

“Stay Safe, Shirley. I’ll See You Shortly!”

Conducting Fieldwork with People with Dementia Before, and (Hopefully) After the Pandemic.

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I look forward to Thursdays. It’s the day when Sarah and Bonnie, her Labradoodle therapist, visit the care home where I conduct my fieldwork. For the last two months, I’ve been regularly visiting Golden Age Care Home for two days a week for my PhD research. I try to understand how people living with dementia develop bonds with therapy-animals. I’ve been finally granted ethics clearance by NHS Scotland A Research Ethics Committee (A, standing for Adults with incapacity of consent), after a labyrinthically complicated, nerve-racking process. People with dementia in general, and even more so those in advanced stages who live in care homes, are labelled as highly vulnerable when it comes to research, given their diminished or lost capacity of consent and their progressive condition. In many cases, their dementia also worsens their mental health and physical condition. This may even end up with aspiration pneumonia caused by the body’s progressive forgetfulness of how to swallow, which can often lead to death. But music, family visits, and cuddling Bonnie lifts people’s spirits. “Anything unusual, anything different is good,” Janet, one of the residents, has told me. But unusual is rare in the care home, although visits happen frequently. Most of the time, people nap in their lazy chairs, the TV on loudly, in a stiff atmosphere unbroken daily until the 3:30 “Tea time!!!”. Some residents have either family living far away, or no one left to visit them. Many will not leave the care home for years, blending with their lazy-boy until they finally succumb to physical death. As literature puts it, they live in social isolation. But residents themselves might not call it as such. They might call it feeling lonely or, as Shirley, another of the residents, put it when lovely carer Joanne hugged a resident: “This is what we need more often.” Some human *presence*, some touch and affection. The literature often labels the agitation, depression, wandering, and anxiety of people diagnosed with dementia as Psychological and Behavioural Symptoms of Dementia (PBSD). Tom Kitwood, with his unique vision, thought of them as responses to a ‘malignant social psychology’: when human presence becomes more isolating than comforting. A comforting presence, such as Bonnie’s, is thus quite often vital.

So, I look forward to Thursdays. Bonnie the therapist animates the stiff atmosphere, even if only through her presence. Her wagging tail and wet nose gets everywhere. And her antics make people burst with laughter. “Oh, my! A dog!”, exclaimed Doreen seeing Bonnie last week. Doreen is a lovely lady living with very advanced dementia, with lively blue eyes whose continual talk sounds unclear and mumbled. Indeed, Bonnie is exactly what her Scottish name means: handsome. Quite often, she makes such a strong impression that links spoken words back to their lost meaning. That links a person with dementia back into a person who delights in a dog’s presence – like all of us actually, dog lovers or not. The other week, Grace, a tiny lady with the expression of grandmotherly kindness, let out a delightful laugh after petting Bonnie, and said a few words: the first I’ve ever heard from her since I started my visits.

But this Thursday, I don’t look forward to it. For the past few weeks, I’ve been plagued (ironic to even use this word these days!) with worries for Golden Age residents. Stories of a deadly virus that tunnels its way into people’s respiratory system have been marching closer and closer, with alarming death statistics happening just down in Italy. Only yesterday, on the 11th March, World Health Organisation declared this virus a pandemic: something absolutely unprecedented. The great human to human risk of contagion makes this virus part of a different social malignancy. Epidemics, even if very local and contained, worry me even more if they come nearby or make their way into a care home. Years ago, while living in New Zealand and working in a care home in the end-of-life ward with dementia care, I witnessed a horrific situation. One of the residents, living with dementia, returned with a stomach bug after spending his Christmas holiday with family. Nothing worrying in that; infection happens often when life draws its final lines. However, no one expected this would transform into a ward killer. The bug spread like wildfire, making its way through staff-members and residents, killing many of the latter and leaving relief workers snowed under. By the end of the infection, the home resembled a battleground. Everyone was exhausted and in grief. This made me extra cautious when applying for my PhD ethics clearance. I saw myself as a potential risk and added into my protocol risk assessment: any signs of infection with a stomach bug or flu – regardless how

insignificant – will stop my visits until all symptoms are cleared for at least 48 hours. But I never foresaw anything like this new virus.

Care homes, and especially those with dementia care, like many hospitals, are familiar with the presence of undesired non-human companions, like MRSA (*Methicillin-Resistant Staphylococcus Aureus*). ‘Superbugs’ that are resistant to usual antibiotics and are hard to get rid of. Maybe not deadly, but they can create a lot of trouble and discomfort. It’s something that about 1 in 30 people carry harmlessly in their nostrils, armpits, groin or buttocks, but which may end up causing more trouble to those who have a wound, burn, catheters, etc. When getting deeper under the skin these can create pain, itchiness, fever and chills, and even dizziness and confusion – which only worsens the symptoms of dementia. It can spread easily inside a care home, despite strict protection measures. The MRSA picture – and its associated infection percentage within care homes – only shows how easily a bug can spread once it gets into a care home, despite its residents’ ‘social isolation’.

I look ahead to this Thursday with great worry. The WHO declaration of pandemic means that the virus is here, ready to take its death toll. Shirley, Doreen, Grace, or Janet could once again become statistics. They have already had their share of these statistics, where no one knows them as Shirley, Doreen, Grace, or Janet: statistics of dementia, of living in care homes, of co-morbidities, of so on and so on. And the PM Boris Johnson and his Tory government decision of not locking down, of leaving the population to develop ‘herd immunity’, sounds like a death sentence to them, as yet one more statistical category to put them in: COVID-19 mortality rates.

Yesterday I visited Golden Age, after emailing Jenny the manager to see if they have any extra protection measures. I was even thinking of suspending my visits regardless of official decisions. But then fears of being sanctioned by the Ethics Committee or University Research Governance (it’s always about ethics and politics!) made me think that I might be too paranoid. But is it too paranoid when there is a pandemic?

When I finally arrived at Golden Age and entered the entrance door access code, the error sound made me think I must have entered it wrongly. So, I entered it again. And again. Then I saw Jenny, behind the doors, telling me they’ve closed down to all visitors only one hour before, and all therapy visits have been suspended. I turned back and headed to the bus stop. On the way out, I looked through the big lounge windows and waved to Shirley, like I always do when I leave Golden Age. She smiles with her usual delight and playful eyes, waving back. I feel a strange mixture of guilt of abandonment and relief. “Stay safe, Shirley. I’ll see you shortly!”, I tell her in my mind. How safe, when, and if I can keep my promise really depends now on all of us.

Note

All names have been anonymised.

ABOUT THE AUTHOR:

Cristina is a medical anthropologist working towards her PhD at the University of Aberdeen. Her PhD research project explores the relationships between people living with dementia in Scottish care facilities and therapy-animals (dogs and owls). Currently she is working with Dr Andrew Whitehouse as editors of a collective volume about the entanglements between ageing and more-than-human companionship (to be published at Rutgers University Press).