Using the Model of Human Occupation to Explore the Role of Occupational Therapy in Hospice

Cayce Marshall, OTDS & Elena Espiritu, OTD/ OTR/L, BCPR
Belmont University School of Occupational Therapy, Nashville, Tennessee

ABSTRACT
This study is a qualitative, phenomenological study exploring the perceptions of four patients in a hospice setting in central Virginia. Results from this study recorded patients’ feelings related to MOHO concepts (volition, habituation, and performance capacity). This study’s findings described what was most important at the end of life from the perspectives of patients in hospice. Understanding patients’ perspectives of what is most important at the end of life can help occupational therapists adapt activities to increase patients’ quality of life.

BACKGROUND
- Occupational therapy and hospice care share common values:
  - Holistic and client-centered approach to patient care
  - Value quality of life (AOTA, 2005)
- Patients in hospice have significant challenges:
  - Difficulty with functional mobility, ADLs, and leisure participation (Agar, et al., 2008)
  - Loss of familiar roles and routines (Kaye, 2006)
- Occupational therapist have an important role in hospice care:
  - Help patients adapt to new roles and routines
  - Legacy work: living wills, collections of favorite recipes, photos
  - Last goals: use activity analysis skills to adapt the task/environment (AOTA, 2005; Alaniz, Cruzen-Baird, Kaminsky, Sahanow, 2014)
- Model of Human Occupation (MOHO)
  - MOHO "seeks to explain how occupation is motivated, patterned and performed" (Costa & Othero, 2012, p. 318)

(References available upon request)

METHODOLOGY
- Research Design: This study was a qualitative, phenomenological study, as all of the participants shared their perceptions of their lived experience of occupational engagement during end-of-life care.
- Participants: Four patients agreed to the interview. Three males and one female with a variety of diagnoses were included in the study. See Table 1.
- Data Collection: Participants engaged in a single interview using structured and open-ended questions (see Table 2) that lasted 15-30 minutes. Interview questions were created using MOHO’s three main components of habituation, volition and performance capacity as a guiding framework.
- Data Analyses: The researcher used QSR NVivo 10, a qualitative data analysis software to organize and code the data. After the audio recordings were transcribed verbatim, it was uploaded into analysis software to organize and code the data. After the audio recordings were transcribed verbatim, it was uploaded into NVivo. Participant responses were then categorized into themes based on words and phrases that the participants emphasized. To enhance the credibility of the findings, member checking was used as the researcher discussed preliminary findings and analysis with participants.

RESULTS
- Volition: Personal causation, interests, and values
  - “I’m going to reintroduce myself to some volunteer work I did at our church, which is working with our food pantry. So, uh I used to kind of chair the committee, again when the cancer hit me and that month I was totally out of it, I just let everything kind of drop. So now I’m going to reintroduce myself to that.”
  - “I bought me a guitar, and uh it was always something I wanted to do in the back of my mind, I like to get my guitar and strum it. So, I went on the Internet to get me lessons, you know, but, uh, I don’t know, one day I do good, the next day I have all kinds of trouble. Sometimes I get the shakes and I hit two or three cords at once, so I back away from that for a couple of days.”
- Habituation: Habits, roles, and routines
  - “It’s like not too much activity, uh boring, a lot of times I can’t do what I want because I don’t have the energy. I like to get out of the house, but um, I sit in bed here like this, it’s boring. I try to think of everything positive, but it still don’t help with the boredom. I just try to take it one day at a time.”
  - “Well, it’s like what you see me doing now, looking at the commercials and the news.”
  - Two participants described how they have shifted their roles to another person. For example, the first participant reported his role is to now make sure his wife is taking care of her responsibilities. The second participant said her daughter now takes care of everything.
- Performance capacity
  - All participants experienced limitations in their performance capacity. Two participants reported having falls as they lost strength in their lower extremities, among other causes. All of the participants reported fatigue as a barrier to participation. The third participant described the difference between being tired and fatigue:
    - “To me, tiredness means you’ve been doing something to get your muscles tired and I’m not muscle tired, I’m just wiped out.”

CONCLUSIONS
- Implications for Occupational Therapy Practice:
  - Findings suggest that patients’ performance capacity influences their habituations, which then affects their volition.
  - Even at the end of life there is a need for occupational therapists to help patients explore interests, and continue to engage in activities.
  - Occupational therapists can help patients to redefine life roles by allowing patients to complete life reviews, and helping patients complete legacy work
  - Occupational therapists can play an important role in fall prevention and fatigue management to enable patients in hospice to continue participating in meaningful occupations
- Areas for Future Research:
  - Focus on OT intervention for patients in hospice and measure patients’ quality of life, pain levels, and overall satisfaction
  - OT’s comfort with intervention for patients who are dying

Table 1: Participant Demographics

<table>
<thead>
<tr>
<th>Participant number</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis</th>
<th>Place of residence</th>
<th>Amount of time in hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>71</td>
<td>M</td>
<td>Carcinosopathy</td>
<td>Home</td>
<td>Over 1 month</td>
</tr>
<tr>
<td>2</td>
<td>76</td>
<td>F</td>
<td>COPD</td>
<td>Home</td>
<td>Over 1 month</td>
</tr>
<tr>
<td>3</td>
<td>75</td>
<td>M</td>
<td>Pancreatic cancer</td>
<td>Home</td>
<td>Over 1 month</td>
</tr>
<tr>
<td>4</td>
<td>91</td>
<td>M</td>
<td>Heart disease</td>
<td>Home</td>
<td>Over 1 month</td>
</tr>
</tbody>
</table>

Table 2: Interview questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Interview questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Question 1</td>
<td>Currently, what is your typical day life? Follow up: How is this different from your daily routines in the past?</td>
</tr>
<tr>
<td>Question 2</td>
<td>What things are most important to you now? Follow up: Have you noticed a change over time in your values?</td>
</tr>
<tr>
<td>Question 3</td>
<td>What are your current roles/responsibilities?</td>
</tr>
<tr>
<td>Question 4</td>
<td>How important is it to you to be able to participate in meaningful activities/occupations?</td>
</tr>
<tr>
<td>Question 5</td>
<td>Do you know what occupational therapy is? Follow up: Have you ever received occupational therapy?</td>
</tr>
</tbody>
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