



Model of Human Occupation

Archived List Serv Discussion

MOHO/OT with People with Advanced Dementia

April 24, 2008

Hi all

I've had a couple of discussions recently with OTs in our organisation working with clients with severe dementia, many of whom get agitated and engage in repetitive behaviours. Both these OTs are struggling

- to engage these clients and
- find a meaningful way of using MOHO *eg virtually all their clients would score R's on a MOHOST.*

The main interventions they have offered so far seem to have been sensory, though they are not always able to persuade their clients to try Snoezelen.

So far I have suggested

- using the Interest Checklist with a carer to try and facilitate the introduction of meaningful objects into their environment
- using the Volitional questionnaire to identify any volitional changes in different environments

Just had a look at the MOHO textbook and read with interest the case study on p337, which gives an example of using the VQ to capture changes when Snoezelen was introduced.

But just wanted to see if any other OTs with experience of working with this client group had any other ideas

Thanks
regards
David

April 24, 2008

Hi David: this is Carmen Gloria from Chile. I have had a long experience with people who have advanced dementia both inside Hospitals and in the Community...The ratings of MOHOST suggests it is absolutely needed you base your interventions on the Re-motivation Process. In the Manual, available at the Clearinghouse, UIC, you can find step

by step in which you learn to center your intervention in a holistic way and the way you have to go about volition.

Usually OTs are used to work with people that already engages in activities, and these realities, are a challenge that teaches us to focus in each person's reality (environment, performance, own occupational history) and if we take in consideration these variables, using the VQ, you can be guided to go at their pace and also feel confident about what you are doing and about the outcomes you see, which are relevant. Sometimes, the key is just how to arrange the physical environment to give meaning to people to give back meaning to their lives. Some others include more intervention.

People have volition at different levels according to their capacities and emotional realities. Some of them can live the process experiencing and choosing, others only feeling the experience of the environment, others living the experience, interpretation, anticipation and choosing. In this group of people we usually find the first two situations, so we, as occupational therapists need to understand those processes.

The VQ and re-motivation process (see Exploration Module for your current question) are key both for people we serve and for therapists confidence about evidence based practice.

My experience in Psycho geriatrics, have been very gratifying and all staff and treatment teams have been able to see the difference, plus nursing and OT support staff were very satisfied when seeing progress through learning to see volitional indicators in a continuum, little by little. The OT guides the process, does it, and evaluates, other staff can learn the VQ and give information and can be key in re-motivation process.

Ask more, if you need. I can write examples of Programs and individuals..

I am glad you brought this up!!

Carmen Gloria de las Heras, MS, OTR

April 24, 2008

Hi David,

It's an interesting problem, and one we're trying to get to grips with here in Newcastle. Recent service changes have meant that hospital admission is avoided for all but the most severely-impaired people with dementia, effectively changing the assessment ward into a challenging behaviour service.

Before these changes we'd tried to establish MoHOST as a baseline assessment tool in the service, but, as in your service, found that people tend to "bottom out". The VQ seemed a possibility, but scoring was also an issue with this tool. My current thinking is that, rather than concerning ourselves with acquiring scores, we should use the structure of MoHOST to compile an Occupational Profile of our clients - we needn't rate it, but can be sure that we're considering all aspects of the individual's past and present

occupational identity. Of course, the beauty of the MoHOST structure is that it allows information gathering from a variety of sources, including carers who may be our only avenue for tapping into the client's former interests, choices, values and patterns.

Even then, I suspect that it may prove difficult to engage many service users, so we end up with a great deal of information, but are still unable to effect change.

It's a controversial viewpoint, but dare I suggest that it is sensitive nursing rather than occupational therapy that these people need, and that resources might be better targeted towards the community and early intervention? I'm not suggesting that they don't have underlying occupational needs, but that the nature of their condition doesn't allow for these to be addressed. Is there any research evidence to support the use of OT with clients with the most severe presentations of dementia? Unfortunately, the recent National Audit into violence on inpatient wards proposed that more meaningful activity was required to reduce levels of aggression, so we might find it a challenge to be allowed to re-focus our skills!

Finally - and I'd love to hear others' views on this - is Snoezlen an occupational therapy intervention? It seems to me that snoezlen is something that older people who cannot express their preferences are subjected to, rather than a meaningful activity they choose to engage in, so they are merely recipients of, rather than participants in a therapeutic process. Discuss!!!

Chris

April 24, 2008

Hi David,

.... and I promised you that I would try not to respond to so many emails in future! I'll be brief though: I suggest using the OPHI 2 by proxy with carers and the Remotivation Process alongside the Volitional Questionnaire.

Sue

April 24, 2008

Yes, In the Re-motivation Manual the OPHI-II is included as a proxy with carers when needed.

carmen gloria

April 24, 2008

Hi everyone,

This is my favorite patient group. I use MOHOST for the initial evaluation. The best

thing you can do though is familiarize yourself with Naomi Feil's work on Validation Therapy. Feil is a social worker that grew up in a nursing home. She identified validation therapy as a method to help people become connected and remain happy until they die. The belief is that validation therapy helps people come to terms with their life - to get through the resolution stage of aging. The reason MOHO works so well with this theory is that much of the behavior we see is ground in people's past occupations. According to Feil, people do not experience time as linear but move back and forth through time. They return to times in their life that are emotion laden. The best therapy you can provide is the opportunity to engage in activities that make up those meaningful occupations. This requires time spent with family to determine what that person did in their life, good and bad. We have spent time getting bottles from the pharmacy, along with a lab coat for a recent patient with Pick's that had worked all his life as a pharmacist. A few Skittles and M & M's and he was engaged.

An interest checklist is difficult with people in advanced stage dementia but having the family do it, then bringing out things to try with the patient will allow you to find what you need to know.

As far as the sensory goes, there are definitely things you need to know about the changes in sensory. Having a good working knowledge of the sensory modulation theory really does help. I think some people have sensory defensiveness but it is really hard to know if that is a result of the dementia process or was always there and because of the disease, they are no longer able to modulate or adapt. We sometimes forget that people with dementia may have had learning disabilities, sensory modulation difficulties and other such issues long before they developed the symptoms of dementia. Tina Champagne has a wonderful book available on her website that is helpful with this. The research is still out on Snoezelen. Tina's website is www.otinnovations.com. You do not need to spend thousands of dollars to provide good sensory modulation activities with people who have dementia. Read up on Barry Reisberg's work on Retro genesis. This theory says that people regress cognitively in the same general pattern and time frame that babies develop. I concur - after 5 years of paying close attention. I can tell you what a person can and cannot do by watching them eat a meal. This is really helpful information when you need to know what a person is able to do as far as self-care. More importantly, this theory really helps with understanding what is appropriate activity for a person at that stage of the disease.

If you were to ask a group of people what is most meaningful in their life (I do this with patients, professionals, and family), they will tell you all of the roles on the role checklist. This has become a fun little experiment for me the last 5 years and has remained consistent with every group. The importance of this to me is that in certain living facilities, opportunities to engage in the activities related to these meaningful roles are NOT available. Using a client centered approach, one of the best things you can do with this population is to create opportunity to participate in activities that make up meaningful roles. Care of children, work related tasks, etc. We have gotten Carpenter tools, when appropriate. We have allowed people to lead groups or activities, etc.

Obviously with guidance and adaptation. The possibilities are endless here.

Another great resource for this population is Carl Helen's book "Alzheimer's Disease: Activity Focused Care." She has a chapter on creating "Life Storybooks" These are simple scrap books that highlight people's lives. These books have all sorts of uses including providing occupational history information to others who come in contact with this person. The books are made to go with people to different places (the hospital, the doctor's office). Gives people an idea of who the person was throughout their life, the whole picture. Also allows people to ask the person about the items in the book. Keeps people connected, and celebrates a lifetime of occupational accomplishments.

I think using MOHO with this population (the theory, not a bunch of evals) makes a big difference in how therapists approach them and engage them. I see huge difference in agitation when I understand what the behavior means and can react accordingly. This is a wonderful group of people to work with, especially if you enjoy problem solving as part of therapy.

Lisa Mahaffey M.S. OTR/L

April 27, 2008

Hello everyone,

As Dr. Kielhofner states, I recently completed my dissertation research in which I examined the experience of volition for persons with moderate dementia in a phenomenological study. I strongly agree with the points addressed in this discussion thus far, and in addition to the excellent resources mentioned thus far, I would also direct those interested in this area to explore further the concepts of person-centered care by Dr. Thomas Kitwood, from the UK, and Tessa Perrin, OT from the UK who has applied these concepts to OT approaches for persons with dementia.

The person-centered care movement began in the UK (stemming from Kitwood's work), and is growing as a standard of practice in the US (See Alzheimer Association-US-Recommended Standards of Practice for Dementia Care), The concepts of person-centered care are very congruent with MOHO, and as such, provide ways to communicate with other dementia care team members.

My exploration of volition in this population revealed the pervasive significance of the social environment in the expression and experience of volition, which can be captured in the VQ. This was a main theme in my research, and highlights the transpersonal nature of volition. This is particularly true when we look at how others recognize, and then respond (or not) to a person's volitional behavior. Unfortunately, many caregivers may often assume low to no motivation (volition) for these individuals, and this can lead to lack of recognition of preferences, with consequences of sensory deprivation and excess disabilities as the limited opportunities are provided for the individual to engage in their environment.

Additionally, the participants in my study demonstrated a great deal of variability in their volition expression, and volitional behaviors (verbal and non-verbal) were often subtle and contradictory. This adds more challenges to caregivers who may not recognize volitional behavior, and/or have adequate skills to respond. Another fascinating finding in my study was that caregivers often do not associate “problem” or “challenging” behaviors as expressions of volition. For example, a person who is “hoarding” (framed as “collecting” behavior in person-centered care) is often creating occupation in an environment with limited supports for meaningful engagement.

Another point that arose in my research is the need to further examine the hierarchy of volition (exploration, competence, and achievement) and how it applies to the experiences of these individuals. For several participants in my study, the volitional narrative was often more reflective of strengths in higher areas (ie, competence) while exhibiting some challenges in exploration. Obviously environmental factors, particularly social, affected this social construction.

This highlights some of the major points. I have attached a handout from the poster session I gave at AOTA last year. I am currently writing these findings into an article for publication. I’d love to dialogue more with everyone working with this population, particularly those using the VQ/Remotivation Process, as I feel it has a great deal of potential to help us provide clinically relevant interventions to better meet the needs of persons with dementia.

Thanks!

Christine

Christine Raber, PhD, OTR/L

April 25, 2008

Snoezelen did not originate as an OT intervention, but sensory integration is and did recently with advances in brain imaging, there is now some evidence for the interventions of Jean A Ayres from applied neuroscience.

In Cornwall, we have a sensory room and a portable sensory cart, the Be SMaRT Cart, which we use with great success with clients with a range of mental health difficulties, including those who self harm and those with dementia.....

In the clients with dementia, supporting vestibular, tactile and proprioceptive function helps to support and maintain sense of body awareness, balance and mobility, and sensory activities support cognitive function, (nothing you know doesn't have to go in through one of your senses before it is processed by the brain and then we respond). (Recent research shows cognitive stimulation is as effective, if not more so in preserving function that cognitive enhancers - this was cited in a recent copy of BAOT Journal, but haven't the copy to hand to cite the reference right at this moment).

I think it is powerful to reflect on research about sensory deprivation - If you remove sensory input from people (well people) they quickly become unwell even psychotic, dementia can 'starve' the brains access to it's input of sensory information and the challenging behaviours that are often seen from older adults can be clearly understood using SI as a model - i.e. the behaviours are a result of a little or misinformed responses to input from the body, the world around them and other people - definitely a not just a role for nurses.....MOHO would explore how decreased access to the ability to process information within the neurological system affects occupational performance. We use the ACIS and VQ with this client group during and after sessions, as the clients tend to become calmer, more aware of their own body, the environment and other, all of which promote and support their ability to engage in occupational activities, be that better performance walking, being able to make eye contact and respond to their husband's hand squeeze, or merely be less agitated and scared and therefore able to get much needed sleep.

We are passionate about supporting older adults in this way and have had some super results with a decrease in challenging behaviours and even with someone with severe diffuse end stage dementia, with an SI programme were able to increase proprioceptive and vestibular activities, these reduced the need for getting proprioceptive and vestibular input head banging and as these help us orientate in space dramatically reduced the crashing into things and other elderly residents - the 'behaviours' that caused the admission gone, it was enough to return someone to a private residential home instead of hospital unit.....

Also some sensory interventions can be taught to relatives, something they can do when going out in a chair or sharing a cup of tea is no longer possible, it helps maintain their sense of involvedness with their loved one with something that can be calming and soothing right at the end.

I will load a PowerPoint presentation onto the Sensory Project website about sensory approaches with the elderly for you all this weekend, as well as a link to an article by Winnie Dunn, one of the author's of the Adult/Adolescent Sensory Profile. (I have given up trying to email PowerPoint files to individuals because of overly robust hospital mail scanners thinking any name cited is patient identifiable data and spamming them or sending warnings to me for breaking confidentiality, and the frustration it causes everyone including all the failed deliveries which crashed my system, so no longer mail out to individuals - Sorry)

see below for more about Snoezlen

Kath Smith

>From Wwikipaedia re Snoezelen History:

Snoezelen or controlled multisensory stimulation is used for people with mental disabilities, and involves exposing them to a soothing and stimulating environment, the "snoezelen room". These rooms are specially designed to deliver stimuli to various senses, using lighting effects, color, sounds, music, scents, etc. The combination of different materials on a wall may be explored using tactile senses, and the floor may be adjusted to stimulate the sense of balance.

Originally developed in the Netherlands in the 1970s, snoezelen rooms have been established in institutions all over the world and are especially common in Germany, where more than 1200 exist. The term "snoezelen" (pronounced like "SNOOzelen") is a neologism formed from the Dutch "snuffelen" (to sniff, to snuffle) and "doezelen" (to doze, to snooze).

Ideally, Snoezelen is a non-directive therapy and can be staged to provide a multi-sensory experience or single sensory focus, simply by adapting the lighting, atmosphere, sounds, and textures to the specific needs of the client at the time of use. There is no formal focus on therapeutic outcome - the focus is to assist users to gain the maximum pleasure from the activity in which they and the enabler are involved. An advantage of Snoezelen is that it does not rely on verbal communication and may be beneficial for people with profound autism, as it may provide stimulation for those who would otherwise be almost impossible to reach.

Snoezelen is used for people with autism and other developmental disabilities, dementia, and brain injury. However, research on the benefits of treatment is scarce, with variable study designs.[1][2]

A small research study carried out in Brussels compared the behavior of nine adult clients with profound autism in both classroom and Snoezelen settings. Though

individual results varied, the study claimed a 50% reduction in distress and stereotypical behavior, and seventy-five percent less aggression and self-injury in the Snoezelen environment.

April 27, 2008

Dear Kath-

Thank you for demonstrating how MOHO can be used in combination with other approaches to practice. As a school therapist working with children with multiple disabilities we used Snoozelen because children were highly interested, and the accessibility of the equipment really gave them a sense of efficacy and capacity to control and interact with their environment. Using the ACIS and VQ with Snoozelen (and other interactive, multi-sensory environments) is a great way to document the impact these environments have on volition and interaction.

Best-

Jessica