

Florida Atlantic University Christine E. Lynn College of Nursing

Connecting the Theory of Bureaucratic Caring to Precision Health

Katherine Chadwell, DNP, MBMSc, APRN, GNP-BC, CPHQ, PhD student



The Christine E. Lynn College of Nursing is dedicated to caring; advancing the science, studying the meaning, practicing the art, and living caring day-to-day.

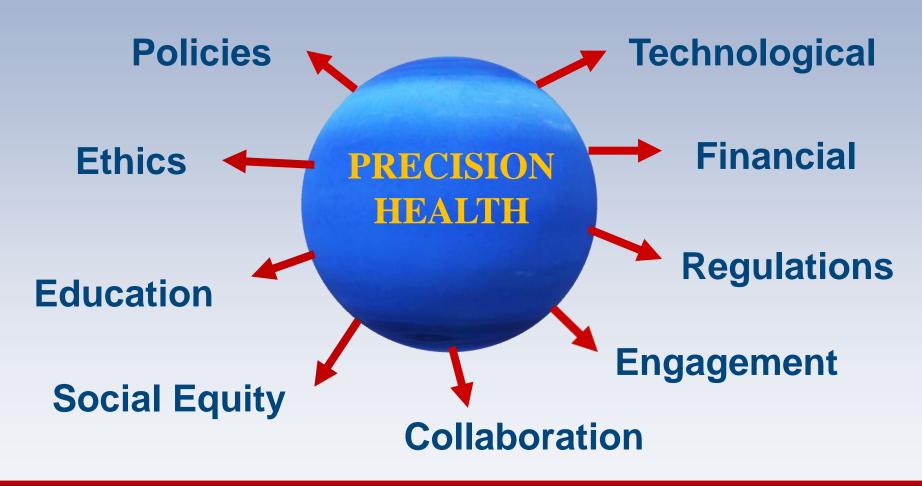
Purpose

- Identify precision health challenges from the literature.
- Present the Theory of Bureaucratic Caring as a framework to address precision health challenges
- Link the Theory of Bureaucratic Caring to Precision health

Precision Health

Completion of the Human Genome Project and advances in technology has fueled a scientific revolution. The precision health initiative is poised to capitalize on these discoveries. However, there are serious challenges to be addressed.

Challenges Identified in the Literature



Addressing Challenges

- Requires a framework that creates a systematic view that supports collaboration and allows for understanding of relationships, prediction, description, explanation, and management of phenomena.
- Nursing's unique view and clinical grounding make nurses uniquely positioned as leaders and collaborators in the precision health movement.

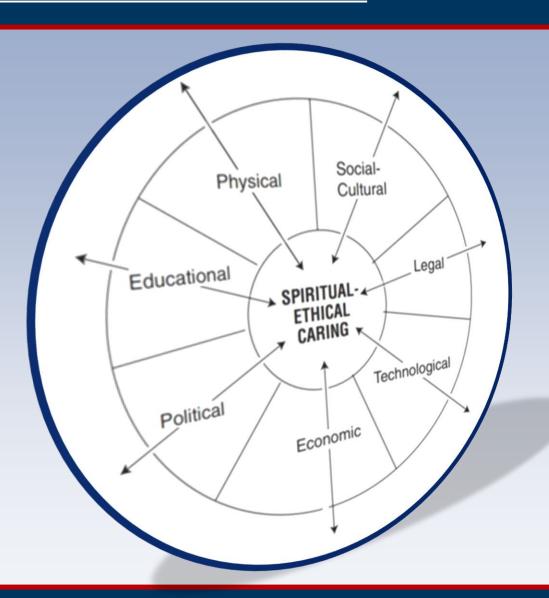
Theory of Bureaucratic Caring



Marilyn Anne Ray, RN, BSN, MSN, MA, PhD, CTN-A, FSfAA, FAAN, FESPCH (hon).

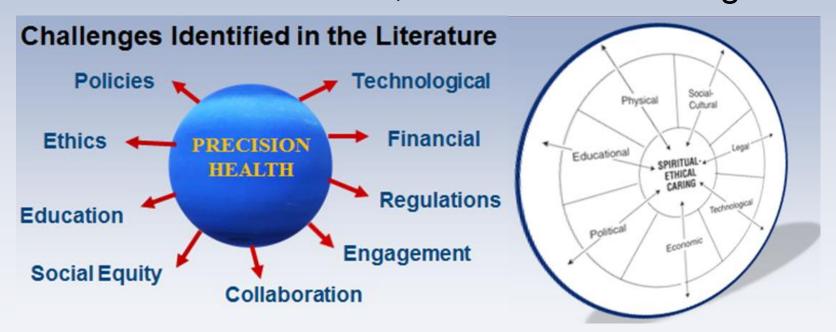
Professor Emeritus at Florida Atlantic University, Christine E. Lynn College of Nursing, Boca Raton, Florida, USA.

Holographic
Theory of
Bureaucratic
Caring



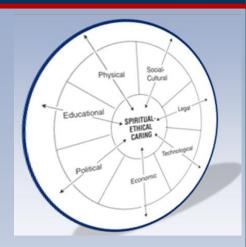
Theory of Bureaucratic Caring

- Aligns with Precision Health Challenges
- Application to complex systems, wholeness, interconnectedness, and focus on caring



Domain: Spiritual-Ethical Caring

 Focuses on values, interconnectedness of body, mind, spirit (holism), and moral choice. Caring as respect, moral obligation, and right action for good of others/culture/society



- Challenge: Ethics, Collaboration
- Example: Privacy, informed consent, values, understanding who one is

Domain: Social- Cultural

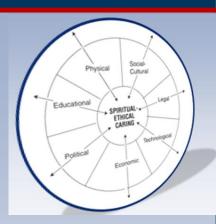
 Focus on meaning of caring within social interactions and support for others: communication, seeking understanding of diverse groups, ethnicities, family, organizations, national and global societal cultures.



- Challenge: Social Equity, Collaboration
- Example: Recruiting diverse groups to precision health, address stigma,

Domain: Educational

 Focus on formal and informal education, includes communication of all aspects of teaching and sharing information and learning, including Inter-professional education and research.



- Challenge: Education
- Example: Healthcare professionals, health literacy regarding genomic information

Domain: Physical

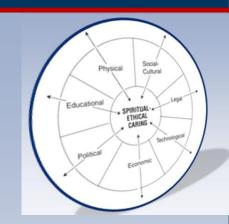
 focus on physical (biological), mental, and emotional states of being, health/illness, healing and dying, interconnectedness of body, mind and spirit and their influence on each other.



- Challenge: Engagement
- Example: Participation in initiative, return of findings

Domain: Political

 Associated with authority, power, and control. Considers systems of hierarchy, roles, responsibilities, governmental influences that lend to competition and cooperation in complex organizations.



- Challenge: Collaboration, Social equity
- Example: Healthcare spending, grant funding, laws (GINA, HIPAA)

Domain: Economic

 Focus on the meaning of caring related to goods, money, services, budget, scarce human and material resources to maintain economic viability of persons, units, and complex organizations.



- Challenge: Financial
- Example: balance clinical and cost effectiveness (drugs, testing), data collection & management

Domain: Technological

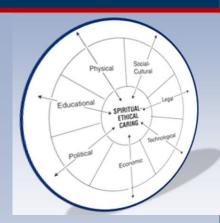
 Focus on nonhuman resources, use of machines, computers, electronic health record, social media, internet, robots, diagnostic tests, pharmacologic agents, skills needed to support persons, families, communities and organizations.



- Challenge: Technological
- Example: Analyzing, Interpreting, Storing of data (Big Data). Synthesize many platforms

Domain: Legal

 Focus on the meaning of caring regarding responsibility and accountability, rules, regulations, policies, standards of practice, rights to privacy, malpractice, defensive medicine and nursing.

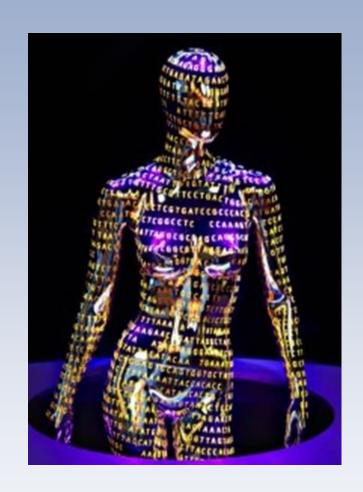


- Challenge: Regulations, Policies, Privacy
- Example: Data security, Authorized use, data, infrastructure, FDA regulation, intellectual property, insurance coverage, DTC testing

Conclusion

- We are at a crossroads in a complex and ever changing environment in healthcare, where caring can bring stability and support health and healing.
- The successful navigation of precision health challenges through the lens of caring offers an opportunity to illuminate the humanity of persons and create an enduring spirit of what matters most.

- While the blending of science, morality, metaphysics, art, and spirituality seems mind boggling, complex issues require thought grounded in the wisdom and understanding of our own humanness
- Perhaps there is a call for "Precision Caring."



References

- Duffy, D. J. (2016). Problems, challenges and promises: perspectives on precision medicine. *Briefings In Bioinformatics*, 17(3), 494-504 doi:10.1093/bib/bbv060
- Leyens, L., Horgan, D., Lal, J. A., Steinhausen, K., Satyamoorthy, K., & Brand, A. (2014).
 Working towards personalization in medicine: main obstacles to reaching this vision from today's perspective. *Personalized Medicine*, 11(7), 641+. doi: 10.2217/pme.14.55
- Ray, M. (2018). Marilyn A. Ray Website. Retrieved from: https://marilynray.com/
- Ray, M. (2018). Theory of bureaucratic caring. In Smith M.J. & Liehr, P.R. (Ed.), Middle Range Theory for Nursing (pp. 107-115). New York, Springer Publishing Company, LLC.
- o Rothstein, M. (2017). Structural Challenges of Precision Medicine: Currents in Contemporary Bioethics. *Journal Of Law, Medicine & Ethics*, *45*(2), 274-279
- Sabatello, M., & Appelbaum, P. S. (2017). The Precision Medicine Nation. Hastings Center Report, 47(4), 19-29. doi:10.1002/hast.736
- Starkweather, A. R., Coleman, B., Barcelona de Mendoza, V., Hickey, K. T., Menzies, V., Fu, M. R., & ... Harper, E. (2018). Strengthen federal and local policies to advance precision health implementation and nurses' impact on healthcare quality and safety. *Nursing Outlook*, 66401-406. doi:10.1016/j.outlook.2018.06.001
- Tully, L. A., & Grady, P. A. (2015). A path forward for genomic nursing research. Research in Nursing & Health, 38(3), 177-179. doi:10.1002/nur.21659
- Watson, J. (2005). Caring science as sacred science (1st ed.). Philadelphia: F.A. Davis Co