

## EC PSYCHOLOGY AND PSYCHIATRY Conceptual Paper

## Religious Leaders are Encouraged to Seek Training to Support Memory-Loss Families

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I would like to explore with you some reflections about my clinical experiences with family-based traditions and rituals, and specifically, those that relate to religion. I will also discuss the issue of memory loss, memory-loss families, and its negative effects on these religious and spiritual traditions and rituals; as well as potential impacts of religion on these families.

While the adult seniors I work with in groups and have consulted with over the last three decades are more concerned about and afraid of memory loss than dying from heart disease or cancer, we seem unable to have good and meaningful family meetings about their concerns. Yes, the issues are important and people have varying views, but the anxiety carried over from previous conversations can be high, in that prior attempts have been very unsuccessful. The worry and stress that elders experience seem to be beyond the ability of many families to work through on their own.

Let us rethink traditions and rituals of religion and then assess how memory loss effects and hinders them in family life over time. Come and sit with me and join the conversation.

Tradition is a belief or series of beliefs passed down from generation to generation by a group or even a larger society with symbolic meaning and significance with its origins generally in the past. It thus may be passed from generation to generation without people necessarily being consciously aware of its roots.

Rituals are a sequence of events or activities performed in a sequestered place and according to pre-established principles; a prescribed ceremony or event that follows a set of rules and regulations bound by tradition or traditions.

While traditions are like strategies, rituals can be visualized as tactics to accomplish and propagate the traditions that are deemed valuable and important enough to be passed down.

All families have rituals. Many are inherited from the distant past, and some are newly created as a family lives and expands its history. There can be multiple experiences that turn into rituals, as they are deemed essential and worthy enough to be carried over time. They transcend experiences because they fit within the family's definition of traditions. They have become validated and become a part of the family's history. These are new, fresh, and honored as vital components of the family's need for continuity and their ongoing search for meaning and value in life.

The Shiva experience, known and practiced by Jews for centuries, is a fundamentally moving seven days of mourning after the loss of a loved one. It has deeply defined principles and activities intended to begin a surviving person's journey into grieving. It is further designed to be a place of being together, so the grieving individuals sense the physical presence of others who have come to be with them.

Having witnessed it before, I was initially horrified by the intensity of grief and loss encouraged in a person and family. Only after I experienced Shiva with the loss of my mother and then my father did I understand Shiva's value in forcing the terrible process of grieving to begin-with no possibility of denial or allowing mourning to be put off. Only after experiencing it did I appreciate the many acts of kindness and love showered on me by the community with gifts of food, and their appearing at the house for seven days to participate in devote prayers and lamentations as key components of this ritual. For it is in mourning and lamenting loss through a prescribed ritual that permits us to begin to open our hearts to more than a loss, but to love and allow ourselves to be loved again.

Much of my psychotherapy practice has been with people who have lost significant others and never fully grieved, and therefore their hearts are filled only with their pain and suffering. There seems to have been little guidance for them to help prepare for and follow through on necessary and appropriate grieving. As a result, there is no emotional space for anything else.

Easily recognized and available rituals for grieving and lamentations can prescribe and facilitate our path in such troubling times. I have emotionally taken some clients back in time to the loss of a loved one and facilitated a much deeper grieving experience with them. The intention was for them to embrace their losses fully and hopefully then be open to a fuller and more complete life. They chose the type of rituals, experiences, and even prayers for their own delayed grieving.

Having spent three decades working with individuals with serious and often fatal illnesses, and with them and their families, I am aware of the tradition-based rituals that can be strengthened or undermined by the challenges faced. I faced the same difficulties living with and through cancer as a younger man. Rituals of sensing a loss of control, embracing a new world of healthcare systems and providers, one's sense of impermanence, and even redefining one's relationship to God are open game.

While listening to the grieving and lamentations of sick people and their families, I began to suggest they set a place at the family table for them-metaphorically and in reality-for if the family does not sense a future with their sick person, it is near impossible for the ill person to create and sustain their place in the family. With all the pain and suffering that occurs, I appear to focus on such a seemingly insignificant ritual. And yet, it is a powerful message and belief that is genuinely passed to the sick person. "We believe in you and for us to have a future together".

People may survive, and people may die. If that person passes away, I ask the family to keep their place at the family table for one year, for all the holidays to occur as a symbol of life and mourning at the same time. During that difficult year, family, friends, and others who also care fill this place as often as possible. They celebrate life while honoring the loss. The place is removed at the end of the year. The place has also served as a reminder that the family has survived and hopefully gotten stronger in that lost place. It is a tradition of life and continuity.

It seems every culture and society has tradition-based rituals for its people to follow and engage in to further the traditions of value to them. Golden Gate Park and its Japanese Garden in San Francisco are wonderful examples of the ritual of seemingly attempting to create a vision of heaven on earth by gardening and landscaping according to specific principles and guidelines. However, the ritual for the Japanese Garden is cross-cultural. In their attempts to recreate the vision of heaven on earth, Chinese monks originated the creation of beautiful gardens. They were later incorporated into Japanese custom and ritual with Zen Buddhism by simplifying their labors to a degree of austerity.

I have talked with people who fashion their own positive and creative personal rituals. Here are some morning ritual topics:

- How they arrange their time in the morning
- How and when they select their clothes or how they do not do so
- How they arise in the morning
- Taking a few deep breaths as a short ritual of meditation
- Saying a prayer
- Inviting the Divine into their hearts
- How they make their bed or leave it as is
- What they love to cook for breakfast
- Where they sit at the table
- How they arrange their way to work
- How they work at home

I believe these are more than habit or time-saving or eliminating the confusion of choice. Our days are filled with examples of rituals, but most are accepted and followed without our conscious awareness of their underlying significance and value to us.

We tend to become fully aware of tradition-based rituals when we cannot follow them any longer. We have done them and sometimes created them as we lived our lives. In hindsight, they appear as small rituals that combine with other rituals to create a more anticipated pathway to our lives. It is in the breakdown of them that we feel less secure, less aware of options, and less sure of the future. Appreciation often comes later when they are no longer available to us.

Losing health, a partner, even a vision of the future will break our dependency on traditions carried into fruition by rituals. What if memory loss occurs, and it often does, in varying degree and intensity? My experience is that such a loss affects people in their past, their present, and their future.

Memory loss affects the past because it deprives people of who they were and where they came from. It takes away their lineage and linkages to those of their family that came before them. They become an orphan within their own family.

It affects their present because it deprives them of the solidarity that connects one experience to another. It cannot fill the gaps all people need to make sense out of their experiences of the "now".

Failing memory affects the future in that it deprives individuals of the wisdom and knowledge gained from their experiences in life and is not available to help them plan for and anticipate their future. The future easily becomes confusing, unclear, and even frightening in that there are no signposts of wisdom already learned to guide them forward.

What about their families? They describe feeling worried, anxious, and fearful of the future. They describe feeling in limbo and ambivalent about what to do or how to do it. These memory-loss families have unique needs.

Memory-loss family is defined as a family unit, which includes one or more people who are experiencing mild to severe cognitive changes and impairment, whether due to advancing age or illness. Mild forms include increasing forgetfulness, while a more severe condition may consist of dementia, such as that found in people with Alzheimer's disease. Dementia can affect memory, language, perception, decision-making, insight, reasoning and other brain and body functions.

The family system could be as small as two people (such as a married couple), or it could extend to the immediate family including children, or extended family that are involved in the well-being and care of the individual experiencing cognitive impairment. "Family" can also include (informal) non-family members who provide care and assistance (often at a distance) with no remuneration. Women generally provide both formal and informal family assistance, most of who have their own families and other responsibilities.

The concept of memory-loss family acknowledges that the effects are not limited to only the person with the impairment; it concerns other family members as well. Relationships, responsibilities and roles in the memory-loss family often shift and change when a serious condition such as Alzheimer's disease or a stroke changes the intellectual and emotional functioning of a family member. Profound feelings of grief, loss and hopelessness can overwhelm the family, if not dealt with in a caring and educated manner.

Memory-loss families tend to fit into one of three major categories as it relates to religion, religious leaders, and religious practices.

- 1. The family's approach towards religion strengthens as they attempt to cope. Such as "It is God's will that this is happening and we will accept it. God gives us what we can handle and we will. There is a master plan, and God will help us. God is the driving force that will get us through this problem". These families derive comfort and direction from religion to help them cope.
- 2. The family rejects religion entirely for comfort or direction. Such as "God doesn't care about the pain He inflicts on us. God cannot help us. We didn't deserve this. Where is God when we need Him? He has deserted us".
- 3. The family takes a wait and see attitude. "We will await what happens and why. There must be a good ending somewhere with His guidance. We know God loves us and hopefully, He will guide us".

Acknowledging the failing memory of a family member is painful and often impossible to accept. Denial and rationalization are significant defenses against such a reality. For example, "It is not happening," (denial) "and if so, we know how to handle it" (rationalization).

For some memory-loss families religion, religious practices, and religious leaders seem to offer little comfort, guidance, and hope. The road is long, and the transformative work to effect change is difficult. I believe that if religion and its practices are to offer guidance, comfort, and direction to memory-loss families, there must be a deeply emotional and psychologically intense connection between families and their religious leaders.

To create and enhance this relationship, religious leaders should have training, supervision, and expertise in a multitude of psychological and psychosocial skills: the dynamics of grief counseling, family systems, enhanced self-awareness (being in the moment), reflection, and psychological depth (mindfulness). Otherwise, religion and its practices will have little positive effect on the challenges that memory-loss families face.

On the one hand, religious leaders have the insight that they are the conduit between memory-loss families and the spiritual dynamics of religion, in that they accept their fundamental importance in this family-oriented work. On the other hand, they may not perceive themselves as needing specialty training and supervision when they believe they are fully competent to fulfill all their tasks to their congregation and religious community. It requires a great deal of insight and professional integrity to seek what they have never perceived as missing in their years of education and practice. My concern is that they will also utilize denial; denial of their inability to be helpful due to lack of training and supervision.

Mary described herself as a religious person, but as her family became a memory-loss family, she lost her faith and belief in her religion, its rituals, and traditions as it had less and less meaning to her. Mary had cared for her husband for a year as he declined into dementia. After struggling with painful ambivalence and the wishes of her three adult children, she placed Bill into a memory care unit at a local nursing home.

She finally stopped attending services but was called one day by her religious leader who told her he heard she had placed Bill and could he talk to her. That began a series of conversations between them that Mary described as focusing on her grief and lamentations. She spent hours crying and weeping, and as she did so, she heard: "Let it out, identify it, recognize it as you, and then express it. There can be no coping with your losses until you do". Mary finally found the permission she needed to explore all her feelings, her fears, her loneliness, her isolation, her guilt, and her anger.

Mary told me she learned about the components of grief she was experiencing, the appropriateness of her feelings, and the permission and encouragement to let them be expressed. Her faith in religion, its rituals and traditions were tested in her mind, but she returned to it with the skillful guidance of one religious leader trained and skilled in the process. There was wisdom to be used, guidance and direction, the beginning of some peace of mind, and even some resolution of her ambivalence. The road to her transformation is long and challenging, but it is there to be found, and she has begun the journey.

Is Mary's case unusual? I think not. It speaks to us about how religion and its practices can provide guidance, strength and wisdom to memory-loss families with the direction and support of an empathic trained leader of the religious community. I have disguised Mary's religion because I believe that all religions require the training of their leaders to do this work necessary for their families who are affected by dementia.

It will be easier to find the experts to do the teaching, training, and supervision. There are qualified teachers to do this if religious leaders will accept the need for it on behalf of the memory-loss families they serve.

Yes, some leaders are trained in their educational programs, some who intuitively sense the skills needed, or some who have learned them through careful self-exploration. These are blessed people and serve the cause. For so many others, skills and knowledge must be

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gained and processed with training and supervision, so they too can serve the needs of their community. The qualities needed by leaders to seek the training include empathy, understanding, and the character to do so. These essential personality traits will carry them to explore and find the training necessary to help these troubled families.

For our memory-loss families, it is best to encourage them to find help from a geriatric specialist or a geriatric center that offers holistic assessment, evaluation, and treatment.

At the same time, seeking vital support from trained and skilled religious leaders may help them turn the corner (they may ask about your training and experience). Provide them with information on the benefits of joining a support group, and help them find one. Stress to them it is essential they remain active and seek help for it is a sign of emotional strength—not one of weakness and uncertainty. They may be coming to the realization, sadly, that memory loss in a loved one only takes away and gives nothing in return.

Always be proactive with your memory-loss family and do not give up. By not giving up, families begin to create new tradition-based rituals to conform to their new reality. Careful guidance by a mental health mentor or guide, in tandem with religious leaders, can facilitate the development of new experiences, family coping strategies, and eventually new tradition-based rituals to replace the expendable ones. Together, we can help a family successfully navigate through their new and uncertain future.

We have talked about families that carry the burdens of chronic illness such as memory loss. I believe that other conflicting issues also cause disconnect between families and religious leaders—which leads to a lack of empathy and support from religion that is so desperately needed. If so, then the same needs for additional education exist. If it is done right, religion and its powerful rituals and traditions will be available to memory-loss families through conversations with their religious leaders.

Memory-loss families and other families often struggle with profound loss. Conversations about the grieving process between families and their religious leaders must move from the traditional cognitive, and intellectual level to a more profound emotional and almost soulful level. This is where real learning, positive change and growth occur.

The need for research exists, and I hope this paper encourages a focus on raising awareness, concern, and action.

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