

et me tell you a story....

ka –
doesn't



UNIVERSITY OF
ALBERTA

nce upon a time...



hoorah



Ta Da!!!!

□ A resource manual is born...



Observing and talking about pain behaviors: A workshop for family members of people with Alzheimer disease and other dementias

A Toolkit for providing successful workshops



e set out to share this world-
changing resource with the world we wanted
to change...

- ❑ 40 rural and urban seniors organizations
- ❑ 4 conference presentations
- ❑ 2 newsletters
- ❑ Multiple relationship building activities with possible field-test sites
- ❑ And....
- ❑ 4 more grant applications to do that testing



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- 'Very nice dear'
 - ""
 - 'Our members don't have pain'
 - 'Great idea but it will upset our staff if families know more than they do'
 - 'sorry, we are volunteers and don't have time to look at all this'
 - We don't fund 'applied' projects

and time passed....

- Team dispersed
- Contacts changed jobs
- Resources depleted
- Enthusiasm exhaustion
- Evangelistic fatigue
- Requests from formal SPs

We built it but they did not come-

My field of dreams was a barren landscape



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- - ut first a short message...

□ [BBC news dementia pain and suffering](#)

□ The [What about God? - Find Internet TV](#)
experience of pain

■ [Link mp4](#)

■ [Link windows media](#)

'Everybody has got something that hurts...I get hurt easy'

Devoted husband killed wife days before golden wedding anniversary

(Daily Mail 2005)

Marian Rhoden: The 83-year-old was strangled while she slept by her mentally ill husband

A devoted husband who strangled his wife after 50 years of marriage was ordered to be detained indefinitely under the Mental Health Act. Frank Rhoden, 80, used a necktie to asphyxiate his 83-year-old wife Marian as she slept at their home. He then tried to kill himself, firstly with his car exhaust fumes and then by deliberately crashing the powerful BMW into a wall. He survived both suicide attempts and was treated in hospital,

The Rhodens, were just days from celebrating their golden wedding anniversary when the tragedy happened on March 24.

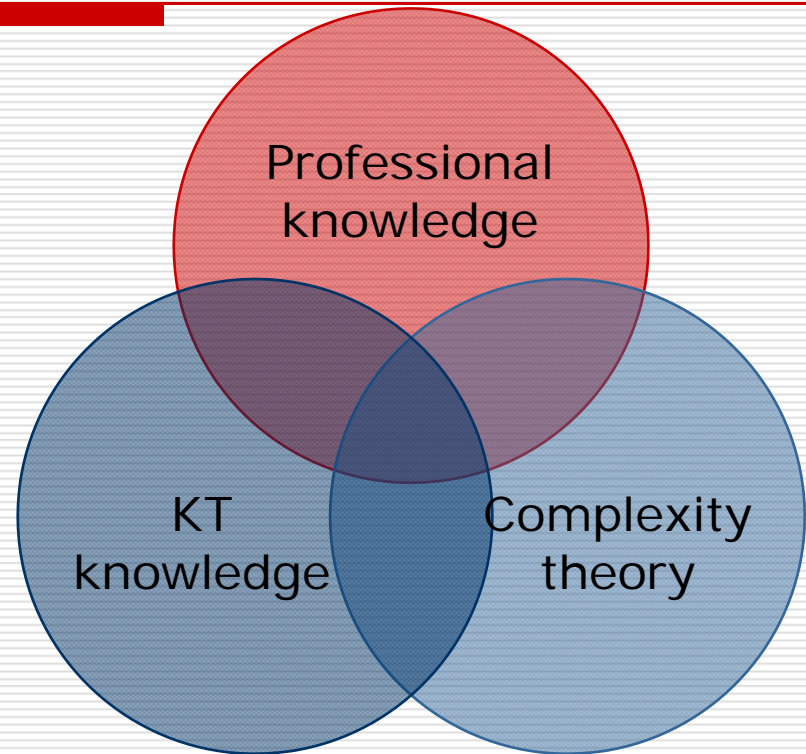
Ex-headmistress Mrs Rhoden was suffering dementia and her health had deteriorated rapidly, she was unable to walk and was in considerable pain.

A post-mortem examination revealed that she would have probably died naturally within days.

Stephen Riordan QC, defending, described the episode as "a tragedy". He added: "Mr Rhoden killed the only woman he had ever loved".



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- Current state of affairs-
 - High need area
 - Resources exist
 - BUT- uptake is limited
 - A linear approach is not working
 - Looking in my toolkit....

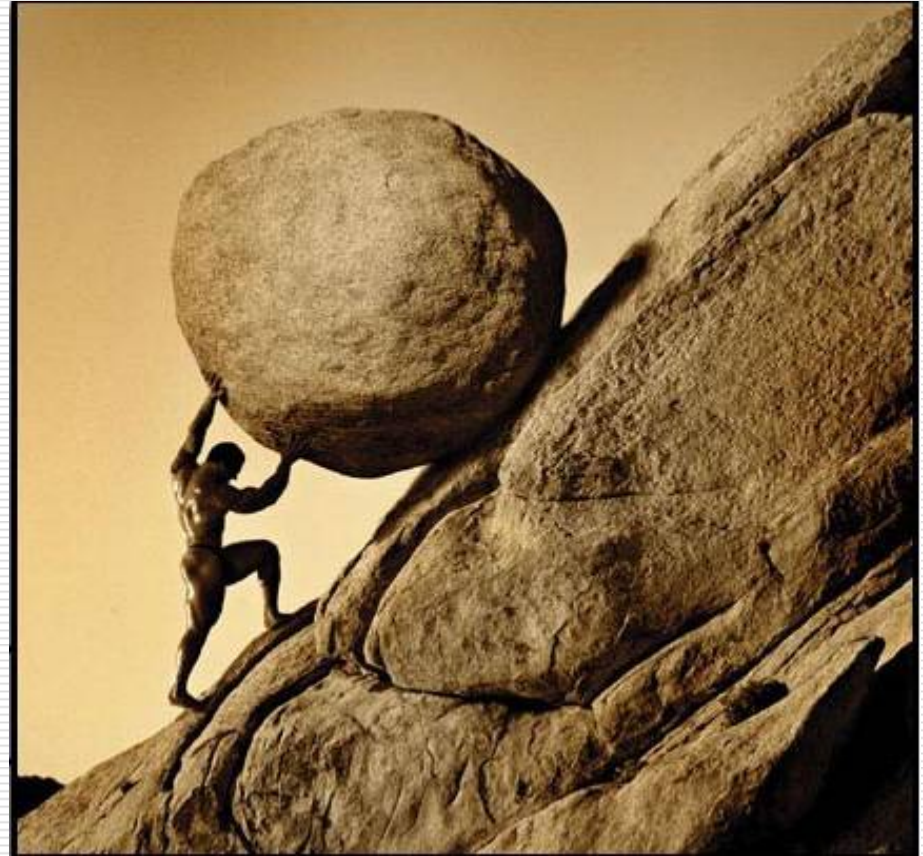


1st -is there a metaphor congruent to all three of these ways of understanding?

Sisyphus?

Nope-

I lack the six-pack and it seems too defeatist



□ Salmon running?

- Yikes, seems a very discouraging image and high risk for poor swimmers!
- Fighting an upstream battle?



Blood, sweat, tears: rivers and all things hydraulic AKA: Kawa (Iwama)

<http://www.kawamodel.com/>

- Rivers (like KT) are complex systems
 - Elements play multiple roles
 - Barriers area also facilitators
- (for example a stick can be an obstacle but it can also be a lever moving elements in unpredicted ways).



2nd – is there a KT theory to guide me? - Integrating Framework for Managing Knowledge across Boundaries (Carlisle 2004)

- innovation occurs at the intersection between domains of knowledge
- Three types of boundaries/intersections:
 1. Syntactic (shared meaning- common language)
 2. Semantic (no shared meaning- need processes that create connection)
 3. Pragmatic (shared meaning cannot be created therefore it is imposed)

Metaphor & Theory = insight (some...)

□ Forces at the boundaries

context:

Off loading?

Fears

Social stigma

Communication barriers

role of community group

poor funding support for geriatric research

NIMT or INT (In my time)?

Awareness of need:

aging myths

lack of attention

research/practice gap

Rush of change

Type 2 boundary:

Semantic- no
shared meaning

Resources:

volunteers

technology

printing

time

he strands are starting to come together....

- I have a metaphor (Kawa) to help me see and that is congruent to my professional ethos
- I have a theory (Integrating Framework-Carlisle) to help me understand what I am seeing (Semantic Boundaries) and what I need next



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- Lessons from Complexity Theory – select characteristics of a complex situation
 - Non-linearity (AKA the power of the Trojan mouse)
 - Emergent behaviors when elements combine
 - Embedded in multiple layers of context
 - look for patterns
 - Follow simple rules



Keep it simple-

1. People need to need the story and they need to trust the story teller

- healthcare system has the resources to build awareness
- healthcare workers are the public too
- myths take time to change
- trust in the ripple and accept elements of NIMT- for example: maybe students are a good target group as they assume change agent roles

Keeping it simple is not easy... and keeping it simple does not mean being 'simplistic'



So now what?

Post-it notes at the ready.... Where would you prioritize your limited resource and why?

1. Teach more classes to healthcare students about pain in the elderly?
2. Target healthcare providers instead of community groups to provide family caregiver education?
3. Post the Toolkit on line and let anyone who wants it use it?
4. Continue to seek funding to test the outcome?

Thank you!

References:

□ Pain & Dementia: IASP Global Year Against Pain in Older Persons

- <http://www.iasp-pain.org//AM/Template.cfm?Section=Home>

□ Complexity theory - <http://www.plexusinstitute.com/>

- Edgware archives
http://www.plexusinstitute.com/edgware/archive/think/main_aidestoc.html

□ KAWA <http://www.kawamodel.com/>

□ Kitson & Bisby (2008) Speeding up the spread

- <http://209.85.173.104/search?q=cache:VgCQzcbFhn8J:www.ahfmr.ab.ca/download.php/fdb47de28f52562a0452b42534d33b39+speeding+up+the+spread&hl=en&ct=clnk&cd=1&gl=ca>