Developing and Pilot-testing a Finding Balance Writing Intervention for Older Adults who are Bereaved after Caregiving

2012 Saskatchewan Hospice Palliative Care Provincial Conference
Moose Jaw, SK
May 31, 2012
Lorraine Holtslander, RN, PhD, CHPCN(c)
Acknowledgements

- The participants
- SHRF New Investigator Grant (2009-2012)
  - Team members: Wendy Duggleby and Ulrich Teucher
- Saskatoon Health Region- Meredith Wild, Janet Martens, Ruth Eliason
- Regina Qu’Appelle Health Region- Dan Cooper, Marcia Sehn, Louise Cadrin
- RN-Research Assistants: Jill Bally, Tammy Gebhardt, Leslie Sparling, Jessica Solar
Background

- Cancer caregiving trajectory tends to be very intense, involving symptom management and steep declines at the end of the patient’s life (Lunney, et al, 2003)
- At 3 months bereavement, 33% of family caregivers (average age 66 years) had clinically significant scores for depressive symptoms and complicated grief (Holtslander and McMillan, 2010)
Background

- Family caregivers are affected by the death of the person as well as the caregiving experience itself (Stajduhar, Martin, and Cairns, 2011)
  - Caregiving strains
  - Relationships
  - Finances
  - Lack of information, services, supports
Background

- Distinct lack of evidence-based interventions
- Writing as an intervention has shown benefit
- “searching for new hope” involved finding balance as a first step (Holtslander and Duggleby, 2009)
- Need for an array of evidence-based approaches to support positive outcomes after the caregiving experience (individualized, tailored to unique needs and situations)
Finding Balance Grounded Theory

- Processes of finding balance
- Grounded theory study with 10 bereaved caregivers (7 women, 3 men)
“Walking a fine line” (Holtslander, Bally, and Steeves, 2010)

Figure 1: The Basic Social Process of Finding Balance: “Walking a fine line”

Walking a fine line

Deep Grieving
- Regrets
- Emptiness
- Solitude
- Physical challenges

Moving Forward
- Being thankful
- Planning the day
- Reaching out
- Taking care of myself

The bereaved caregiver:
- Support
- Spirituality
- Writing
- Walking
Delphi process

- Based on a theory of the intervention (Sidani and Braden, 2011)
  - What aspects of the problem are amenable to change?
  - Identification and choice of treatment activities for each process
  - Tailored, personally relevant information
- International expert consultant (Dr. Robert Neimeyer)
- Local bereavement experts
Conceptual framework

- Dual process model (Stroebe and Schut)
The Finding Balance Intervention

- Self-administered writing tool
- Information from other older adults bereaved after caregiving
- Specific writing activities to address “walking a fine line”, “deep grieving” and “moving forward”
Pilot-testing the FBI

- Mixed methods approach
- Saskatoon and RQHR
- 23 participants recruited
  - 10 control
  - 13 treatment (4 withdrew after 1st visit)

Age range 61 to 85 years (average 73)
Caregiving average of 15 months
Most were of Catholic faith
Pilot-testing the FBI

- Demographic form
- Herth Hope Index
- Hogan Grief Reaction Checklist
- Inventory of Daily Widowed Life
Pilot-testing the FBI

1. What was it like to be part of this study?
2. Was there anything that helped you to participate?
3. Was there anything that hindered you from participating?
4. What did you like best about the “Finding Balance” intervention?
5. What did you like least about the “Finding Balance” intervention?
6. Were there parts of the intervention that you found helpful, or not helpful? Why were they helpful or not helpful?

7. Did you find the Herth Hope Index, the Hogan Grief Reaction Checklist, the Inventory of Daily Widowed Life and the Finding Balance Scale easy or difficult to complete?

8. How can the “Finding Balance” intervention be improved?
Pilot results

Evaluating the study procedures

- Recruitment rates low
- HGRC was dropped after 3 withdrawals
- Difficult to complete the quantitative measures
- Changes were made when possible and will be part of the larger proposal
- Quantitatively unable to detect a change in scores (averages unchanged across groups)
- Many confounders identified (illness, moving, family stress)
Pilot results

Interview/qualitative data was mostly positive

- “It helps to remember by writing it down”
- “Thinking, doing, being helped”
- “I didn’t find it difficult… it was always in the back of my mind that you have to think about this…”
- “Whereas, this is more of a structured thing focused on what you can do to make sure you do have balance in life, things that you might be missing and need to look at.”
Pilot results

- “I really opened up, I really opened up to everything that was in the book to express my feelings and everything. I was apprehensive at first thinking how is this going to help me, but you know it has. It really has. When you first came, this first section and then reading this book, I thought oh man, this is a lot of stuff in here. And then when I started scratching it down it just really helped to get it out… “
Themes from the pilot data: Timing of the intervention

- “some of those questions kind of took me back...this is something that I have to think about that I never did before. I think it’s a good tool. It really is. I just hope that it helps other people like it has helped me.”
- “No it came, I think, at the right time...The timing was a big factor. The first month would have been bad.”
Themes from the pilot data: Timing of the intervention

- “It probably would have been a really good thing if I would have had it right after his death. I think it would have been better then. This way I found handling it now was a little difficult, but I think it would have been a better experience very shortly after his death.”
Themes from the pilot data: Process of focusing on new ideas in finding balance:

- “It was positive. It made me aware of what I have to do and what I shouldn’t do… because I haven’t thought about it [that way]”
- “It made me focus on the idea of finding balance, like looking for balance in my life that I hadn’t really focused on… this is more of a structured thing focused on what you can do to make sure you do have balance in life, things that you might be missing and need to look at.”
Themes from the pilot data: Process of focusing on new ideas in finding balance:

I thought the question *‘are there ways in which you have grown as a person?’* was a good one. I hadn’t thought about that before, and what changes there might have been in some of your belief systems you might have, and what your belief system is… Well, like I said before it made me think about concentrating on the balance part. I’ve been trying to fill in all the spots but now I’m thinking well how balanced are you really… in the last two weeks I’ve sort of paid more attention to where I’m at and what I’m doing.”
Themes from the pilot data: Validation of feelings and helping themselves

- “I really opened up, I really opened up to everything that was in the book to express my feelings.”
- “...it makes me think about the way it’s presented in the book, it sort of validates how you feel that it’s not just me, I’m not the only one, I’m not alone in this, and other people have similar experiences.”
Themes from the pilot data: Validation of feelings and helping themselves

• “I think the book made me aware of the fact that nobody can help me, I have to help myself. It spurred me on to think that way. I mean when you have questions that say “how do you want to get better? How do you want to get rid of these emotions that you have? How are you going to go about it?” What are you going to do, are you going to do this or do that? It kind of brings you to that point in your life where you say to yourself “Well I’ve got to do something”
Pilot results

- Not everyone was comfortable with writing, or being “reminded about thoughts”
- Some editorial changes needed, rearranging the sections
Next steps

- Pilot testing has provided important information to further refine the intervention and the study design
- A larger study, begin recruitment during the caregiving experience and follow into bereavement
- Measures changed to grief (short TRIG), hope and depression
Next steps

- Assess caregiver risk prior
- Examine health and bereavement outcomes, health services utilization
- Age, gender, different diseases
• Questions?
• Comments?
• Suggestions?