The link between spirituality and well-being in people with dementia

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Definition of Spirituality

- A transcendent meaning about life
- Can be expressed through religion, nature, energy, belief in all good, importance of family and community
- The essence of personhood expresses individual uniqueness
- Personal beliefs and values profoundly effect how a person copes with illness.
Creativity linked to Spirituality

• Creativity is associated with meaning and purpose and enhances spirituality (Kerka, 1999)

• Creativity in later life optimizes a person’s functioning in the face of growing constraints of old age (Nakamura & Czikszentmihalyi, 2003)
Spiritual dimension

• To achieve this spiritual dimension, there has to be a meeting of ...
  The carer’s spirituality
  ... and ... 
  The person with dementia’s spirituality.

• It is our spirituality which reaches out and connects in the most meaningful way.
Spiritualities as Self Identity

• Sets of beliefs, stories and practices that respond to a basic human desire to find meaning and purpose in an integrated way
  (Shea 2004)

• A constructed sense of self is dependent on the actions and interactions that a person maintains in a larger social world
  (Daaleman, 2004)
Life stories and reminiscence

“Reminiscing and expressing ourselves through creative activities can help us to experience the reality of interconnectedness and to string together, into a coherent form, the pebbles, pearls and jagged rocks of our own unique life experiences.”

(Sylvia May, Diversional Therapist, 2005)
Research: Choir therapy reduces depression in people with dementia

- A randomized controlled trial
- 41 participants with average Mini Mental Scores of 13.6
- Age range 74 – 93 years, living in hostel care
- 15 psychosocial interventions of choir and reminiscence over 7.5 weeks.
Results indicated that:

- People with dementia experience life through their emotions and have the capacity for a rich inner life.

- People with dementia can express their personhood through creativity and spirituality.

- Choir singing and reminiscence decrease depression in people with dementia.
Results of Research: Depression

Cornell scale of depression in dementia
Results of Research: Interventions

Levels of responsiveness -- communication

[Graph showing communication levels for Choir and Reminiscence over different session numbers.]
Results of Research: Interventions

Levels of responsiveness -- feelings
Results of Research: Interventions

Levels of responsiveness -- mood

![Graph showing mood changes over sessions for Choir and Reminiscence interventions](image-url)
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<td>Life scheme</td>
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Spirituality Index of Well-Being

Pre-intervention results

1 = Minor issue
2 = Medium issue
3 = Big issue
Spirituality Index of Well-Being

Pre Self Efficacy themes

• Helplessness
  - Loneliness/Yearning:
    "I’d rather be in my own place"
  - Helping Self:
    "Living takes a lot of control"
  - Self Identity:
    Loss of “normal self”
  - Limitations imposed by dementia
Pre Self Efficacy themes

- Incompleteness
  - Hopelessness
    - “It’s not important because I only get upset because I’m not well enough”
  - Helping Self:
    - “I feel myself I’m useful”
  - Process of doing versus finishing tasks:
    - “Doesn’t matter to do things rather than finish them”

Spirituality Index of Well-Being
Pre Self Efficacy themes

• Overwhelm with Problems
  ➢ Financial: “My wife/daughter takes all the money”
  ➢ Hopelessness: “There’s someone who rules over you”
  ➢ Personal Insight: “I’m shrinking”
  ➢ Shadowing: “I follow her”
  ➢ Resignation: “Not a great deal I can do about it”
Pre Life Scheme themes

- Purposelessness
  - Losses: husband/wife/daughter
  - Being proactive
  - Doing good deeds and usefulness
  - Being creative: “Can’t sing anymore”
  - Don’t know
  - Resignation: “Everything’s finished”
Spirituality Index of Well-Being

Pre Life Scheme themes

- Meaninglessness
  - “Don’t know any”
  - Family of origin as meaning
  - Broken relationships
- Usefulness
- Lack of activity
- To reproduce gives meaning
Pre Life Scheme themes

• Emptiness
  
  - “It’s there all the time. Got to accept it”
  - “Empty because I used to be a singer”
  - “I worry about living here”
  - “My brain’s not working too good”
  - Angry about abusive marriage.
  - Lack of privacy in hostel living removes self identity and gives emptiness.
Spirituality Index of Well-Being

Learning new information
Spirituality Index of Well-Being

Expressing normal self
Spirituality Index of Well-Being

Self efficacy
Spirituality Index of Well-Being

Expressing humour
Spirituality Index of Well-Being

Post-intervention results

1 = Minor issue
2 = Medium issue
3 = Big issue
Spirituality Index of Well-Being

Post Self Efficacy themes

• Helplessness

• Choices 15/24 felt more empowered to make own choices

• “Choir makes you feel like you were still in the world”

• Helpful to others and being active

• “What’s the good of being wishy-washy?”

• “I try to help myself as much as possible”
Spirituality Index of Well-Being

Post Self Efficacy themes

• Incompleteness

  ➢ “It’s important to finish what I start”

  ➢ Helpless/self identity: “Embarrassing to have a shower with someone watching me because I’m Welsh”

  ➢ “I don’t like loose ends”

  ➢ “Just go with the flow”

  ➢ “I like to see everything done and then go out”
Spirituality Index of Well-Being

Post Self Efficacy themes

• Overwhelm with Problems – 12/24 said they had no problems or overwhelm.
  ➢ Loneliness – miss family, life before dementia
  ➢ Try to help self as much as possible
  ➢ “Singing overcomes negative feelings”
Spirituality Index of Well-Being

Post Life Scheme themes

• Purposelessness
  - Originality: “Got have your own purpose and own reason for doing it”
  - Family gives purpose
  - Activity gives purpose: “I like to pick up your ornaments after our talking group”
  - Loss of career expectations
  - “Not good enough”
Spirituality Index of Well-Being

Post Life Scheme themes

• Meaninglessness
  - Name, culture and country of origin gives meaning and self identity
  - Being “me-myself” gives self identity
  - Reincarnation: “I’m coming back as a singer”
  - Helpfulness and politeness to others gives meaning
Spirituality Index of Well-Being

Post Life Scheme themes

- Emptiness
  - Sadness/ Distancing: “I turn off so it doesn’t hurt”
  - Regrets about not having had a good education
  - Stress overload (PTSD from war trauma)
  - Loneliness: Wants to re-marry so won’t be lonely
  - Empty at night
Spirituality Index of Well-Being

Post Life Scheme themes

- Emptiness
  - Helpfulness helps emptiness
  - Being active helps emptiness
  - Grief and loss – misses partner/family
  - “I don’t wish I was dead anymore”

(choir member)
Spiritual care and person-centred care

• A holistic approach to physical and mental health issues

• Requires listening to the individual and maintaining their rights

• An awareness of the effects of care practices on personhood

• Requires understanding of one’s own personhood and spiritual needs first.

(McDonald, 2008)
Conclusion

“The contributions we make to spiritual aspects of care and the spiritual nourishment we receive in return, occur both in the course of structured programs, (during interactions) and at spontaneous moments when the time is ripe and we must seize it.”

(Sylvia May, Diversional Therapist, 2005)
Conclusion

“God made people because he loves stories.”

(Rabbi Harold Kushner, 1981)

We all have our stories that make us unique and special.

Psychosocial activities can reach into the creative centre of the spirit where we live and have our beings.
Follow-up

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