

This educational event is supported by



HIV, aging and quality of life: Incorporating subjectivity for culturally competent nursing practice

Juan Leyva Moral

Universitat Autònoma de Barcelona, Spain

www.nhivna.org



HIV, AGING AND QUALITY OF LIFE: *Incorporating Subjectivity for Culturally Competent Nursing Practice*

Juan M. Leyva, PhD, MSc, CHNS, RN

Universitat Autònoma de Barcelona (Spain)

Juanmanuel.leyva@uab.cat

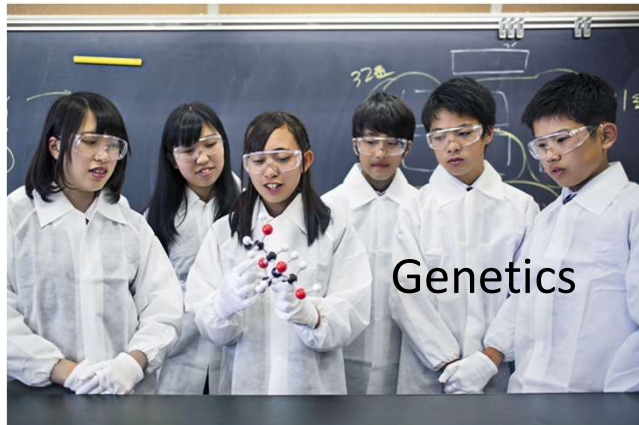
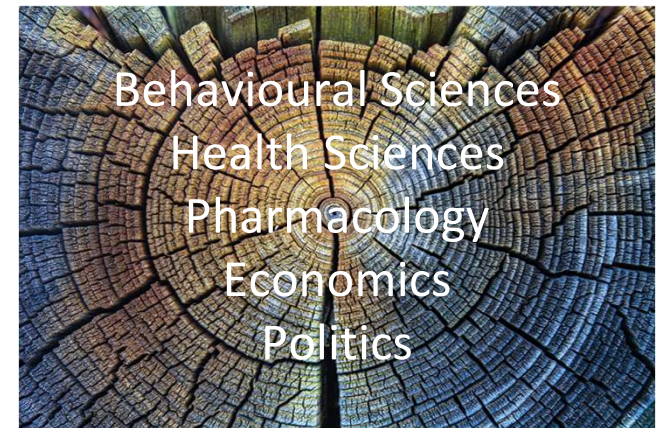
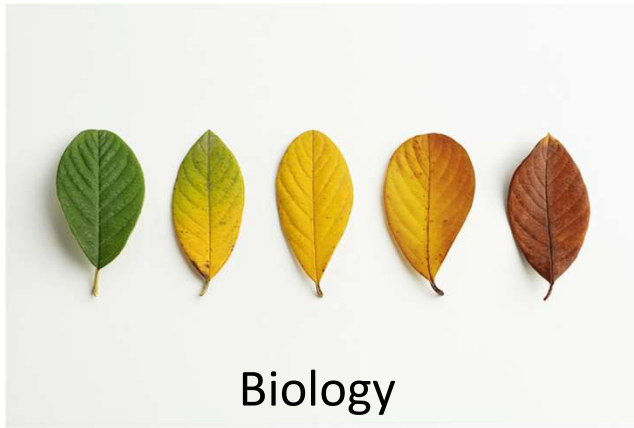
CONFLICT OF INTEREST



Qualitative methods reviewer for ViiV, 2022

Aims

1. To reflect about the concept of Aging & Quality of Life and its different approaches and meanings
2. To critically reflect about our own beliefs and bias about Aging & Quality of Life
3. To promote intersectional analysis, cultural competence, and qualitative methods as tools for deeper understanding of aging and quality of life of people living with HIV



What is Aging?

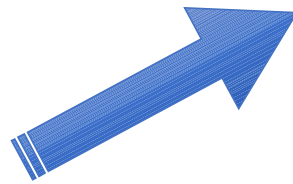
Structrual damage

Functional decline

Depletion

Universal
changes in
phenotype over
the course of a
lifetime

Progressive
increase in the
probability of
death (or
disease)



Focused in **negative aspects** = loss,
“expiration date”, diseases...

What about positive aspects?
Maturity
Spiritual respect
Wisdom

Universal phenomenon?

Pathologization

Imatges en línia



← aging ×

Amb tecnologia de: Bing

Només Creative Commons



skin silhouette clipart icon illustration art concept brain time lapse normal natural hallmarks



Medical News Today The effects of aging: ...



Harvard Health Why Your Face Ages and What You Ca...



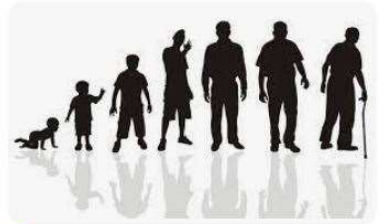
Mount Sinai Aging changes in skin Informatio...



Presbyterian Senior Living What Is (and Isn't) Normal Aging



Women's Health Mistakes That Can Cause Overnight Aging ...



Dr. Jason Fung - The Fasting Method What is aging? | The Fasting Method



SciTechDaily New Potential for Reversing Aging ...



Science News Positive attitudes about aging...



Neuroscience News Feeling Hungry? It Might Just Slow ...



Grosse Pointe Dermatology Anatomy of Facial Aging - Grosse Pointe ...



New York Post to freeze the aging process



Dr. Namnoum Prevent the Signs of Early Aging...



What is Quality of Life?

According to whom?

- Several definitions from different disciplines and contexts

We can even measure it... Really?

- Again, according to whom?

Well-Being?

Mission
impossible

Farquhar M. (1995). Elderly people's definitions of quality of life. *Social science & medicine* (1982), 41(10), 1439–1446.

[https://doi.org/10.1016/0277-9536\(95\)00117-p](https://doi.org/10.1016/0277-9536(95)00117-p)

- Two ways to measure the quality of life:
 1. **Structured** questionnaires/scales:
 - ✓ The concept of quality of life used is the researcher's
 2. **Non-structured** interviews:
 - ✓ Allows subjects to identify the factors which contribute for their meaning of quality of life



Meaning for older adults

Domains	Definition
Health perception	Feeling healthy and not limited by your physical condition
Autonomy	Being able to manage on your own, retaining dignity and not feeling like a burden
Role and activity	Spending time doing activities that bring a sense of value, joy and involvement
Relationships	Having close relationships which makes you feel supported and enable you to mean something for others
Attitude and adaptation	Looking on the bright side of life
Emotional comfort	Feeling at peace
Spirituality	Feeling attached to and experiencing faith and self-development from beliefs, rituals and inner reflection
Home and neighbourhood	Feeling secure at home and living in a pleasant and accessible neighbourhood
Financial security Not feeling restricted by your financial situation	

van Leeuwen, K. M., van Loon, M. S., van Nes, F. A., Bosmans, J. E., de Vet, H. C. W., Ket, J. C. F., Widdershoven, G. A. M., & Ostelo, R. W. J. G. (2019). What does quality of life mean to older adults? A thematic synthesis. *PLoS one*, 14(3), e0213263. <https://doi.org/10.1371/journal.pone.0213263>

So...



<https://www.coib.cat/ca-es/banc-imatges-infermeres.html>

So...



Qualitative data

Quantitative data

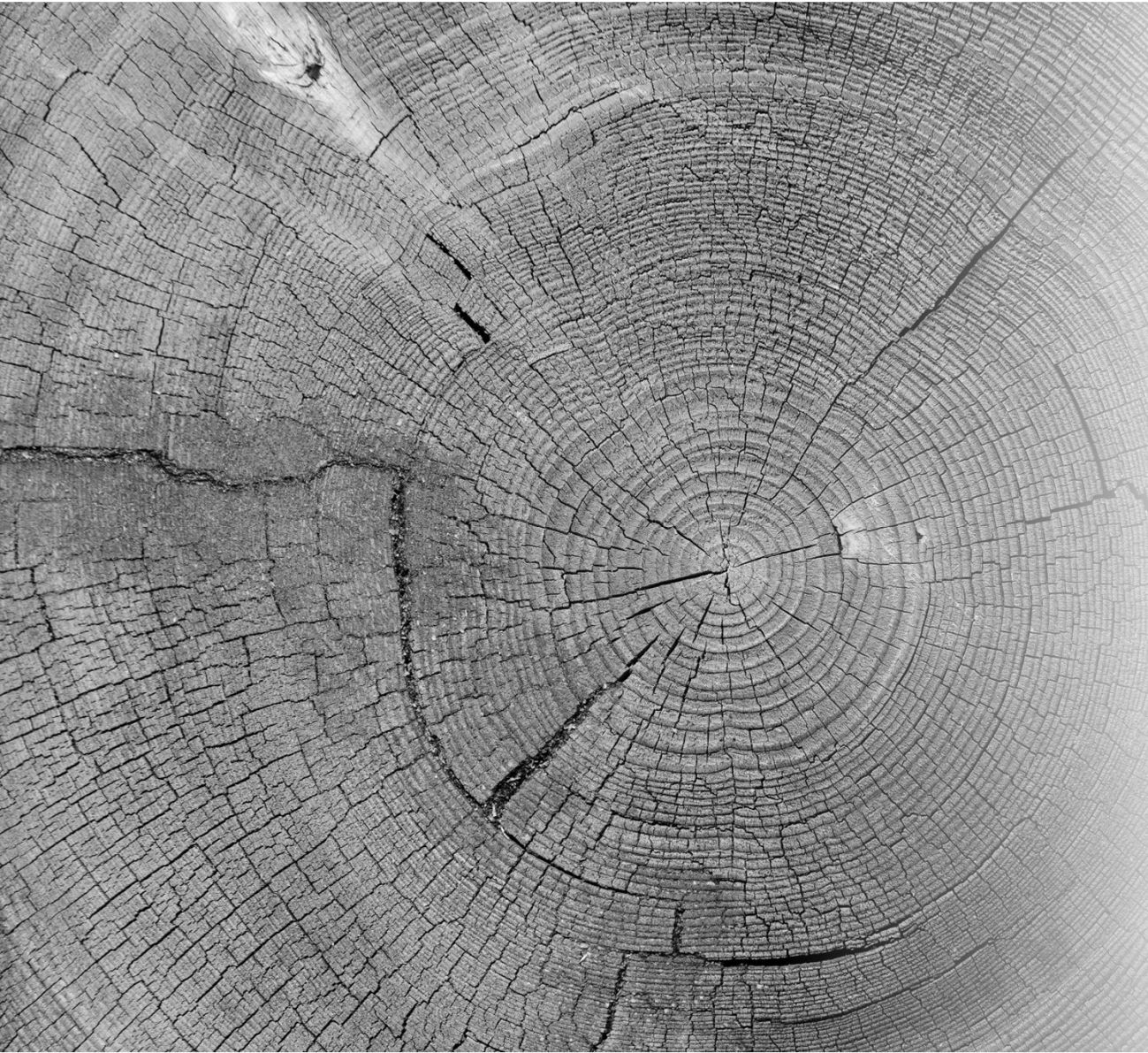
<https://www.coib.cat/ca-es/banc-imatges-infermeres.html>

Emlet, C. A., Harris, L., Pierpaoli, C. M., & Furlotte, C. (2018). "The Journey I Have Been Through": The Role of Religion and Spirituality in Aging Well Among HIV-Positive Older Adults. *Research on aging*, 40(3), 257–280. <https://doi.org/10.1177/0164027517697115>

- **'Aging'**

- Catalyst for examination of life
- It leads to spiritual questions and increased interest in a connection to a higher power.
 - *"growing older, you appreciate stuff, the creation of it, people animals and plants."*





Leyva-Moral, J. M., Martínez-Batlle, F., Vázquez-Naveira, M., Hernández-Fernández, J., & Villar-Salgueiro, M. (2019). The Experience of Growing Old While Living With HIV in Spain: A Phenomenological Study. *The Journal of the Association of Nurses in AIDS Care* : *JANAC*, 30(1), 111–118.
<https://doi.org/10.1097/JNC.0000000000000032>

- **‘Aging’**
 - Physical changes (mostly due to the HIV)
 - Financial problems
 - Loneliness
 - The impact of significant others
 - Coping
 - Acceptance

**“I did not expect to live so long, and look at me, I am 53 and I am still here”
(Adam, male)**

“I feel enormous loneliness and also a lack of love and affection. I have a solitary life. I would say that I am almost totally alone” (Abel, male)

“Doctors’ attention is excellent. Their human quality is just excellent. They are very involved with the cause” (Agustín, male)

“There are still doctors that have bad reactions when they treat a person with HIV” (Adela, female)

“Now you just take a pill and it makes everything easier. You hv some hope now” (Agustín, male)



Solomon, P., Letts, L., O'Brien, K. K., Nixon, S., Baxter, L., & Gervais, N. (2018). 'I'm still here, I'm still alive': Understanding successful aging in the context of HIV. *International journal of STD & AIDS*, 29(2), 172–177. <https://doi.org/10.1177/0956462417721439>

- **‘Successful Aging’**
 - Accepting limitations
 - Staying positive
 - Maintaining social supports
 - Taking responsibility
 - Living a healthy lifestyle
 - Engaging in meaningful activities.



Mutabazi-Mwesigire, D., Seeley, J., Martin, F., & Katamba, A. (2014). Perceptions of quality of life among Ugandan patients living with HIV: a qualitative study. *BMC public health*, 14, 343.
<https://doi.org/10.1186/1471-2458-14-343>

- **‘Quality of life’**
 - Live-ability of the environment
 - Utility of life
 - Life ability of a person
 - Appreciation of life



Geurtsen B. (2005). Quality of life and living with HIV/AIDS in Cambodia. *Journal of transcultural nursing : official journal of the Transcultural Nursing Society*, 16(1), 41–49.

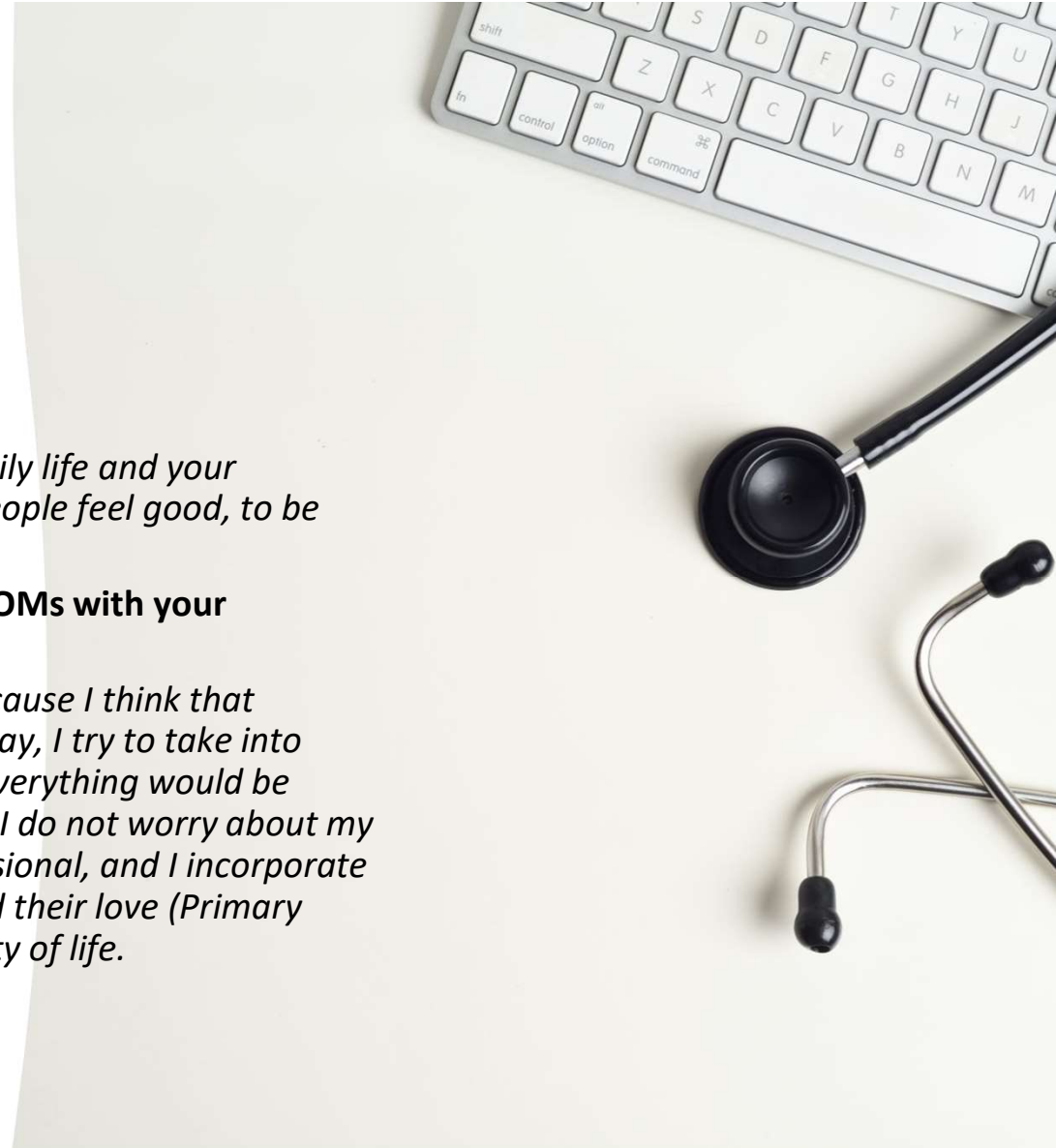
<https://doi.org/10.1177/1043659604270979>

- **‘Quality of Life’**
 - Ability to maintain life functioning
 - Isolation and the desire for connection with others
 - Perceived stigmatization, discrimination, and alienation
 - Anticipating the future (fears)
 - Vulnerable relationships and regrets
 - Being able to meet basic needs
 - Having a sense of belonging
 - Having a safe and caring connection with others

And what about Health Providers?

- **What is Quality of life for you?**
 - *It allows you to be autonomous and enjoy your daily life and your beloved's. I believe that it is a value that makes people feel good, to be able to be helpful to those around us, and we*
- **What would it be like if you routinely used those PROMs with your patients?**
 - *Honestly, I do not think it will be very different because I think that although it is not in an organized and regulated way, I try to take into account this approach. I get the impression that everything would be more orderly and more institutionalized, let's say. I do not worry about my patients because "I am a good girl," I am a professional, and I incorporate all that part of their daily life, their autonomy, and their love (Primary Care Nurse, <25 years of clinical experience) quality of life.*

Data from Mrs. Maria Garro (PhD candidate at UAB)



And what about Health Providers' beliefs?

- **How would you define patients' quality of life?**
 - *When they enjoy a more or less normal life; when they can be at home and cook; when they can go for a walk; when they can chat with others, or see a friend, a family member, or whoever; or when they have some freedom or autonomy of movement.*
- **What kind of health outcomes do you think matter to your patients?**
 - *I believe what the patient values the most is the treatment we give them and that we are aware of them. That we dedicate time, quality time, that you listen to him, okay?, and of course they value the numerical results; If the pressure is well controlled or not, if the sugar values are higher or lower, but all that dressed in love and listening. (GP & Center Director, >25 years of professional experience)*

Data from Mrs. Maria Garro (PhD candidate at UAB)

ENDING S



Loss of Identity: "I shook the pills with my bare hands and then I took a pill of Truvada® and put it over all of the Prezista® pills. I felt kind of rage, rejection; I wanted to project my anger and that's why I put up this discordant note; that's why I decided to title this artwork "Primus inter pares", because that's me. I don't feel superior, I feel myself kind of different, dissimilar"



ART adherence self-management: "I want to do my homework, and I want to get a happy face from my teacher. I also want to get a happy face in my daily living. This does not mean that I will easily forget the sad face, no. I have to learn to live with both of them together although I know the second one will be much stronger."

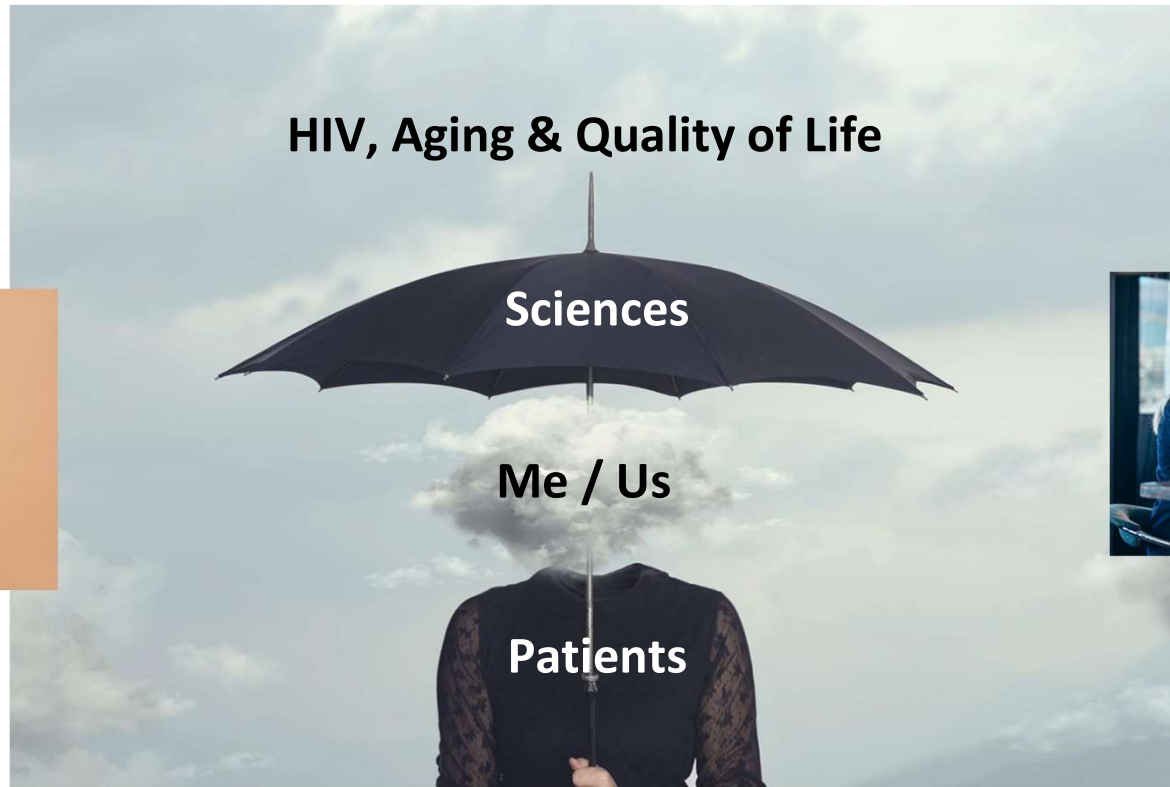


ART as a personal source of faith: "Today, the central star of my universe is this oval shaped orange object that St. John, The Infant Jesus, the Angel and the Virgin Mary seem to pray, to bless and look with divine admiration. The oval shaped orange object is the key of life... 'Revered Prezista®' your are the center of my life"

I can't live with or without you: "A rose, the symbol of love, beauty and perfection is here surrounded by lots of Prezista® pills. This conveys a duality in meaning of the restrictions and agony of being forced to take Prezista®, but also the warmth and fostering of protection derived from the pills against the illness [...] I have to embrace the constricting presence of the pills in order to blossom into the full, healthy life I so desire to live"



So...



Cultural Competence could help you

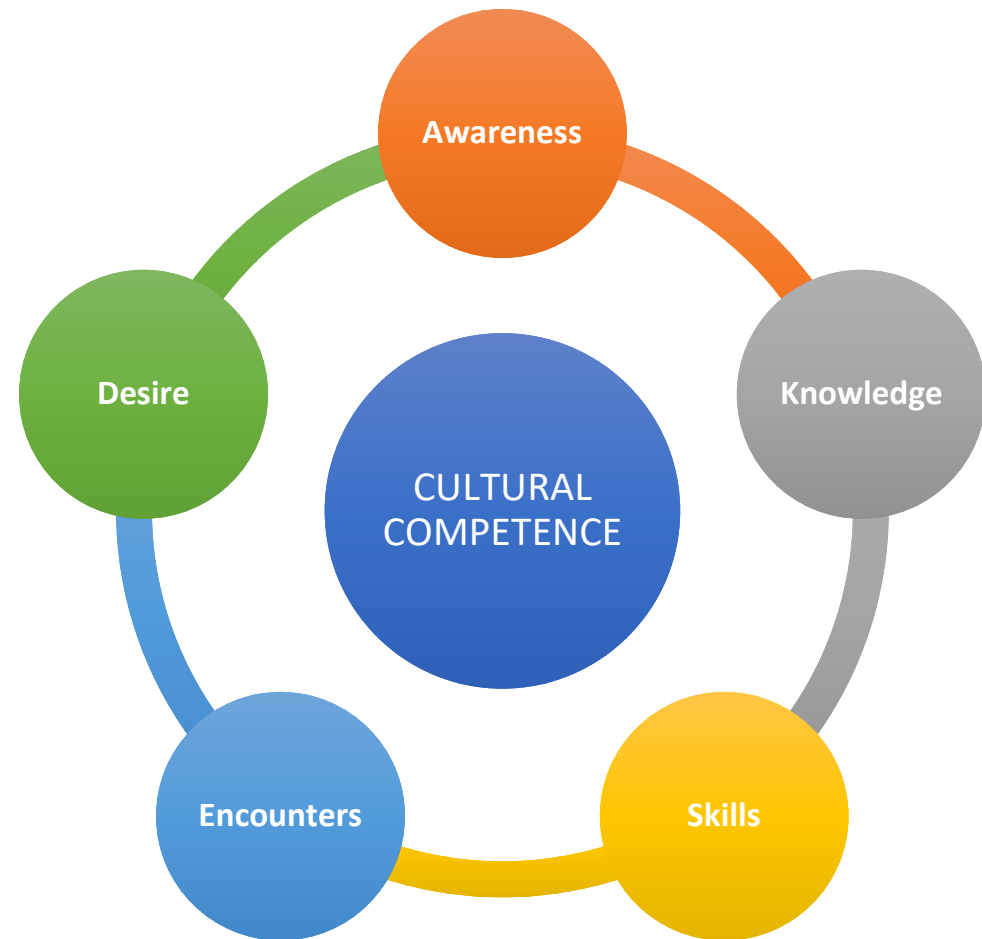
“Cultural competence begins with an awareness of one's own cultural beliefs and practices, and the recognition that others believe in different truths/realities than one's own. It also implies that there is more than one way of doing the same thing in a right manner”

Hermeet K. Kohli, Ruth Huber & Anna C. Faul (2010) Historical and Theoretical Development of Culturally Competent Social Work Practice, *Journal of Teaching in Social Work*, 30:3, 252-271

DOI: [10.1080/08841233.2010.499091](https://doi.org/10.1080/08841233.2010.499091)

Cultural Competence could help you...

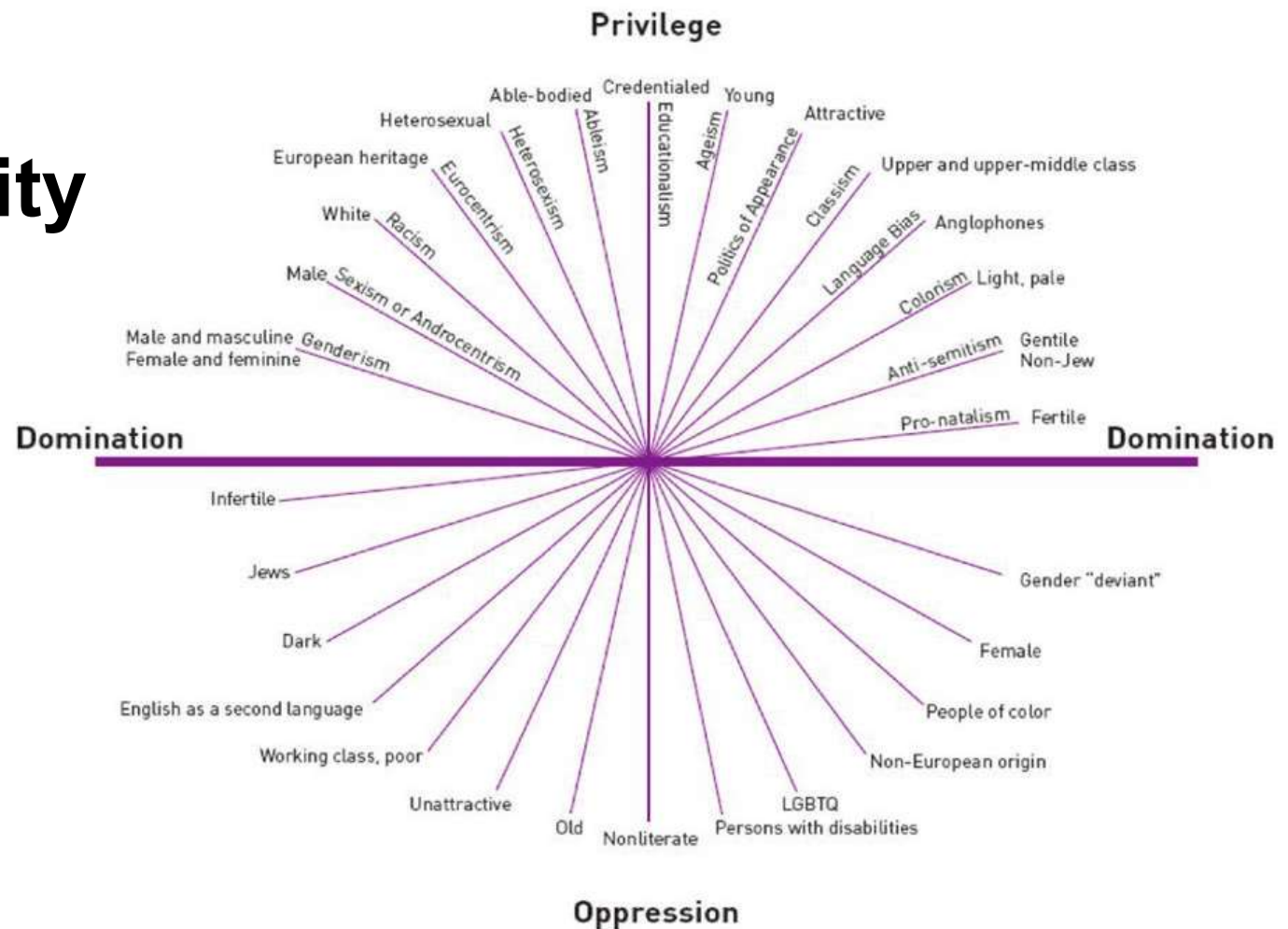
Compassion



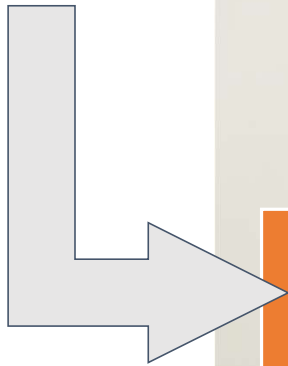
- Papadopoulos I, Tilki M and Taylor G (1998): *Transcultural Care: A guide for Health Care Professionals*. Quay Books. Wilts.
- Campinha-Bacote J. (2002). The Process of Cultural Competence in the Delivery of Healthcare Services: a model of care. *Journal of transcultural nursing: official journal of the Transcultural Nursing Society*, 13(3), 181–201. <https://doi.org/10.1177/10459602013003003>

And intersectionality too...

Morgan, K.P. (1996). *Describing the Emperor's New Clothes: Three Myths of Educational (In-)Equity*. In A. Diller, B. Houston, K.P. Morgan & M. Ayim (Eds). *The Gender Question in Education*. Routledge.



And of course...



Qualitative
methods



Quantitative
methods

<https://www.coib.cat/ca-es/banc-imatges-infermeres.html>



Think about it

- **What are your own personal/professional beliefs?**
- **What are your personal/community background?**
- **What are your professional interesting areas? Why?**
- **How do you stablish caring relationships with your patients?**
- **How important is the social context for you when providing care? Why?**
- **Do you think about privilege & oppression when providing care? Why?**

Final thoughts

- Living with HIV, Quality of Life and Aging are subjective topics.
- Provider & Patient perspective are not the same
- Privilege and oppression influence health beliefs, meanings and outcomes and so does cultural differences



Final thoughts



- Culturally competent nursing practice is essential to providing quality care for diverse patients.
- Understanding cultural differences in healthcare is crucial to promoting patient-centered care and improving health outcomes.
- By taking a subjective approach to HIV, aging, and quality of life, nurses can enhance their cultural competence and provide compassionate care to all patients.



Thank you
Gracias

Juan M. Leyva-Moral
Juanmanuel.Leyva@uab.cat
Twitter @juanleyvamoral