The question of meaning in life: Insights from caregivers and persons with memory loss

Bomin Shim, PhD, RN School of Health Sciences



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"He who has a Why to live for can bear almost any How" - Nietzsche

Victor Frankl

• Finding meaning: A critical aspect of growth or transcendence

• Finding meaning in:

- Love, a relationship
- Creating a work or deed
- Or even in suffering





Finding Meaning in Caring for a Spouse with Dementia



Study Sample quote

 "Not [to] overlook the negative aspect but all you hear is caregiver stress and this and that. If that's all you hear, that's what you'll expect. But there are humorous times. There are positive things, and an opportunity to give back. So people should know that." Research questions

- What meaning do spousal caregivers of persons with dementia find in caregiving?
- How are they able to find meaning?
- How has that meaning changed their caregiving experience?



Research Questions

What meaning do spousal caregivers of individuals with dementia find in caregiving?

How are they able to find meaning?

How has that meaning changed their caregiving experience?



Results (RQ1): Meaning in caregiving

Meaning from spouse

- Keeping spouse at home
- Ongoing commitment to marriage vows
- Men: Returning the love they/family received

Meaning from caregiving

• Growth in caring for another



Sample Quote

"It's a growing experience, a changing experience, [one that] makes you really care for somebody in a lot of ways you might not if you were both on your own tracks. You learn to try to understand what, where they're coming from, and that's very broadening really."



Deciding to Care

Believed their decision was a choice not an obligation

Quote: "First it was a question of do I want to do it or not. I solved that one. So that gave me the meaning. Second one is: Okay, I'm going to be a good husband and not [just] a caregiver."



Accepting the Situation

Initial step towards adopting positive attitude

Quote: "But basically it has shifted from fighting a disease to accepting a disease [...] The sooner you accept that, the easier it is to do the rest."



Choosing a Positive Attitude

Caregivers realized they have a choice of attitude

Quote: "I could be very bitter, but I'm not going to be. I have a choice. What is my attitude going to be? What is my motivation for the day?"



Focusing on the Blessings

Caregivers saw beyond the losses, focused on blessings and humor, took joy in the moment

Quote: "I learned that life does go on and you don't even think about it after a while because you find good things [...] You can appreciate the more simple things of life [...] It's like stopping to smell the roses."



Actively Seeking Resources

Support groups, books, respite, research studies, family and friends

Quote: "First of all joining a support group is very, very helpful. I made friends with one couple, we [...] but you don't worry about it because these people know what you are going through."



Results (RQ2): How? (cont.)

Other common caregiver characteristics

Altruistic values

Discipline and determination to live by one's values

- Faith
- Love
- Social support
- **Past life challenges**



Results (RQ3): Changes from finding meaning?

More peaceful

Growth, broadening of the relationship with spouse in life views and perceptions of the existential meaning of life

The caregiving experience was richer



Sample Quote

"If you took a snapshot of our marriage at different times, sometimes you'd see flowers blooming and things were good. And other times you'd see weeds. Sometimes things that are weeds can end up being flowers. sometimes you let stuff lay in the ground for a while, before it blossoms... it's a love that has grown, that I may not have had earlier."

Publication: Shim, B., Barroso, J., Gilliss, C. L., & Davis, L. L. (2013). Spousal Caregivers Finding Meaning in Dementia Caregiving. *Applied Nursing Research, 26* (3), 121-126.

Conclusions

Acceptance is important to positive caregiving experiences

Finding meaning for caregivers perceiving positive caregiving experiences seems to be an evolving enlightment rather than an active search



Current study: Living with dementia – Spirituality and meaning of life in people with memory loss

"We (our personhood) are more than our abilities, function, or productivity in life"

Research questions:

- What is the experience of living with dementia as a spiritual being?
- How do we understand maintaining a meaningful "lifeworld" while managing life with the losses and gains of dementia?



Emerging themes

Any thoughts to share? Questions?

Thank you! shimb@spu.edu

