Crafting of Psycho-Oncology

Re-writing life stories:
Narrative Approaches in Oncology & Palliative Care

16.6.2018

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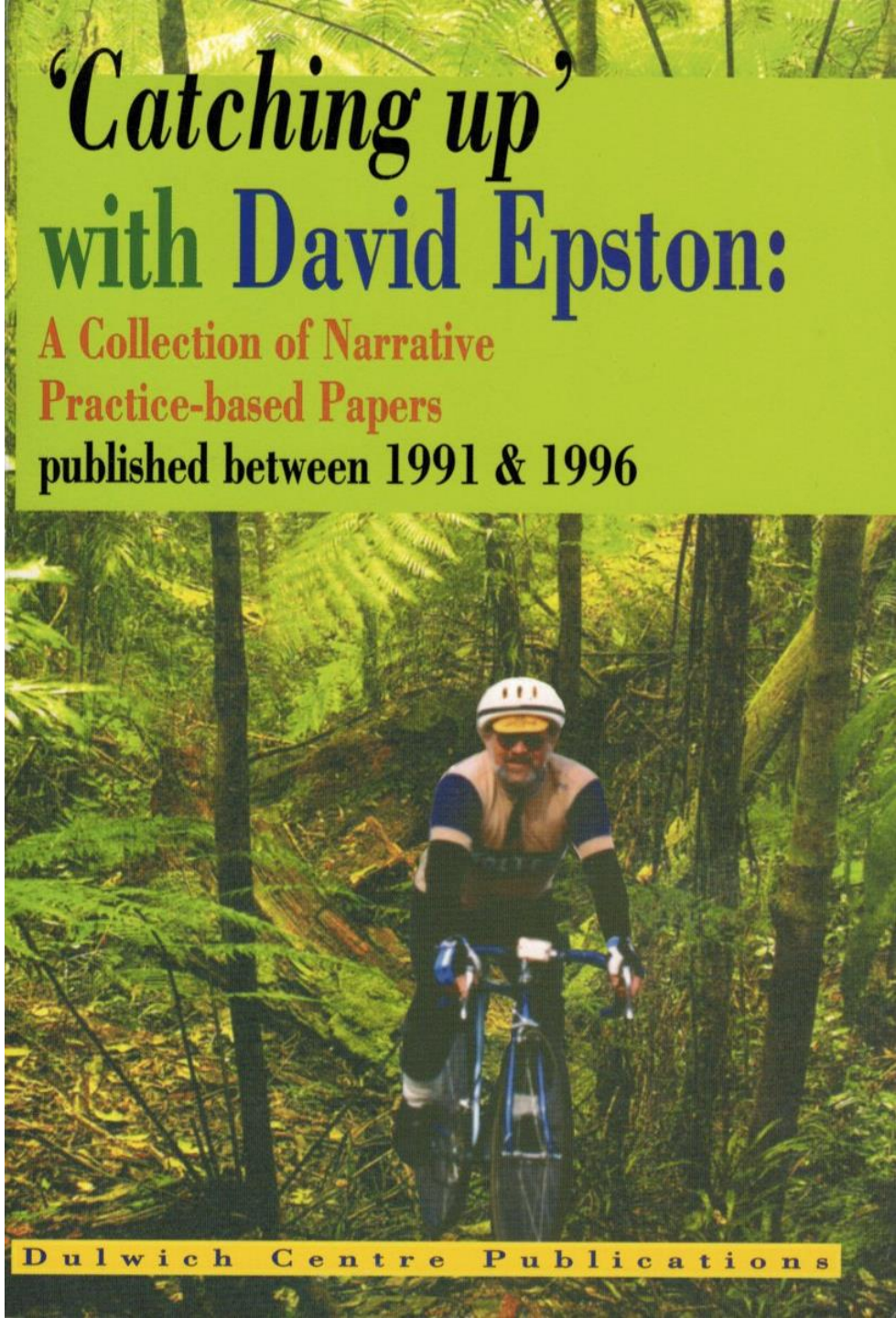
My Intimate history of the Family Therapy

1956	Bateson, Jackson, Haley, and Weakland	Toward the theory of Schizophrenia	Understanding human by focusing the communication not intrapsychic
1961	Jackson and Weakland	Conjoint Family Therapy	Direct observation of whole family interactions
1974	Weakland, Fisch, Watzlawick, and Bodin	Brief Therapy: Focused Problem Resolution	The attempted solutions as a problem
1983	Weakland	‘Family Therapy’ with Individuals	Family(systemic) Therapy with individual
1990	White and Epston	Narrative means to therapeutic ends	Therapeutic metaphor: from system to narrative

Another history of the Family Therapy

- My 11th translation in 2005.
- I had always been interested in the problematising of the notion of the 'problem'. I credit the Mental Research Institute for pioneering this undertaking and it seems very appropriate that John Weakland is here to represent it.(Epston, 1993/1998)



The Philosophy of Terminal Care (Saunders, 1978)

methods of relief which can and should always be given, form a large part of this book. Such knowledge has to be balanced with a detailed consideration of social and personal factors. 'Feelings are facts in this house' as one of the nuns of St Joseph's Hospice put it, and intuitive thinking has to be added to the discursive if we are to approach the full reality of another person. Much of what is written here is concerned with feelings, with emotional and family suffering. These have frequently been described as making up the complex 'total pain' (Fig. 15.1) which our patients have often endured before they come to us, though criticism has been made that this use of words carries the

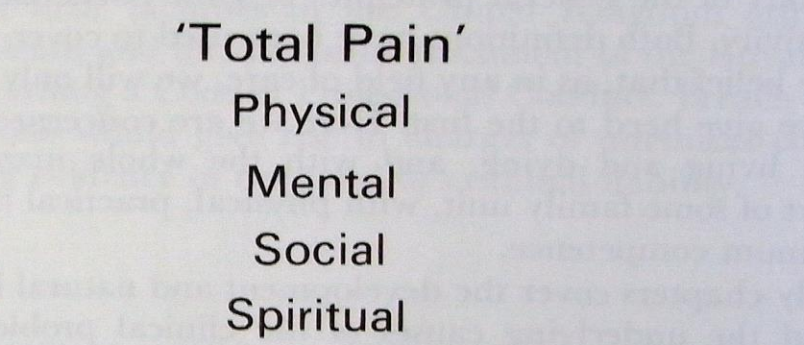


Fig. 15.1. Total pain.

suggestion that such negative emotions should be avoided at all cost (Proudfoot, 1976). The automatic prescribing of antidepressant drugs or tranquillizers is to be deprecated; grief is appropriate and the understanding of suffering and its creative handling may be as important as attempts at its

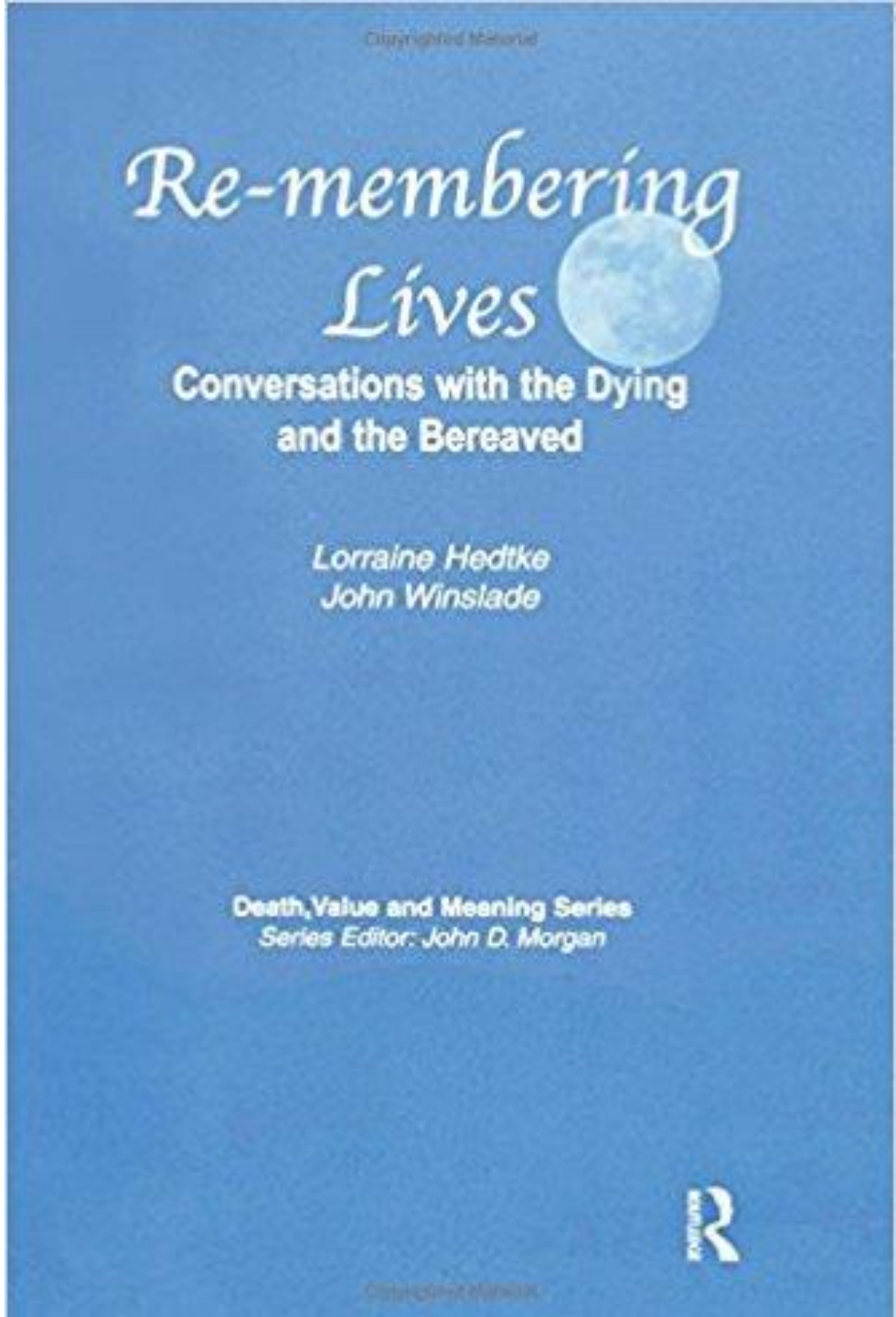
Cicely Saunders, On Dying Well, 1984

- *Approaches to death and dying reveal much of the attitude of society as a whole to the individuals who compose it.*

Hedtke, L and Winslade, J. Re-membering Lives:

Conversation with the dying and the Bereaved, 2004

My 12th translation(2006)



Mr. Derrida (a pseudonym)

- 65 y. o. male,
- The end stage of the gastric cancer
- ex-construction worker
- Living with his wife and their second son.
- First son and daughter were independent.

15 February (Thur.) Intake session of Dignity Therapy (DT)

- “After the cancer treatment, I decided to write something to my families, and the nurse suggested me the Dignity Therapy. I have already considered the answers for 9 questions”.
- “I wondered what a therapist would come and hoped he was not so young”.

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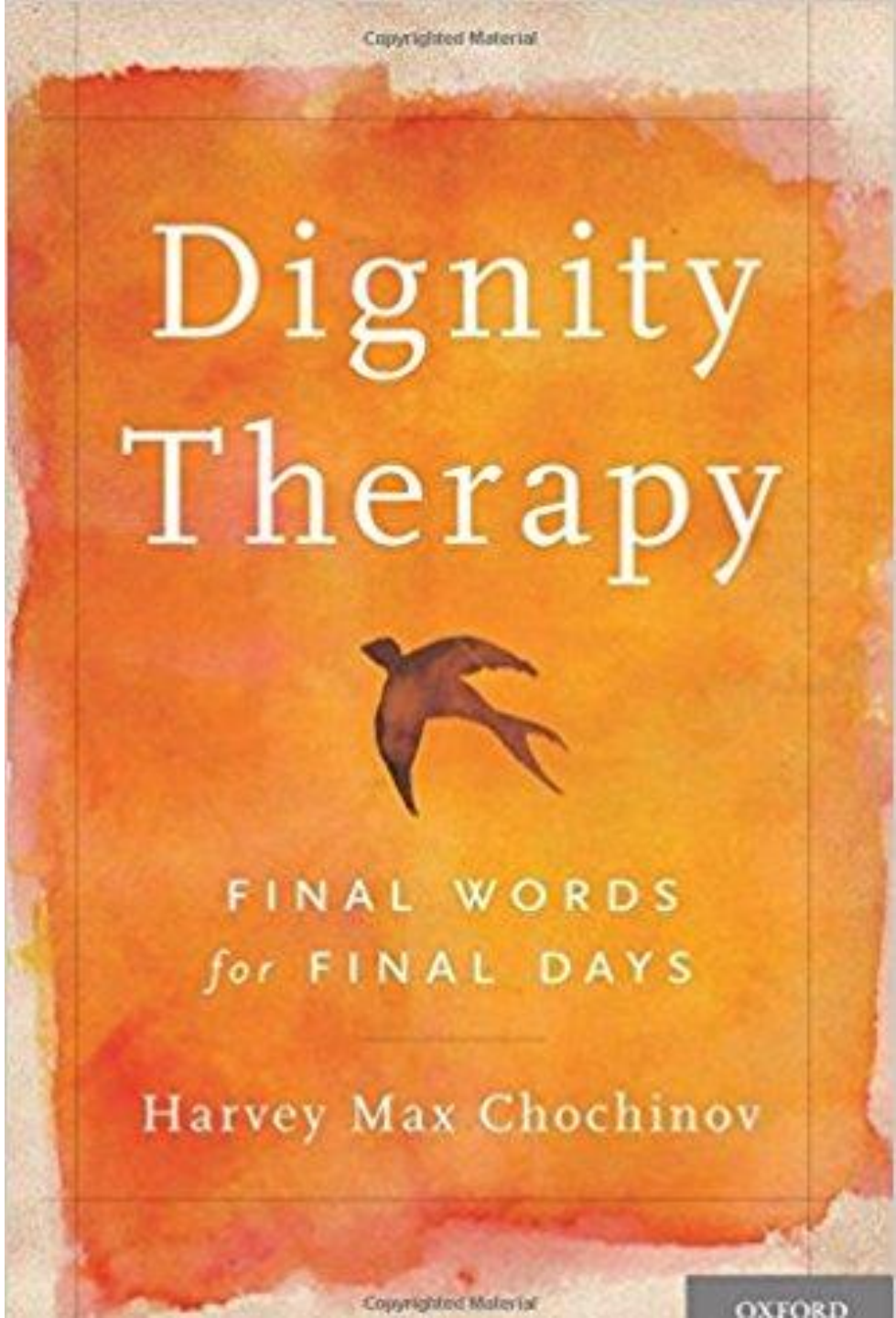
Chochinov, HM: Dignity Therapy: Final words for final days (2012)

- My 19th translation (2013)
- 1) Based on his research about Dignity
- 2) Making the Generativity Documents
- 3) Brief Therapy (minimum 3 sessions)
- 4) Good Evidence by a randomized control trial(300 cases)
- Chochinov,HM et al. Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomized controlled trial. Lancet Oncology 12:753-762,2011



Dignity Psychotherapy Question Protocol (2005)

Tell me a little about your life history, particularly the parts that you either remember most or think are the most important? When did you feel most alive?
Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
What are the most important roles you have played in life(family roles, vocational roles, community-service roles, etc.)? Why were they so important to you, and what do you think you accomplished in those roles?
What are your most important accomplishments, and what do you feel most proud of?
Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say once again?
What are your hopes and dreams for your loved ones?
What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your (son, daughter, husband, wife, parents, others)?
Are there words or perhaps even instructions that you would like to offer your family to help prepare them for the future?
In creating this permanent records, are there other things that you would like included?

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Dignity therapy: Preliminary cross-cultural findings regarding implementation among Japanese advanced cancer patients

Dignity therapy is a novel, brief, and individualized psychotherapeutic intervention developed in Western countries[1,2] and appears to be a feasible and effective approach for addressing the existential distress experienced by advanced cancer patients.[3 4] We investigated the feasibility of providing dignity therapy for terminally ill cancer patients in Japan.

This study consisted of a hospice/palliative care inpatient setting (Study 1) and an inpatient setting in a regional cancer center and/or general hospital (Study 2). The subjects were adult advanced cancer patients whose estimated prognosis was of less than six months. In Study 1, potentially eligible subjects were consecutively enrolled for the study in hospice/palliative care units. In Study 2, trained psychiatrists sampled potentially eligible participants who were expected to benefit from dignity therapy. The current study was approved by the Institutional Review Board and Ethics Committee of each research institution; the trial was registered as UMIN000001140. Written consent was obtained from each patient.

The study procedure was almost the same as that used in the original study.[1] The participation rate of the eligible patients and the completion rate of the participants were evaluated as indicators of the feasibility. The patient's experience undergoing dignity therapy was evaluated using the Dignity Therapy Feedback Questionnaire (DTFQ), which is a self-reported questionnaire developed by Chochinov (personal communication) to evaluate a patient's perception regarding the usefulness of and his or her satisfaction with dignity therapy.

Regarding feasibility, among 22 eligible patients (14%) who had been consecutively admitted to two palliative care units, three subjects participated while 19 patients (86%) refused. Because the refusal rate was much higher than expected and the reason for refusal as described by the subjects suggested a potentially negative influence of introducing dignity therapy to some patients, the research committee decided to stop the consecutive sampling in Study 1. The reasons for refusal were as follows: 'It just makes me think about death'; and 'Why would you recommend such a thing to me when I am dying?' Because there were eight participants in Study 2 (no problems with the enrollment of these subjects were encountered), a total of 11 patients participated and completed the intervention.

Regarding the DTFQ, the following findings were obtained (percentages indicate the proportion of positive responses): usefulness for improving dignity (67%), benefits (56%), improvement of meaning of current situation (56%), improvement of purpose of life (44%), usefulness for ameliorating suffering (44%), helpfulness for family (78%), usefulness for sense of well-being (56%), burden to physical condition (0%), and recommendation for other patients (33%).

Our findings suggest the potential influence of unexpected underlying cultural differences and may have several potential interpretations. First, underlying differences regarding the general attitude toward a 'good death' between Western and Japanese populations may have influenced the lower participation rate. A previous Japanese study demonstrated that 'unawareness of death' is a relevant concept of good death in Japan.[5] Terminally ill cancer patients who wish that they were unaware of their impending death may be less likely to participate in dignity therapy, even though they are receiving specialized palliative inpatient care. Their aversion to participating in the study may not have been due to the dignity therapy per se, but rather, their having been confronted with information that they did not wish to hear. Second, the higher refusal rate in Japan, compared with Western countries (such as a recent randomized trial with a participation rate of 50%),[2] suggests that terminally ill cancer patients in Japan may try to cope with their terminal condition by denying their impending death. While some previous studies have indicated that denial is a commonly observed psychological defense mechanism among cancer patients, [6] Japanese cancer patients may be more likely to cope with their distressing medical condition using denial than Western cancer populations, as suggested by a previous study.[7] Lastly, Japan still has many unique cultural characteristics. For example, because the preferred communication style is generally nonverbal, indirect, and serene, tacit understanding or heart-to-heart communication ('ishin denshin') operates as a powerful traditional value that is possible in a close community.[8] In addition, a previous Japanese study

has demonstrated that Japanese people are less likely to put great value on preparation for death, including saying goodbye to loved ones, and are more likely to emphasize the importance of euphemistic communication.[5].

Although dignity therapy should not be routinely recommended to all terminally ill Japanese cancer patients, this therapy may be promising for patients who hope to leave a legacy.

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Conflict of interest

None declared

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Dignity Therapy: Preliminary cross-cultural findings in Japan.

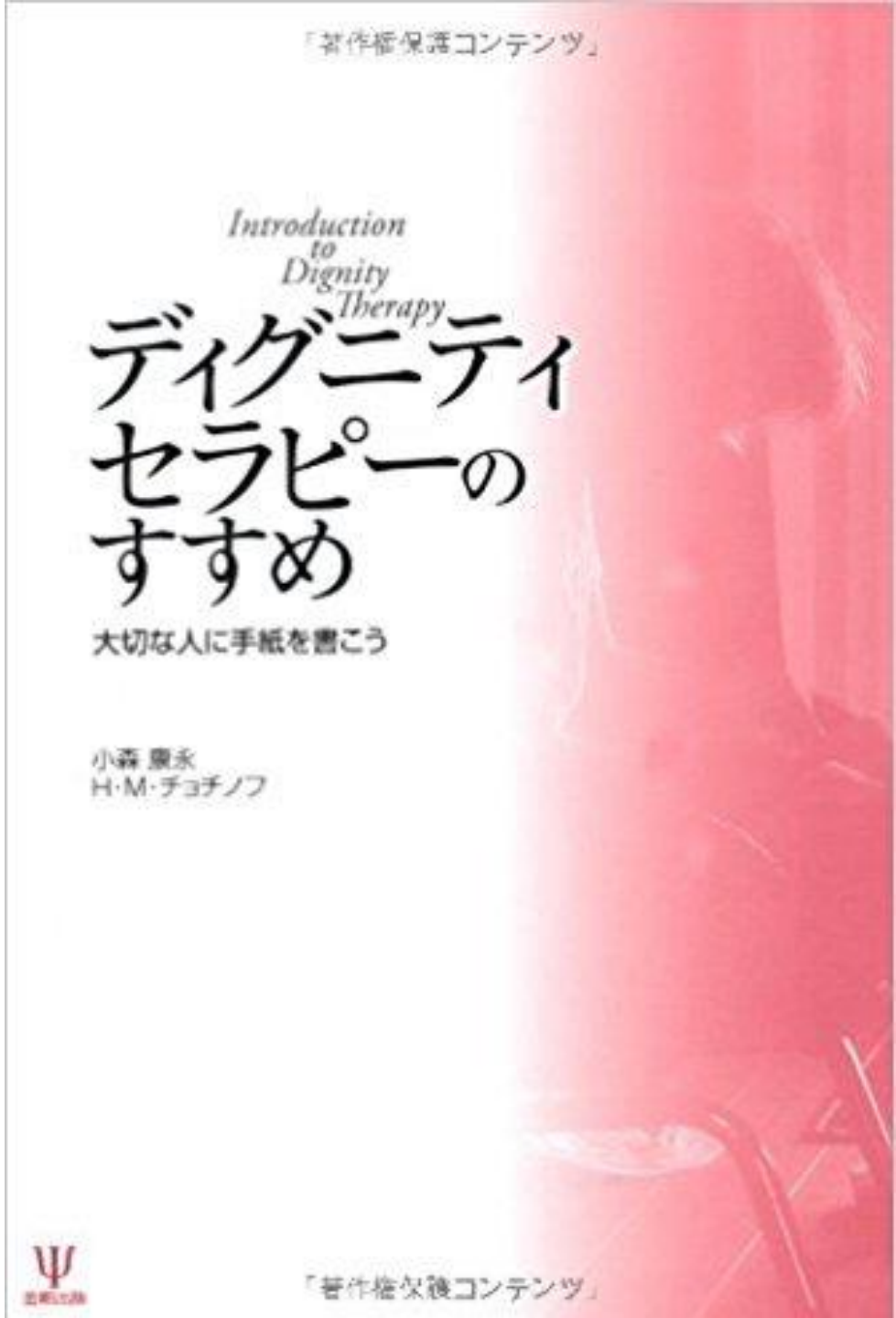
Akechi, T. Akazawa, T. Komori, Y., et al.
Palliative Medicine 26(5):768-769, 2012

Re-membering vs. Dignity Therapy

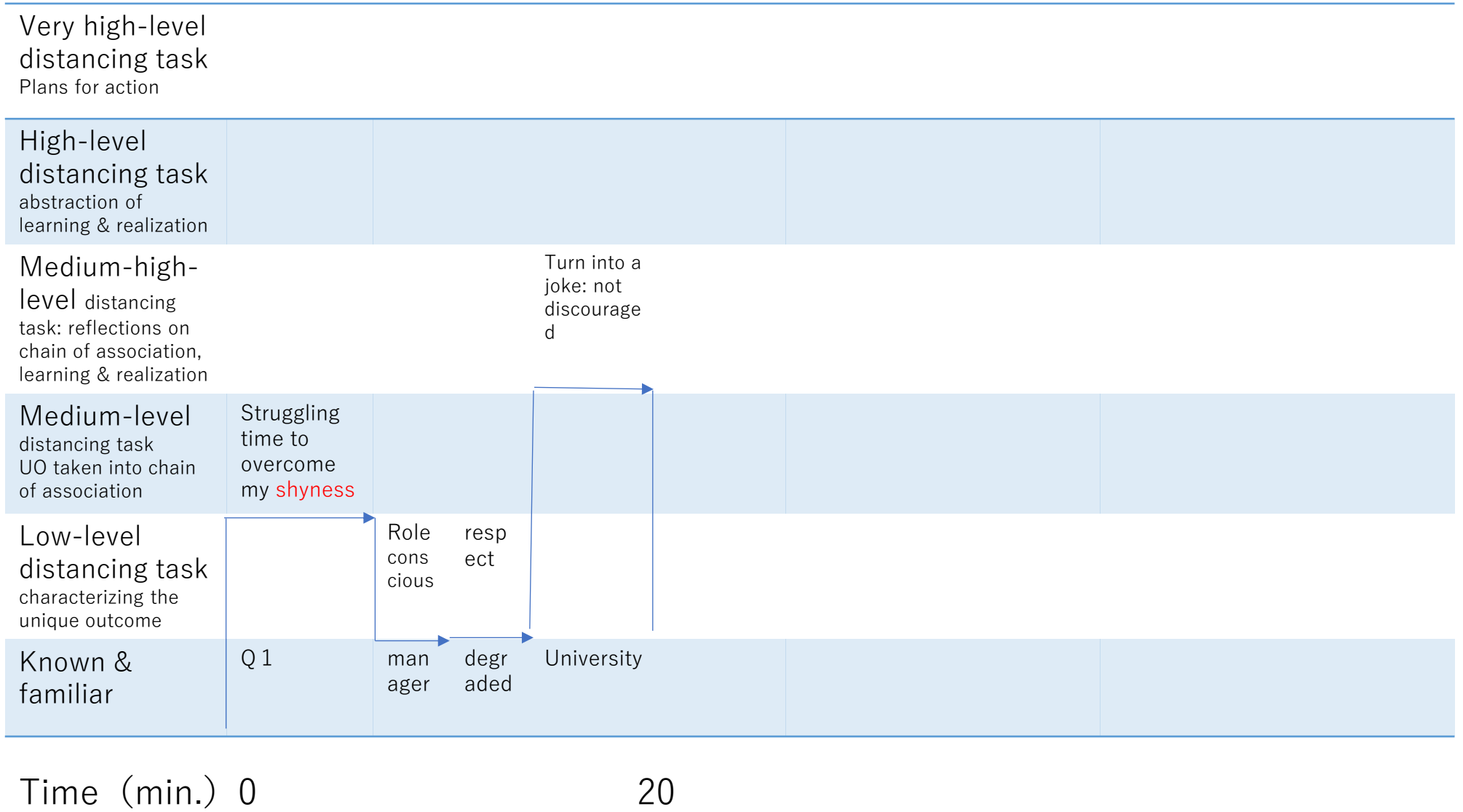
	Re-membering	Dignity Therapy
Background	Narrative Therapy	Psycho-Oncology
An Advocate	Michael White	Harvey M. Chochinov
	Adelaide, Australia	Winnipeg, Canada
Publication	1989	2005
Clients	The bereaved	The dying(terminal illness associated with a life expectancy of < 6 months)
Number of sessions	A few	Minimum 3 sessions
Documents	-	+
Evidence	-	+
notes		

19 February（Mon.）13:10-14:05
DT Recording Session #1

- #1 Tell me a little about your life history, particularly the parts that you either remember most or think are the most important? When did you feel most alive?
- “I was shy. So, I think the most alive when I was struggling to overcome my shyness and I remember three episodes …”
- 20 min.

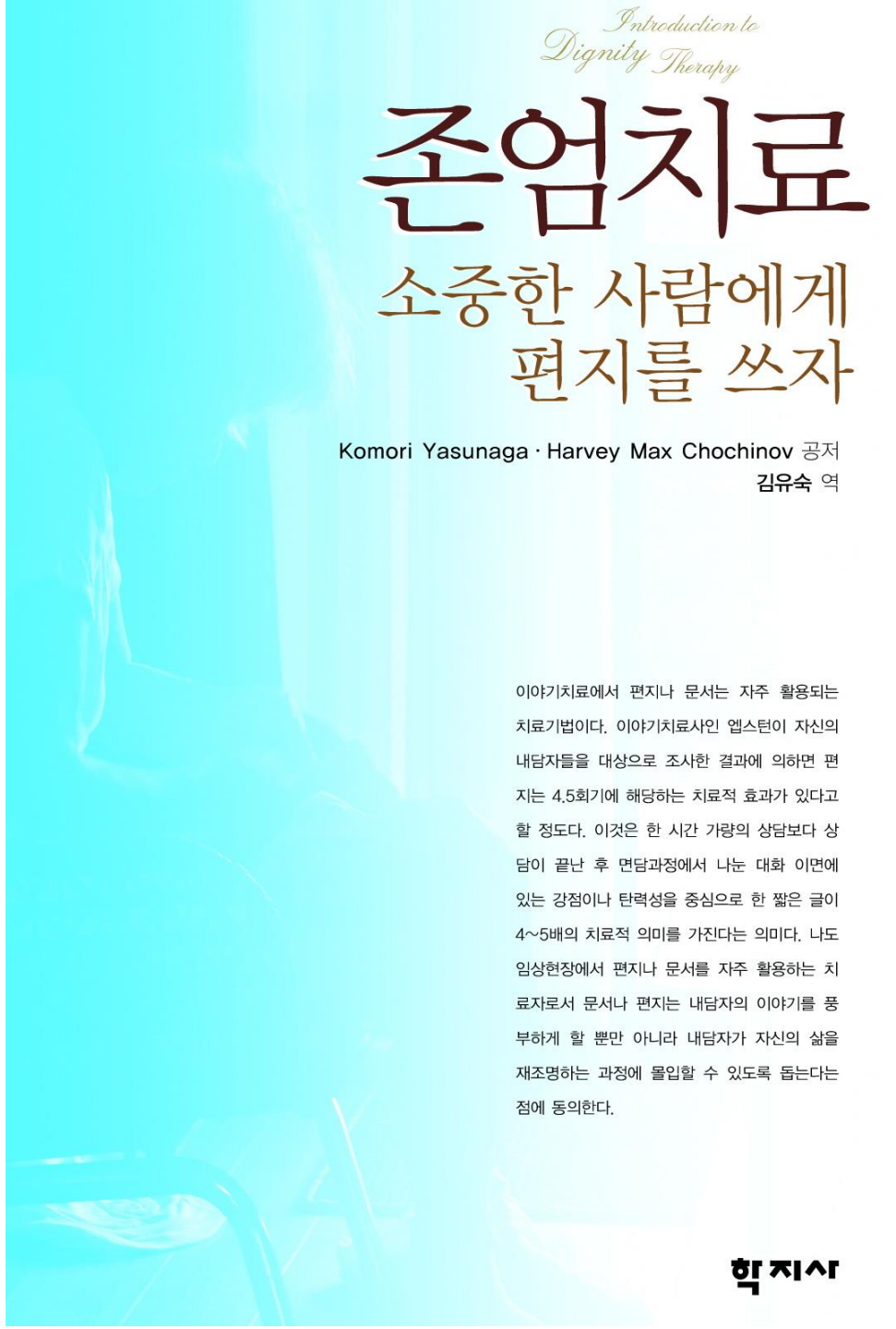


19 February　Scaffolding Conversation #1

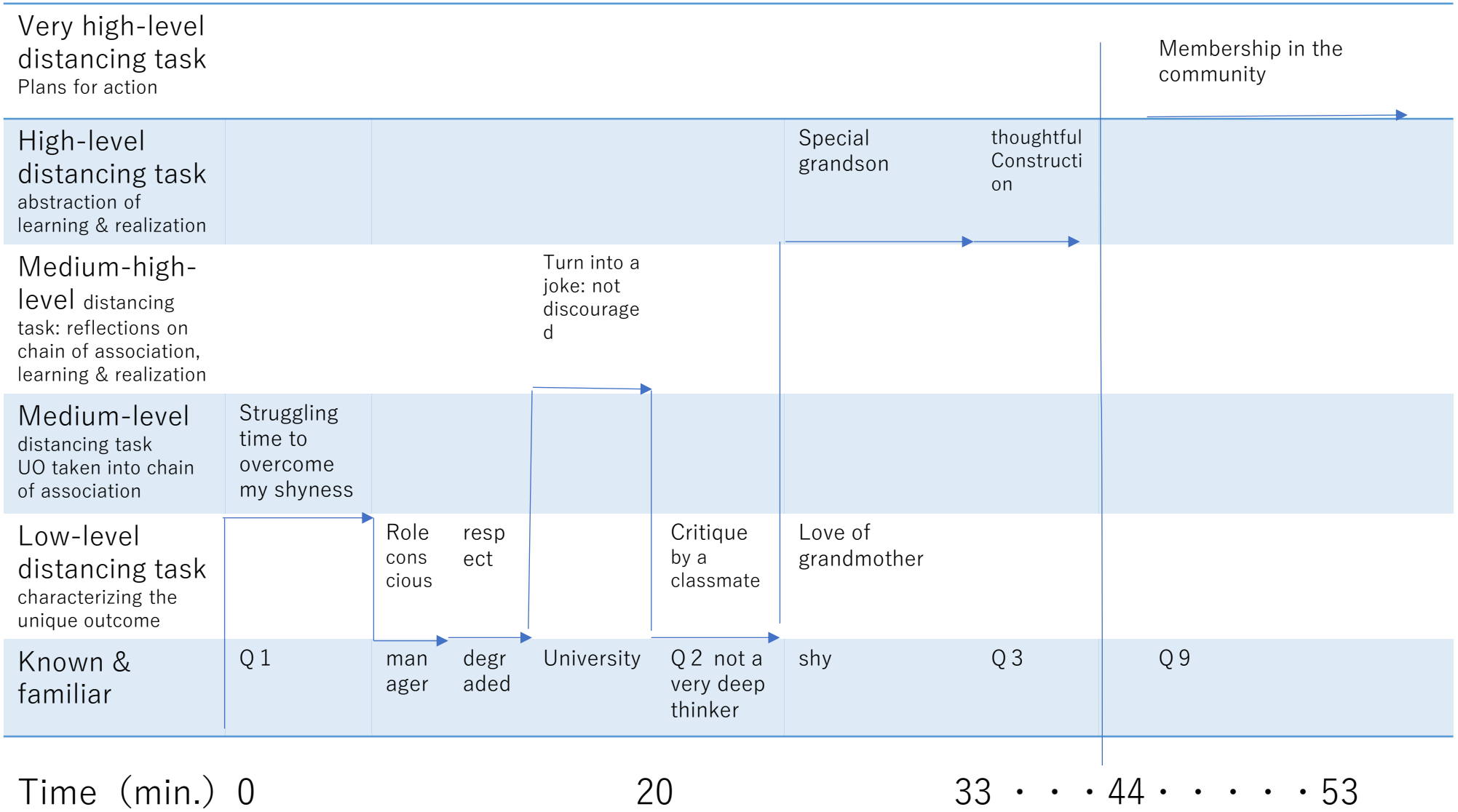


19 February（Mon.）13:10-14:05
DT Recording Session #2

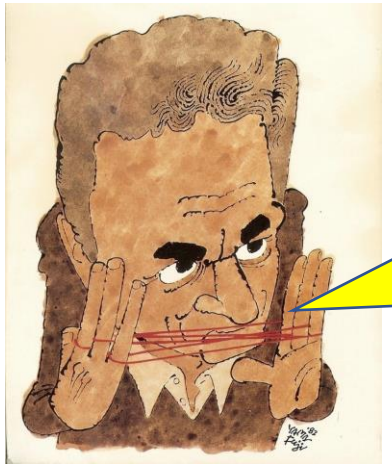
- #2 Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- *12min.*



19 February　Scaffolding Conversation #1-9

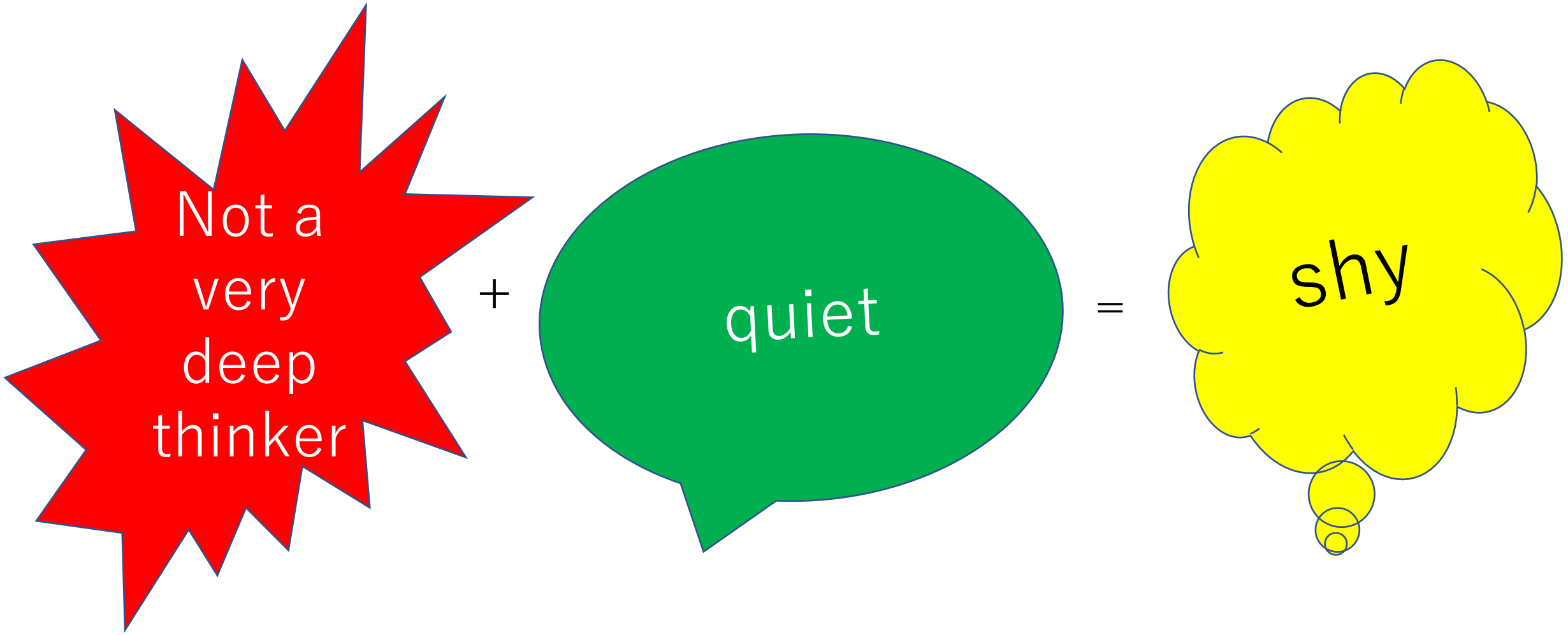


21 February （Wed.）
Generativity Document in DT

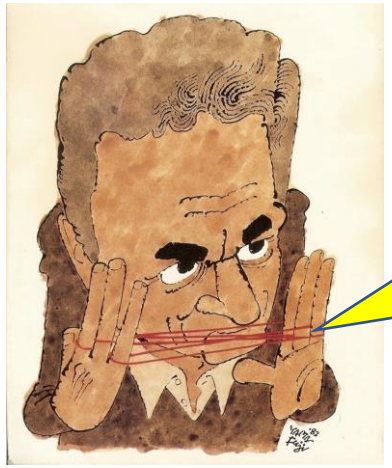


I’m so surprised!
This is what I told you as it is.
How quick you made it!

22 February （Thur.）
DT # 2 revisited : The meaning of ‘shy’



26 February （Mon.） DT # 2 revisited : Re-membering the grand-mother



Wow, I can’t understand why my grandma had treated me so special.

1 March (Thur.) Dialogue with the visitor E

- I heard that you had written the letter to the families and didn’t send them. I think worth the letters even if you don’t send them actually.

5 March（Mon） Writer’s note to DT Generativity Document

- Mr. Derrida told that the struggling time to overcome the shyness is the one he felt most alive. On #2 question, he confessed that his motivation was rooted on the criticism by a classmate, “not a deep thinker”. And suddenly he remembered that his grandma described him quiet when he had a hard time at school, with his brilliant eyes.

私の大切なものを
大切な人たちへ

2018.2.19

ディグニティセラピーの記録

MR. DERRIDA

愛知県がんセンター中央病院精神腫瘍科部作成

5 March （Mon） Writer's note to DT Generativity Document (cont'd)

- Furthermore, in the conversation, it is disclosed that his meaning of "shyness" is special, which implies not not-enough self-expression but his superficial thinking. It seems to be mixed with the classmate's criticism, "not a deep thinker" and his grandma's description, "quiet" and it made the special meaning of "shyness". I believe the episode with those three words are not accidental talk.

私の大切なものを
大切な人たちへ

2018.2.19

ディグニティセラピーの記録

MR. DERRIDA

愛知県がんセンター中央病院精神腫瘍科部作成

9 March (Fri.) Onset of Delirium

- Time disorientation
- Forgetfulness
- No realization that I'm not allowed to use the rescue by oral after the opioid switch from the oral to the injection.
- So real dreams

12 March （Mon.） Palliative Care Team round: The conversation with the ward nurse

- Stick to the oral medications
- Diabetes

12 March (Mon) reflecting by the visitor E

- I realized again that the patient (and the supporting medical workers) are always exposed to the change, the not-knowing of the future. Such a reality becomes heavier when I remember him in his full brightness and clearness.

- After knowing the story of his type I Diabetes, I still think the meaning of not-told. In the Dignity Therapy, should we listen what the patient wants to talk or what the therapist wants to ask? Furthermore, what do we talk and what do we not-talk? We don't talk because it's no worth, or because of the give-up due to the impossibility of enough-talk? What is the reality of not-told? What is the reality of cannot-told?

14 March （Wed.） social

- The visiting of the first son, his wife and their two month baby.
- After 5 minutes the baby started crying and Mr. Derrida told them to leave the room.

14 March （Wed.） spiritual

- The picture in which the first son is feeding the milk to the baby.
- The Black dark hair of the baby
- The not enough life as his father had expected.
- Delirium

14 March （Wed.） biological

- Diabetes

14 March (Wed.) reflecting by visitor E

- I found myself telling that the dialogue is like this. Telling and listening are not completed. If edited or written in the letter, they would be born again and carry the person further. How far he was carried! He was glad to have Dignity Therapy. Yes, this is the simple fact.
- “Diabetes is not worth telling”, he said. We can listen his words such as it is only NOW that he can tell like that. If so, we could hear his another voice. E

14 March (Wed.) reflecting by visitor Y

- Still in my mind is your comment, “there is no magic word, but magic house” in your essay about Saunders’ writing.
- The place where we could talk like this, “Yes, but it is. However …” should be a magic house in a sense.
- Last night I talked with the workers in the jail in Hiroshima, I really hope the magic house in the jails or the approved schools in Japan… Y

15 March (Thur.)
The wife's talk to the nurse

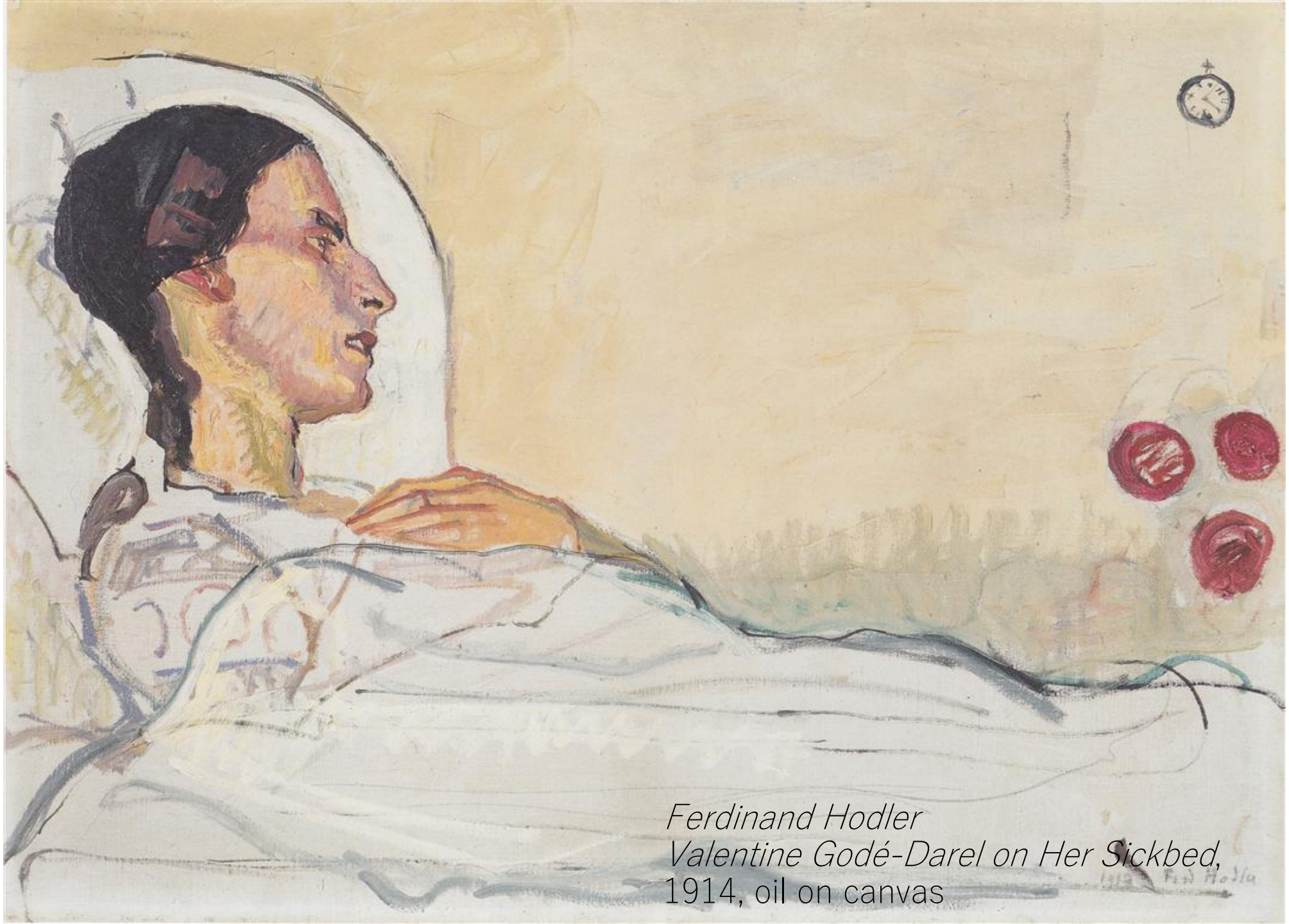
- I was so surprised to see him very calm, then I thought that we could care him at home. How do you think? I have to accept the reality I cannot be here with him when he dies, but somehow I can't give it up…
- To tell the truth, my husband broke up with the first son. But in this situation, I made contact with him and he came up with his daughter and wife. Then, my husband opened his eyes wide, and hold the first granddaughter. We cannot know how the person spend the last stage of life, can we?

19 March （Mon.） biological, social

- The interruption of the consciouness
- Re-union with the best friend

19 March (Mon.) reflecting by visitor E

- In his room, now a little bit different time is flowing, isn't it? The time is crafted by your interchange.
- "It's good to talk about it with laughing". I took what he said literally. He is surrounded by the people who see him, care him with looking at the near future, and remember him.
- Time is not only losing the sequence but also concentrated and enriched. Aion. E



Ferdinand Hodler
Valentine Godé-Darel on Her Sickbed,
1914, oil on canvas

21 March （Thur.） Mr. Derrida died.

26 March (Mon.) Palliative Care Team round

- Chief ward nurse: His wife was asked to stay in the hospital previous night before his death, and she did so. She had a intuition, because his mother died in the hospital due to the cancer in the morning scheduled to transfer to the hospice. It became true, she said.

3 April （Tue.） Frantz Fanon
The Wretched of the Earth, 1969

- If the building of a bridge does not enrich the consciousness of those working on it, then don’t build the bridge, and let the citizens continue to swim across the river or use a ferry. The bridge must not be pitchforked or foisted upon the social landscape by God, but, on the contrary, must be the product of the citizens’ brains and muscles. ・・・The citizen must appropriate the bridge. Then, and only then, is everything possible.

15 May (Tue) Follow up with his widow just after his 49th days anniversary.

- He showed me the documents in the hospital. I found that he was thinking about the family of origin more than the present family. It's just like him, but I felt lonely although I couldn't say it. It is natural to remember the old times when the people are dying, isn't it?
- He was crafting the picture book. It was finished just after his death, so he couldn't see the picture. In the story, the husband in his child age makes friend with his granddaughter. He takes her to the working place of his father gathering laver. The end was so sudden that I advised him the scene he was looking at her forever. He agreed with it. The picture book is now on a family Buddhist altar.

15 May (Tue.) reflecting by visitor E

- Mr. Derrida, who was talking more “the family of origin than the present family”, but crafting the picture book in which “he in child age makes friend with the granddaughter”.
- He was also talking about the family tree and the distance between the first son and him on the day of reunion. Although he, who seems to dislike illogical things, continued building the bridge, he was writing letters, crafting the picture book, and tried the Dignity Therapy in his final days. At this time, everything he did, I want to keep as they are, without a pushy interpretation.
- I like the impression of his wife. It is not a grand finale surrounded by all the thanking family. His last was somehow curt, but unforgettable. I see the power of the Dignity Therapy in such a case. I think the Dignity Therapy is good. I’m so attracted. E

16 May （Wed.） reflecting by visitor Y

- Attending the meeting of AD （anticipation dialogue), I thought of the difference between AD and DT. In AD, every participants would fly to the future and talk about the near future or the present as the past. In DT, the past of the client would be remembered and described for the loved persons to remember him/her in the future. The time sense are different but for both the complicated time sense is needed. That’s why both have the structured questionnaire. By the structured questionnaire, some dialogue could be possible and others are restricted. Then the time sense of client and the time orientation of the narrative are crossing. Y

Tom Andersen
in an interview with photographer Eva Charlotte Nilsen

- With those who want to talk, it's about talking about what they want. And avoid talking about what they don't want to talk about. I think that's one important framework for the whole thing.
- To me it sounds as if you wish to avoid discomfort, is that right?
- It's uncomfortable to discuss difficult issues. So it's hard to avoid unease. But the discomfort has to be bearable. It mustn't be so uncomfortable that people grind to a halt. Which they automatically will do. So it's about trying to - - be a bit sensitive toward the various signs they convey.

25 May (Fri.) reflecting by visitor E

- Reading English translation of my reflecting, I noticed that there are no dichotomy, in which we should describe what the client wants to talk or what the therapist wants to ask.
- In such time sense and interchange, the alternatives would spontaneously rise up and the therapist should catch them both. In Andersen's word, "trying to - - be a bit sensitive toward the various signs they convey". E

Gustave Flaubert, 1872,
in a letter to Ernest Feydeau

When you write the biography of a friend, you must do it as if you were taking revenge for him.

Thank you for listening !