

History, Intertextuality, and Social Power

Leprosy and Self-Understanding in Late Twentieth Century Greece

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Some presentations of the history of leprosy can be seen as paradigmatic stories of how the knowledge of leprosy has been constituted in a historical process. Conflicts in the daily lives of leprosy patients have arisen as a result of two basically opposing stories. One emphasizes the continuity between leprosy in modern life with its existence in an ancient past. The other emphasizes the historical breaking points. These conflicting stories have different repercussions as to which form of knowledge about leprosy is produced or reproduced. Power over the knowledge of leprosy is maintained by people that become accomplices in these stories. This article demonstrates how a Greek woman who suffers from leprosy incorporates her interpretations on history with her self-understanding. The analysis shows how she transforms the painful history into an embodied force using intertextual strategies. Two theoretical frameworks, folkloristic text analysis and discourse analysis in a Foucaultian sense, provide its points of departure. The conclusion points to some of the consequences of a linkage between these two frameworks and shows that the intertextual strategies of leprosy patients can be connected to each. This assumes that intertextuality can be viewed on two analytical levels. One level concerns the strategic intertextual constructs of the leprosy sufferers. The other concerns the contexts of meaning in which these constructs are a part.

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My thoughts about expressive strategies and the control of history are based on my fieldwork between 1987–1993 at a center for social rehabilitation of leprosy patients, in a suburb of Athens.¹ According to the WHO, the spread of leprosy will definitely be able to be stopped by the turn of the century. However, in Greece, there are still a few men and women who undergo regular health controls as a result of the risk for a recurrence of the illness. The painful history of leprosy still lingers like a dark shadow over their daily lives. I did not realise this until I began my fieldwork and my own view of the history of leprosy was questioned by the people whose daily reality I had come to research. Before embarking on a project that is now a book (Drakos 1997), I had produced a radio documentary for Swedish listen-

ers about a now closed asylum for leprosy sufferers on the island of Spinalonga, outside of Crete. I recorded an interview with two men who had been exiled there for many years, and who were subsequently transferred to facility in Athens. They participated, reluctantly, in the interview. Afterwards, I let some of the patients listen to a translated version of the radio documentary. Their critique was harsh. "The story of leprosy patients as living dead must finally come to an end", one of them explained. They did not want to be associated with the leprosy sufferers of a distant past. Discussions regarding the history of leprosy were repeated in many forms during my subsequent fieldwork.

In this article, I will show how a Greek woman, who suffers from leprosy, incorporates her interpretation of history into her self-un-

derstanding. I will discuss the history of leprosy from two dominant interpretative perspectives. One emphasizes the historic continuity between the social existence of leprosy patients today with notions of leprosy in an ancient past. The other emphasizes the breaks in historic continuity. When I speak here about the ways in which leprosy patients control their history I refer to their strategic relationship to these two interpretative perspectives. When I talk about leprosy patients' understanding of self I am referring to how they create themselves a collective I, a subject, which is linked to the ways in which the outside world may make them into objects. I will discuss their construction of a subject in light of their intertextual strategies. This is also how I shall approach the ways in which the self-understanding of leprosy patients is woven together with the construction of history (cf. Feldman 1991:2). I shall soon solidify these ideas and demonstrate how their self-understandings and constructing of history resonate in one proverb. But first, let me sketch the historic background.

Discursive Breaking Points

Despite recent medical advances, leprosy continues to be associated with outdated understandings of the nature of diseases. A decisive reason for this was that these medical advances took place in the context of the expansion and consolidation of European imperialism (cf. Gusow 1989). The first standard scientific work on leprosy was published in the middle of the 19th century, and in 1873 the cause of the illness was linked to a bacteria. The majority of the world's leprosy victims were in Africa and Asia and not in Europe. Leprosy was, therefore, associated with the inhabitants of the colonies. As a result, attitudes towards people infected with leprosy were structured along the same class bound and racist categories that were applied towards the inhabitants of the colonies in general. The fear of leprosy in the industrialized west was based on fears that the illness would also come to taint Europeans. Leprosy was seen as fundamentally different from diseases of the west. The expansion of European imperialism at the end of the 19th century was followed by a

religious renaissance in England and intensified missionary work in the colonies. Prior to the engagement of missionaries in colonial projects, the link between the biblical and the medical concepts of leprosy had not been a central issue for the Christian church. The interest in connecting the two concepts resulted in a paradoxical situation. From the middle of the 19th century and onwards leprosy represented, on the one hand, a more limited medical entity than before. On the other hand, leprosy incorporated all of the connotations of biblical leprosy since it was in the interest of the missions to view medical leprosy as biblical leprosy. A series of incidents point towards the 1940s as another discursive breaking point in the history of leprosy. A central event that changed the conditions for how leprosy patients were viewed, was the creation of the first effective medication. From a medical point of view, leprosy became a treatable disease. The result was that patients were gradually released from the asylums. From a historical perspective, the advances in medicine coincided with the autonomy of the colonies in Asia and Africa, the establishment of new, independent nations and the creation of the WHO. What about today?

Today's profound conflicts concern the discrepancy between the ways leprosy patients present their own history and the ways it is represented in historical writing (cf. White 1981:2 f). I am interested both in how history is constructed in the world surrounding leprosy patients and how they construct it themselves. The interests of the Christian missionaries, in the 19th century, to link leprosy in the colonies with the leprosy of the Bible, is just one example of an attempt, in modern times, to emphasize the historic continuity. But the Christian missionaries have not been alone in making themselves interpreters of such an unbroken history. In reference books, journalism and literary work the leprosy of the Bible has also been used as an effective metaphor of continuity despite medical advances. The story of this continuous history has dominated the discourse on leprosy right up until the middle of this century. Since then, however, historic breaks in the history of leprosy have been emphasized. One example of this can be found in the Greek language where

the term *i nósos tu Chánsen* (i.e. Hansen's disease) is now used instead of *lépra* (i.e. leprosy).

The interpretation of the history of leprosy has had consequences regarding the violence shown daily in the bodily and spatial practices leprosy sufferers are subjected to. And now I come to the woman I mentioned in the introduction. I call her Dina. She was in her 60s when I got to know her, and she emphasizes that things were worse back when she became sick as a twenty year old newlywed in 1960. She told me that her whole family became stigmatized in the eyes of the villagers, and that her husband abandoned her. When the diagnosis was confirmed, she was admitted to the institution in Athens where I met her thirty years later. She had her bed and a few personal possessions in a large hall in the deteriorating women's building at the facility. She has never returned to her home community. Dina's story demonstrates the tenacity of the stereotypes regarding the illness. But her self-awareness prevented me from connecting her story with the ancient history of leprosy. The first time I visited the women's building at the center, in order to speak to the residents, it became clear that Dina was the women's leader. Everybody stepped aside and referred me to her. She positioned me in the middle of the sleeping hall on a rickety chair. She declined my suggestion to sit down, choosing to remain standing in front of me. In this position she encouraged me to pose questions so that she could answer. The other three or four women in the partially occupied hall sat during this time on their beds, forming our audience.

"*O pathós jatρός*"

The obvious way in which Dina made herself the interpreter for the women, and for other patients who were not present, made her narrative both monophonic and polyphonic. The women who expressed their agreement silently or explicitly, contributed to the polyphony and so did the many voices that echoed in Dina's ways of speaking. In her narratives I heard the voices of medical science, the Greek orthodox church, the international leprosy mission as well as several others. And now I come to the proverb.

Early in our first conversation, Dina let these voices speak through a proverb which she subsequently used several times. On this occasion she used a proverb to reply to my comment that she must have had time to do a lot of reflection regarding her experiences with the illness.²

Dina: "Listen

we have been living with it for years [yes] and you can hear people around you saying "The sufferer is doctor" ("*O mathós ine jatρός*"). But we have also heard that from professors who have been passing through. The first professor I met was Markianos, Ioannis Markianos, who was the most renowned leprologist in all of the Balkans, and he travelled abroad to various conferences as a representative for Greece. There were others in his entourage, but for us it was the university lecturers, from the university extension service. Oh, on the fifteenth of every (month) a group came to visit.

Brothers of the weakest (*Adelfi ton elachiston*)

Christian Orthodox, and they held lessons for us in the dining room where we all gathered. Each lesson ((was)) two hours long. The university extension service. Oh, that was *invaluable* for us. Various Christian organizations also came from outside in order to *enlighten* us

about their message. Um, at the same time there were also many meetings and many publications (were distributed), and many parties were organized by the French missionary Raoul Follereau [I have heard his name mentioned].

The French missionary Raoul Follereau began working as a seventeen year old [yes].

And even though he studied to become, um, a theater manager, or whatever it is called, he subsequently visited ((inaudible)) Honolulu. It was there that he saw people who he had just passed by in a vehicle driving into the forest. As soon as they heard the vehicle honk, they *ran away and hid*. And he asked "WHY?"

And in that manner he made an impression on them and he changed his career in order that he could be (lowers voice) a *missionary to the Hansen's disease patients*. He also made annual visits to all of the countries in the world where there were hospitals for (lowers voice) Hansen's disease patients.



The second person from the left is Raoul Follereau, the founder of the international leprosy day, visiting the sewing workshop at the center for leprosy patients at Athens 1961.

And he came here to visit many times and we ate and drank. I shall show you a photograph where we are all together [yes, how nice] Yes.”

By using the proverb she articulated her understanding of self in relationship to how knowledge about her disease has been controlled in different times. The most common Greek version of the proverb is: “*O pathós mathós*”. It means, literally, “The sufferer [is] learned”. In her version (which she reiterated on several occasions) Dina replaced the word *mathós* (learned) with the word *jatrós* (doctor). With her reformulation, “*O pathós jatrós*” (The sufferer [is] doctor), and her ways of embedding it in her speech, she turned the proverb into a significant part in a dialogic negotiation regarding the ways in which the ideas about the disease and its history should be interpreted (cf. Haring 1992:63 ff, Hasan-Rokem 1992, 1994).

Dina emphasized that she had heard many people use the proverb, including a famous leprologist to whom she often referred. So did

many other patients. She suggested a meaning of the proverb by emphasizing the value of having had many years of personal experience with the illness. She also contextualized the proverb in relation to a series of contemporary events, the rehabilitation and education of patients, the mission of the Greek Orthodox church, and not least of all, the annual information campaigns held in conjunction with international leprosy day. By letting these events frame “*O pathós jatrós*”, she linked the proverb not just to actors in the contemporary, surrounding world, but also to a new and different discourse, that is to say, to a new understanding and a new way of speaking about leprosy compared to the older one.

Intertextual Strategies and Social Power

Dina’s contextualization of the proverb is characteristic of the expressive strategies of leprosy patients and of their attempts to control history. I have found that a distinguishing character-



"Welcome our great protector" was written in French above the entrance of the centre for leprosy patients at Athens when the founder of the international leprosy day arrived in 1961.

istic of the conversational conventions used by leprosy patients is that they distance themselves, intertextually, from past conceptions of their disease. In this respect I have been influenced by Charles Briggs' and Richard Bauman's (1992) actor oriented problematization of genre and intertextuality. An important point in Briggs' and Bauman's argument is that intertextuality is not just about describing intertextual connections and relationships, but rather it is about focusing the analysis on how such connections and relationships are created. I am referring to their co-authored article in the *Journal of Linguistic Anthropology* entitled, "Genre, Intertextuality, and Social Power".

Leprosy patients' understanding of self – I am referring here to their constructions of a collective subject – have, since the mid 1950s, been interconnected with their desire to distance themselves, intertextually, from speaking about the leprosy of the past. They have openly expressed critique of history during the annual information campaigns in connection with international leprosy day. During the most

active years of the patients' movement in the 1950s and 60s, the central motto of the campaign was to "free the world from the prejudiced fixation with leprosy's old history". The patient movement emphasized, on posters and flyers that it was possible to cure leprosy and that it no longer posed a societal danger. At the same time, many patients complained that they were subjected to people's prejudices. One of the slogans that was advanced during international leprosy day in 1958 volumes: "Leprosy was cured but the lepers remained". Expressed another way, one can say that the leprosy patients of today are stigmatized by being linked to the lepers of a distant historical past. This stigmatization and the idea of an unbroken historical tradition, has led leprosy patients in Greece to feel forced to protect their personal identities. At first, most of them were adamant about being anonymous in their meetings with me. Many chose, for example, not to reveal their names when I interviewed them. But the secrecy of name and identity was also a strategy to retain an interpretive advantage in conversa-

tions about the illness; that is to say, a strategy to control the possibilities of interpretation in a definite direction.

Dina's accounts of her own history of illness in our first conversation is an example of this. Actually, she waited for over four years, until the seventh period of my fieldwork, to reveal to me that her father had also suffered from leprosy. Now, in hindsight, it is impossible to miss the fact that she consciously refrained from mentioning her father's illness, in order to emphasize causes other than contagion as to why she became sick herself. Instead, she steered my attention towards other themes whenever she got onto the subject of her own contraction of the illness. She compared her contraction of the illness to the suffering that people experienced during the 1946–49 civil war in Greece. She gave no explanation as to why she, in particular, contracted leprosy. She claimed, like most of the other patients, and in contradiction to medical science, that leprosy is an inherited affliction. Her explanation was that all people bear all sorts of bacteria, and that leprosy only breaks out in those who are genetically predisposed to the illness. A reasonable assumption, on her part, was that keeping her father's illness a secret was a prerequisite for my accepting her views on the spreading of leprosy. If, on the other hand, she had begun her story with recounting her father's illness, then she would have immediately created the opportunity for me to interpret her contraction of the illness as being a result of contagion within her own family.

The second time I heard Dina use the proverb was in a conversation regarding the difficulties doctors have in diagnosing leprosy. She gave a self-conscious account of the typical symptoms of leprosy and by using the proverb she emphasized her ability to diagnose the illness.

Dina: (in a low voice) "These are the symptoms of the illness [hmm]. And the sufferer is doctor (*o pathós ine jatrós*). By having followed all of this, if I see someone out in public [she recognizes]³ *I can recognize it*. Yesterday, I went to the marketplace, in order to, to the local marketplace just above here, and I was walking when

I saw someone who, one could say, had developed the illness.

But I don't dare say anything to him

since I don't know how he will take it. |¿But you| I can recognize it now. I am not a doctor or scientific, but since I have been living with the illness and see the symptoms, see the types, see different indications. No matter whom I see outside (lowers voice) *I am able to recognize it*.

(whispers) He has this illness. (raises voice) It could be that he would not believe me if I tell him. But I don't come to an end to recognize it.

Since- some have a benign kind and what they have is insignificant. (whispers) *I recognize it*."

Dina framed the proverb with a story of how she had noticed that a man, who was visiting the local fruit and vegetable market suffered from leprosy. She had never met him before, but still spotted his condition. She emphasized that her ability to identify the outer symptoms of the illness was based on her many years of experience living with the illness. When she used the proverb as support, she converted her stigmatized body into a source of knowledge.

The third time I heard her use the proverb, she embedded it in a story in which she emphasized that leprosy patients are actually better equipped than doctors to evaluate symptoms of the illness and to prescribe medicine. This time the proverb was triggered by my expressing satisfaction with our conversation, which was winding up.

Dina: "Look, we are alive. The sufferer is doctor (*O pathós ine jatrós*). When they go up to a patient and say "Say there, how did you cure your stomach?" Or "how did she get over her influenza? What can I do to get better?" [yes]

That is the meaning of the suffering doctor (*o pathós jatrós*) [yes]. When we arrived here and asked Ioannis Markianos, professor and leprologist. He was the only leprologist in all of the Balkans. Now they are all skin specialists [yes].

Oh, he said to us "You should do this, you should do that!" "Mr. Professor, what more do we need to do for this and that?" "Continue upstairs!"

You should go to the infirmaries, or to your

rooms, you will find *many* doctors there!" He was referring to [¿Did he say so| our fellow patients [yes|. "You will be able to find many doctors who can give you advice." [hmm]

He was referring to those who were suffering [yes|. Since it is patients who are still living and know how they remedied things yesterday [mm] they can also advise you [yes|.

The professor gave them an example: "He should take three tablets a day" [yes|. We who were there: "One shouldn't take three tablets. Don't let it make you bedridden at once, since the medicine is strong" [yes|. "Take one tablet this week [mm|. The second week you can take two [mm|

and after another month, then three." Since a sudden treatment is strong and on top of all the other problems

one does not eat well, one does not sleep well [mm|. "Don't let it make you feel bad [mm| and make you sick and bedridden. Then you can't be treated at all" [mm mm|. You understand, it is systematic to just take a little, a little (bit of medicine) at a time [yes|. We gave that (advice) at once [yes| ((inaudible)) can't take the medicine like that [mm|. We understand the (illness) in reality [mm|

(whispers) Do you understand now? "

As used by Dina the proverb becomes an effective linguistic tool to convert personal experiences into a collective, comprehensive body of knowledge. From that perspective, she was not just using the proverb in order to lend weight to her knowledge of leprosy, but also to control the discourse on knowledge according to how leprosy patients are categorized and evaluated in the outside world. Dina's usage of the proverb, especially in the first instance, when she clearly contextualized it in relationship to the new discourse about leprosy, meant that she maximized the intertextual gap to the older discourse regarding leprosy. At the same time, she sided with her fellow patients' way of talking about the realities of their own illness.

In conclusion, let me say a few words about my own thoughts on intertextuality. It is my contention that the strategic intertextual constructs of the leprosy patients, show how they act as subjects in relation to how they are made

subjects in the outside world. It is also my contention that a focus on intertextuality sheds light on the relationship between genre and discursive contexts. From one perspective, the analysis in this case can give insight into how leprosy patients create intertextual connections and relationships, in the context of genre conventions. From another perspective, the analysis can be focused on how they relate to discourses on leprosy, that is, to how knowledge of leprosy is controlled. The analytical question, in that case is: what constitutes the context of meaning that their intertextual constructs are a part of? I call this context of meaning the intertextual environment. I suspect, taking inspiration from Foucault's thinking, that this intertextual environment is created from a hierarchy of subject positions, where every subject has at its disposal, a convention regarding the way to talk about leprosy. This intertextual environment offers a limited number of possibilities, by which the leprosy patients are categorized and evaluated by the outside world.

To summarize, I have presented an analysis of how a Greek woman, who suffers from leprosy, uses a proverb as an element in an expressive strategy to control the representation of history. I have discussed this strategy in terms of intertextuality in relation to genre and discursive contexts. If intertextuality is viewed from these perspectives, then the intertextual strategies of the leprosy patients – as a form of subjectivation – can be linked both to a discourse analysis and to a textual analysis. One point that I want to make, is that on the one hand the interpretation and textualization of leprosy sufferers' history generates a subject for a certain form of knowledge. But at the same time, the strategic position of the leprosy patients' toward history can result in their changing this subject and converting history into a social force.

Notes

1. This article is based on a paper presented in a panel entitled "Expressive strategies and the control of history: contemporary European and North American cases" at the Annual Meeting of the American Folklore Society in Austin, Texas on October 31, 1997. I am grateful to Barbro Klein and Lotten Gustafsson for comments on this paper.
2. I have had several examples in formulating the structure of the ethnopoetic transcription of the taped interviews. Barbro Klein has indicated that the purpose of an ethnopoetic transcription is neither to achieve word-for-word precision nor easy-to-read texts. Rather, the purpose is to achieve what the American folklorist Dennis Tedlock (1983:7) called "audible sentences" (Klein 1990). In my analysis of the conversations, I have worked with the untranslated Greek versions of the transcripts, which are especially translated into English for this article. For the graphic presentation of the ethnopoetic transcriptions, I have used the following conventions: Pausing: Left line indented indicates pause; High voice volume: CAPITALS; Emphasis: italics; Drawn-out words: a dash after the word-; Inflected acknowledgment, objections: [within brackets]; Inflected questions, or the start of questions: |¿question|; Comments on the transcript or the Greek original version of the translated text: (within parenthesis); Inaudible utterance: ((in double parenthesis)).
3. Inflected acknowledgment, made by a woman in the hall.

References

- Briggs, Charles & Bauman, Richard 1992: Genre, intertextuality, and social power. In: *Journal of Linguistic Anthropology* 2: 131–172.
- Drakos, Georg 1997: *Makt över kropp och hälsa: om leprasjukas självförståelse i dagens Grekland*. [Empowering body and health: Leprosy and self-understanding in late twentieth century Greece.] Stockholm/Stehag.
- Feldman, Allen 1991: *Formations of violence: the narrative of the body and political terror in Northern Ireland*. Chicago.
- Gussow, Zachary 1989: *Leprosy, racism, and public health: social policy in chronic disease control*. Boulder.
- Haring, Lee 1992: *Verbal arts in Madagascar: Performance in historical perspective*. Philadelphia.
- Hasan-Rokem, Galit 1992: Proverbs as inter-ethnic dialogue in Israel. In: *Jewish Folklore & Ethnography Review* 14: 52–54.
- Hasan-Rokem, Galit 1994: Georgian proverbs of dialogue and dialogue of proverbs. In: *Israel. Proverbium* 11: 103–116.
- Klein, Barbro 1990: Transkribering är en analytisk akt. In: *Rig* 73 (2): 41–66.
- Tedlock, Dennis 1983: *The spoken word and the work of interpretation*. Philadelphia.
- White, Hayden, 1981: The value of narrativity in the representation of reality. In: *On narrative*. Mitchell, W. J. T. (ed.) Chicago.