

**Certificate in Integrative Palliative Care – 3**  
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**Week-11**  
**Lecture 82: Exploring the Science behind Spirituality**

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Exploring the 'science'  
behind Spirituality &  
Religiosity

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National Founder President, NAPCAIM

Namaskar, my name is Dr. Abhijit Dam and I am the national president of the National Association of Palliative Care for Ayush and Integrative Medicine. And today in this particular lecture we will be exploring the science behind spirituality and religiosity.

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*"I see spirituality as that which allows a person to experience transcendent meaning in life. This is often expressed as a relationship with God, but it can also be about nature, art, music, family, or community—whatever beliefs and values give a person a sense of meaning and purpose in life. ...Patients learn to cope with and understand their suffering through their spiritual belief, or the spiritual dimension of their lives"*

--Christina Puchalski and Anna L.Romer, "Taking a Spiritual History...." *J of Palliative Med* 3, no. 1 (Spring 2000): 129.

Now, Christina Puchalsky has done a lot of work on spirituality and palliative care. And she actually said that I see spirituality as that which allows a person to experience transcendent meaning in life. This is often expressed as a relationship with God, but it can also be about nature, art, music, family or community.

Whatever beliefs and values give a person a sense of meaning and purpose in life. So, this statement is very important. So, whatever beliefs and values give a person a sense of meaning and purpose in life, that is spirituality. Patients learn to cope with and understand their suffering through their spiritual belief or the spiritual dimension of their lives.

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So, we all have to die. This is something which we all need to accept, but how we die and where we die is something which we can all plan for, right and this is the most dying is the most important event in our life and because that is that means a dissolution of our physical existence, right and so naturally whenever there is a question of a dissolution of our physical existence that would give rise to existential concerns and that would lead to suffering. And whenever there is suffering, spiritual concerns would definitely come in. Like why is this happening to me? Why should I die? Why should I suffer? So or how can I overcome this suffering? There are so many questions and so many ways in which different patients and their families also would address spirituality and religiosity at this particular juncture of time.

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### Coping with Cancer Study

Balboni TA, Vanderweele LJ, Block SD, et al. Religiosity and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. J Clin Oncol 2017;25:555-62

- 230 patients with a diagnosis of advanced cancer and prognosis of less than 1 year were interviewed.
- Patients rated the importance of religion to them and their attendance at religious services before and after their cancer diagnosis
  - 68% identified that religion was very important, 20% found it somewhat important and the remaining 12% found it was not important.
  - Increased religiosity was associated with increased patient distress at the time of the study.
  - religious activities such as prayer and meditation increased from 47% before diagnosis to 61% after diagnosis.
- This study clearly highlights the **importance of spirituality and religion** to patients struggling with serious illness

Now, coming to science and what does science say, there was this coping with cancer study which was done by Balboni and his colleagues, which was basically religiosity and spiritual support amongst advanced cancer patients and associations with end of life treatment preferences and quality of life, right.

So, what were the patient's preferences about end of life and how did religious traditions and their beliefs and spiritual support affected. So, 230 patients with a diagnosis of advanced cancer and prognosis of less than one year were interviewed. Patients rated the importance of religion to them and their attendance at religious services before and after their diagnosis of cancer. 68 percent identified that religion was very important. 20 percent found it somewhat important and the remaining 12 percent found it was not important.

Increased religiosity was associated with increased patient distress at the time of study. So, this was very important that patients who were very religious were actually very distressed also and that is perhaps why they were so religious. Because they were so much distressed that they relied heavily on religion to take care of the distress. Religious activities such as prayer and meditation increased from 47 percent before diagnosis to 61 percent after diagnosis, which means that patients and their families took recourse to religion after their diagnosis. This study clearly highlights the importance of spirituality and religion to patients struggling with serious illness.

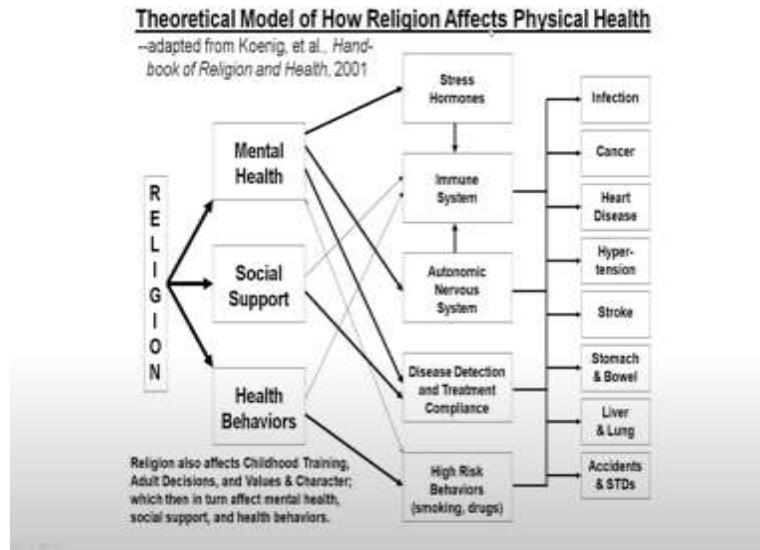
So, now you have scientific proof also that patients seek spirituality and religion when struggling with suffering.

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Now, this picture is that of a, it could be a temple, it could be a place of worship, it could be something like that you know, but I would call this as a place of research. This is a research laboratory you know why because whenever we are suffering we go to this research laboratories with a question that why am I suffering why is this happening to me all of us go to temples we go to mosques we go to churches whenever why do we go we usually go when we are faced with so many problems in existential problems in our lives so there we go and put our sufferings in front of God and ask them to take care of the suffering. So, the research question we take to this research laboratories and there we get answers to our questions. So, these are not places of worship, for me these are places of research where you go to address your spiritual suffering, your mental problems and you get a answer.

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Now, this Koenig and his colleagues, they conceptualized a theoretical model of how religion would affect physical health. Now, religion affects our childhood training because we are not born with any religion as I had said before. We are born with spirituality, with our own inbuilt software of spirituality but religion is imposed with upon us. So, religion affects our childhood training, our adult decisions, our values, character. Now, these in turn would affect our mental health, our social support and health behaviors, which again would affect our level of stress hormones, our immune system, our autonomic nervous system, our disease detection and treatment compliance that is how quickly that we go and have medical help and so on and so forth and whether we have high risk behaviors like smoking, drugs, alcoholism, etcetera or not.

These are also you know directly or indirectly related to our religious models and these interplay of all these factors like stress, immune system, autonomic nervous system, disease detection, etcetera, high risk behavior would lead to infections or cancer, heart disease, hypertension, stroke. So, all these physical ailments would be a result of our religious makeup basically, right. So, this is a theoretical model of how religion would affect physical health, a brilliant model.

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So our local culture where we stay our religion would affect how we adapt to different illnesses like this elderly person living in this mud hut he lives here alone and he is perfectly happy, but for us if we are to live in this mud hut alone we would not perhaps be able to survive for a week out here and this elderly person in spite of his disability he is staying here alone and he is self sufficient.

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### Biopsychological-spiritual model

- Illness is viewed within the context of the complex interplay of **biological, social, psychological** and **spiritual** factors that frame an individual's response
- Consideration has to be given to relationships—the patient's relationship with self and others
- The importance of spirituality, religion and culture in the lives of our patients cannot be overlooked.
  - serve as key components to build the framework by which patients guide decision-making during illness and at the end of life

Then came the biopsychological spiritual model, where illness is viewed with the context of complex interplay of biological, social, psychological and spiritual factors that frame an individual's response.

Consideration has to be given to relationships also, that is the patient's relationship with one own self and with others also. And the importance of spirituality, religion and culture in the lives of patients cannot be overlooked. They serve as key components to build the framework by which patients guide decision making during illness and at the end of life. So, all these factors that is religion and spirituality are so, so very important factors.

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Now, take the example of this lady.

You can see this huge maxillary growth in the maxillary antrum causing massive disfigurement. And at the first look at this lady all of us would be thinking that she must be in severe pain, but actually she was so happy and composed in spite of this huge tumor, because spiritually she was at peace, she had a very good family support system and that helped her to cope with the illness in a beautiful manner. So, this is what, this is how the importance of spirituality and religiosity is in impacting how we suffer or how we do not suffer or how we adapt to our suffering.

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## Definitions

1. **Spirituality:** Spirituality is composed of three aspects:
  1. relationships,
  2. values, and
  3. life purpose.
2. **Religion:** Religion is a personal set or institutionalized system of religious attitudes, beliefs, and practices.
3. **Faith:** A Belief and trust in God based on evidence but without total proof.



Now spirituality is basically composed of three aspects. One is relationships, second is values and third is purpose in life.

Whereas, religion is a personal set or institutionalized system of religious attitudes, beliefs and practices. Now, what is faith? Faith is a belief and trust in God based on evidence, but without total proof. That is faith. I have faith in God, means I have belief and trust in God, but if you ask me to show proof of it, I cannot show you. So, as I said before also, everything cannot be just explained by science.

But they still are there because we can feel them, we can feel them, we can experience them. These are experiential issues which cannot always be documented.

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And there is an intersection between spirituality and religion. Spirituality would address questions like where do I find meaning, how do I feel connected, how should I live, that is spirituality. This is our inbuilt software.

And then religion would address what practices or rites or rituals should I follow. What is right? What is wrong? What is written in my religious book? What is right and what is wrong? What is true? What is false? All this can be addressed by religion. Your particular religion would have a particular set of answers for that. And in the mid, in the intersection comes belief, comfort, reflection, ethics and a sense of awe.

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## Spiritual Distress

- Spiritual distress and spiritual crisis occur when a person is unable to find sources of meaning, hope, love, peace, comfort, strength, and connection in life or when conflict occurs between their beliefs and what is happening in their life (*Anandrajah & Hight*)
- Spiritual distress refers to a disruption in one's beliefs of value system, a shaking of one's basic beliefs (*Hospice & Palliative Nurses Association*)

Spiritual distress and spiritual crisis occur when a person is unable to find sources of meaning, hope, love, peace, comfort, strength and connection in life or when conflict occurs between their beliefs and what is happening in their life.

That is when spiritual distress, when you cannot give your suffering a sense of meaning, why is this happening to me? I have been such a good person and why should I suffer from cancer? My neighbor has been a drunkard all his life, he has been gambling all his life, but look he is so happy and I have been a good person throughout my life, but yet you have given me cancer, why? Spiritual distress refers to a disruption in one's of value system a shaking of one's basic belief. So, where your whole belief system is shaken up that is where you have spiritual distress.

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### Behaviors that erode patient dignity

- Relationships of inequality
- Treated like an object or without respect
- Wishes not honored
- **Loss of control over bodily functions**
- **Loss of ability to choose**
- **Dying in pain & alone/isolated**
- **Loss of meaning/purpose**



You have whole life you have believed in a certain set of moral codes and conduct and then suddenly your whole belief system is shaken up that is spiritual distress. Now, there are certain behaviors that erode patient dignity like relationships of inequality you are giving you are treating that patient differently means you are giving more time to that patient, but you are just you know walking past my bed without even greeting me or treated like an object or without respect you address me as a bed number, bed number 22, bed number 25, but if you remember the names Sharma ji, Varma ji, Singh ji then the patients feel more connected, where the wishes are not honored I want to go home. I want to spend my last days of life at home, but as a doctor you are saying that no, no I will not discharge you, you have to stay in the hospital.

So, my wishes are not being honored. So, there will be distress. Loss of control over bodily functions. So, imagine you are lying on the bed and you are passing feces, you are passing urine in the bed and your young daughter is coming to clean you up. That results in loss of dignity, right.

Loss of ability to choose dying in pain alone or in dying in isolation. Would you like to die alone? Would you like to die in pain? Ask yourself these questions and immediately you can see the amount of distress that it can conjure up or where there is a loss of meaning or purpose in life. Like why am I alive? It would have been better if I died. What is the meaning of life? What is the purpose of life? God has only given me sadness, God has only given me suffering. So, these type of questions also arise in the minds of patients and their family members also, right.

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### Characteristics of spiritual suffering

- Pain, constant & chronic
- Insomnia
- Withdrawal, depression, guilt/self-loathing
- Conflict (family, palliative team, friends)
- Hopelessness
- Lack of sense of humor
- Unforgiveness
- Despair, fear, dread

So, characteristics of spiritual suffering, how would you know that your patient or their family members have spiritual suffering? Where the complaint of pain which is constant and chronic, you are giving them all pain medications, but the patient is still saying no, no, no, I am still having pain. I am suffering, I cannot sleep, there is insomnia, withdrawal, depression, guilt, self loathing, I hate myself, I am basically rotten to the core, that is why God has given me cancer. So, these type of thoughts when it comes to the mind, where there is conflict, the patient is fighting with the family members, they are fighting with everybody for no reason, where there is a sense of hopelessness that nothing can happen to me now, I am doomed, I definitely will die. Lack of sense of humor, unforgiveness that I will never forgive you that sort of thing, despair, fear, sense of dread. So, to recognize spiritual distress you need to question, you need to often question the patient about the meaning of life.

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## Recognising Spiritual distress

- Questioning
  - the meaning of life,
  - where God is during their suffering,
  - see their illness as retribution for a life of poor choices,
  - express anger at God or a higher power
  - sense of direction and purpose has been lost
  - questioning their belief systems
  - directly seeking spiritual help

A simple question would be are you at peace? This is one of the most simple questions which I personally have found to be so very useful. There are a lot of other questioners, we will come to that soon, but the simple question ask your patient, are you at peace? The meaning of life, where God is during their suffering, see their illness as a retribution for a life of poor choices, express anger at God or at a higher power, sense of direction and purpose has been lost, questioning their belief systems or directly seeking spiritual help.

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Now you see this was one of our patients with advanced cancer who used to lie in the Charpai (Hindi word meaning cot) in a small village and she used to lie here alone, but she was so very comfortable. So, she used to lie alone you see the surroundings there is a small dirty drain out here she lying on a Charpai in the you know in the courtyard of the house, but she used to be at peace you know why? Because of this little child, her little grandchild, her grandson. So, she used to lie on this Charpai and watch her little grandchild playing and that gave her a sense of meaning and purpose in life and that helped her to get relief from her suffering.

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### Theme components of a 'good death'

Annals of Medicine, Steinhauser et al. 2000

- pain and symptom management
- clear decision making
- preparation for death
- contributing to others
- affirmation of the whole person
- Completion
  - resolving conflicts
  - saying goodbye
  - spending time with family and friends
  - attending to issues of faith

Now, coming to what constitutes a good death, theme components of a good death. This was published in the Annals of Medicine by Steinhauser in 2000, where there is good pain and symptom management, there is good clear decision making, preparation for death, contribution to others, affirmation of the whole person and a sense of completion. What do you mean by sense of completion? Resolving conflicts, saying goodbye, spending time with family and friends and attending to issues of faith also. So, everybody would have their own different components of a good death, you just ask yourself this simple question, how would I like to die, where would I like to die, where would I like to spend the last days of my life, what do I do suppose I have to die after two days. So, what do I want to do now, make a list and that is your idea of a good death.

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Now, coming to the intersection of spirituality and culture, all patients and their family wish to approach end of life with dignity, self-respect and an opportunity for building and securing their legacy. What differs may be how each individual goes about accomplishing these tasks. So, the goal is the same, but the roads can be different. Culture influences how they make sense of their illness and death as well as how they make end of life decisions. So culture can have a very strong influence on how you approach death and it is important to respect the patient's own cultural system and beliefs, right.

So now the local culture would be determined by the ethnicity or race, spirituality or

religion, level of education, level of acculturation, gender, age, sexual orientation, country of origin and immigration status also. So for example the Hindus of India who have now gone abroad who have settled in London for example, how would they view their culture? Now they have been brought up in India, but now they are settled for a long time in London. So, they would undergo a cultural shift. So, that would depend on the immigration status again. So, there are so many things would affect your culture and we need to respect the cultural and social aspects of the patient.

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So, again here you see this same lady and she is the local culture on the background you can see these are the Ayodhya hills in the border of Jharkhand and West Bengal and this is a village the harvest season is just been over and surrounded by the local family and friends. So, the local culture she is comfortable in such surroundings.

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## Religious coping

- How patients use their religious beliefs to understand and adapt to life stressors.
  - **Positive religious coping** employs constructive reliance on faith to make sense of and find meaning in illness, and is widely associated with greater psychosocial adaptation to stressors.
  - **Negative religious coping** may be more likely to view illness as punishment or divine retribution
    - Points to 'existential crisis'
- Pargament et al
  - Brief R-COPE
  - Positive & negative religious coping scale

Now religious coping, what is religious coping? How patients use their religious beliefs to understand and adapt to life stresses, right? So why am I having cancer? Because I did not go to church, because I did not pray, that is why I am having cancer. So there can be religious coping can be positive or negative. Positive religious coping employs constructive reliance on faith to make sense of and find meaning in illness and is widely associated with greater psychological adaptation to stresses.

So, if you think that no god has given me this suffering maybe there is a reason for this suffering but god is with me in my suffering so this is a positive religious coping and a negative religious coping may be more likely to view illness as a punishment or divine retribution and points to existential crisis that no because I did not go to the church or did not go to the temple or did not pray, did not believe in God, that is why I got the cancer, God has punished me. So, that is negative religious coping and it can lead to existential crisis. And this gentleman called Pargament, he devised a brief religious coping model with scales called the R-COPE, brief R-COPE and positive and negative religious coping scales.

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#### Clinical Practice Guidelines for Quality Palliative Care

<http://www.nationalconsensusproject.org/guideline>

- Spiritual, religious and existential aspects of care are the **fifth** of these eight domains
- Recommend the regular assessment, **reassessment** and documentation of spiritual concerns, as well as interventions to address issues that have been identified.
- Use of standardized tools where possible to assess and identify religious or spiritual/existential background, preferences and beliefs of the patient and family.
- We are also tasked with being advocates for patients' religious and spiritual rituals that bring comfort, especially at the end of life
- The interdisciplinary palliative care team include persons with education and training in pastoral care, and who are skilled in the assessment of and response to common spiritual issues

So, there are so many scales which have been developed by various people. Now, the national consensus project published clinical practice guidelines for quality palliative care and spiritual, religious and existential aspects of care are the fifth of this eight domains.

So, there were eight domains in those and the fifth domain was addressing religious, spiritual and existential aspects of care. They recommend the regular assessment, reassessment and documentation of spiritual concerns as well as interventions to address issues that have been identified. Use of standardized tools were possible to assess and identify religious or spiritual or existential background, preferences and beliefs of the patient and family. Also, they were tasked with being advocates for patients religious and spiritual rituals that bring comfort especially at the end of life. And the interdisciplinary palliative care team included persons with education and training in religious care who are skilled in the assessment of and response to common spiritual issues.

So, religious, addressing religious, spiritual and existential concerns is one of the clinical practice guidelines for quality palliative care. So, you have to do it.

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## **Spiritual questions Inventory**

- Patient's perception of what is going on
- What gives meaning and purpose to life
- How, or whether belief and faith enter in
- Love: by whom do you feel loved-accepted?
- Forgiveness--need it? grant it to others?
- Prayer--for what do you pray?
- Quiet And meditation--what is off center?
- Worship--what restores you to center?

The spiritual questions inventory could be something like patient's perception of what is going on, does the patient know about his disease process, does the patient understand about his prognosis, what gives meaning and purpose to his life, how or when, how or whether belief and faith enter in, love, what is love, do you feel loved or accepted, forgiveness, what about forgiveness, prayer, what is the importance of prayer, for what do you pray. Presence of quiet and meditation, what is off center, worship, what restores you to center.

So, so many questions. So, these can be used in various ways depending on the cultural and the intelligence level of the patient.

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## Taking a spiritual history. . .

- S Spiritual Belief System
- P Personal Spirituality
- I Integration in a Spiritual Community
- R Ritualized Practices and Restrictions
- I Implications for Health Care
- T Terminal Events Planning (advance directives, DNR wishes, DPOA etc..)

So, many scales have been developed like this is the spirit scale, like the spiritual what is your spiritual belief system. What is your personal spirituality? What is your integration in a spiritual community? Do you have ritualized practices and restrictions? What are the implications for healthcare? And do you have any terminal event planning like advanced directives, etcetera?

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Table 3 HOPE spiritual assessment (21)

H

Sources of hope, strength, comfort, meaning, peace, love and connection

O

The role of organized religion for the patient

P

Personal spirituality and practice

E

Effects on medical care and end-of-life decisions

And then there is the HOPE scale for spiritual assessment. HOPE, where H stands for sources of hope strengths, O is for organized religion for the patient, P is for personal

spirituality and practice and E is for effects on medical care and end of life care decisions.

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“It is seldom a **medical man** has true religious views – there is too much pride of intellect”  
- George Eliot

And as I said before it is seldom a medical man has true religious views that is too much pride of the intellect, but then again we have seen that from a scientific domain also that the clinical guidelines for good clinical practice in palliative care, it says very categorically that addressing spiritual, religious and existential domains is very important and mandatory.

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### **The Potentially Significant Influence of Clinicians' Thinking about Spirituality**

- It can be rapidly institutionalized (directly in health care systems and in cooperation with government systems)
- It can quickly develop a tradition, establishing its own “canon” through the health care journal literature
- It can affect people at crucial times in their lives (during health care crises)
- It carries the authority of science and the integrity of medicine (and can be conveyed personally in the physician-patient relationship)
- It can be relatively independent of other traditional streams of thought about spirituality



Now, as clinicians, we can have a very important role to play about how to incorporate spirituality in clinical practice. It can be rapidly institutionalized, it can quickly develop into a tradition. It can affect people at crucial times in their lives. It carries the authority of science and the integrity of medicine and it can be relatively independent of other traditional streams of thought and spirituality.

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Now, these are the two most common views of the relationship of spirituality to religion.

One is where religion becomes an inherent part of spirituality where it is seen as a inherent part of spirituality and where and the second view where religion is seen related to spirituality, it overlaps into spirituality and spirituality overlaps into religion perhaps, but there is a slight distinction between them.

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## **KEY PROBLEMS** **Spirituality & Health Profession**

1. Ambiguity of Terms and Concepts
2. Working Across Cultural Contexts
3. Qualitative vs. Quantitative and Descriptive vs. Intervention
4. Measures: Trait vs. State
5. Size of Effect

Now, we will address certain key problems while addressing spirituality and the health profession.

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### **1. Ambiguity of Terms and Concepts**

*Spiritual/Religious terms and concepts are loosely defined and have various meanings within different theological and cultural traditions.*

The first problem is there is a ambiguity of terms and concepts. Spiritual or religious terms and concepts are loosely defined like what is spirituality? Spirituality can have so many definitions. So when you have multiple definitions for one particular thing that means that the concept is ambiguous, right? So they are loosely defined and have various meanings with different theological and cultural traditions.

So ambiguity of terms and concepts

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The second, now this is of course one our home care team providing comfort to the rural elderly.

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## 2. Working Across Cultural Contexts

*Because spirituality/religion is deeply rooted in cultural contexts, it is hard to standardize studies or generalize findings across the different contexts.*

The second problem is working across cultural context, because spirituality or religion is deeply rooted in cultural context, it is hard to standardize studies or generalize findings across different context, right. So, across different cultural context it is difficult to standardize things.

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So, again our home care team.

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### **3. Qualitative vs. Quantitative Descriptive vs. Interventional**

*Funding and publication favours  
quantitative-interventional studies,  
but qualitative-descriptive studies  
are still needed to lay a foundation  
for this young field of inquiry.*

The third problem is qualitative versus quantitative, descriptive versus interventional.

Now, qualitative studies are mostly, they are based on the phenomenological approach, that is the approach, the lived experiences, how I personally experience it, whereas quantitative studies would focus on numbers. Now funding and publication favors quantitative interventional studies, but qualitative descriptive studies are still needed to lay a foundation for this young field of inquiry.

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#### 4. Measures: Trait vs. State

*Most measures in the field capture spiritual traits and thus do not measure spiritual change.*



And fourth is the measures, that is trait versus state. Most measures in the field capture spiritual traits and thus do not measure spiritual change, because spiritual change does not happen immediately or spiritual changes can be very subtle. So if a person says no, now I feel better, but I feel better mentally, but I do not feel better spiritually, I do not feel better physically.

So this is a very confusing sort of thing which science does not take very well.

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## 5. Size of Effect

*The effect of spirituality on health, or of health on spirituality, may be significant but not dramatic (and hence hard to capture).*

And fifth is the size of effect. The effect of spirituality on health or of health on spirituality may be significant but it is not dramatic whereas if you see quantitative studies they focus on interventional are mostly interventional and they have they focus on p values, right and they are easy to capture whereas spirituality studies are difficult to or hard to capture because the effects are very subtle and sixth is the mechanism of cause and effect.

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## 6. Mechanism of Cause and Effect

*The way that spirituality affects health, or health affects spirituality, appears to be complex.*



The way that spirituality affects health or health affects spirituality appears to be complex, because there are so many different ways by which spirituality can affect health. Thank you.