HEAR MY VOICE:
Learning from the Spiritual Legacies of those Stretched by Serious Illness with Faith and Wisdom to Share

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OVERVIEW

• Introduction to the Hear My Voice Pilot study
  • Rationale
  • Methodology
• Quotes from the spiritual legacies of patients
• Results of the study
• Suggestions for further research and clinical application
• Questions and comments
Tell me, what is it you plan to do with your one wild and precious life?

Mary Oliver, “Summer Day”
HEAR MY VOICE: SPIRITUAL LEGACY PILOT STUDY FOR THOSE WITH ADVANCED DISEASES

Is it feasible for chaplains to develop a personal spiritual legacy document (SLD) with participants with advanced diseases?

Will such a process improve or maintain quality of life, spiritual coping, and spiritual well-being in those who participate?

What can we learn from participants about spirituality and coping?

DEFINITIONS

Spirituality is a search for and connection to what is life-giving, meaningful, inspiring, and instructive.

Spiritual Legacy is a summary of a person’s beliefs, values, and unique life-learned wisdom.
PARTICIPANTS

➢ Adults, 18 years or older, with a neurologic illness or an advanced disease.
➢ Ability to complete study procedures.
➢ Not a psychiatric inpatient or known to have an active intent to cause harm to self/others.
➢ One support person for each primary participant.

METHODOLOGY

➢ Begin after IRB approval.
➢ Recruit and consent participants.
➢ Administer questionnaires at baseline and following intervention.
➢ Provide interview by a board-certified chaplain using a semi-structured interview guide.
➢ Prepare draft of spiritual legacy document (SLD).
➢ Finalize SLD with patient, professionally print and give patient 25 copies.
QUESTIONNAIRES

➤ Functional assessment of chronic illness therapy-Spiritual Well-being Scale (FACIT-Sp-12) (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002).

➤ Quality of Life Linear Analogue Scale (Rummans, Clark, Sloan et al., 2006).

➤ Brief Religious Coping Scale (Pargament, Koenig, & Perez, 2000).

INTERVIEW GUIDE

• Developed by research team and reviewed by staff chaplains.

• Influenced by chaplains’ professional experience and the research of others:
  • FICA (CM Puchalski, MD)
  • Dignity Therapy (HM Chochinov, MD)
  • Religious Coping (KI Pargament, PhD)
INTERVIEW GUIDE
(Piderman, Radecki Breitkopf, Jenkins et al., 2015)

➢ Can you describe your spiritual background? Who was the first person who taught you about your faith? What is spirituality or religion like for you now?

➢ Do you have any regular spiritual or religious practices that have been meaningful to you over your life-time? What about now?

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INTERVIEW GUIDE
(Piderman, Radecki Breitkopf, Jenkins et al., 2015)

➢ What would you consider to be God’s call or your purpose in life? What satisfaction has it brought you? What stresses?

➢ What do you consider the best thing you’ve ever done? Are there other things you’re proud of? Are there ways your family or church or community are better because of you?

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INTERVIEW GUIDE
(Piderman, Radecki Breitkopf, Jenkins et al., 2015)

➢ Have you had periods in your life when you have faced questions about your beliefs or approach to life? Are there any things that nag at you or feel unresolved?

➢ Do you have spiritual guidance or wisdom that you’d like to share with your loved ones or reinforce?

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MICHAEL, 66 YRS, CATHOLIC, with BRAIN CANCER

Discovery (Michael)

• My spiritual background goes all the way back to the time I was born. I was raised as a Roman Catholic, and my family was always very religious.

• I listened to the example of the ones in front of me. From the time I was very young, my parents, my aunts and uncles, and my older siblings all taught me about God and our faith. It was a very rare Sunday that we missed Mass.
Discovery (Michael)

- My parents also taught me how to pray at home. We prayed at the table before we ate and at night. At the end of the day, they asked all of us to come and form a circle for the Rosary and a few other prayers, too.
- The Sisters who taught us at school were also very influential in my life. They helped us to apply our Catholic faith to the everyday life we led and to our interactions with all other people. They especially taught us about the beautiful earth God created.

Conservation (Michael)

- Music has always been an important way for me to pray. I’ve loved a lot of hymns, especially the psalms. I sang songs that helped me to express my faith and to know God better. Singing was different than praying with words.
- I love mornings. I’d get up and raise the shade. The sun would come in, and I’d start singing! It started because I prayed whatever we were practicing for choir or whatever we had sung at mass on Sunday. Those songs stayed with me for a week or so.
Call/Contribution (Michael)

• My first priority has always been the Lord. When I think over my life, I know I was called to be a child of God.

• When I paid the bills, I always wrote the first checks to the church and to the missions. We did it that way on purpose.

• I’ve always felt called to use the talents God gave me for others, in whatever opportunities came along.

• I also felt called to be a man of integrity. Integrity is a value I’d like to leave to my family.

Struggle and Response (Michael)

• I’ve had to stop singing now, because of my brain tumor. Singing out loud hurts my head, and I miss it a lot. But even today there’s often a song in my head.

• I have had some really tough things to deal with, including my son’s death and now this brain tumor. It is so hard to think about letting go of this beautiful world that God created and all the wonderful people I love in it.

• I believe in the Resurrection and in life after death. It helps us face the difficult things with trust and hope and peace. People are praying for us, and I count on them to keep it up!
Wisdom/Guidance (Michael)

• I’d like my family and others who love me to know that these two sayings have been my mottos:
  • Forgive one another.
  • Be a person of integrity.
• I’d also like to leave them with three more words,
  • “I love you.”
Discovery (Kristin)

➢ We grew up on a family farm. One of my favorite memories is getting on my little bike to catch up to Grandma who was taking off with the dogs and going on a walk.

➢ She always had a cross in the palm of her hand with a little beading to put around her thumb. She would always walk with it and I would always ask, “What are you doing, Grandma?”

➢ She would say, “I am praying. I am always praying on these walks.”

Discovery (Kristin)

➢ One day, I asked my dad, “Why don’t we go to church?”

➢ Dad said, “God is everywhere. He is here now. You don’t need to be in a church or go to a temple to be with Him. He is just always there when you need him.”
Conservation (Kristin)

➢ I consider myself to be an agnostic. For me, God is everywhere. In fact, I don’t necessarily consider him to be an individual, like an old man in the sky. I consider him to be in the wind and around everywhere, flowing with you and almost like a spirit.

➢ I feel like that is God reaching out to you. Like watching the barley and wheat blow and the grass blow, I just feel like the Spirit is there with you.

Conservation (Kristin)

➢ I don’t really pray. To me, it is more in my head. I think to myself, What do we got going on today, God? Are you going to help me out? We are going to get through this today. I got you on my side.

➢ I don’t really have a steady prayer before bed or anything, but it is there when if I am upset. Then, I might look to God more versus going to a friend. I might go, I need to be alone. I need to cry and be with God.
Call/Contribution (Kristin)

➢ I think the best thing I have done is just being a kind, gentle-hearted soul to others. Opening my heart to others when needed… “All you need is Love.”

➢ I saw a man chasing a girl. He was after her purse. I stopped to help her. I feel like when I come across those things in life, I need to stop because there are a lot of people who don’t stop and help because people are afraid. If you are afraid of everything, how are you gonna make it through life?

Challenge/Response (Kristin)

• This is something very serious that has happened to me, and I have definitely questioned, “Why me? What did I do to deserve this?”

• I have had those breakdowns and I have also come to an understanding that I believe God has chosen me to do this to inspire people because I have remained very strong, and I am constantly reminded every day by people how much of an inspiration I am …
Challenge/Response (Kristin)

- I believe God has challenged me many times in my life, and this is what has made me into the strong, independent woman I am today. This time, I believe He is trying to form me into a warrior.
- I believe I was given this battle so I can keep strong and show everyone around me strength and perseverance and that weakness is not an option.
- This is by far going to be the toughest battle of my life. I know I can handle it.

Wisdom/Guidance (Kristin)

➢ I love you.

➢ Remember my smile.
Discovery (Fahreen)

• I am Muslim. I was born a Muslim and have been Muslim all my life. As a small child, I watched my parents pray five times a day. I saw them fast during the month of Ramadan, and I joined them in fasting after I was 10. We also visited the Holy Mecca several times.

• Islamic studies and the Quran were both subjects at school, so we learned the basics since we were kids.
Conservation (Fahreen)

• Amna was my best friend. She was from a very religious family. I used to hear her reciting the Holy Quran with a very nice voice, and then we used to sit together with other friends, and she would tell us what her mother read for them from Islamic books. She had a very big impact on me, and I tried to imitate her.

• Although I looked and sounded faithful, I’d say my faith was nil.

Challenge/Response (Fahreen)

• After my illness, I changed. It “rang a bell.” The bell reminded me that each day is given to us because of God’s will, and His mercy and His grace fill it. The success of whatever we do, for whatever reason, is God’s will upon us.
Challenge/Response (Fahreen)

• Now my faith guides my views of looking at several things in life like my relationships, my work, my family, and my responsibilities towards these groups.

• I look to my faith to see whether I’m doing the right or wrong thing, and to help me decide whether this choice will make me feel happier and make God feel happier.

• I think my faith will help me with any of the obstacles that will be coming up in my life, too.

Call/Contribution (Fahreen)

• My purpose in life is to love and worship God the best way I can. I am blessed by being given a second chance to live. It has given me a clear and definitive path to walk through it and try to do the best I can to worship Him, to be better, and to put Him or see Him in all aspects of my life.

• I shall see Him when being a mother, a wife, and in those with whom I work. I shall see Him when being a human being dealing with other human beings.
Wisdom/Guidance (Fahreen)

• I would want all those I love to keep this quote close to their hearts: “Worship God as if you see Him, and, if you don’t see Him, remember that He sees you.”

• I would want us all to remember that God has said in the Holy Quran, “We certainly belong to Allah and to Him we are bound to return.”

RESULTS
Demographics (N = 130)

Age range: 18-102 years (55% > 60 years)
➢ 61% had cancer
➢ 62% female
➢ 43% Protestant; 30% Catholic; 25% Other; 2% Muslim; 1% Jewish
➢ 64% married; 17% single; 14% widowed
➢ 18% 4 year college degree; 37% graduate/prof degree
RESULTS

➢ **Questionnaires**
  ➢ Significant increases in QOL, EWB, SWB and spiritual coping
  ➢ Majority increased or maintained on all measures

➢ **Satisfaction Surveys**
  ➢ 100% would recommend the study to others
  ➢ 88% reported feelings of playing an important role in life
  ➢ 88% thought the SLD would benefit loved ones
RESULTS

• Themes from Framework Analysis
  • Relationship with God
  • Relationship with Others
  • Relationship with Self

AFFIRMATION FROM MICHAEL’S WIFE

Dear Donor,

Our family’s hearts are full of gratitude for your funding the research project “Hear My Voice.”

It is comforting to read and re-read my husband’s words of faith. My daughters have yet to finish reading the document. They need more time but have told me how thankful they are for the gift.

We are all grateful to the staff who helped my husband put his thoughts into words. God bless you and your work.
KRISTIN’S AFFIRMATION

• Good Morning, Kate. Kristin here! I just wanted to drop in and let you know I received my books yesterday, and I’m very excited to start handing them out! And of course, I wanted to thank you again for giving me the opportunity to participate in the study.

• I got to go swimming with the Dolphins but got sick due to swelling in my head from the radiation, but it has continued to go down. I’m on chemo now and have a lot of fatigue, but that’s so much better than being sick.

• Again, thank you so much for having me in the study! Hope you have a great day!

FAHREEN’S AFFIRMATION

• One of the best things I’ve done in life, honestly, is being right here in this room and speaking about the change that has happened in me. Now, I sense the change in my life. I feel the peacefulness that has been brought into my days. Probably, if someone reads or listens to what I’m saying, it might ring a bell somewhere. It might be a wakeup call for others.
SPIRITUAL RESEARCH

If we believe that spiritual processes are crucial and powerful,

we should lift them up, confidently and gratefully,

to the kind of scientific study that will permit them to be shared more widely.

Wm. Miller, 1990
STEP BY STEP FOR A CHAPLAIN RESEARCHER

• Time
• Talent
• Treasure
• Team
  • Variety of expertise
  • Passion
  • Openness to learn from one another
  • Integrity, humility, joy

Spiritual Legacy: The Treasure within Each Person

• Encourage reflection and sharing…
• Listen deeply…
• Preserve the treasure…
• Proclaim the treasure…