The perception of health and diseases across cultures

Introduction

This module discusses how the notions of health and illness and the attitude towards dementia vary across different cultural and socioeconomic backgrounds.



1. Health in a cross cultural perspective

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What is health?

1948 In the World Organisation Health stated that health is: "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." This is an interesting and important declaration but we have to underline that it does not exist a global perception of health. Indeed if we

think about health in a cross cultural perspective we must ask ourselves if our idea of health corresponds to that of the other.

That does not mean that health professionals must know everything about different cultures' ideas and beliefs on health, however they should be aware that diseases, health, illness or sickness care concepts can be perceived in different ways. And we also have to keep in mind that cultures are ever-changing, so understanding people's beliefs about health, healing and disease is an open-ended process.

Different approaches to medicine

Western and Eastern approaches to medicine are different: for example, they have two different conceptions of body, mind and disease. In general, the Western medicine aims for precision, analysis and targeted therapies, while in Eastern medicine the mind-body system is the main focus and care is aimed at harmonizing it.

Another big difference is that Western medicine is specialized: doctors focus on the single organ, in a few minutes' interview, during which the doctor detects the symptoms and prescribes the tests for that particular system. The medical diagnosis follows from the laboratory results and completes what emerged during the interview.

In the Eastern countries, however, traditional medicine always considers the person as a whole: this includes the psychological aspect. The main idea is that body and mind cannot be separated. During interviews, doctors usually ask many questions about the patient's habits, schedules and lifestyles, as well as about intestinal, gastric and urinary functionality. Medical analyses in Eastern medicine are only an integration with respect to what was found through the dialogue with the patient and the evaluation of symptoms.

This first difference between Western and Eastern approaches to health and disease suggests that health professionals should become culturally competent. Certainly no one can become familiar with all cultural health beliefs, but an open-minded and culturally competent approach helps professionals in improving their communicative skills: for example, asking relevant questions to ensure the best health care outcomes possible, while helping to avoid potentially harmful misunderstandings.

Diversity Practices

Given the cultural diversity, healthcare professionals should increase their awareness of how to communicate and care for patients with different cultural backgrounds, also trying to understand the nuances of the culture in which the patient identifies.

For example, it could happen that East Asian patients will not want to openly discuss the issue of death as they see it as an omen. In other cultures, important decisions have to be made by the whole family or approved by the elders. This approach can be very different from Western culture's, in which decisions of this kind are very often made autonomously, regardless of family's decisions. In addition, other cultures rely on traditional healing methods such as acupuncture, coinage, cupping, moxibustion, and other herbal remedies.

In Western medicine, doctors tend to directly inform patients about their illnesses, as specifically as possible. Other cultures, on the other hand, have divergent views on this approach to communication. For example, it is common for professionals in Japan and in some parts of Africa to hide diagnoses from the patient by using indirect language to describe their condition, such as "growth", "mass", "blood disease" or "impure tissue", rather than stating a specific terminal illness. Some Hispanic, Chinese and Pakistani communities tend to protect the terminally ill patients from knowledge of their condition.

In conclusion, as cultures can vary dramatically, care professionals should avoid stereotypes or assumptions about patients' cultural practices.

Avoiding stereotypes

We cannot categorise the different ideas of health and disease in a strict way. It is important to remember that if a person is identified with a particular ethnic or religious group this does not necessarily mean that this person, or their relatives, share the same set of beliefs, which may be associated with ethnicity or religion. The Chinese Government, for example, officially encourages atheism, but in China there is a large number of religions, such as Buddhism, respect for ancestors, Confucianism, Taoism, Shamanism and Christianity: so it is not possible to identify a Chinese person with a religious group.

We always have to keep in mind that patients are individuals who do not have to be defined through their belonging to a particular cultural group. Personal experiences vary greatly depending on different variables such as the immigration process, educational level, former occupations or their origin from urban or rural areas, etc.

Knowledge of the cultural context is important for patient's care. However, sometimes it could be difficult to collect information due to privacy issues or linguistic barriers or because patients are too young or too old or too sick to provide relevant information.

Cultural humility

Healthcare professionals must be aware of the risk of relying on hidden cultural stereotypes while planning a therapeutic path.

Both the healthcare professional and the patient often come from different social and cultural contexts. Cross-cultural medicine recognizes that medical practice is socially and culturally "situated". This is because Western medicine itself is a cultural system and therefore almost all encounters are "cross-cultural". If we look back at the history of medicine in Western culture, we will notice how what was once normal is now considered as malpractice and, in some cases, a crime.



Practicing cross-cultural medicine is a process that requires an open-minded approach to differences to improve patient care: this open-minded attitude is called "cultural humility", which is the "ability to maintain an interpersonal stance that is other-oriented (or open to the other) in relation to aspects of cultural identity that are most important to the [person].1"

Hindus, for example, believe that physical or mental illnesses combine biological, psychological and spiritual aspects. Treatments that do not address all three dimensions may not be considered effective by a Hindu patient. For this reason, healthcare professionals should take these three aspects into account.

Another relevant example concerns the respect of the patient's individual habits, such as sexual lifestyle or use of alcohol: the British General Medical Council emphasizes that 'You must not refuse or delay treatment because you believe that a patient's actions or lifestyle have contributed to their

¹ Hook, J.N. (2013). Cultural Humility: Measuring openness to culturally diverse clients. Journal of Counseling Psychology.

condition'2.

2. Care and cultural differences

International conventions, such as the International Covenant on Economic, Social and Cultural Rights (UNHCHR 1976), ratified by all EU member states, established that access to health care is a basic human right for everyone. This implies that health systems have a precise responsibility to meet the needs of a multiethnic society.

Culture can be defined " [...] as a set of meanings, behavioural norms, values and practices used by members of a particular society, as they construct their unique view of the world. As such, culture deeply informs *every aspect of life and health*" (Mezzich et al. 2009: 384). This definition suggests that "culture" includes **not only ethnicity and religion** but also **socioeconomic factors** (i.e. levels of education, housing conditions, and access to information). The social determinants of health can be defined as: "the circumstances, in which people are born, grow up, live, work and age, and the systems put in place to deal with illness" (WHO 2010). These circumstances are in turn shaped by wider economic, social and political forces (WHO 2010).

The study "Rates for Selected Medicare Services, Age 65 Years and Over, by Race and Income" found that as income increases, ambulatory visits and mammograms increase. The trend is in the opposite direction for emergency room visits and amputations3.

Poorer health is more likely associated with lower socioeconomic status (henceforth SES). Lower SES also leads to fewer diagnostic tests and medications for many chronic diseases to a limited access to health care due to cost and coverage.4

As clearly stated in McMaughan et al. $(2020)^5$, "[...] as wealth increases so does health, with the converse also holding true. Lower economic status leads to poorer health, which in turn leads to a dangerous cycle of further impoverishment. Simply stated, there is a relationship between SES and health, with low SES associated with poorer health".

Extensive evidence showed that ethnic, religious and linguistic factors interact with socioeconomic factors in determining health care behaviours. Therefore, it is necessary to enlarge the cultural dimension of migrant health by including their economic and social context, also to avoid what could be called 'ghetto medicine'.

One important aspect that improves medical care for all patients is to enhance the communication skills of health professionals and their diagnostic sensitivity. Since clinical practice should be patient-centred, communication skills are now part of the curriculum in medical schools. However, when

² https://www.medicinejournal.co.uk/article/S1357-3039(16)30143-8/fulltext

³ https://www.ncbi.nlm.nih.gov/books/NBK221050/

⁴ Nicholas C. Arpey, Anne H. Gaglioti, Marcy E. Rosenbaum (2017). How Socioeconomic Status Affects Patient Perceptions of Health Care: A Qualitative Study. Volume: 8 issue: 3, page(s): 169-175.

⁵ McMaughan DJ, Oloruntoba O and Smith ML (2020) Socioeconomic Status and Access to Healthcare: Interrelated Drivers for Healthy Aging. Front. Public Health 8:231. doi: 10.3389/fpubh.2020.00231

doctors deal with patients coming from different ethnic backgrounds, cultural differences or stereotypes are often assumed and one of the main barriers is **language**.

Europe is multilingual: there are 23 official languages, 60 regional languages and around 175 languages spoken by migrants (Euranet 2010). **Language barriers** lead to poor quality of care. For example, language barriers between health care professionals and patients are associated with greater use of diagnostic investigations, lower uptake of preventive services (such as breast examinations), lower adherence to self-monitoring of blood glucose, and lower patient satisfaction.

To overcome the linguistic and communicative obstacles, it is important to rely on the collaboration between health professionals and **qualified interpreters** when communicating with migrant patients: this improves quality of care and patient satisfaction.

To this aim, some countries, such as Sweden and the Netherlands, organized "community interpreting" systems, already in the 1980s, especially in the social and health sectors. In Sweden, the right to interpreters has been established by law. In southern and central Europe, interpreting services, if available, are often provided by "cultural mediators". However, some European health systems still minimize the significant impact of language barriers on the quality of care.

It is worthwhile highlighting that the use of professional interpreters improves the satisfaction of both patients and health professionals and increases the use of preventive care. It also enhances the reporting of symptoms and decreases misunderstandings. This point brings us to another critical issue, concerning the training of **interpreters**, who should learn important and challenging skills, such as the transmission of medical information to patients and the communication of the patient's reactions to health professionals.

In today's multicultural Europe, being aware of one's own culture, and specifically of one's medical culture, is the first step to become culturally competent (Fox 2005). In some hospitals, services like "cultural consultations" are also available to help clinicians to deal with cultural misunderstandings.

Unfortunately, **cultural stereotypes** still influence medical practice: cultural stereotypes by health professionals may affect clinical decision-making, thus the first step to overcome stereotypes is to become aware of one's own cultural stereotypes on medical practice.

Religious beliefs of migrant patients are another critical issue when health professionals have to deal with patients who disagree with medical recommendations for religious reasons.

For example, if doctors or health care professionals understand and are informed about Hindu or Muslim rites this can help and reassure both patients and relatives, who may be willing to follow and respect particular ritual practices, such as Ramadan or specific mourning or burial practices⁶.

Another example may involve the brain death of a patient: in Western medicine the loss of function of the brainstem is considered actual death. However, this criterion could be perceived negatively by Buddhist and Christian people who believe that only cardiorespiratory death is actual death.

⁶ https://www.medicinejournal.co.uk/article/S1357-3039(16)30143-8/fulltext

Similarly, a doctor may have a philosophical belief that a pre-sentient fetus, especially a severely disabled and incompatible one with life outside the womb, is not a baby: many Christians, on the other hand, consider this belief to be wrong.

In many cultures, **traditional medicine is also associated with religious practices**: this means that it is not unusual for migrants in western countries to combine biomedicine and traditional medicine at the same time. Discussing this issue with patients might help to improve the relationship between patients and health professionals while increasing the understanding of health workers of traditional practices.

The interaction of **religion and gender** is another important and sensitive issue in western medical context. In most European countries, patients in primary care services can choose whether they want to be visited by a male or female physician. However, in hospitals, especially in emergency departments and maternity wards, the issue may be more problematic. To overcome this problem, an open-minded approach by the medical staff is recommended: for example, it might be helpful to offer the possibility to reschedule the consultation, to explain through an interpreter or cultural mediator what will be done during the examination, and to discuss the medical procedures with patients and their families before and after the consultation.

To conclude, when interacting with migrant patients, health professionals need to be aware and prepared to address differences in language, religious beliefs, culture and origin. "Ethnic misunderstandings" are often due to scarce linguistic comprehension: as explained above the use of trained interpreters is therefore an essential tool when the patient and the health care professionals do not share the same language.

Importantly, health care professionals should avoid making assumptions based on "ethnic" considerations without discussing them with the patient.

"A common problem facing medical practitioners when dealing with migrant patients is how to achieve a balance that avoids going too far in cultural interpretations (for example, when confronted with an apparent aggressive attitude of a male patient towards a female doctor) and also avoids a reluctance to take up sensitive subjects (for example, alcohol use or sexuality) altogether, for fear of causing "cultural offence". Indeed, the application of cultural generalities based on language, religion, country of origin, and cultural or socioeconomic grouping of patients can easily degenerate into stereotyping (Fiore 2008)" (Durieux-Paillard, Differences in language, religious beliefs and culture: the need for culturally responsive health services, in Rechel et a. 2011)

It is necessary to underline that stereotypical perceptions of patterns of illness among migrants and ethnic minorities are rarely scientifically based.

"Whether they attend to migrants or other patients, self-awareness of health professionals of their preconceptions, as well as knowing the history and circumstances of patients is fundamental to providing adequate prevention, diagnosis and treatment. This could be summarized as adopting a humble and culturally open-minded approach. Concurrently, health service providers need to have an understanding of the determinants of migrant health and have the capacity to advise migrant patients on their entitlements to health services (Gijon Sanchez et al. 2009). Cultural competence needs to be part of the overall skills, knowledge and attitudes of health professionals and they need to be adequately trained in order to be able to provide appropriate care to diverse patients."

3. The attitude of different ethnic groups about dementia

Dementia is foremost a medical condition, but it needs to be understood and embedded in the cultural contexts.

Cultural values can shape the perceptions of health, with the recognition and response to illnesses, both physical and mental, being largely determined by prior assumptions regarding social norms and acceptance.

For health care professionals, culture is an important factor to take into account during diagnosis for understanding the uptake of services and in formulating ongoing medical care.

Below we report findings comparing how the cultural dimension affects the social representation of dementia and impacts on care and services.

The study run by Calia et al. (2019) investigated the cultural environments of dementia in three national groups (i.e., America, Britain, and China), which differ most with respect to the structure and financing of health care, and reflect distinct wider cultural systems of health.

The study highlights some fundamental differences in the social representations among American, British, and Chinese people in how the condition was perceived to interplay with the cognitive, behavioural and affective dimensions of those living with dementia:

- In the case of American participants, the focus was on the cognitive and physical decline, care was also perceived in terms of managing this decline, with the nursing home being the transition from life to death.
- The introduction of an affective dimension in the British representation, imagining the experience of those affected, humanised the condition, and subsequently the approach to care recognised the concept of relative well-being.
- The Chinese representation included both a behavioural and cognitive dimension, they were both symptom-based, and care was framed as an 'inconvenience'. Care was family centred.

In the UK the rise in the number of people from Black, Asian and Minority Ethnic communities (BAME) has been driven by population growth and immigration. This has indicated a relatively younger profile of BAME people compared to the wider population. This corresponds to an increasing number of older people from BAME groups in the future. Given the future growth and ageing of people from BAME communities we now focus on the issue of dementia. Anyone, regardless of gender, sexuality, ethnicity, ability, or socio-economic background can develop dementia (Bingham et al., 2016). The National Dementia Strategy's aim is to improve end of life, with specific focus on hard-to-reach groups, including those from black, Asian and minority ethnic community and religious groups. Despite this call to improve end-of-life for people living with and dying from dementia, irrespective of their population group, there is evidence that we are neither all equal in life or in death and dying (Crawley and Koffman, 2015).

Disparities in palliative and end-of-life care provision emerge and highlight inadequate assessment and communication, involvement of patients and families in critical decisions, poor uptake of specialist services, and sub-optimal management of symptoms associated with advanced disease.

A common theme running through studies of BAME groups and palliative and end-of-life care is the low usage of palliative care services that may be beneficial. A number of explanations have been suggested to account for this including low referral rates from health professionals, gatekeeping, poor knowledge of services and specifically services related to palliative care, as well as religious and family traditions that may run counter to palliative and hospice care philosophies.

Communication and language barriers are critical to assessing and monitoring palliative care needs. The inability to do so not only affects access to palliative care services but has been shown to be a source of serious problems in clinical consultations and the cause of misunderstandings amongst patients, family members and healthcare providers.

Important communication difficulties arise where there is an over-reliance on a patient's relatives. While it may appear to be easier than accessing an interpreter, it can potentially disadvantage both the doctor and the patient.

Using trained interpreters and appropriately translated materials in the correct language and dialect of the person with dementia is essential in order to avoid relying on family members as interpreters. Use of professional interpreters is essential to provide independence to the voice of the person with dementia, and reduce the stress placed on family members.

Some studies report the communication can be further hindered when the cultural background of the healthcare staff providing social care differs from the person with dementia, and their family.

Communication does not only refer to spoken language. It also involves body language, cultural rules as to what is polite (such as not looking the professionals - especially opposite gender - in the eye) and appropriate behaviours in an unequal gender and power relationships.

While there has been enormous progress in the field of pain in the recent years, the actual delivery of care to individuals in pain is still not adequate. However, as we focus on pain and on why it is too often ineffectively treated, there is evidence that certain minority populations are at higher risk of oligoanalgesia (the ineffective or sub-therapeutic treatment of pain).

In addition, there is also evidence that patients reporting high pain severity also experience prejudice which may be amplified by racism.

Religion and spirituality amongst patients with advanced disease and their families is a central component of physical and psychological well-being and should be carefully considered by health and social care professionals.

To this end, acquiring core competencies in the assessment and management of spiritual and religious care for health and social care professionals working in end-of-life care, including those caring for people with dementia, is highly recommended.

However, this approach is not without criticism; it has a tendency to over-categorise religious and

cultural groups and amplify differences (Gunaratnam, 2003)⁷.

Skills in cultural competence and cultural assessment enable healthcare professionals to ask patients and their families what is important to them rather than over assuming.

4. The main barriers for citizens with dementia of a different ethnicity

In order to efficiently improve access to diagnostic and intervention services for people with dementia who belong to different ethnic groups, it is necessary to understand what are the barriers that hinder it.

Several reasons have been identified⁸:

- attribution of symptoms to normal ageing or to other physical, spiritual or psychological causes;
- denial that there was a problem or normalization of symptoms;
- concerns about the stigma associated with dementia;
- sense of shame that leads to not wanting to let people know what's going on.
- perceived ethical imperative to care for one's own family members without accessing help;
- low educational level;
- negative experiences of the healthcare service and feeling there was nothing that could be done for dementia;
- encountering language barriers;
- economic problems;
- not knowing who to get help from;
- poor availability of instruments that are appropriate for cross-cultural assessment of cognitive skills;
- "color-blindness": treating minorities in the same way as the white (or native) majority.
- lack of appropriate tools for assessing cognitive functions.

Most of the above reasons indicate that the barriers to seeking help for dementia are culturally



specific and that encouraging help-seeking in ethnic minority groups will therefore require an approach that takes these particular concerns into account.

It has been documented, for example, that some South Asian groups do not even have a specific word for referring to 'dementia' in their language. In some cases, people feel uncomfortable talking about it because they are concerned that it will affect the marriage prospects of family members.

For example, in the case of a first-generation immigrant who, however, spent the first few years of life in a rural area of India, who develops

 $^{^7}$ Gunaratnam, Yasmin. (2003). Researching Race and Ethnicity: Methods Knowledge and Power. London: Sage.

⁸ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4222802/

dementia in old age, his cultural points of reference are likely to be very different from secondgeneration people who live around him, such as family members or the community.

Importantly, the experiences of the first years of life strongly influence the perceptions of people with dementia and only by adopting a cross-cultural perspective we could understand certain gestures, attitudes and reactions.

Another cultural issue is the "color-blindness": denying cultural differences and heterogeneous experiences of minorities creates a kind of unintentional racism.

For example, in minority ethnic groups there is a misconception that dementia occurs due to nonbiological causes and that there is nothing that can be done about it.

Regarding the **language** issue, one main aspect is the linguistic barriers between professionals and patients with dementia, between professionals and families. But it is also possible that there are also language barriers between the patient and his own family due to the different educational background within the family. The elderly patients with dementia may not even speak the same language as the family or community members.

Economic problems can limit and delay the search for help by families of elderly people of different ethnicity with dementia; this could contribute to underdiagnosis or late diagnosis of advanced cases.

How to reduce the barriers to help-seeking

We can categorise the barriers hindering help-seeking for dementia in minority ethnic groups into three main groups:

- 1. personal barriers. This relates to the personal dimension, i.e. different beliefs on the cause of the disease due to religious or spiritual convictions;
- 2. social barriers, such as concern for stigma or ethical imperative to care for one's own family members;
- 3. health care barriers, i.e. not knowing who to get help from or any barriers within the health system itself.

There are three main actions we can take to break down the barriers.

Use of qualified interpreters. However, we must be aware of the risk that healthcare professionals may feel the loss of control and feel that they are excluded from the conversation. Therefore, interpreters should receive adequate training.

Recruitment of staff with different linguistic and cultural skills. This could be a good solution, although the question arises of which languages and cultural backgrounds should be represented.

Information campaigns regarding dementia specifically addressed to families, healthcare personnel or caregivers from certain ethnic groups. Targeted or tailored (individualized) communication is important: an English study "looking at increasing the uptake of colorectal cancer screening found

that the uptake was approximately 50% higher in the groups which received targeted or tailored interventions compared with those who only received generic information."⁹ Internationally there are awareness campaigns that use various techniques such as: providing information, hosting social events and facilitating involvement in the arts.

One study that sought to understand whether disseminating information about dementia affects behavior change is that of Hurt et al.¹⁰. Two groups were studied: the first in which participants sought help for subjective memory disorders, the other with those who did not seek help: "Objective cognitive impairment in both groups was the same, but those in the first group, i.e. those seeking help were more likely to believe that their symptoms had more serious consequences and were also more likely to believe that the symptoms were due to a biological cause that could be amenable to medical treatment. This seems to reinforce the argument that altering beliefs about dementia will encourage help-seeking behavior for it. "

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⁹ https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4222802/

¹⁰ Hurt CS, Burns A, Brown RG, Barrowclough C. Why don't older adults with subjective memory complaints seek help? Int J Geriatr Psychiatry 2012; 27:394–400.