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"Social representations and collective memory: remembering a scientific controversy, the Di Bella case"

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Previous studies on the Case

- Montali L. (1999). "I libri sul Caso di Bella: prima analisi di una rappresentazione sociale", *Ikon*, 38, 161-183.
- Colucci F.P., Montali L. (2004). "La terapia Di Bella come caso emblematico del conflitto tra consensuale e reificato: la sua rappresentazione nella stampa". Giornale italiano di psicologia, 1, 141-175.
- Montali L., Colucci F.P., Pieri M. (2005). "Il conflitto tra consensuale e reificato: il caso Di Bella a Porta a Porta". Ricerche di Psicologia, 4, 109-138.
- Colucci F.P., Montali L. (2008). "Comparative application of two methodological approaches to the analysis of discourse". *International Journal of Multiple Research Approaches*, 2, 1, 57-70.

Outline

- The Di Bella Case
- Studying scientific controversies
- The theoretical framework: social representations and collective memory
- The study: aims and method
- Results

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- In early 1997 the Health Ministry concluded that somatostatine could be supplied free of charge only for the treatment of apudomes.
- A few hundreds patients treated by professor Di Bella, suddenly found themselves having to bear the rather high costs of their therapy.

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- Between December 16, 1997 and January 17, 1998, the daily
- proportion of prime time news devoted to the Di Bella case reached 36%
- The average share was 8.4% highlight the Di Bella issue

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- The case came to a head when the mass media began to highlight the Di Bella issue
- Opposition from the centre-right strongly asked the Health Minister to revise her position
- Surveys showed that over 80% of Italians were convinced that the Di Bella's therapy was effective and considered it more 'human' than chemotherapy.

Letters

Di Bella's method of curing cancer is becoming popular in Italy

EDITOR Abbasi has summarised well the situation concerning "Di Bella's method" for cancer. This situation is more serious, however, than it seemed at the meeting in London that Abbasi attended, and it might rapidly contaminate other countries, even those more cold blooded than Italy. It is a clear case of wholesale insanity despite the repeated warnings of oncologists and pharmacologists. There are three new proofs of this.

- The Italian constitutional court has recently decreed that the health service should reimburse the cost of Di Bella's cocktail to all the patients who cannot afford it (more than £20 a day); the health ministry has gone further, allowing it free to practically everybody.²
- A political party, heir of the former Fascist party, has embraced the cause, organising on a national scale
 protest marches and television talk shows, with Di Bella attending, sometimes with his supporters
 displaying banners saying, for example, "Free choice of treatment" and "Chemotherapy means death."
- Rotary International is a worldwide organisation of business and professional leaders supposedly
 wise people. But a Rotary club in Rome and another in Milan have, with press publicity, made Di Bella a
 Paul Harris fellow in recognition of "decades of studies and researches in oncotherapy"; even worse is
 the lack of official reaction from the Rotary district governors expected to supervise the club activities.

A Medline search shows that from 1966 to 1997 Di Bella has published 21 papers, but none dealing with oncology.³ It would be logical to assume that the clinical trials now in progress will give a final and decisive judgment on Di Bella's method, but this is unlikely; in fact, Di Bella has already said that these trials are void since they are not in accordance with the protocol agreed between him and the National Oncology Commission. One example of his complaints, reported by a member of this commission, is that his cocktail was lacking in vitamin C dissolved in mineral water.⁴

The problem, involving not only Italy, is how to restore order and prevent further expansion of this crazy situation.

Rinaldo Pellegrini, Consultant in clinical pharmacology.

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- 2. More patients for Italian anticancer. Scrip 1998; 2345: 3.
- 3. Remuzzi G. Una presunta terapia senza basi scientifiche. Tempo Medico 1998; 40: 2.
- 4. Scanni A. Con Di Bella è una storia senza fine. Corriere Salute 1998; 10: 2.

The Di Bella case: the scientific trial

• The scientific community expressed profound skepticism and dismissed the therapy as ineffective

Views and reviews

Medicine and the media

Di Bella's miracle method

Kamran Abbasi went along to a public meeting to learn about the latest cure for cancer

Luigi Di Bella has the answer to every patient's and every businessman's dream. Pour somatostatin, melatonin,

bromocriptine, and vitamin A into the mix, stir, and bang the cure for cancer. Last weekend, the controversial Italian scientist spread the word about his miracle cure in London, at a public meeting that was broadcast live in Canada.

Be it breast, brain, lung, or gut, Di Bella's method uses the same ingredients of differing potencies. Thousands of patients have been cured over the past 25 years without side effects, he claims, and thousands more Italians are demanding a treatment for which no evidence has been published in a peer reviewed journal.

Di Bella is unconcerned. He has living patients to prove that his method works, and doctors, he believes, are unnecessarily sceptical of innovative treatments, especially this one: "If I were to speak to humankind, I would recommend the use of my protocol, because I have had so many good results."

In 1996 reports from Italy, by the National Oncology Commission and the Pharmacology Commission, concluded that Di Bella's method lacked scientific validity, and the health minister Rosy Bindi responded by asking him for data to support his treatment (BMJ 1998;316:327[Full Text]).

By the end of last year, Di Bella's appearances on Italian television and radio had caused a public frenzy for his banned miracle cure. The dam burst when a judge from Puglia ordered a local hospital to prescribe Di Bella's method. Other regions followed, and Rosy Bindi was forced to begin clinical trials with a panel of international cancer experts established to oversee the results. Not content with Italy, the Di Bella publicity machine has gone global. Di Bella spoke to the European parliament, claiming that he had also cured Alzheimer's disease, multiple sclerosis, and retinitis pigmentosa with somatostatin. Thanks to Di Bella, manufacturers of somatostatin report a boom in demand, pharmacists report thefts, and black marketeers know the street price.

At the meeting, arranged by HDS Studios a production company that claims to be merely "interested" in Di Bella's method the 85 year old retired physiologist, who temporarily held a professorship at the University of Modena, sits hunched over his hand held notes.

After being introduced as a "forerunner in cancer research," Di Bella embarks on a confusing 45 minute monologue about his wonder cure. He claims to use the concept of "quadrilogy," which he tells us he mastered by means of a backwards logic process. Undoubtedly. Four factors affect growth we are told, but which ones, I wonder? His results have been "quite good ones," but how many has he cured? Other patients have certainly improved, but by how much? Who can say? Certainly Di Bella is hesitant to divulge figures.

Di Bella's explanation generates more questions than answers. Yes, he has presented his work at scientific meetings, but Luigi Di Bella feels that his results speak for themselves, and analysis by a prejudiced scientific community is unnecessary.

Brian Wilson, a self proclaimed anti-ageing nutritionist, ends the public meeting by applauding Di Bella's work and his stand against the medical establishment, which, he claims, is hell bent on suppressing cures for cancer, including his own, to profit from expensive and ineffective chemotherapy. Di Bella agrees: "Chemotherapy has never healed a tumour."

Ignoring my doubts, the presenter closes the broadcast by announcing, "Well we're all agreed here." Hmm. The audience applauds enthusiastically, rapt in the hope of a cure for cancer. Di Bella's message is traversing oceans, buoyed by the aspirations of vulnerable cancer patients and desperate relatives. For these people, the scientific community is withholding a lifeline, but Di Bella's method needs substance rather than hype.

Kamran Abbasi.

editorial registrar, BMJ

The Di Bella case: the scientific trial

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Support for a pragmatic health minister

Abstract

Cancer patients in Italy are threatening their own survival through faith in a miracle cure. But the government is justified in sanctioning controlled tests of the therapy, even if it lacks a scientific basis.

Astonishingly and scandalously, a frail 85-year-old physician, Luigi Di Bella, has managed to precipitate a crisis in relations between the public, science and government in Italy with his brand of cancer therapy, a cocktail of vitamins and minerals that also includes the drug somatostatin. Dismissed as ineffective by the scientific establishment, the therapy has nevertheless been hailed as a miracle cure by the public.

Early experience with somatostatin in the 1980s and early 1990s indicated that its theoretical promise as an anticancer agent was limited to some rare neuroendocrine tumours. Nonetheless, Di Bella, postulating that somatostatin stimulates the body to rid itself of any type of cancer, has claimed to have cured thousands of patients (see <u>Nature 391, 217; 1998</u>). But he has no documentation or publications to back his claims. The health minister Rosy Bindi was therefore right earlier last year to ignore requests from so-called Di Bellists to conduct clinical trials for somatostatin in cancer and to place it on the national list of reimbursable drugs.

But the situation has changed dramatically: this is no longer simply a scientific issue but has become polarized and politicized. Demonstrations of tens of thousands have become a regular event, football supporters wave banners demanding freedom of treatment, and reports of cancer sufferers dying because they were denied the Di Bella treatment dominate newspaper headlines and television debates.

The right-wing opposition party Alleanza Nazionale has formally adopted a policy supporting Di Bella _ to be against him is now seen to be left wing _ and, more worryingly, the judiciary has backed Di Bella's case against the government, citing an article in the constitution that guarantees to protect the health of individuals. Local courts have ordered individual patients to be treated with somatostatin without charge, and a national court last month, defying Bindi, ordered the head of the government's pharmaceutical committee to put somatostatin on the national reimbursable drugs list _ an order that has since been overturned by a higher court. Italy's constitutional court is now considering the rights of the judiciary to overrule the government on health issues.

In view of this turmoil, Bindi was right when she decided in January to reverse her decision and order clinical trials to be carried out as soon as possible, despite a lack of scientific basis for the therapy. Ten multicentre phase II trials, designed by the country's leading oncologists, began last week, at an estimated cost of IL20 billion (US\$11 million).

The drama of the Di Bella phenomenon may be perceived as peculiarly Italian, but at its core there are parallels with the history of patient power elsewhere. In the United States, patients dying of AIDS successfully persuaded the Food and Drug Administration (FDA) to deviate from its traditional slow drug licensing procedures and make AZT available before clinical trials were completed.

And in the 1980s the FDA was forced to conduct clinical trails on laetrile, a cyanide containing extract of apricot stones of even less therapeutic value than somatostatin. In both cases, concessions by government proved productive in calming the situation; laetrile is a fad of the past, whereas AZT has found its natural level in AIDS therapy.

Some Italian scientists, at least, deplore the sidelining of science as the government, as they see it, bows to emotional pressure in the Di Bella case. They are right to state the scientific case but wrong to oppose Bindi's pragmatic solution. To ignore the emotional element in the public response is to omit a critical factor from the problem and thereby render it insoluble.

The Di Bella case: the scientific trial

- The scientific community expressed profound skepticism and dismissed the therapy as ineffective
- In march 1999 the Minister made way for an experimental phase which lasted six months and involved 386 patients. A total of 11 Phase II clinical trials were planned.
- A number of physicians and scientists expressed the opinion that the decision to conduct clinical trials in the absence of any published evidence was unethical.
- As soon as the enrollment of patients started, there was a gradual increase in the criticism concerning:
 - how recruitment was being carried out, details of the study protocols and the therapeutic regimen

The Di Bella case: the end

• The trial period ended in October 1999 and its results proved negative for the Di Bella's therapy.

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 Today, four Italian regions partially or totally reimburse their residents for expenses sustained while undergoing the Di Bella's therapy. ne dei criteri di accreditamento. Da una parte ci saranno i criteri base, cioè strutturali. Dall'altra troveremo critori di premislità che potranno essere variabili di anno in anno e attribuiti attraverso alcuni indicatori».

Cosa intende per premialitis?

«E un concetto che vorremmo introdurre anche nell'ambito del pubblico. Un privato che fornisce un esame diagnostico con un im-

la managerialità sarebbe privata-. Che vantaggi avrebbe?

«Da una parte la governance pubblica, dall'altra la visione efficientista del privato e comunque è rischio d'impresa che il privato si prende e partendo dall'assunto che la sanità buona non ti fa rimettere. Poi c'è il project finan-

Che però non viene praticamente usato, soprattutto nel Centrosud.

sarà concesso più tempo prima dell'aumento-delle tasse?

«Devo fare una premessa».

«Negli anni Ottanta le regioni del Nord hanno cominciato amettersi a regime e a chiudese alcuni ospedali. In Veneto e in Toscana i cittadini fecero blocchi stradali. perché il concetto era che l'ospedale dovesse essere sotto casa. Oggi però quelle regioni si trova-

peuvano a parlare di riconversio- Polverini. Che è arrivato-dopo che

trocardiograment, spirometria.



prima forma di assistenza domiciliare e molti interventi di prevenzioni primarias. Il costo-del propetto per lo Stato?

Non solo, la farmacia gestirà una

qualcun altro-

«Sono prestazioni che vanno inserite con un contratto nel Sistema sanitario nazionale. Ed è chiaro che se saranno erogate dalle farmacie non sacanno erogate da

DOTTOR SPERANZA

Luigi Di Bella col figlio Giuseppe Oly

A sette anni dalla morte dell'ideatore

Il metodo Di Bella cura ancora 5mila pazienti Gli oncologi stranieri cominciano a interessarsi

III DORY D'ANZEO

mmm Il 1 luglio di sette anni fa moriva a Moderna Luigi Di Bella, lo scienziato italiano famoso per aver messo a punto una cura contro il cancro a base di inibitori biologici della crescita tumorale isomatostatina, melatonina, retinoidi e vitamina D3), sostanze vitaminiche, biologiche e non tossiche. Definito dal Newswork "Dr Hope", il dottor Sperauza, Luigi Di Bella balzo agli onori delle cronache tra il '97 e il '96 quando, dietro la pressione dei pazienti e dell'opinione pubblica, il suo metodo venne sperimentato negli ospedali italiani mala cura, dopo un breve periodo, venne bollata come "inefficace". Ciò non ha impedito al dottore e al figlio Giuseppe di continuare nella ricerca. E, a distanza di anni, qualcosa deve essersi mosso se, in occasione del "Bit's 3rd World Cancer Congress" tenuto a Singapore a giugno, al professor Giuseppe Di Bella è stato richie sto di presentare una relazione sul Metodo Di Bella (mdb). Sono stati presentati 553 casi cunsti con il mdb-su 29 istotipi diversi. La relazione è stata oggetto d'esame da parte di un consituto scientifico internazionale che vede tra i suoi componenti il premio Nobel Andrew V. Schally. Per la peima volta, dunque, è stata richiesta, accettata e pubblicata a un congresso mondiale di oncologia una relazione completa sul Metodo Di Bella.

«La statistica di 553 casi», afferma Di Bella jr. -è stata già pubblicata agli atti. Non si può parlare di casi sporadici o guarigioni spontance né affermare che il metodo non sia scientifico. In tutti i 29 tipi di tumore considerati, è stato documentato un generale e netto miglioramento della qualità della vita, che in molti casi ha consentito la ripresa dell'attività lavorativa». In alcuni dei casi presentati i pazienti

::: IDATI

LPAZIENTI

Attualmente, il professor Giuseppe Di Bella, assierre ai suoi collaboratori, segue 1200 pazienti mentre si stima che in futta Italia le persone curate col mdb siano circa cinquemita

CURA GLOBALE

Quando si parla di cancro ci si riferisce a una moltitudine di patologie ma, secondo Giuseppe Di Bella, «Il mdb rappresenta una visione terapeutica globale del problema cancro, non frammentaria e settoriale di singoli aspetti della crescitatumorale, ma completa e in grado di intervenire decisamente e senza tossicità su tutti i denominatori comuni dei tumori e su tutti i punti critici dell'insorgenza e progressione tumorale. Il tumore è una deviazione dalla vita normale, che il esdo correggo, assecondando ad exaltando le reazioni vitali-

hanno dovuto far causa alle ASL per ottenere la cura con il metodo Di Bella e glievidenti miglioramenti e guarigioni sono stati esaminati e certificati da tre medici in qualità di periti nominati dai tribunali.

A sette anni dalla sua scompono, quindi, Luigi Di Bella continua a far parlare. Definito, nel migliore dei casi, un illuso o un visionario, se non un ciadatano o un apprendista stregorse, oggi la comunità scientifica internazionale prende in seria considerazione il metodo messo a punto da lui molti anni fa. Sono passati ben 32 ansi, infatti, da quando questo dottore siciliano trapiantato in Emilia aveva intuito che l'ormone della crescita (GH) rappersenta l'interruttore generale che è necessario spegnere in quanto dicettamente implicato nella crescita tumorsie. Assunto oggi comunestiente accettato dalla comunità scientifica. La stessa comunità che sta valutando con rigore le sue ricerche sul modo di inibire l'ormone per restituire al paziente malato di cancro dignità: e una qualità della vita accettabile.

Attualmente, il professor Giuseppe Di Bella, assieme ai suoi collaboratori, segue 1200 pazienti mentre si stima che in tutta Italia le persone curate col mdb siano circa cinquemila. Sul sito ufficiale dedicato al metodo (www.metododibella.org) è possibile consultare le relazioni sui casi di turnore trattati con il metodo. Se è vero che non in tutti i casi ci sono delle guarigioni definitive, è anche vero che si registraspesso un'elevata sopransivenza e un sensibile miglioramento nelle condizioni fisiche del paziente. Come il caso di una pazience affetta da tumore alla mammella che, dopo 14 mesi di cura, presentava una guarigione completa, tuttora pensistente. Risultato ottenuto senza aver perso un giorno di lavoro, né aver accusato disturbi o tossiciti:

In July 2010 at a public meeting organized by Di Bella's son, he declared that there are 1200 patients who are treated with the therapy.

- Controversy as a factor that favours scientific advancements
 - "The history of science... is one long series of theses, set off by ardently advocated antitheses, with ultimate synthesis terminating controversy and marking step forward. Controversy has always been part of the method of science"

Edwin G.

Boring, 1929

Controversy as a factor that favours scientific advancements

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- Controversy as a factor that favours scientific advancements
- science controversies in the public arena ...
 - Mass media's central role: framing scientific controversies as conflicts (Lewenstein, 1995; Neresini, 2000)
 - Public opinion growing perception that experts can and do disagree
 - and that their specialist advice is not necessarily infallible or neutral (Martin and Richards, 1995)

- Controversy as a factor that favours scientific advancements
- Science controversies in the public arena ...
- ... activate interaction processes between science and society (Latour, 1998)
 - Public opinion is implicitly designated as the judge of the controversies
 - It becomes an actor in the negotiation of the real and symbolic values that are exchanged (Bucchi, 1998)

Collective memory and social representations

- The theoretical and empirical affinities between the two concepts:
 - they "have been worked out on Durkheim's lead, explicitly contrasted to Durkheim's collective representation concept" (Laszlo, 2001).

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 - they "have been worked out on Durkheim's lead, explicitly contrasted to Durkheim's collective representation concept" (Laszlo, 2001).
- They both refer to the socio-constructivist approach
 - Social processes and meanings need to be investigated in the framework of, and in relation to, the context where they are constructed and negotiated.

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Collective memory and social representations

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- They both refer to the socioconstructivist approach
- They both study forms of shared knowledge (Liu et al, 2005)
- that are conceptualized as the result of imaginative and constructive processes:
 - "The past is not simply 'received' by the present...the past is modeled, invented, reinvented, and reconstructed by the present." (Assmann, 1997)
 - Representation, rather than being an exact mirror of the object in question, is a process of re-construction and creation (Markova 2000)

The social matrix of knowledge: the construction of the object is based on selective, creative and interpretative activities that are socially oriented (Wagoner 2008, Moscovici, 1992, Halbwachs, 1925):

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- The social matrix of knowledge: the construction of the object is based on selective, creative and interpretative activities that are socially oriented (Wagoner 2008, Moscovici, 1992, Halbwachs, 1925):
 - The media role: they provide the framework and the language in which events are described (Bauer & Gaskell, 1999; Wertsch & Roediger, 2008)
 - Construction and negotiation processes happen in the contexts of local and daily communicative interactions (Arruda, 2003)
 - They are related to groups' aims (Licata, Klein et Van Der Linden, 2006)
 - They are characterized by conflicts and negotiation activities concerning the meanings to be attributed to social objects (Jovchelovitch, 1997, Jedlowski, 1997)

- The social matrix of knowledge: the construction of the object is based on selective, creative and interpretative activities that are socially oriented
- They have a dynamic (Markova, 2000; Reese & Fivush 2008) and pluralistic character (Chrissides, 2008; Wood 1994)
- They are instrumental in maintaining group identity and group stability: coesion and continuity (Laszlo, 2001; Hirst & Manier, 2008)

Aim and Hyphotesis

- The aim: to study the contents and structure of the social representations and of the collective memory of the Di Bella Case
- Our general hypothesis is that the scientific controversy regarding the Di Bella therapy is represented as a conflict between (Farr and Moscovici, 1984):
 - The consensual universe (patients and their relatives, public opinion): Di Bella and is therapy are the symbols of their needs and requests
 - and the reified universe: the official medical practice, the health and scientific institutions and their representatives, the political institutions and their representatives

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- The attribution of this meaning and symbolic value to the Case should imply a ridefinition and rationalization of the results of the scientific trials of the Di bella therapy whose results were negative

Sample

• 41 ex tumor patients and patients' relatives. They were recruited through four Italian associations devoted to provide emotional support and to improve the quality of life of tumor patients

Gender	Women	68%
	Man	32 %
Age	Range	32-76
	Mean	48
Education	Secondary school	17%
	Secondary advanced school	46%
	University	37%
Profession	Housewife	10%
	Employee	54%
	Self-employed person/ Entrepreneur	20%
	Pensioner	17%

Data collection and data analysis

- Semi-structured interviews, starting with two opening questions:
 - If today you recall the so called Di Bella case, what are the first thoughts that come to your mind?
 - If you were asked to tell the Di Bella case to someone who knew nothing about it, which story would you tell?

Data collection

- Semi-structured interviews, starting with two opening questions
- followed by some questions concerning:
 - the actors who played a role in this event: professor Di Bella and his entourage, the magistracy, politicians, mass-media, scientists and physicians, public opinion, patients and their relatives
 - some of the themes and events that characterized the case: the Di Bella therapy, the scientific trial of the therapy, the international echo of the case
- Interviews lasted between 45 and 60 minutes, were taperecorded and were later transcribed verbatim

Data analysis

- Qualitative computer aided content analysis with the sofware N-vivo.
- The coding frame was generated based on a mixed deductive and inductive approach (Hsieh and Shannon 2005):
 - the initial codes were derived theoretically, taking into account the theoretical framework and the research question of the study
 - new themes emerging from the data and sub-categories have been inductively articulated on the basis of the interviewees' answers
- Once the coding frame was established, the second and the third authors coded half of the interviews each
- Finally, they were provided with a range of unlabelled quotations from the interviews they did not analyze and asked to match the quotations to their corresponding coding.

- The somatic traits: the stereotyped representation of Di Bella
 - "I still can see this old guy as if he was here, his slightly stooping figure, whit his white hairs. I think that this little man would not have done something if he was not sure that he could do good for other people." **Ex, 3**
 - "I remember his posture, his slightly stooping figure. He was surely not an haughty person, who thinks a lot of himself" **Fam, 11**
 - "He was an old guy, so he was a typical scientist. I remember him as a nice old guy, that is to say, a person with a lot of experience" Fam, 23
 - "He really looked as a doctor, because he was always wearing a white dress and he also had white hairs. That is to say that he looked as an old doctor." Ex, 18

The somatic traits: the stereotyped representation of Di Bella

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- The Di Bella's communication and relational style:
 - He was not interested in money, power, fame

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 - He was able to infuse people with safety and to inspire confidence
 - "He conveyed a sense of tranquility to me and he infused me with safety. You know, there is always a sort of barrier in the relationship between a patient and his doctor, but thanks to the way he presented himself, he broke it down" Ex, 9
 - "I remember that many people consulted him and that they spoke well of the way he offered his therapy to the patients. They said that he was a nice person and that he treated patients like persons." Fam, 11

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 - "It's a given that there are a lot of patients who were healed. This may be due to his therapy, or to the way he took care of his patients: the physical examinations lasted two hours, he did not want to be paid. Doing like this, the patients felt that they were not cannon folder because they were really carefully attended." Ex, 7

Anchoring

- Concerning expertise: the great scientist
 - Einstein, Rita Levi Montalcini, Archimede, Jenner

"He did not look like Einstein, but he always reminded him to me, because both of them were non conformist" Fam, 17

"When I think about him, it's Einstein who comes to my mind. Like him, he was an innovator, he was different from other people and I think that probably he spent his life doing something important" \mathbf{Ex} , 1

Anchoring

- Concerning expertise: the great scientist
 - Einstein, Rita Levi Montalcini, Archimede, Jenner
- Concerning authority:
 - Ciampi, Pertini
- Concerning his relational style:
 - A grandfather, an old country doctor, Mister Magoo
- Concerning heroism: Don Chisciotte

"They were all against him , he was like Don Chisciotte who tilted at windmills . I remember I liked this because I like the losers. For me he was a loser who struggled for what he believed to be true" Fam, 14

The conflict between the consensual and the reified universe

Anchoring Di Bella's therapy: grassroots medicine

"The Di Bella's therapy brings to my mind the Lorenzo's Oil story. To me, it looks like the experience of Lorenzo's parents, who with many efforts created from scratch an oil that could cure the illness or that could slow down the illness progress." Fam, 5

"The Di Bella case came to a head because there were a lot of patients who were treated, and they were well, they were responding to that treatment and they wanted it without charge. So the all mess started from that, it came from the people" Ex, 4

- "The humanity" of the therapy set against the "official medicine"
 - "I was rather curious regarding this therapy, even because in my opinion it was much more natural if compared to the chemical treatment that I did" \mathbf{Ex} , 11
 - "The other doctors treated the tumor, whereas Di Bella was trying to stop it in the beginning, his aim was to understand where the illness was coming from so that he could get to the source of it. He did not want to get to the point to need chemotherapy that was devastating" **Ex, 16**

The conflict between the consensual and the reified universe

- Anchoring alternative therapies: grassroots medicine
- "The humanity" of the therapy set against the "official medicine"
- Official medicine as a closed economic and power structure

"Just think about how you move ahead in academic career in Italy. So, if somebody is becoming a professor by 'ass-licking' a powerful oncologist professor and suddenly here it comes. Di Bella and his therapy and he can bypass him, I don't know how to explain it... It's like if I said that I created a car that needs water instead of petrol, I would be killed in three days' \mathbf{Ex} , 4

"In my opinion, those who were against Di Bella, notably the hospital doctors, the health ministry, etc., were only interested in the health business which is a very big one. Because if the Di Bella's therapy had worked, chemotherapy would have lost out" Fam, 8

Representations, memory, identity

A typical italian story: a closed-mind country

"I believe that, instead of being supported, Di Bella found strong opposition, above all because in Italy we are used to doing this, when somebody proposes something new, instead of examining the proposal, the proponent is held up to public ridicule." \mathbf{Ex} , $\mathbf{6}$

'It's one of the example of what happens in Italy: in the very first the mass media give a lot of attention, sometimes even too much, to a new medical treatment. But if these treatments are set against the traditional therapy, you can see that for the proponents of the new therapy it's difficult to go on with the trials" Fam, 13

Representations, memory, identity

- A typical Italian story: a closed-mind country
- The Italian national character: superficiality, irrationality, no respect for the rules

"This is a typical Italian story, you can understand it if you place it in the frame of the Italian usual approximation and if you consider the illiteracy that drives us. We are the country that spends more for witchdoctors, witches and wizards. I'm afraid that we dealt with a proposal that was aimed to help unlucky people as if it was a real possibility to cure patients" Fam, 19

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Foreign countries as a mythical reference model

"Di Bella is a really self-made man, he was an Italian, I think he was from Sicily, but in our country he could not prove his discoveries. So he emigrated, it seems to me that he went to the States and they trusted him" Fam, 14

The memory of the Case

- What seems to disappear or to be marginalized :
 - The role of the politics
 - The role of the magistracy
 - The economic issue: the Di Bella patients were asking to have access the therapy free of charge

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- What seems to disappear or to be marginalized:
 - The role of the politics
 - The role of the magistracy
 - The economic issue: the Di Bella patients were asking to have access the therapy free of charge
- What has a central relevance: the conspiracy
 - "It comes to my mind how they ruined the trials of the Di Bella therapy. It comes to my mind that for the trials they administered expired drugs. In short, they did not have the will to verify the therapy's efficacy" Fam, 3
 - "I had the clear feeling that somebody did not like this therapy at all, so that the whole thing had to be stopped. Beyond that, whether the therapy worked or not, I don't know, in my opinion it perhaps worked well for some patients but it did not for others" Fam, 12

Conclusions

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 - in a social context characterized by political and institutional weakness

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 - in a social context characterized by political and institutional weakness
- The utility of the two theoretical concepts:
 - Social representations and collective memories are both built on dichotomies: for example low powered people /high powered people, poor/rich, natural/chemical
 - That are framed in a common narrative template
- An open problem (even for the psychology): the permanence of the Case seems to be linked to some persisting problems and needs, in particular those concerning the patients' experience and relationships with medicine and doctors

Thanks for your attention!

The mass media analysis 1/2

The mass media analysis 1/2

- The first analysis was carried out on two weekly magazines of opposing political ideas, L'Espresso and Panorama
- The <u>contrast</u> between the sacredness of science and the emotional irrationality of the masses emerges.
- The <u>sacredness of science</u> is guaranteed by its founding on universal and necessary rules, by reference made to the authority of the Nobel prizes, by international magazines or by American scientists that have been adopted as a role model.
- This representation of science is in contrast with the <u>irrationality and the emotiveness of the masses</u>, of the people, of the public opinion itself.

The mass media analysis 2/2

The mass media analysis 2/2

- The <u>attitude towards the Di Bella treatment</u> and in general towards cancer <u>has a strong religious tone</u>
 - that emerges from the presentation of the Di Bella character, from the miraculous description of the cases of recovery attributed to the intervention of the Professor from Modena and from the interpretation of the event as a "Religious War".
- Both weekly magazines, but especially *Panorama*, not only represents the contrast and the lack of communication between consensual and reified, but gives voice to the needs of the sick.