

Palliative Care & Clinical Trials and Pharmacovigilance

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Walking the walk of palliative care

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Within the confines of Academia and Research the Human side of Palliative Care sometimes gets lost. On a personal basis and as a Pastor, Care Giver and a Patient Advocate I have gained an understanding of the dynamics and humanity of Palliative Care. This personal involvement has been greatly influenced by multiple life experiences. As a young man in my early teens the daily vigil with my dying grandmother introduced me to a, up to then, life experience that many young people don't experience. Of course, this experience was at a time when "Palliative Care" was neither noted as such, nor fully understood as a needful concept.

As a young Adult, this self-development was more formally influenced through classes in College and Seminary. This was further influenced by multiple job experiences particularly as a hospital orderly in the Emergency Room where multiple facets of medical care came together and had to be coordinated. This formal education time was further influenced over the next thirty-eight-year span of time with my involvement in caring for the families and individuals in various churches. This involved dealing with the complexities of long-term health and multiple medical issues for people and families who were dealing with everything conceivable health wise as well as life ending journeys, be it sudden or over a long period of time

As a Parent and a Husband my personal walk was most significantly influenced partly through my daughters' premature birth, lifelong heart condition and multiple code


situations where life defining decisions that were called for. This was further influenced via my wife (our whole adult married life), her multiple medical issues and multiple "pull the plug" events. At times, the coordination of up to twelve doctors and numerous medical departments and multiple medical facilities in many ways tested the limits of the definition of Palliative Care.

As Palliative Care Professionals and Researchers, study, classes, and roll playing can prepare one to be a care person who addresses many situations much as a doctor or surgeon can likewise learn. But the life experiences can never be taught. They have to be walked. And the personal, human side of this care must always be paramount, and it is to this point that all Palliative Care Professionals must keep themselves focused on. And it is to this point that I have become passionate at keeping professionals focused on.

Speaker Biography

Pastor Bruce Hanson continues with his Patient Advocacy work as an Ambassador for PCORI, a Technical Expert for several Medicare Study groups through the Health Services Advisory Group (HSAG), a couple of patient care study's through Society for Critical Care and through Northwestern University of Chicago. Additionally he serves on several National Organizations as a Patient Advocate Advisor/Consultant (Pharmacy Quality Alliance (PQA), Patient Family Advisor Network PFA network, Institute for Patient and Family Centered Care (IPFCC), University of Iowa City Hospital ICTS advisory board, and the HIT-PFCA that is working on the development of Open Notes and the Patient Portal.

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