

What Families and Patients say about their needs and interactions with Professionals

**Family/Staff Relationships in Continuing Care
Institute for Continuing Care Education and Research**

November 10, 2015

ES Brintnell Professor

Occupational Therapy



Presentation

Focus the Voices of Families

Research and testimonies from community as prerequisite to facility based care

In support of:

Further contributions to informing our discussion on relationships

Core: Centrality of Interactions (dialogue Jonsdottir, 2004)
Communication in the form of
Relational and Intentional Self (Nursing and OT)
Space of “others”

End of life conversations

Directives

Impressive collection

Explanations, Education, Actions, Strategies

Are they making a differences

Are they affective in assisting us in experiencing the response of “others”

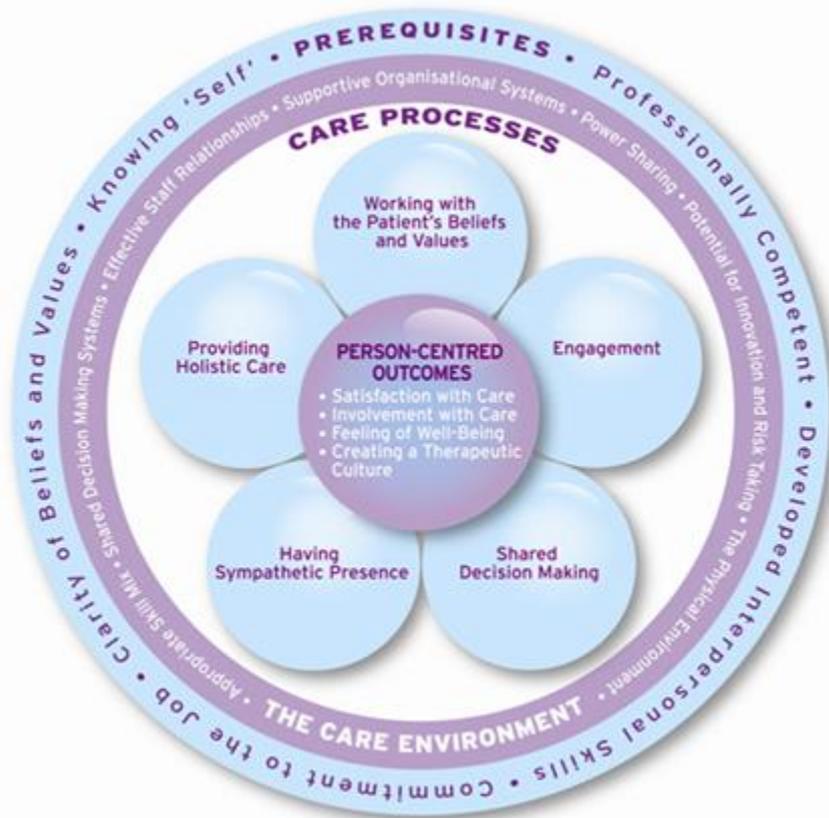
PROMINENCE OF TOPIC HEALTH SERVICE WEBSITES ON FAMILY & PATIENT CENTRED CARE

Relationship in Care

Communication skills and relational abilities are essential core competencies [professional] that are associated with improved health outcomes, better patient adherence, fewer malpractice claims, and enhanced satisfaction with care

(Meyer et al., 2009)

Person-Centred Semantics or Real Differences



an approach to practice established through the formation and fostering of **therapeutic relationships** between all care providers...patients and others significant to them in their lives. It is underpinned by values of respect for persons, individual right to self determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development” [p.13](#).

Family Patient/Client Centred Care and Relationships - Others

Nursing and occupational therapy professions have long history of promoting engagement with their patients, clients, families and caregivers to establish a relationship

Therapeutic

Intentional

Relational

Professional

**ONE OF THE MOST
SINCERE FORMS OF
RESPECT IS ACTUALLY
LISTENING TO WHAT
ANOTHER HAS TO SAY.**

BRYANT H. MCGILL

Exploring Considerations of the “other” in Support of

“Ethical actions attempting to understand the other’s situation, perspective and vulnerability and requires a true engagement with the other” (Austin et al., 2009 p.364).

**Relational Elements
Centrality to Family, staff,
professionals and & care
giver interactions**

Family as “Others” needs to be understood

As Actor, the Family member may have their own issues outside the Caregiver role

Identified family changes in life patterns, in understanding and managing of health experiences, future prospects (Jonsdottir et al., 2004).

Rewarding Dupuis et al., 2004

Burden Fast et al., 2013

Role overload Bastawrous et al., 2014

The World of Caregiver

Bastawrous et al. (2014) notes consequences of juggling the demands of post-stroke caring for a parent in addition to other roles:

- Adult caregivers' relationships with the caregiver's partner and children affected
- Caregivers forego the opportunity to participate in valued activities (both work and leisure-time occupations)

Sandwich Generation

Care for aging family member and their own children

Financial strains result and may increase by adult children moving home needing assistance

Restricted incomes in pensions and investments

After Effects

Primary carers for persons who recently died found themselves “doubly deprived” as result of experience:

Loss of normal activity

Disempowerment in role

Keesing et al., 2011

Their presentation and demeanor may be a result of the complicated elements in their life outside the care giver role- be careful in your interpretations

Ask

The Economic and Productivity Losses Some Caregiver are Experiencing

Catalogue no. 75-006-X

ISSN 2291-0840

Article

Insights on Canadian Society

Family caregiving: What are the consequences?

by *Martin Turcotte*

September 2013



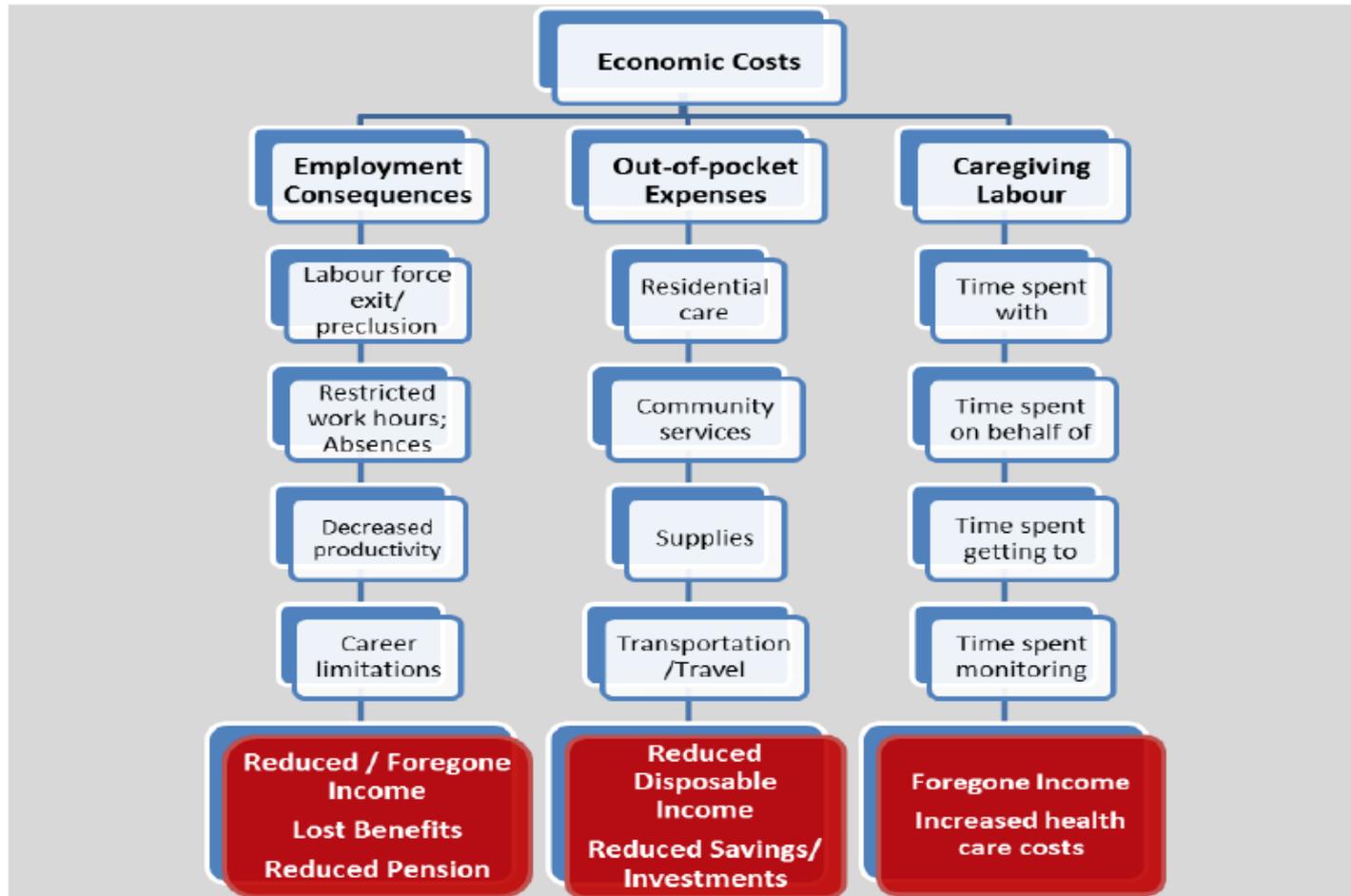
Overview of the study

What types of caregivers provide the most hours and kinds of care? Which ones are the most likely to experience various consequences associated with family caregiving? This article compares the different types of family caregivers, based on the relationship with their primary care receiver.

- In 2012, 8 million Canadians, or 28% of the population aged 15 and over, provided care to family members or friends with a long-term health condition, a disability or problems associated with aging.
- Among these family caregivers, 39% primarily cared for their father or mother, 8% for their spouse or partner, and 5% for their child. The remaining (48%) provided care to other family members or friends.
- Among regular caregivers—those who spent at least 2 hours caregiving each week—38% of those who helped their child, 34% who helped their spouse and 21% who helped their parents reported feeling depressed. Those who cared for a spouse or child also reported more health and psychological problems, mainly because of the intensity of care provided.
- Among regular caregivers, 28% who cared for a child and 20% who cared for a spouse experienced financial difficulties as a result of their caregiving responsibilities. This proportion was 7% among those who regularly helped their parents.
- In 2012, 30% of caregivers of children received government financial assistance, compared with 14% of caregivers of spouses and 5% of caregivers of parents. However, 52% of caregivers of children, 42% of caregivers of spouses and 28% of caregivers of parents would have liked more help than they received.

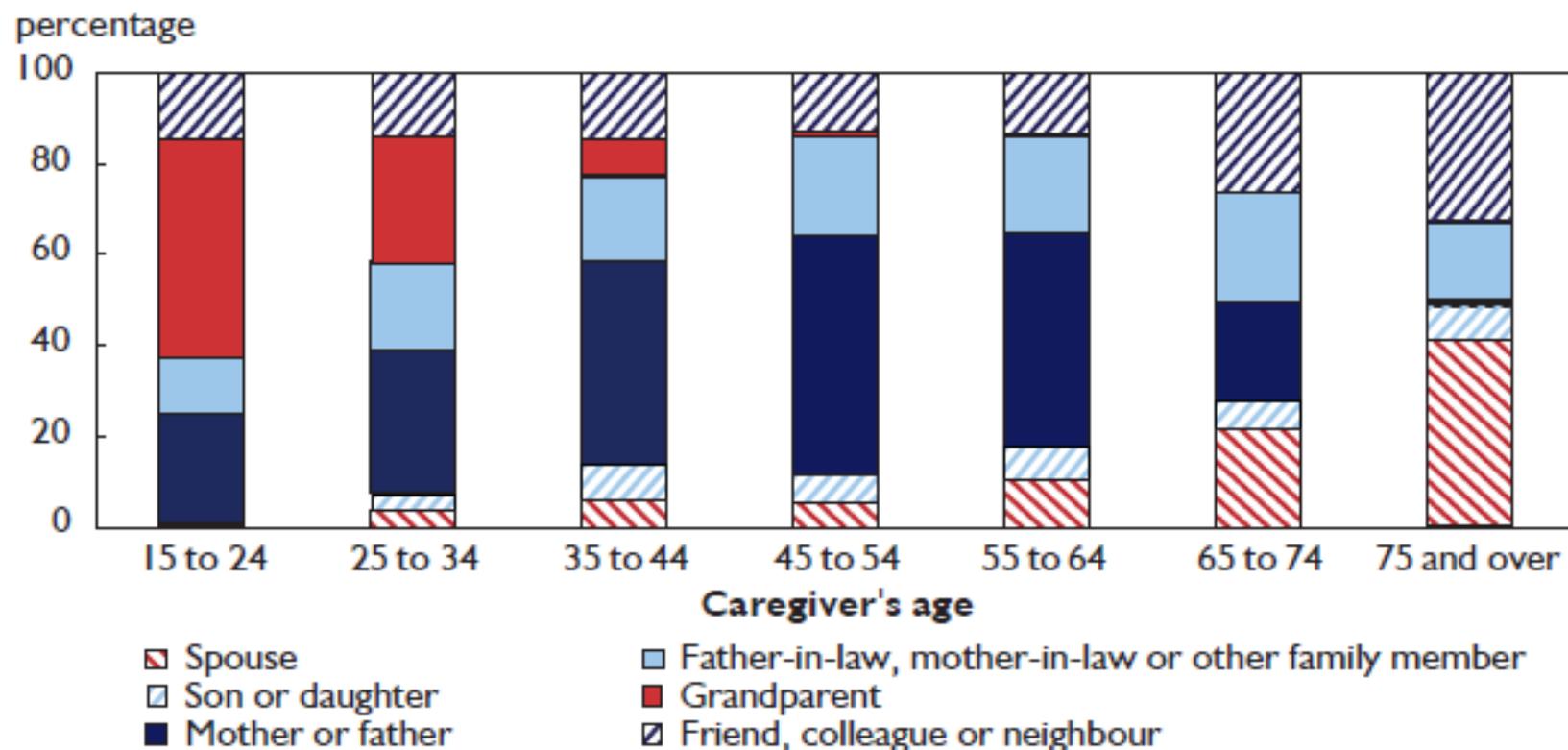
Caregiving Costs

Figure 1. Taxonomy of Economic Costs of Care for Family/Friend Caregivers



Source: Keating, Lero, Lucas, Fast, & Eales, 2011

Primary care receiver, by caregiver's age, 2012



Source: Statistics Canada, General Social Survey, 2012.

Establishing Contact with Families

Kaakinen et al.,(2014) provide suggestions on interactions with and priorities responses to Patient/family needs

Open up Communication and Obtain Family Members' Perspectives

Health services website give similar simple prompts

Source: Kaakinen, J. R., Gedaly-Duff, V., Padgett Coehlo, D., & Harmon Hanson, S. M. (2014) *Family Health Care Nursing: Theory, Practice, and Research*, 4th ed. pp.15-16. Philadelphia: F. A. Davis. Available online at: http://ners.unair.ac.id/materikuliah/ebooksclub.org_Family_Health_Care_Nursing_Theory_Practice_amp_Research_4th_Edition.pdf; p. 314 of the pdf.

The Views and Needs of Caregivers and Clients/patients with Dementia in Community

Some indicators below but overall **the persons and families** wanted more basic , less costly and pragmatic content interventions; all groups values specialist care .

The client and the care givers are collaborators and their opinions must be sought.

Help in Crisis: Person with dementia: – support from families & friends, access to mobile phones & home accommodation to lessen risks

Carers: for assistive technology and home adaptations

Staff and carers: valued training & education, care plans, and well coordinated care.

Staff: only group wanting more intensive interventions: emergency home respite, and extended hours services.

Intervention in Crisis Person with dementia: risks and hazards in home, where as Family Carers sought assistance for carer stress & own MH problems.

Staff: concerns over problems with service organization and coordination.

Some other shared content” physical problem of lower concern but when identified - major Practical interventions highly valued during crisis: adaptations, technical supports, education /training for care givers, flexible home care may assist in preventing hospital admissions,

Toot, S , Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell ,M (2013). Another study of research group under review which adds to this body of knowledge re needs of clients and caregiver,

Other Findings to Support Efforts

Positive Coping in Care Giving is negatively correlated to burden and with wishful thinking strategies related positively

Relationship with depression is highly significant with Burden

C.G. Papastarou et al., 2011.

A preliminary typology of caregivers and effects on service utilization of caregiving counselling

attends to wide difference in family situation and across time, the preliminary typology of Caregiving t may assist clinicians/practitioners to tailor interventions to meet needs of their clients based on information garnered early in therapy, perhaps on intake process.

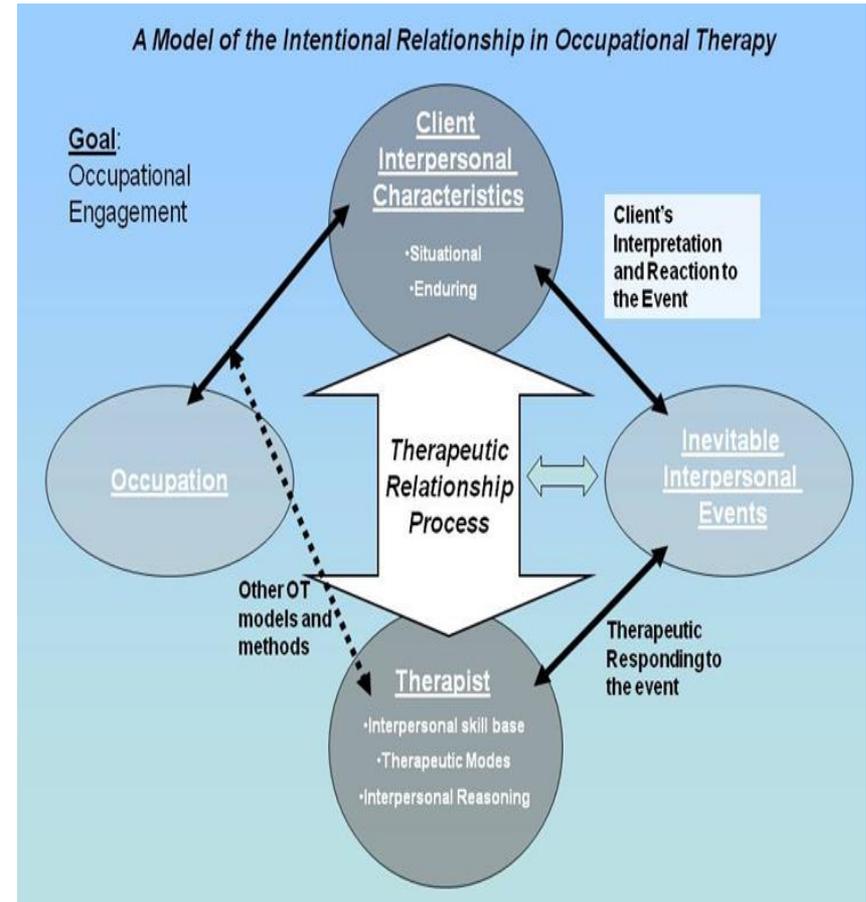
Pepin, R., Williams, A.A., Anderson, LN & Qualls (2013).

Other Approaches Provide Relational Models

OT Intentional Relationship
supplements other practice
models

Interactions count

Grounded in earlier
foundation
of Use of Self (1950's) with a
focus on doing
(occupations) Taylor (2008)



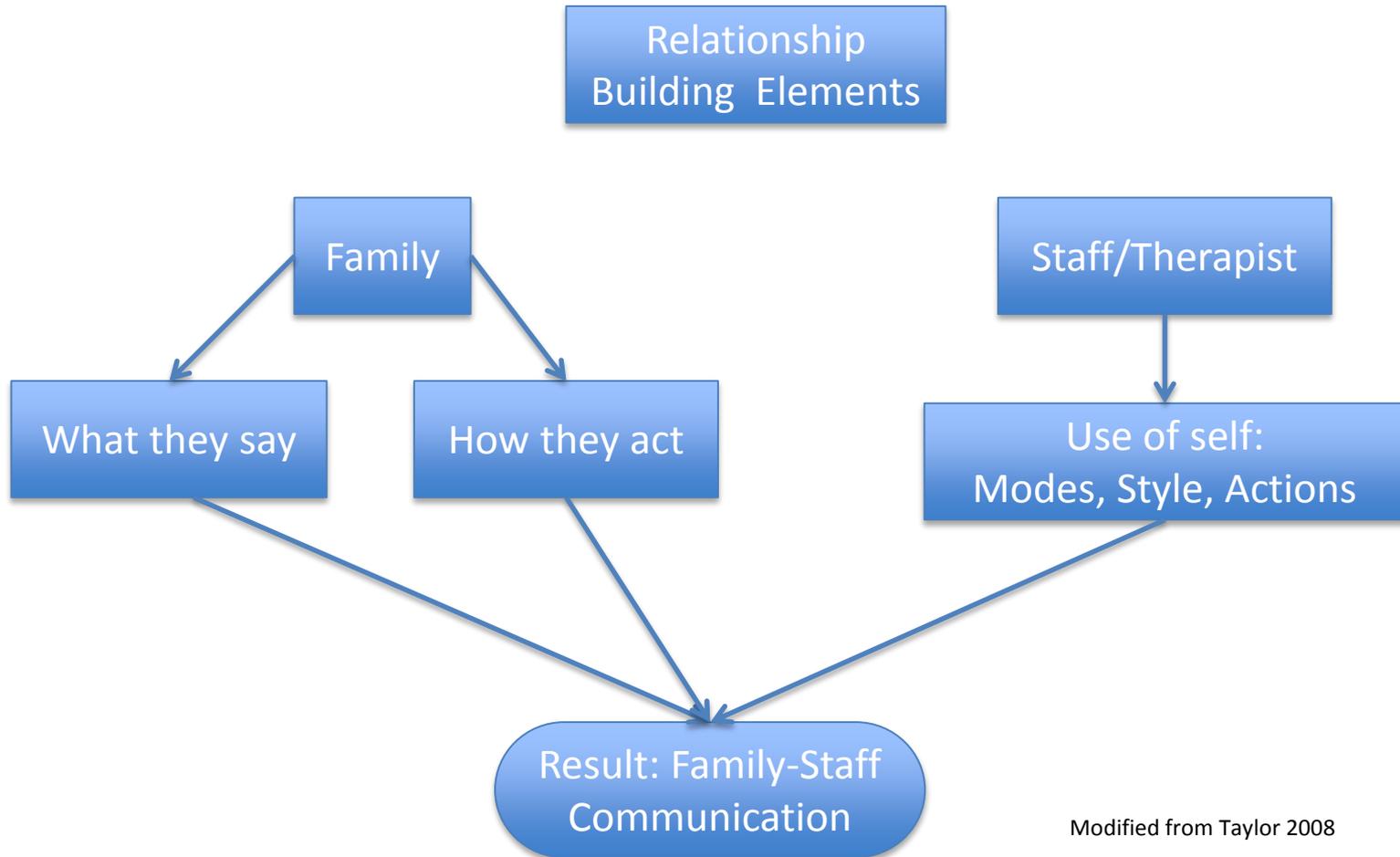
Intentional Relationship

Six possible therapeutic modes or ways of relating to the client/patient:

1. Advocating mode
2. Collaborating mode
3. Empathizing mode
4. Encouraging mode
5. Instructing mode
6. Problem-solving mode

The *therapeutic style* of a therapist is a function of which modes the therapist prefers to use.

Identifying What is Behind the Exchange



Modified from Taylor 2008

Operationalizing

Person-centered care (Edvarsson et al., 2008):

- Individual is an “experiencing” person despite the disease/ conditions
- Offering choices, and respecting them once made
- Using person’s history and biography in care
- Focusing on abilities rather than disabilities
- Supporting individual rights, values, & beliefs
- Unconditional positive regard (Rogerian psychology)
- All behavior is meaningful
- Maximizing potential and providing shared decision-making

Relationship-centred care

- Growing evidence base
- Named the ‘Six Senses Framework’,
- Nurturing these ‘senses’ for residents, their families and staff is a vital part of
 - “... all parties involved in caring (the older person, family carers, and paid or voluntary carers) should experience relationships that promote a sense of:
 - security – to feel safe within relationships;
 - belonging – to feel ‘part’ of things;
 - continuity – to experience links and consistency;
 - purpose – to have a personally valuable goal or goals;
 - achievement – to make progress towards a desired goal or goals;
 - significance – to feel that ‘you’ matter”

University of Sheffield([Nolan et al., 2004, p.49](#))

The Evidence is Scant but Growing

The Family Centredness in Long Term Care
improves outcomes

All models and approaches need evaluation

Source: Kuo et al., (2012)

Example Community Services Seeking to Expand Person Centred Care Options and Programs

Seniors, many with dementia and other Non
Communicative Diseases NCD

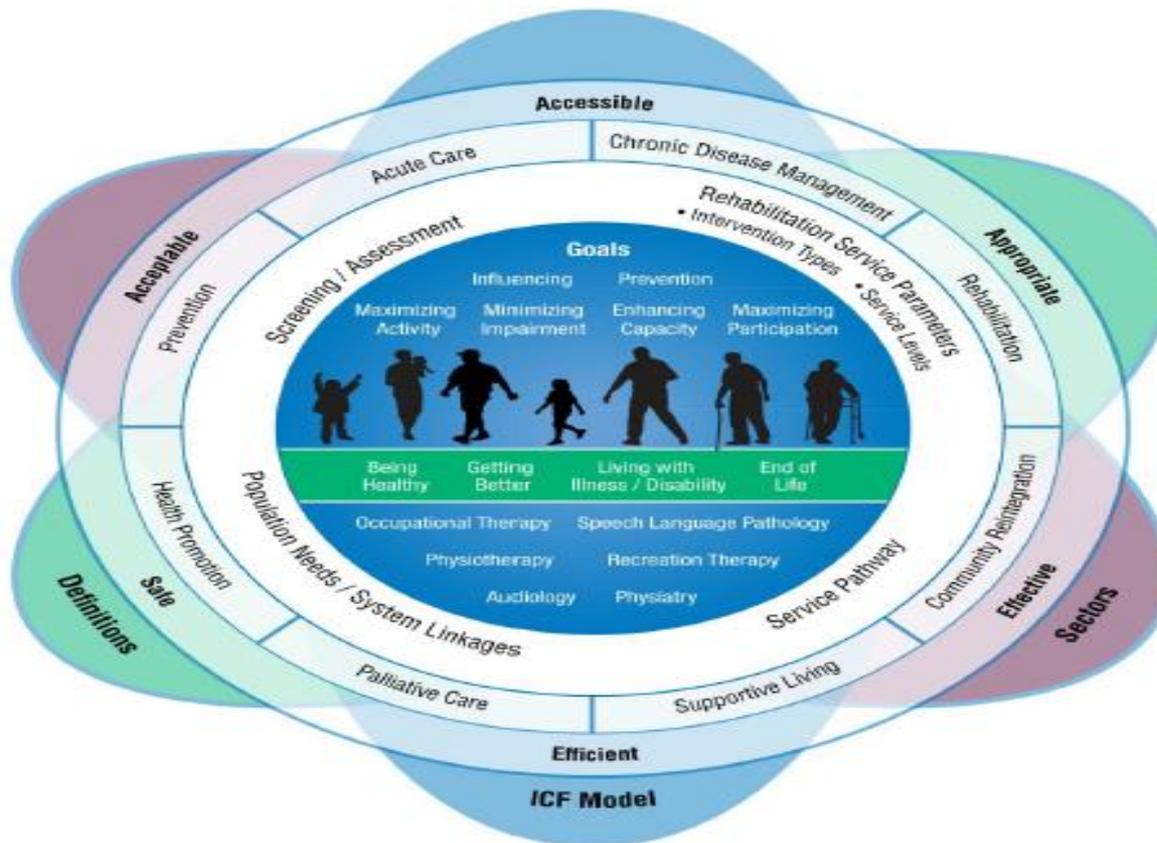
Some younger clients with cognitive impairments

Enhancing function for
meaningful living

Government Policy An Influencing Factor



Rehabilitation Conceptual Framework



Enhancing Function for Meaningful Living

The Service

Based on a business plan developed in an
occupational therapy Private Practice Class

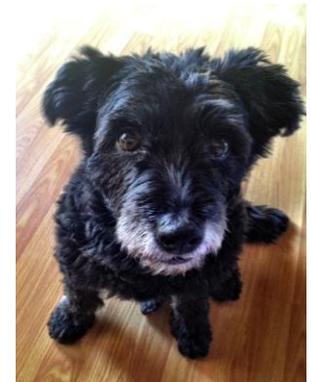


Rehab & Retreat

- Their focus is the needs of the caregiver as well as the identified client
- Individualized cognitive, social and physical activated in home-like environment, with roaming service dogs promoting comfort and well being.
- Core program: promoting social interaction and a variety of activities
- Approach: **Biopsychosocial conceptual framework** – holistic lenses for care of persons with dementia, life balance in caregiver and mitigating their burnout and compassion fatigue; Person-Environment-Occupation (PEO) Model and Lawton's Ecological Model of Aging, which highlights transactions between person and an optimum environment (Lawson, 1974).

The Start

Owner Operator
Occupational Therapist



Testimonials* for Rehab & Retreat

Voices expressing needs and satisfactions

Client

Caregiver

Notes to share: *A Live Environment (people animals music); Satisfied*

- "I really like the daily log notes. I share them with other family members that is an excellent way to keep family in touch with mom and your program. It will also be useful when we make a case to revenue Canada that this therapy should be tax deductible as a health expense. Having students and other young people and even children visit is terrific. Having the menagerie of pets is also nice for Mom" - daughter
- "Movement to music is something that Mom likes to do. Fresh air when it is weather appropriate is a good activity for Mom" - daughter

The Doing Opportunities



Keeping meaning; Immediate sense Competence, Safety and Confidence

- “I love to participate in curling and I can continue to do this with the help from R&R” – D.R.
- “I’m anxious about leaving my mom with paid companions. The academic credentials the therapists at R&R hold give me the confidence my mom is in the best hands.” – F. T.

Individualized Asset Use; Just Right, Purpose; Gratified

- "[The Therapists at Rehab and Retreat] have taken the time to develop considerable understanding both of my father's deficits and his remaining abilities; as a result they have been offering him challenges that build on his strengths/reinforce his confidence and therapies that assist him in remaining largely independent.
- On more than one occasion – when I have picked my father up at the end of a day – I have been very gratified to find him engaged in a project making a gift for one of his grandchildren, and see a look of purpose /satisfaction on his face." – I.E.

The Setting & Engagement



Commitment, Confidence, Success

- "You are both remarkable ladies choosing this line of work for a career. Now, more than ever before we appreciate your dedication." – J. G.
- ... have a deep understanding of the condition and an earnest desire to be of service to the people who have it." – I.E.
- "I find the staff very friendly and helpful. I would highly recommend this care/support to others who need assistance." – S.C.

Connecting, Feeling Good

- Mr. I
- "I think walking is a very good exercise and talking to people is very nice"
- "When I'm at my house I'm on my own. I don't have people to talk to. I have a phone of course but my family live in a different country"
- "I feel better when I leave here"
- "I enjoy the music very much"
- "It's good to move and be active, to feel like I'm alive"

Engaging, Happy

- Mr. G
- "My favourite part is the outings and going with you guys"
- "And the walks and seeing the houses being built in the neighbourhood"

Relief, Hope, A Connected day

- "Even when my husband is having a poor start to the day, when I pick him up at the end of his stay he is encouraged and uplifted." – R.M.
- "... were very welcoming to my father and made him feel right at home. When I picked him up at the end of the day I found that he was in a very good humour and with a bit of a twinkle in his eye. Although he could not recall exactly how his day went, it was clear that he'd spent it well and done some very meaningful things." – I.E.

In the moment enjoyment, Being an individual, Engaged, "feels" competent; Pleased with quality

"Mom does not remember that she was at this program as soon as she leaves it. But she does have an overarching feeling that it is a pleasant thing to do. When she arrives it seems "familiar" to her in a good way. She will never feel a part of it after she leaves. During her stay she enjoys the activities .

We like that she is treated an individual and not just a part of a group of people to be entertained. Her active involvement in everything including dishes and meals makes her feel that she is valued as an individual. She feels competent... That is important.

We see this program as keeping her independent, socialized and in the larger world. It challenges her mind to be active both by challenging her mentally and in physical activity. Doing these things successfully with family is important but doing them independently with strangers to her is also an important component of good mental health" . Says It All.

End of Life & Directive Conversations that Matter

What end-of-life clients expect from health-care professionals:

- respect
- approachability
- genuineness
- empathy
- connectedness
- compassion

Source: Ciemens, E. L., Brant, J., Kersten, D., Mullette, E., & Dickerson, D. (2015). A Qualitative Analysis of Patient and Family Perspectives of Palliative Care. *Journal of Palliative Medicine* 18, (3): 282-285.

Many people think about a decision but don't complete the process



“No heroic actions” – does that include CPR? What Level?

Verbal consultations

Suggested

with a health care professional you trust (not just Physician)

Explore the care levels and situations described

Learn about the possible actions and outcomes

Understand the terms and what follows with each

Advance Directives, End-of-Life Care, and Canadian Law

Each province has its own procedures for making personal directives. Alberta, however, is the only province in Canada that offers a standardized procedure for making them:

- Personal Directives: How to fill out the form.
<http://www.humanservices.alberta.ca/documents/opg-personal-directives-form-opg5521a.pdf>
- Personal Directives: The Form itself.
<http://www.humanservices.alberta.ca/documents/opg-personal-directives-form-opg5521.pdf>
- Personal Directives: How to register one with the Government of Alberta.
<http://www.humanservices.alberta.ca/guardianship-trusteeship/register-a-personal-directive.html>

Advance Directives, End-of-Life Care, and Canadian Law

A personal directive may not be enough to resolve ethical dilemmas regarding the role that the family can play or should play in end-of-life care. Here is an example from the *Toronto Star* (the local arch-rival of *The Globe and Mail*):

- An ethicist's view regarding care of a 95-year-old woman who refuses to eat: <http://www.thestar.com/life/2015/07/11/ethically-speaking-dealing-with-an-aging-loved-one-who-refuses-to-eat.html>
- Other considerations, from a medical doctor: http://www.thestar.com/opinion/letters_to_the_editors/2015/07/16/other-thoughts-on-end-of-life-care.html
- Personal Comment

Thank you for your attention



References

Bastwrous, M., Gignac, M.A., Kapral, M.K., & Cameron J.I. (2014) Adult Daughters providing post- stroke care to parent: A Qualitative Study Of The Impact That Role Overload Has On Lifestyle, Participation and Family Relationships. *Clinical Rehabilitation* 1-9.

Chang. B. W., & John P. Hirdes J. P. (2015) A Cross-Sectional Study to Compare Caregiver Distress Among Korean Canadian, Chinese Canadian, and Other Canadian Home Care Clients. *SAGE Open* April-June : 1– 14

Ciemens, E. L., Brant, J., Kersten, D., Mullette, E., & Dickerson, D. (2015). A Qualitative Analysis of Patient and Family Perspectives of Palliative Care. *Journal of Palliative Medicine* 18, (3): 282-285.

Deragon, J. (2009). What Are The Expectations? The Relational economy : Technology and the Human Network. <http://www.relationship-economy.com/2009/02/what-are-the-expectations/> retrieved November 5 2015

Dupuis, S.I., Epp, T. Smale, B. (2004). Caregivers of persons with dementia: Roles , Experiences, Supports , Coping: A Literature review

Fast, J., Dosman, D., Lero, D., & Lucas, (2013) The Intersection of Caregiving and Employment Across the Life Course. Centre for Families, work and well being; Waterloo University & Research on Aging, Research, and Practice , University of Alberta.

Guidelines for the Client-Centred Practice of Occupational Therapy. (1983). Expert Group (Health Services & Promotion) Ottawa, Ontario, Health and Welfare Canada Publication (October).

Institute for Patient- and Family-Centered Care (2011). Patients And Families As Advisors In Enhancing Safety And Quality: Broadening Our Vision

http://www.ihc.org/education/conferences/APACForum2012/Documents/I1_Toolkit.pdf

Jonsdottir, H., Litchfield M. & Pharris M.D. (2004). The Relational Core of Nursing Practice as Partnership. *Journal of Advanced Nursing* 47(3), 241–250

Kaakinen, J. R., Gedaly-Duff, V., Padgett Coehlo, D., & Harmon Hanson, S. M. (2014) *Family Health Care Nursing: Theory, Practice, and Research*, 4th ed. p. 282. Philadelphia: F. A. Davis

References

- Keesing, S., Rosenwax, L., & McNamara, B. (2011) "Doubly deprived": a post-death qualitative study of primary carers of people who died in Western Australia. *Health and Social Care in the Community* 19, (6): 636-644.
- Kuo, D. Z., Houtrow, , A. J., Arango, P., Kuhlthau, K. A., Simmons, J. M., & Neff, J. M. (2012). Family-Centered Care: Current Applications and Future Directions in Pediatric Health Care. *Maternal and Child Health Journal* 16: 297-305.
- McCance, T., McCormack, B., Dewing, J., (May 31, 2011). An Exploration of Person-Centredness in Practice. *OJIN: The Online Journal of Issues in Nursing* Vol. 16, No. 2, Manuscript 1
- Meyer, E. C., Sellers, D. E. PhD; Browning, D.M., McGuffie, K., Solomon, M. Z., Truog, R.D., (2009). Difficult conversations: Improving communication skills and relational abilities in health care. *Pediatric Critical Care Medicine*, 10 (3) 352-359.
- Nay, R., Garratt, S., & Featherstonehaugh, D. (2014). *Older people: Issues and Innovations*, 4th ed. Sydney, NSW: Elsevier Australia.
- Nolan, M., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond 'person-centred' care: a new vision for gerontological nursing, *International Journal of Older People Nursing [in association with the Journal of Clinical Nursing]*, 13(3a), 45-53.
- Pepin, R., Williams, A.A., Anderson, LN & Qualls, S.H. (2013). **A preliminary typology of caregivers and effects on service utilization of caregiver counseling.** [Aging Ment Health](#). 2013;17(4):495-507. doi: 10.1080/13607863.2012.758232. Epub 2013 Jan 21.
- Rosenbaum, P., King, S., Law. M., King, G & Evans, J (1998), Family-Centred Service: A Conceptual Framework and Research Review. *Physical & Occupational Therapy In Pediatrics*. [18](#), (1), 1-20.
- Street, RL., Makoul, G., Arora, N.J., & Epstein, R.M. (2009). How does communication heal? Pathways linking clinician–patient communication to health outcomes. *Patient Education and Counseling* , 74, (3), 295–301.
- Toot, S. , Hoe, J., Ledgerd, R., Burnell, K., Devine, M., & Orrell ,M (2013). Causes of crisis and appropriate interventions: The views of people with dementia, care and healthcare providers. *Aging & Mental Health*, 17 , 328-335. <http://dx.doi.org/10.1080/13607863.2012.732037>.
- Winsett, R.P., & Hauck, S. (2011). Implementing Relationship-Based Care. *The Journal of Nursing Administration* Vol. 41, No. 6 June 2011

Table 1. The Epidemiology of Caregiver Burden

Domain/Feature	Risk Factor and/or Outcome Status of Caregiving
Demographic	
Female sex	Risk factor for becoming a caregiver and for caregiver burden (>2-fold rate of high caregiver burden compared with men) ¹¹
Low education	Associated with the highest levels of caregiver burden in various conditions, including stroke ¹²
Cohabitation with care recipient	Associated with caregiver burden
Clinical outcomes of caregiver burden	
Mortality	Caregiver burden identified as an independent predictor of caregiver mortality with a 63% increased risk of death ¹³
Weight loss	Caregiver burden associated with caregiver weight loss
Poor self-care	Higher incidence of low self-care behaviors and of ignoring self-health ¹⁴
Sleep deprivation	Especially common in caregivers of dementia patients who have disruption to the sleep-wake cycle and may also be a risk factor for caregiver burden
Psychosocial	
Depression and depressive symptoms	Identified as risk factor for and outcome of caregiver burden ¹⁵
Coping strategies	Using a smaller number of coping strategies (eg, seeking advice, exercising) associated with caregiver burden in caregivers of dementia patients ¹⁶
Perceived patient distress	Greater likelihood of experiencing caregiver burden in caregivers who perceive distress in the care recipient
Social isolation and decreased social activity	Risk factors for caregiver burden and outcomes of caregiver burden ¹⁷
Anxiety	An outcome of caregiving in caregivers to advanced cancer patients ¹⁸
Suicide	An outcome of caregiver burden
Caregiving context	
Caregiving time and effort	Duration in the caregiving role and hours spent caregiving associated with caregiver burden
Financial stress	A risk factor for caregiver burden and an outcome of caregiver burden ¹⁹
Lack of choice	Lack of choice in becoming a caregiver associated with caregiver burden ²⁰
Inability to continue regular employment	Caregiving may preclude regular employment; when more than 1 potential caregiver exists, the family member who is not regularly employed is more likely to assume the caregiving role

Table 2. Topics and Selected Questions for Caregiver Assessment

Category	Question
Context of care	
Caregiver relationship to care recipient	What is the caregiver's relationship to the patient? How long has the caregiver been in this role?
Family caregiver profile	What is educational background of the caregiver? Is the caregiver employed?
Additional caregivers	Are other family members or friends involved in providing care? Are paid caregivers (eg, home health aides) involved?
Living arrangements	Does the caregiver live in the same household as the care recipient?
Physical environment	Does the care recipient's home have grab bars and other adaptive devices and necessary equipment to assist with care? Is the care recipient homebound?
Caregiver's perception of care recipient's overall health	
Cognitive status	Is the patient cognitively impaired? How does this affect care provision?
Health, functional status, prognosis, and goals of care	What medical problems does the care recipient have? What is the caregiver's perception of the care recipient's medical problems and prognosis, and goals of care? What are the goals of care according to the care recipient?
Caregiving needs	Is the care recipient totally dependent 24/7 or is only partial assistance required? Is there evidence that the caregiver is providing adequate care?
Assessment of caregiver values	
Willingness to provide and agree to care	Is the caregiver willing to undertake the caregiver role? Is the care recipient willing to accept care provision?
Cultural norms	What types of care arrangements are considered culturally acceptable for this family?
Assessment of caregiver health	
Self-rated health	How does the caregiver assess his or her own health?
Health profile	Does the caregiver have any functional limitations that affect the ability to act as caregiver?
Mental health	Does the caregiver feel she or he is under a lot of stress? Is there evidence of anxiety, depression, suicidal ideation?
Quality of life	How does the caregiver rate his or her quality of life?
Impact of caregiving	Is the caregiver socially isolated? Does the caregiver feel his or her health has suffered because of caregiving?
Assessment of caregiver knowledge and skills	
Caregiving confidence	How knowledgeable does the caregiver feel about the care recipient's condition?
Caregiver competence	Does the caregiver have appropriate knowledge of medical tasks required to provide care (wound care, transferring patient, health literacy for administering complex medication regimen, etc)?
Assessment of caregiver resources	
Social support	Do friends and family assist the care recipient so that the caregiver has time off?
Coping strategies	What does the caregiver do to relieve stress and tension?
Financial resources	Does the caregiver feel financial strain associated with the caregiving? Does the caregiver have access to all financial benefits and entitlements for which the care recipient is eligible?
Community resources and services	Is the caregiver aware of available community resources and services (caregiver support programs, religious organizations, volunteer agencies, respite services)?

Adapted from the Family Caregiver Alliance,³² Zarit et al,³³ and Parks and Novielli.³⁴