Keeping Hope and the Spirit Alive in Sharing the Care

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Goal
Examine how religious/spiritual concerns and belief systems influence how carers provide care.
Goal
Explore how a “spiritual” perspective can be integrated into work with care partners.
Some Assumptions

- All families are unique systems.
- Family members and family systems can change.
- Families have strengths as well as concerns.
More Assumptions

- Persons may be at different places along the family developmental cycle.
- What is effective for one generation may not work for another.
- Carers can build on resiliency and reciprocity.
More Assumptions

- Each family has unique religious and or spiritual perspectives.
- Concerns around meaning and purpose loom large.
- All in the family need to maintain hope.
Each family develops unique imperatives about who should care and how care should be provided within its own system.
Perspectives on Caring

- Derive from societal, religious and cultural values.
- Influence roles played by various family members.
- Rules about caring are derived from spiritual/religious precepts.
Issues of spiritual/religious significance for families

- Family definitions can be based on religious principles.
- Loss and grief loom large.
- Independence/dependence/interdependence questions have spiritual underpinnings.
Religious/Spiritual Issues for Families

- Beliefs about “respecting elders” and “honoring parents” derive from religious teaching.
- Carers feel guilt about what they “ought” to do based on religious/spiritual beliefs.
Spiritual Themes in Caring

- Independency and reciprocity
- Lessons of what the “frail” teach the “strong”
- Coping with loss and grief
Spiritual Themes

- “Personhood” of care partners
- Obligation and entitlement between generations
- Self-care dilemmas
- Making sense of suffering
- Hope
A CareSharing Approach

- Person receiving care +
- Person giving care =
- CARE PARTNERS
CareSharing

• Is key to person-centered provision of assistance
• Includes the person giving and the person giving care as care partners.
• Builds on strengths
CareSharing

- Is based in the resiliency of the family unit
- Is not negated by physical or mental changes
- Affirms worth, respect and dignity of all
Hope is a crucial part of CareSharing.
Attributes of Hope

- Hope is a transcendent process.
- Hope is a rational thought process.
- Hope is a relational process.
- Hope is a spiritual process.

Farran et. al. (1995)
Hope as a Rational Thought Process

- **G** Goals
- **R** Resources
- **A** Action
- **C** Control
- **T** Time

Farran et. al. (1995)
“Hope Changes”
Keeping Hope Alive

- Hope is found in little and big things.
- Be mindful that hope must be reasonable and realistic.
- Remember "cor," the Latin root for heart, is the center of encourage and courage!
Keeping Hope Alive

- Remind carers of what cared for PERSON still CAN do.
- Give permission for carers to practice self-care.
- Walk “side by side” and “shoulder to shoulder” with care partners.
“Hope is like a road in the country; there was never a road, but when many people walk on it, the road comes into existence.”

Lin Yutang
Keeping Hope Alive

● Help find “bridges” to hope.
● Assist with finding things to look forward to.
● Encourage care partners to reach out.
● Remind carers they cannot be all things to all people.
“Hope is not about believing that we can change things. Hope is about believing what we do makes a difference.”

Havel
Understanding Family Dynamics Assists Service Providers, Religious/Spiritual Communities, and Care Partners to Keep Hope and Heart and the Spirit Alive for All Involved.
Family Dynamics

- Roles
- Rules
- Secrets
- Responsibilities
Maintaining the role of “family member” for the person cared for is KEY.
Secrets

- All families have them; some have been hidden for years.
- Old secrets may not be today’s secrets.
- Shame exists around secrets.
- Needs for forgiveness and healing are often present.
Responsibilities

- Families constantly balance responsibilities.
- Each family works out its own equilibrium.
- Conflicts can exist between work and home.
Responsibilities

- Issues come up between generations and belief systems can interfere.
- Competing responsibilities can overwhelm persons.
- There are benefits in assisting families to evaluate and make choices.
Family Feelings

- Exist for both care partners.
- Need to be acknowledged and named. Naming decreases negative power.
- Are not “good” or “bad.” They are.
- Sharing with others makes them more bearable.
Family Feelings

- Sadness
- Fear
- Anger
- Guilt
Family Feelings

- Helplessness
- Hopelessness
- Powerlessness
- Ambivalence
It is Also Possible to Share

- Laughter
- Love
- Joy
- The “spiritual”
Assessment of Family Relationships

- What long term positive interactions exist for the family?
- Is this a family history of conflicted relationships?
- What are the family strengths?
Assessment of Family Relationships

- What has worked in the past for this family that could be used now?
- What new skills could they learn?
- What is the best way to offer assistance?
Ethical Dilemmas For the Family

- Revolve around “quality of life”
- What to tell...who to tell of the diagnosis and functional concerns
“Quality of life” has many meanings. Each person has a unique definition. Know how each care partner perceives this.
More Ethical Dilemmas

- Safety vs. autonomy
- Driving
- Decision making challenges
- Bounded choices
Goals for Helping Families Cope:

- Change from a “crisis mentality” to a “comforting presence.”
- Small steps can move from stigma and stagnation to “well-being.”
How Religious/Spiritual Themes Can be Integrated in Practice to Keep Hope Alive
Putting Themes in Practice

- Assess how the “spiritual” is understood by families. Build on their definitions.
- Utilize spiritual “strengths” and “inner resources.”
Themes Into Practice

- Affirm a sense of resiliency.
- Explore beliefs about what is owed between generations.
- Be present to both care partners.
- Emphasize the “personhood of all.”
Themes into Practice

- Listen to stories.
- Explore the meaning of suffering.
- Work on unfinished business.
- Consider sadness, loss and grief.
Themes into Practice

- Reframe self care questions.
- Discuss bounded choices.
- Maintain hope.
- Use creative arts.
- Remember seed planting.
Integrating the Spiritual Into Work With Families

- Utilize the gifts of all ages to keep the family functioning.
- Assist in negotiating barriers to service provision.
- Know how beliefs affect choices.
Integrating the Spiritual

- Model effective communication skills.
- Teach limit setting.
- Stress contingency planning.
- Build on “community” to assist families.
Integrating the Spiritual

- Make intentional use of spiritual support persons when appropriate.
- Understand how precepts and beliefs may affect family’s end of life decision making.
Spiritual/Religious Community as Support

- Educate faith communities in ways to best offer support to care partners.
- Carers who have been “givers” can learn to be receivers by examining beliefs about “independence”.
Spiritual/Religious Community As Support

- Spiritual communities and service agencies can work together to offer assistance to care partners.
- Remember all have a common goal of assisting care partners.
Spiritual/Religious Community As Support

- May need assistance in overcoming physical and emotional barriers to support care partners
- Can offer respite care, support group space, and friendly visiting
Spiritual/Religious Community As Support

- Can offer retreats for care partners
- May adapt specific rituals or create new ones to deal with caregiving transitions
- May remind carers of to share the “spiritual”
Spiritual Leaders As Resource

- Clergy/other spiritual leaders can be resources.
- They need help with communication with families.
- Providers and these leaders can learn respectful referral skills.
“Hope is an act of collaboration. It cannot be achieved alone. We offer grains or fragments of hope to one another so that everyone’s sense of possibility can grow. In this way we can do together what might seem impossible alone. “

Kathleen Fischer

Resources
