

### Experiences of Communication 'Disorder' & Difference in the world of Mental Health Disorders

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### **Aims**

Aim

 To explore a number of 'then and now' narratives to discover if there is a common a concern for issues of communication and mental health disorder (MHD)

Question

• Could such accounts shed light on the perplexing nature of MHD, with communication being a core part of that perplexity?

Discussion

 Drawing on historical & contemporary narratives of those affected by a MHD, one may at least attempt to bear witness to the experience of communication 'disorder' or difference in this context

### Background

- Speech and language therapy (SLT) in adult psychiatry
  - relatively recent (e.g. Emerson & Enderby, 1996; Walsh et al, 2007); has a broad focus on communication than on mechanics of speech, voice or hearing
- Psychiatry textbook accounts
  - fall short of describing what may be the real, living experience of a MHD and its all too frequent bedfellow the experience of *communication 'disorder'* or *difference*
- Communication by definition interpersonal
  - both practitioners & those with MHDs need to understand how these communication difficulties arise, and how best to deal with them
- 1st person accounts hear the other's 'voice' (Kovarksy & Curran, 2007)
  - 'an analysis of narratives is a key avenue towards identifying and understanding how people construct their realities and how they might be changed for therapeutic purposes' (Fook, 2012 p78)

### Narrative (Fook, 2012)

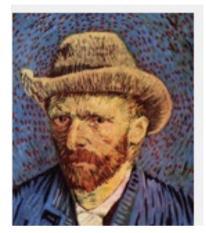
'a sense of a happening and a consequence which follows' (p79)

'Narratives are regarded as particular constructions of a situation or event told from the perspective of whoever is constructing the story, and for particular purposes. It is recognised that, in one sense, everybody creates narratives or 'stories', as they can only be communicated through language, whose meanings are limited by time and context' (p195)

Is there a collective narrative of communication in experiences of a mental health disorder, that resonates across time and place?

What is this narrative?

Can it be used to inform practice?



Van Gogh (1853-1890)



Janet Frame (1924-2004)



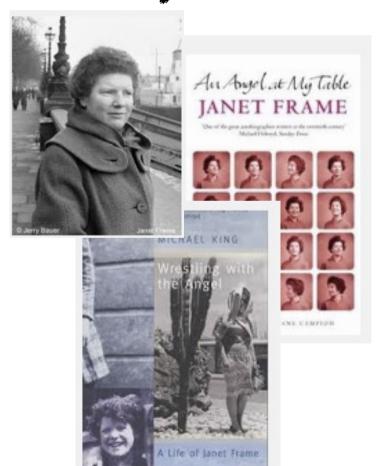
(2009)

## "well the truth is, we cannot speak other than by our paintings"

- Letter from Vincent van Gogh to Theo van Gogh, Etten, September 1881
  - http://www.webexhibits.org/vangogh/

- Periods of psychosis (?)
- Borderline Personality
  Disorder (van Meekeren, 2003)
- 902 letters to brother Theo (Aug 1882-1890)
- focus on letters written in final 2 years of his life: 184 letters (quotes totaling 7200 words)

"[writing is...] a boon, analgesic, and so on. I think it is all that matters to me. I dread emerging from it each day" (Frame, 1994)



New Zealand novelist and poet

- who although may have been misdiagnosed with schizophrenia, experienced mental health and communication challenges well documented in:

Frame, J. (1989): Janet Frame: The complete Autobiography. The Women's Press: London.

King, M. (2000). Wrestling with the Angel: A life of Janet Frame. London: Picador.

# 'How do you feel about your ability to communicate and express yourself? What is it like to talk/chat to other people?'

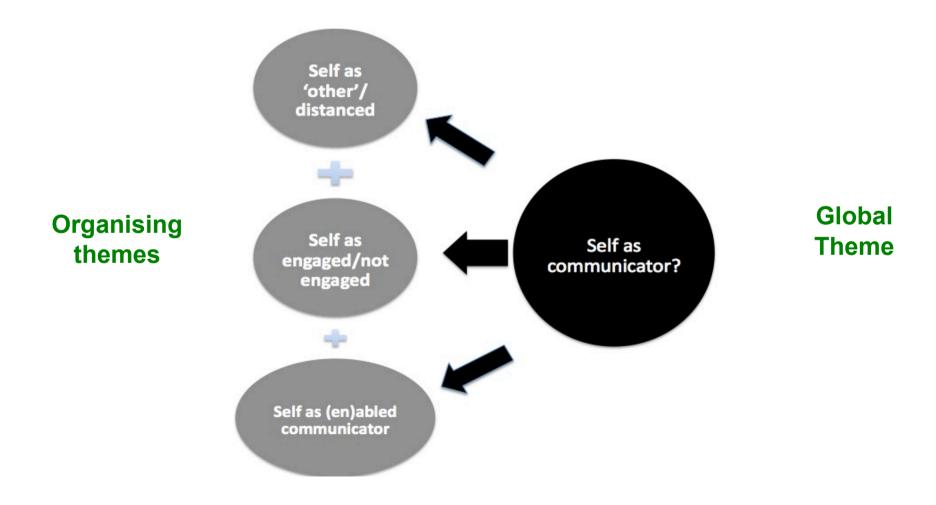


- Seven in-depth interviews, totalling 12 hours of audio recording
- People with a diagnosis of (chronic) schizophrenia
- Age range: 25 years to 52 years
- Lots of different backgrounds
  & occupations

### Analysis of data

- Analysis across the data sets; applied thematic content analysis (e.g. Attride-Stirling, 2001), involves:
  - Coding of material
  - Identifying themes
  - Constructing the thematic networks
  - Describing and exploring the thematic networks
- Notion of 'self'
  - notion of identity as different 'dialogical selves' which interact with one another to create a particular view of self experience (Lysaker & Lysaker, 2010)
- One thematic network, described today

### Figure 1: Thematic network



Organising theme I

### SELF AS 'OTHER'/DISTANCED

### Van Gogh

'For me, life may well continue in solitude. I have never perceived those to whom I have been most attached other than as through a glass, darkly.' (12th June 1890)

'Really, I think it would be torture for other people as well as for myself if I were to leave the hospital, for I feel and am, as it were, paralyzed when it comes to acting and shifting for myself. Later on - well, let's wait and see.' (24th April 1889)

#### Janet Frame

"I had become a third person, at home at Willow-glen and now here in Auckland. Sometimes, as if I were my own obituary, people asked, 'What was she?' As if an archaeological find stood before them and they were applying with eyes, heart and mind, a 'carbon' test to name, date and place me-and if only I had a place!' (p. 215, 1989)

"No one thought to ask me why I had screamed at my mother, no one asked me what my plans were for the future. I became an instant third person, or even person-less, as in the official note made about [me], 'Refused to leave hospital'. (p. 191, 1989)

'I felt as if my life was overturned by this sudden division of people into 'ordinary' people in the street, and these 'secret' people whom few had seen or talked to but whom many spoke of with derision, laughter, fear'. (p. 193, 1989)

I. SELF AS 'OTHER' /DISTANCED

### Person with schizophrenia

P1 "I feel quiet, too quiet like when people are sitting down talking, having conversations and things like that (3) I don't really say much and I feel like the odd one out" (p. 53 lines 31-34 PSZ)

P1- "part of our sickness, cause we are not fully functioned like" (p.53 lines 18-21)

P5 people "ignore me" (p.70, line 695) and make "jokes when I am not feeling well".

I. SELF AS 'OTHER' /DISTANCED

Organising theme II

### SELF AS ENGAGED/NOT ENGAGED

### Van Gogh

"almost no wish to see friends" (22nd May 1889)

'not sufficiently master of my head to be able [to communicate] (2<sup>nd</sup> July 1889)

"could not write" [ ideas] were "futile and incoherent" ( 17th January, 1889)

II. SELF AS ENGAGED/NOT ENGAGED

#### Janet Frame

'I cannot talk about myself. I cannot. Every month I go to the hospital and [see] one of the doctors from Seacliff...I have been able scarcely to say a word to them ...I just go into a kind of dream probably to escape their questioning. And my voice won't work. And if it did it would utter what they would think to be utter nonsense...I keep silent because physically, I cannot speak'. (1949; in King, 2000; 103)

"My stay with my sister and her husband was not successful. They and their infant son enclosed one another and while I stood awkwardly in the background, and if anyone called and looked my way, my shyness and self consciousness, arising from my feeling of being nowhere, increased when my sister's friends asked, 'How is she?' 'Does she like being in Auckland?' (p. 215, 1989)

"Sometimes when I began to say what I really felt, using a simile or metaphor, an image, I saw the embarrassment in my listener's eyes here was the mad person speaking". (p. 215, 1989)

II. SELF AS ENGAGED/NOT ENGAGED

#### Person with schizophrenia

"even myself, when I am talking myself I hear the words coming out of my mouth but I can't really (3) understand, I think I am talking a load of crap" (p. 52, P1 lines 72-75).

" you're not really sure what you think is important is what they think is important " (p. 69 P7, lines 593-595)

"friends of mine get frustrated [in communication] and they say "what's wrong with you WHAT IS WRONG WITH YOU?" (p. 69 P2 Lines 831-834)

II. SELF AS ENGAGED/NOT ENGAGED

Organising theme III

# SELF AS AN (EN-)ABLED COMMUNICATOR

#### Van Gogh

'I have been feeling better since I wrote you, and though I do not know if it will last, I do not want to wait any longer before writing you again.' (3rd September 1889).

[letter writing/receiving gives him] 'pleasure' (17<sup>th</sup> Nov 1889) [and helps him to] 'to climb again out of present state of prostration I am in " (2<sup>nd</sup> May 1890); 'write me a few lines one of these days' (2<sup>nd</sup> July 1889)

'What I want to tell you is that the wisest thing to do is not to long for complete recovery, not to long to get back more strength than I have now, and I shall probably get used to the idea that I shall be broken a little sooner or a little later - what does it matter after all? (2<sup>nd</sup> July 1889)

#### Janet Frame

'I was taking my new status seriously. If the world of the mad were the world where I officially belonged (lifelong disease, no cure, no hope), the I would use it to survive. I would excel in it. I sensed it did not exclude my being a poet.' (p.198, 1989)

'My place was set, then, at the terrible feast. I had no illusions about 'greatness' but at least I could endow my work and – when necessary- m life with the mark of my schizophrenia'. (p.201, 1989)

"...I had, like a spider, woven about me numerous threads which invisibly reached all those who 'knew' and bound them to a paralysis of fixed pose and expressions and feelings that made me unhappy and lonely but gave me also a recognition of the power of having spun the web and the powerlessness of those trapped within it". (p.194, 1989)

#### Person with schizophrenia

[re hearing voices, she] takes no notice of them...I concentrate on real people in front of me and things like that (P1, lines 1129-1132, p. 56)

"communication was a way of helping me out if my illness rather than ...eh...a barrier (P2, lines 560-561)

" communication was a way... of therapy, it was a way of getting myself well (P2, lines 583-584)

### So what?

- -confluence of perspectives across sources and time, noteworthy in terms of consistency
- -collective narrative of disempowerment/empowerment re communication?
- words of those who have experienced MHDs, must inform any healthcare practice
- notion of *working alongside* people with mental health disorders important
- c.f. (SLT) Social Model (Duchan, 2001) Recovery Model (Anthony, 1993)

Recovery Model

'Living with' mental health difficulty

Person as an active agent in the recovery process

Recovery is something a person does, not something that is done to them

Collaboration

SLT social model

'Living with' communication disorder

Goal setting from perspective of the person

Authentic involvement of the person

Partnership

'new meaning and purpose in one's life as one grows beyond the catastrophic effects of [psychiatric] illness'

It is a means to develop a

(Anthony, 1993; 527)

### **Conclusions**

Need to redefine our definition of communication to consider

- (i) a shared responsibility for communication 'disorder', yet respect difference, also
- (ii) remaining open to hearing accounts of communication 'selves' as construed by person

Janet Frame was 'driven' to write her story in order to put the "I" back into biographical accounts, maybe it is time for us to put the "I" back into mental healthcare, where communication is concerned

Without such witness, how can we even begin to weave a context in which communication can be respected, supported and empowered as part of 'disorders' that are labelled 'psychiatric'?

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