‘. . . and then no more kisses!’ Exploring patients’ experiences on multidrug-resistant bacterial microorganisms and hygiene measures in end-of-life care

A mixed-methods study

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Abstract

Background: In end-of-life care hygiene, measures concerning multidrug-resistant bacterial microorganisms may contradict the palliative care approach of social inclusion and be burdensome for patients.

Objectives: To integrate patients’ perspectives on handling multidrug-resistant bacterial microorganisms at their end of life, their quality of life, the impact of positive multidrug-resistant bacterial microorganisms’ diagnosis, protection and isolation measures on their well-being and patients’ wishes and needs regarding their care.

Design: A mixed-methods convergent parallel design embedded quantitative data on the patients’ multidrug-resistant bacterial microorganisms’ trajectory and quality of life assessed by the Schedule for the Evaluation of Individual Quality of Life in qualitative data collection via interviews and focus groups. Data analysis was performed according to Grounded Theory and qualitative and quantitative results were interrelated.

Setting/participants: Between March 2014 and September 2015 at two hospitals adult patients diagnosed with multidrug-resistant bacterial microorganisms and treated in a palliative care department or a geriatric ward were included in the sample group.

Results: Patients in end-of-life and geriatric care reported emotional and social impact through multidrug-resistant bacterial microorganisms’ diagnosis itself, hygiene measures and lack of information. This impact affects aspects relevant to the patients’ quality of life. Patients’ wishes for comprehensive communication/information and reduction of social strain were identified from the focus group discussion.

Conclusion: Patients would benefit from comprehensible information on multidrug-resistant bacterial microorganisms. Strategies minimizing social exclusion and emotional impact of multidrug-resistant bacterial microorganisms’ diagnosis in end-of-life care are needed as well as adaption or supplementation of standard multidrug-resistant bacterial microorganisms’ policies of hospitals.

Keywords

Palliative care, geriatrics, drug resistance, multiple, quality of life, hygiene, infection control

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What is already known about the topic?

- In specialized palliative care, up to 11.6% of patients are colonized or infected with multidrug-resistant bacterial microorganisms.
- Protection and isolation measures are potentially stressful to the individual, as studies for non-palliative care patients have indicated.

What this paper adds?

- The individual patients' perceptions of how their multidrug-resistant bacterial microorganisms' diagnosis and the respective protective hygiene measures affect them vary widely.
- End-of-life care patients miss information about risks, report emotional and social impacts due to multidrug-resistant bacterial microorganisms' diagnosis and protection and isolation measures.
- Multidrug-resistant bacterial microorganisms aggravate individual discomfort and influence quality of life for palliative care and geriatric patients at their end of life. Some patients feel massively restricted and threatened by multidrug-resistant bacterial microorganisms.

Implications for practice, theory or policy

- Patients' experiences at their end of life indicate that they would benefit from more comprehensible information on multidrug-resistant bacterial microorganisms and its management.
- Measures against stigmatization, social exclusion and emotional impact of multidrug-resistant bacterial microorganisms are needed.

Background

Physical, psychological, spiritual and social burden is common in case of progressive diseases and long-term conditions.^{1,2} One priority in end-of-life care is to address this burden in order to maintain or possibly improve patients' quality of life. Additional procedures such as hygiene measures due to the carriage of or infection with multidrug-resistant bacterial microorganisms (e.g. methicillin-resistant *Staphylococcus aureus* or multidrug-resistant Gram-negative bacteria) may aggravate individual discomfort. In hospitals in general, efficient isolation and eradication measures are crucial in case of multidrug-resistant bacterial microorganisms for individual patient safety and for infection control.³ However, protection and isolation measures are potentially stressful to the individual, as studies for non-palliative care patients have indicated.^{4–16} In specialized palliative care up to 11.6% of patients are colonized or infected with multidrug-resistant bacterial microorganisms.^{17–22} The evidence on how patients at the end of life perceive the diagnosis of multidrug-resistant bacterial microorganisms and the protection and isolation measures in hospitals²³ is scarce. The study at hand, focusing on patients' experiences with multidrug-resistant bacterial microorganisms, was part of a consortium project dealing with the handling of multidrug-resistant bacterial microorganisms at the end of life and aiming at the development of recommendations (M-EndoL – MRSA in End-of-Life Care funded by the Federal Ministry of Education and Research 01GY1314).²⁴

Objectives

The aim was to integrate patients' perspectives into theoretical assumptions and deduce recommendations on handling multidrug-resistant bacterial microorganisms at the end of life. The research questions were as follows: (1) How do patients describe their multidrug-resistant bacterial microorganisms' trajectories? (2) How do patients with positive multidrug-resistant bacterial microorganisms finding assess their quality of life? (3) How do multidrug-resistant bacterial microorganisms themselves and the isolation measures impact patients? (4) In what way do multidrug-resistant bacterial microorganisms influence what quality of life means to patients? (5) What needs and wishes do patients with multidrug-resistant bacterial microorganisms have regarding their care?

Design

From a pragmatism- and constructivism-based epistemic approach, the mixed-methods design was judged to best fit the research questions.^{25,26} The complementary strengths and weaknesses of the different methods are met by the convergent parallel design²⁷ in which the methods are used simultaneously. Hence, in this study, a quantitative component was embedded in qualitative data collection and analysis²⁷ with the qualitative component being dominant in the mixed-methods study design. Due to the scarce evidence, an explorative design was chosen which draws on the quantitative component in its supportive capacity.

Table 1. Inclusion and exclusion criteria.

Inclusion criteria	Exclusion criteria
<p>≥18 years</p> <p>Sufficient fluency to report on experiences with multidrug-resistant bacterial microorganisms in German</p> <p>Physical ability to participate</p> <p>Psychological ability to participate</p> <p>Multidrug-resistant bacterial microorganisms' infection or colonization</p>	<p><18 years</p> <p>Insufficient fluency in German</p> <p>Insufficient physical ability, for example, drowsiness, weakness, high symptom burden and low general condition</p> <p>Patient emotionally did not feel able to participate, anxiety</p> <p>No multidrug-resistant bacterial microorganisms' carriage or infection</p>

The mixed-methods study is reported according to the GRAMMS guideline for reporting mixed-methods research.²⁸ Qualitative interview and focus group methods are reported following the COREQ checklist for reporting qualitative research.²⁹

Setting

Patients were defined as approaching end of life in this study if they were terminally ill with a progressive disease, a life expectancy of 6–12 months and treated in palliative care because of physical, psychological, social or spiritual burden and geriatric patients who were older than 70 years and diagnosed with a typical geriatric multi-morbidity according to ICD-10-GM.³⁰ Palliative care patients have a mean life expectancy of 51.7 (± 72.5) days after discharge from the palliative care unit.³¹ Corresponding figures are not available from geriatrics. However, clinical experience has shown that the general life expectancy of hospitalized geriatric patients in the age of 70–94 years and in regard of the severity of comorbidities is reduced to such an extent that we are talking about an end-of-life situation according to our definition.^{32,33}

Those patients are treated at the palliative care unit, by the hospital palliative care support team at acute wards and at the geriatric department. The hygiene measures and isolation procedure policies of both study centres varied. The palliative care unit with six single and two double rooms, without negative pressure isolation rooms, was located in the hospital campus as a separate ward. Screening strategy was full screening of all patients at admission. The single rooms included mantraps providing space for changing protective clothing and hand disinfections. Visitors and staff members were allowed to enter the room without personal protective equipment for social contacts whereas protective clothing was required if staff members had physical contact during medical or nursing tasks.

The geriatric department was organized into wards and a total of 90 beds. Single-room accommodation for patients with multidrug-resistant bacterial microorganisms' infection or colonization was standard; the door had to stay closed and flagged with a sign. The screening was triggered by risk stratification. Trolleys fitted with protective equipment were

provided to enable fulfilment of hygiene precautions. Alongside hand hygiene, personal protective equipment (including protective clothing, cap and filtering facepiece respirators) was required for staff members (medical, nursing and therapeutic) and visitors. This was accordingly for the acute wards palliative patients who were treated by the hospital palliative care support team.

Sampling

Eligible patients were defined by inclusion and exclusion criteria that were assessed by staff members of the wards on request of the research team (see Table 1). Convenience sampling of all adult patients diagnosed with multidrug-resistant bacterial microorganisms and treated at the palliative care unit or by the hospital palliative care support team at acute wards (recruiting centre university hospital Erlangen) or at the geriatric ward (recruiting centre hospital Regensburg) was performed.

Recruitment

Recruitment took place from March 2014 to September 2015. Patients fulfilling the inclusion criteria were personally invited to study participation by trained researchers during inpatient stay. They were informed about the study's aim, the approximate duration of the interview and if they did not want to decide on participation immediately further appointments in the following days were provided. Ethical issues addressed in the personally given and written information were potential risks, benefits and voluntariness of participation as well as data protection aspects. Patients were given time to ask questions and the presence of family was facilitated if requested. Patients had the possibility to withdraw the participation at any time. Interviews took place directly after giving information or an appointment was made according to the participants' preferences.

Data collection

A qualitative semi-structured interview was performed with all patients who consented to participate in the study, supplemented by six questions on their individual

multidrug-resistant bacterial microorganisms' trajectory, an overall rating on quality of life (How would you rate your current quality of life? 11-point scale with 0 *very poor* to 10 *ideal*) and the Schedule for the Evaluation of Individual Quality of Life with direct weighting procedure (SEIQoL-DW).³⁴ The semi-structured approach consisted of open questions without underlying a priori assumptions and facilitated the presentation of guiding questions on the topic of interest (experiences with multidrug-resistant bacterial microorganisms) and allowed the interviewers to deepen reports through individual enquiries according to participants' answers. The intention was to gain theoretical assumptions on patients' experiences with multidrug-resistant bacterial microorganisms in end-of-life care in hospitals. Interviews were held in the patient room or at the patient's home after discharge. A focus group with patients and patient representatives took place at the geriatric ward in February 2016. Only geriatric ward patients were recruited for the focus group due to their longer duration of hospital stay and longer survival time compared to the patients of the palliative care unit. For personal characteristics of researchers, see Authorship.

Instruments

Prior to the study, the researchers received a face-to-face interview and focus group discussions training. Researchers did not establish a relationship with participants prior to study commencement. For the face-to-face interviews (performed by S.S., A.S., F.A.H. or M.H.), a semi-structured interview guideline was developed, designed and piloted to elicit patients' experiences on the multidrug-resistant bacterial microorganisms' diagnosis and hygiene measures. In addition, patients were asked to give information on the time of diagnosis, the type of information given and by whom, former diagnoses, symptoms, and management. In the interview individuals' quality of life was assessed through SEIQoL-DW.³⁴ The SEIQoL assessment requires the participants' capacity to give information on aspects determining one's quality of life. The five most important aspects in the participant's life are to be specified by the participant, followed by a rating of the level of satisfaction with the quality of life determining aspects and a direct weighting procedure with a disc that is used to indicate the relative importance of each quality-of-life aspect.

According to the inclusion criteria, the ability to participate was based on a subjective assessment of staff members. The assessment was repeated by the interviewer at the time of interview. The purpose was to avoid wrong assessments of ability to participate due to changes in the patient's constitution. The patients' ability to participate was rated (*very good*: no difficulties in understanding and answering the questions; *good*: few additional explanations needed or participants with sensory impairment;

moderate: participants were unfocused or needed several explanations), the quality of gained data (*very good*: high data density; *good*: sufficient picture of participants' individual perceptions and experiences; *moderate*: unclear whether all participants' answers referred to both multidrug-resistant bacterial microorganisms and the end-of-life situation) and whether the quantitative part was fully completed (yes/no).

For the focus group discussion, text samples from the face-to-face interviews on social and emotional impact, stigmatization and coping strategies of multidrug-resistant bacterial microorganisms were chosen to stimulate group discussion between participants. The moderators (J.T., A.S.) focused on obtaining the group's concrete wishes and suggestions on dealing with multidrug-resistant bacterial microorganisms in the hospital setting.

Data processing and analysis

All interviews and the focus group discussion were digitally recorded and transcribed verbatim by trained student assistants for analysis using the transcription software f4.³⁵

Each interview transcript (qualitative part) was analysed using procedures of Grounded Theory³⁶ modified by Strauss and Corbin³⁷ in MAXQDA.³⁸ The procedures provided an understanding of patients' construction of their personal situation, to develop hypotheses based on the narrative and to draw theoretical assumptions. The coding was performed independently by two researchers. First, they administered open coding by selecting meaningful units of text as anchors and marked them with descriptive codes. Second, they arranged codes similar in content to concepts representing important topics. Third, the researchers compared their codings in order to reach an agreement. In case this did not lead to a common result, a third researcher was consulted.

During further analysis, the researchers outlined broader categories combining similar concepts in the manner of an axial coding strategy. The process of data analysis was supported by the regular writing of theoretical memos by the researchers to define codes, concepts or categories and to note arising ideas.

To ensure methodological rigour, codes, concepts and categories were checked at regular intervals for concise description and clear definitions of categories and concepts by a fourth researcher. The resulting code structure was used to analyse the focus group interview deductively. New codes from the focus group were added inductively if text phrases did not fit in the given code structure from the interviews.

Quantitative data were analysed descriptively with SPSS 21;³⁹ SEIQoL-DW with its satisfaction levels, weights of quality-of-life aspects and the index was analysed according to the routine of O'Boyle et al.³⁴ To prepare for integration findings from qualitative data on the impact of

Table 2. Completeness of data and quality-of-life measures.

Completeness of data		
Ability to participate (<i>n</i> = 43)	Very good	55.8%
	Good	32.6%
	Moderate	16.3%
Complete quantitative data set (<i>n</i> = 43)	Yes	53.5%
	No	46.5%
SEIQoL-DW (<i>n</i> = 43)	Filled in	90.7%
	No	9.3%
	Five aspects reported	61.5%
	Less than five aspects reported (SEIQoL-DW index could not be calculated)	No ^a 38.5%
Data on trajectory	Yes	90.7%
	No	9.3%
Impact	Social	41.9%
	Emotional	62.8%
	Non	23.3%
Quality-of-life measures	Mean	Standard deviation (SD), range
Overall quality-of-life estimation (<i>n</i> = 37)	5.5	SD 2.8, range 0–10
SEIQoL-DW Index (<i>n</i> = 22)	63.9	SD 21.1, range 8–98.5
Quality-of-life aspects	Family and social environment	79.1%
	Health	60.5%
	Leisure	46.5%
	Attitudes towards life	27.9%
	Living	23.3%
	Eating and drinking	25.6%
	Autonomy and mobility	18.6%
	Work and financial safety	2.3%

SEIQoL-DW: Schedule for the Evaluation of Individual Quality of Life with direct weighting procedure; SD: standard deviation.

^aSEIQoL-DW index could not be calculated.

multidrug-resistant bacterial microorganisms on patients were operationalized: two researchers (M.H., S.K.) independently rated the patients' quotations gathered in the categories emotional impact, social impact and information deficit as negative or unclear/not applicable. If ratings differed, they were discussed and jointly decided. In addition, the aspects patients stated as relevant for their quality of life in the SeiQoL-DW were categorized by both researchers. Data on emotional and social impact and information deficit and categorized quality-of-life aspects was dovetailed using cross-tables. Driven inferences led to theoretical assumptions.

Results

Recruitment

The consecutive inclusion of patients in both recruiting centres was stopped as soon as the analysis of collected data showed consolidated theoretical assumptions on the patients' perspectives on multidrug-resistant bacterial microorganisms (data saturation).

Study sample

Altogether 44 interviews took place (geriatric care: *n* = 27, palliative care: *n* = 17) and 25 participants were female. Mean age was 76.14 ± 10.6 years (range: 42–93 years). If patients' cognitive or emotional ability to participate turned out to be insufficient, interviews were discarded (one case). Therefore, 43 interviews were available for further analysis. Interviewers' ratings on patients' ability to participate and completion of quantitative data are shown in Table 2.

The patients' focus group discussion took place with eight participants: three geriatric patients known from face-to-face interviews, two previously unknown patients recruited after the interview phase, two relatives of patients, speaking in terms of their deceased loved ones, and a staff member in the role of a proponent.

Data collection

The mean duration of the interviews was 42.4 ± 23.6 min (range: 8–115 min), whereas in *n* = 20 cases quantitative assessment was not fully completed. Interviews took

place at the patient's room in the ward in all cases but one that was administered at the patient's home. Some interviews took place together with the patient's proxy.

The focus group discussion took place at a hospital ward room and lasted 90 min including a short break.

Findings on multidrug-resistant bacterial microorganisms' trajectory and quality of life

Multidrug-resistant bacterial microorganisms' trajectory. Details on the multidrug-resistant bacterial microorganisms' diagnosis of the study population are included in Table 4.

Few patients reported symptoms caused by multidrug-resistant bacterial microorganisms ($n=6$) such as cystitis; fever, cold, weakness, diarrhoea, urge to urinate; oral thrush; pain; and distress. Patients who received therapy ($n=21$) mentioned – partially in combination – antibiotics ($n=5$), nasal ointments ($n=7$), lozenges ($n=1$) and mouth-wash ($n=3$).

Information on multidrug-resistant bacterial microorganisms' diagnosis was given verbally in 35 cases, and no patient reported written information. Most patients were informed by a doctor ($n=20$) and/or nurse ($n=12$), others did not remember ($n=9$).

Quality-of-life aspects. Overall quality-of-life estimation was 5.5 (SD = 2.8, range = 0–10, $n=37$). For $n=22$ patients, the SEIQoL-DW Index was calculated: 63.9 (SD = 21.1; median = 65.5, range = 8–98.5).

Further findings on quality of life are shown in Table 2.

Few patients mentioned the multidrug-resistant bacterial microorganisms' diagnosis when being asked about their quality of life: '[. . .] a restriction in the whole quality of life. I often wanted to go out to the café at 4 pm, but one cannot. I have to stay inside my room' (p. 26).

Findings from coding analysis of the face-to-face interviews

The individual patients' perceptions of how their multidrug-resistant bacterial microorganisms' diagnosis and the respective hygiene measures affected them varied widely. While most patients ($n=35$) initially denied to perceive any effects for themselves 'No [consequences], not the least, not at all. What kind of consequences would that be? After all, you don't feel pain or anything when you have this. I don't think about the germ at all throughout the day' (p. 26) or were unsure about the effects, others expressed feeling massively restricted in their quality of life or even fearing a deterioration of the underlying disease or their general condition ($n=8$). '[. . .] that my bad condition was perhaps caused by the germ. That may be a wrong conclusion now, but the idea did come to my mind then' (p. 1).

Partly, the reported reason for assuming no or little impact was the subordination of the multidrug-resistant bacterial microorganisms to the main life-limiting disease or other symptoms: '[. . .] so many other fears and concerns are dominant for me – the cancer diagnosis. That is why the germ does not bother me much at the moment' (p. 12).

Patients' answers to the questions on changes and effects of multidrug-resistant bacterial microorganisms reveal a general challenge to distinguish consequences of the multidrug-resistant bacterial microorganisms from other disease-related symptoms: 'I am unable to distinguish between the symptoms that are caused by Parkinson's disease and others caused by the therapy of the multidrug-resistant bacterial microorganisms' (p. 35).

Nevertheless, patients ($n=30$) had open questions on the multidrug-resistant bacterial microorganisms' situation or stated information deficits. The location and species of the multidrug-resistant bacterial microorganisms diagnosed was unclear, or questions on the available means to treat/heal the multidrug-resistant bacterial microorganisms' colonization/infection were asked during the interviews. Patients wondered about the risks of multidrug-resistant bacterial microorganisms and about how they should behave towards others to protect them from being colonized/infected. The fear that it could have been the patient's own fault was also expressed.

Most patients stated that the staff had not behaved differently since multidrug-resistant bacterial microorganisms' diagnosis, except some ($n=10$) who described implications on care due to the necessity of protective clothing:

You are in the room alone and the nurses come in much rarer because they have to cover themselves. Otherwise they come in more frequently and have a look. But if they have to wear protective clothing, they wait and only come in when there are several things to do. (p. 42)

Patients complained that the use of protective clothing was inconsistent and questioned the usefulness. Others were concerned about their future treatment and care such as their admission to a nursing home and about the multidrug-resistant bacterial microorganisms' diagnosis being recorded in the patient chart.

Partly, patients evaluated their own knowledge as being insufficient 'I do not know anything about the germ, except that I have it' (p. 24). Few report good knowledge from informative talks with their general practitioner and their own professional background. Patients reported assumptions on the risks caused by multidrug-resistant bacterial microorganisms, on localization and how colonization/infection could have taken place, and whether or how the multidrug-resistant bacterial microorganisms could be eradicated.

The self-reported emotional impact of multidrug-resistant bacterial microorganisms' carriage or infection includes spontaneous reactions and long-lasting emotions. Patients

Table 3. Code relation matrix on impact of multidrug-resistant bacterial microorganisms' diagnosis and quality-of-life aspects (categorized).

	Family & Social Environment	Health	Leisure	Attitudes towards Life	Living	Eating & Drinking	Autonomy & Mobility	Work & financial Safety
Impact								
Social n = 16	15	9	10	6	3	5	7	0
Emotional n = 25	23	15	16	7	7	9	4	0
None n = 9	7	9	2	3	1	2	1	1

Grey colour indicates that more than half of participants reporting social, emotional or no impact had mentioned the quality-of-life aspects related in the matrix.

expressed unspecific feelings like being in a strange or awkward situation, feeling a little sad, irritated, confused or nervous because of the multidrug-resistant bacterial microorganisms' diagnosis. The most frequently mentioned feelings are fear, fright and sadness. Patients felt anger, hate, uncertainty, burden, astonishment, consternation and shame. One patient felt a life-threat: '[. . .] I kind of thought, "Oops, now you're going over there soon." [. . .] The [multidrug-resistant bacterial microorganisms] takes my life away' (p. 11).

Patients experienced effects of multidrug-resistant bacterial microorganisms and isolation measures on their social life on different occasions. Patients reported feeling upset because of the constrained participation in social life, such as family celebrations, travelling, daily social activities, due to isolation measures, leading to loneliness. Isolation measures were described as a 'dungeon' or 'being jailed'. Others were disturbed by the fact that they could not see who was coming into the room due to the protective clothing. Patients perceived stigmatization 'You feel like a leper. You are always stigmatized' (p. 42).

Patients recognized changes in the behaviour of staff, family and other visitors that influenced their social relationships. Others were worried about reactions of family and friends when they would be discharged: 'For me, the only important thing was [. . .] how will my friends react?' (p. 29). Patients reported having changed their own behaviour towards their family: 'We did not touch each other anymore. [. . .] No kisses. That was not nice. We are married 52 years, each day there was a kiss in the morning and one in the evening, and then no more kisses' (p. 13).

Integrated results

Altogether 76.7% of participants reported social or emotional impact or both; 23.3% noticed no impact (see Table 2).

Categorization of relevant aspects for quality of life out of the SEIQoL-DW analysis allowed us to rank the different aspects (see Table 2).

The integration of quantitative and qualitative results (see Table 3) shows that impacts are reported more often by patients naming family and social environment, health, leisure and autonomy as important aspects of their quality of life. Concurrence is frequently for emotional impact and family and social environment, health and leisure.

Patients who had known the diagnosis for more than 4 weeks were socially and/or emotionally impacted in 87.5% of the cases, and the percentage was lower for patients with a shorter period since diagnosis (71.4%). The rate of patients who were negatively impacted socially and/or emotionally was higher for those who had a former multidrug-resistant bacterial microorganisms' diagnosis and insufficient information. Male patients and patients who stayed at a geriatric ward reported social and/or emotional impact due to multidrug-resistant bacterial microorganisms more often than females and palliative ward patients. Please see Table 4.

Findings from coding analysis of focus group discussion

Focus group discussion findings show that patients' wishes and suggestions for dealing with multidrug-resistant bacterial microorganisms mainly concern information and communication: Concrete suggestions were given in the focus group on the manner and content of information given to patients, for example, information about differing use of protective measures within the hospital and outpatient care or information material for patients includes contact persons.

Furthermore, patients expect the consequent application of standardized hygiene measures by staff. In

Figure 1. Framework on patients' experiences with multidrug-resistant bacterial microorganisms in end-of-life care in hospitals.

risks and reported emotional and social impacts of multidrug-resistant bacterial microorganisms' diagnosis and of protection and isolation measures. Some patients felt massively restricted and threatened by the multidrug-resistant bacterial microorganisms' diagnosis. Relating social and emotional impact of multidrug-resistant bacterial microorganisms' diagnosis with the aspects relevant for the patients' quality of life shows that impacts appear more frequently in connection with the quality-of-life aspects family and social environment, health, leisure, and autonomy and mobility.

The main requests from patients were modified communication and more information about multidrug-resistant bacterial microorganisms' diagnosis. They also expressed that stigmatization and constraints in social life should be minimized.

Strengths and weaknesses/limitations of the study

Patients were asked about their current experiences with multidrug-resistant bacterial microorganisms' diagnosis

and isolation measures and about their quality of life. Adopting an attitude of openness, we did not directly ask them to relate those experiences and their quality-of-life estimation to their upcoming death. Quality-of-life aspects therefore might not be directly correlated to the end-of-life situation. A follow-up of the interviewees was not applied and therefore their survival time stays unknown.

The composite mixed-methods design held challenges concerning the aggregation and synthesis of the results due to heterogeneous data collection and analysis. The data collection took place simultaneously but quantitative and qualitative data were collected independently. Data collection did not mesh in the form of a circular process but qualitative and quantitative assessments were conducted in a single interview session with the participant. The chosen procedure brought breadth and depths to the understanding⁴⁰ of the impact of multidrug-resistant bacterial microorganisms in end-of-life care and led to theoretical assumptions that allowed us to further develop recommendations on dealing with multidrug-resistant bacterial microorganisms in end-of-life care.

Results from qualitative parts of the project do not allow for statistical analysis and generalization. Shortcomings stem from the missing data for quantitative assessment. Nevertheless, the synthesis of outcomes turned out to be fruitful; the integration of different perspectives was useful for the development of the theoretical assumptions and integrated patients' voices into clinically relevant recommendations.²⁴

What this study adds

The findings of this study could inform the development of national and international end-of-life care-specific concepts and guidelines for dealing with patients confronted with a diagnosis of multidrug-resistant bacterial microorganisms. For end-of-life care patients, the recommendation to make 'prevention and control an organizational patient safety priority'⁴¹ should always be related to quality of life and well-being. There is a need to discuss and examine very carefully which hygiene measures and prevention procedures are absolutely necessary while caring for the individual patient. National and international strategies and guidelines for disease control and prevention^{3,42,43} retain their validity, but should be supplemented accordingly to the aforementioned considerations. Findings on the importance of providing clear and direct information to patients – an issue that was already investigated by Gleeson²³ – should guide institutions' own policies in dealing with multidrug-resistant bacterial microorganisms for their end-of-life care patients in a more individualized manner. Considering patients' wishes and concrete suggestions and at the same time ensuring other patients' and third parties' safety is an ongoing challenge for palliative and geriatric care and hygiene professionals as well as for policy makers.

Conclusion

Patients' experiences at their end of life indicate that they would benefit from more comprehensible information on multidrug-resistant bacterial microorganisms and its management. Measures against stigmatization, social exclusion and emotional impact of multidrug-resistant bacterial microorganisms' diagnosis are needed. Future research should investigate if the implementation of recommendations that have emerged from the findings of this study is effective and if the patients' voices are heard.

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Authorship

M.H. made a substantial contribution to acquisition (conducting interviews), analysis and interpretation of data and drafted the article. M.H.'s occupation at the time of the study was social worker, nursing scientist and worked as a researcher. A.S. made a substantial contribution to acquisition (conducting interviews, focus groups), analysis and interpretation of data and drafted the article with M.H.. A.S.'s occupation at the time of the study was nursing and health scientist and he worked as a researcher. S.S. made a substantial contribution to the concept and design of the work and to acquisition (conducting interviews), analysis or interpretation of data, conceptualized and revised the draft critically. S.S.'s occupation at the time of the study was graduate psychologist and she worked as a senior researcher. C.O. made a substantial contribution to the concept and design of the work and the interpretation of data and revised the draft critically. F.A.H. made a substantial contribution to acquisition (conducting interviews, focus groups), analysis and interpretation of data, conceptualized and revised the draft critically. F.A.H.'s occupation at the time of the study was medical anthropologist and she worked as a researcher. J.T. made a substantial contribution to acquisition (conducting interviews, focus groups), analysis and interpretation of data and revised the draft critically. J.T.'s occupation at the time of the study was psychologist and she worked as researcher. T.A. made a substantial contribution to analysis and interpretation of data and revised the draft critically. K.R. made a substantial contribution to analysis of SEIQoL-DW data, revised the SEIQoL-DW part of the manuscript draft. C.S. made a substantial contribution to the concept and design of the work and the interpretation of data and revised the draft critically. All authors approved the present version to be published.

Data management and sharing

The datasets analysed during this study are available from the corresponding author on reasonable request.

Research ethics and patient consent

The consortium study was approved by the Ethics Committee of the Faculty of Medicine, FAU Erlangen: 302_13 B, 15.01.2014 and the Institutional Review Board Regensburg and by the appointed data protection officers. 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. Informed consent was obtained from all individual participants included in the study.

Declaration of conflicting interests

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