by cell phone did not consent to participate to the interview because they were stressed by the idea to recall the time of hospitalization that constitutes a selection bias.

The implications in practice after our intervention is that we now propose to patients placed in isolation a psychological support, if needed, and we insist on the fact that such due precautions are not necessary after discharge, namely in their home.

Further investigations with more individuals are warranted to support the reliability and transferability of our findings.

CONCLUSIONS

This qualitative study, among 11 patients previously admitted for an infection owing to an MDRO, revealed some patients' worries. MDR infections are negatively impacting patient's lived experience even after hospital discharge, partly because of prior implementation of isolation precautions. Therefore, the patient is willing to "be free from carriage" and is self-questioning about limitation or therapeutic arsenal in the future that is responsible for anxiety. We believe that physicians, including juniors, need to better communicate regarding those themes during hospitalization. Also, we need to raise awareness in general practitioners to answer patients' questioning after discharge and use reassurance measures for him and his close surroundings.

Acknowledgments

Authors would like to thank all the patients who gave consent to participate in the study and their colleagues.

References

1. European Centre for Disease Prevention and Control. Antimicrobial resistance surveillance in Europe. 2015. Available from: https://ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/antimicrobial-resistance-europe-2015.pdf. Accessed April 10, 2019.
2. Colomb-Cotinat M, Lacoste J, Coignard B, Vaux S, Brun-Buisson C, Jarlier V, et al. Morbidité et mortalité des infections à bactéries multi-résistantes aux antibiotiques en France en 2012. Etude Burden BMR, rapport: Juin 2015 [Internet]. Institut de veille sanitaire. 2015. Available from: http://invs.santepubliquefrance.fr/fr/Publications-et-outils/Rapports-et-syntheses/Maladies-infectieuses/2015/Morbidite-et-mortalite-des-infections-a-bacteries-multi-resistantes-aux-antibiotiques-en-France-en-2012. Accessed April 10, 2019.
3. Vaux S, Carbonne A, Thiolet JM, Jarlier V, Coignard B. RAISIN and Expert Laboratories Groups. Emergence of carbapenemase-producing Enterobacteriaceae in France, 2004 to 2011. Euro Surveill 2011;16.
4. Subiros M, Bervas C, Venier A, Colomb Cotinat M, Soing Altrach S, Pontiès V, et al. Entérocoques résistants aux glycopeptides dans les établissements de santé en France: données épidémiologiques du signalement des infections nosocomiales, Juillet 2001-Juin 2015 [Internet]. 2016. Available from: http://invs.santepubliquefrance.fr/beh/2016/24-25/pdf/2016_24-25_3.pdf. Accessed April 10, 2019.
5. Morgan DJ, Diekema DJ, Sepkowitz K, Perencevich EN. Adverse outcomes associated with contact precautions: a review of the literature. Am J Infect Control 2009;37:85-93.
6. Guilley-Lerondeau B, Bourigault C, Guille des Buttes A-C, Birgand G, Lepelletier D. Adverse effects of isolation: a prospective matched cohort study including 90 direct interviews of hospitalized patients in a French University Hospital. Eur J Clin Microbiol Infect Dis 2017;36:75-80.
7. Institut de veille Sanitaire (InVS). Surveillance des bactéries multirésistantes dans les établissements de santé en France. Réseau BMR–Raisin–Résultats. Available from: http://invs.santepubliquefrance.fr/Publications-et-outils/Rapports-et-syntheses/Maladies-infectieuses/2015/Surveillance-des-bacteries-multiresistantes-dans-les-etablissements-de-sante-en-France. Accessed
8. Lupión-Mendoza C, Antúnez-Domínguez MJ, González-Fernández C, Romero-Brioso C, Rodriguez-Bano J. Effects of isolation on patients and staff. Am J Infect Control 2015;43:397-9.
9. Muenks CE, Sewell WC, Hogan PG, Thompson RM, Ross DG, Wang JW, et al. Methicillin-resistant *Staphylococcus aureus*: the effects are more than skin deep. J Pediatr 2018;199:158-65.
10. Day HR, Perencevich EN, Harris AD, Gruber-Baldini AL, Himelhoch SS, Brown CH, et al. Depression, anxiety, and moods of hospitalized patients under contact precautions. Infect Control Hosp Epidemiol 2013;34:251-8.
11. Bassetti M, Poulakou G, Ruppe E, Bouza E, Van Hal SJ, Brink A. Antimicrobial resistance in the next 30 years, humankind, bugs and drugs: a visionary approach. Intensive Care Med 2017;43:1464-75.
12. Tosas Auguet O, Betley JR, Stabler RA, Patel A, Ioannou A, Marbach H, et al. Evidence for community transmission of community-associated but not health-care-associated methicillin-resistant *Staphylococcus aureus* strains linked to social and

material deprivation: spatial analysis of cross-sectional data. PLoS Med 2016;13: e1001944.
13. Nicolas-Chanoine M-H, Gruson C, Bialek-Davenet S, Bertrand X, Thomas-Jean F, Bert F, et al. 10-Fold increase (2006-11) in the rate of healthy subjects with extended-spectrum-lactamase-producing *Escherichia coli* faecal carriage in a Parisian check-up centre. J Antimicrob Chemother 2013;68:562-8.
14. Wiklund S, Hallberg U, Kahlmeter G, Tammelin A. Living with extended-spectrum β-lactamase: a qualitative study of patient experiences. Am J Infect Control 2013;41:723-7.
15. Wiklund S, Örtqvist Å, Berlin A, Stamm C, Broliden K. Experiences and consequences of living with extended-spectrum β-lactamase–producing bacteria: a qualitative study. Am J Infect Control 2018;46:1394-9.