

Dementia and End of Life Communication

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Introduction

- Dementia – neglected area, particularly in communication
- Negative connotations and attitudes
 - fear of the economic cost of health and social services
- The WHO reminds us that the aging population is in fact a positive indicator of social development and public health

Normal vs pathological aging

The process of aging however, brings with it important changes in communication :

- Normal decline in communication functioning
- An increase of disability and health issues which are typically referred to as pathological aging.

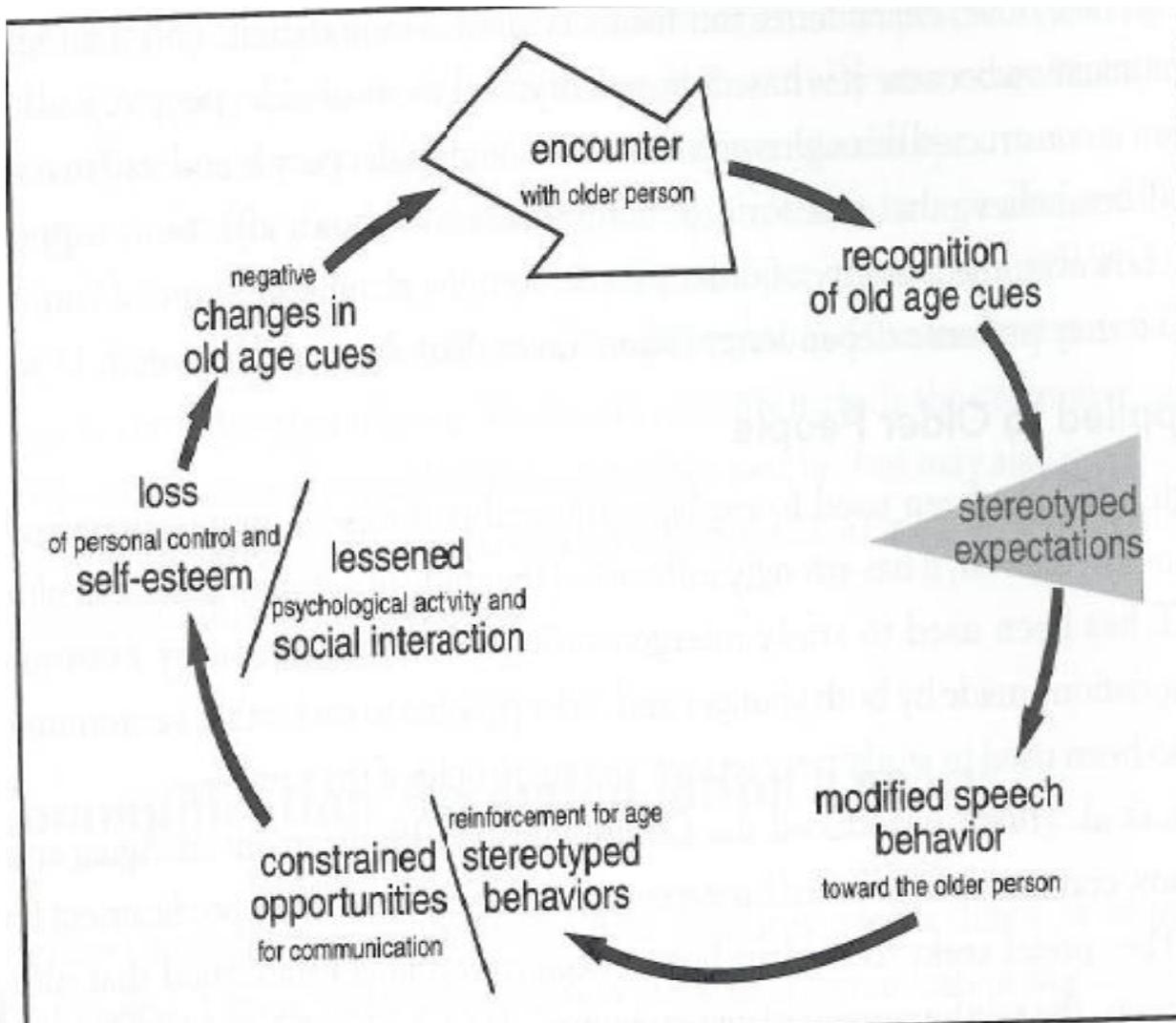
Normal decline in communication:

- language comprehension: short –term memory, understanding embedded clauses
- expressive language: less complex grammatical constructions, recalling people’s names. Forgetting names can substitute with pronouns – it etc. Not necessarily forgotten, but problems retrieving them.
- Increase in vocabulary with age (until 70ys) (Park et al. 2002).
- Presbycusis
- Inhibitory capacity – if this ability declines it can have dramatic effects on communication “off-target verbosity” – engaging in lengthy narratives that tend to drift away from their starting point. (frontal lobe damage)

Pathological Aging: Alzheimers

- Complex brain disease that causes minor confusion and mental malfunction later on.
- Syntax (grammar) is intact, **semantic (meaning) and word processes (lexical)** become progressively impaired. Difficulty coming up with the right word for things- - **broader problems with the meaning of language.**
- **Flashes of lucidity** – which indicates the person is still there and probably knows more than is apparent a lot of the time.
- “No cure, no help, no hope”

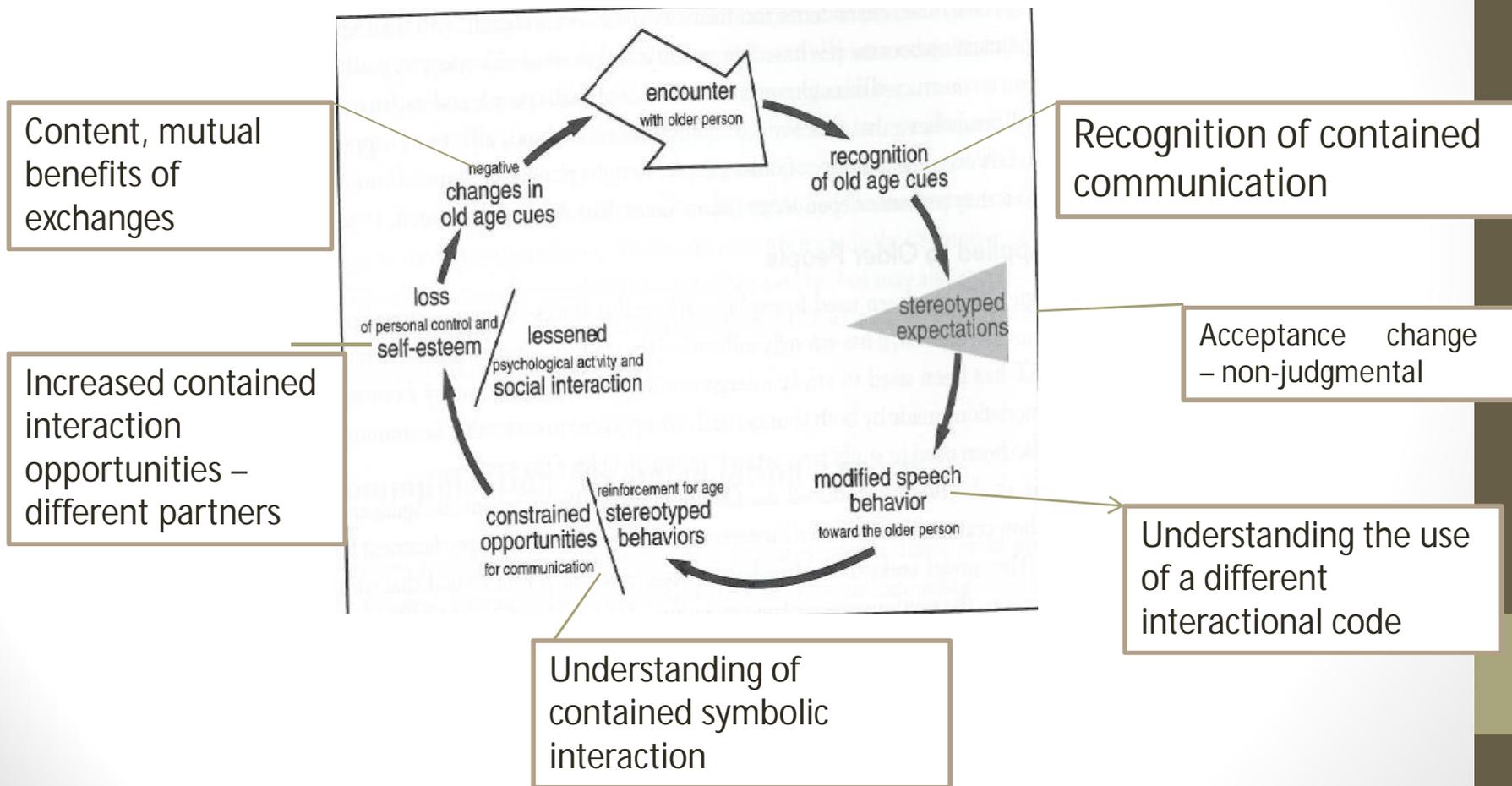
Communication Predicament in Aging Model (Ryan, Meredith, MacClean & Orange (1995))



Different perspective on aging

- On being a Person and Personhood maintained
- That those with dementia have the same value, the same needs and the same rights as everyone else and that they are to be brought fully into the arena of moral concern
- A view of personhood which meets at least four criteria (Kitwood, 2004):
 - Reveal our moral obligations
 - Valid in terms of psychology that focuses on experience, action and spirituality
 - It must illuminate care practice
 - Fully compatible with findings of neuro-science
- The dialectics of dementia: neurological impairment – compensated for by positive person work
- Pivotal role of the quality of care

From a deficit to an enhancement model of aging in communication (partially based on Ryan et al., 1995)



Using this model for further discussion

- 1. Recognition of contained communication
- 2. Acceptance of change – non judgmental
- 3. Use of a different interactional code?
- 4. Understanding of symbolic interaction (themes)?
- 5. Increased opportunities for interaction with different partners
- 6. Content, mutual benefit of exchanges

1. Recognition of old age cues

Conversational features:

Signs of ALZ

- Fewer adherence to conventions of conversations
- Less sensitive to others in conversation
- Shrinking vocabulary
- Fluctuating relevance of responses
- Topic maintenance and turn-taking problems
- Unable to engage in extended discourse/short turns
- Partners have difficulty in following verbal output
- Disrupted reference and cohesion
- Empty language, primary use of indefinite terms
- Uses more words

Healthy aging: Contained communication?

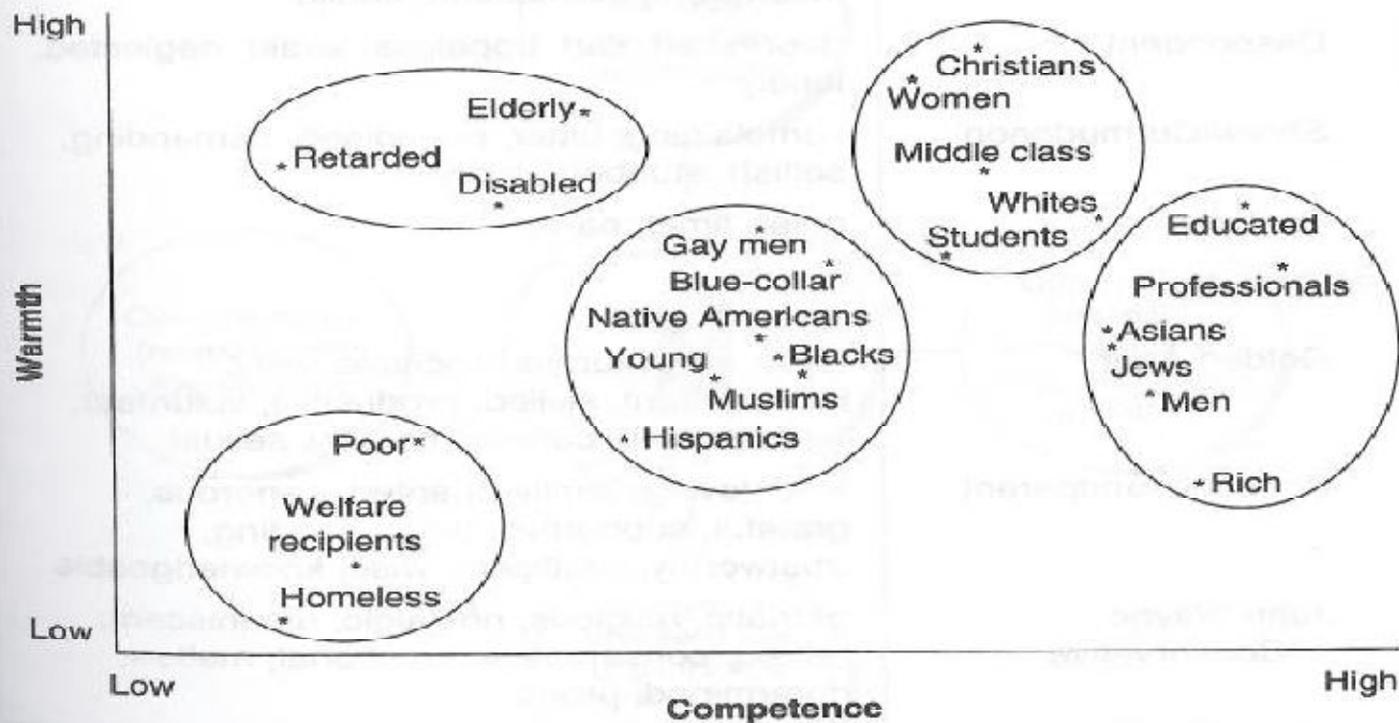
- Adhering to a different interactional code:
 - Restricted vs elaborate speech code
 - Contained/Restricted symbolic meaning
 - Contained/Restricted communication opportunities

2. Acceptance: non-judgmental

- Measuring attitudes toward aging: emotive response
- Stereotypes: mental representation
 - 2 dimensions underlying our mental representations of aging: (Harwood, 2007)
 - A dimension relating to health, activity and attractiveness (declining)
 - A dimension relating to wisdom, kindness and generosity (increasing)
 - Older people are relatively low on competence, high on warmth – low status or societal respect

American Social Groups and Perceived Competence

Figure 3.1 American Social Groups Arrayed Along Perceived Competence and Perceived Warmth and Sorted by Cluster Analysis



SOURCE: From Cuddy, A. J. C., & Fiske, S. J., "Doddering but dear: Process, content, and function in stereotyping of older persons." In T. D. Nelson (Ed.), *Ageism: Stereotyping and prejudice against older persons*, copyright © 2002. Reprinted with permission from MIT Press.

Meet Batia

3. Modified speech behavior: *More comparable to using a different code?*

- Code= a set of organizing **principles** behind the language employed by members of a social group (Littlejohn, 2002, p. 278)
- The language we use reflect and shape our social group (Bernstein, 1971). The code that a person uses symbolizes their social identity.

- Basil Bernstein (1971): Class, codes and control.
 - Restricted vs elaborated codes: Not intended as evaluative categories
 - Restricted: more suited to a context in which a great deal is taken for granted knowledge. More contextualized. Vast amount of meaning with few words – each with complex set of connotations. Draws on background knowledge and shared understanding – creates a sense of belonging to a group – close groups
 - Elaborated: spells everything out “not because it is better but because it is necessary so that everyone can understand it” (Atherton, 2002). Code stands on its own
 - Bernstein (1971): one code is not better than another

codes

:45 And who are **they?**

Any people who ask you questions about Hollywood and Hollywood and Hollywood are driving you nuts. But you don't say a word. You say, "Oh, it's a nice show. Isn't it a charming show..." blah blah blah lalalala... **Because you don't handle it. It's too much for a human being.**

1:44 But then how do you feel afterwards?

You don't feel afterwards. You just survive it.

1:55 And that's survival?

(Nods head)

Is that how you survived in Poland?

In Poland? You don't survive Poland. You just get through the material as fast as you can.

***2:12 When you were a little girl, do you remember it?

No. I don't remember anything I don't want to. You know, you just have to survive.

2:25 But when you came to New Zealand, you came to Wellington?

We came to Wellington. To a big city. **That was already a huge city and everything was already mapped out for you, and you just go through the paces.** And you say, "Goodbye. That was fun, wasn't it?" (laughs)

Batia interaction

- Use of non-specific language: you, they, ask you questions
- Highly contextualized:
 - use of gestures (emblems, facial expressions etc)
 - strategies to compensate for memory loss and ..
 - Reflecting need for social closeness/intimacy?

Contained/Restricted code?

4. Understanding use of symbols in development of meaning

- Meaning: triadic relationship of meaning; i.e. gesture, adjustment and social action (Mead 1962, p. 81).
- Generalized other: awareness of others – internalized
- Self: me (social roles – organized set of attitudes of others that you assume) and I (response of organism to the attitude of others) – creative, sense of freedom and initiative. Both aspects of self in tension – personality.

Examples: Batia

Ex 1

:45 And who are they?

Any people who ask you questions about **Hollywood and Hollywood and Hollywood are driving you nuts**. But you don't say a word. You say, "Oh, it's a nice show. Isn't it a charming show..." blah blah blah lalalala... Because you don't handle it. It's too much for a human being.

1:44 But then how do you feel afterwards?

You don't feel afterwards. You just survive it.

examples

EX 2

4:12 Is there anyone you can be real with?

No

Nobody?

(shakes head No)

There was one, a chap who played something or another. At any rate, there was no reality there. **You had to play the game.** And you have to do it. And there's nothing you can do about it.

4:45 Doesn't that make you feel heavy in your heart?

No. You start making it all very funny. That's all there is to it.

4:56 Is that all there is to life?

Don't ask questions like that because they will die.

What do you mean?

People don't like you to be asking questions. In other words—what you see and what you act is all the same show. People don't do anything seriously.

Huh

You can't be yourself. You can't be anybody else. You just stand and say, "That was very nice. That's charming. It really was fun." (looks seriously at Naomi) And get away. Or else they'll just squeeze you to death.

5:45 But you have Batia Levy left, don't you?

You bet I have Batia Levy left. And they can't destroy **it**. That's something you are sure of—who you are. That you've just shown a show, and it's a very nice show. And "Goodbye, everyone, have a nice day. Isn't the weather splendid?" blablalalalala (laughs) And that's all.

George Herbert Mead: Self – interaction between “I and me” as part of the self

Me: social roles

I: Individualistic, creative ability to relate to social roles

Different sense of self?

- Hollywood: generalized other? Emptiness
- Show: playing the game, empty
- You don't feel afterwards: empty – withdrawal

So – what does this mean for intervention?

- Developing shared meaning:
 - understanding the thematic context and what they represent–symbolization
 - Different reality – and context: emotional engagement not just rational
- Understanding the code
 - Words/gestures used
 - Need for social closeness

5. Increase opportunities for interaction

How?

- Supportive communication
 - The role of supportive communication: Dreher (2001) effective communication with AD may often involve not arguing about the truth of a particular statement. Truth may well not be relevant in the context. It might lead to more productive and useful responses. Sabat (1999) describes “indirect repair” – clarifying, questioning, restating to confirm understanding.
- Naomi Feil: Non-judgmental empathic listening
- Central role of empathic listening

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Thank you's

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