

Queering Graphic Medicine

On the Aesthetic Education of Caregivers

The Specificities of Form and Genre
in Comics about Dementia Care

Graphic Medicine 2019, 12 July, Brighton, UK



Project Personnel

Ernesto Priego, City, University of
London

Abi Roper, City, University of
London

Marie-Pier Caron, Douglas College,
Canada

Ruhina Rana, Douglas College,
Canada

Peter Wilkins, Douglas College,
Canada

Simon Grennan, University of
Chester

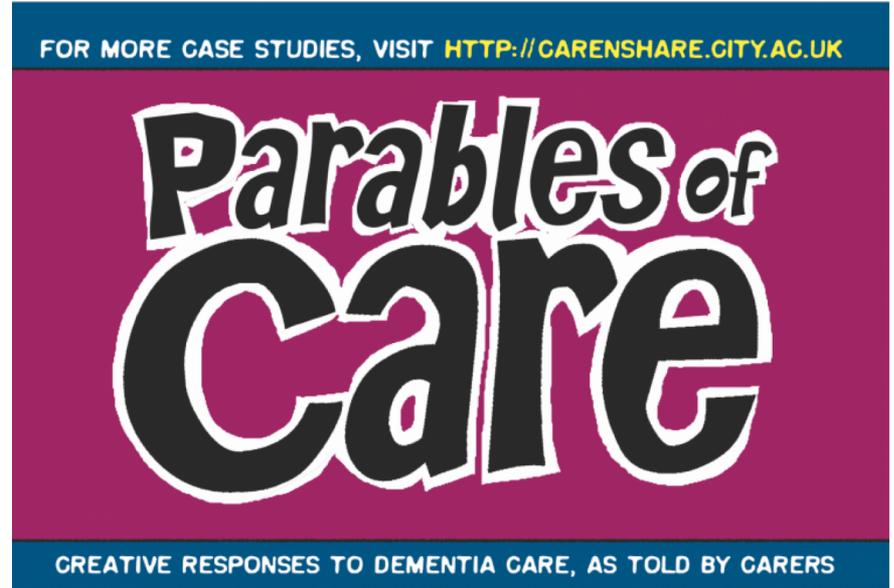
Querying Dementia: The Parables of Care Project

Dr Ernesto Priego

Centre for Human-Computer
Interaction Design

City, University of London

@ernestopriego



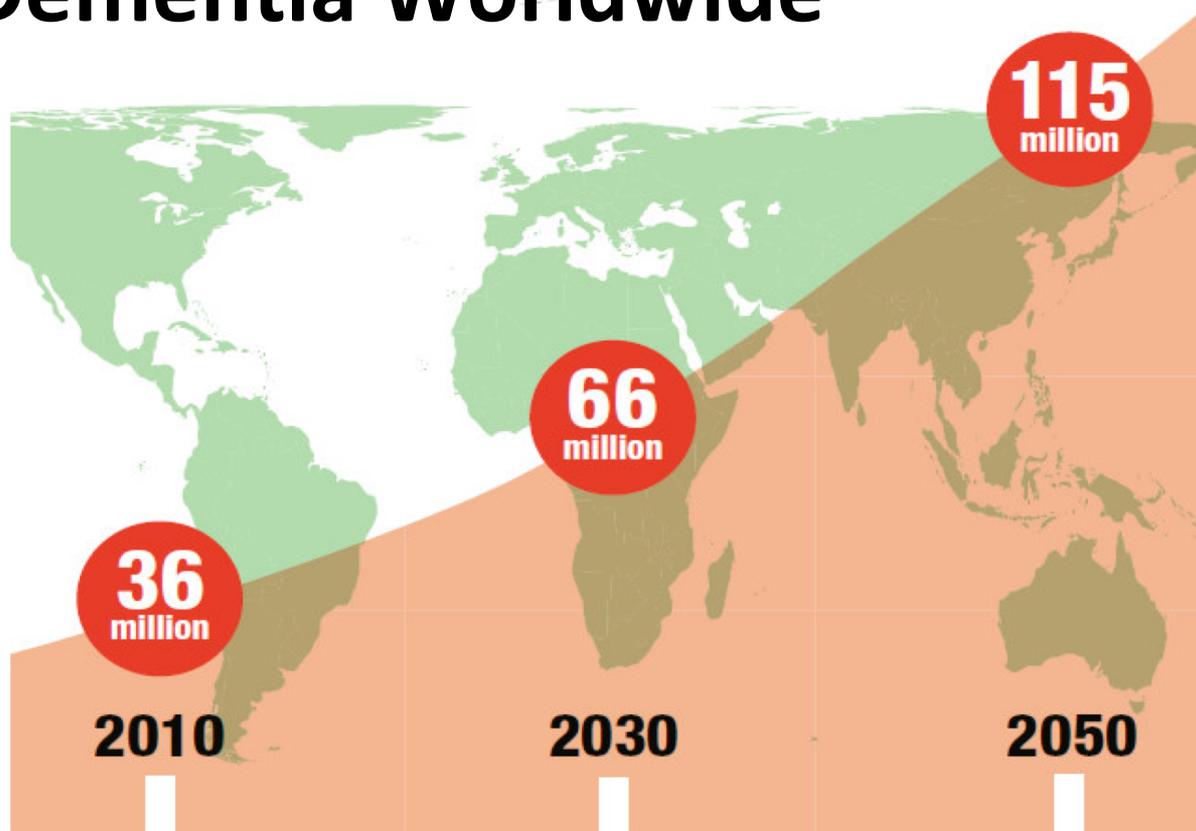
What is Dementia?

“The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.”



(Source: Alzheimer's Society)

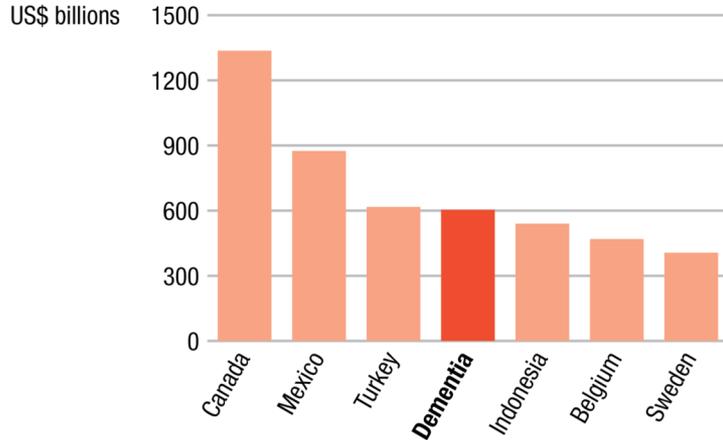
Dementia Worldwide



(Source: Dr. Jacob Roy Kuriakose, Alzheimer's Disease International)

Dementia Worldwide

Cost of dementia compared to national economies

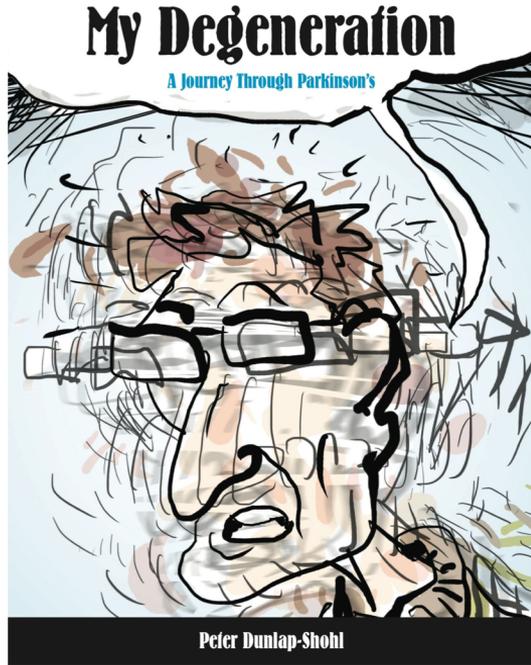


US\$604 billion in 2010

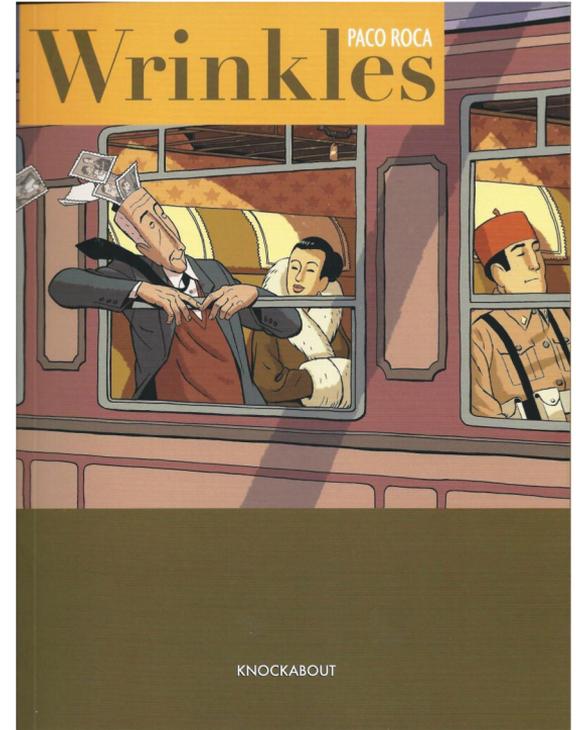
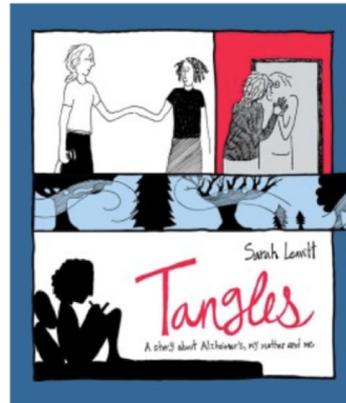
- **Includes direct medical costs, direct non-medical costs and costs of informal (family) care**

(Source: Dr. Jacob Roy Kuriakose, Alzheimer's Disease International)

Background

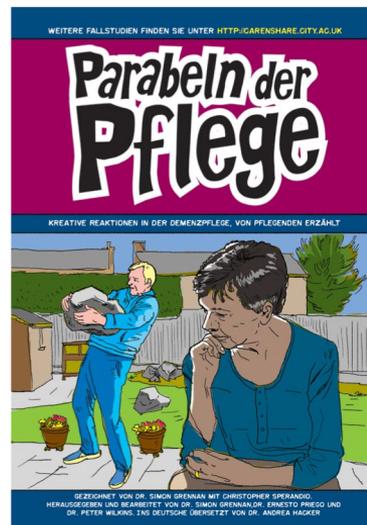
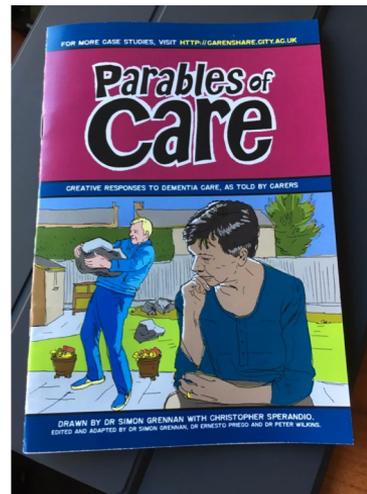


<http://memories.sutueatsflies.com/>

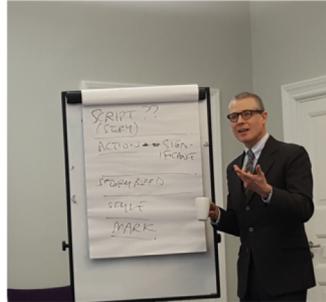


16-Page Comic!

- ***Parables of Care*** explores the potential of comics to enhance the impact of dementia care research.
- ***Parables of Care*** was edited and adapted by Dr Simon Grennan (University of Chester) Dr Ernesto Priego (City, University of London) and Dr Peter Wilkins (Douglas College).
- ***Parables of Care*** was drawn by [Dr Simon Grennan](#) with [Christopher Sperandio](#).
- Translations! German, Spanish...



Connected Projects – User-Centred Design Methods



Adapting Cases from City's Care N Share App



CITY UNIVERSITY
LONDON

The Suffolk Brokerage



CareNShare

sharing best practice across the older adult care sector

In which work setting might this situation be found?

(Choose as many as needed)

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Residential/nursing home | <input type="checkbox"/> Acute care |
| <input type="checkbox"/> Live-in care | <input type="checkbox"/> Day services |
| <input type="checkbox"/> Domiciliary/hourly care/sheltered housing | <input type="checkbox"/> Other |

What is your role?

- | | |
|---|--|
| <input type="checkbox"/> Carer/senior carer | <input type="checkbox"/> Housekeeping/Domestic staff |
| <input type="checkbox"/> Manager | <input type="checkbox"/> GP |
| <input type="checkbox"/> Activities staff | <input type="checkbox"/> Specialist (eg OP/PT/SALT/SW) |
| <input type="checkbox"/> Catering/kitchen | <input type="checkbox"/> Other |

Enter a suitable name/title for this case

Please describe the situation

How did this situation make you feel?

careshare.city.ac.uk/casedetails.php

CareNShare



[Back to other matched good care practices](#)

Reflect on how the different people experienced the situation below, and use their care plan to create a care plan for your current situation. You can also use the creative guidance at the bottom of the page to help you.

Alarmed by reflections

[Create PDF](#)



When my husband James who is living with dementia, saw his reflection in television screens and window glass, he would interpret this as other people. He would get out of his chair, point, wave his arms, glare and shout "Go, gone away!" But if you shout at your reflection what does it do - it shouts back, James would race over to the windows and, still shouting, bang on the glass. I would try and comfort him, saying "there's nobody there" and "there's nothing to worry about," but often he could not be consoled. This case is adapted from *And Still The Music* Plays by Graham Stokes, pages 66-70

How Different People Experience The Situation

- ▶ How the staff member(s) felt
- ▶ How the older person might be feeling

Care Plan / Action Plans: Good Practice Examples

- ▶ The Environment

So the carers in this case...

tried to eliminate the chances of this happening by encouraging the resident to be in one of two rooms - a small, cosy lounge and the resident's bedroom - both of which they removed mirrors and TVs from, and kept the curtains drawn when dark. How could you implement this good practice in your care work?

And more generally, have you considered...

- ▶ how the older person's personality affects their wants and needs?
- ▶ which activities match the older person's interests?

Other considerations

For more learning, these external links might be useful...

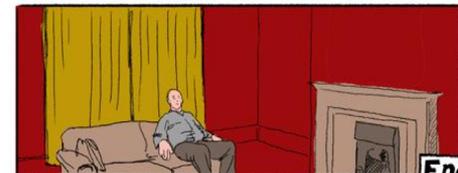
- ▶ [SCIE: dementia friendly environments](#)
- ▶ [Kings Fund: Developing supportive design for people with dementia](#)

Comments

(Contributed comments are moderated by our team before being made public. [Click here](#) to learn more.)

[Add comment](#)

Shouted at Reflections



End

<http://careshare.city.ac.uk/>

Parables

- Ambiguity – General Applicability

- Analogy with many situations



Yonkoma as form

Plan A: Funny Faces



KAPOW!



More on our public impact at

<https://blogs.city.ac.uk/parablesofcare/readers-on-parables-of-care/>

Co-designing for Aphasia Poetry as Form – Insights from a Sibling Project

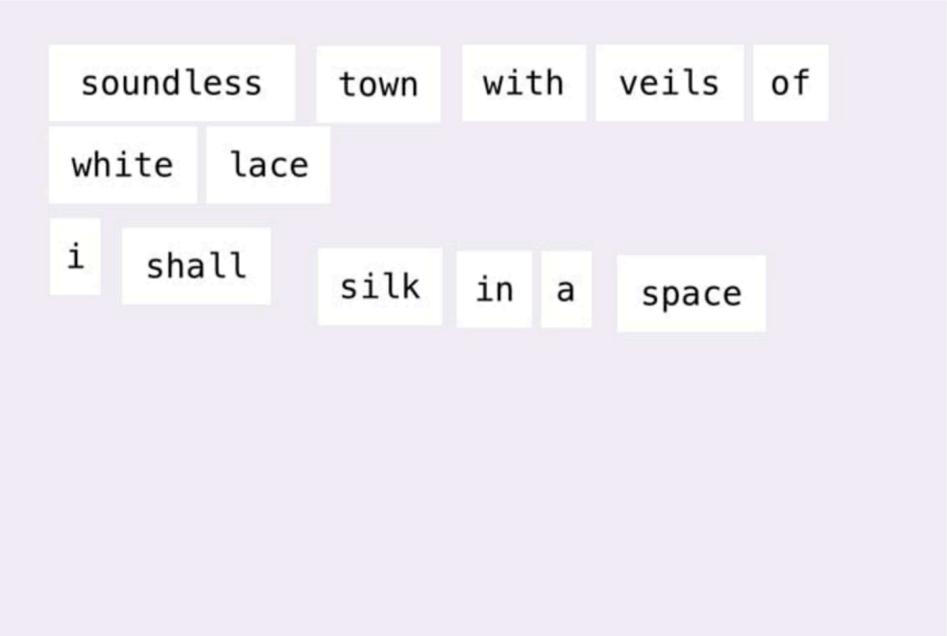
Dr Abi Roper

INCA Project, Centre for Human-
Computer Interaction Design

City, University of London

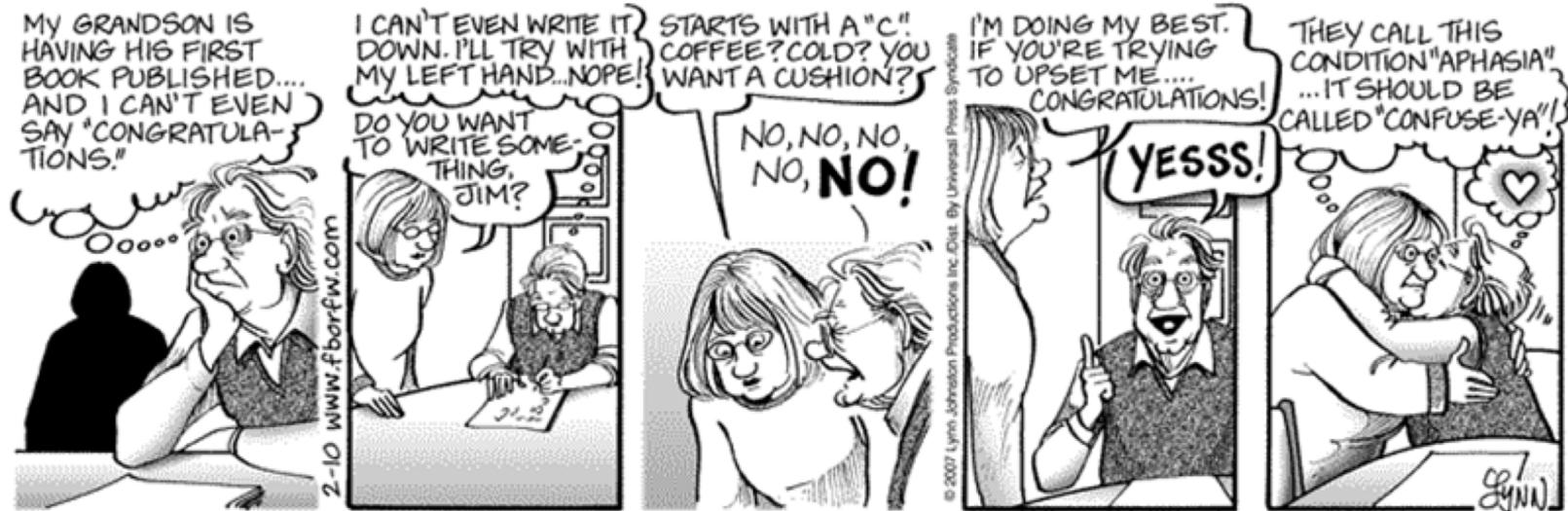
@abracabadger

@incaproject



soundless town with veils of
white lace
i shall silk in a space

Aphasia



Grandpa Jim. From the storyline "Jim's Stroke"

Image reproduced with permission of Lynn Johnston and Entercom Canada Inc

Available at: https://fborfw.com/strip_fix/saturday-february-10-2007/

Aphasia





Aphasia

Co-Design

Arrange



white snow of white white as

shall

step down shall walk

walk through town

white

in

Read word OFF ON

New word

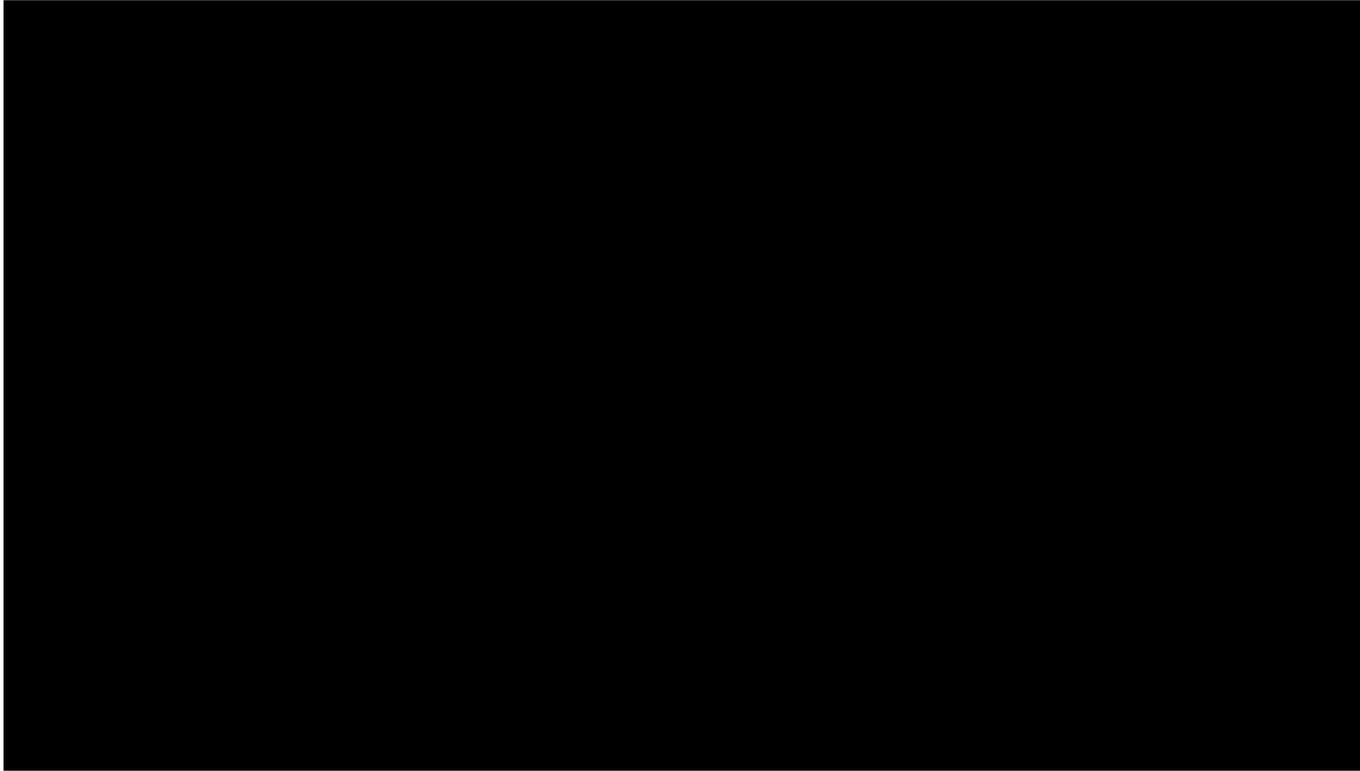
Drag here to delete

◀ Back

Next ▶



MakeWrite App



Aphasia
Re-Connect

Comics and Health Literacy; The Douglas College Dementia Comics Project

Marie-Pier Caron
Nursing Faculty
Douglas Project, Canada
@mpcmpc



Art by Melissa Martins



21

Around **50 million**
people have
dementia worldwide



Nearly **10 million**
new cases every
year – one every 3
seconds

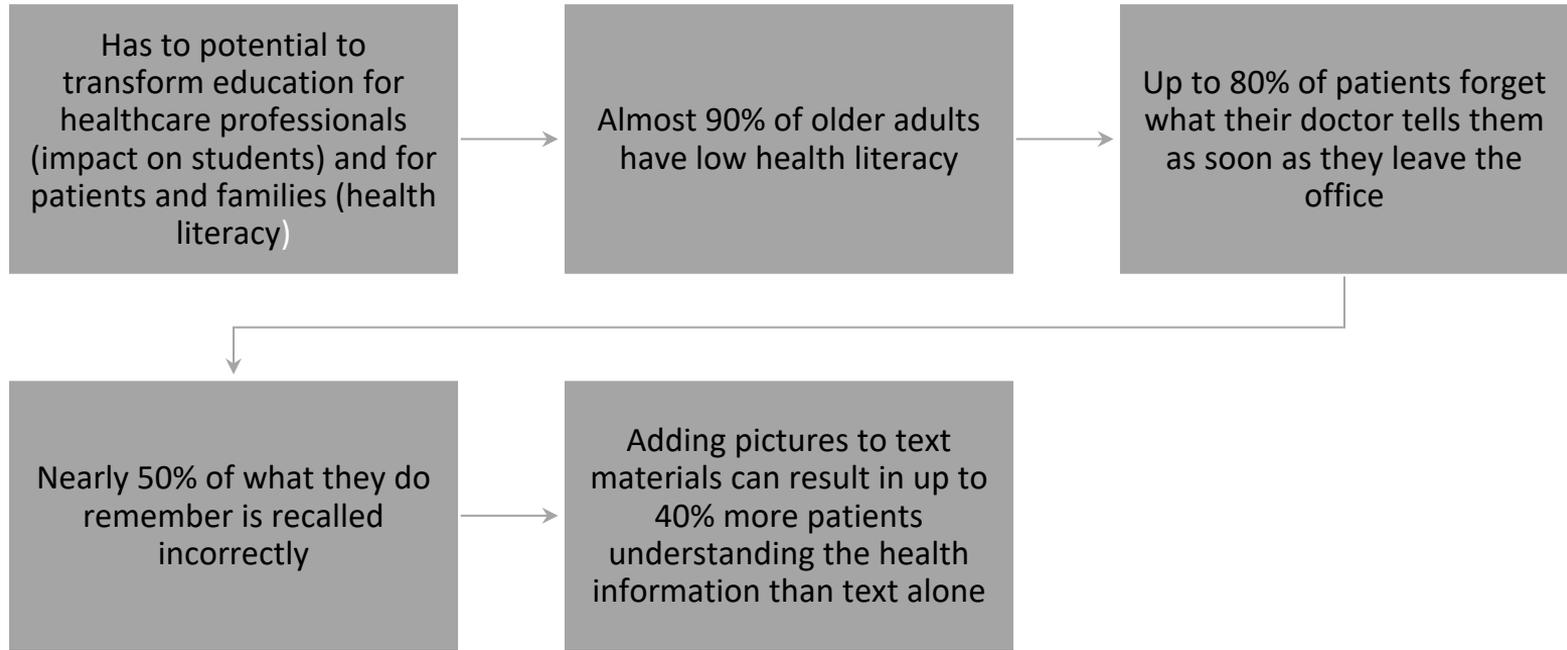


Dementia cost: **\$818 billion** - The majority
of care is provided
by family carers.

My Mom is Not Alone!

WHO – Global Action Plan on the Public Health Response to Dementia

- Enhance dementia research and interventions
- Influence government policy-making
- Improve service delivery and risk reduction
 - Parables of Care is used in our nursing curriculum – **training tool**
- Build our capacity by:
 - Participating in training programmes on dementia, including programmes aimed at **identifying and reducing carer stress and burnout.**



Graphic Medicine in Nursing Education

In the US, 60% of all Alzheimer's caregivers are women

At the age of 65, women have a 1 in 6 chance of developing Alzheimer's, compared to a 1 in 11 chance for men

In Australia, nearly 2/3 of all dementia-related deaths were women; in the US, 2/3 of those living with the disease are women

In England and Wales as well as in Australia, dementia has become the leading cause of death for women

Gender and Dementia

Emotional Labour of Care; The Douglas College Dementia Comics Project

Ruhina Rana
Nursing Faculty
Douglas Project, Canada



Art by Melissa Martins

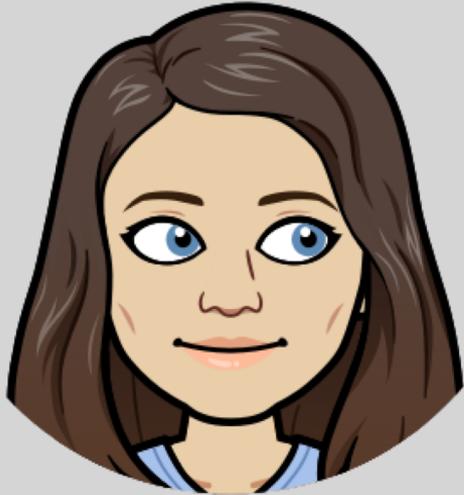
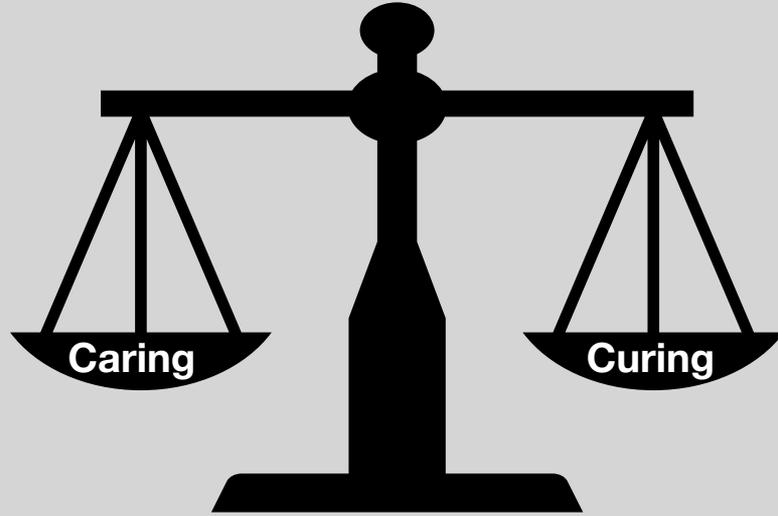
Graphic Healthcare?

Nurses in Canada prefer “Graphic Healthcare” over “Graphic Medicine” because as nurses we are separate and distinct from medicine



Avatar created by Bitmoji

Nursing vs Medicine



It's all about the relationship!

Why this is Graphic Art Important in Dementia Care?

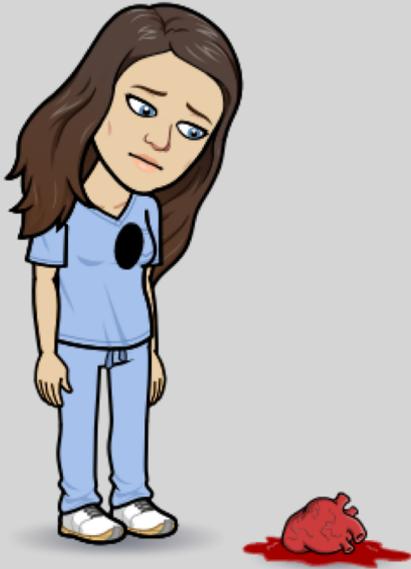
Development of shared language & experiences to regain control over dementia, rather than it overwhelming and controlling us



Emotional Labour of Caregiving

**Caring for someone with
Dementia can take an emotional
toll.**

**How do we prepare healthcare
providers and family members for
this?**



Transforming Healthcare & Education



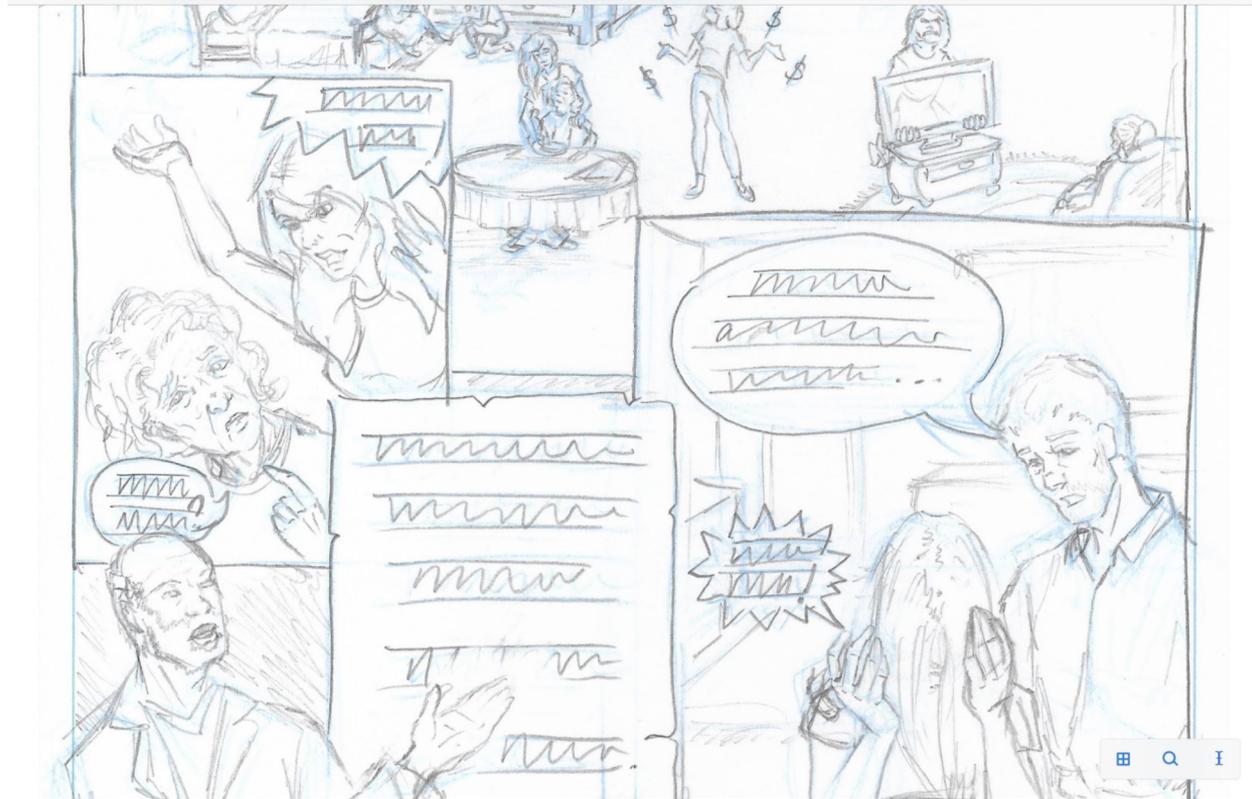
- **Sharing narratives through art so that the affective domain can be explored in-depth.**
- **Not a how-to manual, rather a way to share the emotional labour of caring for people with dementia.**
- **The outcome is to ensure that caregivers understand the complex experience of dementia care and to know they are not alone.**

**From Parables to
Tragedy: Genre and
Dementia.
The Douglas College
Dementia Comics
Project**

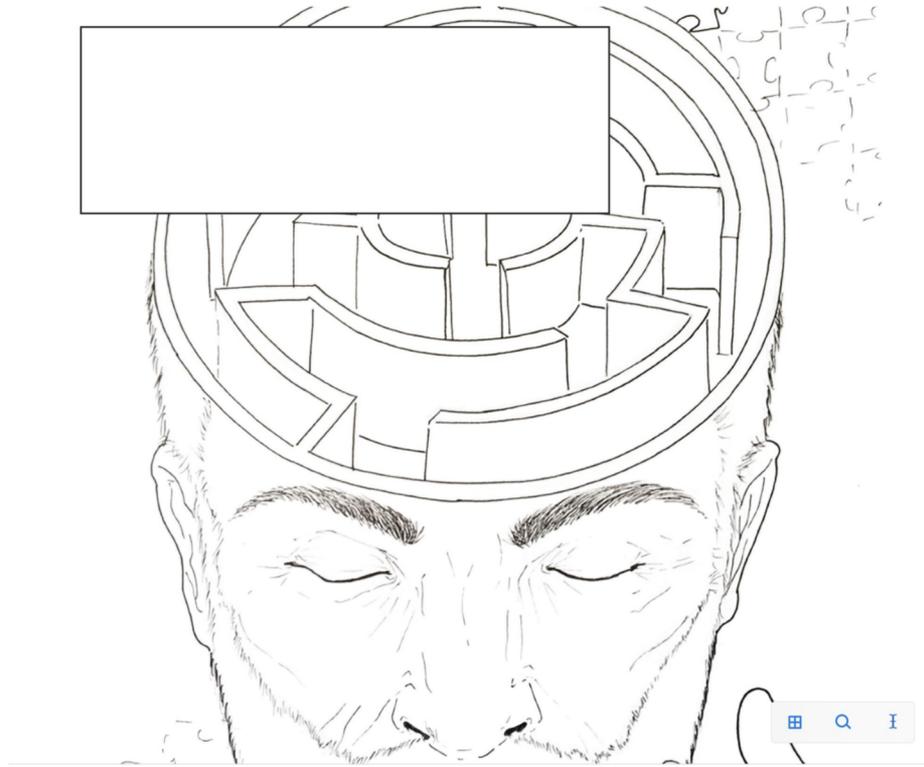
Dr Peter Wilkins
Douglas Project, Canada



Art by Melissa Martins



Greek Tragedy



Prologue/Epilogue



Episodes

WHEN FAMILY VISITS FOR
THE HOLIDAYS THEY ASK LOTS
OF QUESTIONS



Chorus

From Why Comics? to What Comics?



Sketches from an interview from the Douglas College Dementia Comics Project. Art by Peter Wilkins

Panel Discussion!