# Changes Toolkit for Rural Palliative Care Patients and their Family Caregivers

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- Trainee on this grant

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# BACKGROUND

- End of life care in rural areas is suboptimal ( Kelley, Habjan & Aegard, 2004; McConigley, Kristjanson & Nikoletti, 2001)

- Paucity of research available regarding rural older palliative care patients (Robinson et al., 2009)

- Increasing recognition that palliative care and end of life care involves complex transitions (Marsella, 2009; Burge, Lawson, Critchley & Maxwell, 2005)

# BACKGROUND

- Transitions are ongoing processes characterized by change for an individual (Olsson & Ek, 2002)

- Transitions cause dislocation, disorientation, and disruption leading to confusion and trauma ( Kralik, Visentin & van Loon, 2006; Ronaldson & Devery, 2001)

- Lack of evidence-based tools

# RESEARCH ON TRANSITIONS

The research on transitions in palliative care generally focuses on two types:

a)    The transition into receiving palliative care (Bolmsjo, 2008)

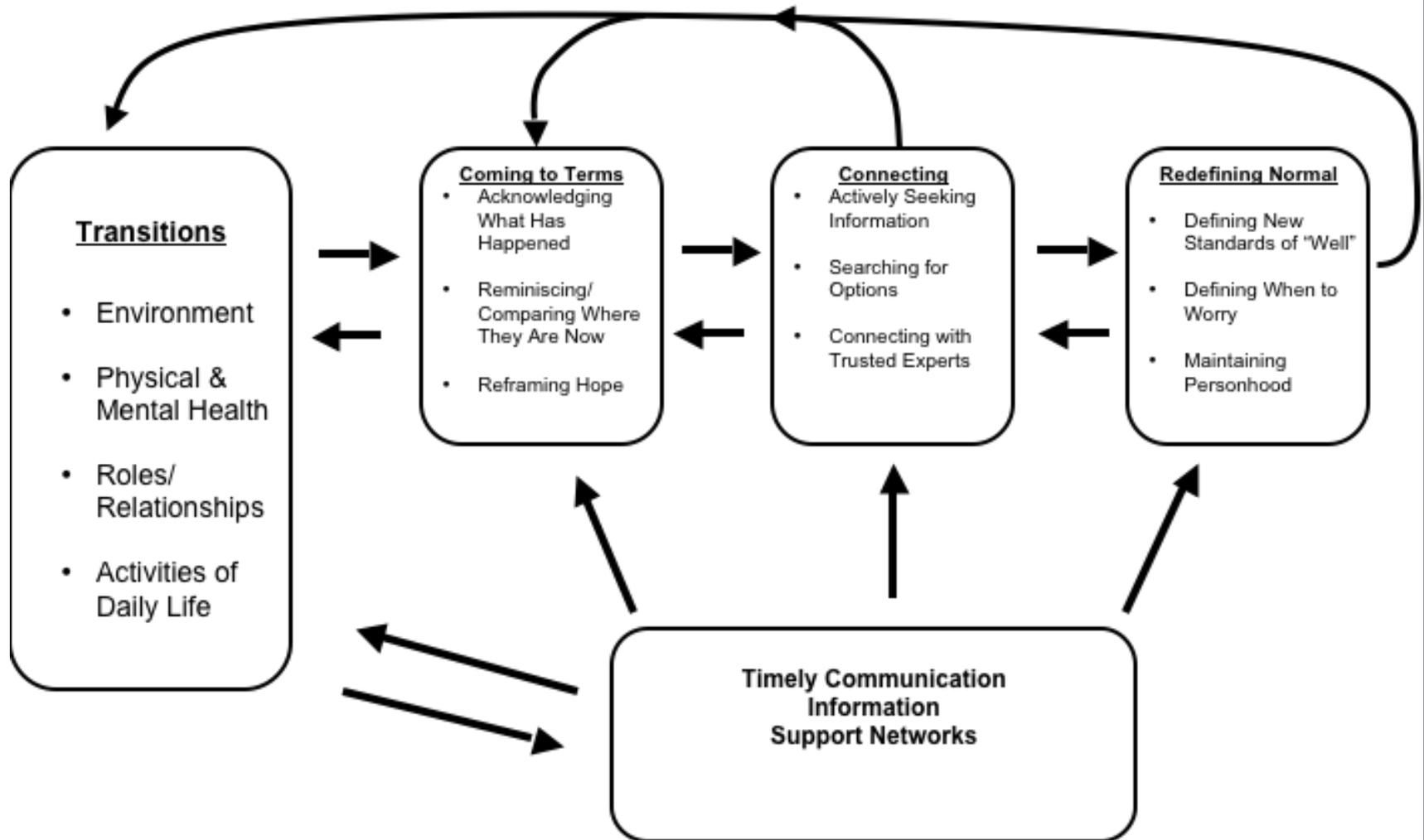b)    Health systems transitions (Burge et al., 2005; Lawson, Burge, Critchley & McIntrye, 2006)

# PURPOSE

To develop and pilot test a Transition Toolkit suitable for terminally ill patients and their families that supports them during transitions

# Step 1

## Developing a Theoretical Understanding:

## Qualitative Study of Transition Experience

# Transitions of Persons with Advanced Disease and Their Care Givers



**Transitions**

- Environment
- Physical & Mental Health
- Roles/ Relationships
- Activities of Daily Life

**Coming to Terms**
- Acknowledging What Has Happened
- Reminiscing/ Comparing Where They Are Now
- Reframing Hope

**Connecting**
- Actively Seeking Information
- Searching for Options
- Connecting with Trusted Experts

**Redefining Normal**
- Defining New Standards of "Well"
- Defining When to Worry
- Maintaining Personhood

**Timely Communication Information Support Networks**

# Step 2:

# Development of Tool Using 3-Phased Delphi with an Expert Panel

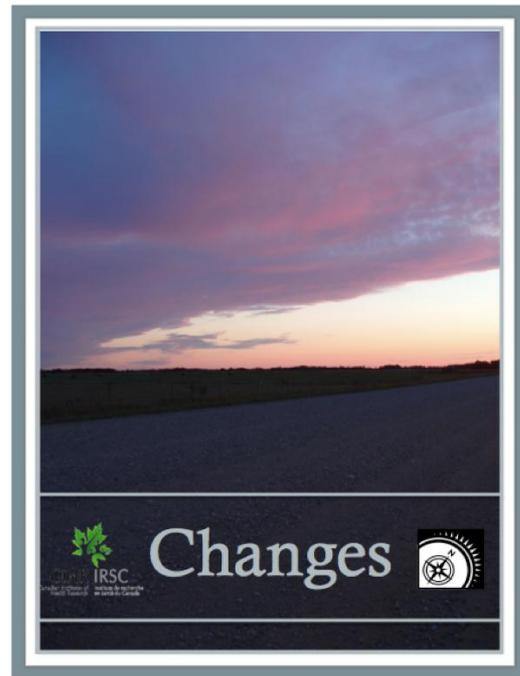- Phase 1:  Free brainstorming based on theory

- Phase 2:

    The comprehensive list of strategies were ranked for effectiveness by expert panel

    The top 3 strategies in each theme area were distinguished for phase 3

- Phase 3:

    The top 3 ranked strategies from each section were sent to expert panel for comments and opinions of whether or not they agree

# CHANGES

# Step 3:

## Pilot Testing of Changes Tool for Palliative Patients and their Family Caregivers

# PURPOSE

- The purpose of this pilot study was to evaluate the "Changes" tool for ease of use, feasibility, and acceptability for palliative care patients and their family caregivers in rural communities

- An additional aim was to evaluate the study procedures to determine if they were realistic and workable

# RECRUITMENT

- Recruited through the Saskatoon Health Region Palliative Home Care Program
- Recruited through the Cross Cancer Institute Pain and Symptom Palliative Clinic
- 8 palliative care patients and 8 family caregivers participated
- Patients diagnoses: COPD (n=1) and Ca

# DATA COLLECTION

**Initial Visit**

Obtain informed written consent  (patient and caregiver).

Complete demographic forms,

Explain tool with standardized instructions and present binder.

Schedule second visit.

**Second Visit (approximately one week later)**

Obtain checklist of activities worked on and time spent on each.

Complete "Changes" Transition Tool Evaluation Questionnaire

Qualitative  Open ended  Evaluation Interview

# RESULTS

Context of Pilot Study

- Acceptance of rural living
- Difficulty with access to services
- Driving distances

# RESULTS

| | Question | Mean (STD). Score (min-max) |
|---|---|---|
| Ease of use | Were the directions clear? | 4.4 (.5). (4-5) |
| | Were you sure of what you were expected to do? | 4. 4 (0.9). (3-5) |
| Feasibility | Did you have the energy to complete what you wanted to? | 3.2 (1.1). (2-5) |
| | Were you able to complete the activities you wanted to? | 3.0 (1.8). (1-5) |
| | Did you have time to carry out the activities you wanted to? | 4.0 (1.1). (3-5) |
| Acceptability | Do you feel working with the Changes binder increased your ability to deal with transitions? | 3.7 (1.2). (2-5) |
| | Would you do it again ? | 4.3 (1.1). (3-5) |
| | Would you recommend to someone else? | 4.4 (0.8). (3-5) |

# RESULTS

Evaluation Interview

- Connecting with others
- Helpfulness of binder
- Recommendations

# RESULTS

## THEMES

- Overwhelming Change
- Being Taken Care Of
- Connections
- Giving Back

# Overwhelming Change

- Changes or transitions a large part of the study participant's lives

- "And isn't it strange how your yesterday's normal is not today's normal?"

# Being Taken Care Of

o Quality of communication affected palliative patients and their family caregivers feeling well taken care of or not

o "I have to say that it has made it easier for me this past winter just to know there was somebody there somebody that cared someone with knowledge as well as uh resource."

o "I wish the medical professionals would care more about their patients, because some day it may be them in the system waiting in waiting rooms and waiting for test results, not getting answers and getting the run around."

# Connections

- Connections with family were important

- "If not connected to your family, you rely on healthcare more, and it's not always able to fill in the gaps [like family can]."

# Giving Back

- Sense of altruism

- "Well you know, if it helps somebody else, it's well worth my time, so you know it's not that, there's other people, there's hundreds of people going through the same thing."

# DISCUSSION

## Evaluation of Changes

- Data suggests that "Changes" was easy to use, feasible and acceptable
- Both sets of data beneficial to revise tool

# DISCUSSION

Overwhelming Change

- All participants dealing with transitions
  (Khalili, 2007; Schumacher & Meleis, 1994; Duggleby et al, 2010)

- Difficulties in dealing with transitions
  (Marsella, 2009; Grunfeld, Folkes & Urquhart, 2008)

- Rural patients wish to remain in home communities (Wilson et al., 2009; Evans, Stone & Elwyn, 2003)

# DISCUSSION

Being Taken Care Of

- Health care provider communication and quality end of life care (Royak-Schaler et al., 2006; Cherlin et al., 2005; Heyland et al., 2006)

- Communication outcomes: positive versus negative (Grunfeld et al., 2008)

# DISCUSSION

Connections

- Valuable to both palliative patients and family caregivers (Hudson & Payne, 2011)

- Roles and relationships (Khalili, 2007; Duggleby & Berry, 2005; Schumacher & Meleis, 1994))

- Factors affecting disconnection (Khalili, 2007)

- New finding in resilience

- Family caregivers play a critical role (Waldrop, Kramer, Skretny & Milch, 2005; Bolmsjo, 2008; Duggleby et al., 2010)

# DISCUSSION

## Giving Back

- Literature supports the sense of altruism displayed by study participants (White, Hardy, Glishenan, Charles & Pinkerton, 2008; Kendall et al., 2007, Dobratz, 2003; Ross & Combleet, 2003)

- Study participants really are giving back (Heyland et al., 2005; White & Hardy, 2010)

# DISCUSSION

Rural

- Issues of driving distances supported in literature (Hughes, Ingleton, Noble & Clark, 2004; Goodridge, Hutchinson, Wilson & Ross, 2011)

- Previous research describes palliative care services in some rural areas as limited, however, data obtained from all study participants regarding palliative care personnel and services suggesting otherwise (Kelley et al., 2004)

# LIMITATIONS

- Sample characteristics
- Challenges researching palliative population
- Study design

# IMPLICATIONS FOR PRACTICE

- Revision of tool based on palliative care patients and their family caregivers
- Supporting patients through transitions is an important nursing function and "Changes" is a tool to aide this function
- Increase communication and provision of information

# PALLIATIVE PATIENTS AND CAREGIVERS

**Table 2: Patient and Family Caregiver Evaluation of Changes Toolkit**

| Evaluation Characteristics | Mean (SD) (n=7) |
|---|---|
| The directions were clear for each activity I wanted to do. | 3.83 (1.169) |
| I had enough energy to complete each activity I wanted to do. | 2.50 (1.732) |
| I had enough time to complete each activity I wanted to do. | 2.75 (1.708) |
| The Changes binder increased my ability to deal with transitions. | 3.33 (1.033) |
| I would recommend the Changes binder to someone else. | 4.17 (0.753) |
| The Changes binder is portable if I need to take it from place to place. | 3.33 (1.633) |
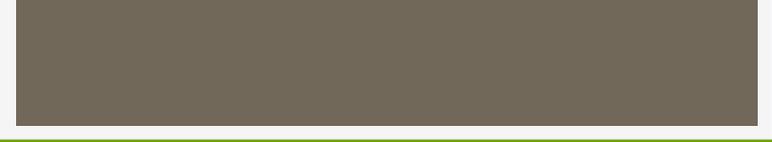
A caregiver wrote when asked what worked well with the Changes Toolkit was:

"....*Understanding the care I needed, where I can find HELP, and where I must to get it. Knowing I'm not alone in this illness and knowing hope to live with hope. This Binder helps me to understand things that I didn't know about and some things I did not understand and wonder about......THANK YOU...*"

# EVALUATION HEALTH CARE PROFESSIONALS

| Evaluation Characteristics | Mean (SD) |
|---|---|
| Were the directions about who should receive the tool clear for you? | 4.0 (0.98) |
| Were you sure of what you would be expected to do with the tool? | 3.2 (0.75) |
| Did you feel that the participants were able to use the tool without difficulty? | 3.4 (1.3) |
| Would you recommend the tool to others? | 4.4 (0.89) |
| Do you feel that working with the Changes binder helped patients and families deal with transitions? | 3.5 (0.58) |
| Do you feel that the binger improved your communication with patients and families? | 4.7 (0.58) |
| Do you feel that the binder helped you discuss advanced care planning? | 4.2 (0.50) |
| Do you feel that the binder provided a starting point for nurses or social workers to start conversations with families about end of life transitions? | 5 (0.00) |
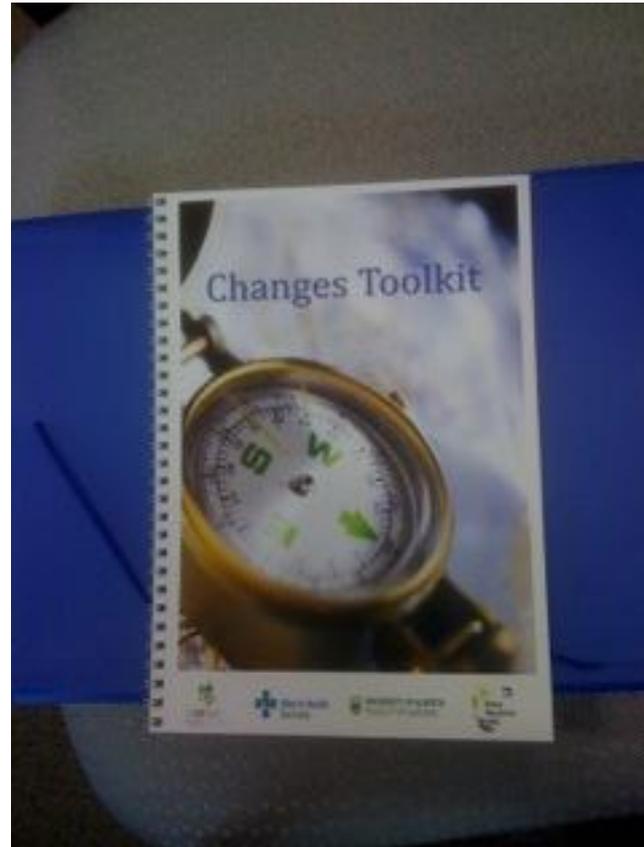
# DEVELOPMENT OF ONLINE AND MOBILE TOOLKIT

- www.changestoolkit.ca
- Includes an evaluation component
- Mobile App

Welcome
to the

# CHANGES
## TOOLKIT

Email Address

Password

Login

Keep me logged in ☐

Forgot your password? *Click here to reset your password.*

Don't have an account?

**Create an Account**

This site is intended for palliative care patients and their family caregivers.

## Activities

These activities and resources were developed from a research study to help you deal with transitions. In this site you will find activities where you can write things down or upload pictures and documents that you feel will help you. These activities will "save as you go" so you can come and go as you please.

## Resources

You will also find reading materials, important contact information, links to useful websites, a travelling health record, a video, a personal calendar, and more. There is also an evaluation form we would like you to complete.

## Mobile

If you prefer, we also have a mobile version of this site. Simply visit this same page from your smart phone or tablet and you will automatically see the mobile version. Note that you cannot add or edit

Welcome, **Wendy**. [ *Logout* ]

Text Size | *Decrease*  *Reset*  *Increase*

# Introduction

This toolkit is about life changes. It is meant to help you prepare for possible changes, and to connect you with services in your community. It has suggestions and information about resources to help you. It is based on what people receiving palliative care, their families, and health care providers have told us.

This toolkit can be used as you wish, by you and those close to you.

You may choose to use different sections of this toolkit depending on what you feel you need. There is no need to complete any of the sections. It is up to you. You may want to share some sections with others. You are free to add or remove text, photos, and document files. Make it your own.

We hope that this toolkit will be of help to you.

Please complete the evaluation in the last section to help us improve this toolkit for others like yourself. It will take about 20 minutes. Thank you.

*Now go to the Menu and choose any section to begin!*

# IMPLICATIONS FOR RESEARCH

- A broader spectrum of age groups, geographical, cultural, and care settings
- Larger sample sizes
- Other diseases such as chronic renal disease and congestive heart failure
- Outcome evaluation such as patient satisfaction, hope and quality of life, and health care costs

# CONCLUSION

- Deeply distressing time for patients with terminal disease and their families
- Continued evaluation of "Changes" is an important step in improving the transitions experienced by rural palliative care patients and their family caregivers
- Provides a concrete and viable intervention

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