An Affect Education Model for Caregivers: A Two-Person Centred Approach for Managing Behavioural and Psychological Symptoms of Dementia in Long-Term Care

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Faculty/Presenter Disclosure

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- Relationships with commercial interests: Nil
Disclosure of Commercial Support

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Mitigating Potential Bias

- Not applicable.
Background: Feelings of Front-line LTC Workers (G.P.A. Final Report, 2005)

- Many report feeling fearful, helpless, vulnerable.
- Preoccupied with worry about managing situations.
- Embarrassed by behavioural outbursts because might be perceived by others as incompetent.
- Unsupported and alone with burden of challenging residents.
- BPSD → caregiver stress

- Considered safer first-line approach (Best Practice Guidelines by many organizations in many countries, including Alzheimer’s Society of Ontario and Canada, IPA).

- Studies show only modest benefit in both reducing symptoms in PWD and caregivers.

- Even when combined with medication and environmental modifications.
Can the Effectiveness of Current Approaches be Enhanced?

- Behaviours: meaningful, responsive, attempts to communicate feelings/needs, and

- Change practice of primarily looking at person with BPSD as sole contributant to problems (aggressive or resistant to care).

- An emotionally stressed caregiver may respond in ways that elicits more difficult behaviour from PWD.
New Approach: Problems are Co-constructed
The 7 Question Affect Education Model
(Focuses on Understanding Emotions of Other and Oneself)

1. What am I feeling?
2. Why am I feeling this way?
3. What would I like to do or say?
4. What would be the consequences?
5. What is the other feeling?
6. Why is the other feeling this way?
7. What would my ego (or mature self) now do or say?

(Zeisel, 2009)
Example: Z is an 85-year-old man in LTC Wandering Hallways, Shouting “Help me, help me”.

1. What am I (the caregiver) feeling?
   “Frustrated, impatient, helpless”

2. Why am I feeling this way?
   “Nothing helps him stop and others are unaware or don’t appreciate how difficult this is ... I have other people to care for.”

3. What would I like to say or do to Mr. Z at this moment?
   “I can’t figure out what you want. If you don’t want anything, why do you continually call out? I’m going to lock you in your room and ask the doctor to sedate you, for your own good, of course.”

4. What effect would that have on the relationship?
   “I’d feel unprofessional and guilty. I should stop blaming you. If I calm down, maybe you’ll respond in a different way.”
5. **What is he (Mr. Z) feeling?**
   Umm. I’ve been too caught up in how I’m feeling to think about this. Maybe “Help me, help me” means “Help me find myself again” and he’s searching for help because he feels abandoned.”

6. **Why is he (Mr. Z) feeling this way?**
   “Mr. Z has lost a sense of who he is and of being cared for. It’s curious he’s so forgetful but he doesn’t forget to keep searching.”

7. **What would my ego (mature self) like to say to him now?**
   “I will pay more attention to you, not just your behaviour. I will empathize with your sense of feeling lost by calming down and saying in a non-rushed tone “You must be feeling lost and helpless...it must be hard not to find the help you’re looking for...Someone who was there for you and cared and helped you...I’ll try be there for you, and even though, you don’t understand my words, maybe you’ll respond to my gentler tone and understanding of you.”
So what does this model teach us?

- To focus on emotional/affective world of both individuals.

- It’s normal to feel impatient, frustrated or even angry at times. Hopefully, with the help of this approach we can CALM DOWN and reflect and understand what we’re feeling, rather than just react.

- ‘We all have feelings – it’s how we handle our feelings’ - that’s most important.
“It’s not just what residents and families do to us, it’s also what we do.”

When we accept personal responsibility, we (hopefully) stop blaming others and improved relationships/interactions occur.

“Sometimes we have to remind ourselves to pause for a moment and to reflect on how we feel. I believe that this contributes to developing as physicians (health care providers) – learning how to care for patients rather than to interact with diseases.” (Donix, AJP, 2016)

Client-centred care
Affect Education Model Research Pilot Study

- Nursing staff and personal support workers from 2 LTC homes taught the Affect Education Model over the course of 5 weekly 30 minutes group sessions

- Quantitative Measures:
  - 5 surveys administered before and after the affect education sessions and after a four months follow up (in just/LTC because of numbers)

- Qualitative Measures:
  - Focus groups conducted after the last affect education session.
Qualitative Data – Focus Group (30 minutes)

Study Participants

<table>
<thead>
<tr>
<th>LTC A</th>
<th>LTC B</th>
</tr>
</thead>
<tbody>
<tr>
<td>17 staff from all floors that had persons with dementia (PWD)</td>
<td>6 staff from the Transitional Behavioural Support Unit (TBSU):</td>
</tr>
<tr>
<td>• 7 personal support workers</td>
<td>• 2 personal support workers</td>
</tr>
<tr>
<td>• 5 registered practical nurses</td>
<td>• 3 registered practical nurses</td>
</tr>
<tr>
<td>• 1 registered nurse</td>
<td>• 1 registered nurse</td>
</tr>
<tr>
<td>• 4 unknown</td>
<td></td>
</tr>
<tr>
<td>• <strong>Two 45-minute focus groups, audio recorded</strong></td>
<td>• <strong>Two 20-minute focus groups, audio recorded</strong></td>
</tr>
<tr>
<td>• Led by on-site staff social worker</td>
<td>• Led by on-site research assistant</td>
</tr>
</tbody>
</table>
Focus Group Data Analysis

- Transcripts reviewed by research team
- Content analysis identified 4 common themes
Theme 1: Facilitators and Barriers Perceived in Current Care Delivery/Culture

LTC - A

Factors promoting care delivery:
- Strong team support, positive attitude and relationships

Barriers:
- new staff and PSWs either lack support or respond negatively to stress
- lack of management presence
Theme 1: Facilitators and Barriers Perceived in Current Care Delivery/Culture

**LTC - B**

Factors promoting care delivery:
- Culture of staff valuing clients and focus on being present and functioning as a team.

Barriers:
- Heavy workloads and schedules and on occasion hard not to take stress home.
Theme 2: Reflections on the Affect Education Model Teaching Experience

**LTC – A**

Staff appreciated:
- Safe/small group size where could freely express opinions
- Opportunity to share learning and client management strategies (case-based)
- Reinforced current practices by providing reminders of past learned strategies.
- A sense of improved resourcefulness for managing difficult clients and increased work efficacy (although no change on stress)
Theme 2: Reflections on the Affect Education Model Experience

LTC – B
- Sessions helpful in sharing ideas and being reacquainted with past training techniques
- Barriers to delivery of sessions:
  - Timing of sessions *not* favourable as during busiest day
  - Length of sessions *not* long enough, hindering opportunity to ask questions
  - Noisy environment – *nursing station in middle of unit* – making it difficult to focus
- (I took what I was able to get).
Theme 3: Impact of the Affect Education Model on Staff Care Delivery

**LTC – A: Positive**

- Heightened awareness of client’s needs and behaviours
- Increased sense of control of their emotions

**P:** “For me, to calm down and focus on understanding the resident’s need or family’s need...don’t lose your temper.”

- Greater preparedness as felt more equipped to assist less experienced colleagues

**P:** “Just realizing the emotional effect of the job on others, just stepping back and giving others a chance before I get in there thinking that I can do things. Just listening, just assessing...”
LTC – A: Positive continued

- Clients exhibited less responsive behaviour
- Colleagues more patient

P: “A lot of them (colleagues) are more patient, they try to analyze their resident as a whole, not just the behaviour at the time. So that’s improvement.”

P: “I like that this model is teaching that when you walk into the situation and you’re frustrated and don’t know where to start, and you’re going off...”

P: “Now you step back and think.”

P: “But before, I take it.”
Theme 3: Impact of the Affect Education Model on Staff Care Delivery continued

**LTC – A: Concerns**

- remembering to use strategies when faced with more aggressive clients.

**P:** “If the resident doesn’t want to get up at 7:30 – 8 a.m., you cannot force her, no matter how gentle and calm you are.”

- (Yes, can only do the best you can)
Theme 3: Impact of the Affect Education Model on Staff Care Delivery continued

**LTC – B: Similarities – Positive**

- Heightened awareness of their emotions and increased awareness of clients’ and one’s own needs and behaviours

**P:** “For instance, one patient where it would take 45 minutes to give meds... To be thoughtful, this is the patient, this is my emotions, how I’m feeling.”
Theme 3: Impact of the Affect Education Model on Staff Care Delivery continued

LTC – B: Similarities - positive

- Greater preparedness as felt more equipped with strategies in managing clients and assisting colleagues

P: “It also helped us acknowledge the fact we’re only humans and sometimes our colleagues get frustrated as well and in that instance, as part of the team, you’re able to help your colleagues, when you see that they are frustrated.”
Impact of Model on Staff Care Delivery, continued

LTC – B: Similarly

- A few staff expressed concern about remembering the strategies when faced with more difficult clients, complex situations, or their own stress.

P: “This is a behavioural unit...so applying this method doesn’t always work on this floor, because you know it’s just the nature of the floor. We have all kinds of problems here.”

P: “Sometimes when you haven’t eaten, it’s kind of hard to regulate your emotions, but I think it’s helpful.”
Theme 3: Impact of the Affect Education Model on Staff Care Delivery, continued

LTC – B: (Similarly/Differently)

- Sessions improved previous understanding of model and knowledge consolidation

P: “Applied throughout. I have more understanding now than before.”

- Others did not find model particularly helpful.

P: “It did not help. Nothing came from it, but I’m just more mindful.” (That’s good!)
Theme 4: Future Affect Education Model Implementation

**LTC – A**

- Dissemination strategies where trained staff would approach and mentor new or less experienced staff

- Future refresher sessions

- Model be available to staff of all disciplines, including part-time workers

- An overall sense of appreciation of model and interest in how findings would translate, “We want our input out there...because we just don’t want to be here like sharing emotions and then not seeing results at the end.”
Theme 4: Future Affect Education Model Implementation

**LTC – B: Similarly**

- Described communication strategies to ensure all staff are aware of strategies and to remind staff of model’s techniques
- Handouts
- Poster of model on wall
- To adapt teaching of sessions to schedules of all staff shifts
- Longer duration, off-site, better time for each shift
- Quieter, small environment
- Teaching to staff of other units as these staff also encounter clients with responsive behaviours
Qualitative Study Limitations

- Difficult to determine whether thematic saturation achieved as only 2 focus groups in one site conducted and in LTC – B, 3 participants could not stay for full intended duration due to the constraints in their shifts schedule.

- Other stresses could not be controlled for, which limited number, length and location of sessions, as well as morale between sessions.
Quantitative Methods (Only from LTC-A)

- Selected 13 items from the 5 questionnaires for analysis
- Descriptive summaries
- Fisher’s exact and Wilcoxon tests for group comparisons
- Paired t-tests to assess change in item scores between two time points
- Cohen’s D(av)\(^1\) to estimate effect sizes
- Mean profile models\(^2\) were used to assess whether any baseline participant characteristics were associated with changes in item scores across all time points with an adjustment for repeated measures within individual.
- Sensitivity analyses for each of the mean profile models using multiple imputation to assess impact of loss of follow up

\(^1\) Lakens D., Calculating and reporting effect sizes to facilitate cumulative science: a practical primer for t-tests and ANOVAs. Frontiers in Psychology 2013 Volume 4 Article 863.

\(^2\) Fitzmaurice GM, Laird NM, Ware JH. Applied Longitudinal Analysis, 2\(^{nd}\) Ed. 2011 John Wiley & Sons, Inc.
Study Participation

- 57 participants enrolled into the study at the LTC A site
- 14 participants were excluded from the analysis sample
  - 3 did not complete the baseline assessment
  - 11 due to data quality issues (e.g. missing or incorrect assessment dates)
- 43 remained in the analysis sample
  - 34 had measures at all three time points
  - 7 were lost to follow up (1 had pre measures only and 6 had pre and post measures only)
- There were no statistical differences between the baseline characteristics of those included in the analysis sample versus those excluded
  - p-values ranged from 0.13 to 0.89, results not shown
- Study conducted from September 2015 through May 2016
Baseline Characteristics (N=43)

- Mostly female (97%)
- Average age was 47.4 (SD=9.3)
- Had at least some college or university education (78%)
- English was their primary language (62%)
- Personal support workers (PSW) (55%), nurses (45%)
- Most worked the day shift (55%)
- Most had **previous** training to manage BPSD (68%)
- Average years in practice:
  - 14.1 years (SD=8.5) of practice in LTC
  - 11.6 years (SD=9.1) working with individuals with BPSD
  - 6.5 years (SD=7.8) as an LTC community PSW
Questionnaires:

1. Inventory of nursing self efficacy
2. Maslach Burnout Inventory
3. Attitudes of Health Care Personnel Towards Demented Patients Questionnaire
4. Nursing Care and Work Assessment Scale
   - All non-significant
5. Staff Satisfaction Questionnaire
Conclusions From Quantitative Study

- There was evidence that the Affect Education sessions improved participants’ sense of safety related to their jobs
  - younger participants considered their job to be less safe compared to older participants
- There was evidence that the Affect Education sessions improved participants’ sense of job satisfaction
  - those with shorter durations working as a PSW characterized their job as more frustrating
  - (Not surprisingly, new/inexperienced staff benefit most)
- Other group differences:
  - participants who have worked longer as a PSW generally reported feeling less strain in contact with people with BPSD
  - participants who worked longer with individuals with BPSD were more likely to disagree with ‘I seldom have to try and understand what the patients/residents think about care’
- There was little to no change in the other selected items across time
  - other associations between items and demographic characteristics were not confirmed in the sensitivity analyses which assessed the impact of missing item responses due to loss of follow up
Quantitative Study Limitations

- Small analysis sample size from one site only who stated were functioning, trained experienced team
- Limited statistical power and generalizability
- Missing data issues related to:
  - incomplete baseline assessments (including demographic data)
  - linkage of survey responses across time
  - incomplete responses to all items in questionnaires
  - loss of follow up
- **Difficult for study participants to be able to attend Affect Education sessions and complete assessments**
  - came late, left early, skipped sessions
  - Difficulty in finding proper scales that measured changes that occur
Thank you.

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