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ABSTRACT
Chaplains are charged with the essential task of reflecting on their experiences and developing their insights into formats that can be shared with others. This brief report summarizes the spiritual distress and coping of four participants in the Hear My Voice pilot study for patients with advanced diseases, and includes questions for reflection on spiritual care and further research. It emphasizes the importance of taking time to listen deeply to one’s experiences and the work of others to gain insight and perspective, contribute to the knowledge of others in writing, teaching, and research, and advance best practices in spiritual care.

KEYWORDS
Chaplaincy; coping; practice guidelines; spiritual distress; spiritual legacy

Background
When I was a child, I loved the sight of the majestic mountains that surrounded our city, and I loved hiking and skiing in them. They had an awesome quality that led me to an appreciation and gratitude for nature and the Creator. Amazing was the growing perspective I gained from their heights, as I looked at the city below. Somehow, new detail and connections emerged. When I descended, I always felt blessed by my experience and felt that I had been on holy ground.

As chaplains we know firsthand that spiritual care is full of blessed experiences – at the bedside, in waiting rooms, in hallways and cafeterias. Over and over again, chaplains are invited to holy mountains with patients, their loved ones and staff as they review their current circumstances and seek perspective in the context of their lives and beliefs. We are privileged to join them as they disclose profound suffering and distress, and as they seek and choose pathways that will help them find their way in the midst of their vulnerability. These encounters lead us to holy mountains of our own, where we reflect on our experiences, affirming and challenging our existing views and informing the care we provide.

One of the themes most apparent to me from my reflections over the years is the need for patients to be respected and heard in their spiritual distress and to make sense of it in a way that brings them direction and peace. Though it is not easy to enter into such difficult places with people, I have concluded that this is exactly where chaplains are called to be and where we can be most helpful.

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In 2011, I had the opportunity to translate my reflections into a mixed-method pilot study for patients with advanced illnesses. The study is called Hear My Voice (HMV) and its main objective is to provide an intervention that improves participants’ quality of life and spiritual well-being. The intervention gives participants an opportunity to review their lives, including times of spiritual struggle, during a semi-structured interview with a board certified chaplain, and to prepare a personal spiritual legacy as a keepsake for themselves or to share with others.

From July 2012 to January 2017, 98 participants were interviewed and 59 completed all aspects of the study. Previous publications provide the interview questions and describe the feasibility of the study and quantitative and qualitative results with early groups of patients (Piderman, Egginton, et al., 2017; Piderman, Radecki Breitkopf, et al., 2017; Piderman, Radecki Breitkopf, Jenkins, Euerle, et al., 2015; Piderman, Radecki Breitkopf, Jenkins, Lovejoy, et al., 2015; Sytsma et al., 2018). Subsequent manuscripts will involve analysis of the final data.

In the meantime, I invite the reader to join on me the holy mountains with four HMV participants (not included in previous manuscripts), and consider how their experience of spiritual distress and coping might inform future clinical work and research. Pseudonyms have been used and details that would clearly identify the patients have been changed.

Will
Will was a professional man in his mid-sixties with a child-born religious faith that had been nurtured by his parents. He had been diagnosed with metastatic cancer, and lived with intense pain and chronic fatigue. His symptoms led him to retire from his beloved profession, but he remained committed to his family and ministries in his church.

Will’s experience of spiritual distress included dealing with the congenital illness and ultimate death of his infant son decades previous. During that time, his pastor said to him, “God must have great confidence in you to allow something like this.” While Will wasn’t sure he agreed with his pastor’s words, they challenged him to revisit the biblical teaching that “God’s ways are higher than our ways.” Will’s scientific background led him to rely heavily on his intellect, but he had found logic and reason unsatisfactory at this tragic time. He concluded, “God operates through time and in ways that we won’t understand.” This perspective gave him peace.

Will’s cancer diagnosis confronted him once again with a devastating situation, defying explanation. He said, “That is clearly the most hard, the worst thing I have ever experienced.” At first, he turned to his intellect for insight, but shortly afterwards, “just quit” and renewed his trust in God. He said, “You either believe whole-heartedly or you don’t,” and he found that he did.

Steve
Steve was a retired man in his early 70s who had been living with cancer for five years. It had been kept at bay with various treatments, but was now progressing. He was housebound and no longer able to sit or even lie comfortably because of pain.

Steve described himself as an agnostic. He believed in a divine being but saw religion as “man-made,” and wanted nothing to do with it. He had worked in the mountains of
the Pacific Northwest where he had come to know and love the Coastal Redwoods. He described these trees in meticulous detail and said that he was always awed by their size and grandeur. He found that the Redwoods gave him a direct connection to the divine, “without man’s intervention and interpretation,” and felt that his spirituality flourished in their presence. He said that it was difficult to keep that spiritual connection alive when he moved away, and that it was even more difficult now that he was confined.

As a young soldier, Steve managed his reaction to the challenges he faced by incorporating his memories of the Redwoods into a process of visualization. This helped him to connect again to the divine being he had met there and find peace. Now, in the midst of pain and anxiety, he longed to rekindle that connection by going to the Redwoods. Since that was not possible, Steve again visualized himself deep in the forest. “If today is too bad, I can go to yesterday [in the Redwoods] … It is hard to do especially if something is coming up that I have no idea what is involved or what is going to happen, say medically, but that is when it is more necessary for me … because the anxiety doesn’t do you any good.” Steve retained a fascination with the way Redwoods reproduce, through sprouts that grow where a felled tree lands. This image gave him a comforting hope that somehow life continues after death.

**Sally**

Sally was a centenarian. Her eye sight and hearing were compromised, and she had difficulty walking, but she had learned to “make the best of it” and focused on helping others. Sally had been raised in a strict religious home and had maintained a close relationship with God. She was no longer able to get to church, but prayed privately each day. She found solace in imagining herself at worship and each night took the initiative to bless those she lived with.

Sally thought she was in relatively good health and expected to “go on a little further.” She felt blindsided by her cancer diagnosis and experienced acute distress. “I kept thinking, Oh my God, why did it have to happen now that I have this to do and that to do? I think I was in tears for two days.”

Then Sally went to the resource that had brought her comfort and guidance throughout her life – prayer - and she was able to enter into her well-developed acceptance of life as it is and her concern for others. “I just said a few prayers and got myself organized again. I don’t want to feel sorry for myself. I don’t want to be a burden. I just take life as it is … And if you need anything – well, let me know, I will do it.”

**Anna**

Anna was college age and had been ill with cancer for several years. She knew young people had cancer, like those in the Special Olympics, but never expected it to “mess with” her body. She described in detail the toll surgery, treatment and the cancer itself had taken on her. She longed to be a little girl again without “a care in the world.”

Anna thought her relationship with God was “pretty tight” but lost heart when her prayers seemed to be unanswered. “I read about all of these scriptures where Jesus just said, ‘Father, un-blind this man,’ and he is fine, so why can’t He just come down for...
five minutes and do that for me?” Despite her deep disappointment, she took the advice of others and tried to take one day at a time. She also said the Serenity Prayer often.

Anna struggled to find some benefit in her experience, “When you are puking for the 20th time from chemo, it is hard to remember that maybe part of this is your struggle so someday you can help other people.” Initially, she resisted comments from others that she was an “inspiration.” She didn’t always feel like it, but said, “I have worked on that over the years and I have realized - you know what, maybe you are [an inspiration] and that is the only purpose that I am here - to help other people.”

**Reflection and application**

Will, Steve, Sally, and Anna all experienced painful spiritual distress and shared it openly, but distress was not the end of the story for them. Rather, they all chose to seek ways to cope. Will found solace in his trust in God. Steve turned to memories of the Redwoods. Sally embraced acceptance through her prayer and resumed her previous practices of generosity. Anna sought serenity and meaning by voicing her hopes and accepting her reality. The older participants were able to use past experiences to help them address the present, while Anna, with much less life experience, leaned on the perspectives of others.

Reflecting on these HMV participants led me to develop more questions for reflection regarding my spiritual care:

What expressions of spiritual distress are hardest for me to listen to? What is my initial reaction to them? What is the basis of this reaction? What helps me respond from a more wholesome and integrated place?

Would it be helpful for me to ask those in my care directly about their spiritual distress? If so, when would be the best time? What specific words would be appropriate in the assessment of such a sensitive area?

What resources do patients (and others) have within themselves that help them cope with spiritual struggle? How do I best inquire about these without sidestepping the important ministry of being present in struggle? Could reminders of a patient’s personal resources be prepared and preserved in some way for his or her use during difficult times? Could such resources be identified in the medical record to guide chaplains and others who support a patient spiritually?

My reflections also led to research questions that could be explored with the data acquired from all participants in the HMV study. For example: Is there a difference between the spiritual distress and spiritual resources of those who are religiously affiliated and those who are not? Is there a difference in the expression of spiritual distress or the spiritual resources of older and younger patients? Does one group improve more than the other? Answers to the first question would help us understand the growing number of people who find spirituality outside of religion and also deepen our understanding of those who remain religiously affiliated. Answers to the second question would inform age specific competencies, while answers to the third would help us consider needed modifications to our intervention for specific groups.
Conclusion

In *Spiritual Care in Practice*, Mitchell states, “Reflective practice is an essential part of chaplaincy practice, not an optional extra” (Mitchell, 2015). Such reflection can benefit chaplains and their ministry directly, but also it can lead to the important work of writing, teaching and research. Our profession needs this work so that we and others can grow in the understanding of the spiritual issues people face during times of illness and develop best practices in addressing them (Fitchett, 2011). Beginning can seem daunting, and indeed, there can be a steep learning curve for those whose education and training is related to spiritual care. However, writing, teaching and research all begin with reflection – choosing to take time to listen deeply to our experiences and the work of others. Whether we go to the mountains, sit in a recliner or dwell in another place we find sacred, reflection is a necessary first step towards promoting excellence in the care we provide, honing the fruit of our reflection and sharing it more broadly. In this way, reflection can lead to reflection, and more!

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