

## Nurturing Hope at the End of Life

Workshop  
16<sup>th</sup> International Congress on  
Care of the Terminally Ill-  
Montreal Sept. 29, 2006.



## Presenters

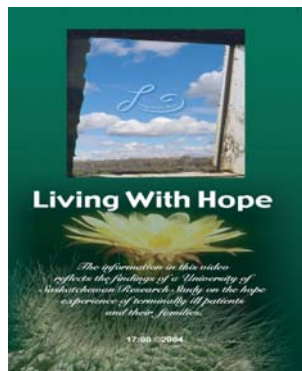
- Wendy Duggleby, DSN, RN, AOCN
- David Popkin, MD, CM, FRCSC, FSOGC, FACOG
- Lorraine Holtslander, PhD (c), RN
- Dan Cooper, MDIV
- Karen Wright, PhD, RN



<http://www.usask.ca/nursing/research/livingwithhope>

## Workshop

- “Living with Hope” DVD
- Case Study
- Evidence Based Ways to Foster Hope:
  - Palliative Patient
  - Family Caregiver
  - Health Care Professional



Gold Camera Award International Film Competition 2005

## Case Study A Physician's Perspective on Hope

Dr. David Popkin  
Vice-President Care Services  
Saskatchewan Cancer Agency

## Mrs. J.P.: Hope Not Cancer

- September 2004: Advanced Ovarian Cancer
- September 16: Total Abdominal Hysterectomy and Bilateral Salpingoophorectomy, omentectomy and multiple peritoneal biopsies
- *Mrs. J.P. and her family hoped that she did not have cancer*

## Mrs. J.P. Hope for a Cure

- October 15 :First Chemotherapy
- Good response to chemotherapy
- *Mrs. J.P., her family and her oncologist hope that her chemotherapy would cure her cancer*

## Mrs. J.P.: Transforming Hope

- May 25 CT Scan confirmed recurrent of the ovarian cancer.
- Oncologist informed her that cure was no longer a realistic hope
- *Mrs. J.P., and her family found it hard to accept that cure was now beyond reach. With the help of others they still hoped for a cure, but also hoped for comfort.*

## Hope: Leaving Something Behind

- Over the next year Ms. JP was placed on three different treatment regimes which failed.
- With the crisis and distress associated with this Mrs. J.P. and her family found it more difficult to maintain their hope.
- December 2005 I turned to our research

Leaving Something Behind:  
Choose One of These:

#1 Write or ask someone to help you write one or more letters to someone:



#2 Begin a Hope Collection:



#3 Begin an "About Me" Collection

## Begin an "About Me Collection"

- December 2005: Mrs. J.P. began writing in a journal something very personal in her life that she might want to share with her children, thus leaving a legacy.
- January 2006: The hope activity greatly improved her hope.

©LWH

## Mrs. J.P: Hope for Short Term Goals

- Started 4<sup>th</sup> line treatment: free of pain
- Her goal was to attend her daughter's wedding in February 2006 and son's wedding in July 2006.
- Attended Daughter's Wedding: February, 2006

## Mrs. J.P." Hope for comfort and peace and family

- May: Cancer progressed
- Focus on quality of life, no more cytotoxic drugs.
- Palliative Home Care
- Attended Son's Wedding
- Mrs. J.P's hope was for comfort and peace at the end of life and her family's future.

## Aspects of Spiritual Assessment and Hope-based Care Planning Mrs. J. P.

*Rev. Dan Cooper, MDiv.  
Palliative Care Services  
Regina Qu'Appelle Health Region*

## MQOL Existential Sub-Scale and Hope

In our most recent study, 60 terminally ill elderly cancer patients cared for at home in Saskatchewan were randomly assigned to a group utilizing the Living With Hope Program or to a control group:

- The treatment group reported significantly higher scores on the MQOL existential subscale than the control group.
  - This subscale (items 9 – 14) is a measure of meaning, life fulfillment, self-worth, control and enjoyment of life)
- The treatment group also reported significantly higher scores on the HFI temporality and future subscale than the control.
  - This subscale is defined as having goals and a positive outlook on life

Duggleby, W., Degner, L., Williams, A., Wright, K., Cooper, D., Popkin, D., and Holstlander, L. (2006). Living with Hope: Initial evaluation of a Psychosocial Hope Intervention for Older Palliative Home Care Patients. Submitted for publication (*Journal of Pain and Symptom Management*).

## Source of Hope May Be Unrelated to Treatment

"In a recent survey of more than 7,500 patients, 70.6% indicated that it was faith/God/Higher Power contrasted with 28.5% who saw their treatment as a source of hope."

Rodrigues, B., Rodrigues, D., and Casey D. L. (2000). Spiritual needs and chaplaincy services: A national empirical study on chaplaincy encounters in health care. Medford, OR: Providence Health System, 76 pp. Cited in Driscoll, J. (2001). Spirituality and religion in end-of-life care. *Journal of Palliative Medicine*, 4 (3): 333.

## CHPCA Definition of Spirituality

**"An existential construct inclusive of all the ways in which a person makes meaning and organizes his/her sense of self around a personal set of beliefs, values and relationships.**

**This is sometimes understood in terms of transcendence or inspiration. Involvement in a community of faith and practice may or may not be a part of an individual's spirituality."**

Ferrie, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., West, P. (2002, March). A model to guide hospice palliative care: Based on national principles and norms of practice. Ottawa, ON: Canadian Hospice Palliative Care Association.

## Community Religious Connection

- Mrs. J. P. is a Roman Catholic who has not attended church regularly.
- She has turned to family and friends for support for the most part.
- She met with Fr. X of St. X's RC parish in Saskatoon for spiritual guidance on one occasion. It is likely that this priest will be called upon to assist with a memorial service when this is required.

## Personal Spirituality

- Mrs. J. P.'s spirituality appears rooted in her relationships with family and friends.
- Golf is an important activity, suggesting a spirituality connected to nature.
- She is not actively religious but has access to religious services as required.

Cooper, D. (2006, August). Existential Needs and the Spirituality of Golfing / Just One More Round of Golf. [Case Studies]. Developing Spiritual Care Capacity for Hospice Palliative Care: A Canadian Curricular Resource (Version 1.0). © The Pallium Project. Available from <http://www.chc.ca.net/marketing/pallium.htm>

## Hope Note: Relationships and Goals

- Attending her daughter's wedding in February, 2006 was an important goal.
- A further goal was to travel to California to attend her son's wedding in July, 2006. She was successful in achieving her second short term goal. She just returned to Saskatoon.)

## Hope Note: Legacy Work

- Mrs. J. P. improves her ability to cope with her eventual death by journaling.
- She plans to leave her journals as a legacy for her family.

## Recommendations: Explore Spirituality

- Exploration of aspects of personal spirituality (both patient and family members) might prove beneficial in identifying sources of hope, meaning and purpose
  - E. g. supporting patient's capacity to enjoy golf for as long as possible may be an important team hope-based intervention for patient and family

## Recommendations: Further Legacy Work

- Further discussion of legacy work – e. g. videos, letters, give-aways, etc. – would be appropriate and might further support her hope-based work which is evidently energizing for her

## Recommendations: Further Hope Work

- LWHP might assist the patient to enhance and maintain hope, particularly as she continues to transition from hope for a cure, to hope for longevity, to hope for a better death

Cooper, D. (1999, May 13-15, unpublished). *The transformation of hope*. A presentation to the Hope Research Forum, Rays of Hope: Approaching the 21<sup>st</sup> Century. Canadian Association of Psychosocial Oncology, Edmonton, Alberta.

Duggleby, W. and Wright, K. (2005). Transforming hope: How elderly palliative patients live with hope. [Electronic Version]. *Canadian Journal of Nursing Research*, 37(2), 71-84.

## Last Plans

- When Mrs. J. P. appears prepared to discuss memorial service plans, she might be encouraged to contact her religious resource person for advance planning, as this often proves helpful in preparation for a peaceful death.
- Memorial planning may be perceived as an achievable goal, supportive of relationships, a means of closure and as an affirmation of personal spirituality

## Mrs. J.P's Family's Experience of Hope

Lorraine Holtslander, PhD (c) ,RN  
College of Nursing

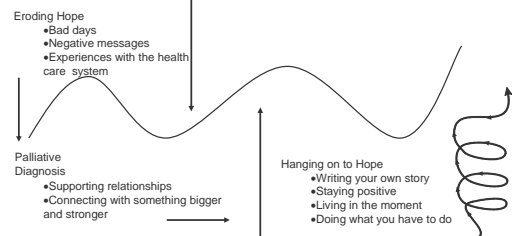
## The Family Caregiver's Experience of Hope

- Grounded theory research, 10 caregivers interviewed, 18 interviews, conducted by the researcher, Master's thesis research
- Research funded by CIHR
- Holtslander, L., Duggleby, W., Williams, A. W., Wright, K. (2005). The experience of hope for informal caregivers of palliative patients. *Journal of Palliative Care*, 21(4), 285-292.

## Research Findings

- Hope was defined by the participants as inner strength that gave them the courage and ability to go through a difficult situation. Hope was dynamic and a choice.
- Main concern: "Eroding hope"
- Basic social process: "Hanging on to Hope"
- Focus of hope for the patient, themselves, and their families. They wanted to do a good job, to not give up.

## The Process of Hanging on to Hope for Informal Caregivers of Palliative Patients



## Stories of the Present



Take 5 minutes near the end of the day to reflect

Everyday, write in this binder; try to focus on:  
*Reflections*  
*Challenges*  
*What gave you hope today*

Remember to focus on *your* experiences  
This is about you right now  
Write about your day in any way you'd like;  
use point form if you'd like  
Don't worry about grammar or spelling

## Results

- 5.5 journal entries per week
- 9.28 minutes per day on journals
- Video helped them understand hope
- Described journals as easy, short and simple to do.

## Results

- Salient Points:
  - Found hope in different ways
  - Looking for positives
  - Benefit of concentrating on themselves
  - Finding a bigger picture

## Implications for Practice

- Pay attention to the caregiver's experience of hope – the fluctuations, erosions, importance of spirituality and support to hang on to hope
- Encourage and support recharging – specific activities to maintain hope
- Providing information – including family in decision-making, preparing for the future
- Fostering a positive approach – goals, legacy, refocusing
- Offer and respect choices – encourage "writing your own story" allow for individuality, control,
- Foster family relationships – facilitate important family events, provide counseling if needed

## Mrs. J.P's Professional Caregivers' Experience of Hope

Dr. Karen Wright  
College of Nursing  
University of Saskatchewan

## Palliative Care Health Care Providers' Descriptions of Hope

- Mixed method quantitative, qualitative study of 113 palliative care workers.
- Participants completed HHI, demographic questionnaire, open ended questions.
- Purpose of study
  - To explore and describe palliative health care providers' descriptions of hope.  
(nurses, physicians, social workers, aides, administrators, volunteers pastoral care, etc)

## Open ended survey questions

- How do you describe your hope?
- Under what circumstances do you feel the greatest hope when working/caring for patients and families?
- When do you feel the greatest hopelessness when caring/working with patients and families?
- Give an example of how hope helped you care/work with patients and families.
- What enhances your hope. What drains your hope?

## Qualitative Research Findings

- **Hope as peace**
  - “My hope is for peace”
- **Hope as a positive future**
  - “Hope is the light at the end of the tunnel”
  - “Hope is that the future is better”
- **Hope as spirituality** (faith and finding meaning and purpose)
  - “Faith in something better”.
  - “Hope is finding meaning and purpose in what you are doing”.

## Research Findings (cont')

- **Hope is about making a difference**
  - “To make someone’s day better gives me hope”.
  - “Hope is looking at a situation and feeling I am able to change something to make things better”.
- **Identifying symbols of hope**
  - “bright sunshine, warm breeze etc”

## How Hope Assists Caring/ Working With Patients/Families

- **Provides a environment for positive communication.**
  - “it helps to develop a relationship with patients”.
  - “Helps patients and families go through the grieving process”
- **Provides a place to offer hope**
  - “My own hope allows me to see patient’s life beyond their illness. It helps me see small miracles that may otherwise gone unseen”.

## ■ Hope helps to provide comfort

- “Hope assists in managing symptoms and seeing your patient comforted”.
- “The hope I have has given me inner peace to be able to care for palliative clients with empathy and provide comfort”.

## Factors Hindering Hope

- Feeling that I am not making a difference.
- When patients have no faith or beliefs.
- When there aren’t sufficient resources to fulfill patient’s needs.
- When there is no peace, or acceptance and patients are not ready to die or accept their fate.
- When pain is not controlled.
- When there is non supportive relationships in the family or other health professionals.

## Implications for Practice

- Creating “hope focused” environments in palliative care settings
  - Exploring factors that are conducive to fostering hope in palliative care professionals
    - Hope focused workshops for professionals
    - Identify and develop hope strategies and interventions in the workplace
- Exploring hope with patients and families
  - Creating opportunities to identify, foster, and maintain hope throughout the palliative care experience
    - Hope symbols, hope strategies etc
- Further hope research with professionals

## Signs of Hope



“Although illness brings chaos and undermines hope in life, we seek to comfort those who are ill whether or not they can be physically cured. We do so by being a sign of hope so that others might live and die in hope.”



Cardinal Bernardin (2000), cited in *Catholic Health Association of Saskatchewan Communiqué*, 16:1