

End-of-Life Care and Meaning: An Occupational Therapy Perspective

(Session #74)

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Objectives

1. Apply a theoretical framework for addressing meaning in life (MIL) in the context of occupational therapy
2. Identify interventions used by occupational therapists to promote MIL at the end of life both nationally and internationally
3. Use occupational therapy assessments to support a client's sense of MIL at the end of life
4. Identify and address barriers that occupational therapists experience in service delivery in end-of-life (EOL) care

Areas of Meaning Addressed by OT in EOL care:

1. "Participation in meaningful life occupations" (AOTA, 2011).
2. "Continuing to search for meaning and purpose in life and one's relationship to a higher being, also referred to as spirituality" (AOTA, 2011)

Areas of Meaning Addressed by OT in EOL care:

1. Occupational Meaning
2. Life Meaning

How do occupational therapists promote MIL in clients at the end of life?

Methods

- Online survey of occupational therapists
- Closed- and open- ended questions
- Investigated:
 - Interventions and assessments
 - Utilization of life review
 - Barriers

Received 82 Responses





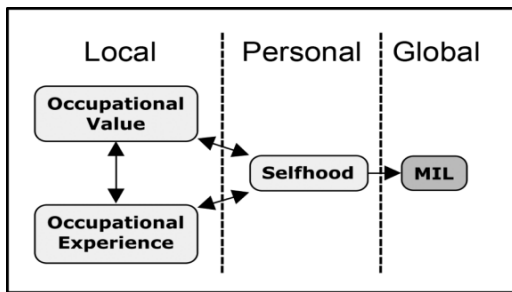
**How to
Define
Meaning?**

How do OTs
define “meaning?”

The Need for an OT Framework on Meaning

- Central mechanism (CAOT, 2002; Crabtree, 1998; Fisher, 1998; Hasselkus, 2002; Nelson, 1994; Persson, Erlandsson, Eklund, & Iwarsson, 2001; Trombly, 1995)
- Confusion of terms (Hammel, 2004)

Meaning in Occupation and Life (MOL) Framework



Personal Meaning - Selfhood

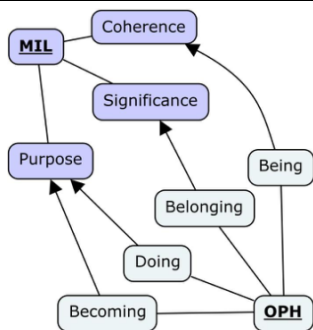
- Translational role (Christiansen, 1999)
- How is this relevant to me?

Global Meaning - MIL (Martela & Steger, 2016)

Coherence	Comprehend life circumstances
Significance	Self-evaluation of one's life
Purpose	Lifelong goal

Local Meaning - Occupational Perspective of Health (OPH) (Hammel, 2004; Hitch, Pepin, & Stagnitti, 2014)

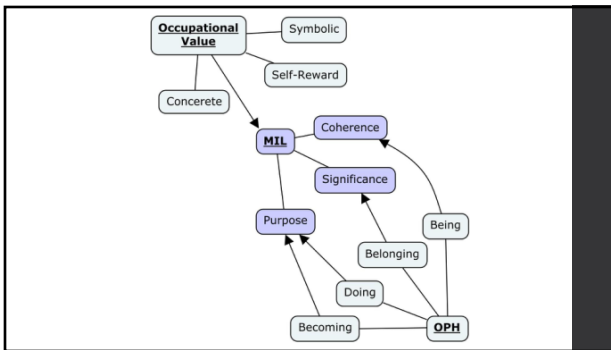
Doing	Goal-directed activity
Being	Self-evaluation, expression of identity, and stillness
Becoming	Aspiring towards progress and maintenance
Belonging	Giving and receiving within groups



Local Meaning – Value and Meaning in Occupations

(ValMO) model (Persson, Erlandsson, Eklund, & Iwarsson, 2001)

Concrete	Tangible, functional outcomes such as a product or skill
Self-Reward	Enjoyment; flow experience or physiological pleasure
Symbolic	Personally, culturally, or universally symbolic functions



Assessment (King, 2004)

Build an occupational profile through some of the following:

- Home environment
- Story
- Concerns and aspirations
- Roles, performance patterns, and “flow” experiences
- Relative importance of coherence, significance, and purpose?
 - What do they feel contributes to these areas? What are potential barriers?
- Establish realistic goals
- Assess facilitators and barriers

Case Study: Mary

Mary is a 70-year old woman admitted to the oncology unit at your hospital due to a malignant tumor. She is undergoing chemotherapy and is very deconditioned. She is able to sit up at the edge of the bed for basic grooming tasks but moves very slowly and has significant balance deficits. She is not ambulating but can slowly transfer to a wheelchair with moderate assistance using a front-wheeled walker.

Case Study: Mary - MIL Pre-Intervention

Coherence	Not religious. Feels resigned. Disease is a "natural process."
Significance	Loss of spouse and mothering roles prior to onset. Enjoys knitting group. Does not believe her passing will be significant.
Purpose	Loss of role as a housekeeper post-admit.

Case Study: Mary - ValMO & Selfhood

Concrete	Knitting = Desired product
Self-Reward	Knitting = Soothing
Symbolic	Knitting = Social opportunities
Selfhood	Loss of sense of self

Case Study: Mary - Intervention & OPH

Doing	Clear goal. Improved mental clarity.
Being	Return to roles and expression of identity.
Becoming	Motivated to fulfill her role in the project.
Belonging	Fostered deeper relationships in knitting group.

Case Study: Mary - MIL Post-Intervention

Coherence	Better connection to life story.
Significance	Improved self-appraisal and greater connection to social group and other patients.
Purpose	Return to nurturing role. Renewed sense of purpose.

Occupational Therapists in EOL Care:

- (i) are integral to quality care for people living with a life-threatening illness;
- (ii) have the ability to improve quality of life by assisting in pain and symptom control; and,
- (iii) can keep clients engaged in meaningful occupations.

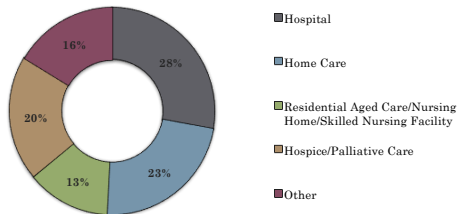
(Hammill, Bye, & Cook, 2014, p. 585)

Meaningful Occupations

Empirical studies have researched and found the following occupations to be meaningful at the end of life.

- Preparation for death, continuing life, and waiting (Jacques & Hasselkus, 2004)
- Continuation of life (Lala & Kinsella, 2011)
- Sense of control (Kealey & McIntyre, 2005)

EOL Care Settings of Survey Respondents



Proponents of Meaning

The majority of survey respondents indicated that they felt it was part of their role as occupational therapists to support a client's sense of MIL with:

- Purpose (74 out of 75 respondents)
- Significance (63 out of 73 respondents)
- Coherence (65 out of 78 respondents)

Purpose (99%)

- Discussion
- Life review/narrative approaches
- Modifying goals
- Attending to valued occupations

*"...establish new goals coherent with their value systems and interests."
"...help identify past meaningful roles and modify/adapt to allow participation, [and] facilitate exploration in new roles."*

Significance (86%)

- Discussion and listening
- Life review and reflection
- Connecting with family

*"...video making of life stories and documenting life work."
"...reflection on what is meaningful."*

Coherence (83%)

- Discussion/counseling
- Listening
- Creative occupation/expressive activities
- Attending to spiritual needs
- Addressing client goals

*"...pictures/scrapbooking," and "art, music, and journaling."
"...[praying] with patients when they wanted to do so."*

Formal and Informal Assessments

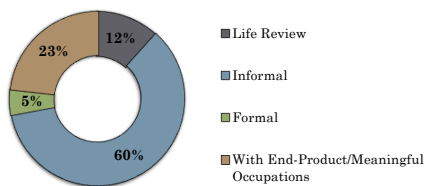
Of the 79 responses, 50 (63.29%) occupational therapists reported not utilizing assessments for evaluation of sense of MIL among clients. Those who did, used an informal or indirect evaluation of meaning.

- COPM (n = 9)
- Informal evaluation (n = 11)
- Depression (Geriatric/Beck) (n = 4)
- Quality of life (McGill/other) (n = 3)
- Holistic needs assessment (n = 2)
- Inventory checklists (n = 2)

Life Review Interventions

- Of 66 respondents, more than half of them (59%) utilize dignity therapy, life review, or other legacy building related concepts in their therapeutic approach.
- Among the 39 participants who utilize legacy building concepts, 46% of them use them “most of the time.”

Legacy Building Related Concepts Implemented in Practice



Summary: Interventions and Assessments

Survey responses indicate that occupational therapists around the world are adhering to the roots of the profession when addressing a client's MIL at the end of life.

Barriers

Barriers to OT services in EOL care

- 1) Institutional protocols
- 2) Client limitations
- 3) Lack of support from family and friends
- 4) Reimbursement

Barriers to using life review methods

- 1) Client limitations
- 2) Institutional protocols
- 3) Lack of support from family and friends

Institutional Protocols

Respondents noted deficits in the following:

- TIME: *"...good care simply takes time and most systems don't seem to allow for this."*
- RESOURCES: *"...productivity/caseload"* are major obstacles.
- ENVIRONMENT: *"...a hospital is an anti-death environment."*

Client Limitations

Diagnoses

- Clients in a medically fragile state
- Clients experiencing “*fear or denial*”
- Clients with physical or cognitive limitations

Willingness to participate

Lack of Support from Family and Friends

Clinicians worldwide indicated that families were often...

- “*in denial,*” or,
- “*in a different place*” than the clients;
- “*not supporting a patient’s wishes.*”

Reimbursement Issues

- Identifying how to bill for the types of care which support assessing MIL in EOL care.
- Lack of reimbursable reasons to see a client in this context.

Reflection

While 34 out of 67 participants (51%) indicated that participating in the survey helped them gain new insight into their practice with clients at the end of life, 41 participants (61%) shared *how* reflecting on their practice through this survey helped them.

Implications for Occupational Therapy Practice

- Education on the role of OT in EOL care
- Allowing more time for client and occupational therapist interaction
- Familiarization with the assessments available
- Familiarization with meaningful interventions
- Future research

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