

THE LANGUAGE REVOLUTION

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In memory of Alan, a very special person with Alzheimer, and to his daughter Joy,
who passionately put into practice the concept of «global care».

The growing interest towards non-pharmacological therapies and a « global » or «multimodal» model of care in dementia in the last few years is leading not only to a profound change in the practical approach to people facing this disease and their families, but also to an important « side effect » : the «revolution of language».

Just before the launch of the journal «Non-pharmacological Therapies of Dementia », I had a vigorous discussion with some members of the Editorial Board about the policy of the journal.

The first focus of discussion was how to designate people we are caring for : John Zeisel, in particular, underlined the importance to establish policies that employ the most effective terms. As a medical doctor and a person of Neo-latin origin, I am very attached to the term “patient“. This term comes from the Latin “patior”, that is “to suffer”. When I decided to be a medical doctor, my idea as a young woman was to help to reduce other people’s suffering. I don’t like the term “client”, because it’s associated with money in Neo-latin minds.

But John wrote to me: “Just the correct terminology to use is a vital issue. For example: You write that you “hate the term “clients” that we use in the USA.” Firstly, we in the US are not homogeneous. Secondly, this is not a cultural issue but an intellectual one. My own choice—and the one I use in my book—is never to use the word “patient” but instead to refer only to “people living with Alzheimer’s” or dementia. Why? Because when I or anybody goes to the doctor I am a “patient.” When I leave the doctor’s office (or the hospital or the clinic) I am a person who may have a medical problem. Why are people living with Alzheimer’s not allowed the same freedom and independence from the stigma of illness? Why are they labelled “patients” just because they have a diagnosis? In English, the term “client” means something very specific = the user of a service, for example someone who goes every day to a day center might be said to be a “client” of that day center. I have an agent for my book; I am her client. To assume that everyone with a diagnosis of Alzheimer’s or another form of dementia is a “sufferer” is a big assumption”.

However, as the same criticism for the term “patient” can be applied to the term “client”, we agreed to apply the expression “people living with Alzheimer’s disease or dementia”, or to abbreviate to “people with Alzheimer’s disease or dementia”.

This change in the way one refers to people we are caring for is becoming more common in both scientific and popular journals, even if the medical world continues to be reluctant to implement this change. It will surely become the norm in the end, as both Family Associations and people with dementia themselves (see for example the newsletter edited by Richard Taylor, the author of “Alzheimer’s from the Inside Out”) are advocating more and more the right to maintain the dignity of human beings. In the first preparatory meeting of the project *Wisdem* (www.wisdem.com), led by John Zeisel, the working group (that I had the honor to participate in) stated that the objective of all kinds of interventions (pharmacological or not) for people living with Alzheimer’s disease were to support human rights, as defined by the United Nations. In this meeting we discussed at length the name to attribute to therapies for people with dementia, other than drugs, without finding a real solution. The same discussion took place before the launch of the journal, and it focused on both the term “non-pharmacological” and the term “therapies”. Rose-Marie Drees wrote to me: “When I read the title of the proposed journal I had some doubts, first of all because of the word ‘therapies’. In my opinion, it would be better to broaden the field by using the term ‘interventions’ (different types of care, e.g. emotion-oriented care, would then be included as well). I would also prefer to talk about “psychological and psychosocial interventions” instead of “non-pharmacological” to be clear about what we mean. I am aware of the fact that in the medical field doctors like to summarize all these interventions as non-pharmacological, but I prefer to mention these interventions by their own name and not as non-.... It will just take some time for doctors to get used to the fact that this field has its own identity, I suppose that in the end it will be much clearer. Just think about it...”

I thought about it. Rose Marie is partially right. But the term “psychosocial interventions”, which is currently used by many professionals, doesn’t capture the whole array of therapies which in my mind could appear in the journal. Is music therapy a psychosocial one? And what about alternative medicine? Therefore I leave the term “non-pharmacological” even if I recognize that it isn’t an ideal word. Another reason for which I think that the term “psychosocial” doesn’t entirely describe reality is the following: are we sure that a biological component is not present in these treatments? We know, for example, that music therapy can change physiological parameters. So, a more precise term could be psychobiosocial therapies. Such a term would also avoid that the medical world discard these treatments as simply not relevant for their work (“It’s not my area”).

My dream, as you know, in an ideal world where medical practitioners (who are still the first professionals to be consulted by people with dementia and their families) work in a multi professional team and prescribe psychobiosocial therapies in the same way as drugs when appropriate. Other professionals, belonging to the multiprofessional team, will verify the correctness of the prescription (or will suggest the required therapy if the medical doctor hasn’t done this), a detailed treatment plan will be put into place. Conversely, people with dementia actually often only receive information and have access to non-pharmacological therapies in a very convoluted manner, thanks to informal channels of information.

As far as the term “therapy” is concerned, Alfredo Raglio wrote: “Interventions” or “treatment” are very generic terms. For this reason I prefer the term “therapy”. I share his opinion: in the English Collins-Cobuild Dictionary “therapy” is defined as “the treatment of

mental or physical illness without the use of drugs or operations”, while “treatment” can have different meanings, including “medical attention given to a sick or injured person or animal” and for “approach” eleven meanings are listed.

In fact, the discussion between the Editorial Board and myself prior to the publication of the journal, was not only limited to the use of correct terminology; an even more important point was in question and that was what constitutes “scientific” evidence? Two different visions of the problem faced each other. John Zeisel wrote:” There is an assumption, even among non-pharm advocates, that the random assignment double blind control group methodology used to evaluate medication effectiveness is the “gold standard” of methods. I disagree; as do many others. To agree would make it impossible to “scientifically” evaluate many non-pharm approaches.” Alfredo Raglio answered: “As far as the scientific evidence is concerned, I think that methodological criteria of RCT studies are very important and useful in research; in my opinion it is also important to promote single-case studies and studies that put the attention on “evidence based practice” and on the therapeutic process evaluation (what happens in the treatment? How to evaluate this?).” Aimee Spector added “ I agree that many approaches are in their infancy and that explorative, qualitative research, would be the best means of investigation. These studies should definitely be published. It may be worth having some guidelines though, for example some recent controlled trials have not used randomisation and present no rationale as to why not - this approach should be questioned.” In my opinion, a rigorous approach in scientific (I use the term in its large sense) research is an obligation, in order to demonstrate the usefulness of all kinds of therapy. According to the specific situation, different kinds of study approaches (RCT trials, single-case studies, observational studies, pilot researches, etc.) will be appropriate. But in every case methodology must be accurately designed.

Now let me remind you that in the draft version of DSM V the term “dementia” is replaced by “Major Neurocognitive Disorder” (do medical doctors begin to be sensitive to the social handicap of people diagnosed as “demented”?) and now also allow me to cite an article, written by a French geriatrician, Michel Davin, about the use of the term “demented” applied to elderly people with cognitive decline and the stigma associated with the terms “dementia” and “Alzheimer’s”. For those of you who speak French, I suggest you to read the whole article:

...Qui va pouvoir annoncer à son conjoint , à ses enfants cette terrible nouvelle : « Ton pere ,votre grand pere est dément ? »

Le terme de démence est synonyme d’inhumanité « Ce n’est plus mon mari ,ce n’est plus un être humain , c’est un dément »

C’est un mot barbare , peut être même un barbarysme , qui nie toute la capacité restante du patient : son affectivité majeure qu’il ne peut pas exprimer , sa spiritualité , toutes ses ressources enfouies qui ne demandent qu’à être stimulées ; et les équipes de soignants le savent , lorsqu’elles obtiennent des résultats non pas spectaculaires mais tellement enrichissants de la part de soi disant « grands déments » (quelques mots de ceux qui ne parlaient plus depuis des mois ,une reprise d’activité simple , un sourire chez certains totalement inexpressifs depuis si longtemps,etc..).

Qu’y a t il de dément chez un patient qui perd un peu la mémoire ,qui a quelques difficultés d’orientation dans le temps , qui fait des erreurs dans ses comptes , mais qui continue à peindre des toiles ou à rire avec ses petits enfants ? Qu’y a t il dans leur regard sinon une détresse incommensurable et/ou une anxiété infinie ?...

Dans notre société de mesure , de tests , de records , de standardisation , de normalisation , qui pourra dire à quel moment précis on bascule dans la démence ?

Non, ce ne sont pas des déments , ce sont des malades comme les autres,... autrement atteints que les autres patients car ils perdent tout doucement , à petit feu , ce qui fait le propre de l'homme : la pensée et la parole .

Dans bon nombre d'établissements , dont certains hopitaux locaux par exemple qui sont à la base de notre systeme hospitalier ,on ne parle plus d'unités Alzheimer ,mais d'unités protégées avec des patients désorientés et déambulants , terme parfaitement adapté à la réalité quotidienne et dénué de toute connotation péjorative , évitant de penser à un ghetto ou de pratiquer une discrimination .

Rappelons nous que les mots ont un extraordinaire pouvoir de construction de l'Individu mais aussi de déconstruction...

...Who would be able to inform his/her spouse, or his/her children : « Your father, your great-father is demented?.

The word « dementia » is a synonym for inhumanity : « He's no more my husband, he's no more a human being, he's demented. It's a barbaric word, maybe even a barbarism, which denies all remaining capability of the patient :his/her chief affection capacities that he/she cannot express, his/her spiritual life, all his/her hidden resources which need to be stimulated; and caring teams know this, when they obtain results which are not spectacular, but very enriching, from the so-called « severely demented » (some words from someone who has been not speaking for some months, the recuperation of a simple activity, a smile from people who have been inexpressive for a long time).

Where is dementia in a patient with a slight memory loss, who has some orientation problems, who can no longer do simple calculations, but who expresses himself through his paintings or laughing with his grandchildren? What can you see in his eyes besides a great unhappiness and/or infinite anxiety?

In several institutes, e.g in some local hospitals which are at the bottom of our hospital system, the term « Alzheimer units » has been replaced by « protected units with disoriented and walking patients », a term perfectly adapted to everyday reality and devoid of all negative connotation, and which avoids associations of a ghetto or of practicing discrimination.

We should remind ourselves that words have an extraordinary power of construction of the human person but also of deconstruction...

I leave you to think about it.

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