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Twelve tips to teach culturally sensitive palliative care

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ABSTRACT

With an increasingly ageing population there will be a rising demand for palliative care, including from older migrants and ethnic minorities. While many (future) physicians are unfamiliar with specific needs of older migrants and ethnic minorities regarding care and communication in palliative care, this may be challenging for them to deal with. Moreover, even many medical teachers also feel unprepared to teach palliative care and culturally sensitive communication to students. In order to support medical teachers, we suggest twelve tips to teach culturally sensitive palliative care to guide the development and implementation of teaching this topic to medical students. Drawn from literature and our own experiences as teachers, these twelve tips provide practical guidance to both teachers and curriculum designers when designing and implementing education about culturally sensitive palliative care.

KEYWORDS

Community-oriented; death and dying; palliative care; migrants and ethnic minorities

Introduction

The number of older migrants is growing in European and other developed countries (Eurostat 2015). It is expected that their numbers will quickly increase in coming decades (Central Bureau of Statistics Netherlands 2009). With an increasingly ageing population there will be a rising demand for palliative care. Palliative care is an essential part of all health care systems and is recognized by the World Health Organization under the human right to health (WHO 2018). Palliative care improves the quality of life of patients and their families facing the problems associated with a life-threatening illness, by preventing and relieving suffering through the early identification, adequate assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual (WHO 2018). While palliative care education is increasingly acknowledged as important in the medical curriculum (Ellmann et al. 2012), there is a lack of attention to culturally sensitive palliative care (Fitzpatrick et al. 2017) and medical teachers often feel unprepared to teach this to students (Rollins et al. 2013; Lu et al. 2014). This is a missed opportunity because physicians are being presented with needs and preferences from migrant and ethnic minority patients and their families they are unfamiliar with (Pentaris and Thomsen 2020). Providing palliative care to older migrants and ethnic minorities may evoke insecurity for physicians (Torres et al. 2016). In order to support teachers to prepare future physicians to deliver palliative care tailored to needs of diverse patient groups, we

present twelve suggestions to teach culturally sensitive palliative care to medical students. They are based on literature and extensive experience of the authors as teachers, researchers and of one author as GP.

Tip 1

Teaching person-centeredness is the key

All patients are unique and teaching person-centeredness to students is a first step in providing culturally sensitive care (Epner and Baile 2012). While migrant and ethnic minority patients may have specific cultural or religious needs, beliefs and practices around palliative care (See Tips 4–8), it is not possible, useful or practical for teachers to propose a ‘cook book’ approach in which students are learned the key ‘do’s and don’ts’ for each cultural group (Epner and Baile 2012). For teachers this means that they should teach students to understand patients’ needs, values, and preferences by exploring patients’ needs and have empathy. Students should be taught never to assume patient’s preferences and needs, but to be able to identify them by eliciting the perspective of the patient and family and by learning to be creative and sensitive when eliciting this perspective. Empathy and compassion are key aspects of high-quality person-centered healthcare, but particularly important for palliative care (Ngo-Metzger et al. 2008). Unfortunately, physicians tend to miss opportunities to empathize with patients during consultations (Morse et al. 2008) and rather focus on discussing biomedical issues.

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Due to lack of providers' competencies to manage linguistic or cultural barriers, there may even be less empathy, social talk and rapport-building with migrant and ethnic minority patients (Elliott et al. 2016). One way to teach students about empathy in an intercultural context, is by using the BELIEF model (Dobbie et al. 2003). This model helps students to elicit the patient perspective by asking: Beliefs about health (What caused your illness/problem?); Explanation (Why did it happen at this time?); Learn (Help me to understand your belief/opinion); Impact (How is this illness/problem impacting your life?); Empathy (This must be very difficult for you); Feelings (How are you feeling about it?). Key to this model is to have a learning and empathic attitude towards patients and their family in order to build trust. Students can discuss relevant patient cases or vignettes in small groups and practice the BELIEF model in role play with standardized patients (Dobbie et al. 2003). How teachers can develop patient cases, vignettes or standardized patient descriptions is addressed in Tip 11.

Tip 2

Introduce health literacy as an important factor

Taking health literacy of patients into account is something most students have to learn. Teachers may point out that many older migrants and older ethnic minorities (like many elderly) have had little formal education and therefore might have limited health literacy skills (Esser 2006) resulting in knowledge gaps about palliative care (Jansky et al. 2019). This may be reinforced by the fact that migrants, while living most of their lives away from relatives and friends in their home country, may miss direct confrontations and experiences of seeing elderly with worsening conditions die (Hayes et al. 2020). Patients with limited health literacy generally have limited understanding of end of life terminology such as malignant, terminal, prognosis, hospice, and palliative care (Ladin et al. 2018). This may be reinforced by a language barrier (See Tip 3). Limited health literacy can impede access to appropriate health services such as having end of life conversations and is associated with higher rates of aggressive treatment in the last month of life and dying in the hospital rather than at home (Volandes et al. 2008). Teachers can illustrate the prevalence of health literacy, sensitize students to the experiences of the low-literate patient, and show the consequences to patient outcomes. In role-play with simulated patients, students can use the teach-back method and receive feedback on whether they made sure their explanation was clear to the patient. Another way to teach students to take health literacy into account are exercises to reformulate notes about medical terminology into patient's own words (e.g. 'pain-killer' instead of 'analgesic') (Zoberi et al. 2008). The task of the student is to recognize the jargon or difficult language and to rewrite the note using more patient-centered language, using language that is simple, yet still meaningful.

Tip 3

Teach how to take language barriers into account

Nowadays medical schools offer students classes about how to deal with language barriers and how to involve an

interpreter. In palliative care it is even more essential that students learn how to deal with language barriers. Many older migrants have a low proficiency in the language of the host country (Esser 2006). A review study found that in case of language barriers, relatives were frequently asked to interpret information about prognosis, diagnosis, and assess symptom management for patients at the end of life (Silva et al. 2016). As a result, patients may have inadequate understanding about their diagnosis and prognosis, have worse pain management and anxiety management at the end of life (Silva et al. 2016). Words that may be lost in translation are for example 'palliative care', 'sedation', 'reanimation' or 'hospice'. Teachers therefore need to make students aware of how a language barrier influences the quality of palliative care. In addition, teachers need to teach to students how to use a professional interpreter. In case of breaking bad news across language barriers (See Tip 5), a professional interpreter should always be used. Specific materials that teachers can use are e-learning (see for example Ikram et al. 2015) and role play.

Tip 4

Teach how to talk about death and dying in a (culturally) sensitive manner

While it is thought that in some cultures, discussing death openly is inappropriate out of a belief that 'bad things happen after you say them out loud' (Hayes et al. 2020) or the belief that talking openly about death and dying is taking away the patient's hope (Hayes et al. 2020), patients generally have their own preferences in talking about dying (Kirk et al. 2004). It is important to carefully examine how patients talk about their death and to adjust communication about this topic to their communication style and information needs at that moment. In addition, patients may have cultural and religious rituals around death, such as following protocols around touching and cleaning bodies. Teachers can challenge students to reflect on their own ideas about death and dying and invite them to share these views in the classroom. This might enable students to experience that their view is one among many. Having students from diverse ethnic and religious background share their views in the classroom, can also help students to realise that there are many perspectives. Reflexive questions for students may include: Is death the end of everything, or a passage to an afterlife? What would I want for my death? How can I encourage a patient to talk about their wishes and needs with regard to dying? Students should be aware of their own ideas about death and dying, and be aware of values that may be more dominant than others. For example, a dominant vision of care providers about dying is that it is important to accept imminent death, whereas other people prefer to fight death until the end (Broom and Cavenagh 2010).

Tip 5

Teach different ways of breaking bad news

Medical students in Western Europe and North America are trained to disclose the diagnosis of a life-limiting disease to patients (Girgis and Sanson-Fisher 1995). This is based on the principle of patient autonomy assuming that patients

have the right to know their health status, in order to make informed treatment decisions, think about how to spend the time that is left or make specific arrangements e.g., on testaments. Patients, however, have various preferences regarding hearing bad news, influenced by cultural background, coping strategies and the phase of the disease. Older migrants and ethnic minorities who are less 'used' to direct and full disclosure, may prefer a more careful approach to breaking bad news (Matsumura et al. 2002). For example, a 72-year-old Chinese American participant in a US study (Chi et al. 2018) preferred communication about bad news 'to go around in circles until you finally get to the target'. Similarly, a 59-year-old Chinese American felt that when the physician is 'too direct, sometimes it's a turnoff. I think you have to bring it up gently'. Whereas students are often trained to deliver the bad news first and directly to the patient and use the rest of the time to support and comfort the patient, students may also be trained in other communication skills such as to introduce the fact that bad news will be shared, outlining all the tests that have been done and then deliver the bad news. Other ways to communicate bad news include: refrain from giving a prognosis but stress that the situation is serious and explain that if the patient wants to do certain things, this should be done soon; reassure that you will continue to take care of the patient and will not abandon the patient and family (Barclay et al. 2007); inform that you no longer have any treatment options resulting in cure, but plenty that can help relieve symptoms, rather than stating that a patient is incurably ill (Oosterveld-Vlug et al. 2017). Most importantly is to teach students to listen to patients and relatives and engage them in a dialogue about preferences for truth disclosure, decision-making and the role of the family (Barclay et al. 2007; Oosterveld-Vlug et al. 2017). Students can be taught to elicit preferences and ask questions such as: 'We are going to do an number of tests. Who would you like me to discuss the results with? With you alone, with you and your relatives, with just your relatives?'. Or when the disease is serious: 'Can you tell me about what you know about your disease/situation?' What would you like to know about your disease? (De Graeff et al. 2012). Additionally, students can be taught to ask questions such as: 'Do your relatives know about your condition? When was the last time they visited you? Do they have plans to visit you soon?'. Using these types of questions students communicate that the prognosis is serious without explicitly saying to the patient that he or she is going to die soon (Epner and Baile 2012). Teachers can provide students with an overview of different strategies about breaking bad news, followed by a discussion of how to use them in a culturally sensitive manner. In role play students can practice delivering bad news. Skills to break bad news in a culturally sensitive and person-centered way can be trained with simulated patients who are provided with different scripts about preferences. Video vignettes can be used to facilitate discussion on how to deliver bad news in a culturally sensitive manner (Lubimir and Wen 2011).

Tip 6

Teaching how to engage in shared decision-making

Shared decision-making between physicians and patients is essential, also in palliative care. With shared-decision-

making, physicians provide patients with relevant information and proceed to understand needs, values, and preferences of the patient, in order to determine – together with the patient – the best possible options for the patient. Shared-decision-making can be impeded due to lack of competencies of care provider to manage linguistic or cultural differences. Students should be taught to engage patients in shared-decision-making even when this is more difficult e.g. due to linguistic barriers (See Tip 3). In addition, communication with older patients can take the form of a 'triad' between physician, patient and a close relative. For older migrants, the relative often helps to resolve language problems (Van Eechoud et al. 2017). This may result in a situation in which relatives play an important role in the decision-making process. Research showed that the best way of shared decision-making about palliative care with older migrants is acknowledging the family around the patient as a 'care management group' and give them an equal role in communication and decision-making (De Graeff et al. 2012). In role play or video vignettes, students can learn how to communicate with patients as a care management group.

Tip 7

Teach how to discuss pain management in a culturally sensitive way

Pain is among the most common symptoms experienced at the end of life (Martin and Barkley 2016). Research has shown that migrant patients received less pain medication during palliative care than non-migrants (Hoffman et al. 2016). Cultural and religious beliefs about the meaning of pain can affect how patients perceive pain, for example, the belief that pain is a part of God's plan, a penance for sins, a test of faith or the belief that pain is a sign of progress towards recovery. Patients who believe that pain should be endured may report a low pain score (Martin and Barkley 2016). Religious beliefs can influence perceptions about pain management at the end of life, but many different opinions exist between and within religions about pain relief and what is and isn't 'allowed'. For instance for some Muslims a clear mind can be valued because of the wish to perform daily prayers and to utter the declarations of faith as the last words in life shortly before death (Oueslati 2018). Misconceptions held by patients (migrants and non-migrants) such as that opioids cause drowsiness or unconsciousness or that they hasten death, can also be a barrier to their use (Martin and Barkley 2016). Decisions to not administer pain medication may also be influenced by unconscious bias by physicians about how migrants express pain (Suurmond et al. 2010). Teachers can teach students how to discuss pain management at the end of life. Questions that students could learn to ask to patients are: What does pain mean to you? Do you want relief from pain, and if so, how would you like it to be treated? How can we do justice to the desire to perform certain rituals and yet relieve your pain? Furthermore, students should be aware of the misconceptions regarding pain medication and be able to address them (Martin and Barkley 2016). They should acknowledge that pain is generally more often underestimated rather than exaggerated (Kirby et al. 2018) and they can be taught how to bring up pain management

more than once after a first refusal and to discuss the reasons for rejecting pain relief (see Epner and Baile (2012) for an example of how to discuss this in a person-centered way).

Tip 8

Teach students different perceptions about withholding and withdrawing life-sustaining treatments

Medical decisions to actively terminate life-sustaining equipment or medication can be difficult for patients and relatives. Factors such as age and being a parent are positively associated with a preference for a prolonged life, even if this is at the expense of the its quality (Stiggelbout et al. 1996). Religious beliefs may also influence perceptions about active termination of life-sustaining treatment in the final stages of life. Ahaddour et al. (2018) showed that the belief in God's sovereign power over the domain of life and death and in God's almightiness (e.g. belief in a miracle) could lead respondents to oppose withholding and withdrawing life-sustaining treatments, but the same argument was used to approve of withholding and withdrawing life-sustaining treatments as a form of acceptance of God's decree. Students should be aware that perceptions are diverse (Ahaddour et al. 2018) and that religious beliefs also play a role for non-migrants. While quality of life is a subjective concept that people interpret in different ways (Westra et al. 2009), teachers should challenge students to discuss/put into words their own understanding of concepts such as quality of life and unnecessary suffering. In classrooms students can be invited to reflect on their own perceptions and explore the diversity of these perspectives. In addition, teachers can offer role-play in which students practice communication skills that leaves room for hope for the patient and family, within the limits of what physicians can do, for example by emphasizing the 'natural' character of terminating curative treatment, rather than explaining that they would like to 'give the patient the chance to die' (Westra et al. 2009). Spiritual counselors could help coming to terms with issues around meaning, suffering, their own values and their belief system. Teachers can invite spiritual counselors but also cultural mediators from different backgrounds to give students insight in their roles within the hospital. Students will in future know where to find professionals who can help with dilemmas in end-of-life care.

Tip 9

Teach students to look beyond culture and migration. The concept of intersectionality

Decisions concerning palliative care are not only influenced by culture or ethnicity, but also by the interplay of gender, age, educational level or personal preferences, in short: person-centered care (we keep coming back to it!). One study (Skulason et al. 2014) found that women were more likely to initiate death talk in palliative care settings than men. Another study found that educational level was associated with preferences regarding end-of-life care more than ethnic background (Volandes 2008). Children of

migrants take over the norms and values of the host country and their preferences about telling the diagnosis are gradually changing from their parents. Intersectionality, the idea that social categorizations such as ethnicity, class, age and gender are interconnected, is often seen as difficult to integrate in the curriculum (Powell Sears 2012). In order to promote the use of the concept of intersectionality in medical schools, Powell Sears (2012) suggests different exercises, for example to support doctors to reflect on their social class and immigration status, age, sexuality, gender and geographic location.

Tip 10

Doctors have a culture too

Central to teaching about culturally sensitive care is that students become aware of their own (implicit) cultural norms. A study in the US showed that Caucasian-American doctors were more likely to promote advance directives and to support early end-of-life discussions, whereas Afro-American doctors tended to request more life-sustaining treatments (Mebane et al. 1999). A European study showed that physicians' intentions to discuss prognosis with patients and families varied largely across countries. The percentage of physicians who said that they would actively inform patients about a bad prognosis varied between 52% in Italy to 99% in Sweden (Voorhees et al. 2009). There are different exercises available for teachers to teach students awareness about own cultural norms and values (Ring et al. 2008). This of course starts with teachers themselves doing these exercises to acknowledge their own (implicit) values and norms.

Tip 11

Use educational materials

Developing scripts, cases, vignettes and patient descriptions about culturally sensitive palliative care can be challenging. Examples can, however, be found, see in Lubimir and Wen (2011), Ellman et al. (2012), Epner and Baile (2012), Van Schaik et al. (2014) and on <https://physiciansapply.ca/cases/case-2-cross-cultural-communication>. For instance, Epner and Baile write about how physicians can engage in person-centered communication with patients at the end of life by describing a person-centered conversation between a physician and a 65-year-old African American man whose daughter is resistant to palliative care for her father. Inspired by her religious convictions, she said things such as 'keep fighting' and 'do everything that is medically possible'. Epner and Baile show that the best approach is to validate, explore, and empathize with the patient and family. Lubimir and Wen describe a problem-based learning case that involves a Chinese-speaking widow and her eldest son, who are waiting in the Emergency Room and need to be told about the progression of her cancer. The case can be used to teach students about the appropriate use of medical interpreters, and to teach about decision-making involving both the patient and the family. Students can be divided in small groups, be provided with a script and assigned roles of patient, son, physician, and observer. Skills to break bad news in a culturally sensitive and

person-centered way can be trained using simulated patients, who can be provided with a script.

An innovative way is to invite to the medical school, persons from a migrant or ethnic minority community who has been a caregiver to a recently deceased loved one. This calls for a network within migrant communities and involves a lot of work but can be a very rewarding experience for all. Patient stories of the community can be shared and discussed in class to promote students' attitudes such as respect and awareness of own cultural norms and values. In role-play, for example, members from an ethnic minority community, can be trained to be a simulated patient. In that role they can critique a physician, telling them how they felt after a consultation about their goals of care, or about a serious and/or terminal prognosis. This type of teaching is now being piloted (<https://www.uab.edu/news/research/item/10969-community-members-train-doctors-on-culturally-appropriate-palliative-care>).

Tip 12

Integrate throughout curriculum

Culturally sensitive palliative care should be integrated throughout the curriculum, including pre-clinical and clinical years, preferably in general classes (e.g., communication training; lectures about geriatrics) rather than elective classes about migrant and ethnic minority patients. Moreover, merely integrating in the curriculum one lecture about palliative care to Muslims and a workshop about delivering bad news in a culturally sensitive manner, is not sufficient. We recommend that all issues raised in previous tips should be taught to all students and be assessed during the entire curriculum.

Conclusions

We have suggested twelve tips for developing education about culturally sensitive palliative care. They encourage teachers to design challenging and important education to support students to deliver care to a generally vulnerable group. Discovering multiple perspectives on death and dying, students learn to prioritize values of patients and family members rather than those of the professional. This ultimately results in medical students who are prepared to provide optimal palliative care to diverse patient populations. Moreover, with the focus on person-centeredness, these twelve tips support students to deliver person-centered palliative care to all patients.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

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