

PAPER

Pushing boundaries—culture-sensitive care in oncology and palliative care: a qualitative study

Beate Schrank¹ | Tamara Rumpold² | Michaela Amering³ | Eva Katharina Masel² |
Herbert Watzke² | Sophie Schur^{2*}

¹Department of Psychiatry and Psychotherapy, University Hospital Tulln, Karl Landsteiner University of Health Sciences, Tulln, Austria

²Clinical Division of Palliative Care, Department of Internal Medicine I, Medical University of Vienna, Vienna, Austria

³Department of Psychiatry and Psychotherapy, Medical University of Vienna, Vienna, Austria

Correspondence

Sophie Schur, Department for Internal Medicine I, Medical University of Vienna, Waehringer Guertel 18-20, 1090 Vienna, Austria.

Email: sophie.schur@meduniwien.ac.at

Abstract

Objective In increasingly globalized societies, patient-centered cancer care requires culture-sensitive approaches in order to ensure patients well-being. While migrant patients' needs are frequently reported in the literature, staff members' perception of work with migrant patients, associated challenges, or individual work approaches are largely unknown. This study addresses this research gap through qualitative exploration of experiences of multicultural health care professionals in supportive oncology and palliative care, working with patients from different cultural backgrounds. This study aims to understand staff experience of the impact of culture on cancer care.

Methods This study was conducted at the Medical University of Vienna, including staff from different settings of oncology and palliative care, in different professional positions, and with a range of individual migration backgrounds. Semistructured interviews were conducted with 21 staff members working with patients from different cultural backgrounds. Interviews explored views on the impact of culture on care were audio-taped, transcribed, and analyzed using a rigorous method of thematic analysis, enhanced with grounded theory techniques.

Results Interviews revealed 4 key topics: culture-specific differences, assumed reasons for differences, consequences of multicultural care, and tools for culture-sensitive care. Strategies to better deal with migrant patients and their families were suggested to improve work satisfaction amongst staff.

Conclusions This study identifies relevant staff challenges in work with migrant patients. Concrete suggestions for improvement include measures on an organizational level, team level, and personal tools. The suggested measures are applicable to improve work satisfaction and culture-sensitive care not only in cancer care but also in other areas of medicine.

KEYWORDS

cancer, culture, migration, palliative care, supportive oncology

1 | BACKGROUND

Addressing the needs of patients and their caregivers throughout an illness and at the end of life is a central task of palliative care.¹ However, as the meaning of illness and experience of quality of life are culture bound,² this task can be particularly complex and challenging when it comes to patients and caregivers with migrant background.

Although European countries have been a traditional destination of immigration for decades, research on the influence of ethnic

diversity on clinical encounters in cancer care is sparse.^{3,4} As a result, culture in end-of-life care has recently been proposed as a research priority in Europe.⁴

Areas that are strongly connected to culture and particularly relevant for the provision of adequate palliative care include communication and religion. Communication has a major impact on diagnosis, appropriate treatment, patient and family satisfaction, and quality of care.^{5,6} Cultural factors, above all language barriers,⁷ are recognized to impact on the quality of communication.⁸ Furthermore, religion

and spirituality are strongly associated with quality of life, acceptance of life-prolonging measures, reluctance to withdraw life support, and disapproval of assisted suicide.^{9,10} Other important culture-related variables relevant for palliative care include expression of pain, preferences for end-of-life discussions, family structures, and dying rituals.^{11–13}

While the number of published studies on patients' cultural needs and their perception of culture sensitivity in medical care has increased in the last decades,^{14,17,18} little is known about staff perceptions, attitudes, and approaches when dealing with migrant patients. Evidence of staff experience is a necessary basis for the improvements in culture-sensitive care. Therefore, this qualitative study aimed to understand how staff in multiprofessional health care teams in cancer care experience working with patients with different cultural backgrounds.

2 | METHODS

This study used semistructured interviews to explore staff experience. The study protocol was approved by the Ethics Committee of the Medical University of Vienna (963/2011).

2.1 | Sample

This analysis was part of a larger qualitative study including interviews with health care staff, patients, and their relatives, focusing on the experience of health care staff with culture-sensitive care. We used purposive sampling according to a predefined sampling frame between July and December 2014. The sampling frame aimed to facilitate recruitment of a diverse sample and maximize the variety of views and opinions collected. It clustered eligible participants according to age group, gender, profession, cancer care setting, and work experience, considering the frequency of each group. Recruitment targeted potential participants aiming for a balanced coverage of all clusters in the study sample. Overall, participants with different professional backgrounds were recruited from 5 services dealing with adult cancer patients, ie, oncology outpatient service, oncology day clinic, oncology inpatient ward, palliative care ward, and radiation oncology at the General Hospital Vienna. Recruitment was conducted alongside the analysis with the goal of theoretical saturation.¹⁵

2.2 | Procedures

Interviews were conducted by three authors (BS, TR, and SS). A topic guide was developed based on a thorough review of the existing literature, listing a number of potentially relevant topics in a neutral nondirective style to stimulate discussion. The topic guide started with broad and open questions such as "When you think about working with patients/relatives with a migrant background, what comes to your mind?" Initial open questions gave participants a high degree of control over the conversation allowing new topics to be discussed as they emerged. Follow-up prompts were used to stimulate in-depth descriptions. When interviewees ceased generating own ideas, interviewers introduced topics from the topic guide. The topic guide was iteratively adapted according to the concurrent analysis adding newly emerging

topics. Interviews lasted 30–135 minutes. They were audio-recorded, transcribed verbatim, and anonymized.

2.3 | Analysis

Transcripts were coded using NVivo10. We applied thematic analysis using a combination of inductive and theoretically driven techniques.¹⁶ The rigor of the analysis was enhanced by using techniques taken from grounded theory including iterative inductive coding, line-by-line coding, constant comparison, seeking negative cases, the use of memos throughout the analysis process, and summary tables to organize clusters of topics.¹⁵

Themes were identified, coded, and checked for fidelity in an inductive process. This process involved iterative coding following regular inspection of the data and discussion amongst researchers, leading to an increasingly refined organization of data into emerging thematic entities. The initial descriptive analysis stage was followed by a more interpretative approach at later stages of the analysis. Three raters (BS, TR, and SS) independently coded transcripts. Alternative interpretations, groupings of categories, and interrelations between them were discussed, consensus reached, and the emerging framework was adapted iteratively.

3 | RESULTS

Theoretical saturation was reached at 21 participants. Their characteristics are displayed in Table 1. Four key themes emerged from the data; the final coding frame is summarized in Table 2. Themes and subthemes are outlined in detail in Section 3. Illustrative quotes are displayed in the Supporting Information.

3.1 | Culture-specific differences

Seven clusters of culture-specific differences between migrant and native patients were identified. These were considered to shape culture-specific care needs and to affect care provision.

3.1.1 | Social structure

Extensive family systems of migrant patients with large groups of visitors were a pervasive theme. Muslim families with a guest worker history were most salient for staff, while solitary immigrants from European countries or overseas were hardly ever mentioned. Strong hierarchies and patriarchal structures were suspected to lead to an intrafamilial withholding of information, especially with women and children. Similarly, treatment decisions depending on the "head of the family" might result in restricted female autonomy. Gender aspects were perceived differently by different professions, but nurses felt most practically affected by patients requesting care only from the same gender staff, and there was a general feeling that male senior physicians were treated with more respect than other staff members.

3.1.2 | Dealing with support

Migrant patients were perceived to have more family support and hence use less support services. However, if culture-sensitive services were available, patients seemed to appreciate the possibility. The

TABLE 1 Socio-demographic variables of study participants (N = 21)

Variable	Mean	SD
Age	42 (range: 22-64)	11, 41
N (%)		
Gender		
Female	15 (71)	
Profession		
Physicians	8 (37)	
Nurses	6 (29)	
Psychologists	4 (19)	
Spiritual care	1 (5)	
Social worker	1 (5)	
Volunteers	1 (5)	
Migrant background		
Yes	5 (24)	
Birthplace		
Austria: Vienna (capital) and surroundings	7 (34)	
Austria: rural areas (ie, within country migration)	8 (37)	
Other countries	6 (29)	

demands placed on staff by migrant patients and their families were perceived as sometimes exaggerated or undue; at the same time, migrant patients were recognized to show gratitude in a warmer and heartier way.

3.1.3 | Language barriers and culture-specific terms

The most prominent barrier was communication, including language as well as culture-specific expressions, euphemisms, or avoidance of certain terms. For example, a patient who repeatedly talked about "the time to go home" (Interview #1) did not refer to discharge but his process of dying. Picking up such culture-specific peculiarities was decisive for meaningful communication.

3.1.4 | Models of disease

Different cultures were thought to kindle different ideas about cancer, medical treatment, and alternative medicine. While native patients seemed to use alternative methods in addition to evidence-based treatment, those with migrant background were perceived to use alternative methods instead, potentially travelling to their home country to receive specific nonmedical treatments. At the same time, migrant patients were reported as more appreciative of western evidence-based medicine because of poorer medical care in their home country.

3.1.5 | Expression of emotions and symptoms

Migrant patients were perceived to show their feelings in a more intense, expressive, and emotional way. For example, expression of grief would appear more dramatic and significantly noisier compared with native relatives. At the same time, psychological symptoms seemed to be rarely reported, especially by male and older patients.

3.1.6 | Traditions and rituals

A prominent example for traditions impacting on hospital routines was the assumed obligation to visit sick relatives, resulting in excessive numbers of visitors who bring large quantities of homemade food. Interviewees also recognized foreign rituals in relation to death and dying, such as the "need to have a candle burning upon death" (Interview #20), "having to put the body on the ground" (Interview #10), or specific funeral rites.

3.1.7 | Attitude towards death

End-of-life communication was a challenge given the difficulties to identify migrant patients' preferences for disclosure about diagnosis and prognosis. Often, there was a perceived preference for nondisclosure and relatives were suspected to impede end-of-life communication by demanding concealment or refusing to translate relevant information.

3.2 | Reasons for differences

Staff attempted to explain and understand culture-specific differences. The subjective understanding served as the basis for individual approaches dealing with the corresponding challenges.

3.2.1 | Experience in the home country

Experiences, eg, of different health care standards, were assumed to shape patients' and relatives' expectation towards quality of care. This might present as mistrust towards staff, or relatives taking over nursing responsibilities. Traumatization was also considered important in shaping patients' needs, eg, more detailed information and reassurance before interventions in order to avoid re-traumatization.

3.2.2 | Socio-demographics

Migrant patients with certain socio-demographic characteristics were recognized to have more problems in adapting to Austrian lifestyle. These included older patients, those with lower education levels, "lower social class" (Interview #05), and those coming from rural areas.

3.2.3 | Isolation

Some migrant patients were perceived to live relatively secluded from wider society, with social contact restricted to fellow migrants. Such patients were particularly difficult to reach because of their suspected lack of interest in Austrian culture or knowledge and large families replacing external support.

3.3 | Consequences of multicultural care

Cultural differences affect both patients and staff. Interviewees identified 3 groups of consequences of working with migrant patients and relatives.

3.3.1 | Emotions

The range of emotions evoked by work with migrant patients was vast, including positive, negative, and ambivalent feelings. Positive emotions included feelings of relief resulting from a reduced workload because

TABLE 2 Final coding frame for the thematic analysis

Culture-specific Differences
Social structure
Family system
Hierarchy
Gender aspects
Dealing with support
Use of services
Interaction with staff
Language barriers and culture-specific terms
Models of disease
Expression of emotions and symptoms
Traditions and rituals
Attitude towards dying and death
Reasons for Differences
Personal experience in the home country
Socio-demographics
Isolation
Consequences of Multicultural Care
Emotions
Positive emotions
Negative emotions
Ambivalent emotions
Stimulated actions
Understanding and accepting differences
Establishing a connection with patients and relatives
Establishing order
Providing best possible treatment
Finding personal coping mechanisms
Collateral damages
To other patients
To staff members
To relatives
To treatment provision
Tools for Culture-sensitive Care
Organizational measures
Team-level measures
Personal tools

of family support or reward and motivation following the warm expression of gratitude. Participants also took great pride in self-growth and expanding their horizon. Negative emotions included anxiety, helplessness, self-insufficiency, and uncertainty. Subjectively undue demands could evoke feelings of anger and depreciation. An example of particular ambivalence was work with patients sharing the same migrant background with staff. Being able to understand and help in a situation in which all other staff was left helpless could boost self-esteem and lend particular value to work. However, excessive demands might result from patients specifically seeking connection with migrant staff and fellow staff easily dumping work on them using patient preference as an excuse. Importantly, migrant staff members reported own insecurities of identity and feelings of embarrassment on the account of patient behavior.

3.3.2 | Stimulated actions

A range of individual strategies was used to deal with challenges posed by migrant patients, which clustered in 5 groups of actions.

Action 1 "Understanding and accepting differences" Related strategies included making sure to actively listen, showing interest in new experiences and knowledge, striving for tolerance and respect for differences, checking the literature for more information, and drawing on one's own previous experience with the patient's culture.

Action 2 "Establishing a connection" Related strategies included explicitly looking out for communalities, using patients' phrases and terms and focusing on body language. Professional interpreters were wished for but often not available. Alternative translators, eg, other hospital staff with a migrant background or relatives, were used reluctantly because of concerns about trustworthiness and undue burden.

Action 3 "Establishing order" Sometimes the establishment of order appeared necessary, eg, when staff felt overwhelmed in the face of large numbers of upset or excessively demanding relatives. Related strategies included acting as a unity within the team, requesting crisis intervention personnel, or alerting security services.

Action 4 "Providing best possible treatment" Interviewees took pride in doing the best they could to respond to assumed culturally determined needs. These involved small practical tasks, like heating up food brought by relatives, protecting patients' privacy, considering traumatization, and adapting disclosure of information accordingly, or organizing confession-specific pastoral care. "Bending rules" (Interview 14) also appeared helpful to cope with culture-specific needs, eg, extending visiting times beyond official limits or condoning hospital routines, but was a source of conflict within the team.

Action 5 "Finding personal coping mechanisms" Individual coping strategies to deal with culturally determined challenges varied widely, but included "to pigeonhole patients from different cultures because it simplifies matters" (Interview #1), applying a wait-and-see behavior instead of immediate action, purposefully looking out for the positive side of situations, employing humor, or consciously setting personal boundaries.

3.3.3 | Collateral damages

Given the existing service structure, the culture clash on the ward was perceived to have damaging consequences for staff, caregivers, and service provision. For staff, there were not only individual adverse effects, such as negative feelings, but also negative consequences on a team level, such as disagreement on the meaning of differences. For example, large families were perceived not only as help when taking over nursing tasks but also as a hindrance when disrupting hospital routines, or disturbing other patients. There was also disagreement on the best ways to deal with culture-specific needs. Displaying frustration in the face of challenges might be mistaken as a sign of intolerance or racism and met with depreciation or cause conflict among the team.

Migrant relatives' needs and well-being were also seen at risk of being neglected. Relatives having to fill in as interpreters were perceived as a major problem, especially when children were involved. This task does not only put them in a difficult position but might also be a source of mistrust and misunderstanding, eg, when staff suspects intentional inadequate translation. Other indicators of poor communication were patients repeatedly referring to the outpatient clinic for further advice or not being able to comply with instructions.

3.4 | Tools for culture-sensitive care

Suggestions to improve culture-sensitive care for migrant patients and to create a better working environment were proposed on three levels.

3.4.1 | Organizational measures

Better availability of specific staff, such as professional interpreters, spiritual care workers, or psychologists with different cultural backgrounds, was deemed essential for better care and work experience.

3.4.2 | Team-level measures

Explicit team consensus on controversial issues, such as bending rules, was recommended. Team building interventions with a focus on multicultural staff backgrounds may help foster interest and understanding for different cultures. Team meetings and supervision could not only provide structured opportunities to discuss challenges in culture-sensitive care but also offer information and share experience, eg, using case presentations followed by team discussion.

3.4.3 | Personal tools

Every staff member working with migrant patients was considered responsible for their own development of cultural awareness. Corresponding suggestions included not only the use of self-reflection and interest but also the willingness to learn from own mistakes. Helpful attitudes included a focus on the positive aspects of migration.

4 | DISCUSSION

Migration and the cultural integration of migrants is a topic currently broadly covered in the media. Multicultural societies have long become a reality, and supporting positive and synergistic ways of living together is not only a political duty but also an obligation for social and health care services. Cultural needs strongly impact on quality of life and become increasingly important at the end of life.¹⁷⁻¹⁹ Consequently, experiences of migrant patients in various fields of health care have received attention in the scientific literature,²⁰⁻²² but recommendations on how to attend to cultural needs in palliative care are currently missing.²³ To our knowledge, this study is the first to address how staff in multiprofessional and multicultural health care teams in cancer care experience working with patients with different cultural backgrounds and how they deal with associated challenges.

In Austria, dominant immigration stems from the Balkans and Middle East.²⁴ The perceived dominance of migrants with large families reflects European migration politics in the economic boom years with large numbers of guest workers, mainly from rural areas, who were

joined by their families in the 1970s and 1980s, and are still often found to be marginalized and fall below average in terms of socio-demographic characteristics, such as educational achievement or income.²⁵ Solitary migrants from other countries, who may not be perceived as members of a dominant minority, appeared to pose less of a challenge to staff. While migrant populations differ in other countries, the structure of differences and how differences are perceived in health care will be broadly transferrable.

The culture-specific differences highlighted in the present study are consistent with findings in the previous literature, especially the understanding and expression of pain,^{12,26} and large family systems with high levels of involvement.¹² Perceived lower service use of migrant patients in this study is only partly confirmed by the literature, which shows service use to differ depending on ethnicity and cancer stage.²⁷

Reported challenges for staff were partly similar to those found in a nononcological caregiver cohort in Sweden.²⁸ Especially the previously described importance of adequate communication²⁹⁻³¹ is confirmed as a central topic. Language was seen as a major barrier to adequate care,²⁸ and despite the lack of professional interpreters, there were concerns about using relatives as translators.^{7,32} As observed in other situations, eg, court proceedings, migrant patients could benefit from professional interpretation via telephone.³³ However, the implementation of telemedical devices such as telephone services in palliative care might be difficult given the emotionally challenging nature of conversations for both patients and interpreters.

4.1 | Practical relevance of the results

Participants suggested a number of improvements and reported a broad scope of personal strategies to deal with the challenges posed by migrant patients. These suggestions can serve as a basis to improve culture-sensitive care and work satisfaction. First, on an organizational level, improvements are possible through (1) provision of staff with specific training, especially interpreters, and personal with diverse cultural background; (2) structured information and education; and (3) by supporting personal development amongst staff including self-reflection and the adoption of personally helpful attitudes and coping strategies.

Second, on a team level, actions may include (1) the development of agreements on ways to deal with challenging situations including explicit "dos and don'ts"; (2) team building measures, eg, including a focus on multicultural staff backgrounds, to reduce tensions caused by differing approaches and attitudes towards people with migrant background; and (3) fostering a team culture of interest and acceptance, eg, through structured opportunities to discuss challenges in culture-sensitive care and share information and experience.

Third, adaptive personal tools for dealing with the challenges of culture-sensitive care need to be fostered. While this may be possible as one aspect of team interventions, staff might also be offered opportunities for individual development, eg, through individual supervision, or specific further education.

Improving cultural competency with specific trainings might be a promising mechanism to reduce health disparities. However, many trainings lack evidence of impact on health care staff or patients³⁴ or

on patients' adherence or health outcomes.³⁵ The establishment of new trainings might further improve culture-sensitive care but requires specific attention to the challenges associated with it.

4.2 | Limitations

This study only recruited staff from one large tertiary treatment center. However, we followed a theoretically driven predefined sampling frame to ensure a broad spectrum of backgrounds and views. Nurses and doctors were overrepresented in comparison with social workers, spiritual workers, and other "small" professions given their generally higher number of posts in health care. Women were overrepresented in the sample because the number of female employees outweighs that of male employees, especially in nursing and in the small professions. However, the sampling frame ensured that a wide range of participants were included. This study focused on staff experiences; hence, the reported needs and behaviors of patients and relatives cannot be verified. Participants tended to conflate the concepts of culture and religion. While this does not reflect a scientific position, it is likely to mirror a real world understanding. The interview topic may have stimulated a concern about appearing racist in participants, which may have led them to preferably reporting positive stories or denying prejudices. While the study did elicit a range of negative views, opinions on the very negative end of the spectrum may have been missed because of social desirability effects.

4.3 | Strengths

To our knowledge, this is the first study to gain insight in end-of-life care with migrant patients in Central Europe. The analysis was conducted by a team with different professional backgrounds and different migration experiences. This ensured a sensitive and balanced data analysis. Results shed light on staff experiences in a challenging aspect of work commonly encountered in many if not all areas of medicine and may be relevant and practically useful beyond oncology and palliative care.

5 | CONCLUSIONS

For staff working with migrant patients and their relatives in cancer care, still multiple challenges exist. However, as visible in our study sample, staff naturally adopts a range of useful strategies to handle these challenges. The results of this study can serve as a basis to suggest specific measures on 3 levels, ie, organization, team, and individual staff members, to improve culture-sensitive care not only in cancer care but also in other areas of medicine.

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CONFLICT OF INTEREST

No conflicts of interest have been declared.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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